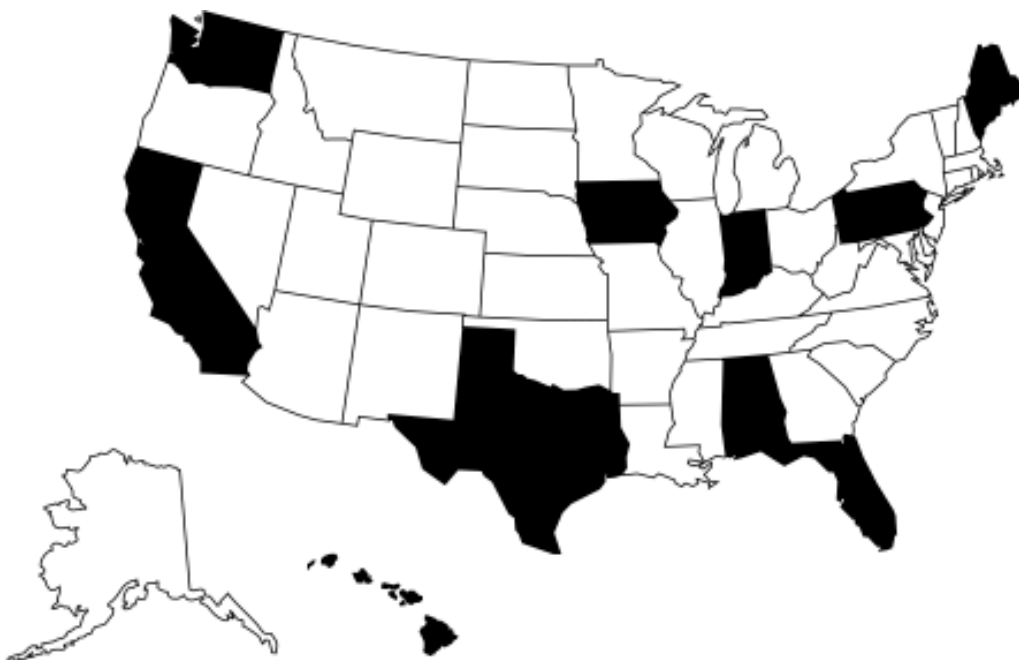

Family Caregiver Support:
*Policies, Perceptions and Practices in 10 States Since Passage
of the National Family Caregiver Support Program*

November 2002





About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.

25th Anniversary Year

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By

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PREFACE

This report summarizes the preliminary experiences of 10 states grappling with a growing issue facing the nation: how to support and sustain those who are the backbone of our long-term care system, family and informal caregivers of the elderly and adults with disabilities. We hope this report will broaden the perspective of policymakers and program administrators at the federal, state and local levels to:

- ✧ Advance the public debate about the explicit provision of family support within the context of long-term care systems development
- ✧ Increase understanding of ways to use public funds strategically to support family and informal caregivers
- ✧ Assist the aging network to implement the evolving National Family Caregiver Support Program more effectively
- ✧ Serve as a reference point for future progress
- ✧ Better anticipate emerging issues that are likely to shape the future

This report is a starting point. As states continue to struggle with budget shortfalls, reign in long-term care expenditures and address the mandate of the Supreme Court's *Olmstead* decision, it is our hope that policymakers, program administrators and advocates will learn from these 10 states, which offer an array of approaches and structures. In the end, we hope that—in every state—we will be better able to identify and respond to families in need.

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Sandra L. Newman
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*National Center on Caregiving
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We especially are grateful to the 140 individuals in the 10 states who provided the information for this study, responded to follow-up questions and reviewed their respective state profiles. These state officials and key stakeholders gave generously of their time and expertise to provide us with their perspectives and the information that allowed us to conduct this study. This report could not have been prepared without their cooperation and support.

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EXECUTIVE SUMMARY

BACKGROUND

Recognizing and supporting families and friends who provide care is a critical component of a comprehensive long-term care system. Family caregivers need support services themselves because they oftentimes face emotional, physical and financial problems as they access, coordinate and provide care to their loved ones. Policymakers are increasingly recognizing that family caregiving that helps a person with disabilities remain at home can save public dollars that might otherwise be spent on that individual in a nursing home.

Until recently, federal public policy has neither acknowledged nor supported the service needs of families in their caregiving role. The Older Americans Act (OAA) Amendments of 2000, in authorizing the creation of the National Family Caregiver Support Program (NFCSP), provides the most significant legislative accomplishment to date on behalf of family caregivers. Little is known about how states have implemented the NFCSP and how these new caregiver support services coordinate with other federal or state-funded home and community-based care programs.

PURPOSE

This report summarizes the preliminary experiences of 10 states in providing caregiver support services after the passage of the NFCSP. It identifies commonalities and differences among the states, highlights crosscutting themes, offers issues for the future and presents the individual state profiles that describe each state's approach to providing support services to family and friends of the elderly and adults with disabilities. Along with having diverse populations, the 10 profiled states offer varying philosophies, policies, administrative structures and program models of caregiver support.

This report arises from a one-year project designed to give an understanding, through a case study approach, of caregiver programs, services and trends in states. The study focused on caregivers services administered under the newly created NFCSP, Medicaid waivers, state general funds and other state funding streams. The in-depth focus on state programs is intended to stimulate discussion among state leaders about how best to integrate the new NFCSP funds into existing programmatic infrastructures to coordinate systems of care.

METHOD

To collect the information for this study, project staff used the key informant method through extensive in-person interviews with state officials and major stakeholders in 10 states. The goal was to gather the views and opinions of key informants in a range of states: those states at the forefront in caregiver policies and services and those states just beginning to provide caregiver support as a result of the creation of the NFCSP.

The 10 states selected for this study represent about 37% of the U.S. population and include: Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas and Washington. The states were selected based on a range of criteria including: largest populations of older persons; mix of urban and rural states; geographical representation of U.S. regions; populations with cultural diversity; and substantial as well as limited previous involvement in caregiver support services.

Two-person project teams conducted site visits to the 10 states between March and July 2002. In all, 61 interviews took place in the case study states, 31 involving state officials and 30 with key stakeholders. In total, 140 state officials and stakeholders contributed their views to the project and this report. Follow-up calls to the key informants were made, when necessary, to clarify information or responses. Each key informant received the draft case study, compiled from all the interviews in the given state, to verify the accuracy of the information. Supplemental information also was obtained from public documents, state websites and a literature review.

COMMONALITIES, DIFFERENCES AND CROSSCUTTING THEMES AMONG THE STATES

State Administrative Structure:

- ✧ Due to multiple funding sources, divergent eligibility criteria and different types of services provided, case study states are using a variety of approaches to administer their caregiver support and home and community-based service programs.

State System of Caregiver Support:

- ✧ Little consensus exists among the states about the recognition of families as a central component of a comprehensive long-term care system.
- ✧ Providing explicit support for family and friends of frail elders represents a paradigm shift.
- ✧ State variations in caregiver support are as diverse as the states.
- ✧ States are not using consistent terminology to refer to caregivers.

Program Background/Development:

- ✧ Key informants had diverging views about the planning process used to launch the NFCSP within the states.
- ✧ The two main challenges in developing and implementing caregiver support services in the case study states are limited funding and workforce shortages.

Funding:

- ✧ The funding level of the NFCSP is too low to meet the multifaceted needs of family caregivers.
- ✧ The NFCSP fills a gap for low to moderate income family caregivers.
- ✧ States are using a variety of fiscal strategies in developing systems of caregiver support.
- ✧ Family and informal caregivers represent a new constituency to serve in the midst of an economic downturn.

Program Administration:

- ✧ States vary widely in their NFCSP program design and administration.
- ✧ Some states set aside NFCSP funds for research and program innovations.
- ✧ To make the most efficient use of limited resources and use economies of scale, in several states a proportion of the base NFCSP allocation to each AAA is being used for joint activities of statewide impact.

Program Eligibility/Assessment:

- ✧ Respondents disagreed about whether or not family and informal caregivers should be considered clients or consumers in the long-term care system and have access to their own support services.
- ✧ Great variation exists among the states in their approaches to caregiver assessment.
- ✧ Medicaid officials recognized that they would like to help family caregivers but stringent rules largely keep them from doing so.

Services:

- ✧ States vary in how they have designed their caregiver support services under the NFCSP and integrated caregiver support into their home and community-based service system.
- ✧ The attempt to support flexibility at the local level appears to have promoted a variability of service options that paradoxically limits, rather than enhances, choices for family caregivers.
- ✧ Respite care and supplemental services (e.g., consumable supplies) are seen as the top service needs of family caregivers.

Consumer Direction:

- ✧ States differ in the extent to which their family caregivers have consumer-directed options, both within the caregiver support program under the NFCSP and within their state-funded home and community-based service programs.
- ✧ In states with consumer direction for respite care, most families choose relatives, friends or other persons they already know.
- ✧ All states are looking for ways to meet caregiver needs, even if formal consumer direction is not yet an option.

Quality Assurance:

- ✧ Uniform data collection on family caregivers, particularly outcome data, is lacking across states, making it difficult to measure the impact of services on families and assure quality.

Systems Development:

- ✧ Some states are developing a patchwork caregiver support system, which creates a complicated system that is difficult to access.
- ✧ States differ in the degree to which their caregiver support program is integrated into other long-term care programs, as do state officials' views about this issue.
- ✧ Generally the NFCSP was in its entry stage, with state departments outside the State Unit on Aging having little knowledge of the new program.

State Involvement of Family Caregivers in Olmstead Decision Planning:

- ✧ The aging network in general and family caregivers of the elderly in particular were not found to be active participants to date in state *Olmstead* task forces.
- ✧ States' Real Choice Systems Change grants are not addressing family caregiving issues.

ISSUES FOR THE FUTURE

From the lessons learned through the experiences of these 10 states, issues for the future were identified. Seven issues call for attention:

1. Family support should be an explicit objective of all federal and state long-term care policies and programs.
2. The funding level of the NFCSP must be raised to effect broad policy reform and systems change such that family caregivers are seen as true partners in long-term care.
3. To reduce fragmentation and increase quality of care, federal and state programs targeted to the elderly and to persons with disabilities need to be linked to those that target the family caregiver.
4. NFCSP reporting requirements need to address caregiver outcomes and uniform standards for caregiver assessment.
5. The NFCSP should build on state interest in exploring consumer direction in both caregiver support programs and home and community-based services.
6. States should be given more opportunities to learn about promising practices.
7. The shortage of direct care workers needs increased attention at the federal and state levels.

INTRODUCTION

Recognizing and supporting families and friends who provide care is a critical component of a comprehensive long-term care system. Despite some recent reforms, long-term care continues to pose major challenges: people who need long-term care often do not get the care they need or prefer, and caregiving and financial burdens on families are often heavy.¹

Well into the 21st century, caregiving will be a major part of the American family experience. Family members and other informal caregivers, such as friends and neighbors, are the backbone of our long-term care system, providing largely unpaid assistance to loved ones with chronic illnesses and disabilities. Without question, the economic value of family care is staggering. At an estimated value of \$257 billion nationally (in 2000 dollars), informal caregiving greatly surpasses the costs associated with home health care (\$32 billion) and nursing home care (\$92 billion).²

Caregivers need support services themselves because they oftentimes face emotional, physical and financial problems as they access, coordinate and provide care to their loved ones. To ease the burden on the more expensive formal long-term care system, a range of services and service options must be in place to sustain family caregivers.³ Indeed, the availability of family and informal caregivers is often the deciding factor in determining whether an individual can remain at home or must turn to more costly nursing home care.⁴ In recent years, policymakers have begun to recognize that family caregiving that helps people with disabilities remain at home can save public dollars that might otherwise be spent on that individual in a nursing home.⁵

Until recently, federal public policy has neither acknowledged nor supported the service needs of families in their caregiving role. The Older Americans Act (OAA) Amendments of 2000, in authorizing the creation of the National Family Caregiver Support Program (NFCSP), stands as the most significant legislative accomplishment to date on behalf of family caregivers.⁶ The NFCSP recognizes and encourages the vital role caregivers play in the country's home and community-based services, offering five categories of support for caregivers in a coordinated and responsive manner.⁷ This national program, implemented through the aging network (i.e., Administration on Aging, State Units on Aging, Area Agencies on Aging and service providers), includes the following support:

1. Information to caregivers about available services
2. Assistance to caregivers in gaining access to supportive services
3. Individual counseling, support groups and caregiver training to assist caregivers in making decisions and solving problems related to their roles
4. Respite care to temporarily relieve caregivers from their responsibilities
5. Supplemental services, on a limited basis, to complement the care provided by caregivers

Although caregiving and long-term care now command attention in Congress as well as in state legislatures, information on and analysis of caregiver support services within the context of long-term care and the new NFCSP are lacking. Little is known about states' experiences in providing caregiver support: whether in states that have well-developed systems of caregiver support services funded largely with state general revenues, or in states that have just begun to create programs through the new federal resources provided by the NFCSP.

BACKGROUND

As evidenced by the passage of the NFCSP in 2000, the federal government is playing an increasingly important role in supporting family caregivers of older persons. States, however, have led the way in designing and financing strategies to help families in their caregiving role. States have generally supported and sustained caregiving families through four main strategies: (1) direct services (e.g., information and assistance, respite care), (2) financial compensation, including direct payments or vouchers that promote consumer direction and let caregivers choose goods and/or services, (3) tax incentives and (4) family leave policies.⁸

States have strong incentives and interest in sustaining family caregiving:

- ✧ Most people who need long-term care prefer to receive assistance and services at home and to stay in their communities, near family and friends, for as long as possible.
- ✧ Families, not institutions or service providers, provide most long-term care services. Virtually all older persons (about 95%) living in noninstitutionalized settings receive assistance from relatives and friends. About two out of three older persons (67%) living in the community rely solely on informal help, mainly from wives and adult daughters.⁹
- ✧ Families can be an important part of the solution to serious long-term care system problems such as the shortage of frontline workers.

The states' efforts to support family caregivers, particularly with the new resources provided by the NFCSP, take place in the context of three other recent developments: the tobacco settlements, the *Olmstead* decision and the new federal initiative "Systems Change" Grants for home and community-based care.¹⁰

- ✧ In November 1998, state attorneys general and the tobacco industry reached a Master Settlement Agreement that included \$246 billion to be paid over a 25-year period to 46 states, five territories and the District of Columbia. Previously, the other four states—Florida, Minnesota, Mississippi and Texas—had reached agreements totaling \$40 billion over a 25-year period, bringing the total due from the industry nationally to \$286 billion. States can use a portion of these funds for home and community-based services and support for family caregivers.¹¹
- ✧ In June 1999, the U. S. Supreme Court ruled in the landmark case *Olmstead v. L.C.* that states are required to provide services to certain persons with disabilities in community settings rather than in institutions. In essence, *Olmstead* requires that states plan for and undertake two basic activities that could serve as blueprints for future long-term care reforms: (1) restructuring existing programs and services to promote community integration and (2) establishing an individualized assessment process to design community services. While the full implications of *Olmstead* for family caregivers are unclear, family involvement in the planning and implementation of *Olmstead* is central to creating community services for persons with disabilities.^{12, 13}
- ✧ In January 2001, the Centers for Medicare and Medicaid Services (CMS) announced a new grant program to include Real Choice Systems Change grants designed to help states improve community long term support systems for people with disabilities and their families. These grants present opportunities for aging, disability and family advocates to shape state policy to strengthen caregiving families.

The important role of the Medicaid program must also be noted in any effort to understand how states are integrating funding, including that from the NFCSP, to sustain family caregivers. Medicaid is the major source of public funding for home and community-based care. Financed by the federal government and the states, Medicaid, as an entitlement program, has an enormous impact on state budgets, with substantial implications for state policy overall and for state policy concerning family caregivers in particular. State policymakers have more flexibility under Medicaid waivers for home and community-based care than under the traditional Medicaid program, so it is not surprising that the percentage of Medicaid spending on home and community-based care doubled between 1994 and 1999 and that estimated expenditures for home and community-based waiver services were \$15.8 billion in FY 2002, almost double the expenditures in FY 1998.¹⁴ Medicaid spending on institutional care has grown more slowly, however, but still accounts for 70.5% of Medicaid long-term care.¹⁵ Medicaid reimbursable services through the federal share of funds must address the beneficiary's needs rather than the needs of the family caregiver or "family unit,"¹⁶ but states can offer respite and other services (e.g., home modifications, education and training), indirectly benefiting family caregivers under Medicaid home and community-based services waivers. Currently, services cannot be provided directly to benefit the family or informal caregiver.

A further factor affecting states' abilities to address health and long-term care issues, including family caregiver support, is the current downturn in the economy. Medicaid budget shortfalls will continue to be a main concern in many states this year, even though some state lawmakers seek to expand their state's Medicaid waivers.¹⁷ Despite the trend toward more Medicaid waivers, little is known about which state waiver services support caregivers and how these services coordinate with other federal (e.g., NFCSP) or state funding streams.

PURPOSE OF STUDY

This report summarizes the preliminary experiences of 10 states after the passage of the NFCSP. It describes the approaches of these states to providing support services to family or friends of the elderly and to adults with disabilities and identifies crosscutting themes and issues for the future. Along with having diverse populations, the 10 profiled states offer varying philosophies, policies, administrative structures and program models of caregiver support.

The report arises from a one-year project designed to give an understanding, through a case study approach, of caregiver programs, services and trends in states. The project's qualitative study focused on caregiver services administered under the newly created NFCSP, Medicaid waivers, state general funds and other state funding streams. The 10 profiled states include some with advanced caregiver systems and others that are just beginning to support caregivers. The states studied are:

- ✧ Alabama
- ✧ California
- ✧ Florida
- ✧ Hawaii
- ✧ Indiana
- ✧ Iowa
- ✧ Maine
- ✧ Pennsylvania
- ✧ Texas
- ✧ Washington

ORGANIZATION OF REPORT

Following a description of the study methodology, we summarize the commonalities and differences among the 10 states, identify crosscutting themes, address issues for the future and then present the individual state profiles. Each state profile offers an in-depth description of critical factors that influence the development, implementation and coordination of caregiver support within the context of a state's home and community-based care system. Providing such an in-depth focus on state programs is intended to stimulate discussions among state leaders about how best to integrate the new NFCSP funding stream into existing programmatic infrastructures to coordinate systems of care. Each profile has 15 sections and two tables:

- ✧ Overview
- ✧ Introduction
- ✧ Background
- ✧ State Administrative Structure
- ✧ Overview of State System of Caregiver Support
- ✧ Program Background/Development
- ✧ Funding
- ✧ Program Administration
- ✧ Program Eligibility/Assessment Process
- ✧ Services
- ✧ Consumer Direction
- ✧ Quality Assurance and Evaluation
- ✧ Systems Development
- ✧ State Involvement of Family Caregivers in *Olmstead* Decision Planning
- ✧ Other Policy Issues
- ✧ Table 1, Selected Characteristics of the State and the United States, 2000
- ✧ Table 2, Program Characteristics of the State's Family Caregiver Support Services

State government officials and key stakeholders provided information for this study through interviews and documents. The government officials were executive branch leaders who administer caregiver support services for the elderly and for persons with disabilities—whether through the NFCSP, state general funds, Medicaid home and community-based services waivers or other state funding streams. The stakeholders represented private organizations, consumer groups and other local programs that support family and informal caregivers. Throughout the report, we use the terms “key informants,” “respondents” and “observers” interchangeably to refer to the individuals interviewed. Where appropriate, state officials or stakeholders are delineated to represent their perspectives. Appendix A includes a list of the persons interviewed for this study.

METHODS

To collect the information for this project, we used the key informant method through extensive in-person interviews with state officials and major stakeholders in 10 states. The goal was to gather the views and opinions of key informants in a range of states: those states at the forefront in caregiver policies and services and those just beginning to provide caregiver support as a result of the creation of the NFCSP. We obtained supplemental information from public documents, state websites and a literature review. Expenditure data were collected for the most recent fiscal year available, usually 2001 but sometimes 2002.

Within the array of caregiver support services across the life span, we chose to focus on services to caregivers of the elderly (aged 60+) and younger persons with physical disabilities or with adult-onset cognitive impairment (e.g., Huntington's disease, traumatic brain injury). Consequently, this report does not specifically address caregiver support services for grandparents raising grandchildren or for caregivers of people with developmental disabilities.

For purposes of the study, the term "family caregiver" is used broadly and includes relatives, friends or neighbors who provide care. These persons may be primary or secondary caregivers, may provide full-time or part-time help and may live with the person being cared for or live separately.

IDENTIFICATION OF STATES, PROGRAMS AND KEY INFORMANTS

Project staff identified potential case study states through a literature review and discussions with the project's advisory committee. Our intent was to select five "old" states, whose programs represent best practice in caregiver support, and five "new" states, where explicit support to caregiving families was emerging as a result of the NFCSP. The findings of Family Caregiver Alliance's (FCA) 1999 study, *Survey of Fifteen States' Caregiver Support Programs*, informed the search for the "old" states.

In selecting the sample of states for the study, we used several criteria: largest populations of older persons; mix of urban and rural states; geographical representation of U.S. regions; populations with cultural diversity; and substantial as well as limited previous involvement in caregiver support services. We also examined states' Medicaid home and community-based care waivers to identify spending, caseloads and services related (or potentially related) to family caregivers. Last, we looked at how states were tapping tobacco settlement revenues for home and community-based services in general or for caregiver support in particular, the use of state general funds for caregiver support services and the existence of replicable program models. The states that met the inclusion criteria for "old" states were California, Florida, Iowa^a, Pennsylvania and Washington. The "new" states selected were Alabama, Hawaii, Indiana, Maine and Texas. Together, these 10 states represent about 37% of the total U.S. population.

In each of the 10 selected states, project staff contacted officials responsible for the following programs: NFCSP, Aged/Disabled Medicaid waiver, state-funded home and community-based services programs, and state-funded caregiver support program. These state officials were generally located

a Because of its sizable aging population, Iowa has focused on the development of home and community-based services, including support for family caregivers through respite care, for a number of years. Our site visit with state officials pointed out that the provision of explicit caregiver support did not occur in Iowa until the passage of the NFCSP, however.

within the State Unit on Aging or the Medicaid agency. Also contacted were representatives of stakeholder groups seen as having the most knowledge of and interest in caregiver support programs (e.g., Area Agencies on Aging, Alzheimer's Association chapters, Caregiver Resource Centers). We made every effort to identify informants who had involvement in and insights about the history, actual program operations and practice, and who understood family caregiving issues in their state. In addition, each key informant who agreed to be interviewed was asked to nominate other government officials or stakeholders whom he or she considered to be knowledgeable about the state's caregiver support system. In total, 140 state officials and stakeholders contributed their views to the project and this report.

DATA COLLECTION

Open-ended, structured site visit protocols were developed with input from the project's advisory committee. Survey A, which was administered only to government officials addressed 10 areas: overview of state system; program background; eligibility/assessment process; program administration; services; funding; consumer direction; quality assurance and evaluation; systems development; and other policy issues (see Appendix B). Survey B, which was administered to the states' key stakeholders, consisted of nine questions taken from Survey A (see Appendix C).

State officials and stakeholders in every selected state agreed to participate in the in-person interviews. Prior to the site visits, each key informant received a copy of the interview protocol (Survey A or Survey B). Two-person project teams conducted site visits to the 10 states between March and July 2002. Due to scheduling conflicts, a few interviews were conducted by telephone, and two interviews (one Washington State stakeholder and one Iowa government official) could not be scheduled during the data collection period. On average, the interviews with state officials took two hours each to complete, whereas stakeholders' interviews took, on average, between 30 and 45 minutes each. In all, 61 interviews took place in the 10 states, 31 involving state officials and 30 with key stakeholders. In most cases, more than one state official or stakeholder representative participated in an interview. When this occurred, their responses were considered as one.

With the informants' permission, the majority of interviews were tape-recorded in order to facilitate analysis of the findings. Following each site visit, the data gleaned from each interview were compiled and summarized. Follow-up calls to the key informants were made, when necessary, to clarify information or responses. Each key informant received the draft case study, compiled from all the interviews in the given state, to verify the accuracy of information.

COMMONALITIES, DIFFERENCES AND CROSSCUTTING THEMES AMONG THE STATES

This section reports on our findings and synthesizes the commonalities, differences and major themes identified in this study. This framework provides an overall context for the information presented and discussed in the subsequent individual 10 state profiles.

STATE ADMINISTRATIVE STRUCTURE

Due to multiple funding sources, divergent eligibility criteria and different types of services provided, case study states are using a variety of approaches to administer their caregiver support and home and community-based services programs. Some states (IN, ME, WA) centralize all administrative responsibility in one state department which serves the elderly, younger persons with physical disabilities, and their family caregivers. Another state (PA) utilizes this centralized approach for its programs for the elderly and their family caregivers only. Other states (AL, HI, IA) generally administer programs to support family caregivers through two agencies; typically the NFCSP and some state-funded programs are within the State Unit on Aging, whereas the Aged/Disabled Medicaid waiver for home and community-based services is in the Medicaid agency. In the three largest states studied (CA, FL, TX), administrative responsibility for caregiver support and home and community-based services spreads across numerous state agencies, making coordination and integration difficult. Moreover, administrative fragmentation at the state level leads to greater fragmentation at the local level, where family caregivers attempt to access services.

STATE SYSTEM OF CAREGIVER SUPPORT

Little consensus exists among states about the recognition of families as a central component of a comprehensive long-term care system. We asked all key informants, both state officials and stakeholders, whether family and informal caregivers were recognized as a central component of a comprehensive long-term care system, such as in state statute, in other state policies (e.g., family and medical leave) or in the provision of other home and community-based care programs and services. In all but one state (PA), key informants within the state disagreed substantially on this question. Mainly, state officials' views differed from the perceptions of stakeholders. State officials generally believed that family caregivers were recognized, whereas most key stakeholders did not believe this was the case. Stakeholders typically held the view that family caregivers were neither adequately recognized nor supported in their state's long-term care system.

Providing explicit support for family and friends of frail elders represents a paradigm shift. Viewing family caregivers as a "consumer" or "client" population is a relatively new concept for many State Units on Aging, Area Agencies on Aging and Medicaid home and community-based services waiver programs. In states that were beginning to provide a range of caregiver support services as a result of the NFCSP, family caregivers were typically viewed as a "new constituency." Some state and area agencies on aging (HI, ME, TX) found this paradigm shift challenging. They identified the tension between serving the older person (i.e., the care recipient), who is the traditional client in the long-term care system, and addressing the family caregivers' needs as distinct but related to the needs of the care recipient, which is the new mandate.

State variations in caregiver support are as diverse as the states. Explicit policy attention to caregiver support services emerged only recently, with the passage of the NFCSP, in six of the states we studied (AL, HI, IA, IN, ME, TX). Other states (CA, FL, PA, WA), through state law and state funding, had well-established programs to support and sustain family and informal caregivers prior to the enactment of the NFCSP. Nevertheless, all case study states were immersed in the early stages of program development or expansion due to the new federally funded caregiver support program. Great variations were found in philosophy and approaches to caregiver support from state to state and, in some cases, in programs within states. States used the new NFCSP funds in a variety of ways. For example:

- ✧ Pennsylvania and Washington, two states that are at the forefront in caregiver support, are augmenting their existing state-funded caregiver programs with the new federal NFCSP funds, enabling them to broaden eligibility and expand the range and scope of existing caregiver support services within a coherent system.
- ✧ Alabama, in the early stages of program development, has been able to provide a consistent approach to caregiver support wherever families live in the state, in part because it had no separate programs into which to integrate the NFCSP.
- ✧ California, a state with a wide array of publicly funded programs, made the policy choice to administer the NFCSP outside of the state's established, state-funded program that explicitly provides caregiver support to families and friends of adults with cognitive impairment, creating a new challenge to system coordination.
- ✧ Maine, a state with a well-coordinated and centrally administered long-term care system, made the policy choice to maintain a "stand-alone" identity for the emerging NFCSP, rather than to integrate caregiver support into the state's single point of entry to the long-term care system. Maine took this approach because the NFCSP has different eligibility and reporting requirements and a "new" identified consumer (i.e., family caregiver).

States are not using consistent terminology to refer to caregivers. States have differentiated caregiving as a growing policy issue but don't use the term "caregiver" consistently. In Indiana, for example, a commission on caregiving deals only with paid caregivers (i.e., direct care workers), not with family members.

PROGRAM BACKGROUND/DEVELOPMENT

Key informants have diverging views about the planning process used to launch the NFCSP within the states. Government officials in the State Units on Aging responsible for administering the NFCSP generally believed they involved all major stakeholders as well as family caregivers themselves in the planning process for the new caregiver program. Stakeholders and Medicaid waiver officials saw a different picture. Most Medicaid waiver officials were not well informed about the NFCSP, and most stakeholders either felt generally excluded from the state or local planning process, or were not highly aware of how the NFCSP was being implemented in their state.

The two main challenges in developing and implementing caregiver support services in the case study states are limited funding and workforce shortages. With regard to the NFCSP specifically, states were facing several initial challenges in implementing and coordinating the new federally funded program with other funding streams:

- ❖ Identifying sources for the required 25% NFCSP state match. In California and Texas, the required match was a source of concern among both state officials and AAA staff.
- ❖ Promoting flexibility at the local level while maintaining statewide standards (AL, CA, FL, WA).
- ❖ Gearing up to meet the short time frame to launch the NFCSP and implement the program quickly with limited guidelines (CA, FL, HI, TX).
- ❖ Conforming to new reporting requirements and integrating the new reporting mechanisms across funding streams (HI, ME, TX).

FUNDING

The funding level of the NFCSP is too low to meet the multifaceted needs of family caregivers. All case study states received modest amounts of funds under the NFCSP, ranging in FY 2002 from a high of \$12.6 million in California to a low of \$639,540 in Hawaii. When compared to spending for other home and community-based services, like Medicaid waiver funds spent on respite care, the funding appears even more limited.

- ❖ Medicaid home and community-based service waivers play an important role in financing respite care for caregivers, even though the client or beneficiary is considered to be the consumer (i.e., the care recipient), not the family caregiver or family unit.
- ❖ All states realized that the NFCSP represents the first federal law to recognize and support caregiving families and the first major nationwide initiative under the Older Americans Act since the 1970s.¹⁸

The NFCSP fills a gap for low to moderate income family caregivers. The NFCSP provides, for the first time, some minimal support to moderate-income families who are not Medicaid eligible and for whom there are limited or no state-funded caregiver support programs. Middle income families—who are above the eligibility limit for most other publicly funded programs—often cannot afford to pay for needed respite and other caregiver supports. Consequently, middle income caregivers are often the most at risk for impoverishment.

States are using a variety of fiscal strategies in developing systems of caregiver support.

- ❖ Several states fund significant multifaceted caregiver support programs from their state general revenues (CA, PA, WA).
- ❖ Other states (FL, ME) are using the NFCSP to broaden caregiver support services beyond state-funded respite programs and aim to work with families earlier in the process of caregiving.
- ❖ Five states (AL, FL, IA, PA, TX) are using portions of their tobacco settlement revenues to expand home and community-based care services in general. Two of those states (IA, TX) are also using those funds to expand respite options for family caregivers.

Family and informal caregivers represent a new constituency to serve in the midst of an economic downturn. With the weakened economy hitting virtually all the states visited, key informants observed that their states were very cautious this year in allocating or planning on new funding for caregiver support programs, beyond the infusion of federal funds under the NFCSP. Family caregiver support was not affected this past year, but states were preoccupied with what would happen in the coming year. Although states felt that expanding caregiver support programs would reduce the strain on Medicaid and other home and community-based programs, respondents felt current budget shortfalls made program expansion unlikely in the near future.

- ✧ State budgets won't recover quickly. The real problem will likely occur in FY 2003, when states that avoided program reductions in FY 2002 will be forced to address the decline in revenues and growing budget deficits.
- ✧ Many states used "rainy day funds" to solve FY 2002 budget shortfalls, but these funds are now depleted.

PROGRAM ADMINISTRATION

States vary widely in their NFCSP program design and administration. For example:

- ✧ Iowa offers a centralized model coordinated by the state's AAA Association.
- ✧ Pennsylvania and Indiana have highly integrated service models that are generally seamless to the consumer and to the family.
- ✧ Hawaii and Texas have a decentralized model, offering each AAA the flexibility to best meet local needs.

Some states set aside NFCSP funds for research and program innovations. Three states (AL, CA, HI) chose to contract with state universities to use a portion of the federal dollars to conduct statewide caregiver surveys to improve understanding of the needs of families. Three other states (ME, TX, WA) developed seed grants and special projects to meet local need, support innovation and build on informal infrastructures rather than deliver services only through each state's AAAs. For example:

- ✧ Texas has awarded seed grants to faith-based and other organizations to provide respite care.
- ✧ Maine set aside funds for contracts with local community agencies or businesses to reach caregivers earlier.
- ✧ Washington has provided funds for special projects known as "innovations in caregiver support" that target underserved populations.

To make the most efficient use of limited resources and to use economies of scale, several states are using a portion of the base NFCSP allocation to each AAA for joint activities of statewide impact. In four case study states (AL, IA, IN, ME), AAAs have collaborated on outreach and marketing efforts (e.g., statewide logo and tag line, toll-free number, website, brochures) by pooling dollars at the state level to promote a consistent, statewide identity for the new caregiver program. Numerous key informants felt this was an important, strategic activity during the start-up of the NFCSP to make the public aware of the new caregiver program and its services and to reach people who care for their loved ones but who do not identify themselves with the term "caregiver."

PROGRAM ELIGIBILITY/ASSESSMENT

Respondents disagreed about whether or not family and informal caregivers should be considered clients or consumers in the long-term care system and whether they should have access to their own support services.

- ✧ Nearly half (47%) of the respondents who were state officials considered the care recipient (i.e., the elderly individual or person with disabilities) the client. Not surprisingly, the majority of these responses came from administrators of home and community-based Medicaid waiver programs.
- ✧ About 27% of state officials considered both the care recipient and the caregiver to be clients, taking a more “family systems” approach to service eligibility.
- ✧ Only 23% of state officials identified the family caregiver as their primary client, and the programs they administered were typically state funded with explicit mandates to serve family and informal caregivers.
- ✧ Surprisingly, only half of the State Unit on Aging respondents (AL, CA, FL, HI, ME) identified family caregivers as the primary client under the NFCSP.
- ✧ Stakeholders, in contrast to state officials, uniformly embraced the notion of the family caregiver as the consumer or client.

Great variation exists among the states in their approaches to caregiver assessment. Indeed, variation was seen within a given state across its caregiver support programs. Although virtually all state programs use some type of an assessment tool to determine the care plan for the older individual or for the person with disabilities, few uniformly assess the needs and situation of the family caregiver. Typically, within state-funded and Medicaid home and community-based waiver programs, caregiver assessment is viewed as a minor part of the overall assessment of the care recipient, with a brief section identifying whether the care recipient has a family caregiver, the type and frequency of help provided to the care recipient and the willingness of the family member to continue in the caring role. Moreover, what minimal information is collected on family caregivers is typically not aggregated and reported statewide. Less common, even within the emerging NFCSP in the states, are distinct caregiver screening tools or more comprehensive, outcome-based assessment instruments that address the caregiver’s needs and situation, looking at the caregiver’s level of distress and caregiver depression, social support, physical health and the caregiver’s own service needs. In particular, state and local implementation of caregiver assessment policy, tools and procedures under the NFCSP were at very different stages of development across the states. Often, caregiver assessment varied from one local area to another.

- ✧ Pennsylvania and Florida were the only states utilizing a consistent assessment instrument, including a caregiver component, for all home and community-based programs (i.e., NFCSP, state funded, Medicaid waivers).
- ✧ Washington State is working to incorporate a caregiver assessment into its uniform assessment tool for all long-term care programs.
- ✧ Six of the remaining states (CA, HI, IA, IN, ME, TX) had not yet set uniform caregiver statewide assessment standards under the NFCSP at the time of the site visits.
- ✧ Alabama, in partnership with its AAAs, has developed uniform assessment standards representing a required, minimum data set on family caregivers.

- ✧ California utilizes a distinct assessment tool focusing on the needs and situation of the caregiver in its state-funded Caregiver Resource Center system. California does not use this tool in the NFCSP or in other state programs that provide some support to family caregivers, however.

Medicaid officials recognized that they would like to help family caregivers, but stringent rules largely keep them from doing so. Under Medicaid, the care recipient, not the caregiver or the family unit, is the beneficiary or client. A frequent observation was that local case managers for Medicaid-eligible individuals generally take into account the availability and willingness of family caregivers to provide care and the amount of unpaid care family members, friends or neighbors provide. In fact, the amount of informal family care available affects the amount and type of services approved for the Medicaid-eligible care recipient. Although most Medicaid home and community-based care waivers include the service component of respite care to offer some relief for the primary caregiver, other caregiver support services (e.g., family consultation) are not typically part of the waiver package.

SERVICES

States vary in how they have designed their caregiver support services under the NFCSP and integrated caregiver support into their home and community-based service system. Within the majority of the 10 case study states, caregivers in different parts of the state could not access the same package of caregiver support services under the emerging NFCSP. States that already had some component of caregiver support through state-funded programs utilized the NFCSP to expand the range and amount of services to family caregivers. For example:

- ✧ Florida, Maine, Texas and Washington all had explicit state-funded respite programs before the passage of the NFCSP. With the new federal caregiver funds, these states have broadened service delivery to family caregivers beyond respite care.
- ✧ Pennsylvania utilized the NFCSP funds to supplement and expand a range of services under its existing state-funded caregiver support program.
- ✧ In many parts of California, the AAAs contracted with the state-funded Caregiver Resource Centers to expand the population of caregivers they serve.
- ✧ Washington State has offered counseling for family caregivers, a service not previously allowable under its state-funded caregiver support program.

The attempt to support flexibility at the local level appears to have promoted a variability of service options that paradoxically limits, rather than enhances, choices for family caregivers. With minimal funds, states faced a difficult balancing act: giving AAAs local flexibility that encourages individualized options to meeting caregiver needs, while simultaneously setting statewide standards and uniformity so that family caregivers can access a core set of caregiver support services and service delivery options regardless of where they live. In general, the balance has been tipped toward local flexibility, resulting in a highly inconsistent range of services, varying by locality.

Respite care and supplemental services (e.g., assistive devices, consumable supplies, home modifications) are seen as the top service needs of family caregivers. The majority of respondents—state officials and stakeholders alike—noted several different services and service options that families need, suggesting that, consistent with the intent of the NFCSP, family caregivers require a multifaceted system of support to meet their individualized and changing situations.

CONSUMER DIRECTION

States differ in the extent to which their family caregivers have consumer-directed options, both within the caregiver support program under the NFCSP and within their state-funded home and community-based service programs. The NFCSP neither precludes nor mandates direct payments to family caregivers. Thus a state may allow direct payments or a voucher system for services (e.g., respite, supplemental services) and give families maximum control as to how, when and by whom respite is provided and/or the option of purchasing goods or services that directly meet their needs.

- ✧ Pennsylvania's family caregiver support program (state funded and NFCSP) allows for consumer direction. Families can hire their own respite providers or be reimbursed for the purchase of almost any goods or services except prescription drugs. Friends and neighbors can be paid to provide care, but family caregivers themselves cannot be. The state's other home and community-based programs, including the Aged Medicaid waiver, allow payment of family members, except spouses, to provide care.
- ✧ In California, although the traditional Aged Medicaid waiver does not offer a consumer-directed option, the state's In-Home Supportive Services (IHSS) program (funded by the optional Medicaid personal assistance benefit and state funds) does. The state places no restrictions on the hiring of and payment to family members for IHSS; use of state funds allows any family member, including a parent or spouse, to be a paid care provider. California's state-funded caregiver support program, the Caregiver Resource Center system, also allows for consumer direction. Primary family caregivers may choose from a range of respite options, including the hiring of other family or friends to provide respite care. Under the NFCSP, there is no statewide policy on consumer direction, and AAAs have not yet implemented this option.
- ✧ Florida does not permit consumer direction under its traditional Aged/Disabled Medicaid waiver. Florida's federal Cash and Counseling demonstration and the state's recently enacted state-funded consumer-directed care project (and the NFCSP) serve that purpose, however.

In states with consumer direction for respite care, most families choose relatives, friends or other persons they already know. For example, in the Aged/Disabled waiver programs in Hawaii and Washington State, about 90% and 50% of the respite workers, respectively, are family members.

All states are looking for ways to meet caregivers' needs, even if formal consumer direction is not yet an option. For example, Alabama, a state with few resources overall and with limited funding under the NFCSP, does not allow direct payment to family caregivers. However, the state offers caregivers a menu of services, creatively uses supplemental services and respite to meet caregivers' needs and allows AAAs to use a voucher system (employed by all AAAs and typically capped at \$500 per year per family client).

QUALITY ASSURANCE AND EVALUATION

Uniform data collection on family caregivers, particularly outcome data, is lacking across states, making it difficult to measure the impact of services on families and to assure quality.

The NFCSP has minimal reporting requirements, focusing primarily on the number of caregivers served, services provided and expenditures. Nevertheless, the states reported problems with these requirements:

- ✧ Playing the “waiting game” to see if and when the federal government might alter current minimal reporting requirements.
- ✧ Reconciling the aging network’s current data collection focused on the older person as the client with the new mandate to collect minimal data on the family caregiver as the client.
- ✧ Facing delays caused by state budget problems in implementing computer systems capable of tracking data for both the care recipient and the caregiver.

SYSTEMS DEVELOPMENT

Some states are developing a patchwork caregiver support system, which creates a complicated system that is difficult to access. State approaches to systems development and family care issues varied greatly, but few of the case study states had a consistent package of caregiver supports. Instead, they had a range of programs with different eligibility requirements, divergent funding sources and varied funding levels. The elderly, persons with disabilities and their families may not appreciate the concept of local flexibility as they try to negotiate a complex service maze. The overall lack of consistency in states’ caregiver support programs specifically and in home and community-based services generally is particularly frustrating for long-distance caregivers. They find that different services are provided by different agencies in different states. To help consumers navigate the complexity, some states are working on improving the service delivery system so that it is seamless for the consumer:

- ✧ Several of the case study states (FL, IA, IN, PA, WA) are using their AAAs as a single point-of-entry for all of the state’s caregiver support and home and community-based services, regardless of the administering agency or funding stream.
- ✧ One state (IN) also is exploring the “no wrong door” approach, whereby clients (including family caregivers) can access all programs through the local office of any state agency, as well as through the AAA.

States differ in the degree to which their caregiver support program is integrated into other long-term care programs, as do state officials’ views about this issue.

- ✧ Officials in five states were in full agreement about the degree of integration. In four states (FL, HI, IA, PA) officials agreed that their caregiver support program was integrated into their state’s other home and community-based care programs. In one (ME), officials agreed the state had chosen to maintain a “stand-alone” identity for the new NFCSP, which serves the family caregiver because the state’s centralized, integrated long-term care system focuses on the older individual or person with disabilities as the consumer.
- ✧ In five states (AL, CA, IN, TX, WA), officials within the state did not agree about the status of their caregiver support programs. Some saw it as integrated, some as “stand-alone” and some as having both elements.

Generally the NFCSP was in its entry stage, with state departments outside the State Unit on Aging having little knowledge of the new program. Whether a state used an “umbrella” or a separate agency model, limited diffusion of knowledge about the NFCSP had occurred at the time of the site visits. In some cases, coordination was a challenge even among different divisions within the same agency. Even when staff from the State Unit on Aging and the Medicaid waiver program had a close working relationship, as was the case in five states (FL, IN, ME, PA, WA), Medicaid waiver staff were not well informed about the NFCSP.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

The aging network in general and family caregivers of the elderly in particular were not found to be active participants to date in state Olmstead task forces. Despite the broad goals of the *Olmstead* decision to reform long-term care and promote integrated service delivery and a shift from institutional to home and community-based care, relatively few of the key informants (state officials or stakeholders) discussed the implications for family caregivers of the elderly and of persons with disabilities. In their planning documents, two states specifically identified the need to support family caregivers: California in the preliminary values statement of its planning council for *Olmstead* and Indiana as one of six major policy directions to be pursued. Texas reported having a family caregiver of an older person as a member of its *Olmstead* task force. In most of the other states, the family members on these task forces were parents of children with developmental disabilities.

States’ Real Choice Systems Change grants are not addressing family caregiver issues. These federal grants are one tool to help states modify and enrich their community supports to meet *Olmstead*’s mandate. Although most of the State Units on Aging in this study were involved in Systems Change grant activities, only one state (IN) identified family caregivers as an explicit target group under its grant.

ISSUES FOR THE FUTURE

From the lessons learned through the experiences of these 10 states, we can begin to identify issues for the future. Seven issues call for attention:

1. *Family support should be an explicit objective of all federal and state long-term care policies and programs.* A current flaw in the home and community-based service system is the heavy reliance on family and informal caregivers in most Medicaid waiver and state-funded programs. Family and friends bear most of the burden of accessing, coordinating and providing long-term care in the community without the supports necessary to sustain them in the caregiving role. As states focus on long-term care reform, including reducing reliance on nursing homes and strengthening integrated and coordinated systems of home and community-based services, the impacts of these policy shifts on family caregivers must be considered. Home and community-based services must support family and informal networks. States and the federal government can begin to address these policy choices in Medicaid waivers, *Olmstead* planning and Real Choice Systems Change grants.
 - a. Reforms are needed in Aged/Disabled Medicaid waivers to pursue a “family systems” approach. Current Medicaid policy prohibits: (1) the direct provision of services to benefit the family or informal caregiver; and (2) payment to spouses or parents of minor children to provide care. The Medicaid program could meet the needs of care recipients better by explicitly providing meaningful support to caregivers. Considering the *family* unit (i.e., the older individual or person with disabilities *and* his or her family or informal caregiver) as the beneficiary in the waiver program could streamline eligibility, assessment and service provision.
 - b. The implications of the Supreme Court’s *Olmstead* decision for family caregivers remain unclear. As states continue to develop their state plans, family caregivers of the elderly and their advocates need to be integrally involved.
 - c. States should use their Real Choice Systems Change grants to acknowledge and strengthen all caregiving families, promoting policy development in the areas of interagency collaboration, data collection and systems integration.
2. *The funding level of the NFCSP must be raised to effect broad policy reform and systems change such that family caregivers are seen as true partners in long-term care.* The modest level of NFCSP funding leaves gaps in caregiver support services that vary substantially from state to state as well as within states. Resources should ensure that all families have access to at least a minimum level of caregiver support regardless of where they live. Increasing funds for the NFCSP will support family caregivers and help to sustain them in their caregiver role, in turn reducing the fiscal pressures on Medicaid and other state-funded home and community-based programs at both the state and federal level.

3. ***To reduce fragmentation and increase quality of care, federal and state programs targeted to the elderly and to persons with disabilities need to be linked to those that target the family and informal caregiver.*** We can learn from our past mistakes in home and community-based care as we work to build a coherent and adequately funded caregiver support system. We must not re-create or contribute to fragmentation of services that leave caregivers confused and overwhelmed, posing major barriers to finding and using the help they need. Single point-of-entry at local levels and seamless service delivery across funding streams appear to reduce the greatest frustration of families, particularly long-distance caregivers, in locating and accessing services. Coordination of caregiver support services at both the state and local levels is a critical strategic objective. Then family caregivers can choose from a full array of services and service options that will meet their needs, values and preferences. Sound ways to develop systems that will work for family caregivers include:
 - a. Building caregiver support services on existing infrastructures in states where high quality programs already exist.
 - b. Promoting a “family systems” philosophy and approach to long-term care reform that includes both the care recipient and the family caregiver as legitimate “clients.”
 - c. Improving assessment tools in the NFCSP, Medicaid waivers and state-funded caregiver support programs to collect information and assess the needs of both the care recipient and the family caregiver.
 - d. Integrating a caregiver assessment component into a state’s uniform assessment tool for all long-term care programs.
 - e. Implementing a single point-of-entry through which all publicly funded home and community-based services within a state may be accessed.
4. ***NFCSP reporting requirements need to address caregiver outcomes and uniform standards for caregiver assessment.*** Current data collection provides a minimal measure of service effort under the new NFCSP, focusing primarily on the number of caregivers served, services provided and expenditures. Designing a uniform, outcome-driven information system would be a worthwhile investment to assure quality care and to advance public policy for caregiving families. The current information and reporting system could be strengthened to provide the federal government, state agencies, AAAs and service providers with uniform standards for: (1) collecting data on the characteristics of families who use specific types of services; (2) incorporating measures of service intensity (i.e., the amount of a particular service used by a family caregiver); (3) emphasizing quality indicators based on caregivers’ experience; and (4) adopting outcome measures to assess the impact of services on families.

Although the NFCSP promotes a multifaceted approach to service provision for family caregivers, there is no mandate for caregiver assessment. Understanding the role, multiple stressors and particular situation of the family caregiver is essential to any care plan developed for the care recipient.^{19, 20} Caregiver assessment legitimizes the needs of family caregivers themselves as distinct but related to those of the care recipient.^{21, 22} Families would benefit significantly from a common approach to caregiver assessment that:

- a. Identifies the particular needs of the caregiver.
 - b. Approaches issues and the development of a plan of care from the caregiver's perspective and culture.
 - c. Focuses on the outcomes the caregiver wants for family support.
 - d. Ensures that the caregiver's own health and well-being are maintained.
5. *The NFCSP should build on state interest in exploring consumer direction in both caregiver support programs and home and community-based services.* State officials in all programs (NFCSP, state funded, Medicaid waivers) had high interest in consumer direction. The NFCSP presents an opportunity to expand consumer-directed programs specifically aimed at offering family and informal caregivers the choice to select goods or services that will benefit them *directly*. Consumer direction is not a single approach. Rather, it is a range of models that can vary in terms of how much decision making, control and autonomy are shifted from service providers to the consumers of services.²³ As some researchers conclude, "The ultimate way to maximize choice is to ensure that people have the cash to purchase the services they prefer."²⁴ Under the NFCSP specifically, states can choose to offer consumer-directed options, including supplemental services (e.g., assistive devices, consumable supplies, home modifications), a range of respite options and payment to family caregivers to provide respite care.
6. *States should be given more opportunities to learn about promising practices.* States want to know what other states are doing to support and strengthen family and informal caregivers. They want examples of successful state legislation (e.g., tax credits, expanded family and medical leave, lifespan respite) to foster legislative or regulatory changes to enhance the NFCSP and other home and community-based efforts in their own states. They also want "promising practice" models for specific caregiver programs, service delivery options (e.g., consumer-directed approaches), integrated client tracking systems that link the care recipient and the caregiver, examples of caregiver assessment tools for use by practitioners who work with caregivers and successful strategies to coordinate and integrate caregiver support into their state's broader long-term care reform efforts.
7. *The shortage of direct care workers needs increased attention at the federal and state levels.* Many key informants described the labor shortage for direct care workers as a crisis, particularly in rural areas, that is affecting care to the elderly, and to persons with disabilities, as well as support for family caregivers. As states look to the future with the aging of the population, all state officials—regardless of whether they administer the NFCSP, Aged/Disabled Medicaid waivers, state-funded caregiver support or home and community-based programs—face increasing pressures to recruit and retain a trained workforce that delivers quality long-term care and supports caregiving families.

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ALABAMA

OVERVIEW

Alabama is a southern state with substantial rural, low-income and minority populations. The state's current long-term care system provides minimal home and community-based care services, constrained by low state revenues and a strong nursing home lobby, although efforts are being made to expand home and community-based care. State-only-funded programs for the elderly and for persons with disabilities are extremely limited because of the state's antitax sentiments.

State policy attention to caregiver support services emerged only recently, with the passage of the National Family Caregiver Support Program (NFCSP) and the infusion of federal funds into Alabama's state budget. The state's developing caregiver support services are characterized by:

- ✧ Centralized policymaking and administration with statewide policies and standards to ensure a consistent approach to caregiver support
- ✧ A statewide logo and name, *Alabama Cares*, to promote a consistent, statewide identity for the program
- ✧ Flexibility to meet the individual needs of family caregivers at the local level

Alabama respondents noted that the major service needs of family caregivers are (1) supplemental services (e.g., consumable supplies, home modification), (2) respite care and education about the need for respite and (3) skills training.

As Alabama continues to develop its caregiver support program, a key consideration will be the coordination between *Alabama Cares* and the broader long-term care system, particularly through the Aged/Disabled Medicaid waiver.

INTRODUCTION

Alabama represents a "new" state that is providing caregiver support for the first time as a result of the passage of the National Family Caregiver Support Program (NFCSP). The project team conducted a site visit on March 18 and 19, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

- ✧ Alabama Department of Senior Services
 - ◆ *Alabama Cares* (NFCSP funded)
 - ◆ Aged/Disabled Medicaid waiver
 - ◆ Federal Alzheimer's disease Demonstration Grant to States

- ✧ Alabama Department of Public Health
 - ◆ Aged/Disabled Medicaid waiver
- ✧ Alabama Medicaid Agency, Long-Term Care Division
 - ◆ Aged/Disabled Medicaid waiver
 - ◆ Real Choice Systems Change grant

Stakeholders interviewed were from:

- ✧ Alabama Association of Area Agencies on Aging
- ✧ Alzheimer's Resource Center, Dothan, Alabama

Two programs are featured:

1. *Alabama Cares*
2. Aged/Disabled Medicaid waiver

BACKGROUND

Alabama is a southern state with a population of 4.5 million residing in 67 counties.¹ Most of the residents are native to the state, with 76% of the citizens born in Alabama.²

The state has substantial rural, low-income and minority populations. Nearly one-third of Alabama's population lives in rural areas.³ In 2000, personal income per capita was \$23,471, compared to the national average of \$29,676.⁴ About 16.2% of Alabama's residents live below the federal poverty level (vs. 13.3% U.S.).⁵ Alabama ranks 43rd nationally in percentage of households with Internet access.⁶ The racial makeup of the state's population also differs significantly from that of the United States as a whole. Compared to the national average, Alabama has more than twice the proportion of African Americans (26% vs. 12.3% U.S.) and a much lower proportion of Hispanic persons (1.7% vs. 12.5% U.S.)⁷ (table 1).

An estimated 769,880 persons in Alabama, or 17.3 % of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Alabama ranks 14th nationally in the proportion of older persons (ages 60+) residing in the state.⁸ Similar to the state's population as a whole and compared with the national average, Alabama has more than twice the proportion of African Americans ages 60+ (18.7% vs. 8.4% U.S.) and a somewhat lower proportion of Hispanic older persons (0.6% vs. 5.4% U.S.).⁹

Alabama ranks 26th nationally in the proportion of its population ages 85 and older. In 2000, 67,301 persons, or 1.5% of Alabama's population, were ages 85+.¹⁰

An estimated 423,143 family caregivers reside in Alabama. These family caregivers provide about 393 million hours of caregiving per year at an estimated value of \$3.2 billion in 1997.¹¹

Alabama has one of the lowest tax burdens of any state in the nation, reflecting the state's conservative fiscal policies.¹² Key informants noted that Alabama's health and social programs are relatively limited—historically and currently—because of the state's antitax sentiments.

Table 1. Selected Characteristics of ALABAMA and the UNITED STATES, 2000 ^a

	Alabama	United States
Total Population Characteristics		
Total Pop. ^b	4,447,100	281,421,906
% African American ^c	26.0%	12.3%
% Hispanic ^d	1.7%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	769,880	45,797,200
% 60+ ^f	17.3%	16.3%
National ranking 60+ ^g	14	NA
Pop. 65+ ^h	579,798	34,991,753
% 65+ ⁱ	13.0%	12.4%
National ranking 65+ ^j	21	NA
Pop. 85+ ^k	67,301	4,239,587
% 85+ ^l	1.5%	1.5%
National ranking 85+ ^m	26	NA
% increase 1990–2000 60+ pop. ⁿ	9.5%	9.4%
% White (60+) ^o	79.6%	82.4%
% African American (60+)	18.7%	8.4%
% Hispanic (60+)	0.6%	5.4%
% Asian (60+)	0.3%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics ^p		
# of caregivers (1997)	423,143	25,798,370
Caregiving hours (millions) (1997)	393.9	24,013.1
Value of caregiving (millions) (1997)	\$3,221.8	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$23,471	\$29,676
% of pop. below poverty (1997) ^r	16.2%	13.3%
Internet		
% of households w/Internet access (2001) ^s	35.5%	41.5%
Nat'l ranking of households w/Internet access	43	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Alabama, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Alabama.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for younger adults with physical disabilities are administered largely through two state agencies: the Department of Senior Services and the Department of Public Health. The programs administered by these state agencies generally rely on federal funds with minimal state match; state-only-funded programs are extremely limited. Respondents pointed out that programs are designed primarily to meet basic federal requirements and to maximize federal funds while minimizing state spending.

The Alabama Department of Senior Services (ADSS) is a freestanding department that serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP. The governor appoints the executive director, who has cabinet-level status. Under contract with the Alabama Medicaid Agency, ADSS administers half of the Aged/Disabled Medicaid waiver (with the Department of Health Services) and also administers a federal Alzheimer's disease demonstration grant for dementia caregivers.

The infrastructure of Alabama's aging network is a statewide system of 13 Area Agencies on Aging (AAAs), ranging from one to 10 counties in each area. The ADSS utilizes the AAAs to provide case management under its portion of the Medicaid waiver; direct services are not provided. The majority of organizations designated as AAAs in the state are "umbrella" agencies. Typically, quasi-governmental agencies are formed by multijurisdictional agreements (e.g., regional planning commissions) for mutual planning purposes.

Alabama's Aged/Disabled Medicaid waiver was originally approved in 1981. Three agencies are involved. The Alabama Medicaid Agency¹³ is responsible for oversight as the "single state agency" for Medicaid. That agency contracts with both the ADSS and the Department of Public Health to administer the program and to deliver services to about 5,800 beneficiaries in the state (7,000 total slots).^a

The Alabama Department of Public Health (ADPH) is a freestanding department of the state government whose mission is to protect the public's health through disease prevention and the provision of public health services. The director of the department, the state health officer, is appointed by the governor and has cabinet-level status. Under contract with the Alabama Medicaid Agency, ADPH administers the other half of the Aged/Disabled Medicaid waiver (with the ADSS) under the Bureau of Home and Community Services, Division of Community Services. Unlike the ADSS, the ADPH is both an administrator and a provider of services (through the county health departments) under the Aged/Disabled Medicaid waiver.

In October 2001, the Centers for Medicare and Medicaid Services (CMS) awarded the Alabama Medicaid Agency, Long Term Care Division a Real Choice Systems Change grant. Three state agencies are involved: the Medicaid Agency (as the lead agency) and the Departments of Senior Services and of Mental Health and Mental Retardation. State officials noted that the intent of the three-year grant is to develop a home and community-based system for the elderly and for younger persons with disabilities, primarily in response to the *Olmstead* decision. Respondents noted that family caregivers are not a current focus of the grant.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

All case study respondents noted that Alabama does not have a comprehensive long-term care system, although efforts are being made to expand home and community-based care. Alabama's current long-term care system has limited home and community-based programs, constrained by low state revenues and a strong nursing home lobby. In recent years, however, the current governor, Donald Siegelman (D), has shown a strong interest in improving long-term care for the elderly and for persons with disabilities and has made one of his major health priorities the expansion of home and community-based care. To date, the multiyear effort to shift limited resources from institutional to home and community-based care has been focused on the care recipient, not on the family caregiver or the family unit.

Prior to the passage of the NFCSP under the Older Americans Act Amendments in 2000, caregiver support was not a policy issue or an interest of state leaders in Alabama. Respondents noted that Alabama is just beginning to recognize that family caregivers need support services and is now taking a more "family systems" approach. Virtually all respondents commented that family caregivers are a "new client population" in Alabama. One respondent commented, "The limited public dollars for

a Another 1915 (c) waiver, approved in 1992 and administered by the Department of Rehabilitative Services, is known as the "homebound waiver" and targeted for the younger disabled with severe disabilities (e.g., multiple sclerosis, traumatic brain injury). Respite care was initially a covered service. It wasn't used because many of the younger disabled did not have family caregivers, however, so it was eliminated from the waiver and is no longer covered. A third 1915 (c) waiver serves individuals with mental retardation or developmental disabilities and is administered by the Department of Mental Health and Mental Retardation. In FY 2002, a new 1915 (c) waiver will begin for Alzheimer's disease and related dementias.

home and community-based care are focused on the care recipient, not the family caregiver.” Another observer noted that the traditional value system in the South is such that you “take care of your own for as long as possible.” These traditional values play a significant role in shaping public policy. In the rural areas especially, there are very few services; families who keep their loved ones at home must “go it alone” to provide care and receive virtually no support or assistance from the formal care system.

Two programs in Alabama specifically address the needs of persons with Alzheimer’s disease and their families. In the early 1990s, the legislature passed the Dementia Education and Training Act, thereby establishing a small state general fund program (approximately \$150,000 per year), administered by the Alabama Department of Mental Health and Mental Retardation, to provide limited education and training in the community on Alzheimer’s disease. In 2001, the ADSS received a three-year federal Alzheimer’s disease Demonstration Grant to States from the U.S. Administration on Aging (\$350,000 federal funds per year) to expand education on Alzheimer’s disease and to offer limited respite (through the AAAs) to dementia caregivers only. This federal demonstration is considered a “stand-alone” program, functioning apart from other Older Americans Act programs at the state and local levels.

Family and informal caregivers are not explicitly recognized as a central component of the current long-term care system, and the state does not yet have a system of support in place to assist family caregivers. The main publicly funded programs to address caregiver needs are the new federally funded *Alabama Cares* program administered by the ADSS (funded under the NFCSP); limited respite care through the Aged/Disabled Medicaid waiver; and the small, state-funded Alzheimer’s education program and the federal Alzheimer’s demonstration grant targeted to dementia caregivers.

Alabama Cares—the name for the NFCSP in the state—is the first program in Alabama to focus explicitly on the needs of family caregivers. Through implementation of the new federal program, the ADSS intends to build caregiver support into existing state infrastructures, primarily through the AAAs, coordination with other state departments (e.g., ADPH) and long-term care planning efforts and partnerships with existing agencies and organizations in the community.

PROGRAM BACKGROUND/DEVELOPMENT

The original impetus for Alabama’s family caregiver support program was passage of the Older Americans Act Amendments in 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. Prior to passage of the NFCSP, no statewide caregiver support program existed in the state. Alabama’s ADSS began planning for the establishment of the new program in March 2001.

Similar to the state’s other health and social service programs, the ADSS wanted to centralize policymaking and administrative decisions at the state level for the new caregiver support program. To promote public awareness of the statewide program and to assure statewide standards, the ADSS named the new caregiver support program *Alabama Cares: Caregiver Assistance with Resources, Education and Services*. At the time of the site-visit interviews, ADSS and the AAAs described themselves as being in the start-up of program development; the state and aging network had not yet completed a full year of implementation.

When developing *Alabama Cares*, the state looked at caregiver support programs in New Jersey, North Carolina and Wisconsin as models. The 13 AAAs held public forums and focus groups to involve caregivers in the planning process at the local level. The Alabama Department of Senior Services required the AAAs to have an approved area plan amendment before going out to bid for caregiver support services. Programs and services were phased in through the state's 13 AAAs between July 2001 and March 2002. The ADSS strongly recommended that each AAA establish the position of *Alabama Cares* coordinator for the purpose of managing caregiver support services at the local level. When the ADSS began planning for the program in the Spring of 2001, the department recognized that implementation of a successful statewide program would require a dedicated staff person to coordinate statewide efforts. The state *Alabama Cares* coordinator was hired in August 2001.

Most rewarding: Key informants noted the most rewarding aspect of the program's development has been the positive feedback from the community, from both family members and service providers. Prior to the development and implementation of *Alabama Cares*, there was no explicit caregiver support program in the state. Families have commented that the program "gives people hope." The respondents also stated that the flexibility from the Administration on Aging (AoA) has enabled Alabama to (1) develop statewide standards and (2) allow the AAAs flexibility to be creative in meeting caregiver needs.

Biggest challenge: According to the key informants of state officials and stakeholders, there were two major challenges of the program's development in the first year of program start-up. First is a lack of direct service workers to provide respite care, particularly in rural areas. The state is experiencing a growing shortage of direct care workers in long-term care settings. Many of the providers for respite care under *Alabama Cares* are also Medicaid waiver providers. Finalizing service contracts with providers so that families have a choice and range of service options at the local level has been a real challenge. Second, when the ADSS was designing the caregiver support program, it wanted to include a voucher program for respite as well as supplemental services that would be uniform across the AAAs. However, this first year the AAAs were not able to reach consensus on the amount of the voucher per family caregiver. As a result, families can receive more respite care or supplemental services in some of the state's regions than in other areas. While most of the AAAs voucher at \$500 per family client per year, some AAAs voucher at higher amounts, up to \$1,000 per family client per year.

To ensure that family caregivers are indeed part of the ongoing planning process for *Alabama Cares*, the ADSS, under contract with the University of Alabama at Birmingham, conducted a statewide long-term care survey in the summer of 2002, which included a series of questions on family and informal caregiving. Results will be used to shape the state's next four-year state plan on aging (FY 2003-06) and to provide caregiver data to state leaders involved in Alabama's long-term care planning efforts.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—*Alabama Cares* received \$1.74 million in federal funds, with \$579,000 in state match, for a total of \$2.3 million, or 4.6% of the overall ADSS budget. The majority of the federal funds were carried over to FY 2002. In FY 2002, the federal share of NFCSP funds was increased to \$1.98 million.

In FY 2001, the total cost of services under the Aged/Disabled waiver in Alabama was \$36.8 million. Of those funds, 15%, or \$5.4 million, was spent overall for respite care under the waiver. These two sources of limited funds and the federal Alzheimer's grant are essentially the only public dollars in the state to support and strengthen family caregivers of older persons.

Alabama has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid and to support home and community-based care. Funds have not been appropriated specifically for caregiver support services. In FY 2001, Alabama received about \$115 million in tobacco settlement revenues. Of those funds, about \$37 million were transferred to the state's general fund for Medicaid. Another \$6.3 million were specifically used for the Aged/Disabled Medicaid waiver, and \$1.8 million were used for the Senior Services Trust Fund to provide home and community-based services. Respondents commented that even though a relatively small portion of the tobacco revenues are targeted to aging-related programs, this revenue source is vital for aging programs, given the lack of state-specific funds for support services.

Key informants described the current budget situation in Alabama as “very lean” and “fragile.” The downturn in the economy has not thus far impacted services to support family caregivers. The state has not experienced any problems in maintaining the required 25% state match for *Alabama Cares*.

PROGRAM ADMINISTRATION

The ADSS sees its role in the development and implementation of the state's first caregiver support program to be in the areas of oversight, policy development, technical assistance, funding, publicity and program awareness. Policy development and program administration are centralized at the state level and moving toward a single point of entry at the AAAs. The ADSS emphasizes the development of statewide policies and standards to ensure a consistent approach to caregiver support with flexibility to meet the needs of family caregivers at the local level. The ADSS develops policies for the program with input from the AAAs.

The ADSS has focused resources on publicizing *Alabama Cares* by developing a statewide brochure, posters and a website. The posters have been placed in all of the 350+ senior centers in the state. To get a consistent message out to the public about the new program, the ADSS has developed a logo for *Alabama Cares* to promote an “identity” for the new program. The state *Alabama Cares* coordinator is a strong advocate for family caregivers and frequently speaks throughout the state to increase awareness of caregiver needs and the new Alabama support program.

State Medicaid officials did not identify a role for their agency with regard to caregiver support services in Alabama. Case study respondents frequently noted that the concept of “family caregiver support” was new to the state, even though respite care has long been covered under the Aged/Disabled Medicaid waiver.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for *Alabama Cares* is consistent with federal requirements under the Older Americans Act; the program is for family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers ages 60 and over who care for children ages 18 or younger.^b For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or have cognitive impairment. A uniform, statewide sliding fee scale is used for services such as respite care. Cost-sharing is based on the care recipient's income, rather than on the caregiver's household income. Most family caregivers served to date have been low income (below the poverty line) or low to moderate income, ADSS staff noted. The family caregiver is considered the client in the program.

Client assessment standards are uniform across the state. The ADSS in partnership with the AAAs adapted the existing client assessment tool to include a caregiver component; thus the assessment focuses on both the care recipient and the family caregiver. There are about 10 questions for the family caregiver, representing a required minimum data set. Some AAAs have added additional assessment items to their tools. As part of the assessment process, informal care is considered on a case-by-case basis in the authorization of paid services for the care recipient. The assessment with the care recipient and the family caregiver is generally conducted in person, usually in the home. Follow-up with a family client is required at least two times per year.

Eligibility for the Aged/Disabled Medicaid waiver program is consistent with federal requirements; it includes recipients of Supplemental Security Income (SSI) or State Supplementation who meet the medical criteria for Medicaid nursing home level of care. Respondents noted that the care recipient is the identified client in the program. One observer from ADPH believed that both the care recipient and the family caregiver should be considered the "client" in the waiver program, because respite care is a covered service in Alabama.

A standard application is required for all Medicaid services, including waiver services in Alabama. This is considered the assessment, and client eligibility is reassessed annually. Consistent with Medicaid policy in general, respondents noted that the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is considered in the authorization of paid services for the care recipient. Respondents acknowledged that although the state *should* assess the family caregiver's needs and ability to provide care, it currently does not; only the care recipient is assessed.

^b This includes caregivers ages 60+ who are caring for children affected with mental retardation or who have developmental disabilities.

SERVICES

Rather than focus on one specific service category, the state required that each of the AAAs make available all NFCSP core services to family caregivers in order to develop a multifaceted system of caregiver support. Following the standard assessment, the intent is to give caregivers the following menu of services to choose from to help meet their needs:

- ✧ Information
- ✧ Assistance
- ✧ Individual counseling, support groups and training
- ✧ Respite care (voucher program)
- ✧ Supplemental services (voucher program)

At the time of the site visit (March 2002), about 450 family caregivers had received services through *Alabama Cares*.

Alabama's AAAs typically are not direct service providers, but provide largely information and assistance, assessment and case management. AAAs are permitted to be direct service providers but first must request a waiver from the state. Some AAAs have requested and received waivers to provide counseling to caregivers in-house.

All 13 AAAs subcontract with local providers for respite care through a voucher program, including in-home, adult day services (where they exist), overnight in a facility and weekend respite options. Respondents noted that the cost per hour for a respite provider in Alabama is typically between \$10.00 and \$14.50 per hour. The family caregiver gets the voucher and a list of service providers for respite and supplemental services (e.g., home modifications). The family client is responsible for selecting a provider and arranging services. In Alabama, about 70 to 80% of the AAAs' NFCSP allocation is for respite assistance. Because of the newness of the program, including the concept of "respite care" and "getting a break," the state *Alabama Cares* coordinator has encouraged the AAAs to focus attention on education and training, particularly in the start-up year of the statewide program. Education is needed to inform family caregivers about the benefits of respite care for themselves as well as for the care recipient.

Given the limited funding overall, there is a cap on the amount of respite and supplemental services per family caregiver. The cap varies from one AAA to another, typically at \$500 per year, resulting in a limited respite benefit. State officials noted that a few AAAs are vouchering for respite at up to \$1,000 per year. According to key informants, the respite component, however limited in funding, is filling an important service gap by providing at least minimal respite assistance—as a preventive service—to family caregivers who are not eligible for respite under the Medicaid waiver because their loved one is not severely functionally impaired.

Under the Aged/Disabled Medicaid waiver, respite services are the only service type specifically provided for family caregivers, up to 720 hours per year. Covered respite services include both skilled and unskilled in-home respite assistance and adult day health services. Waiting lists exist for all Medicaid waiver services, not just for respite care. Respondents expressed hope that the new *Alabama Cares* program will offer respite assistance to family caregivers who don't qualify for waiver services so that they can get some relief: to those in the low-middle income group who care for loved ones not severely functionally disabled. The Medicaid waiver officials identified the need to provide education and skills training for caregivers. This is currently not covered under their waiver, but respondents pointed out that many families lack the necessary skills to provide care at home.

Major services needed by caregivers: At the ADSS, supplemental services were identified as the major service category needed by family caregivers. Supplemental services are allowable under the federal NFCSP on a limited basis to complement care provided by caregivers. (No more than 20% of the federal funding should be used in this service category.) Examples of supplemental services provided in Alabama include chore services (e.g., putting running water in a caregiver's home that doesn't have the necessary equipment), wheelchair ramps, emergency response systems and barber services in the home. State officials at the ADSS also identified major service needs as education and training about caregiver issues in general as well as respite care. Several waiver key informants pointed to the need for better resource coordination to guide families through the service delivery system. Stakeholders noted respite care as the major service needed by family caregivers, followed by supplemental services (e.g., consumable supplies, home modifications).

Table 2. Family Caregiver Support Services in Alabama

Program	<i>Alabama Cares</i>	Aged/Disabled Medicaid Waiver
State Administrative Responsibility	Alabama Department of Senior Services	Alabama Medicaid Agency contracts with Alabama Department of Senior Services (ADSS) and Department of Public Health (ADPH)
Local Service Delivery	AAAs ^a —information, assistance, assessment & case management ^b (AAAs are not direct service providers but contract for respite care & supplemental services)	AAAs—case management only (under contract with ADSS) County Public Health Departments—case management and service provision (under contract with ADPH)
Funding Source	Older Americans Act, Title III-E	Medicaid 1915(c) waiver
Expenditures FY 2001	\$1.74 million ^c (for all caregiver support services)	\$5.4 million (for respite care only)
Client Population	Family & informal caregiver	Care recipient
Eligibility Criteria		
Age	60+ care recipient Family caregivers of any age	18+ care recipient
Income	None	SSI or State Supplementation
Functional Ability	For respite and supplemental services—at least 2 ADLs or cognitive impairment for care recipient	Nursing home level of care
Uniform, Statewide Caregiver Assessment	Yes	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care
Respite Cap	Varies by AAA from \$500 to \$1,000/year \$500/year average	720 hours/year
Consumer Direction	Not formally. Some elements of consumer direction are offered. Family caregivers can choose own provider from voucher list of home care agencies and can set number of hours of help they need. They can also purchase goods & services (e.g., consumable supplies, home repairs) under the supplemental services category.	No
Family Caregivers Paid as Respite Providers	No	No

a AAAs = Area Agencies on Aging.

b Some Alabama AAAs have received a waiver to provide caregiver counseling in-house.

c Federal funds only; the majority of federal funds were carried over to FY 2002.

CONSUMER DIRECTION

Neither *Alabama Cares* nor the Aged/Disabled waiver offers a formal consumer-directed option, and neither program permits payment to family caregivers to provide respite care. Respondents commented that there is the perception in the state that quality control and fiscal accountability could be lost if consumer direction were allowed. The ADSS observers commented that the respite and supplemental services voucher system of *Alabama Cares* makes some elements of consumer direction available. Family caregivers can choose their own provider from the list of voucher home care agencies, for example, and can set the number of hours of help they need. Allowable benefits under the supplemental services voucher include goods and services—whatever the caregiver needs to keep a loved one at home.

The Medicaid officials pointed out that Alabama would soon be permitted to offer consumer direction to younger persons with disabilities only under their homebound waiver.

QUALITY ASSURANCE AND EVALUATION

The state has developed a uniform client enrollment and tracking procedure for family caregivers served in *Alabama Cares*. All AAAs are required to use the standard assessment form for the caregiver (known as the Client Enrollment Form), which includes basic demographic data on the family caregiver (e.g., relationship to care recipient, age, gender, race), an assessment of informal supports and constraints on the caregiver (e.g., employed, lacks knowledge/skills), a stress vulnerability survey and a nutritional risk survey. The information is then transferred to the state's information management system. Caregiver data collection is in a manual format. The state is in the process of automating the entire data collection system for a coordinated, centralized statewide client tracking system.

Alabama is collecting data on caregiver outcomes through its uniform assessment process, particularly the stress vulnerability survey. This 21-item measure was developed by Lyle Miller and Alma Dell Smith, psychologists at Boston University Medical Center, and adapted for use by ADSS and Alabama's AAAs.

Given the early stage of development of *Alabama Cares*, the state has made strong progress in setting and refining program standards, developing a uniform yet flexible approach to service delivery and structuring quality assurance activities to ensure that services provide value to family caregivers. The state, in partnership with the AAAs, has developed regional program standards and minimal indicators for a number of functions, including client file maintenance, coordinator training, media activities, outreach, partnership development and targeting for underserved populations. In this way, the state ensures a consistent, uniform approach to serving family caregivers. Exhibit A highlights examples of program standards and minimum indicators to track performance.

Under the Aged/Disabled Medicaid waiver, respondents noted that no information is currently collected on family caregivers. In general, this is because the “client” of the program is viewed as solely the care recipient.

Exhibit A. *Alabama Cares* Selected Regional Program Standards: Targeting Underserved

<i>Definition of Targeting Underserved:</i> Specifically directing information and/or programs to the socially and/or economically underserved through various outreach methods.	
Standard	Minimum Indicator
1. Each Coordinator will strive to develop and/or use culturally sensitive material for ethnic caregivers.	1. Coordinators should research ethnicities and their respective feelings towards the receipt of outside assistance as well as the traditional role of the family in caregiving.
2. Each Coordinator will strive to alleviate the reservations held by various groups about enlisting the assistance of social service agencies.	2. Coordinators should develop a trusting relationship and credible reputation with community leaders in order to be more effective and accepted in the community.
3. Each Coordinator will strive to hold meetings, trainings, etc., in locations that are easily accessible and comforting to the family caregiver.	3. Coordinators should hold meetings in the “comfort zones” in the underserved community, so as to foster greater participation of, and connectivity with, family clients.

Source: Alabama Department of Senior Services, Regional Program Standards, October 2001.

SYSTEMS DEVELOPMENT

Alabama Cares has been well received in its first year of start-up by both family caregivers and service providers in the community, according to the key informants. It has been important to provide centralized policy development, program standards and administrative oversight while at the same time encouraging flexibility in service delivery at the local level to meet family needs.

Key informants from the Medicaid waiver program hope that the new federal dollars for family caregiver support under *Alabama Cares* will assist family members who “fall between the cracks”—those who are ineligible for Medicaid services but who have few resources to purchase services on their own.

At the time of the site visit, the state had not yet completed the first year of program implementation. The state, in partnership with the AAAs, will continue to refine the process and procedures and to focus on increasing the visibility of family caregivers in Alabama.

In the emerging system of support, caregiver services are coordinated at the local level by the 13 AAAs. At the state level, services are coordinated at ADSS, primarily through the state *Alabama Cares* coordinator, who interacts frequently with coordinators at the AAA level. Respondents during the Medicaid interview noted that caregiver support services are not yet coordinated at the state level, however.

Alabama does not have a body whose mission is to coordinate family caregiver support services across state departments. The development of a long-term care system is just beginning to take hold in the state, and the ADSS is interested in including family caregivers in policy discussions in the future. All respondents stated that a goal of the new *Alabama Cares* program is to integrate the caregiver support program into Alabama's emerging long-term care system rather than to develop a stand-alone program.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In January 2000, the governor appointed a long-term care task force to advise his administration on how to improve long-term care services for older persons and to promote home and community-based care. Key informants noted that family caregiving issues have not been an issue of debate.

Alabama received a grant from the Center for Health Care Strategies to develop a comprehensive plan in response to the *Olmstead* decision. Officials from the long-term care division of the Alabama Medicaid Agency are spearheading this effort. ADSS officials expressed some frustration that the state has not involved family caregivers of the elderly in the planning process. *Alabama Cares* was a brand-new program when *Olmstead* planning began, and with minimal funding and limited staff, efforts were directed to "getting the caregiver support program off the ground," rather than to developing policy in long-term care. Although the primary focus of the governor's task force has been to seek ways to expand home and community-based services for older people and for younger persons with disabilities, family caregiver issues have yet to be addressed in the state plan.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high, medium, low) is placed on caregiver support?" Key informants interviewed felt that, overall, Alabama tended to place "low" to "low-medium" priority on caregiver support services. One state official did not offer an opinion. State officials and stakeholders did not differ in their responses.

Number of Key Informants	Priority on Caregiver Support
2	→ Low
1	→→→ Low - Medium
1	→→→→→ High

Benefits and challenges: Alabama case study respondents identified three aspects of their program that are most beneficial to family caregivers:

1. The general support afforded to family caregivers—just knowing the program exists is a "life line" to families
2. The new focus on caregiver assessment—to better understand the needs of individual caregivers and the impact of caregiving on their quality of life
3. Respite care—to give families a break, particularly for family caregivers not eligible for respite under the Medicaid waiver

The following challenges were reported:

- ✧ Lack of trained direct care providers
- ✧ Need to get the aging network and those who work with the elderly to broaden their focus to address the needs of family caregivers, not just the needs of the older person, as client
- ✧ Limited funding to meet the needs of individual caregivers (Older Americans Act and Medicaid)
- ✧ Lack of skills training for caregivers (Medicaid)

Major lesson learned: Alabama's respondents expressed a belief that "the need is great and resources are few" in their state. In the first year of start-up of *Alabama Cares*, several respondents commented that some families who need help the most are reluctant to use services. Family caregivers need to be educated about service options and how they can be of help to both the caregiver and the care recipient.

Other case study respondents from the Aged/Disabled Medicaid waiver program pointed to the need for more flexibility by the federal government (i.e., CMS) and the state in allowing more consumer direction, including paying families to provide care. To address this and other issues, the state plans to review its entire Medicaid program over the next few years. One observer commented, "Medicaid rules are not flexible. Now, Alabama consumers are on the Internet and they know that other states are more flexible than we are. We must allow more flexibility to meet family needs."

Opportunity for expanding caregiver support: All Alabama respondents were pessimistic about new initiatives or state expansion of state-funded programs to support and strengthen family caregivers over the next three to five years. Alabama has historically not provided health and human services programs beyond minimum federal requirements or established programs with state revenues. Nevertheless, over the past few years, the budget for the state's ADSS has grown from \$30 million to \$50 million, and the key informants—both state officials and stakeholders—want to keep the momentum for growth and to focus on caregiver issues.

Recommendations for other states: Key informants offered several recommendations based on their experience to date:

- ✧ Don't reinvent the wheel.
- ✧ Involve all stakeholders in planning and program implementation.
- ✧ Pursue partnerships and collaborate.
- ✧ Be flexible and don't overregulate.
- ✧ Recognize that caregiver needs and situations vary (e.g., rural vs. urban, ethnic differences, income level).
- ✧ Be optimistic.

NOTES

- 1 MapStats-Alabama, *www.fedstats.gov* (June 2002).
- 2 Alabama Department of Senior Services, *State Plan on Aging: 1999-2002*.
- 3 Ibid.
- 4 U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000," (news release), *www.bea.doc.gov/bea/newsrel/spi0401.htm* (2001).
- 5 MapStats-Alabama.
- 6 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, *www.governing.com/source.htm*. Source for Internet access is the National Telecommunications and Information Administration, 2001.
- 7 Ibid.
- 8 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group*, *www.aoa.gov/aoa/stats/2000pop/percentxstate.html* (April 1, 2000).
- 9 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Percent of Persons 60+ by Race and Hispanic Origin-by State-2000*, *www.aoa.gov/aoa/stats/2000pop/percent60plusrace-ho.html*.
- 10 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States*, *www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html* (2000).
- 11 P. Arno and M. Memmott., *Estimated Value of Informal Caregiving: Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- 12 B.A. Ormond and A. Wigton, *Recent Changes in Health Policy for Low-Income People in Alabama*.(Washington, D.C.: The Urban Institute, 2002).
- 13 The Alabama Medicaid Agency, the state's "single state agency" for Medicaid, directly administers the nonwaiver home and community-based Medicaid program.



OVERVIEW

California is the largest state in the nation, with about one of every eight people in the United States living within its borders.¹ The state has a sizable foreign-born population and is distinguished by its ethnic and racial makeup. Compared to the nation as a whole, California has a much greater proportion of Hispanic and Asian older persons and a smaller proportion of African American older persons.

California has a wide array of publicly funded long-term care programs administered by many state departments having different eligibility requirements, target populations and services. As a result, the state's home and community-based service system and caregiver support services are considerably fragmented, impeding policy reform and system coordination. Despite recent budget challenges, the state's efforts to expand long-term care options and support for families include the enactment of a \$500 state caregiver tax credit in 2000; moderate state general revenues directed at home and community-based care and caregiving support; and, most recently, the enactment of the first paid family leave law in the United States.

Policy attention to caregiver support services has been an explicit component of California's long-term care system since 1979, when a pilot project created the first prototype of a Caregiver Resource Center (CRC) system. A statewide CRC program was enacted in 1984 and is administered by the California Department of Mental Health (DMH); 11 CRCs now serve California's family caregivers of adults with cognitive impairment and with other chronic conditions. California's CRC system was one of the models on which the National Family Caregiver Support Program (NFCSP) was based. With the enactment of the NFCSP through the aging network and the California Department of Aging, the state's caregiver support services are now characterized by:

- ❖ Multiple caregiver support programs and services administered by various state agencies
- ❖ A unique administrative structure whereby two well-developed systems that serve large populations of older persons and their caregivers are currently managed not by the state's aging department but by its mental health and social services departments
- ❖ A large and growing state- and county-funded in-home supportive services program, also funded by Medi-Cal (California's Medicaid program), with consumer direction and direct payment to family caregivers
- ❖ Flexibility to meet the individual needs of family caregivers at the local level

California respondents noted that the major service needs of family caregivers are (1) respite, (2) family consultation, (3) support groups, (4) caregiver education and training and (5) assistance in finding formal care providers.

As California continues to expand its caregiver support programs, a key consideration will be how the state reduces fragmentation and coordinates among the state's multiple services and programs that provide support to California's family and informal caregivers.

INTRODUCTION

California represents an “old” state that provided caregiver support services prior to the passage of the NFCSP. The project team conducted in-person site visits and telephone interviews between June 12 and July 19, 2002, with government officials and key stakeholders. The team interviewed staff from the following state agencies and programs within those agencies:

California Department of Aging

- ✧ Family Caregiver Support Program (NFCSP funded)
- ✧ Aged Medicaid waiver (Multipurpose Senior Services Program)
- ✧ Alzheimer’s Day Care Resource Center (state funded)
- ✧ Alzheimer’s Day Health Care (federally and state funded)

California Department of Health Services

- ✧ Aged Medicaid waiver (Multipurpose Senior Services Program)

California Department of Mental Health

- ✧ Caregiver Resource Centers (state funded)

California Department of Social Services

- ✧ In-Home Supportive Services (federally and state funded)

California Health and Human Services Agency

- ✧ Long-Term Care Council (state funded)

Stakeholders interviewed were from:

- ✧ Alzheimer’s Association, California Council
- ✧ California Association of Adult Day Services
- ✧ California Association of Area Agencies on Aging
- ✧ California Association of Caregiver Resource Centers
- ✧ University of California at Berkeley, School of Social Welfare

Six programs are featured in this profile:

1. California NFCSP
2. Caregiver Resource Center System
3. In-Home Supportive Services
4. Aged Medicaid waiver
5. Alzheimer’s Day Care Resource Center
6. Adult Day Health Care

BACKGROUND

California is the largest state in the nation, with a population of 33.9 million residing in 58 counties.² The state is “highly urban” with metropolitan areas of more than 1 million people accounting for about three-fourths of the total population.³ California also has the highest concentration of immigrants in the nation, with foreign-born residents representing around one-quarter of the population.⁴

In 2000, personal income per capita was \$32,275, compared to the national average of \$29,676.⁵ About 16.0% of California's population live below the federal poverty level (vs. 13.3% U.S.).⁶ California ranks 10th nationally in percentage of households with Internet access.⁷ Compared to the national average, California has half the proportion of African Americans (6.7% vs. 12.3% U.S.) and a significantly greater proportion of Hispanic persons (32.4% vs. 12.5% U.S.)⁸ (table 1).

An estimated 4.7 million persons in California, or 14.0% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). California ranks 46th nationally in its proportion of older residents (ages 60+).⁹ As with the state's population as a whole, California has a smaller proportion of African Americans ages 60+ as compared to the national average (5.3% vs. 8.4% U.S.) and a much greater proportion of Hispanic older persons (14.3% vs. 5.4% U.S.).¹⁰ Of note is California's population of Asians ages 60+, which is almost five times the national average (10.2% vs. 2.5% U.S.).

California ranks 43rd nationally in the proportion of its population ages 85 and older. In 2000, 425,657 persons, or 1.3% of California's population, were ages 85+.¹¹

An estimated 3 million family caregivers reside in California. These family caregivers provide about 2.8 billion hours of caregiving per year at an estimated value in 1997 of \$22.9 billion.¹²

Although the tax burden on California residents is about the same as the national average (\$11.34 per \$100 vs. \$11.30 U.S.),¹³ California's budget depends heavily on personal income tax and investment-related income (i.e., capital gains and stock options). The economic downturn has been especially severe in this huge state. In 2002, California experienced a \$23.6 billion deficit, stemming from a drop in personal income tax collections in 2001–02 and 2002–03.¹⁴ Forecasts suggest that the state will face substantial budget deficits for at least the next few years.¹⁵

Table 1. Selected Characteristics of CALIFORNIA and the UNITED STATES, 2000 ^a

	California	United States
Total Population Characteristics		
Total Pop. ^b	33,871,648	281,421,906
% African American ^c	6.7%	12.3%
% Hispanic ^d	32.4%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	4,742,499	45,797,200
% 60+ ^f	14.0%	16.3%
National ranking 60+ ^g	46	NA
Pop. 65+ ^h	3,595,658	34,991,753
% 65+ ⁱ	10.6%	12.4%
National ranking 65+ ^j	46	NA
Pop. 85+ ^k	425,657	4,239,587
% 85+ ^l	1.3%	1.5%
National ranking 85+ ^m	43	NA
% increase 1990–2000 60+ pop. ⁿ	12.0%	9.4%
% White (60+) ^o	67.9%	82.4%
% African American (60+)	5.3%	8.4%
% Hispanic (60+)	14.3%	5.4%
% Asian (60+)	10.2%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.2%	0.1%
% Amer. Indian/Alaska Native (60+)	0.4%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	3,009,523	25,798,370
Caregiving hours (millions) (1997)	2,801.3	24,013.1
Value of caregiving (millions) (1997)	\$22,914.3	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$32,275	\$29,676
% of pop. below poverty (1997) ^r	16.0%	13.3%
Internet		
% of households w/Internet access (2001) ^s	46.7%	41.5%
Nat'l ranking of households w/Internet access	10	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-California, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-California.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

California has a complex system of agencies and departments through which aging, health and social services are administered. The umbrella agency is the California Health and Human Services Agency (CHHSA). Of its 15 boards and departments, four oversee (either explicitly or implicitly) services that support family and informal caregivers: the California Department of Aging (CDA) and the California Department of Mental Health (DMH) explicitly; and the California Department of Social Services (DSS) and the California Department of Health Services (DHS) implicitly. California has committed sizable state general funds to programs that support family caregivers within all of these agencies except the DHS.

In 1999, CHHSA established the Long-Term Care Council^a to improve system coordination of long-term care, including the state's efforts to develop a more integrated system of home and community-based services and supports for family and informal caregivers. The council is composed of the heads of eight CHHSA departments that provide long-term care services.

The CDA serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP, among other programs. The governor appoints the director, who reports to the secretary of CHHSA.

a The council was authorized in A.B. 452 (chapter 895, statutes of 1998).

The infrastructure of California's aging network is a statewide system of 33 Area Agencies on Aging (AAAs) that serve areas ranging in area from part of one county (the city of Los Angeles) to five counties. Nineteen of the 33 AAAs are units of county government, six are private nonprofit agencies, six have "joint powers agreements,"^b one is co-located within a university and one is a unit of city government. In 1979, the AAAs incorporated the California Association of AAAs (C4A), whose mission is to, "develop a statewide system of comprehensive and integrated home and community-based services for older persons and adults with disabilities through advocacy, coordination, and education."¹⁶ Currently, 32 of the 33 AAAs are members.

California has six Medicaid waivers providing home and community-based services to different populations. The one that specifically serves the frail elderly as the Aged Medicaid waiver is known in California as the Multipurpose Senior Services Program (MSSP). It was originally approved in 1977 as a four-year demonstration and research project. The program provides case management and a range of other home and community-based services. The DHS is responsible for oversight as the "single state agency" for Medicaid. The DHS contracts with CDA to administer the program to approximately 14,600 unduplicated beneficiaries in the state (11,789 slots).

California also has the first state-funded program providing explicit family caregiver support in the country, the CRC system, administered through the DMH. The DMH, in turn, contracts with regionally based CRCs to provide an array of caregiver services. DMH also contracts with the Statewide Resources Consultant (SRC) to operate a statewide information and technical assistance clearinghouse. To aid DMH in the implementation of the CRC system, the SRC provides consultation, training, research and technical program assistance to the CRCs and other organizations in the state. The prototype for this system was first funded through a pilot project in the San Francisco Bay Area in 1979. A statewide system was phased in between 1985 and 1989. Currently, 11 nonprofit CRCs serve the entire state; they served more than 14,000 caregivers in FY 2001–02.

The DSS administers the sizable statewide In-Home Supportive Services (IHSS) program, launched in 1973. That program receives significant state general funds, county funds and federal Medicaid dollars (through the Personal Care Services Program). IHSS provides 25 home care services, including respite care, to elderly individuals and people with disabilities who need assistance to remain in their homes. More than 274,000 clients were served in 2001, of whom about 60% were 65 years or older.

The DHS administers the California Partnership for Long-Term Care; California is one of four states in the country to have implemented a public/private partnership to provide long-term care insurance. Californians have the option to purchase an approved long-term care insurance policy that includes an asset protection component and respite care benefits for family caregivers. Under the program, for each dollar that a consumer's policy pays out in benefits, the consumer may shelter a dollar of assets for Medicaid eligibility purposes.¹⁷

^b In California, a "joint powers agreement" is a quasigovernmental body composed of local government officials, generally from several different counties, that have joined together.

The DHS also oversees nine sites for the diagnosis and treatment of Alzheimer's disease, known as Alzheimer's Disease Research Centers. These state-sponsored university medical centers provide clinical assessments of individuals with memory problems, family conferences and treatment planning following the evaluation, support groups for caregivers and training and education for professionals and family caregivers.

In 2002, the DSS was awarded a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS). The DSS will use the approximately \$1.4 million to:¹⁸

- ✧ Develop training, educational materials and other methods of support to aid IHSS consumers so that they can better understand IHSS and develop the skills required to self-direct their care
- ✧ Identify training and other support needs of IHSS providers and create materials, tools and work aids that will enable providers to improve the quality of care they provide
- ✧ Develop training and work aids to enable IHSS social workers to perform better IHSS needs assessments, particularly for disabled children and persons with cognitive and psychiatric disabilities
- ✧ Assist county eligibility workers to properly assess eligibility for disability-related programs

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT ^c

In California, several laws provide explicit recognition of family and informal caregivers. State statute has recognized family caregivers since 1979, when the first piece of legislation that laid the groundwork for the state's CRC system was enacted. In 1984, legislation replicated the CRC system statewide. As part of the governor's *Aging with Dignity* initiative in 2000, a modest \$500 caregiver tax credit was enacted to provide at least some assistance to cope with the oftentimes high costs associated with providing care for a loved one. The initiative also included a series of long-term care "innovation" grants, training and rate increases for some formal care providers and other components. Most recently, in 2002, California passed the first paid family leave bill in the nation, expanding on the federal family and medical leave act by providing up to six weeks of paid leave (100% employee funded) for workers who need to care for a new child or a seriously ill family member.

California has historically invested state general funds in developing in-home and community-based services for older persons. Although there has been some Medicaid expansion in recent years, the focus has been on the State Children's Health Insurance Program (S-CHIP), rather than on long-term care services. Current growth has been constrained by Medicaid budget shortfalls, and by a relatively fiscally conservative governor, Gray Davis (D), whose focus has been on education and other services for children.¹⁹

^c For information on Program Background/Development on California's programs serving family and informal caregivers, see Family Caregiver Alliance's October 1999 *Survey of Fifteen States; Caregiver Support Programs: Final Report*.

Considerable fragmentation characterizes the California system, with programs administered out of various departments having different eligibility requirements, services and target populations. Many of California's publicly funded programs providing caregiver support predate the passage of the NFCSP under the Older Americans Act Amendments of 2000. The most significant program is the state-funded CRC system administered by the DMH. With the passage of the NFCSP under the Older Americans Act, another state department, CDA, began administering caregiver support with the federal NFCSP dollars. Thus, the CDA and the DMH both administer programs that support caregivers directly. The DMH's well-established CRC program focuses on caregivers of adult-onset brain diseases/disorders and dementia and operates through 11 contracts with nonprofit agencies to deliver a wide array of services, whereas CDA's NFCSP serves a more broadly defined population, consistent with Administration on Aging (AoA) guidelines, and provides funding, via a formula, to the state's 33 AAAs. In turn, the AAAs either provide caregiver support services directly or subcontract with service providers in the local community. Initially there was tension between the two programs, but at the time of the site visit, state officials from both administering departments, as well as a variety of stakeholders, reported that the two programs are increasingly working together to collaborate and to avoid—to the degree possible—duplicative administration and service delivery. The AAAs, for example, are using some of their NFCSP dollars to subcontract with many of the CRCs to provide caregiver support services.

Family caregivers also benefit indirectly through several other CDA programs and the DSS-administered IHSS. Significant CDA programs that assist family and informal caregivers are the Alzheimer's Day Care Resource Centers (ADCRC), Adult Day Health Care (ADHC), the Aged Medicaid waiver (the Multipurpose Senior Services Programs, or MSSP), Linkages (a case management program) and the Senior Companion program.

California state officials concurred that family and informal caregivers are explicitly recognized as a central component of the current long-term care system. One state government respondent tied the higher recognition to the increasing number of public policymakers who are facing their own caregiving issues. While programs still tend to focus on the beneficiary for targeting services, the respondent saw an increasing recognition of the informal support network within all of California's programs. Stakeholders did not agree. One asked, "Are we all agreeing that there *is* a comprehensive long-term care system that caregivers can be a central component of?" Another said that there is some recognition, but so much that family caregivers do and pay for is taken for granted, and that it is a real frustration. The fact that the IHSS program pays family caregivers is positive, the respondent pointed out, particularly since other states do not have programs of this magnitude. One stakeholder observed that significantly greater funds would be invested in respite care, family training and other supports if caregivers were truly recognized.

Most rewarding: Key informants noted that the significant influx of funding for caregiver support services has been most rewarding. The secondary impacts of the NFCSP have also been rewarding, CDA officials said, providing the example that the state's Health Insurance Counseling and Advocacy Program (HICAP) has a caregiver component.^d Respondents felt that the focus on caregiving would

^d California was one of 13 states to start a state-funded HICAP program before federal funds were made available from CMS in 1992.

bring more people together, encouraging them to get out of their “silos” to work more collaboratively and serve a broader array of individuals. Informants from the DMH pointed to the quality of care being delivered by the CRCs as most rewarding. The most rewarding aspect IHSS officials identified in their program is that it has worked to keep people at home.

Biggest challenge: The range of challenges cited by key informants reflected the different stages of development among California’s caregiver programs. For the NFCSP, respondents from CDA identified:

- ❖ Procurement of the state match; AAAs are concerned that they may not be able to come up with the funds
- ❖ Implementation of the program and the distribution of funds in a reasonable time frame
- ❖ The “tug” between state standards and local flexibility
- ❖ The demands and complexities of implementing a new program that represents a major paradigm shift to serving the caregiver, rather than directly serving the care recipient (i.e., the older person)

DMH officials cited funding issues as the biggest challenge, saying that there is so much need and not enough money, with a long waiting list of people who need services. From the DHS perspective, the biggest challenges were that the Aged Medicaid waiver was not yet available in all counties and that providing all the necessary home and community-based services while still remaining cost neutral was difficult. The complexity in administering the IHSS program was the biggest challenge identified by DSS informants.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—California’s NFCSP received \$10.8 million in federal funds. That sum represents 8.8% of the overall CDA budget. In FY 2002, California received about \$12.6 million for the NFCSP. Exhibit A shows funding levels for other CDA programs that provide some caregiver support services.

Exhibit A. FY 2001–02 California Department of Aging Program Expenditures

	State General Funds	Federal Funds
ADCRC	\$4.2 million	\$355,000
ADHC	\$1.3 million	\$1.4 million
Linkages	\$8.1 million	none
MSSP ^e	\$833,000	\$879,000

For FY 2001–02, the DMH expended \$11.7 million in state general funds for the CRCs. While that sum approximates California’s federal NFCSP funding, it is a small proportion of DMH’s overall budget of \$2.13 billion.²⁰

^e These funds are for state operations. MSSP also receives significant “local assistance” provided by DHS. For FY 2001–02, DHS provided \$38.5 million.

For FY 2001–02, the IHSS program had a state general funds allocation of \$72.4 million, which represents about 2.5% of the total DSS budget.²¹ Key informants noted that counties contribute another 17% for IHSS. The nonfederal portion (referred to as “residual”) represents 20% of IHSS funding, according to informants; Medicaid covers the other 80%. California maintains a residual program, in large part, so that spouses or parents can be paid providers of IHSS, which Medicaid rules do not allow.

For FY 2001–02, the total cost of services under the Aged Medicaid waiver (MSSP) in California was \$40.2 million.

California can expect to receive \$25 billion in tobacco settlement revenues over the next 25 years.²² The settlement revenues are divided as follows: 50% to the state, 40% to the counties and 10% to the state’s largest cities of Los Angeles, San Diego, San Francisco and San Jose. California has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid, although not specifically to expand home and community-based care. For FY 2002, the governor allocated \$170 million for Medicaid, a smaller proportion than originally planned.²³ In response to the state’s growing fiscal crisis, the governor instead dedicated more tobacco settlement monies to the state’s reserve account.

Major fiscal challenges await California as state leaders struggle to address the approximately \$24 billion budget shortfall. Stakeholders and state officials alike saw California’s budget situation as a crisis state. One state official called it “catastrophic” and “unprecedented;” another said it was “dismal.” Stakeholders characterized the budget situation as “dismal and likely to remain grim for two to four years” and “bad...extremely bad.”

At the time of the site visit, few state officials reported major cuts to their programs and services. One respondent, however, emphasized that innovation was likely to suffer and that, with the threat of state job cuts, justifying new staff for program development was a challenge. Administrative cuts for IHSS at the local level had been proposed, DSS officials noted. (Social workers, employed by County Departments of Social Services, do the assessments, authorize services and sometimes assist clients in hiring and overseeing individual providers.) With regard to the NFCSP, officials said that it would be challenging to come up with the required NFCSP matching funds, which currently must come from the CDA budget. In 2001, California used a series of innovation grants from the governor’s *Aging with Dignity* initiative that had been awarded to some of the AAAs as the source for the required match. With the innovation grants no longer available and with no new state general funds allocated, CDA officials reported that some AAAs were very worried that they would be unable to come up with the required match.

PROGRAM ADMINISTRATION

CDA officials see their agency's role in the development and implementation of the NFCSP as one of planning, policy development, administration, coordination, priority setting and evaluation of all state activities related to the objectives of the program. In turn, they view the AAAs as "having a far-reaching mandate for program administration, planning and coordination." As one respondent put it, "AAAs are responsible for the development of service systems that include not only program components directly administered by the AAA, but also those administered by other agencies." Although the CDA has focused on developing state standards, one stakeholder indicated that the flexibility provided to the AAAs means inconsistency across Planning and Service Areas (PSAs) in terms of services, assessment and reporting requirements. In this regard, CDA officials commented that the balance between statewide standards and local flexibility is a delicate one and thought the issue would evolve as program implementation continued.

Publicity efforts for the NFCSP are mainly being conducted by the AAAs through newsletters, billboards, public service announcements and cable television program appearances. Innovative "info vans" are providing mobile outreach to caregivers, which is particularly useful in rural areas, CDA respondents pointed out. One stakeholder characterized the vans as "Information and Assistance on wheels." Currently, 24 AAAs operate a total of 35 vans, most of which have been purchased directly by the AAAs.

The DMH respondents identified their role as a collaborative one involving the CRC Association (made up of the 11 CRC programs) and the SRC. The 11 CRCs administer the program at the regional level, and the SRC provides statewide coordination and technical assistance.

The DSS is the administering agency for the IHSS program and is responsible for statewide policy and the appeal process. At the local level, counties carry out day-to-day operations and policy implementation and are responsible for establishing and determining eligibility and authorizing services. Respondents underscored the increasing importance of Public Authorities, California's regional municipal governing bodies, as well. The DSS engages in many activities, with a focus on maximizing federal Medicaid reimbursement.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for California's NFCSP mirrors federal requirements under the Older Americans Act: It is for family or informal caregivers of any age who provide care to persons 60 years or older and for caregivers ages 60 or over who are caring for children age 18 or younger.^f For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or two instrumental activities of daily living (IADLs). The family caregiver is considered the client in the program.

^f Including caregivers 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

Uniform client assessment standards are not used in the NFCSP. The CDA is working to develop such standards for the NFCSP, possibly refining the assessment tool that they use for the Aged Medicaid waiver (MSSP) and the Linkages program, with the hopes of having one consistent tool used for all three programs. State officials noted that they also have consulted with the state's CRCs on the use of their caregiver assessment tool in these programs.

The DMH has uniform assessment standards across the 11 CRCs; the CRCs all utilize the same in-home caregiver assessment tool. For the CRC system, caregivers of adults (ages 18 and over) with adult-onset cognitive impairments are eligible for services. There are no income eligibility requirements. The family caregiver is considered the client in the program.

Both the IHSS and the Aged Medicaid waiver programs have uniform assessment standards, although each uses a different instrument. In both programs, the care recipient is the identified client. DSS officials noted that the IHSS assessment instrument, which collects data that become part of the state's Case Management Information and Payroll System (CMIPS), has no questions about family and informal caregivers. Informal care is taken into account in the authorization of paid services for the care recipient. Informal care is identified as an "alternative resource" available to the care recipient. Within the Aged Medicaid waiver, state officials indicated that the informal care provided by family caregivers does not have a tremendous impact; because many Medicaid waiver clients also use IHSS services, however, the amount of informal care is considered in authorizing personal care and other services.

Eligibility for the Aged Medicaid waiver is consistent with federal functional eligibility requirements: Enrollees must meet medical criteria for Medicaid nursing home level of care. For the IHSS program the care recipient must be at least 65 years of age, blind or disabled and eligible to receive Supplemental Security Income (SSI). Income eligibility standards, known as "share of cost," are also somewhat flexible in the IHSS program. Share of cost allows those whose income is above the SSI threshold to maintain eligibility for the programs, provided they make a contribution based on both income and amount of authorized services. Generally speaking, share of cost provides the greatest assistance to those whose income is not substantially above the income limits and who have a high level of need.

SERVICES

Although some of California's AAAs provide services in all five NFCSP service categories, each AAA is not required to provide every service. AAAs may provide services directly or through a subcontract with other providers. The availability of services depends upon the AAA's particular community and the needs identified through the area planning process. CDA respondents indicated that they had mapped a "service matrix" to track the various services that each AAA offers. Services include outreach, community education, information and assistance, comprehensive assessment, case management, transportation, assisted transportation, counseling, caregiver support groups, caregiver training, respite care, minor home modification, placement, homemaker and chore services, home security and safety, visitation, assistive devices, home-delivered meals, legal assistance, peer counseling, translation services and income support/material aid. Many AAAs subcontract with a CRC for some services. Officials of the CDA report that some AAAs may be utilizing county mental health department staff to perform assessments.

Whereas the NFCSP does not impose a cap for respite services, individual AAAs may do so if they choose. None has, to the knowledge of the CDA respondents. State guidelines allow for in-home, adult day services and for overnight and weekend respite, but some services may not be available at the local level because of worker and budget shortages. AAAs have the flexibility to allow caregivers to “bank” respite services.

The CRC system offers a comprehensive range of family support options in every region of the state. Services include specialized information and assistance; in-home assessment; family consultation and care planning; family meetings; individualized, group or family counseling; psychoeducational groups; support groups; legal and financial consultation with attorneys; education and training; and an array of respite options. The CRC system has a \$3,600 yearly cap for respite services. Key informants indicated that the cap was set because of budget constraints and as a way to keep the waiting list moving. Respondents also indicated that the cap helps consumers count on and plan around a set amount of money. In-home (both agency-based and with independent providers), adult day services and respite weekends (including camps and group respite) are some of the options available under the CRC program. Consumers may “bank” respite services for 12 months.

Under the Aged Medicaid waiver (MSSP), family caregivers may benefit from respite services, home modifications, education and family training, and no stated cap exists for respite service. Covered respite services include in-home respite assistance, adult day health services, overnight in a family and hospice-based respite for those with terminal illnesses.

The NFCSP and CRC system are California’s programs with the explicit goal of providing support to family and informal caregivers, other publicly funded programs also offer services that include some measure of caregiver support. These programs, along with the administering agency, are detailed below.

Exhibit B. Services for California Family Caregivers by Publicly-Funded Program

	Program	Respite	Support Groups	Caregiver Training & Education	Home Modifications	Chore or Personal Care
CDA	NFCSP	Yes	Yes	Yes	Yes	Yes
	ADCRC	Yes	Yes	Yes	No	No
	ADHC	Yes	No	No	No	Yes
	Aged Medicaid Waiver	Yes	No	No	No	Yes
DSS	IHSS	Yes	No	No	No	Yes
DMH	CRCs	Yes	Yes	Yes	No	Yes

Major services needed by caregivers: Medicaid, IHSS and DMH officials cited respite care as the major service needed; DMH respondents added that the assessment with family consultation usually lead to the provision of respite care services. Respite has been the highest-funded service category under the NFCSP. Although respite services are commonly seen as “the most vital,” CDA officials reported that “some providers suggest this service goes unused because caregivers who wait a relatively long time before seeking formal assistance with some tasks, and in the early stages of caregiving, don’t require formal respite.” Thus, CDA staff also noted the importance of recognizing the need for assistance and getting access to services. Most stakeholders identified respite as the major service needed. One stakeholder indicated that family caregivers might identify respite as the major service needed, but in fact family consultations are more important because the resulting plan of care would better equip a caregiver to handle a situation. Support groups, caregiver education and training and assistance in finding formal care providers were identified by stakeholders as services needed by family caregivers.

Table 2. Family Caregiver Support Services in California

Program	California NFCSP	Caregiver Resource Center System(CRC)	In-Home Supportive Services(IHSS)	Aged Medicaid Waiver(MSSP)	Alzheimer's Day Care Resource Center	Adult Day Health Care
State Administrative Responsibility	California Department of Aging	California Department of Mental Health	California Department of Social Services	California Department of Aging	California Department of Aging	California Department of Aging
Local Service Delivery	AAAs ^a	Caregiver Resource Centers (statewide system)	County welfare Departments, Public Authorities and contract providers	Local service providers	AAAs	DHS and local service providers
Funding Source	Older Americans Act, Title III-E	State general funds	State general funds, Medicaid Title XIX & Title XX, Block Grant funds, county funds	Medicaid ^b 1915 (c) waiver, state general funds	State general funds	Medicaid, state general funds
Expenditures FY 2001–02	\$12.6 million	\$11.7 million	\$72.4 million	\$40.2 million	\$4.6 million	\$1.4 million
Client Population	Family & informal caregiver	Family & informal caregiver	Care recipient	Care recipient	Family & informal caregiver & care recipient	Family & informal caregiver & care recipient
Eligibility Criteria:						
Age	60+ care recipient Family caregivers of any age of persons age 60+ ^c	18+ care recipient Family caregivers of any age	65+ care recipient	65+ care recipient	None	18+ care recipient
Monthly Income	None	None	SSI-eligible	300% of federal poverty rate	None	300% of federal poverty rate
Assets	None	None	\$2,000	\$2,000	None	\$2,000
Functional Ability	For all support services except access and information, care recipient must have at least 2 ADLs or IADL needs	Adult-onset cognitive impairment	Blind or disabled	Nursing home level of care	Dementia diagnosis	Frail, elderly and impaired adults

a AAAs = Area Agencies on Aging.

b In California, Medicaid is referred to as Medi-Cal.

c Also caregivers 60+ providing care to a person with developmental disability or a grandparent caregiver raising a child.

Table 2. Family Caregiver Support Services in California (continued)

Program	California NFCSP	Caregiver Resource Center System(CRC)	In-Home Supportive Services(IHSS)	Aged Medicaid Waiver(MSSP)	Alzheimer's Day Care Resource Center	Adult Day Health Care
Uniform, Statewide Caregiver Assessment	No	Yes	No	No	No	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	Information Assistance In-home assessment Family consultation Care planning Family meetings, individual & group family counseling Psychoeducation & support groups Legal & financial consultations Education, training Link2Care Internet Range of respite options	Respite care Chore or personal care	Respite care Chore or personal care	Respite care Support groups Caregiver training and education	Respite care
Respite Cap	Varies by AAA	\$3,600/year	Yes 8 hours/ week	No	No	No
Consumer Direction	Yes ^e	Yes	Yes	No	No	No
Family Caregivers Paid as Respite Providers	Permissible but not utilized by the AAAs	Yes	Yes	No	No	No

^d Within these categories, AAAs provide a range of services including transportation, minor home modifications, homemaker and chore services, assistive devices, home delivered meals, legal assistance, peer counseling and other services.

^e CDA has authorized the use of consumer direction. At the time of the site visit, no AAA offered this option, however.

CONSUMER DIRECTION

Although the NFCSP permits consumer direction through a cash benefit, none of California's AAAs have taken that approach in the initial implementation of the program. CDA respondents indicated that the AAAs have not had time to establish auditable administrative procedures that would be needed in order to implement a consumer-directed option for families. In contrast, the CRC system administered by the DMH has consumer direction as a central tenet of the program. The CRCs' family consultants develop the plan of care with the consumer (i.e., family or friend) out of a menu of services. For those family caregivers who prefer in-home respite, families can choose one of two mechanisms: the vendor in-home respite program (i.e., agency-based), in which caregivers receive vouchers to purchase services through home care agencies under contract with the CRC; or the direct pay respite program (i.e., consumer directed), whereby caregivers are given vouchers to hire and manage their own respite workers. The agency-based in-home respite program is available from all 11 CRCs; nine of the 11 CRCs also offer the consumer-directed "direct pay" option and allow family caregivers to hire their own family, friends or neighbors to provide respite care.

Although the traditional Aged Medicaid waiver (MSSP) does not offer a consumer-directed option, the IHSS program administered by the DSS does, and that option is widely available and utilized. The IHSS receives funding from both the optional Medicaid personal assistance benefit and state general funds and, with regard to Medicaid, is authorized through a state plan amendment rather than through a home and community-based waiver. California places no state restrictions on the hiring of family members as IHSS workers, and by utilizing state funds, it allows all family members (including parents and spouses) to be paid care providers. An estimated 43% of IHSS providers are relatives of the care recipient.²⁴ The consumer-directed option, known in the state as the individual provider mode of delivery, is available in all 58 counties. In contrast, the contract agency mode (i.e., home-care agency model) is available in only 12 California counties. IHSS officials pointed out that many of the consumers they serve also get services under the state's Aged Medicaid waiver, so in effect, IHSS functions as the Medicaid waiver's consumer-directed option.

QUALITY ASSURANCE AND EVALUATION

The CDA has four oversight functions to evaluate the NFCSP, including budget review and approval, area plan review and approval, on-site monitoring and analysis of program data. The state currently collects a variety of demographic data on NFCSP consumers, including gender, age, race/ethnicity, marital status and employment; it also tracks relationship between caregiver and care recipient, multiple caregiving, poverty, whether the caregiver lives alone and whether an Adult Protective Services (APS) referral is involved. The CDA currently uses a paper data-reporting system. State officials plan to continue the "temporary" paper system to allow the program to remain fluid, to reduce the burden on AAAs and providers and to make it easier to adapt to changes in federal reporting requirements. The current system is an aggregate system, which is consistent with AoA reporting requirements. The CDA believes that a move toward a client-level system would allow for cross tabulations of variables and enable the CDA to perform more sophisticated data analysis. For now, the data will have to "speak for itself," CDA respondents said.

The CDA has contracted with the University of California at Berkeley to develop a profile of caregivers and care recipients in California using a random-sample, statewide telephone survey of adults who are providing care to a person age 50 or older and focus groups. Data being collected include:

- ❖ Social and demographic characteristics
- ❖ Caregiver and care recipient health and functioning
- ❖ Care provided by caregivers and caregiver services
- ❖ Support received and the impact of caregiving on the caregiver

Follow-up telephone interviews will focus on a variety of issues, including the caregiver's extent of knowledge about local caregiver support programs, utilization patterns, program effectiveness, predictors of service use and nonuse, unmet needs and client satisfaction. The university will also work with CDA and selected AAAs to examine the impact of caregiver programs on caregivers and care recipients.

At the time of the site visit, the uniform caregiver assessment instrument used by the DMH's CRC system was being revised, and a new automated client-tracking and data collection system was in the process of being implemented to assist with planning, service scheduling and other needs. The CRCs collect data on caregiver outcomes. The SRC also plays a significant role in data collection for the CRC system, tracking and profiling information on caregivers and care recipients in the program, service utilization, expenditures, hours of respite providers and major needs identified by family caregivers within the CRC system. The SRC prepares quarterly and annual reports for DMH.

Within the Aged Medicaid waiver (MSSP), data collected on family and informal caregivers are limited to basic demographic information: name and telephone number, relationship to the care recipient and hours available to provide care.

Under the IHSS program, data collected on family caregivers are also limited to basic demographic information such as age, ethnicity and relationship to the care recipient. The system, known as the Case Management Information and Payroll System (CMIPS), is automated. Although the fiscal intermediary can run special reports, there is a time lag in getting results. To evaluate the program, IHSS looks at county and statewide service utilization aggregates and conducts site visits (by state DSS staff) that include client satisfaction surveys.

SYSTEMS DEVELOPMENT

California has historically had a complex and fragmented long-term care system, administered by numerous state agencies. Adding to the confusing and complicated structure and administration, many of the state programs are operated through local government agencies and private nonprofit organizations, creating an even more confusing array of eligibility requirements and different services and service delivery options that pose barriers to consumers who attempt to access help in their communities.

"We're a little bit ahead of other states because of the high level of interest with the legislature and governor paying attention to how we develop a family caregiver support program," said one state official, referring to the statewide system that was in place pre-NFCSP. The official went on to say that when the NFCSP funding came in, there was a great deal of interest from AAAs, the legislature

and other aging and long-term care advocates to look at caregiving from a new, family approach, which is a little different from other Older Americans Act programs that focus on the care recipient. The CRC system was viewed as a positive program but limited in the population it serves; the new program allowed the state to serve a broader group beyond the population of caregivers of adults with cognitive impairment (e.g., Alzheimer's disease, stroke, traumatic brain injury). The state legislature, through budget-control language, has assured no duplication of services at the local level.

In terms of coordination of caregiver support services at the state and local levels, informants had divergent views. The CDA officials interviewed believed that state-level coordination exists and identified existing federal requirements as a barrier to a greater level of integration and coordination. Other state officials were less optimistic and believed that caregiver support services were not highly coordinated in the state or well integrated into California's other home and community-based care programs. Stakeholders representing a variety of agencies and groups felt that there was little state-level coordination and characterized the CDA, with the implementation of the NFCSP, as having delegated coordination to the AAAs at the local level, irrespective of the "already-in-place" state-funded CRC system administered by DMH.

The CDA characterized the NFCSP implementation process as methodical and thoughtful, and one that included "everyone" at the table. In view of the initial skepticism about giving the funding to the AAAs, rather than to the CRCs, they felt they had had to "climb uphill" and defend the local process, rather than step in and push for uniformity across the AAAs in their request for proposals (RFPs). State officials commented that although they hadn't wanted to "reinvent the wheel" with the NFCSP (referring to the preexisting CRC program), they had first had to make sure that what was already in place was "the right wheel." "Development of a seamless system of services that is consumer-focused is always a goal and remains a significant undertaking," one respondent said. "With the implementation of the NFCSP, every effort is being made to avoid creating an additional 'silo' program." Methods being used to assist in this integration are heavy reliance on the AAA's local planning process; maintenance of maximum local flexibility, consistent with the AoA direction; and the development of projects designed to specifically integrate the program into existing long-term care programs (e.g., integration of the care management assessment tools with caregiver assessment tools).

The AAAs coordinate caregiver services at the local level through the AAA's planning and contracting process. The CRC system also coordinates services at the local level, through the regional CRCs, with the SRC assisting the system to develop statewide standards and resources, such as a new information technology system. Some AAAs subcontract with CRCs to build on the infrastructure in place and to enhance coordination. For example, the Orange County AAA subcontracts all of its NFCSP service funds with the existing Orange CRC to expand support for caregivers in Orange County.

Most respondents mentioned the Long-Term Care (LTC) Council, within the CHHSA, as the body that is coordinating caregiver support services across state departments. Several stakeholders pointed out, however, that the council's mission is much broader than just caregiver support and that caregiver support has not been a major issue addressed by the council.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

The LTC Council is composed of the heads of all relevant departments (Developmental Services, Health Services, Rehabilitation, Mental Health, Social Services, Aging, Veterans Affairs and the Office of Statewide Health Planning and Development). It is the main body charged with *Olmstead* planning and implementation. Created in 1999 through legislation (A.B. 452), the council's mission is to "provide state-level leadership in developing a coordinated long-term care system that includes a full array of services, that promotes personal choice and independence while also assuring fiscal responsibility and equitable access to all long-term care consumers."²⁵

The LTC Council has issued a values statement that includes:

- ✧ Honoring choice, dignity, independence and quality of life
- ✧ Seeking input from consumers, family caregivers and the community
- ✧ Supporting caregivers
- ✧ Making sure that a long-term care workforce is available
- ✧ Encouraging flexibility and innovation
- ✧ Providing education on the potential need for long-term care and on viable options available to help individuals plan ahead for that potential need

The LTC Council has set up six work groups, or subcommittees, to focus on various issues. The council is working to identify barriers to mental health coverage for persons with Alzheimer's disease and other forms of dementia and ways to overcome those barriers. The CHHSA has also developed an *Olmstead* planning and work group and has offered limited reimbursement for travel expenses necessary for consumers to enable them to participate. In 2002, CHHSA planned a series of *Olmstead* forums throughout the state to provide input into the state's *Olmstead* plan documents.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" Although responses were mixed, no key informant saw the priority as greater than "medium." Most state officials agreed that the priority on caregiver support was "medium," although DMH respondents saw it as "low - medium." Stakeholders' assessments varied, with three indicating "low," one "low - medium" and two "medium."

Number of Key Informants	Priority on Caregiver Support
3	→ Low
2	→→ Low-Medium
5	→→→ Medium

Benefits and challenges: CDA respondents felt that it was too early to predict the impact of the NFCSP. Other California case study respondents identified a variety of benefits their programs offer to family caregivers:

- ✧ Assessment with family consultation and respite (DMH)
- ✧ Information and support—the overall support available from persons who are knowledgeable about the situations of caregivers (DMH)
- ✧ Flexibility in maintaining individuals in a home setting (DHS)
- ✧ Especially for poor families, the ability to stay with families and give back to them by providing care (DSS)
- ✧ The natural knowledge of family, friends and neighbors who have long-term relationships with the individual who needs care and can provide better services than could a stranger (DSS)

When asked to identify the three main challenges for implementing family caregiver support programs in California, state respondents noted the following:

- ✧ Limited federal funding (DHS, DMH, DSS, CDA)
- ✧ Lack of flexibility with federal funds, which keeps states from doing what needs to be done (DHS)
- ✧ Lack of policies that require some responsible party to keep family caregiver support out in front, across all departments, reminding all service providers involved in long-term care programs (DHS)
- ✧ Duplicative administrative structures for caregiver support programs (DMH)
- ✧ A requirement that programs serve the entire state, which discourages piloting innovative measures (DSS)
- ✧ Shortages of staff to implement programs (CDA)
- ✧ A short time frame for program implementation (CDA)

Major lessons learned:

- ✧ Developing the family approach enhances the way all CDA programs and services are delivered. “We learned as a department that caregiving is a family issue, not in a vacuum,” said one CDA informant.
- ✧ Integrating all caregiver support services poses a big challenge. It is important to avoid developing yet another categorical program, when what is needed is a coordinated system of support services that reach the caregiver and other beneficiaries in the caregiver’s informal network.
- ✧ “People who do the caregiving and people in the field are phenomenal,” one DMH official said. “They have incredible strengths and they don’t get enough recognition for their work, which is largely a labor of love.”
- ✧ Flexibility at the state level, as well as at the service levels, is important. “Listen, be flexible and be creative in finding options to fill needs. Nothing is absolute.”

- ✧ The family caregiver can be the client. It is important to give value to family care and the spiritual, intellectual and emotional health of family caregivers.
- ✧ Listening is important. “If you just listen to people, they wander through their problems and often come up with solutions themselves,” said one respondent.
- ✧ The social work model—that of supporting the family unit—has worked well in the IHSS program because it allows clients the right to choose their providers while remaining in their own home community, respondents from the IHSS program at the DSS said.

Opportunity for expanding caregiver support: Respondents were mixed in their views as to whether state-funded programs to support family caregivers would be expanded in California in the next three to five years. Respondents from CDA thought expansion would occur, dependent upon the pace of economic recovery and driven by the *Olmstead* plan. Another key informant said that expansion would not be a surprise because family caregiving continues to surface more and more. Officials from IHSS hoped to improve wages and benefits for paid family caregivers; they cited budget concerns as the “limiting factor,” however. IHSS respondents said that recent legislation (A.B. 925) signed into law creates a significant infrastructure intended to increase job opportunities for Californians with disabilities by allowing IHSS to be extended to the workplace. DMH officials felt that all was contingent upon the budget and upon fixing structural problems, saying that the data and information available from the CRC program, along with *Olmstead* planning, should lead to expansion opportunities.

Recommendations for other states: State officials in California had several recommendations for other states:

- ✧ Listen to family caregivers when designing programs, but get beyond “the stories” to hear the real issue, then figure out how to deal with it in the bureaucracy (DHS).
- ✧ Take a collaborative rather than an adversarial approach. Work across departmental lines: See what other state agencies have in common with yours, and work together; collaborate and partner with other existing agencies administering related programs (DHS, DMH and CDA).
- ✧ Seek a stable, reliable funding source (DMH).
- ✧ Don’t reinvent the wheel. Look at other states with effective caregiver support programs and build on those (DMH).
- ✧ Adopt a creative/flexible approach; preserve a broad interpretation of the law (CDA).
- ✧ Place a high value on the role that family caregivers can play; expand home-care programs so that family and informal caregivers can be paid to provide services (DSS).

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OVERVIEW

Florida is a relatively large southeastern state with one of the most racially and ethnically diverse populations in the nation. The state's current long-term care system provides home and community-based services, with many programs aimed at maintaining individuals in the least restrictive environment. Florida has strong antitax sentiments, which influence new program implementation and program expansion. Despite this, an active legislature and the highest proportion of elderly residents in the nation have resulted in an abundant yet fragmented array of programs serving older persons.

Caregiver support services have been a component of many of Florida's state-funded home and community-based services. Despite previously existing respite care components and income support, passage of the National Family Caregiver Support Program (NFCSP) has allowed a significant and explicit focus on family and informal caregivers in Florida for the first time. The state's caregiver support services are characterized by:

- ✧ Centralized policymaking, with flexibility to meet the individual needs of family caregivers at the local level
- ✧ A privatized aging network and service delivery
- ✧ Many publicly funded programs that suffer from a lack of coordination and integration

Florida respondents noted that the major service needs of family caregivers are (1) respite care, (2) help with navigating the maze of services and (3) support groups and other ways to provide social and emotional support.

As Florida addresses long-term care reform and develops a statewide caregiver support program, a key consideration will be integration and coordination of the range of caregiver support services so that they are "seamless" to Florida's family caregivers.

INTRODUCTION

Florida represents an "old" state that administered programs for family and informal caregivers before enactment of the NFCSP. The project team conducted a site visit on June 3 and 4, 2002, through in-person interviews^a with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Florida Agency for Health Care Administration

- ✧ Aged/Disabled Medicaid waiver

^a All interviews except one were conducted in person. One key informant participated in one interview through phone conference.

Florida Department of Elder Affairs

- ✧ National Family Caregiver Support Program (NFCSP funded)
- ✧ Home Care for the Elderly (state funded)
- ✧ Community Care for the Elderly (state funded)
- ✧ Alzheimer's Disease Initiative (state funded)
- ✧ Respite for Elders Living in Everyday Families (state funded)
- ✧ Support Through Alzheimer's Relief System (federally and state funded)
- ✧ Aged/Disabled Medicaid waiver
- ✧ Consumer-Directed Care Project (Cash and Counseling Demonstration; federally, state and foundation funded)

Florida Department of Management Services, Americans with Disabilities (ADA) Working Group

- ✧ Real Choice Partnership Project

Stakeholders interviewed were from:

- ✧ Florida Association of Area Agencies on Aging, West Palm Beach
- ✧ Area Agency on Aging of North Florida, Tallahassee
- ✧ Alzheimer's Resource Center, Tallahassee

The seven following programs are featured in this profile:

1. Florida NFCSP
2. Home Care for the Elderly
3. Community Care for the Elderly
4. Alzheimer's Disease Initiative
5. Respite for Elders Living in Everyday Families (RELIEF)
6. Consumer-Directed Care Project
7. Aged/Disabled Medicaid waiver

BACKGROUND

Florida is a large southeastern state with a population of nearly 16 million residing in 67 counties.¹ In fact, Florida is the fourth most populous state in the United States.²

The state has substantial low-income and minority populations. In 2000, personal income per capita was \$28,145, compared to the national average of \$29,676.³ About 14.4% of Florida's population live below the federal poverty level (vs. 13.3% U.S.).⁴ Florida is also primarily urban, with about 93% of its population residing in metropolitan areas.⁵ Florida ranks 17th nationally in percentage of households with Internet access.⁶ Florida is more ethnically and racially diverse than the nation as a whole. Compared to the national average, Florida has a greater proportion of both African Americans (14.6% vs. 12.3% U.S.) and Hispanic persons (16.8% vs. 12.5% U.S.)⁷ (table 1).

Florida has a large and growing elderly population. An estimated 3.6 million persons in Florida, or 22% of the state's population were 60 years or older in 2000 (vs. 16.3% U.S.). Florida ranks first nationally in the number of older persons (ages 60+) residing in the state.⁸ Further, the percentage of Florida's older persons increased substantially over that of the United States as a whole from 1990 to 2000 (16.3% vs. 9.4% U.S.). Unlike the state's population as a whole, Florida's proportion of

African Americans ages 60+ is slightly lower than that of the nation (6.6% vs. 8.4% U.S.). For Hispanics ages 60+, the proportion almost doubles compared to that of the United States as a whole (10.7% vs. 5.4% U.S.).⁹

Florida ranks fourth in the nation in the proportion of the population age 85 or older. In 2000, 331,287 persons, or 2.1% of Florida's population were ages 85+.¹⁰ Despite the relatively high population of older persons in Florida, the median age of state residents is 38.7.¹¹ This is partly because of the large populations of college students in several of Florida's cities (e.g., Jacksonville, Tallahassee, Miami). Florida's high levels of net interstate and net international migration will account for most of the state's population growth until the year 2025.¹²

An estimated 1,472,899 family caregivers reside in Florida. These family caregivers provide about 1.4 billion hours of caregiving per year at an estimated value in 1997 of \$11.2 billion.¹³

Florida's economic characteristics vary. In 1998, job growth in Florida was more than double the rate of job growth in the nation as a whole,^b but the economic picture has changed in recent years.¹⁴ The Medicaid program has experienced significant shortfalls, to the tune of \$1.5 billion during the 2001 legislative session.¹⁵ Growth in enrollment, home and community-based services and health care costs are cited as reasons for the shortfalls.¹⁶ Florida ranks 42nd in terms of state/local tax burden for residents, probably because there is no state personal income tax.¹⁷

^b Projected job growth for Florida was 2.9% in FY 1997–98 compared to 1.3% for the nation.

Table 1. Selected Characteristics of FLORIDA and the UNITED STATES, 2000 ^a

	Florida	United States
Total Population Characteristics		
Total Pop. ^b	15,982,378	281,421,906
% African American ^c	14.6%	12.3%
% Hispanic ^d	16.8%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	3,545,093	45,797,200
% 60+ ^f	22.2%	16.3%
National ranking 60+ ^g	1	NA
Pop. 65+ ^h	2,807,597	34,991,753
% 65+ ⁱ	17.6%	12.4%
National ranking 65+ ^j	1	NA
Pop. 85+ ^k	331,287	4,239,587
% 85+ ^l	2.1%	1.5%
National ranking 85+ ^m	4	NA
% increase 1990–2000 60+ pop. ⁿ	16.3%	9.4%
% White (60+) ^o	81.2%	82.4%
% African American (60+)	6.6%	8.4%
% Hispanic (60+)	10.7%	5.4%
% Asian (60+)	0.7%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics ^p		
# of caregivers (1997)	1,472,899	25,798,370
Caregiving hours (millions) (1997)	1,371.0	24,013.1
Value of caregiving (millions) (1997)	\$11,214.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$28,145	\$29,676
% of pop. below poverty (1997) ^r	14.4%	13.3%
Internet		
% of households w/Internet access (2001) ^s	43.2%	41.5%
Nat'l ranking of households w/Internet access	17	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Florida, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islander and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Florida.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies: the Department of Elder Affairs (DOEA) and the Agency for Health Care Administration (AHCA). The AHCA develops and carries out policies related to the Medicaid program. The programs administered by these state agencies rely on federal funds along with significant state general funds. Particularly in the growth years in the early and mid-1990s, Florida legislated many programs to serve the elderly and persons with disabilities. Key informants cited the legislature as the impetus for the enactment of many existing programs.

The DOEA is a freestanding department, serving as the State Unit on Aging and administering the provisions of the federal Older Americans Act, including the new NFCSP. In addition, the DOEA administers the following programs that serve older persons and their family caregivers: Community Care for the Elderly, Alzheimer's Disease Initiative, Home Care for the Elderly, Respite for Elders Living in Everyday Families (RELIEF), Consumer-Directed Care Project and Support Through Alzheimer's Relief Systems (STARS). The governor appoints the secretary of the department. The DOEA, under an interagency agreement with the Florida AHCA, also administers the Assisted Living for the Elderly and Aged/Disabled Medicaid waivers.¹⁸

The infrastructure of Florida's aging network is a statewide system of 11 Area Agencies on Aging (AAAs), private, nonprofit agencies that cover geographic regions ranging from one to 15 counties. Each AAA has at least one Medicaid waiver specialist to enroll and monitor provider operations. DOEA staff, using the Comprehensive Assessment and Review and Evaluation Services (CARES) evaluation instrument, determines functional eligibility for Medicaid waiver services. Each Planning and Service Area (PSA) has CARES staff who are sometimes colocated with the AAA.¹⁹ Most of the other programs serving older persons are run through the AAAs, which subcontract with service providers for these non-Medicaid services.

Florida's Aged/Disabled Medicaid waiver was originally approved in 1982. The Florida AHCA is responsible as the "single state agency" for oversight of Medicaid. The Agency sets program policy and the DOEA operates the Medicaid waiver program serving about 13,335 beneficiaries in the state (29,736 total slots).^c

Florida was also awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services in 2002. Referred to as the Real Choice Partnership Project, it is administratively housed within the Department of Management Services and falls under the Americans with Disabilities (ADA) Working Group, which was created by Executive Order. The ADA Working Group, which serves primarily the developmental disability community, was placed in the Department of Management Services because its work cuts across so many departments. The Real Choice grant will create a Clearinghouse on Disability and develop three pilot sites to improve the structure to deliver services. It will include cross-cultural, cross-age coalition building. Ultimately, the mission of the grant is to eliminate current barriers to offering services in the least restrictive setting. The ADA Working Group considers itself the *Olmstead* Task Force, although not all key informants identified it as such.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Florida has historically invested state general funds in developing services for older persons. Increasingly, however, there has been an emphasis on moving older persons from state-only-funded programs to programs that receive federal matching funds, such as the Medicaid home and community-based care waivers. The state's growing fiscal conservatism may be due to the political shift in the executive and legislative branches of government in 1998, with Republican Jeb Bush taking the gubernatorial lead and with republican majorities in the Florida House and Senate.²⁰

Florida's current long-term care system has developed in a fragmented way, with many programs beginning as the result of legislation, rather than from a systems development perspective. Recently, however, Florida enacted legislation, S.B. 1276, establishing the Office of Long-Term Care Policy to create a more integrated, streamlined approach to policy development and program administration.

Many of Florida's programs providing caregiver support predate the passage of the NFCSP under the Older Americans Act Amendments of 2000. Programs assisting caregivers are housed in two DOEA divisions: Statewide Community Based Services and Volunteer and Community Services. The Division of Volunteer and Community Services provides education, intervention, and prevention services and develops and enhances community supports for elders, their families and caregivers.

c Florida has 11 Medicaid Home and Community-Based Services waivers. They include the Aged/Disabled waiver implemented in 1982; Developmental Services waiver implemented in 1985; Channeling waiver implemented in 1985; Project AIDS Care implemented in 1989; Model waiver implemented in 1991 (serving only five clients); Assisted Living for the Elderly implemented in 1995; Supportive Living implemented in 1995; Nursing Home Diversion implemented in 1997; Family Planning implemented in 1998; Traumatic Brain Injury/Spinal Cord Injury waiver implemented in 1999; and Consumer Directed Care demo (Cash and Counseling Demonstration project) implemented in 2000.

Family and informal caregivers are explicitly recognized as a central component of the current long-term care system. A DOEA official indicated that the recognition was partially because of the increase in resources for caregiver programs on the state level. One stakeholder said that explicit recognition in state statute was only in the Home Care for the Elderly program, however. Medicaid officials stated that recognition is not formal; but rather provided through the development of home and community-based waiver services. Although many Florida programs do provide caregiver support services, (e.g., respite care), no state-funded program has specifically targeted family and informal caregivers. Programs such as Home Care for the Elderly provide a limited financial subsidy and RELIEF provides respite and other limited informal supports. These programs are not as comprehensive as the NFCSP.

Florida is one of three states chosen to participate in the national demonstration project known as Cash and Counseling.^d At the state level, the program is referred to as the Consumer-Directed Care Project and is administered by the DOEA. The national program is a partnership among the CMS, the U.S. Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE) and The Robert Wood Johnson Foundation. Florida also contributes state general funds to the program. The program is implemented under an 1115 Medicaid waiver and was initiated to research issues and questions about Medicaid recipients managing their own care. Enrollees can hire and direct employees of their choosing, including family and friends. The waiver allows for enrollment of 6,000 Florida residents meeting functional criteria and already enrolled in Florida's Medicaid waivers. Populations include frail elderly, adults with physical and developmental disabilities and children with developmental disabilities. As of August 1, 2002, almost 3,000 people were enrolled in the demonstration project. The state's inclination to develop programs serving older persons includes the enactment of a state consumer-directed care project building on its demonstration project. The state project is administered by the AHCA, as opposed to the DOEA. The enactment was part of S.B. 1276.

Although the DOEA administers a variety of programs serving older persons, the system is not seamless to the consumer. Duplicative and often fragmented services may challenge consumers to understand and make sense of Florida's system of care. This is confounded by the fact that not all programs provide services statewide, such as the STARS program, available in five of Florida's 11 AAAs. Said one stakeholder, "[It's] a nightmare to get services. Programs are split up among so many different departments. Families have to go to so many places to get help." While Florida is primarily urban, one stakeholder indicated that serving rural populations is still challenging, particularly because of the workforce shortage. This means that even if services are available, providers may not be. One solution Florida has begun to implement is the expansion of the Consumer-Directed Care Project to serve more people than in the federal demonstration project. Another promising direction is the recent establishment of the Office of Long-Term Care Policy to address fragmentation and integration issues.

^d The other two states chosen to participate are Arkansas and New Jersey.

PROGRAM BACKGROUND/DEVELOPMENT ^e

The original impetus for Florida's family caregiver support program was passage of the Older Americans Act Amendments in 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. While the NFCSP is the only program administered by the DOEA that specifically targets services to caregivers, other programs do provide some measure of caregiver support. These include the Home Care for the Elderly program, established in 1977, which provides caregivers with a "no strings attached" subsidy up to \$106 per month. DOEA surveys indicate that the funds are most often used for food (32%), medical supplies (23%) and household bills (15%). Only 3% of caregivers served use the subsidy for respite.²¹

Key informants observed that Florida is still in the start-up phase of the NFCSP. Programs and services were phased in, with AAAs contracting for services beginning in October 2001. The DOEA began in the start-up and development phase by developing guidelines, stating that it worked with AAA staff and learned what the AAAs wanted to do with the program. State officials indicated that a joint meeting in November 2001 with AAA directors was the impetus for starting an NFCSP work group to achieve consensus on a variety of program issues.

The DOEA has given AAAs flexibility to design programs that best meet local needs, although one key informant said that "the flexibility has thrown us off.... We are just beginning to appreciate it and it is increasing creativity." Further, a respondent indicated that "as long as you are doing good, it's okay." State officials have said that they would like to see more uniformity across the state but have indicated that this would be problematic because local planning groups have varying interests.

Most rewarding: Key informants noted that the most rewarding aspect of the program's development has been the significant influx of funding truly devoted to caregiver needs and to helping struggling families. Further, one respondent commented that the focus is upon providing relief to caregivers, saying, "To maintain the individual in the community...to have caregivers and support them is key."

Biggest challenge: According to key informants, one of the biggest challenges in developing the program has been to properly interpret the program guidelines of the U.S. Administration on Aging (AoA). Also cited is the challenge of developing a baseline for expectations.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—Florida's NFCSP received \$8.7 million in federal funds, or slightly more than 3%^f of the overall DOEA budget.²² In FY 2002, the federal share of NFCSP funds was increased, with Florida receiving a total of about \$10 million. By comparison, in FY 2001, the total cost of services under the Aged/Disabled Medicaid waiver in Florida was \$82.2 million, serving about 13,000 people, including some 12,000 older persons. Of

^e Additional background information on Florida's programs serving family and informal caregivers can be found in *Survey of Fifteen States: Caregiver Support Programs: Final Report* (San Francisco: Family Caregiver Alliance, October 1999).

^f DOEA's FY 2002 appropriation is \$305.5 million, which includes \$72 million in federal funds for the Aged/Disabled Medicaid waiver.

this amount, approximately \$8.2 million went for respite care. The annual per capita cost under the Aged/Disabled waiver was \$7,656. Expenditures for the Aged/Disabled waiver represent about 3% of AHCA's expenditures under the Medicaid program.

Florida has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid and to support home and community-based care. Funds have not been appropriated specifically for caregiver support services, however. In FY 2002, Florida received \$731 million in tobacco settlement revenues and carried over approximately \$100 million in unspent funds from the prior fiscal year.²³ Of those funds, the DOEA received \$25 million, with \$3 million earmarked for assisted living and home and community-based care.²⁴ Medicaid programs received \$68 million.²⁵ Most of the tobacco funds, however, went to the Lawton Chiles Endowment Fund for Children and the Elderly. Of the \$200 million given to the trust fund, \$25.1 million were allocated for the DOEA to fund programs such as osteoporosis screenings.²⁶

Key informants said that the budget situation is not as bad in Florida as in other states and ascribed this to conservative steps taken early on by the legislature. Indeed, the Florida legislature has called three sessions to address state budget issues. Despite staff cuts at the DOEA, services have not been affected, and respondents indicated that the legislature is making a real commitment to the aging network. Medicaid officials portrayed a somewhat rosier picture in Florida than in other states. They indicated that the Aged/Disabled Medicaid waiver had not been significantly affected because of some surpluses and because of interest in moving people from state-funded programs into Medicaid waiver programs.

PROGRAM ADMINISTRATION

The DOEA sees its role in developing and implementing the state's first explicit caregiver support program as being in the areas of oversight, design, implementation, policy development, evaluation and quality control. In the words of DOEA respondents, "We monitor and survey consumers directly." State officials indicated that they also play an indirect role in developing state legislation by providing information, perspective and policy development. Policy development and program administration are centralized at the state level.

State officials emphasized the role that AAAs play in serving Florida's older persons, since 94% of the DOEA's funding is through services delivered by private nonprofits, either by the AAAs or through subcontractors. Further, DOEA expects the AAAs to develop local policy, while the DOEA provides the broad guidelines for this effort. Respondents indicated that one reason for the emphasis on flexibility to meet local needs is that demographics vary widely across the state. The median age for the entire state is 38.7 years,²⁷ with a median age of 54.3 in Charlotte County²⁸ but of 29.1²⁹ in Alachua County, where the University of Florida is located.

While the DOEA publicizes the NFCSP in its newsletter, "Elder Update," and has sponsored a state Caregiver Forum, AAAs are responsible for the majority of publicity efforts. Some AAAs, such as the Area Agency on Aging of North Florida, have focused resources on billboard and radio advertising.

State Medicaid officials indicated that their role is to make sure that programs operate appropriately; they said they had "no other direct role."

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for Florida's family caregiver support program is consistent with federal requirements under the Older Americans Act: the program is open to family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers age 60 or older who are caring for children age 18 or younger.^g For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or two instrumental activities of daily living (IADLs). The family caregiver is considered the client in the program.

Client assessment standards are uniform across the state. For the NFCSP, the assessment is usually completed by a "lead agency," subcontracted by an AAA to assess clients for most of their programs. State officials noted that the assessment tool, known as the 701B, focuses on both the caregiver and the care recipient, although respondents characterized the caregiver section as informal. The 701B is used for all of Florida's home and community-based services for the elderly.

Caregiver questions include:

- ✧ How is your own health?
- ✧ How long have you been providing care?
- ✧ How likely is it that you will continue to provide care?
- ✧ Since you began providing care, have various aspects of your life become better, stayed the same or worsened?

Informal care is taken into account in the authorization of paid services for the care recipient, with DOEA officials indicating that the assessor looks at what services are being provided by family and friends. All assessments are done in home. Consumers are reassessed annually if they are receiving "hard" services, such as respite care, whereas reassessment can vary, if it takes place at all, for recipients of "soft" services (e.g., information, assistance, support groups).

Eligibility for the Aged/Disabled Medicaid waiver program is consistent with federal requirements regarding functional eligibility: enrollees must meet medical criteria for Medicaid nursing home level of care. The assessment is conducted by CARES staff. Financially, waiver participants must have income at 90% or less of the federal poverty level and meet Florida's asset limit (\$2,000 for an individual, \$3,000 for a couple). Recently, the state "also reduced income eligibility thresholds for the state's elderly and disabled Medicaid expansion program, causing an additional 1,500 beneficiaries to lose coverage."³⁰

Respondents noted that the care recipient is the identified client in the Medicaid waiver program but said that the mind-set is to take the family caregiver into account. Consistent with Medicaid policy generally, respondents noted that the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. This means services may be reduced for a care recipient with an available family caregiver.

^g This includes caregivers 60+ who are caring for children affected with mental retardation or who have developmental disabilities.

SERVICES

Although some of Florida's AAAs may provide services in all five NFCSP service categories, all services may not be available in each county even within an AAA's PSA. One rationale offered for the variability is the interest not to duplicate services. Because some of Florida's other home and community-based service programs also vary by county, services may be otherwise available in some parts of a PSA and unavailable elsewhere.

AAAs have the option to provide direct services to family caregivers, and many do, offering such services as counseling, training (professional and nonprofessional), organization of caregiver forums and family consultation. Each AAA has a staff person to assist in local coordination of the NFCSP and may provide some of these services.

Under the NFCSP, there is no cap for respite services, although individual AAAs may impose one if they choose. Informally, \$999 is referred to as a possible level of capped respite, but state officials indicated that this is not a formal cap and that the issue is not about caps but about encouraging the caregiver to get out of the home to receive respite in the first place. In-home, adult day services and overnight and weekend respite are all allowed under state guidelines, although worker shortages and budgets may affect the availability of overnight and weekend respite. Respondents said that waiting lists do exist for respite and indicated that they are because of NFCSP funding shortages.

Under the Aged/Disabled Medicaid waiver, respite services, education and family training are the only services specifically provided for family caregivers. Under the Aged/Disabled waiver, there is no stated respite service cap, but the respite must be of a "short-term nature."^h Covered respite services include in-home respite assistance, adult day health services, overnight facility-based respite and weekend respite. Respite camps are not specifically prohibited, but approval for this service would be based on the qualifications of providers, according to state Medicaid officials. Waiting lists, referred to as "assessed priority consumer lists" exist for some Medicaid waivers; respondents indicated that network capacity is the primary reason for the wait. Consumers on the list are ranked on a scale of 1 to 5. Staff indicated that they are now serving the 2s on the list, with a total priority list of about 2,000 consumers.

Major services needed by caregivers: At the DOEA, respite care, support groups, help with navigating the maze of social services and technology (e.g., home kits for surveillance and distance communication for caregivers who are far away) were identified as the major services needed by family caregivers. Respondents indicated that caregivers also needed something that would allow them to take the respite. This could be transportation to get somewhere or, respondents said, a place to go. Medicaid waiver staff and some stakeholders also indicated that respite is the major service needed by caregivers. Stakeholders pointed out the importance of breaking the mold of "in-home, alone" respite and that adult day care services provide socialization for the care recipient and give the caregiver a real break. Respite outside of the traditional eight-to-five workday, as well as service coordination and in-home counseling, were also cited by stakeholders as services needed by caregivers.

^h Florida's Channeling waiver caps respite at 14 days per fiscal year. State officials said that a caregiver who needs more relief than this is in danger of caregiver "burnout," which could then cause the care recipient to deteriorate. They indicated that a request for excessive respite is considered to be a sentinel event.

Table 2. Family Caregiver Support Services in Florida

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer- Directed Care Project	Aged/ Disabled Medicaid Waiver
State Administrative Responsibility	DOEA	DOEA	DOEA	DOEA	DOEA	DOEA ^a	DOEA ^b
Local Service Delivery	AAAs ^c	AAAs	Lead agencies ^d	AAAs	NA (with assistance, consumer chooses service providers)	AAAs Direct local service provider agencies ^e	AAAs
Funding Source	Older Americans Act, Title III-E	State general funds	State general funds Tobacco settlement funds	State general funds	State general funds	Medicaid 1915 (c) waiver Robert Wood Johnson Foundation State general funds	Medicaid 1915 (c) waiver
Expenditures FY 2001–02	\$10 million	\$9.5 million	\$42.4million	\$12.2million ^f	\$1.3 million	\$1.5 million ^g	\$82.2million Approximately \$8.2 million for respite care ^h

^a The DOEA has administrative responsibility for the Cash and Counseling Demonstration project (known as Consumer-Directed Care Project), but the AHCA has administrative responsibility for the state-enacted component of the Consumer-Directed Care Project.

^b AHCA sets program policy for the Aged/Disabled Medicaid waiver.

^c AAAs = Area Agencies on Aging.

^d Lead agencies are composed of 42 nonprofit organizations and 10 county/local government agencies.

^e RELIEF is available in 12 Florida counties.

^f Expenditures represent funding for all components of the program: respite care, memory disorder clinics/model day care and brain bank. Respite was funded at \$7.8 million for FY 2001–02 and served 3,890 clients (excluding clients who received only model day care services).

^g Expenditures are for FY 2000–01 and represent combined federal, state and foundation funding.

^h Respite share represents figures from FY 2000–01.

Table 2. Family Caregiver Support Services in Florida (continued)

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer- Directed Care Project	Aged/ Disabled Medicaid Waiver
Client Population	Family & informal caregiver	Elderly 60+ in family living situation	Care recipient family caregiver	Care recipient family caregiver	Full-time caregiver of frail, homebound elderly	Frail, elderly, adults w/ physical disabilities, adults and children w/ developmental disabilities	Care recipient
Eligibility Criteria:							
Age	60+ care recipient Family caregivers of any age of persons 60+	60+ care recipient	60+ care recipient	18+ care recipient	60+ care recipient	variable	18+ care recipient
Monthly Income	None	\$1,536	Sliding scale co-payment	Optional sliding scale co-payment	None	\$1,536	\$1,536
Assets	None	\$2,000	None	None	None	\$2,000	\$2,000
Functional Ability	For respite and supplemental services, care recipient must have at least 2 ADLs or IADL needs	Nursing home level of care; adult caregiver providing care or to locate care	Functional impairment ⁱ	Diagnosis of Alzheimer's or other memory disorder	Frail elderly	Nursing home level of care; must be able to direct own care	Nursing home level of care for care recipient
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes	Yes	Yes	No	No

i Florida's *Resource Manual* also indicates that, per statute, "primary consideration for services is given to elderly persons who are referred and determined by adult protective services to be victims of abuse, neglect, or exploitation who are in need of immediate services to prevent further harm."

Table 2. Family Caregiver Support Services in Florida (continued)

Program	Florida NFCSP	Home Care for the Elderly	Community Care for the Elderly	Alzheimer's Disease Initiative	Respite for Elders Living in Everyday Families (RELIEF)	Consumer-Directed Care Project	Aged/ Disabled Medicaid Waiver
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	\$106 cash subsidy per month	Respite (adult day health and other)	Respite Training "Other support services"	Respite	Menu of services needed as determined by care recipient	Respite Family training Education Support
Respite Cap	Varies by AAA	NA	Varies by AAA	Varies by AAA	4 hours/week	Level of respite needed determined by care recipient	No stated cap; respite must be of "a short-term nature"
Consumer Direction	Yes	Yes ^j	No	No	No ^k	Yes	No
Family Caregivers Paid as Respite Providers	Yes	No	No	No	No	Yes	No

^j In addition to the basic subsidy, special subsidies may be authorized for some consumers to be used for services that help maintain individuals at home.

^k Services are provided by trained volunteers, including but not limited to AmeriCorps and Senior Companion volunteers. Some participants may receive stipends.

CONSUMER DIRECTION

The state has built consumer direction into the NFCSP program so that all consumers have the option of paying family and informal caregivers to provide respite and personal care. Respondents indicated that reimbursement for personal care is not specified, but is simply allowed as a component of respite care, however. Respondents stated that the idea of “getting consumers involved in determining their own destiny” had influenced the incorporation of consumer direction into the NFCSP.

The traditional Aged/Disabled Medicaid waiver does not provide for consumer direction. Medicaid officials said that the consumer-directed care projects (federal Cash and Counseling Demonstration and the recently enacted state-passed consumer-directed care project) serve that purpose.

QUALITY ASSURANCE AND EVALUATION

The state has developed a uniform client enrollment and tracking procedure for the DOEA’s programs and services. Although the system is uniform, however, certain data elements are specific to each program, so that Community Care for the Elderly may not require the same information as Older Americans Act programs. The database is called Client Information Registration Tracking System (CIRTS). Once data is collected, it is “batch entered.”

The DOEA is still in the process of determining all of the information to be captured under CIRTS for the NFCSP. Staff indicated that they have set up a work group with the AAAs to decide what data should be captured. Further, respondents noted that AAAs felt that the DOEA was exceeding its authority with its proposed requirements. As of the June 2002 site visit, this issue had not been resolved.

In many of the programs serving older persons, Florida is under legislative mandate to measure outcomes. Key informants did not expect this practice to change for the state-run NFCSP.

Under the Aged/Disabled Medicaid waiver, respondents indicated that some data are collected about caregivers—but specifics were not offered. Medicaid staff did note that the Channeling waiver may collect more caregiver information because a stronger case management focus increases the interaction between the case manager and the caregiver.

SYSTEMS DEVELOPMENT

Respondents indicated that they are still in the early stages of implementing the NFCSP and that it was too soon to describe their experience with the program. Key informants did state, however, that Florida was “ahead of the curve” in terms of supporting caregivers, considering the variety of programs serving older persons and their caregivers.

State officials have identified the Office of Long-Term Care Policy as the entity charged with coordination of family caregiver support services across state departments. This office was created in S.B. 1276 in the 2002 legislative session and will be housed in the DOEA. S.B. 1276 also instructs the DOEA and AHCA to determine ways “to transition all state-funded services” for older persons into, “a managed, integrated LTC delivery system under the direction of a single entity.”³¹

Caregiver services are coordinated at the local level by the AAAs, who have responsibility for coordinating most all services and ensuring that services are seamless to consumers. Stakeholders have

commented, however, that services are coordinated within programs but not across programs. At the state level, services are coordinated at the DOEA, through monitoring of AAA services, review of AAA area plans and development of Florida's State Plan on Aging.

Respondents said that the NFCSP is integrated into the state's other long-term care programs, although some indicated that tension between local and state efforts has challenged efforts to fully integrate services.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

Florida has been relatively active in response to the U.S. Supreme Court's *Olmstead* decision. Activities include a state expansion on the federal Ticket to Work legislation, which allows disabled individuals to return to work while still retaining Medicaid coverage. The federal bill caps income eligibility at 90% of poverty level, or \$7,740. Florida's program is much more expansive, however, capping eligibility at 250% of poverty level, or \$21,475. The state's two Systems Change grants have also focused on integrated service delivery and enhancement of home and community-based services for the disabled.

Although it is not officially designated as such, the ADA Working Group acts as the state's *Olmstead* task force. In addition, Florida had a blue ribbon committee on long-term care that has since disbanded. The committee held public forums, but although caregivers had the opportunity to be involved, one key informant indicated that no special effort had been made to ensure their participation.

OTHER POLICY ISSUES

State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, responses were mixed. Medicaid officials and some DOEA respondents agreed that the priority was "medium," whereas another DOEA official indicated a "high" priority. Two stakeholders cited a "low" priority, and one stakeholder stated that the priority was "high."

Number of Key Informants	Priority on Caregiver Support
2	→ Low
2	→→→ Medium
2	→→→→→ High

Benefits and challenges: Florida case study respondents identified four aspects of their program that are most beneficial to family caregivers:

1. Respite care—to free up a family, providing caregivers with the opportunity to enjoy something "other than being tied down" to their responsibilities

2. Availability of in-home services—so caregivers do not have to “carry the client all over creation”
3. Nonmedical services (such as personal care and chore services)—to free up the caregiver to do other things
4. Waiver services—to provide the family with an alternative to placing the care recipient in a nursing home

When asked to identify the three main challenges for implementing family caregiver support programs in the state of Florida, respondents noted the following:

- ✧ Obtaining funding—particularly convincing legislators that programs need priority and cost-containment measures
- ✧ Standardizing programs and services using the current model of decentralized, privatized service delivery
- ✧ Coordinating and collaborating with stakeholders to achieve consensus
- ✧ Garnering public support and acceptance of new programs, particularly given Florida’s strong antitax sentiments
- ✧ Working with communities that are not accepting of human service programs—e.g., with communities in which a stigma is associated with certain types of care, such as nursing homes, so that families may place a care recipient in an assisted living facility to avoid that stigma even if it is not clinically the most appropriate setting

Major lesson learned: Key informants identified two major lessons learned in providing caregiver support services:

- ✧ Programs that have to cut services face great challenges. One respondent offered the example of the Home Care for the Elderly program when the DOEA suggested that the \$106 monthly subsidy would have to end as recipients transitioned to Medicaid services. There was a “painful uproar” from clients. Yet as one state official observed, this small cash subsidy program is the “most effective of all our programs in terms of nursing home diversion.”
- ✧ Greater flexibility in meeting the needs of family caregivers is better for the caregiver and the care recipient.

Opportunity for expanding caregiver support: Respondents indicated that Florida’s future is unclear as it pertains to expanding caregiver support services. Although some thought it likely that the state would expand community options and consumer-directed care, others based program expansion on the success of transferring clients from programs funded exclusively with state dollars to Medicaid.

Recommendations for other states: State officials in Florida had several recommendations for other states:

- ✧ Do not take the “cookie cutter” approach to program design.
- ✧ Develop systems more.
- ✧ Build partnerships and develop collaborations at the local level, in the beginning phases of program development.

NOTES

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- 21 Horacio Soberon-Ferrer, Strategic Management & Evaluation Coordinator, DOEA. Personal communication, October 23, 2002.
- 22 Florida Department of Elder Affairs, *2002 Resource Manual*.
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- 26 Ibid.
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- 28 U.S. Census Bureau, press releases, www.census.gov (October 3, 2001).
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- 30 A. Yemane and I. Hill, *Health Policy for Low-Income People*.
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OVERVIEW

Hawaii is unique in its geographic location and boundaries as well as in its ethnic and cultural diversity. Hawaii's current long-term care system is constrained by a long tradition of reliance on families to "take care of their own." A shortage of nursing home beds, home and community-based service options and trained direct care workers adds further challenges to Hawaii's long-term care system, with an even greater impact on the rural neighbor islands.

Hawaii does not yet have a system of support in place for family caregivers, although the needs of families have received increased attention in recent years. In February 2002, Hawaii Governor Ben Cayetano (D) proclaimed the year 2002 as "The Year of the Caregiver" in recognition of the new National Family Caregiver Support Program (NFCSP).

The state's emerging caregiver support services are characterized by:

- ✧ A focus on collaboration and partnerships through a state-level caregiver coordinator whose position is state funded rather than federally funded under the NFCSP
- ✧ The development of culturally appropriate caregiver support services on each of the Hawaiian islands
- ✧ Pursuit of a decentralized approach to program development and service delivery

Hawaii's respondents noted that the major service needs of family caregivers are (1) respite care, (2) counseling, (3) help to navigate the long-term care system, particularly in rural areas and for Native Hawaiians, (4) supplemental services (e.g., consumable supplies) and (5) education, specifically skills-based training.

As Hawaii addresses long-term care reform and develops a statewide caregiver support system, a key consideration will be how the state is to achieve its goal: to integrate caregiver support services into Hawaii's other long-term care programs and to build on the infrastructure in place.

INTRODUCTION

Hawaii represents a "new" state that is beginning to explicitly provide caregiver support services as a result of the passage of the NFCSP. The project team conducted a site visit on May 21 and 22, 2002, with in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies interviewed include:

Hawaii Department of Health, Executive Office on Aging

- ✧ Family caregiver support program (NFCSP funded)
- ✧ Kupuna Care program for home and community-based care (state funded)

Hawaii Department of Human Services, Social Services Division, Adult and Community Care Services Branch

- ✧ Aged/Disabled Medicaid waivers
- ✧ Real Choice Systems Change grant

Stakeholders interviewed were from

- ✧ Hawaii Area Agency on Aging Directors and Program Specialists
- ✧ University of Hawaii, Center on Aging
- ✧ Alzheimer's Association, Aloha Chapter
- ✧ Honolulu Gerontology Program
- ✧ Alu Like, Native Hawaiian Elderly Services Project

Three programs are featured:

1. Family caregiver support program
2. Kupuna Care
3. Aged/Disabled Medicaid waivers

BACKGROUND

Hawaii is 2,400 miles from the west coast of the continental United States. It is unique in its geographic location and boundaries as well as in its ethnic and cultural diversity. Hawaii ranks 42nd in population nationally, with about 1.2 million persons residing in four counties covering eight major islands. Hawaii is considered one the healthiest states in the nation, with low infant mortality rates and high life expectancy.¹

The vast majority of Hawaii's population (72%) reside on the island of Oahu in the city and county of Honolulu. The remainder of the state's residents (28%) reside on the rural "neighbor islands" in the counties of Hawaii (12%), Maui (11%) and Kauai (5%). In 2000, personal income per capita was \$28,221. Although Hawaii's per capita income is under the national average (\$29,676² U.S.), Hawaii has proportionately fewer people living below the federal poverty level than the United States as a whole (11.1% vs. 13.3% U.S.).³ About 43% of Hawaii's households have Internet access, with the state ranking 18th nationally⁴ (table 1).

Hawaii is a multicultural state, with a minority of white residents. In 2000, the ethnic breakdown for the state was Hawaiian/part Hawaiian (22.1%), Caucasian (20.5%), Japanese (18.3%), Filipino (12.3%) and Chinese (4.1%).⁵

Hawaii's elders are known as *na Kupuna*. The state's older population is both increasing and aging at a rapid rate. Between 1990 and 2000, the 60+ population increased by some 19%, compared to about 9% nationally. Even more dramatically, between 1990 and 2000, the Hawaiian 85+ population increased nearly twice as fast as the national average (68.9% vs. 37.6% U.S.).⁶ An estimated 207,001 persons in Hawaii, or 17 percent of the state's population, were 60 years or older in 2000, higher than the national average of 16.3%. Hawaii ranks 20th nationally in the percentage of older persons (60+) residing in the state.⁷ About 17,564 persons, or about 1% of the state's population, were 85 years or older in 2000⁸.

The racial makeup of the state's older population is the most diverse in the nation and differs significantly from that of the United States as a whole, with a minority of older white persons (22.7% vs. 82.4% U.S.) and a predominant Asian population (60.6% vs. 2.5% U.S.). Some 5.5% of the state's 60+ population is Native Hawaiian. Compared to the national average, Hawaii has proportionately fewer older African Americans (0.4% vs. 8.4% U.S.) and older Hispanics (2.6% vs. 5.4% U.S.).⁹

Consistent with the state as a whole, about 75% of Hawaii's total older population (ages 60+) reside in the city and county of Honolulu. On the neighbor islands, about 13% of the state's older population live in the county of Hawaii on the Big Island, 10% in Maui County and about 5% in Kauai County.

An estimated 114,872 family caregivers reside in Hawaii. These family caregivers provide about 107 million hours of caregiving per year at an estimated value in 1997 of about \$875 million.¹⁰

Hawaii has recovered somewhat from a major recession in the mid-1990s. Hawaii's economy, however, depends on tourism, which brought \$10.9 billion to the state in 2000. Thus the state is very concerned about the impact that the economic downturn on the United States mainland will have on tourism to Hawaii.

Housing is expensive in the state because of limited availability and the high price of land. The state ranks 48th nationally in the home ownership rate.¹¹ Hawaii has a relatively low tax burden compared to other states and no state personal property tax. Rather, property taxes are collected through county assessments. The cost of living for a family of four has been estimated to be 27% higher than the U.S. average.¹² Geographic boundaries on neighbor islands pose barriers to getting quality health and social services. Because of the state's antitax sentiments, Hawaii's health and social programs are relatively limited.

Table 1. Selected Characteristics of HAWAII and the UNITED STATES, 2000 ^a

	Hawaii	United States
Total Population Characteristics		
Total Pop. ^b	1,211,537	281,421,906
% African American ^c	1.8%	12.3%
% Hispanic ^d	7.2%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	207,001	45,797,200
% 60+ ^f	17.1%	16.3%
National ranking 60+ ^g	20	NA
Pop. 65+ ^h	160,601	34,991,753
% 65+ ⁱ	13.3%	12.4%
National ranking 65+ ^j	16	NA
Pop. 85+ ^k	17,564	4,239,587
% 85+ ^l	1.4%	1.5%
National ranking 85+ ^m	30	NA
% increase 1990–2000 60+ pop. ⁿ	19.1%	9.4%
% White (60+) ^o	22.7%	82.4%
% African American (60+)	0.4%	8.4%
% Hispanic (60+)	2.6%	5.4%
% Asian (60+)	60.6%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	5.5%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics ^p		
# of caregivers (1997)	114,872	25,798,370
Caregiving hours (millions) (1997)	106.9	24,013.1
Value of caregiving (millions) (1997)	\$874.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$28,221	\$29,676
% of pop. below poverty (1997) ^r	11.1%	13.3%
Internet		
% of households w/Internet access (2001) ^s	43.0%	41.5%
Nat'l ranking of households w/Internet access	18	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Hawaii, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
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- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
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- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
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- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
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STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies in Hawaii: the Executive Office on Aging (EOA) in the Department of Health and the Department of Human Services (DHS). Several key informants noted that the EOA has been viewed as serving the "well elderly" and non-Medicaid-eligible older population, and the DHS, through the Medicaid and Medicaid waiver programs, has traditionally served the state's more frail and low-income older population.

The EOA is administratively attached to the Department of Health, serving as the State Unit on Aging (SUA) and administering the provisions of the federal Older Americans Act, including the new NFCSP. Programmatically, the EOA executive director reports to the governor. The EOA also administers Hawaii's state-funded home and community-based care program, now known as *Kupuna Care*. In 1999, the program was given this title and reorganized to increase accountability and management of services. Eligibility standards, service authorization and client cost-sharing were developed to promote greater program efficiencies.

In addition to the EOA, the infrastructure of Hawaii's aging network is a statewide system of four Area Agencies on Aging (AAAs), all located in county government, and private agencies under contract to EOA and the AAAs. The four AAAs serve Kauai County, the city and county of Honolulu, Maui and Kalawao and Hawaii County on the Big Island. The AAAs are not direct service providers; rather, they subcontract with providers in the community to do case management and deliver services to the older population. The roles of the AAAs vary from county to county. The Honolulu AAA on the Island of Oahu, with about 75% of the state's total older population, is by far the largest AAA and has the most community resources. Because there are many different aging-related agencies in Honolulu, that AAA's primary role is coordination among the programs and services. However, outlying areas of Oahu have some of the same problems as neighbor islands, that

is, few services and relatively long driving distances to get care. On the neighbor islands, which are relatively rural and have few resources, the AAAs are the primary focal points for information and services.

The DHS serves as the “single state agency” for administering the Medicaid program. The department operates two 1915 (c) Aged/Disabled waivers, which were originally approved in 1983. The first, the Nursing Home Without Walls (NHWW) waiver, serves persons of all ages with serious or chronic illnesses or disabilities who want to remain in their own homes. The second, the Residential Alternative Community Care (RACC) waiver, is for eligible adults (ages 18+) who need a residence in an assisted-living facility or in a group family home that provides assistance with care needs. Case management teams of social workers and nurses, employed by the state, deliver services. Six case management teams work on the island of Oahu. One case management team is located on each neighbor island.^a

In October 2001, the Hawaii DHS was awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The University of Hawaii, Center on Disability Studies, serves as a subcontractor. Other key state agencies involved include two Department of Health divisions and the EOA. The aim of the three-year grant is to develop a common assessment tool and a website to promote single entry to the long-term care system. Family caregiver issues are not a current focus of the grant.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Long-term care has been a major interest of Hawaii’s lawmakers in recent years. Many bills have been introduced, including some to expand home and community-based care, restructure the administration of aging and long-term care programs and create an affordable method of financing long-term care. Lawmakers have debated legislation for long-term care reform; however, few proposals have been enacted. In 2002, some bills addressing long-term care and the needs of family caregivers were again introduced. Only two were passed, H.B. 2638 and S. 2416. Hawaii Governor Ben Cayetano signed H.B. 2638, creating the Hawaii Long-Term Care Benefits Fund and a board of trustees to pay state residents’ long-term care costs. The Trust Fund would apply to all age groups in the state, regardless of income. The intent of the original legislation was to create a financing system based on a social insurance model, although this component was dropped from the final proposal. Several case study respondents said that lawmakers would be back next year to reintroduce the more comprehensive bill. A second piece of legislation (S. 2416) signed into law by the governor requires the EOA to hold a long-term care summit. Key informants from the EOA said that such a summit would address family caregiver issues.

Several factors constrain Hawaii’s current long-term care system. The first is Hawaii’s relatively low proportion of nursing home beds, the third lowest in the United States for those 65–84 years of age and the lowest ratio in the nation for those 85 years or older.¹³ Traditionally, Hawaii has depended on extended family to provide long-term care at home to address the shortage of nursing home beds.

^a The DHS also administers a Mental Retardation/Developmental Disabilities (MR/DD) waiver, an HIV Community Care waiver and a Medically Fragile waiver for children.

Because of the high cost of living in the state, particularly for housing, extended families most commonly live together in one household. Often, three or four generations live together, creating a high proportion of intergenerational housing in Hawaii. These traditional values have played a significant role in shaping Hawaii's public policies.

The second challenge to Hawaii's long-term care system is the severe shortage of trained long-term care providers, particularly on the neighbor islands. One Medicaid official commented that a lack of trained social workers, nurses and personal care workers on some islands may mean that qualified and trained personnel are not available to provide some home and community-based services even though clients are entitled to the services. Long-term care (i.e., home and community-based services as well as nursing homes) is more available in Honolulu on the island of Oahu, the population center, than anywhere else in the state.

Finally, all respondents talked about the cultural value in Hawaii of taking care of family in one's own home, where the older person is happiest and most cherished. One respondent pointed out that "tradition dictates that among Native Hawaiian families, caregiving for an older person who is ill or disabled is a task that is delegated to a chosen member of the family, generally female." Increasingly, however, family members must work more than one job just to survive and no one is left at home to provide care. In some cultural groups, asking for help to care for a family member is considered shameful. Also still prevalent today, however, is the cultural value of older persons who do not want to be a burden to the family.

Hawaii has no formal state statute recognizing family caregivers as a central component of a comprehensive long-term care system, although respondents believed state law implies such recognition because of the state's tradition of reliance on family care. Some observers expressed the belief that caregiver support services have not been a priority within the long-term care reform debates because "our values are to take care of our own." Others believed that key trends—nursing home bed shortages, limited home and community-based care, aging of the baby boomers and the high proportion of Hawaiian women in the labor force juggling work and caregiving—are causing state leaders to begin shaping public policy to recognize that family caregivers need support services themselves to sustain them in their caregiving role.

Today, Hawaii is slowly changing its attitudes about family caregivers and recognizing that caregivers have their own needs for support, not just relying on them to provide the bulk of long-term care. In February 2002, in recognition of the new NFCSP funds, the governor joined the mayors of all four of Hawaii's counties to proclaim the year 2002 as "The Year of the Family Caregiver." This proclamation promoted awareness of and support for caregiver issues by recognizing family caregiving as a vital piece in the long-term care of Hawaii's older population and by recognizing the importance of providing support services to sustain family caregivers. On the island of Kauai, the mayor is a family caregiver herself and has spoken about her situation and the need for support numerous times.

Multicultural caregiving initiatives: Two demonstration projects are currently being implemented in Hawaii to address the needs of the state's diverse caregiving population. The projects' goals are to strengthen Hawaii's caregiver support services and to provide effective models and promising practices for replication by other states.

- ✧ Under the leadership of the EOA, Hawaii has a five-year history of work to improve end-of-life care. In 2001, the University of Hawaii's Center on Aging received a three-year NFCSP innovation grant to explore the impact of group-targeted messages and individually tailored support on end-of-life planning by multiethnic caregivers of older persons receiving long-term care services. The Center on Aging will develop a series of four booklets to include messages targeted to caregivers at three stages: (1) prior to self-identification as a caregiver, (2) during active home-based caregiving and (3) after the care recipient's institutionalization or death. Working with community partners, the project aims to provide 600 caregivers with the message booklets and support through either caregiver training or counseling, and to document culturally linked barriers to end-of-life planning and strategies to address them.
- ✧ Alu Like is a primarily federally funded Native Hawaiian service organization. In 2001, the agency received a three-year Native American caregivers grant under the NFCSP to design and test quality standards and assurance mechanisms for multifaceted systems of support for family caregivers.^b The project will provide direct services to Native Hawaiian family caregivers, develop culturally appropriate training manuals, conduct education programs and evaluate results. Part of the project will involve paying family caregivers to provide respite.

PROGRAM BACKGROUND/DEVELOPMENT

In the late 1980s, the EOA developed the first long-term care plan for Hawaii, which implicitly recognized the need to support family caregivers in order to sustain the long-term care system. Over the past 15 years, the main focus of the EOA's caregiver initiatives has been on caregiver education and training. One observer noted that "really good skills training is what family caregivers say they need." A number of projects were developed during this time, including a seven-week program through community colleges to train family caregivers, publication of a booklet on caregiving and a study of state employees to estimate the prevalence of employed caregivers in state government.

Prior to the passage of the NFCSP in 2000, no statewide caregiver support program existed in Hawaii. Respondents pointed out that most of the advocacy efforts over the past two decades have been to expand home and community-based care for the older person, not specifically to address the needs of the family caregiver or to take a "family systems" approach to service delivery.

The EOA began planning for the establishment of the new program in January 2001. To identify innovative models that could be implemented in the state, Hawaii looked at Wisconsin's Alzheimer's disease program, California's caregiver resource centers, Louisiana's respite sitters program, Minnesota's program to pay family caregivers and Pennsylvania's "cash grant" program. The state also reviewed the lessons learned from Hawaii's federal Alzheimer's Disease Demonstration Grant to States. This federal demonstration, undertaken in the early 1990s, provided a stipend to participating caregivers in exchange for training on how to care for their frail family members with dementia. The project also used "low-tech" friendship approach, using volunteers to provide respite care. The EOA and the AAAs also utilized the Administration on Aging (AoA) listserv to stimulate program development and conducted focus groups to better understand the needs of family caregivers.

^b The Hana Community Health Center on Maui also received a Native American caregivers demonstration grant under the NFCSP. Their project will identify and prioritize the needs of Native Hawaiian family caregivers.

Like other small states, Hawaii did not receive any administrative funds to operate the NFCSP at the state level. All of the federal funds were passed through to the four AAAs. The EOA recognized, however, the importance of maintaining a statewide focus on caregiving and in September 2001, hired a caregiver coordinator whose position is state funded. The coordinator heads up the Caregivers Resource Initiative (CRI) project. Although the NFCSP served as the catalyst for the CRI project, it is not directly related to it in terms of services. The intent of the state project is to assist and enhance caregiver support efforts at the state and local level by partnering and collaborating with various stakeholders in the community to develop caregiver resources; increase access to information on caregiver services and issues; and increase support for caregivers throughout the state. A statewide family caregiving network, newsletter and website are being developed to further the intent of the state project.

To ensure that family caregivers are indeed part of the ongoing planning process for the new family caregiver support program, the EOA contracted with the University of Hawaii's Center on Aging to conduct a statewide caregiver survey during the summer of 2002. Results will be used to help shape the state's next four-year state plan on aging (FY 2003–06) and to provide caregiver data to state leaders involved in Hawaii's long-term care reform efforts.

Because of the limited federal NFCSP funds coming to Hawaii, the EOA did not take a centralized or system's development approach during the start-up phase of the new program or require that all the AAAs provide all caregiver support services. Rather, the EOA gave the AAAs much flexibility in designing their caregiver support program so the EOA asked each of the four AAAs to come up with a plan for identifying which services would work best in each county and what outcomes to expect. Each AAA has conducted small-scale needs assessments and focus groups with caregivers. Services were slow to start up and were phased in over several months. The counties of Maui and Kauai started providing services in July 2001. Honolulu's start-up was in September 2001. On the Big Island of Hawaii, service delivery did not begin until March 2002.

Because of the wide disparity in funding for caregiver support at the local level, with the Honolulu AAA receiving nearly two-thirds of the federal NFCSP funds for services in the state (\$410,000 per year) and the other three AAAs receiving NFCSP funds ranging from only \$62,000 to about \$97,000 per year, the EOA did not recommend that each AAA establish a caregiver coordinator or specialist position. Both the Honolulu and Big Island AAAs hired designated caregiver specialists.

Most rewarding: Key informants noted that the most rewarding aspect of the program's development has been the recognition of family caregivers as a "new constituency" in the state. The federal funds, although very limited, have allowed Hawaii to begin focusing specifically on the needs of family caregivers.

Biggest challenge: State officials acknowledged that the program has been hard to "get off the ground" because of the limited federal funds and the "push to spend the dollars so quickly." Respondents expressed frustration in the lack of overall guidance from the federal government, particularly in data collection, program evaluation and outcomes.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Hawaii received \$564,300 in federal funds. The majority of the federal funds were carried over to the next fiscal year. In FY 2002, the federal share of the NFCSP was increased to \$639,540, or only about 6% of the EOA's \$12 million budget.

In contrast, Hawaii's expenditures for the state-funded home and community-based care program, Kupuna Care, administered by the EOA, was \$4.4 million in FY 2001 and \$4.9 million in FY 2002. In FY 2001, the total cost of services under the two Medicaid Aged/Disabled waivers administered by the DHS was \$38.3 million. The state Medicaid official was unable to estimate the amount spent overall for respite care under the two waivers.

Hawaii received nearly \$39 million in tobacco settlement funds during FY 2000 and \$42 million in FY 2001. The state elected not to use these revenues to shore up state spending on Medicaid, expand home and community-based care or fund caregiver support services. Rather, the state has used the funds for health promotion and disease prevention activities through the Department of Health, to establish an emergency and budget reserve "rainy day" fund and, more recently, to help pay for the construction of a new medical school at the University of Hawaii.

Key informants generally described Hawaii's current budget situation as stable, with level funding and no impact to date on the new family caregiver support program. Hawaii has used state administrative funds from the EOA budget for the caregiver coordinator position and in-kind contributions from the AAAs to maintain the required 25% state match for the NFCSP funds.

Unlike other states, Hawaii experienced a budget crisis beginning in 1994, and in the mid- to late 1990s, major service cuts were made to health and social service programs. Several state leaders and stakeholders expressed apprehension about next year's budget. The economic downturn on the U.S. mainland will likely adversely affect Hawaii's tourism industry, which is a major source of state revenue. There is real potential for a major economic slump, yet again, in Hawaii.

PROGRAM ADMINISTRATION

The EOA sees its role in the development and implementation of Hawaii's first statewide caregiver support program to be in the areas of oversight, needs assessment and evaluation to ensure that family caregiver support services are integrated into the state's long-term care system. One state official commented that caregiver support is "extremely politically attractive." Respondents noted that during the program start-up phase, policy development has been a joint undertaking between the EOA and the four AAAs. One observer noted that the next phase of program implementation, when the state attempts to implement a systems development approach to caregiver support services, will be more difficult.

The EOA has focused its resources on gathering a range of information on family caregivers to aid in understanding the "big picture" and examining what is possible for Hawaii to accomplish. By partnering with the University of Hawaii's Center on Aging to conduct a statewide caregiver survey, the EOA hopes to better understand "what works and doesn't work for Hawaii's families." Through the state's caregiver coordinator, the EOA has an important presence, serving as a linkage to community groups and agencies throughout the state.

The Medicaid waiver respondent did not identify a role for the DHS with regard to caregiver support services in Hawaii and noted that the department was not involved in the planning process for the new federally funded family caregiver support program. The respondent stated that policies are not developed specifically for family caregivers in the Medicaid waiver programs, because the focus is on the care recipient (i.e., the client).

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Family caregiver support program: Eligibility for Hawaii's caregiver support program is consistent with federal requirements under the Older Americans Act: family or informal caregivers of any age who provide care to persons ages 60 and older, as well as caregivers ages 60 and older who are caring for children ages 18 or younger.^c For respite and supplemental services, the older person (age 60+) must need help with at least two activities of daily living (ADLs) or have cognitive impairment. The family caregiver is considered the client in the new program.

State officials noted that the EOA's caregiver coordinator is developing a family caregiver network across Hawaii to develop a coordinated system of information on caregiver issues. There will be no age requirement to participate. Using its state funds, Hawaii will thus be able to go beyond the federal age restrictions and involve family caregivers who are caring for adults under the age of 60.

While Hawaii's Kupuna Care program has a uniform intake/assessment process, the EOA has not yet established uniform assessment standards for Hawaii's AAAs or required the AAAs to utilize a common intake form for the caregiver support program. The EOA has encouraged all AAAs to use the Kupuna Care common intake form more broadly for family caregivers as well, but few AAAs have adopted this approach. Because of the small level of funding overall and the very early stage of program development, respondents noted each AAA is utilizing its own methods and forms. The county of Hawaii is currently developing an automated caregiver assessment tool.

Kupuna Care: To be eligible for Hawaii's state-funded home and community based services program, Kupuna Care, a person must meet the following requirements:

- ✧ Be age 60 or older
- ✧ Not be covered by a comparable government or private service
- ✧ Not reside in an institution
- ✧ Have two or more ADL/IADL (instrumental activities of daily living) limitations or substantive cognitive impairment
- ✧ Need help with one or more identified limitations in activities of daily living

Each AAA contracts with locally based case managers to make eligibility determinations and develop care plans for clients. The AAAs also contract with service providers who deliver direct services. The intake and assessment tool focuses on the care recipient. As part of the assessment process, the extent of informal care and the ability of the family caregiver to provide care are taken into account in the authorization of paid services for the care recipient.

^c Including caregivers 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

Medicaid waivers: Eligibility for the two Aged/Disabled waivers are based on income level (supplemental security income, or SSI), functional criteria (Medicaid nursing home level of care) and age (18+ for the RACC waiver and all ages for the NHWW waiver). Consistent with Medicaid policy, the care recipient is the identified client in the program. The case management team includes a social worker and a nurse who are employed by the DHS. The case managers reassess every six months and call the client monthly. One observer noted that even though the focus is on the care recipient, the family caregiver is oftentimes part of the assessment process.

The state has no uniform assessment standards for the waiver programs. Some waiver programs are using a common assessment tool, such as the NHWW waiver, and include questions about the family caregiver's ability to provide care. Consistent with Medicaid policy in general, respondents noted that the extent of informal care is always taken into account in the authorization of paid services for the care recipient. The assessment tool for the NHWW waiver focuses on both the care recipient and the family caregiver. It includes questions about informal support in general and about the primary family caregiver in particular. For example:

- ❖ Data are collected about the type of help provided to the care recipient by family, friends and neighbors; name and age of the caregiver; relationship to the care recipient and employment status and number of days and hours the caregiver works.
- ❖ Data are collected about the primary family caregiver, including name, age, relationship to care recipient, ability to read, ability to work and employment status and work hours.
- ❖ The primary family caregiver is asked 12 yes/no questions to assess his or her ability to provide care, regarding such things as whether the caregiver has other family responsibilities, has health problems that impact caregiving or has difficulty making decisions.
- ❖ The primary family caregiver is asked the open-ended question, "What would you do if you were unable to care for the care recipient?"

SERVICES

Hawaii offers limited home and community-based services and support for family caregivers through its state-funded Kupuna Care program and the Aged/Disabled Medicaid waivers, as well as through the new federally funded family caregiver support program.

Family caregiver support program: Given the very limited federal NFCSP funds in Hawaii, the state did not mandate that each AAA provide all caregiver support services. Each AAA has the flexibility to provide a different package of caregiver support services based on local needs and resources. Limited respite care, individual counseling and supplemental services are available in every AAA region, however. According to several stakeholders, family caregivers' access to support services varies widely from county to county (i.e., island to island), with services unevenly distributed across Hawaii. Statewide, all five categories of services are funded: information, assistance, counseling/support groups/training, respite care and supplemental services.

At the time of the site visit, Hawaii's AAAs were utilizing diverse approaches to provide caregiver support services. The Hawaii AAA on the Big Island is developing a family consultation program to provide information and support to family caregivers and assist them through the long-term care system, for example. On Kauai, a series of caregiver training programs is being developed. In Honolulu and on Maui, case management is being offered to family caregivers.

Supplemental services are a key component of Hawaii's caregiver support program and are, according to several state officials and stakeholders, filling an important gap in service delivery. On the Big Island, the Hawaii AAA has paid for the installation of lifeline emergency response equipment in one home, for example, so that a family caregiver could return to work and have peace of mind that her loved one was safe. In another case, the AAA has paid for bookkeeper services for a caregiver who needed help in managing day-to-day household finances. In Honolulu, the AAA is providing transportation services for a caregiver that are not related to the care recipient's medical needs.

The state and the AAAs have generally taken a low-key approach to publicizing the program because of the limited federal funds in the start-up year. There are no waiting lists for services at this time. Unlike other "new" states that are providing explicit caregiver support for the first time, Hawaii elected not to require the AAAs to pool a proportion of their base allocation for joint activities with statewide impact. State officials expressed interest in pursuing this option if Hawaii receives additional federal funds under the NFCSP to provide caregiver support.

Kupuna Care: This state-funded program served about 5,300 older persons in Hawaii in 2001, with a waiting list of nearly 500 older persons. According to state respondents, the waiting list has since been reduced because of the new federal funding for family caregiver support services. In the Kupuna Care program, services are designed to be "client centered and family supportive," allowing older adults to live at home with independence and dignity.¹⁴ Each AAA contracts with local private sector providers for the delivery of eight core services: adult day care, assisted transportation, attendant care (i.e., companion assistance), case management, chore services (e.g., yard work), home-delivered meals, homemaker services, and personal care. Interestingly, although the program is intended to be "family supportive" and implicitly assists family caregivers by offering them relief through adult day services and personal care, etc., respite care is not an explicit, covered service.

Medicaid waivers: Hawaii's Medicaid NHWW waiver does not differentiate between personal care, nursing and respite. Thus, Hawaii likely provides more respite care under the NHWW Medicaid waiver than is reflected in reports. The waiver program used to cap the amount of respite for family caregivers but stopped doing so about five years ago. When hours of benefits are assessed, a care recipient who has good family support will likely get fewer hours of service. Key informants noted that Hawaii's NHWW Medicaid waiver also covers other services that can help the family caregiver, such as home modifications and adult day services. There are 1,055 clients served under the NHWW waiver.

Under the state's RACC Medicaid waiver, respite is also a covered service. Care recipients may be served in an assisted living facility or in a family home that provides personal care, homemaking services and transportation as needed. Individuals may also receive private-duty nursing services, respite care and/or adult day health services as needed. This waiver, which serves 845 clients, is the most popular in Hawaii and has a waiting list for program authorization.

Major services needed by caregivers: State officials and stakeholders viewed respite care—in a variety of formats (e.g., overnight, weekend options) and in sufficient amounts to make a difference in the quality of life for the caregiver—as a major need of caregivers. Counseling was another major need identified by both state officials and stakeholders. Stakeholders noted several other service needs, including information and access to services to help caregivers navigate the long-term care system

(particularly in rural areas and for Native Hawaiians) and financial relief. Stakeholders also believed that the supplemental services allowable under the NFCSP were critical to the well-being of family caregivers. Last, state officials also identified the ongoing need for caregiver education and training, specifically for skills-based training.

Findings from a 1995 Alu Like survey conducted among Native Hawaiian family caregivers indicated that caregivers were generally knowledgeable about available services in the community but were reluctant to use services, primarily because of cultural values. Service utilization was low because of attitudes that such home and community-based services were “not for Hawaiians” and also because of the stigma and shame attached to asking for help and using services. Further affecting service utilization was the notion of “family members being neglectful of their *kupuna* [elder] by having them turn to strangers to meet their needs.”

Table 2. Family Caregiver Support Services in Hawaii

Program	Family Caregiver Support Program	Kupuna Care	Aged/Disabled Medicaid waivers^a
State Administrative Responsibility	Executive Office on Aging, Department of Health	Executive Office on Aging, Department of Health	Department of Human Services
Local Service Delivery	AAAs ^b Subcontractors for case management Service providers/contractors	AAAs Subcontractors for case management Service providers/contractors	State nurses & social workers for assessment & case management Service providers/contractors
Funding Source	Older Americans Act, Title III-E State General Fund ^c	State General Fund	Medicaid 1915 (c) waivers
Expenditures FY 2001	\$564,300—federal (for all caregiver support services) \$113,000—state (Caregivers Resources Initiative Project)	\$4.4 million	\$38.3 million
Client Population	Family & informal caregiver	Care recipient	Care recipient
Eligibility Criteria:			
Age	60+ care recipient Family caregivers of persons 60+	60+ care recipient	NHWW: all ages RACC: 18+
Income	None	Cost sharing for clients about 150% of poverty	SSI level 100% of poverty
Functional Ability	For respite & supplemental services only—at least two ADLs or cognitive impairment for care recipient	2+ ADLs/IADLs or significantly reduced mental capacity 1+ unmet ADL/IADL need	Nursing home level of care
Uniform, Statewide Caregiver Assessment	No	No (uniform intake/assessment for care recipient only)	No (uniform care recipient assessment only)

^a Two Aged/Disabled Waivers: Nursing Homes Without Walls (NHWW) and Residential Alternative Community Care (RACC).

^b AAAs = Area Agencies on Aging.

^c For EOA Caregivers Resources Initiative Project, including the EOA Caregiver Coordinator position.

Table 2. Family Caregiver Support Services in Hawaii (continued)

Program	Family Caregiver Support Program	Kupuna Care	Aged/Disabled Medicaid waivers
Service Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	None ^e	Respite care Home modifications
Respite Care	None	None	None
Consumer Direction	Not formally. Some elements of consumer direction are offered. Family caregivers can purchase goods & services (e.g., consumable supplies, home repairs) under the supplemental services category.	No	Yes
Family Caregivers Paid as Respite Providers	No	No	Yes

^d All services provided in Hawaii, however, each AAA does not offer all services.

^e Although respite isn't a covered service, the care recipient does have access to limited adult day services.

CONSUMER DIRECTION

Neither the new NFCSP in Hawaii nor the state-funded Kupuna Care program offers a formal consumer-directed option, nor do these programs pay family caregivers to provide care. Respondents commented that there has been a perception in the state, slowly changing, that quality control would be lost if consumer direction were allowed and if clients could hire, manage and fire their own workers, including family members.

Key informants noted that the state has not adopted any policy on payment to family caregivers for respite care under the NFCSP. Even so, the AAAs, for the time being, are not offering this option. All of Hawaii's AAAs contract for respite services with local agencies and providers only; families cannot hire their own respite provider and serve as the employer, except in Honolulu, where respite subsidies are available. The EOA observers acknowledged that some elements of consumer direction are available through the provision of NFCSP supplemental services, which allow families to purchase goods and services that they need to keep their relative at home.

Hawaii is in the early stages of considering consumer direction as an option in its home and community-based service system. The EOA is planning to implement a state-funded demonstration on consumer direction in Kupuna Care, beginning in July 2003, to allow family members to be paid to care for their older relatives at home. One EOA respondent commented that "we have to be able to pay family caregivers. Not every family member can afford to quit a job to give care. It may mean the difference [between] keeping someone at home or placing them in a nursing home. This is particularly important in rural areas where there simply are no providers."

Consumer direction *is* offered under the Aged/Disabled Medicaid waivers, allowing care recipients to hire their own personal care attendant or respite worker, including neighbors, friends or family. Because of severe workforce shortages in the state, consumer-directed services, including the hiring of family members, are becoming more widely used. Respondents noted that under the consumer-directed option, family members provide about 90% of care. In Hawaii, the state serves as the fiscal intermediary for the consumer-directed component. Checks are issued in the worker's name but are delivered to the care recipient's home.

Family members can also be paid to provide personal care under Hawaii's Medicaid waivers. Consistent with federal policy, spouses or parents of minor children cannot be paid under the waiver programs. No formal training is required for family members, and criminal background checks for family caregivers are not required either.

QUALITY ASSURANCE AND EVALUATION

Hawaii is utilizing the AoA's minimum data collection requirements for the family caregiver support program: type of service to caregiver (e.g., information, assistance), number of caregivers served by type of service, units of service provided (e.g., information contact, respite hours) and expenditures per service type. Caregiver demographics are also collected, but not consistently across all four AAAs. At this early stage of program start-up, each AAA is collecting different caregiver information based on its interests and resources. The Honolulu AAA, which has by far the largest funding, for example, conducts psychosocial caregiver assessments. In contrast, the Maui AAA, with very limited funding, collects only basic demographic information on the caregiver (e.g., age, gender). The EOA will be working with the AAAs to standardize data collection across the state.

EOA respondents expressed frustration that their current data collection practices under the new family caregiver support program are not as standardized or complete as they would like. Without a consistent, outcomes-oriented data set for all AAAs, state officials acknowledged that they will be hampered in their efforts to advocate for caregiver issues in the larger context of long-term care reform. Currently, the EOA and the AAAs are in the process of automating data collection with both SAMS 2000 and Beacon software that will allow all EOA-administered programs to utilize a uniform service utilization and client tracking system. At the time of the site visit, the Hawaii AAA on the Big Island was the only AAA to have implemented the automated tracking system. All the AAAs and the EOA had purchased the software and received training.

Outcome measures vary from AAA to AAA, and there are no statewide standards. Some AAAs focus on caregiver outcomes; others do not. The Honolulu AAA plans to examine caregiver outcomes through its assessment process. Caregivers who receive services through their AAA will be pre- and post-evaluated on level of well-being and stress. The University of Hawaii's Center on Aging has evaluated the state-funded Kupuna Care program through a client satisfaction survey and plans to assist the EOA by conducting a caregiver satisfaction survey.

Under Hawaii's Aged/Disabled Medicaid waivers, family caregiver information is not specifically tracked. Although the case managers collect caregiver information as part of the assessment process of the care recipient, the data are not aggregated by DHS. The waiver programs use a paper format to collect information; reporting is not yet automated, but this is planned.

SYSTEMS DEVELOPMENT

Respondents, both state officials and stakeholders, commented that the first year of start-up and implementation of the new caregiver support program has been one of "testing" and experimentation to determine what works and what does not work, particularly in providing culturally appropriate services on each island. One stakeholder commented that the challenge "is to integrate the NFCSP into the wider Older Americans Act so that we don't have one program focusing on the older person and one on the family." Several respondents noted that there has been much confusion statewide about "who is the client—the older person or the family caregiver—and with limited resources, who is the priority"?

The state has taken a decentralized approach to program development, allowing Hawaii's AAAs much flexibility to shape their caregiver support services to meet the local needs of family caregivers and to integrate service delivery with Kupuna Care. After the first full year of implementation, the EOA and AAAs will identify "best practices" to shape statewide policy. The Hawaii AAA on the Big Island intends to regionalize services and establish caregiver resource centers in nine rural areas of the island, for example. State officials noted that they will look closely at this model to see if it could be replicated on the neighbor islands.

The EOA caregiver coordinator is taking a lead role in coordinating caregiver information and support at the state level and is serving as a resource to the AAAs. She is also examining what other states are doing to support families to help shape Hawaii's policies and programs, reviewing caregiver training curricula for replication and building a broad-based caregiver coalition throughout the state.

Hawaii does not have a body whose mission is coordination of family caregiver support services across state departments. Through the efforts of the caregiver coordinator, the EOA is taking the lead to develop a roundtable coalition to involve key stakeholders from other state departments (e.g., DHS) and the private sector. The Medicaid waiver respondent acknowledged the need to increase coordination across state departments as well as at the local level. Several other stakeholders noted that, although there has been minimal communication between aging and Medicaid services, this is beginning to change as Hawaii works to expand home and community-based services.

The state's intent is to integrate caregiver support services into Hawaii's other long-term care programs and to build on the infrastructure already in place. The challenge in Hawaii, commented several respondents, is that the home and community-based care system has few resources to meet the needs of the family—be it the older person or the caregiver.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In May 2000, the Hawaii legislature passed a concurrent resolution to establish an *Olmstead* planning task force. In response, the state set up a planning committee chaired by the directors of the Departments of Human Services and Health and the executive director of the Center for Independent Living.¹⁵ The EOA executive director is a member of the planning committee. Family caregivers are involved in the planning process, primarily representing families in the Mental Retardation/Developmental Disabilities system. Key informants noted that family caregiver issues for the elderly have not been a focus of the planning discussions.

The committee's top priority is information management: to increase awareness of what resources are available and to develop a single point of entry for the long-term care system. Hawaii's planning effort, through its Systems Change grant noted earlier in this report, is also focusing on developing a uniform assessment tool to better identify who is eligible for what services and to link assessment to the information management system being developed.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, respondents disagreed in their assessment of caregiver support as a state priority. EOA officials generally felt the priority was "low," although the Medicaid official gave "high" priority to caregiver support in the state. Stakeholders, on the other hand, tended to express either "low" or "medium" priority.

Number of Key Informants	Priority on Caregiver Support
4	→ Low
2	→→→ Medium
2	→→→→→ High

Benefits and challenges: Hawaii's key informants identified four aspects of their program that are most beneficial to family caregivers:

- ✧ Respite care—to give families a break, particularly for family caregivers not eligible for respite under the Medicaid waivers
- ✧ A broad menu of caregiver support—to provide information, assistance and caregiver training designed specifically to meet the needs of family caregivers
- ✧ Flexibility—to design caregiver support services to meet the individual and culturally appropriate needs of Hawaii's diverse families
- ✧ Under the Medicaid waivers, personal care and nursing—to relieve the family caregiver

The following challenges were reported:

- ✧ Very limited funding to develop a statewide caregiver support program
- ✧ A severe labor shortage; a lack of trained direct-care workers, particularly on the more rural and isolated neighbor islands
- ✧ The need to develop a new program with a “new constituency”
- ✧ Lack of a uniform service package across the state; some neighbor islands don't have all the support services; not all islands have the same capacity and trained staff

Major lesson learned: The view of Hawaii's state leaders is “don't make assumptions that we know what caregivers want.” Respondents emphasized the importance of conducting caregiver assessments and developing services that are individually driven and culturally appropriate, rather than “menu driven.”

Opportunity for expanding caregiver support: Hawaii's state respondents were split on their views on expansion of caregiver support over the next three to five years. At the EOA, state leaders were generally optimistic and expressed the view that “the economy will improve and we will have successes. The legislature will be compelled to fund caregiver support programs as the baby boomers age.” At the DHS, on the other hand, the respondent was more cautious and pessimistic, commenting that “Hawaii has no money. The state is heavily dependent on tourism, and the legislature won't tax.”

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- ✧ Have adequate funding and staff before you advertise the program and services.
- ✧ Address the issue that caregivers don't self-identify and often don't recognize the term “caregiver” as applying to their family situation.
- ✧ Collaborate with other groups and form partnerships to meet the needs of the caregiver.
- ✧ Develop targeted training to meet the individual and culturally appropriate needs of families.
- ✧ Ensure flexibility in service design and delivery at the local level by offering a wide service package with options to meet caregiver's individual needs.
- ✧ Conduct caregiver assessments and ask caregivers what they need.

NOTES

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- 10 Informal caregivers are family and friends of adults with disabilities or of older persons. Data source: "Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997," prepared for the Alzheimer's Association by Peter Arno, PhD, and Margaret Memmott, March 1999.
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INDIANA

OVERVIEW

Indiana is a moderately sized midwestern state, characterized by a relatively homogenous and increasing rural population. The state's current long-term care system has been recognized for its innovation and for its significant state funding for home and community-based services. Although programs are decentralized, with a single point of entry at the local level and consolidated administration at the state level, frequent reorganizations, programmatic shifts and significant budget shortfalls have challenged this approach.

Some state policy attention to caregiver support services has existed since 1987, although focused attention on this population has emerged only recently, with the passage of the National Family Caregiver Support Program (NFCSP) and the infusion of federal funds into Indiana's state budget. The state's developing caregiver support services are characterized by:

- ✧ Integrated programs and services, with a single point of entry
- ✧ A statewide logo and tag line to promote a consistent, statewide identity for the program
- ✧ A decentralized approach to service delivery, with statewide standards

Indiana respondents noted that the major service needs of family caregivers are (1) respite care, (2) information and ongoing support, (3) emergency services and (4) support groups.

INTRODUCTION

Indiana represents a "new" state in this study. Specific caregiver support programs were not in place prior to the passage of the NFCSP. The project team conducted a site visit on May 21 and 22, 2002, interviewing government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Family and Social Services Administration, Division of Disability, Aging and Rehabilitative Services

- ✧ Family Caregiver Support Program (NFCSP funded)
- ✧ Community and Home Options to Institutional Care for the Elderly and Persons with Disabilities (CHOICE) program (state funded)
- ✧ Aged/Disabled Medicaid waiver

Stakeholders interviewed were from

- ✧ Indiana Association of Area Agencies on Aging
- ✧ Alzheimer's Association, Central Indiana Chapter

Three programs are featured:

1. Family Caregiver Support Program
2. CHOICE
3. Aged/Disabled Medicaid waiver

BACKGROUND

Indiana is a midsized midwestern state with a population of 6.1 million people who reside in 92 counties. Nearly two-thirds of the state's residents live in urban areas (64.9% in 1990).¹ Recent growth has occurred disproportionately in rural areas, however, reflecting a long-term pattern of suburbanization that many feel threatens the economic and social viability of both communities and rural areas.²

In 2000, personal income per capita was \$27,011, lower than the national average of \$29,676.³ About 10% of Indiana's population live below the federal poverty level (vs. 13.3% U.S.).⁴ Indiana ranks 32nd nationally in percentage of households with Internet access.⁵ The racial makeup of the state's population differs somewhat from that of the United States as a whole, with Indiana having a smaller proportion of both African American (8.4% vs. 12.3% U.S.) and Hispanic (3.5% vs. 12.5% U.S.) persons⁶ (table 1).

An estimated 988,506 persons in Indiana were 60 years or older in 2000, with Indiana having the same proportion of older persons as the nation as a whole (16.3%). Indiana ranks 29th nationally in the number of older persons (ages 60+) residing in the state.⁷ Similar to the state's population as a whole and compared to the national average, Indiana has a smaller proportion of African American (5.9% vs. 8.4% U.S.) and Hispanic (1.1% vs. 5.4% U.S.) persons ages 60+.⁸ Indiana ranks 28th nationally in the proportion of its population ages 85 and older. In 2000, 91,558 persons, or 1.5% of Indiana's population, were ages 85+.⁹

An estimated 568,307 family caregivers reside in Indiana. These family caregivers provide about 529 million hours of caregiving per year at an estimated value in 1997 of \$4.3 billion.¹⁰

With a state tax revenue in 2001 of \$10.2 billion, or \$1,669 per capita, Indiana ranks 38th among all of the states. As a share of personal income, total state taxes dropped from 6.5 % in 2000 to 6% in 2001.¹¹ Key informants noted that Indiana had a budget surplus two years prior and, like many other states, had instituted a number of tax cuts and, "permanent give-backs, which evaporated the budget." Projections of tax growth then were not based on good numbers, informants reported. Since then, 100,000 jobs have been lost in the state. Indiana's constitution requires a balanced budget, so programs must be cut if tax revenues are insufficient.

Table 1. Selected Characteristics of INDIANA and the UNITED STATES, 2000 ^a

	Indiana	United States
Total Population Characteristics		
Total Pop. ^b	6,080,485	281,421,906
% African American ^c	8.4%	12.3%
% Hispanic ^d	3.5%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	988,506	45,797,200
% 60+ ^f	16.3%	16.3%
National ranking 60+ ^g	29	NA
Pop. 65+ ^h	752,831	34,991,753
% 65+ ⁱ	12.4%	12.4%
National ranking 65+ ^j	28	NA
Pop. 85+ ^k	91,558	4,239,587
% 85+ ^l	1.5%	1.5%
National ranking 85+ ^m	28	NA
% increase 1990–2000 60+ pop. ⁿ	5.3%	9.4%
% White (60+) ^o	92.0%	82.4%
% African American (60+)	5.9%	8.4%
% Hispanic (60+)	1.1%	5.4%
% Asian (60+)	0.4%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics ^p		
# of caregivers (1997)	568,307	25,798,370
Caregiving hours (millions) (1997)	529.0	24,013.1
Value of caregiving (millions) (1997)	\$4,327.1	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$27,011	\$29,676
% of pop. below poverty (1997) ^r	9.9%	13.3%
Internet		
% of households w/Internet access (2001) ^s	39.4%	41.5%
Nat'l ranking of households w/Internet access	32	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Indiana, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Indiana.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Indiana has a multilayered system of agencies and divisions through which aging, health and social services are administered. The umbrella agency, the Family and Social Services Administration (FSSA), houses the Division of Disability, Aging and Rehabilitative Services (DDARS), the division through which caregiver support services for the elderly and for adults with physical disabilities are administered. More specifically, DDARS' mission is to provide "leadership and support to enable older adults and persons with disabilities to maximize their independence and self-sufficiency."

Within the DDARS, the Bureau of Aging and In-Home Services (BAIHS) provides a broad range of in-home and community-based services to older adults and to persons of all ages with disabilities. It serves as the State Unit on Aging, administering the provisions of the federal Older Americans Act, including the new NFCSP. At the time of the site visit, FSSA had recently been reorganized, and the bureau's director and assistant director positions both were vacant.

The DDARS coordinates other community-based and protective services, including congregate meals, information and referral, legal services, ombudsman, preventive health services, adult protective services, adult guardianship, senior employment, nursing home preadmission screening and annual resident review, the residential care assistance program and money management and representative payee programs.¹² The BAIHS administers the statewide IN-Home Services program, which was implemented in July 1992. This is Indiana's case management system, which brings together funding from several sources to provide an integrated, single point of entry for consumers at the Area Agency on Aging (AAA) level. In addition, Indiana's aging network includes a statewide system of 16 AAAs, all nonprofit organizations. The areas covered by the individual AAAs range from two to nine counties: Two of the AAAs are affiliated with private universities. The DDARS contracts with the AAAs to administer funds for the state-funded CHOICE program as well as for the IN-Home Services case management system. Persons of all ages with disabilities may access services through the

AAAs. The AAAs' local administrative functions, in addition to case management, include budgeting, oversight, monitoring, quality assurance and submission of fiscal claims to the DDARS.¹³ The AAAs arrange for individually needed services through subcontracts with local vendors and rarely provide direct services themselves. If no other agency is available to provide a specific service, however, the AAA may be granted a waiver from DDARS to deliver that service.

The FSSA serves as the "single state agency" for Medicaid, and its Office of Medicaid Policy and Planning has oversight responsibility for the day-to-day operations of Indiana's Medicaid program. Administration of the Medicaid waivers, however, is through the BAIHS, rather than through the Office of Medicaid Policy and Planning. Persons desiring Medicaid waiver services can apply at any of many different local offices statewide, including AAAs, Vocational Rehabilitation, Bureau of Developmental Disabilities Services and the Division of Family and Children.

Original approval for the Aged/Disabled Medicaid waiver occurred in 1984.^a In FY 2001, with the original federally approved level of 2,500 slots still in effect, 2,352 individuals were served under this waiver. Indiana has made a major change in its Medicaid strategy in the recent past, maximizing Medicaid reimbursement by moving clients from the state-funded program to Medicaid. The state has now received federal approval for an additional 10,000 slots, bringing the total to 12,500 for FY 2003.¹⁴ Because the state legislature must also approve the expansion, not all additional spots have been filled, however. The legislature approved 822 new slots for FY 2002 and another 813 for FY 2003.¹⁵ A significant gap will soon exist between the number of waiver slots authorized by the federal government and the number authorized by the state, which holds implications for *Olmstead*-related planning and implementation.

In 2002, Indiana received nearly \$1.4 million through the Centers for Medicare and Medicaid Services (CMS) Real Choice Systems Change grant. The grant was awarded to the FSSA with the goals of (1) creating an enduring, system-wide infrastructure to support consumer-directed community-based supports and services, (2) involving all relevant state agencies and private partners, (3) continuing education and information for and from older adults and persons with disabilities and their families or caregivers about options and barriers in the system of community supports and services, (4) assisting consumers in recruiting and training providers, (5) expanding the services and supports available through consumer direction, (6) ensuring that consumers are safe and are not abandoned when they have problems with services and supports, (7) monitoring changes taking place and (8) evaluating changes in services and supports in order to replicate when appropriate and to ensure that desired changes are integrated into the perceptions and actions of all communities.¹⁶

^a Indiana has implemented seven Home and Community-Based Medicaid waivers: Aged/Disabled, Autism, Developmental Disabilities, Medically Fragile Children, Traumatic Brain Injury, Assisted Living and Support Services.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Indiana has a long history of innovation and support for community-based long-term care. In 1998, the National Governors Association recognized Indiana for giving care managers the authority to blend funds for home care services and for decentralizing power across the state's 16 AAAs.¹⁷

Indiana's home and community-based services to families and their caregivers are provided through the IN-Home Services program. Programs and funding sources include the new NFCSP, CHOICE, the Aged/Disabled Medicaid waiver, Social Services Block Grant (SSBG) funds, an Alzheimer's Disease Demonstration Grant to States funded by the U.S. Administration on Aging and a CMS Real Choice Systems Change grant.

The CHOICE program is Indiana's only program providing services to family and informal caregivers that is exclusively state funded. The CHOICE program, providing home and community-based services to older persons and to persons with disabilities, was enacted as a pilot program in 1987 and expanded statewide in 1992. The program has received national recognition and is popular with state legislators, a number of whom have themselves used CHOICE for their family members. Indiana's governor appoints a board to govern the program.

SSBG has also provided funding for home and community-based services, which has been allocated to the DDARS since 1992. These monies pay for a portion of respite care, adult day health services, attendant care, transportation, home-delivered meals, homemaker services, home health services and supplies. In FY 2001, 46,704 persons in Indiana received assistance through SSBG-funded services.

Indiana's Governor's Task Force on Alzheimer's Disease and Related Senile Dementia was established in 1987. This task force assists the DDARS "by identifying areas of concern to be addressed, recommending services to meet the needs, recommending the development of training materials, and compiling available research."¹⁸ Five grants, totaling \$83,894, were awarded in FY 2001 to meet the needs of individuals with Alzheimer's or a related condition and their families.

When asked if family caregivers were a central component of a comprehensive long-term care system, Indiana state officials uniformly responded that family caregivers are increasingly being recognized in this capacity. To support this notion, respondents cited evidence of this recognition: legislation passed in 2001, the CHOICE enabling legislation^b and questions about informal support in the state's E-Screen, the instrument used for assessment for waiver and CHOICE services, as well as for nursing home preadmission screening. The legislation creating CHOICE was the state's first legislation to mention caregivers explicitly. The bill also established the Governor's Commission on Caregivers. This commission was focused on workforce shortage issues associated with formal caregivers, however, rather than on supporting family and informal caregivers. Respondents also pointed to other legislation, passed in 2001, that allows recipients of CHOICE and Medicaid waiver services to direct their attendant care services workers (with the written approval of the attending physician), enabling certain family members to be hired as attendants.^c Although Indiana does not yet have a caregiver tax credit, the state's Department of Revenue was reported to be working on it.

^b CHOICE was created through Senate Enrolled Act 215 in 1987.

^c Parents of minors, spouses or other adults legally responsible for the individual may not be compensated, however.

Within all of the state's long-term care programs, the priority for supporting caregivers was seen to be growing, one informant said that support for caregivers was particularly important "especially if we want to move people into the community or keep people in the community." One respondent noted a small shift, for the first time, toward more support for community-based long-term care. According to one respondent, nursing home funding has been "in a different pot and has been fairly unassailable."

Stakeholders in Indiana did not believe that family caregivers were receiving much state recognition. As one pointed out, "In terms of getting state dollars, programs in place, we're just trying to make it on the radar screen." Another said that research is needed to educate legislators about the caregiver's role and needs. The state's focus, they believed, is still primarily on the care recipient, which they ascribed to the notion that "the patient seems needier." Stakeholders noted hope in two developments for family caregivers, however. First, in 2002, the legislature passed a concurrent study resolution that directs the legislature to set up a study committee to look at rebalancing Indiana's long-term care systems. Explicit emphases for this study include enabling more people to stay in their own homes, under the care of their families, and providing family caregivers with governmental assistance for their "medical, financial and emotional support."¹⁹ Second, the governor has proclaimed November to be Caregiver Month.

Key informants saw a number of strengths in Indiana's current caregiver support system. These include flexibility through NFCSP funding, the cooperation across departments to look at caregiving issues and the flexibility offered through Indiana's newest Medicaid waiver, Support Services (administered by the Bureau of Developmental Disability Services), which includes a "family subsidy," with funds going directly to the family to purchase what they need, as well as training for informal and family caregivers (with a limit of \$2,000 per person annually). One respondent saw Indiana's "blank slate" as a strength. In terms of building caregiver support services into existing infrastructures, respondents pointed to the addition of consumer-directed care to every Medicaid waiver program and to the addition of family and caregiver training to the waivers.

PROGRAM BACKGROUND/DEVELOPMENT

The only program specifically for family caregivers in Indiana is the new NFCSP. Because all community-based long-term care programs (including NFCSP) are integrated and delivered through the AAAs, however, it is important to understand the operations of all three main programs in order to understand the support available to Indiana's family caregivers. These programs are CHOICE, the Aged/Disabled Medicaid waiver and the NFCSP.

NFCSP: After receiving notification from the Administration on Aging (AoA) that NFSCP funding would be available, the BAIHS asked the AAAs to include goals and indicators for the new program in their area plans for July 1, 2001, to June 30, 2002. The AAAs worked collectively on publicity and outreach, pooling funds to develop a statewide caregiver campaign. The Indiana Association for Area Agencies on Aging (I4A) and an advertising agency assisted with the effort. They developed four radio commercials, three television commercials and a brochure, all featuring the same logo and tag line ("Compassion. Connections. Care. Area Agencies on Aging/Partners of the Indiana Caregivers Alliance") to promote a consistent, statewide identity. The advertising agency also conducted a public relations workshop for the AAAs and helped them contact their local media to place their public service announcements (PSAs). Additionally, a statewide toll-free telephone number connects automatically into the caller's local AAA or if the caller is out of state, the Indianapolis AAA.

The AAAs have been slowly implementing their plans, with one having just begun in March 2002. Each of the AAAs has a designated “caregiver coordinator,” who may be a member of the information and referral (I&R) staff, a case manager, a community outreach worker (as in one case) or the AAA director (as in another). Calls from caregivers are directed to the coordinator. Respondents indicated that coordinators try to balance the needs of new callers with those of caregivers whose loved one is already on a waiting list for CHOICE or Medicaid waiver services. (The wait for CHOICE is up to three years.) Each AAA has oriented its provider network to the NFCSP services and eligibility criteria in an effort to achieve a “mind shift” about who the client may be (i.e., the caregiver, not the care recipient).

At the time of the site visit, standardized products had not been developed, but the care coordinators, meeting as a group, were working on this. They had developed a Family Caregiver Referral Form for use by all AAAs, had drafted a memorandum on billing issues and were trying to get caregiver information included in IN-Site, the automated data collection and reporting system. The care coordinators were reported to be doing a lot of policy development and networking with one another. Two or three AAAs were working with the BAIHS to develop a cost-sharing method for services, such as transportation, as had been done in North Carolina and Ohio.

At the state level, the BAIHS looked to North Carolina, Ohio, Pennsylvania and California in developing its approach. The BAIHS worked closely with I4A to launch the program. In December 2001, the BAIHS spelled out its expectations in a memorandum to the AAAs, including reporting units of service in line with the BAIHS operations manual. Family caregivers have been, and will continue to be, involved through AAA advisory committees and through the area plan development process. The state intends to spotlight the program and the AAAs’ efforts at the October 2002 Governor’s Conference. There have been state press releases and local public relations activities, including AAA involvement in county fairs and with local Alzheimer’s Association chapters.

CHOICE: The CHOICE program pilot, approved by the state legislature in 1987, expanded statewide in 1992. The program was designed to serve people who did not meet Medicaid eligibility criteria (particularly financial criteria). With the state’s recent effort to maximize Medicaid revenue, there has been a concomitant effort to transfer CHOICE recipients who qualify for Medicaid to the Aged/Disabled Medicaid waiver program. Many do not wish to be transferred, however.

Aged/Disabled Medicaid waiver: Original approval for this waiver occurred in 1984.

Most rewarding: Respondents indicated that the NFCSP provides Indiana with another option, with a lot more flexibility than the Aged/Disabled Medicaid waiver, saying, “It allows us to address the waiting list for CHOICE and Medicaid.” It also allows those with limited need to be reached.

Regarding the CHOICE program, one key informant indicated that the program “has become a rallying cry.” It is a “very good, very popular program which has had good press” and brought people into the AAAs, the respondent said. The individual who needs service is not required to apply for Medicaid. CHOICE is “a lifeline for many to remain in their own homes.”

Biggest challenge: The newness of the program and the activities necessary to “get settled” and “up and running,” including to develop public awareness, have been particularly challenging. Respondents indicated that funding and waiting list size are among the CHOICE program’s biggest challenges. During the past fiscal year, a budget increase was slated for CHOICE. Because of the state’s fiscal situation, however, some of these funds were “reverted” or given back to the state. One stakeholder explained that the money being saved as consumers are transferred from CHOICE to Medicaid waiver status is going back into the state general fund to help offset the tax deficit, rather than to enable CHOICE to serve people now on the waiting list. Another noted that state staff have been focused on the state’s fiscal constraints: No one is dedicated to developing new programs under the present circumstances.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Indiana received \$2.3 million in federal funds. In FY 2002, the federal share of the NFCSP increased to \$2.6 million. State officials did not provide the proportion of NFCSP funds to the total BAIHS budget.

In FY 2001, 12,537 individuals were served through CHOICE, while an additional 11,922 persons were on the waiting list to receive services. State officials did not provide the expenditures through the Aged/Disabled Medicaid waiver in FY 2001–02, or for the CHOICE program.

The average annual expenditure per person in CHOICE in FY 2001 was \$7,234. The average monthly expenditure through CHOICE is about 71% of that through the Aged/Disabled Medicaid waiver (\$603 vs. \$848).

Indiana received about \$141 million in tobacco settlement revenues in FY 2001 and another \$170 million in FY 2002. Indiana’s tobacco settlement fund utilization was in flux at the time of the site visit. Prior to the budget crisis, the state had earmarked all of its tobacco funds for health purposes, including the creation of Hoosier Rx (a prescription drug program for older residents) and a new appropriation for services targeting individuals with developmental disabilities. In light of current revenue shortfalls, “reversion” of the tobacco funds was under way. A Medicaid 1115 waiver request reported to be under development would have also made use of the tobacco funds for the required state match, but this new appropriation of \$20 million was apparently going to be used for other state budget purposes.

The impact of the downturn in the economy on services to support family caregivers remains unknown. “There is a great effort within FSSA to not cut programs,” one respondent said. “So far there have been no cuts in services. Moving clients from state general fund programs to Medicaid or other federal programs has been the strategy.” Cuts in CHOICE were seen as likely if no new revenue could be found, however.

The state budget situation was described variously as “pretty bad,” “tight,” “very challenging” and “dismal.” Revenues had been down three successive quarters, and recovery was expected to take three years, even if revenues improved immediately. Whereas Indiana had previously projected excessive growth, state officials now expect a “no-growth” period to predominate for the next several years. State employees had not received raises for three years, and all agencies had been asked to make cuts.

One respondent reported that CHOICE had been cut, the expansion of the Medicaid waiver program had slowed and plans were under way to divert people eligible for nursing homes into home and community-based services (without adding funds to those services). A strong nursing home lobby exists in Indiana, and nursing home operators have sued the state on various issues; these suits were expected to cost millions of dollars, further depleting the resources available for home and community-based services.

PROGRAM ADMINISTRATION

NFCSP: In Indiana, services are viewed as separate components, rather than as part of a larger, multicomponent family caregiver support program. The BAIHS sees its role in administering the NFCSP as one of overseeing and encouraging flexibility. Respondents indicated that the AAAs have the flexibility to do anything, so long as it is in the plan of care. AAAs can provide any or all of the five NFCSP service categories in any combination. The caregiver support program is administered at the local (AAA) level through contracts.

Policies for caregiver services are being developed using a very broad framework. Care coordinators can run questions by the state, but they are encouraged to use their flexibility. Comparing the NFCSP to the Medicaid waiver, one key informant observed, “This program is much easier to administer.”

The state’s role in policy development is to encourage consistency across the state. For that reason, accreditation of the AAAs is being pursued through the National Council on Accreditation for Children and Family Services, which is developing Indiana-specific standards. By 2006, all AAAs are expected to be accredited.

CHOICE: The program is administered locally through the AAAs. The state uses the Title III formula to allocate the CHOICE budget. AAAs have memoranda of understanding with providers and AAA staff to do assessments, arrange for services and pay bills. They also act as the fiscal intermediary, or they contract for fiscal intermediary services for consumers who wish to be the employer of record. Each AAA must submit to the DDARS a CHOICE Plan as a component of the area plan. Policies for CHOICE are reviewed by BAIHS staff, with AAA input, then reviewed by the CHOICE board.

Aged/Disabled Medicaid waiver: AAAs administer the program locally. AAA’s role for Medicaid waivers is similar to its role for CHOICE, except that the fiscal intermediary, EDS, pays the bills. The waiver and CHOICE look similar to consumers, but not to providers.

Both the legislature and CMS must approve any substantive policy changes for the Aged/Disabled Medicaid waiver. For example, CMS approved consumer-directed service after the Indiana legislature enacted legislation allowing this.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

NFCSP: Indiana's NFCSP uses AoA eligibility guidelines. Both the care recipient and the caregiver are considered the client, however. Currently, information about the caregiver is captured through case notes in IN-Site; work is under way to develop specific questions for inclusion. The case notes can be "data mined." Presently no uniform assessment standards for caregiver need are in use across the state.

Caregiver coordinators do not create care plans like the ones that care managers for CHOICE and Medicaid waiver do, but they are using the Family Caregiver Referral Form and are working to gain the cooperation of I&R staff in using this form. The I&R staff reported that they were not yet getting all of the right information.

CHOICE: To be eligible for CHOICE, an individual must be a resident of Indiana, ages 60 or older or any age with disabilities, and unable to perform two or more Activities of Daily Living (ADLs) or Instrumental Activities of Daily Living (IADLs). The number of ADL deficits required to receive services through CHOICE has changed over time, from two to one and now back to two again. That determination is made using the Long Term Care Services Eligibility Screen (E-Screen).

There are no financial eligibility criteria for CHOICE, but income determines share of cost, using a sliding scale. Eligibility for the sliding scale starts at incomes less than 350% of poverty. The cost-share formula is designed to protect an individual's monthly income (after paying for CHOICE services) from falling below 151% of poverty.²⁰ Persons paying privately are not responsible for the cost of case management, the initial assessment and the care plan.

The care recipient, rather than the family caregiver, is considered the client in CHOICE. At least 20% of the AAA's CHOICE service dollars must be used for persons under the age of 60 with disabilities. The CHOICE program also taps Temporary Assistance to Needy Families funds on behalf of children under the age of 18, providing up to \$2,000 per year for these clients for family caregivers to participate in support groups or obtain educational materials.

The state's role in policy development is to encourage consistency across the state. Uniform assessment standards are used across Indiana for CHOICE, and these are incorporated in the E-Screen. The care manager records informal care, which affects what is included in the care plan. The family caregiver's needs and ability to provide care are assessed informally, as a "judgment call" by the assessor, and recorded in case notes.

Aged/Disabled Medicaid waiver: The E-screen is also used to assess eligibility for the Medicaid waiver. Beneficiaries must have difficulty with at least three ADLs or IADLs. They also must be categorically needy or have countable incomes at or below 300% of Supplemental Security Income (SSI), with assets not to exceed \$1,500.

SERVICES

NFCSP: Under the NFCSP, services are delivered locally. All five of the permissible NFCSP service components are being provided in the state, although not necessarily by each AAA. They are:

1. Information to caregivers about available services (all AAAs)
2. Assistance to caregivers in gaining access to supportive services (all AAAs)
3. Individual counseling, organization of support groups and caregiver training to assist caregivers in making decisions and solving problems related to their caregiving roles (some AAAs)
4. Respite care to temporarily relieve caregivers from their caregiving responsibilities (all AAAs)
5. Supplemental services, on a limited basis, to complement the care provided by caregivers (some AAAs)

AAAs' care coordinators generally arrange for respite care, referring caregivers to support groups (and sometimes developing and facilitating such groups) and providing education and training. Respondents reported that the Fort Wayne AAA had set up an information session for caregivers at a major employer's location and found, to its surprise, that 90% of those who showed up were men. This session led to the development of an ongoing support group.

AAAs have the flexibility to offer various types of respite, including in-home care, adult day services and overnight in a facility. No cap is being used for respite, nor are AAAs yet allowing caregivers to "bank" respite benefits. One AAA is piloting the use of respite vouchers that family caregivers can use to attend support group meetings.

CHOICE: Services that support family caregivers through CHOICE are seen as part of a multicomponent program. Among caregiver support services that may be included in a CHOICE care plan are respite care, "other services" (including home modifications or adaptive aids) and training.

There are no caps on respite, per se. Respite services may be delivered in the home, in adult day care, overnight in a facility and on a weekend—but not through camps. Respite benefits may be "banked" and used whenever needed, except that the dollar limit for the quarterly care plan may not be exceeded within CHOICE. Case management is considered an AAA administrative function and is excluded from the calculation of cost. With limited funding, the total care plan has a maximum.

There is no cap for any service provided through CHOICE, except for the total care plan guidelines tied to the CMS skilled nursing facility index. The program has implemented a system of cost-sharing. A former expenditure cap of around \$5,000 per individual per year no longer exists.

Aged/Disabled Medicaid waiver: Caregiver support services through the Medicaid waiver are seen as part of a multicomponent program. Services include respite care, home modifications and reimbursement for adaptive devices. Several forms of respite are provided, including in-home care, adult day care and overnight and weekends in a facility—but not camps.

As in CHOICE, respite is not capped, per se. Respite benefits may be "banked" and used whenever needed.

Access to some services, such as home modification, is difficult to obtain in rural areas. Respondents believed that access to providers is easier for CHOICE recipients than for Medicaid recipients because reimbursement is better and faster and paperwork requirements are less onerous.

Although reimbursement rate limits exist for particular Medicaid waiver services, there is no cap for any service provided through the Aged and Disabled Medicaid waiver, except for the total care plan guidelines tied to the CMS skilled nursing facility index.

Extensive waiting lists exist for CHOICE and Medicaid waiver services. The passage of the NFCSP has not changed the waiting list for either CHOICE or the waiver, although it has enabled some family caregivers to obtain limited services for a relative on a waiting list. Respondents believed that the scope of services provided in CHOICE and in the Medicaid waiver was sufficient. The issue was waiting lists, not range of services offered.

Major service needed by caregivers: Most respondents believed that respite was the major service needed by family caregivers. One stakeholder saw information and ongoing support through the course of the disease as most important and indicated that ongoing support included education, emotional support, in-depth guidance and direction (consultation) and support groups. One respondent said “What caregivers think they want is respite, but after that they want information.” Another informant, a family caregiver who first self-identified as such during the site visit, observed that working caregivers need help to keep their jobs while fulfilling caregiving responsibilities. Other needs cited were emergency services and support groups for grandparents raising grandchildren.

Table 2. Family Caregiver Support Services in Indiana

Program	Family Caregiver Support Program	CHOICE	Aged/Disabled Medicaid Waiver
State Administrative Responsibility	FSSA's Bureau of Aging and In-Home Services	FSSA's Bureau of Aging and In-Home Services	FSSA's Bureau of Aging and In-Home Services
Local Service Delivery	AAAs—information, assistance, assessment & case management Service providers/contractors	AAAs Service providers/contractors; AAA may get waiver also to provide specific services if no other agency is available	AAAs—case management Service providers/contractors; AAA may get waiver also to provide specific services if no other agency is available
Funding Source	Older Americans Act, Title III-E	State general funds	Medicaid 1915 (c) waiver
Expenditures FY 2001	\$2.3 million	\$38.8 million ^a	\$23.9 million ^b
Client Population	Family & informal caregiver	Care recipient	Care recipient
Eligibility Criteria:			
Age	60+ care recipient Family caregivers of persons age 60+	All ages	All ages
Income	None	None	SSI level; \$1,500 in assets
Functional Ability	For respite & supplemental services, care recipient must have at least 2 ADLs or cognitive impairment	2+ ADLs/IADLs	3+ ADLs/IADLs
Uniform, Statewide Caregiver Assessment	No	No; uniform care recipient assessment only with limited information on caregiver	No; uniform care recipient assessment only with limited information on caregiver
Service Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^c	Respite, home modifications	Respite, home modifications, adaptive aids and devices
Respite Cap	No	No	No
Consumer Direction	No	Pilot project only	No
Family Caregivers Paid as Respite Providers	No	No	No

^a Indiana Family and Social Services Administration, *Statewide In-Home Services Annual Report, 2001*. (Indianapolis: Bureau of Aging and In-Home Services) 9.

^b Ibid, 6. Total is estimated based on average per person per month cost of \$848.08 and enrollment of 2,342.

^c All services provided in Indiana; each AAA does not offer all services, however.

CONSUMER DIRECTION

Indiana's CHOICE program has had a pilot program to provide consumer-directed attendant care for two years. (Parents, spouses and legally responsible adults are not eligible to provide attendant care.) New state legislation provides for a registry, criminal background checks and delivery of services beyond attendant care by a worker, if the physician states, in writing, that the care recipient is competent to manage this care and that the care is safe. At the time of the site visit, 250 to 300 CHOICE clients were using the consumer-directed option.

The pilot came about through the advocacy of clients. Ironically, one chief advocate, a mother of two medically fragile children, had been unable to use this option herself because the care recipient must be capable of hiring, firing and giving instructions to the worker as well as have a backup worker in place. Difficulty in making a backup arrangement was cited as a barrier to use of the option, although a client can have both provider-delivered and consumer-directed care simultaneously—that is, can hire one care provider directly and use an agency provider for the backup.

While the Aged/Disabled Medicaid waiver does not have a consumer-directed attendant care component, both the waiver and CHOICE have other consumer-directed elements. Care recipients in both programs can hire and fire their own workers and can choose from a list of providers for respite care and other services, such as transportation. Parents and spouses are not eligible for reimbursement, however.

Respondents indicated that further implementation of the consumer-directed option had been slowed due to interpretation of the fiscal intermediary provision. The AAAs received training from the Internal Revenue Service about the use of a fiscal intermediary so that the AAA would not be considered the employer. Some clients have contended, however, that the state legislation allows “anyone who is qualified” to be able to act as an intermediary, whereas the state has sought to select a fixed set of people from which a client could choose.

A consumer-directed option is not available in the NFCSP, so that the option can first be refined in CHOICE and the Medicaid waiver. Other than the respite voucher pilot, no direct payments to family caregivers are being made.

QUALITY ASSURANCE AND EVALUATION

AAA staff collect data about family caregivers of persons seeking CHOICE or Medicaid waiver services through informal electronic case notes in the E-Screen. A strength of the state's current data collection practices is the systematic collection of some information, including billing codes and progress notes. Respite units could thus be pulled out and tracked if desired.

Respondents noted limitations of their data collection practices as difficulties in aggregating data and lack of a specific caregiver assessment. Outcomes data are collected only anecdotally through case notes. The E-Screen focuses on the care recipient and includes just three yes/no statements related to informal support. These are:

1. The person has no friends or relatives who are able or willing to provide needed assistance, support, and personal or chore services.

2. Friends or relatives who have been providing needed assistance are no longer able or willing to continue to provide help.
3. Friends or relatives who have been providing needed assistance are not able or willing to increase the amount of help needed to meet changing conditions.

The E-Screen also provides a space for the case manager to summarize the Preliminary Care Plan and prompts the assessor to include “informal supports and other service arrangements.”

To supplement the information collected through the E-Screen, the AAAs have designed a Family Caregiver Program Referral form that collects the following information:

- ✧ Date and referral source
- ✧ Primary caregiver information (county, name, address, telephone number, Social Security number, birth date, age)
- ✧ Care recipient information (name, address, age, birth date, income, relationship to caregiver, length of time caregiver has been caring, diagnosis)
- ✧ Hospital or nursing home discharge date
- ✧ Constraints on primary caregiver (poor health/frail, employed, lacks knowledge/skills, lives at a distance, financial strain, lacks support system, poor relationship with consumer, providing care to others as well, experiencing emotional concerns, other)
- ✧ Obstacles to caregiving (ramp, stairs, no washer/dryer, location, supplies)
- ✧ Service requested
- ✧ Monthly caregiver supplies (item, average monthly cost, who pays)

To evaluate program success, the state monitors service utilization through IN-Site, makes site visits to the AAAs and home visits to clients and does satisfaction surveys. AAAs must survey 5 to 10% of their in-home services clients. The satisfaction survey was designed under a Robert Wood Johnson Foundation grant as a mechanism to provide regular, anonymous feedback to vendors every six months. If a client reports a problem with health, safety or exploitation, an investigation must be completed under the state's Quality Assurance Improvement Program.

Over time, the FSSA's new Bureau of Quality Improvement Services will expand its focus to include other programs, although it is working now only with the Developmental Disability system. Outcome measures are not now used to evaluate the program, mainly because of data set problems. Although the state would like to look at the impact of the CHOICE program on nursing home utilization, that effort has been hampered by the fact that institutional and community-based programs use different data sets. A coalition of five AAAs is looking at caregiver outcomes, with the goal of highlighting these at the October 2002 Governor's Conference. Cost-effectiveness comparisons with nursing homes are done for CHOICE and the Medicaid waivers. Finally, BAIHS's Program Evaluation and Accreditation Unit plans to look at CHOICE, using IN-Site data and visits.

SYSTEMS DEVELOPMENT

Key informants felt that the main impact of the first year of the NFCSP was to put the focus on the caregiver in care planning and to shift thinking. The NFCSP also has brought other players to the table—for example, the Alzheimer's Association—both locally and at the state level. The new program has encouraged the use of new technology, including a pilot program for Alzheimer's disease patients. This pilot is experimenting with the use of fall mats by beds, video cameras and door monitors. The five families served through the pilot have reported positive results.

In terms of coordination of caregiver support services at the state and local levels, informants had varying views. All state agency staff interviewed believed that state-level coordination existed, citing the setting of waiver policy at the state level, the approval of plans of care for Medicaid waiver services and the NFCSP coordination by BAIHS, in collaboration with I4A and the AAAs. On the other hand, stakeholders felt there was no state-level coordination and saw the state as having delegated coordination completely to the AAAs. As to local coordination, most saw AAA staff as fulfilling this function. Several mentioned that the AAAs all have a staff person in place who focuses specifically on caregivers. One stakeholder asserted that caregiver support services “aren't really coordinated locally,” however. “There may be an informal network,” one respondent said, “but most referrals for caregiver services, in the respondent's experience, come from physicians, friends and general word of mouth, rather than through AAA staff.”

Indiana does not have a body whose mission is to coordinate family caregiver support services across state departments. One respondent noted that the Long-Term Care Advisory Group, within the Office of Medicaid Policy and Planning, might be fulfilling this function to some degree. One stakeholder offered that FSSA might say it had such a coordination vehicle, “but it is disjointed.” State respondents differed as to whether they thought Indiana's support program for family caregivers is integrated into the state's other long-term care programs or stands alone. “What there is of it is integrated,” observed one informant.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

Indiana has had an *Olmstead* task force and has engaged persons with disabilities and their families and advocates in the state's *Olmstead* plan development. Governor Frank O'Bannon (D), through executive order on September 18, 2000, instructed FSSA to:

- ✧ Conduct a comprehensive study of all services and programs available to people with disabilities in Indiana
- ✧ Evaluate current systems of service delivery
- ✧ Identify the array of services available and assess the demand and desire for these services in a less restrictive setting
- ✧ Identify barriers to achieving total integration into the community where the demand exists

The secretary of FSSA appointed an internal action team, composed of top administrators of programs for persons with disabilities and three subcommittees made up of consumers, families, providers and advocates. The subcommittees were focused on mental health, developmental disabilities and

aging/physical disabilities. Family members of consumers had the opportunity to express their concerns at three public meetings throughout the state in November 2000 and at 12 public meetings during which the draft plan was presented. The FSSA, as required, developed a report summarizing its *Olmstead* planning activities and resulting recommendations. Entitled *Olmstead-Comprehensive Plan for Community Integration and Support of Persons with Disabilities*, this report identifies six major policy directions and related options. The first two of the identified policy directions have direct impact on family caregivers.

1. **Increase Consumer Choice: Enable individuals to receive the types of services they desire in the location they prefer.** *Options:* Reduce reliance on institutional care by de-emphasizing nursing home care and reducing the state facilities' census; use savings from decreased use of institutions to expand community-based care; use waiver mechanisms to make a full range of community supports available; cultivate new and creative community-based options.
2. **Support the informal network of family, friends, neighbors and communities.** *Options:* Develop methods for families and advocates to participate in quality assurance systems; strengthen education, training and respite services for family caregivers.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, Indiana stakeholders agreed that the priority was "low," whereas BAIHS officials gave "high" priority to caregiver support in the state. One stakeholder did not respond.

Number of Key Informants	Priority on Caregiver Support
1	No response
3	→ Low
1	→→→→→ High

Benefits and challenges: Key informants cited several aspects of the caregiver support program that are most beneficial to family caregivers:

- ✧ Respite
- ✧ Training, especially to recognize when they need help
- ✧ Support programs
- ✧ Tips from peers

The challenges reported were the following:

- ✧ Need for a clear idea of the purpose of the program so that state and local staff and providers can be trained
- ✧ Funds needed to expand in a tight fiscal situation
- ✧ Limited use in Indiana of vouchers for anything
- ✧ Attitudes of the older population, who advocate for children's issues but not for themselves
- ✧ Baby boomers' lack of education on the issues and on the need to push for services

Major lessons learned:

- ✧ Caregivers do not have *one* specific need—they are a diverse group, and no one easy solution exists
- ✧ Because of the complexity of providing caregiver support, the program is changing as it is implemented
- ✧ The importance of flexibility must be emphasized
- ✧ It is important to be open to learning more about who caregivers are and to discovering new populations of caregivers, such as male employed caregivers

Opportunity for expanding caregiver support: Respondents noted several legislative or regulatory changes that might enhance Indiana's family caregiver support programs. One suggested that Indiana needed to have specific legislation recognizing family caregivers and their need for support. Another underscored the importance of solving the fiscal intermediary issue, thereby bringing consumer choice into the Medicaid waiver programs. The need to add questions about the family caregiver to the E-Screen was also noted.

Despite the current fiscal situation, most respondents expected to see expansion over the next three to five years in Indiana's state-funded programs to support family caregivers. The prospects for expanding programs that are exclusively state funded were not good, but some expansion was seen as possible by using Medicaid waiver services to complement CHOICE services. Moving Medicaid-eligible CHOICE recipients to the Aged and Disabled waiver was seen as key to maximizing federal dollars and enabling CHOICE to reach more people.

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- ✧ Work closely with the AAAs to develop and deliver the program.
- ✧ Design the system to fit the change you are trying to make, rather than try to fit it into your current system. Don't feel that you have to squeeze your caregiver program into the current box. You can get a new box if you need to.
- ✧ Keep caregivers in the center of the program. Listening is key, and bureaucrats often are not good listeners.

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OVERVIEW

Iowa is a midwestern state with a relatively homogenous, rural population. The state ranks fourth in the country in the proportion of residents ages 60 and older, and second in the proportion of persons ages 85 and older. Iowa's current long-term care system provides a mix of institutional and home and community-based care services, with a decentralized approach to best meet local needs. State-only-funded programs for the elderly and for persons with disabilities are comparatively limited, which may have been influenced by a strong nursing home lobby. In the last few years, however, there has been a greater focus on developing a range of programs and services to offer consumer choice, partly because of an attempt to reduce nursing home costs and unused nursing home beds.

State policy attention to caregiver support services emerged only recently, with the passage of the National Family Caregiver Support Program (NFCSP) and the infusion of federal funds into Iowa's state budget. The state's developing caregiver support services are characterized by:

- ✧ Utilization of the Iowa Association of Area Agencies on Aging as the coordinating body for statewide policymaking and administration
- ✧ Flexibility to meet the individual needs of family caregivers at the local level
- ✧ Consumer choice

Iowa respondents noted that the major service needs of family caregivers are (1) respite care, (2) assistance navigating the system and (3) help with physical needs, such as transportation.

INTRODUCTION

Iowa represents a state that is now explicitly providing caregiver support as a result of the passage of the NFCSP. The project team conducted a site visit between May 6 and 7, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Iowa Department of Elder Affairs

- ✧ *Iowa Family Caregiver* (NFCSP funded)

Iowa Department of Human Services

- ✧ Aged/Disabled Medicaid waivers
- ✧ Real Choice Systems Change grant

Stakeholders interviewed were from:

- ✧ Iowa Association of Area Agencies on Aging
- ✧ Alzheimer's Association

Two programs are featured:

1. *Iowa Family Caregiver*
2. Aged Medicaid waiver

BACKGROUND

Iowa is a midwestern state that ranks 30th in the nation in population density, with 2.9 million people residing in 99 counties.¹ The state has substantial rural populations, with relatively little racial and ethnic diversity. In 2000, personal income per capita was \$26,723, compared to the national average of \$29,676.² About 10% of Iowa's population live below the federal poverty level (vs. 13.3% U.S.).³ Iowa ranks 33rd nationally in percentage of households with Internet access.⁴ The racial makeup of the state's population differs significantly from that of the United States as a whole. Compared to the national average, Iowa has a significantly smaller proportion of African Americans (2.1% vs. 12.3% U.S.) and a much lower proportion of Hispanic persons (2.8% vs. 12.5% U.S.)⁵ (table 1).

An estimated 554,573 persons in Iowa, or 19% of the state's population, were 60 or older in 2000 (vs. 16.3% U.S.). Iowa ranks fourth nationally in the number of persons ages 60+ residing in the state.⁶ Similar to the state's population as a whole, and compared to the national average, Iowa has a significantly smaller percentage of African Americans ages 60+ (0.9% vs. 8.4% U.S.) and of Hispanic older persons (0.6% vs. 5.4% U.S.).⁷

Iowa ranks second in the country in the proportion of its population ages 85 and older. In 2000, 65,118 persons, or 2.2% of Iowa's population, were ages 85+.⁸

An estimated 277,860 family caregivers reside in Iowa. These family caregivers provide about 258 million hours of caregiving per year at an estimated value in 1997 of \$2.1 billion.⁹

Although Iowa has many facility-based long-term care options, a major effort has been made in recent years to convert nursing homes to assisted living and adult day health facilities. Like many states, Iowa experienced substantial growth in its tax base and state revenue in the 1990s. As a result of this growth, starting in 1995, the state legislature enacted substantial tax cuts, to the tune of approximately \$500 million annually.¹⁰

Table 1. Selected Characteristics of IOWA and the UNITED STATES, 2000 ^a

	Iowa	United States
Total Population Characteristics		
Total Pop. ^b	2,926,324	281,421,906
% African American ^c	2.1%	12.3%
% Hispanic ^d	2.8%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	554,573	45,797,200
% 60+ ^f	19.0%	16.3%
National ranking 60+ ^g	4	NA
Pop. 65+ ^h	436,213	34,991,753
% 65+ ⁱ	14.9%	12.4%
National ranking 65+ ^j	4	NA
Pop. 85+ ^k	65,118	4,239,587
% 85+ ^l	2.2%	1.5%
National ranking 85+ ^m	2	NA
% increase 1990–2000 60+ pop. ⁿ	0.2%	9.4%
% White (60+) ^o	97.7%	82.4%
% African American (60+)	0.9%	8.4%
% Hispanic (60+)	0.6%	5.4%
% Asian (60+)	0.4%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics ^p		
# of caregivers (1997)	277,860	25,798,370
Caregiving hours (millions) (1997)	258.6	24,013.1
Value of caregiving (millions) (1997)	\$2,115.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$26,723	\$29,676
% of pop. below poverty (1997) ^r	9.9%	13.3%
Internet		
% of households w/Internet access (2001) ^s	39.0%	41.5%
Nat'l ranking of households w/Internet access	33	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Iowa, *www.fedstats.gov* (June 2002).

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STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies: the Iowa Department of Elder Affairs (IDEA) and the Department of Human Services (DHS). In recent years, Iowa has sought to expand resources for home and community-based services as its aging population has grown. One key informant pointed out that the current emphasis in Iowa is on maximizing federal funds while minimizing state spending.

Iowa's long-term care system is characterized by shared responsibility for care between state and county governments. Many of Iowa's 475 nursing homes are county-run. Home and community-based services are delivered by the state's private provider network, which provide the majority of services in Iowa's communities.¹¹ Area Agencies on Aging (AAAs), on the other hand, carry out assessments and care management.

The IDEA is a freestanding department that serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP. The governor appoints the executive director, who has cabinet-level status.

The infrastructure of Iowa's aging network is a statewide system of 13 nonprofit AAAs that provide services to areas ranging from three to 10 counties. Home and community-based services to the older population are coordinated at the local level through the AAAs and a well-developed care management system. Each of Iowa's counties has a care management team facilitated by the AAA. Public health nurses from county health departments generally determine functional eligibility for programs, while DHS staff determine financial eligibility. The rest of the care management team, who

meet on a regular basis, consist of volunteers from the faith communities, private providers (e.g., hospitals, nursing facilities, adult day care) and other representatives as needed (e.g., police, attorneys). Older persons as well as the family caregiver are always invited to the team meeting. Most of the AAAs contract out for services rather than provide support services directly. The Iowa Association of AAAs (I4A) is relatively active, with several paid staff members.

DHS is Iowa's "single state agency" for Medicaid. DHS administers Iowa's Aged Medicaid waiver, which was originally approved in 1989.^a When it was first approved, the state legislature mandated that four state departments (Elder Affairs, Public Health, Human Services and Inspections and Appeals) come together to develop a long-term care unit. The intent was for the body to coordinate administration and oversee planning of services to older adults.¹²

The DHS has administrative responsibility for the waiver. Currently, the IDEA's only role with regard to the waiver is to provide case management through a contract with the DHS. In turn, the IDEA subcontracts with the AAAs to provide case management to waiver participants. The Aged Medicaid waiver serves about 4,300 participants.^b

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Iowa has the fourth-highest proportion of persons ages 60 and older in the nation. Although the NFCSP represents the first explicit effort to support family caregivers in Iowa, state leaders have been encouraged because of the sizable aging population to focus efforts on the development of home and community-based alternatives, including some support for family caregivers through respite care. One respondent indicated that helping older persons maintain their independence is the top priority in Iowa, followed by helping the family caregiver.

Iowa's efforts include establishment of the Senior Living Trust Fund in 1999 by the Iowa legislature. The trust was specifically developed with state general funds to expand home and community-based service options by making available some of the state's 8,000 unused nursing home beds to provide space for adult day health, respite care and assisted living care.¹³ The trust was part of a larger legislative effort enacted, known as the Comprehensive Senior Living Program. The goal of the legislation was to create a comprehensive, long-term care system focusing on consumer direction, balance in offering institutional and home and community-based services and support of the quality of life of older Iowans.¹⁴ Both the legislative and executive branches appear to support this initiative; however, \$20 million was transferred in FY 2002 from the trust to pay for other state services.¹⁵ At the time of the site visit, the IDEA had administered \$4.1 million of the trust to provide local services through the state's AAAs.

a In Iowa, the Aged Medicaid waiver is referred to as the Elderly Waiver.

b The Department of Human Services has six Medicaid home and community-based service waivers. They include the Ill and Handicapped waiver, serving those from birth to age 65; the Aged Medicaid waiver, serving those ages 65+; the Brain Injury waiver; the Mental Retardation waiver; an AIDS/HIV waiver; and a Physical Disability waiver, serving individuals ages 18 to 64.

Iowa state officials have also tried to shift some focus from institutional care to noninstitutional care by focusing policy attention on developing affordable assisted living and developing adult day health oversight. Since 1988, Iowa has committed state funds to support Alzheimer's Association chapters throughout the state. However, due to state budget shortfalls, state funds for Alzheimer's services were discontinued in FY 2002. In addition to putting state funds toward Alzheimer's Association chapters, the state has been awarded a federal Alzheimer's Disease Demonstration Grant to States, which has been funded since FY 2001. Iowa has also established the Case Management Program for the Frail Elderly, funded through a mix of state general funds and federal funds through the Aged Medicaid waiver.

Iowa Family Caregiver—the name for the NFCSP in the state—is the first program in Iowa to focus explicitly on the needs of family caregivers. The IDEA, through implementation of the new federal program, intends to build caregiver support into existing state infrastructures, primarily through Iowa's AAAs.

Recently, Iowa was also awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The DHS Division of Mental Health/Development Disabilities has primary responsibility for the grant. Goals of the grant are to move the disability services system away from the traditional medical model toward a model driven by consumer choice, with home and community-based options, and to design an individualized, consumer-centered process to assess individual preferences and needs. Respondents noted that family caregivers of the elderly are not viewed as a priority target group under this grant.

The DHS has implemented several programs that expand focus on home and community-based services. The first is of the consumer-directed attendant care (CDAC) program, implemented through a change to Iowa's Medicaid state plan. CDAC allows a family caregiver to be a paid provider under all of Iowa's Medicaid waivers. DHS also administers a family support subsidy (the In-Home Health Care program) and a rent subsidy program. Both of the subsidies could help ease some of the financial burden associated with caring for a chronically ill family member; the In-Home Health Care program also provides respite services and care management.

When asked if family and informal caregivers were recognized as a central component of a comprehensive long-term care system, case study key informants varied in their opinions. One respondent observed that help from family, friends and neighbors was taken for granted and that the state of Iowa recognizes that it would "be in dire shape without family caregivers."

PROGRAM BACKGROUND/DEVELOPMENT

The original impetus for Iowa's family caregiver support program was the passage of the Older Americans Act Amendments of 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. Prior to passage of the NFCSP, no statewide caregiver support program existed in the state. When the IDEA began its planning process for the new program, it brought the AAAs together to look at various options to develop a coordinated system of caregiver support in the state. One stakeholder pointed out that the planning sessions have focused on a coordinated information and referral system.

The Iowa Association of AAAs (I4A) developed the name *Iowa Family Caregiver*, which appears on Iowa's NFCSP website as well as on its publicity materials, in order to promote a consistent, state-wide identity for the program.

Most rewarding: State officials of the IDEA noted the most rewarding aspect of *Iowa Family Caregiver* has been “to allow us to focus on the family caregiver. We have always helped caregivers but not explicitly.” Medicaid officials indicated that the most rewarding aspect of the Aged Medicaid waiver was the ability through it to allow older persons to remain at home and in their communities, which allows consumers more control over their lives. Medicaid officials did not comment on the impact of Medicaid waiver services on family caregivers.

Biggest challenge: According to key informants, designing a public awareness campaign to effectively reach families when they most need it has been a challenge. Respondents expanded on this idea by indicating that family members are challenged to identify themselves as family caregivers, and professionals are challenged to provide services when the caregiver needs it. The administration of multiple funding streams was also identified as a challenge.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—Iowa *Family Caregiver* received \$1.4 million in federal funds. In FY 2002, the federal share of NFCSP funds was increased, with Iowa's allocation increasing to \$1.8 million, or about 6% of IDEA's total budget.

In contrast, in FY 2001, total expenditures under the state's Aged Medicaid waiver were \$12.6 million, or about 3% of the total DHS Medicaid budget. Key informants were unable to identify the proportion of the Aged Medicaid waiver spent on respite care.

Iowa received nearly \$56 million in tobacco settlement funds during FY 2000 and about \$60 million in FY 2001. Iowa plans to use significant funds from the tobacco settlement toward home and community-based services. The Iowa legislature established a health care endowment, which will receive tobacco settlement funds as well as general revenue, earmarking funds for capital improvement projects and health care services.¹⁶ In addition to this, the FY 2003 proposed budget includes several allocations for tobacco funds, including \$313,565 for the state match for the Aged Medicaid waiver and \$1.1 million for an expansion of respite care services. State officials also indicated that tobacco funds have been used in part of the state efforts to transition nursing homes and assisted living facilities to use for facility-based respite, under the state's Senior Living Trust.

When asked to describe the current budget situation in their state, Iowa key informants indicated that they were suffering, like all other states. The IDEA has been able to use funds from the Senior Living Trust and NFCSP dollars to compensate for some budget cuts. The IDEA has reduced some case management and direct service funding going to the AAAs. One stakeholder pointed out that home and community-based services had gotten new funding, even though the state budget was not in good shape.

Officials from the DHS indicated that the state was “in crisis,” and said that they were “scrambling to keep what we have.” The department has had to lay off some staff and cut services.

According to the National Conference of State Legislatures, Iowa's Medicaid program is facing \$18.6 million in service cuts necessitated by a 4.3% across-the-board cut.¹⁷ In February 2002, the Iowa legislature mandated an additional 3% across-the-board cut.

PROGRAM ADMINISTRATION

Iowa's AAAs play a predominant role in administering programs that serve older persons, specifically with regard to implementation of the NFCSP. As one key informant noted, "Iowa has a local system of care, not a state system." The IDEA serves as a pass-through for all Older Americans Act funds, including the NFCSP, with the I4A serving as primary coordinator of the program.

Several key informants commented that Iowa's aging services have historically been administered through shared responsibility between the IDEA and the state's AAAs. Policymaking and administrative decisions are centralized through I4A, rather than through IDEA. *Iowa Family Caregiver* is administered by a caregiver coordinator, who previously served (for 12 years) as executive director of the IDEA. The coordinator began in March 2001.

The IDEA sees its role in the development and implementation of the state's first caregiver support program as one of oversight. State officials at the IDEA said that they also seek other sources of funding and are now looking at the administration of similar programs in other states. One stakeholder commented that the IDEA should have an increasing role in monitoring the caregiver support program and examine outcomes. Although the IDEA and I4A work collaboratively to administer the caregiver program, the I4A handles the majority of program administration issues while keeping IDEA informed of programmatic issues. I4A's board of directors must approve changes in *Iowa Family Caregiver* policies and services. IDEA staff overseeing the *Iowa Family Caregiver* program at the state level devote 10% of their time to this program.

I4A has focused on developing a statewide approach, encouraging AAAs to develop support services that best meet local consumer need. Referring to the developing caregiver support program, one respondent indicated that one of the keys to a successful program is to "under-promise and over-deliver."

Each AAA in Iowa has hired a caregiver specialist to assist consumers with *Iowa Family Caregiver* services. Further, each AAA pools some funding for development of a joint website, resource development, a toll-free number for a single point of entry and development of a marketing/publicity and education plan, all part of an effort toward a consistent, statewide approach. In 2001, each AAA committed 20% of its funds to I4A for this effort. For 2002, each contributes 15%. Two of the 13 AAAs opted out of the pooled funding approach but do contribute funds for website development and other services.

State Medicaid officials identified their role as funder of the Aged Medicaid waiver, policy developer, overseer and, in contract with agencies, provider of training. State officials characterized their relationship with program managers at the local level as a "cooperative effort." In developing policies for caregiver support services, respondents indicated that they constantly refine rules and regulations to meet the needs of consumers and their families, with a focus on developing consensus among interested parties. Their intent is to achieve uniformity among all of Iowa's Medicaid waivers, while retaining flexibility to meet individual needs at the local level. Medicaid officials put forward the

example of changing the respite rules in all of their Medicaid waivers, which, after two years to complete, resulted in families being paid and in more flexible reimbursement rules.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Iowa Family Caregiver: Eligibility is consistent with federal requirements under the Older Americans Act. Family or informal caregivers of any age who provide care to persons 60 years and older are eligible, as are caregivers ages 60 and older who care for children ages 18 or younger.^c For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or two instrumental activities of daily living (IADLs). There are no income eligibility requirements.

Iowa's case management is an integral part of all of its programs serving older persons, including *Iowa Family Caregiver*. One respondent indicated that it was, "almost impossible for us to talk about the NFCSP without talking about case management." With regard to the case management program, the assessment process is uniform across the state and contains a brief, standard caregiver assessment, approximately six questions long, including basic demographic information, the ability of the caregiver to provide care and some indication of stress level. Now that the NFCSP has been implemented, responses to the caregiver questions trigger a referral for the family caregiver from the older person's case manager to a caregiver specialist at the AAA. Within *Iowa Family Caregiver* specifically, however, there are not uniform assessment standards. Although the AAAs operate both the case management program and *Iowa Family Caregiver*, key informants noted that there is no uniform intake or assessment specifically under the program. In fact, not all caregivers are assessed—only those whose care recipient goes through the case management system at the AAA.

State officials from IDEA indicated that both the caregiver and the care recipient are considered the client in *Iowa Family Caregiver*. The key informant from I4A believed the family caregiver is the identified client in the program, however.

Aged Medicaid waiver: Eligibility is consistent with federal Medicaid requirements extended to recipients of Supplemental Security Income (SSI) or to those whose income does not exceed 300% of the maximum monthly payment under SSI and who meet the medical criteria for Medicaid nursing home level of care. Respondents noted that the care recipient is the identified client in the program.

Regarding Iowa's Aged Medicaid waiver, uniform assessment standards exist to determine the level of care required but not to determine each client's service needs. The DHS has adapted the CMS Outcome and Assessment Information Set (OASIS) in this effort. Consistent with Medicaid policy generally, respondents noted that the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. Respondents stated that they assess the family caregiver's needs and ability to provide care only if the care recipient chooses the family member as a care provider.

^c This includes caregivers 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

SERVICES

Each AAA in Iowa offers all of the five core NFCSP services to family caregivers, but each provides a different level of service based on its funding allocation under the NFCSP. These services include:

- ✧ Information
- ✧ Assistance
- ✧ Individual counseling, support groups and training
- ✧ Respite care (voucher program)
- ✧ Supplemental services (voucher program)

Iowa's AAAs are not typically direct service providers, except that each AAA family caregiver specialist does provide some direct services, such as information and referral, public education and maintenance of a resource database. Respondents indicated that most NFCSP funds are used for information and assistance, with other services including respite and supplemental services, (including the provision of legal assistance) and the purchase of emergency response systems. AAAs have the flexibility to meet local needs. In this vein, staff have been creative when trying to assist caregivers. As one example, a farmer was supplied with rechargeable batteries for his walkie-talkie so that he could stay in contact with his wife while he was on the farm.

In the *Iowa Family Caregiver* program, AAAs have the option to provide in-home, adult day services and facility-based respite. Worker and provider shortages—particularly in rural areas—may mean that certain types of respite are unavailable in some areas. Early on, some AAAs chose to cap the amount of funds for respite, but this is no longer practiced. Rather, some AAAs now cap supplemental services, although there is no standard amount across AAAs.

Under the state's Aged Medicaid waiver, respite care for caregivers is provided, including adult day services.²³ Iowa's Aged Medicaid waiver offers in-home, adult day care and facility-based respite, as well as respite camps. Respite provided outside of a consumer's home is limited to 72 continuous hours, however. The waiver has an overall cost cap of \$1,052 per month for nursing level of care and \$2,480 for skilled level of care. Within this cap is a limit of 14 days of continuous, 24-hour respite.

Major services needed by caregivers: Iowa stakeholders indicated that caregivers needed assistance navigating “the system.” Identification of the major service needed varied among state officials. Officials from IDEA cited information and assistance. Medicaid respondents indicated that respite and assistance with physical needs, such as transportation, were the major services needed. Medicaid officials went on to say that “Iowans like to take care of their family and as a result, burn themselves out.”

d All of Iowa's six Medicaid waivers include respite care as a service category.

Table 2. Family Caregiver Support Services in Iowa

Program	Iowa Family Caregiver	Aged Medicaid waiver
State Administrative Responsibility	Iowa Department of Elder Affairs	Iowa Department of Human Services
Local Service Delivery	AAAs ^a Local service agencies	AAAs—case management only (under contract with IDEA) Local service agencies
Funding Source	Older Americans Act, Title III-E	Medicaid 1915 (c) waiver
Expenditures FY 2001	\$1.4 million ^b	\$12.6 million
Client Population	Family & informal caregiver	Care recipient
Eligibility Criteria		
Age	60+ care recipient Family caregivers of any age of persons 60+	65+ care recipient
Income	None	Up to 300% of SSI
Functional Ability	For respite and supplemental services—at least 2 ADLs or cognitive impairment for care recipient	Nursing home level of care for care recipient
Uniform, Statewide Caregiver Assessment	No	No
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care
Respite Cap	Not required and varies by AAA	Monthly cost cap of \$1,052, 14-day cap of 24-hour, continuous respite care
Consumer Direction	Yes; consumers choose from a menu of services and can hire family and friends to provide respite care through a voucher system	Yes; Consumer-Directed Attendant Care component of waiver
Family Caregivers Paid as Respite Providers	Yes	Yes

a AAAs = Area Agencies on Aging.

b Federal funds only.

CONSUMER DIRECTION

Both *Iowa Family Caregiver* and the Aged Medicaid waiver offer consumer-directed options. With *Iowa Family Caregiver*, consumer direction varies by AAA. The care manager determines the menu of services that would be appropriate for each family caregiver. The family caregiver then decides which services to use to meet his or her needs. If respite care is one of these services, caregivers have the option of hiring family and friends to provide it. There are intentionally no restrictions on who can provide respite, partly because of a lack of providers in Iowa's vast rural areas. Further, respondents indicated that Iowans could be particularly concerned about having "strangers" provide care and generally are more comfortable with family and informal providers.

Under *Iowa Family Caregiver*, family and informal respite providers are paid through a voucher system. This same voucher can be used for other services. One family caregiver had requested transportation reimbursement to take her husband to the doctor, for example. Although she had her own automobile, the battery had died, and she could not afford to replace it. The AAA offered to buy the caregiver a new car battery in lieu of transportation, for which a voucher was provided.

Iowa's Aged Medicaid waiver also includes a consumer-directed element, known as consumer-directed attendant care. This allows the Medicaid recipient to hire a care worker to provide respite and personal assistance services. Providers must conform to the following DHS requirements: (1) must be 18 years of age or older, (2) must be qualified by training or experience to carry out the consumer's plan of care pursuant to the IDEA-approved service plan, (3) must not be the spouse of the care recipient and (4) must not be the recipient of respite services paid through the waiver on behalf of a consumer who receives waiver services. While formal providers, such as adult day health, must have a certificate of formal training, family caregivers do not need this training to serve as providers. A family caregiver who chooses to be a provider cannot receive paid respite care, however.

QUALITY ASSURANCE AND EVALUATION

The state does not require, nor does I4A use, a standard intake form or assessment tool. As mentioned previously, the assessment is uniform only when the care recipient is assessed through the formal case management program. In terms of data collection, respondents indicated that they collect "what the [federal government] requires." Although Iowa is moving toward an electronic system, data currently are entered manually. Key informants noted that a new, electronic system will allow them to monitor the program on a quarterly basis, and to track service utilization, clients served and so on. Respondents pointed out that AAA staff vary in level of skill, and AAAs vary in level of technology. Although Iowa is currently collecting data on caregiver outcomes, the state is interested in incorporating the Federal Performance Outcomes Measurement Project (POMP) in the NFCSP.

Under the Aged Medicaid waiver, respondents indicated that "not much" is collected about family caregivers and noted that the only data provided regards the services paid for under the consumer-directed care program (i.e., what has been provided and billed and who the provider is). The DHS has a new computer program for its automated data collection system and is moving toward an outcome-based system of data collection for all Medicaid waivers. Respondents pointed out that data collection is limited to the care recipient—not to the family caregiver—because the "client" of the program is viewed solely as the care recipient.

SYSTEMS DEVELOPMENT

Respondents characterized their experience implementing the NFCSP in Iowa as largely positive, noting that it has been a vehicle to enhance collaboration and coordination. Further, they commented that it has brought out stakeholders with whom the AAAs had not worked before implementation of the program. Because of the newness of the program, I4A is continuing to refine its programs and services. As an example, it is offering and/or requiring more formal training for each AAA caregiver specialist to ensure a more consistent approach. This would also ensure specific familiarity with *Iowa Family Caregiver* services, rather than with only the AAA's menu of services focusing on the care recipient.

Medicaid officials were not familiar with the NFCSP in Iowa and had no role in developing the program.

Regarding the Aged Medicaid waiver, state officials indicated that services are coordinated at the state level but that service delivery is at the local level. Both Medicaid waiver and *Iowa Family Caregiver* respondents indicated that their programs are integrated into the state's other long-term care programs, because of the state's focus on case management, although Medicaid officials indicated that the integration is only "to some degree."

Iowa does not have a body whose mission is coordination of family caregiver support services across state departments. One stakeholder indicated that IDEA has held some strategic planning sessions with regard to caregiver support. The respondent also indicated that the Senior Living Trust has a coordinating unit, but caregiver support has not been addressed in this context. Officials of the IDEA indicated that *Iowa Family Caregiver* is integrated into the state's other long-term care programs rather than being a stand-alone program.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In response to the Supreme Court's recent *Olmstead* decision, Iowa's governor identified the DHS as the lead agency in this effort. DHS conducted public meetings and site visits to assist it in developing its *Olmstead* report, submitted in August 2002.¹⁸

Iowa used to have a specific *Olmstead* task force, but respondents noted that the task force had changed its name in 2002 to the *Olmstead* Real Choices Consumer Task Force. The task force includes representation from IDEA and family members, although not specifically from family caregivers of older persons.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?” Stakeholder responses varied, with two identifying a “low” level of priority and one identifying a “high” priority. State officials were also mixed, with one respondent stating that there was a “medium” priority, the other a “high” priority.

Number of Key Informants	Priority on Caregiver Support
2	→ Low
1	→→→ Medium
2	→→→→→ High

Benefits and challenges: Iowa case study respondents identified three aspects of their program that are most beneficial to family caregivers:

1. The one-stop shop approach for *Iowa Family Caregiver*—including a toll-free number and a website providing information on the program
2. Assessment—because family caregivers do not always know what they need
3. Respite care—to give families a break and also peace of mind

When asked to identify the challenges for implementing family caregiver support programs in their state, Iowa respondents noted the following:

- ❖ Public awareness—getting the word out is expensive
- ❖ Service coordination

Major lesson learned: The view of Iowa’s respondents is that *Iowa Family Caregiver* has helped move the aging network to broaden its focus on family issues, particularly in helping adult children. The program has also encouraged respondents to relook at the allocation of resources. Although the state had been moving in that direction, key informants indicated that it has been easier with the resources and tools that the NFCSP has provided. In terms of this paradigm shift, one key informant characterized the NFCSP as an “awakening.”

Other state officials from the Aged Medicaid waiver program discussed the struggle between providing flexibility and ensuring oversight. They also pointed out the difficulty in defining quality, especially in consistency between consumer and provider perceptions of quality. Finally, respondents indicated that providing caregiver support is a balancing act.

State officials also commented the waiver could support family caregivers even more if Medicaid law were changed to allow spouses or parents of minor children to be paid providers of care. The officials pointed out that “it is less expensive and [these family members] do a better job.”

Opportunity for expanding caregiver support: All Iowa respondents indicated that new initiatives or expansion of state-funded programs to support and strengthen family caregivers over the next three to five years would depend on the budget situation. One key informant indicated that the current emphasis in Iowa is on programs that receive federal matching funds, rather than only state general funds.

Recommendations for other states: Respondents made a variety of recommendations:

- ✧ Being flexible and encourage the development of partnerships and collaborations.
- ✧ “Build support in your state...so when the time comes [to start up new programs] there is not strong opposition.”
- ✧ Meet the needs of older persons and their families.

NOTES

- 1 MapStats-Iowa, *www.fedstats.gov* (June 2002).
- 2 U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), *www.bea.doc.gov/bea/newsrel/spi0401.htm* (2001).
- 3 MapStats-Iowa.
- 4 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, *www.governing.com/source.htm*. Source for Internet access is the National Telecommunications and Information Administration, 2001.
- 5 Ibid.
- 6 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group*, *www.aoa.gov/aoa/stats/2000pop/percentxstate.html* (April 1, 2000).
- 7 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, *www.aoa.gov/aoa/stats/2000pop/percent60plusrace-ho.html*.
- 8 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States*, *www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html* (2000).
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- 16 Health Policy Tracking Service, *Major Health Care Policies: 50 State Profiles, 2001* (Denver, Colorado: Health Policy Tracking Service/National Conference of State Legislatures, January 2002).
- 17 National Conference of State Legislatures, *Health Policy Brief* (Denver, Colorado: National Conference of State Legislatures, March 2002).
- 18 National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A Work in Progress* (Denver, Colorado: National Conference of State Legislatures, 2002).



OVERVIEW

Maine is a relatively small, rural New England state with a substantial lower-income population and few minorities. Over the past decade, the state has accomplished incremental long-term care reform by centralizing uniform assessment and care coordination, providing a broad array of home and community-based services, focusing on the consumer (i.e., care recipient) and offering flexible options in service delivery to meet consumers' needs. By 1997, more people were receiving care at home than in nursing homes.

The concept that family caregivers need support services themselves is relatively new for Maine; the state's long-term care system is based on viewing of only the care recipient as the client. Prior to passage of the National Family Caregiver Support Program (NFCSP), caregiver support in Maine was limited to the state's Alzheimer's Respite Program. Maine's developing caregiver support services are characterized by efforts to:

- ❖ Build on Maine's existing home and community-based services to broaden service delivery beyond respite care and reach a population wider than dementia caregivers alone
- ❖ Identify and work with families earlier in the process of caregiving
- ❖ Centralize policymaking and administration at the state level, mandate uniform data collection and provide flexibility to meet individual needs of caregivers at the local level
- ❖ Maintain a stand-alone identity for the new NFCSP program, rather than to integrate caregiver support into Maine's long-term care system

Maine respondents noted that the major service needs of family caregivers are (1) the ability of family members to self-identify as caregivers, (2) education and training on caregiver issues, (3) information, support and care management and (4) trained and consistent direct care workers to provide respite care.

As Maine develops its caregiver support program and at the same time expands home and community care, key considerations will be (1) whether the state views family caregivers as legitimate consumers themselves and (2) coordination of caregiver support with Maine's single point of entry to the long-term care system.

INTRODUCTION

Passage of the NFCSP has allowed Maine to expand services to family caregivers who need help because of a range of illnesses or disabilities beyond Alzheimer's disease and related dementias. The project team conducted site visits between April 15 and 16, 2002, through in-person interviews with

government officials and key stakeholders. One additional interview was conducted in person in early April, and the final interview was conducted by telephone in early July 2002. State agencies and programs within those agencies interviewed include:

Maine Department of Human Services, Bureau of Elder and Adult Services

- ✧ Family Caregiver Support Program (NFCSP funded)
- ✧ Home Based Care Program (state funded)
- ✧ Alzheimer's Respite (state funded)
- ✧ Aged, Disabled and Consumer Directed Medicaid waivers
- ✧ Alzheimer's Disease Demonstration Grant to States (federally funded)

Maine Department of Human Services, Bureau of Medical Services (Muskie School of Public Service, subcontractor)

- ✧ Real Choice Systems Change grant

Stakeholders interviewed were:

- ✧ Maine Area Agency on Aging Caregiver Coordinators
- ✧ Alzheimer's Association of Maine

Four programs are featured:

1. Family Caregiver Support Program
2. Home Based Care Program for the elderly and other adults
3. Alzheimer's Respite Program
4. Aged and Disabled Medicaid waivers

BACKGROUND

Maine is a relatively small, rural New England state with a population of nearly 1.3 million residing in 16 counties. Maine ranks 40th in population nationally. Although it is a small state in size (about 320 miles long and 210 miles wide), it is almost as large as all of the other five New England states combined.¹ Most of the residents are native to the state, with Maine ranking first in the United States in home ownership rate.²

The state has substantial rural and lower-income populations and few minorities. Nearly 60% of Maine's population live in rural areas.³ In 2000, Maine ranked 37th in personal income per capita at \$25,623, compared to the national average of \$29,676.⁴ Although per capita income is less than the national average, Maine has proportionately fewer people living below the federal poverty level than the national average (10.7% vs. 13.3% U.S.).⁵ The racial makeup of the state's population differs significantly from that of the United States as a whole, with a nearly all-white population and few African Americans (0.5% vs. 12.3% U.S.) or Hispanics (0.7% vs. 12.5% U.S.) (table 1).

Maine ranks 20th nationally in percentage of households with Internet access.⁶ About 15% of Maine's population use the Internet to obtain information about or locate services for older people.⁷

An estimated 238,099 persons in Maine, or 18.7% of the state's population, were 60 years or older in 2000, higher than the national average (16.3% U.S.). Maine ranks fifth nationally in the percentage of older persons (60+) residing in the state.⁸ Similar to the state's population as a whole, Maine has a largely white older population (98.6% vs. 82.4% U.S.) and few older minorities.⁹

Maine ranks 11th nationally in the proportion of its population ages 85 and older. In 2000, 23,316 persons, or 1.8% of Maine's total population, were ages 85+.¹⁰

An estimated 123,712 family caregivers reside in Maine. These family caregivers provide about 115 million hours of caregiving per year at an estimated value in 1997 of \$942 million.¹¹ About 47% of Maine's citizens report routinely helping out an older family member, and 11% say they routinely take time off from work to provide care.¹²

Maine is a progressive state with a history of implementing innovative health and human services programs. Key informants noted that Maine has had almost a decade of incremental reform to achieve a coherent system of long-term care. The goal of this system is to provide equal access to home and community-based services wherever consumers live in the state. Maine has a wide range of state- and Medicaid-funded programs for the elderly and for persons with disabilities to help people who need assistance to remain in their homes.

Table 1. Selected Characteristics of MAINE and the UNITED STATES, 2000 ^a

	Maine	United States
Total Population Characteristics		
Total Pop. ^b	1,274,923	281,421,906
% African American ^c	0.5%	12.3%
% Hispanic ^d	0.7%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	238,099	45,797,200
% 60+ ^f	18.7%	16.3%
National ranking 60+ ^g	5	NA
Pop. 65+ ^h	183,402	34,991,753
% 65+ ⁱ	14.4%	12.4%
National ranking 65+ ^j	7	NA
Pop. 85+ ^k	23,316	4,239,587
% 85+ ^l	1.8%	1.5%
National ranking 85+ ^m	11	NA
% increase 1990–2000 60+ pop. ⁿ	9.4%	9.4%
% White (60+) ^o	98.6%	82.4%
% African American (60+)	0.2%	8.4%
% Hispanic (60+)	0.3%	5.4%
% Asian (60+)	0.3%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	123,712	25,798,370
Caregiving hours (millions) (1997)	115.2	24,013.1
Value of caregiving (millions) (1997)	\$941.9	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$25,623	\$29,676
% of pop. below poverty (1997) ^r	10.7%	13.3%
Internet		
% of households w/Internet access (2001) ^s	42.6%	41.5%
Nat'l ranking of households w/Internet access	20	NA

a Unless otherwise noted, all data are from 2000.

b Mapstats-Maine, *www.fedstats.gov* (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
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- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
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- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
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- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r Mapstats-Maine.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Maine utilizes a highly centralized approach to accessing and managing its long-term care programs, including the home and community-based care system. Caregiver support services for the elderly and for adults with physical disabilities are centrally administered by one state agency, the Department of Human Services (DHS).^a That department serves as the single state agency responsible for administering the Medicaid program, now known as MaineCare, effective July 2002.¹³ The department has five Bureaus: Elder and Adult Services, Child and Family Services, Health, Medical Services and Family Independence.

The Bureau of Elder and Adult Services (BEAS) serves as the State Unit on Aging to administer the provisions of the federal Older Americans Act, including the new NFCSP. The BEAS also administers the Aged and Disabled Medicaid waivers, a federal Alzheimer's Disease Demonstration Grant to States and state-funded programs in home and community-based care for the elderly and for adults with disabilities, including home based care and Alzheimer's respite programs.

The infrastructure of Maine's aging network is a statewide system of five nonprofit Area Agencies on Aging (AAAs), ranging from a one-county service area in the northern part of the state to a six-county AAA in the central part of the state. The AAAs provide a range of services under the Older Americans Act and coordinate services under the state-funded Alzheimer's respite program.

a Effective July 2002, oversight for all of Maine's consumer-directed personal assistance programs (through state funds and MaineCare, including the Consumer Directed Medicaid waiver) were transferred from the Department of Human Services, Bureau of Elderly and Adult Services, to the Department of Labor, Bureau of Rehabilitation Services. Alpha One, the state's Center for Independent Living, serves as the designated agency to coordinate home care programs for adults with physical disabilities who are able to direct their own care.

Maine's long-term care system underwent significant reform in 1996. Both executive branch and legislative branch leaders supported the move to a more integrated system of care. Specifically, BEAS changed from using the five AAAs to assess consumer needs and provide home care coordination to using two agencies to carry out these functions under the state-funded home care program. One agency does the assessments; a separate agency provides care coordination. This resulted in significant reductions in administrative costs and led to a consistent, statewide approach to eligibility and service delivery. Through a request for proposal process, the single agency selected to do assessments was Goold Health Systems, and the single agency chosen to provide care coordination was one of the AAAs, Seniors-Plus, in the western part of the state. Elder Independence of Maine, a division of Seniors-Plus, was designated as the statewide home care coordination agency. Today, Elder Independence manages all home care services delivered through agencies.^b

Three 1915 (c) Medicaid waivers have, until recently, been administered by BEAS.^c The waiver for persons ages 60 and older was originally approved in 1985, and it served about 1,300 persons in 2001. A second consumer-directed model waiver for persons 18 and older was also approved in 1985. State respondents noted that about 26% of the 325 clients served in the consumer-directed waiver are 65 years of age or older. The third Medicaid waiver is for adults ages 18 to 59 with disabilities. This waiver was approved in 1994, and about 500 persons were served in 2001.

In October 2001, the Maine Department of Human Services, Bureau of Medical Services, was awarded a Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The grant's focus is largely interdepartmental, involving representatives from five departments (Human Services, Behavioral and Developmental Services, Education, Labor and Corrections). The purpose of the grant is to (1) improve existing community-based services in specific ways (e.g., offer greater consumer choice and control, consumer voice, interdepartmental collaboration and data integration) and (2) address gaps in service and supports (e.g., provide greater consumer access and availability of qualified personal-assistance workers, affordable housing, transportation and information). Key informants noted that the grant does not have any direct project activity related to family caregiver issues.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Maine's long-term care system is characterized by uniformity in assessment and care coordination through a single point of entry, a broad array of home care and residential resources, a focus on the consumer (i.e., care recipient) and flexibility in service delivery to meet the consumer's needs. As a result of a budget crisis in 1993, Maine adopted a policy of long-term care reform to reduce reliance on institutional long-term care and to offer consumers a wider range of affordable choices in home and community-based care. In 1997, case study respondents noted that, for the first time, more

^b Alpha One, the state's Center for Independent Living, manages the consumer-directed programs with independent providers.

^c Effective July 2002, the Department of Labor, Bureau of Rehabilitation Services, administers the Consumer Directed Medicaid waiver. The Department of Behavioral and Developmental Services administers a waiver for individuals with mental retardation or developmental disabilities (MR/DD).

people in need of long-term care received help at home, rather than in nursing facilities. Reliance on nursing home care has continued to decline dramatically, reducing the costs of care overall. The total number of persons who received long-term care services increased from 19,803 in 1995 to 25,455 in 2001. At the same time, per person spending on long-term care in all settings (e.g., nursing homes, home care) was reduced from \$14,985 in 1995 to \$10,952 in 2001.¹⁴

Maine does not yet have a comprehensive system of support in place for family caregivers. Prior to the passage of the NFCSP under the Older Americans Act Amendments in 2000, caregiver support was neither a major policy issue nor a major interest of state leaders in Maine, although some support had been provided to caregivers of persons with Alzheimer's disease or other dementias through a state-funded Alzheimer's respite program and two federally funded Alzheimer's Disease Demonstration Grants to States. State leaders commented that recognizing family caregivers who need support services themselves—as part of the system of long-term care—is a new concept for Maine because their long-term care system is based on looking only at the care recipient as the client. Moreover, several respondents expressed confusion over the notion of the family caregiver as a “client” in long-term care. Respondents also noted that although family caregivers are not explicitly recognized in state statute, respite care for family caregivers has been part of the state-funded home based program since 1981. According to one stakeholder, however, the state's entire home and community-based care system was built upon the presumption that family and informal caregivers could provide day-to-day care to complement formal services. Another observer commented that the “entire system takes family caregivers for granted.”

Given that the state has successfully reduced reliance on nursing homes and has seen the use of home and community-based care double, it is interesting that none of the key informants discussed the potential impact of this shift on Maine's family caregivers and on their need for support services to sustain them in their caregiving role. One stakeholder noted that a major challenge has been to “get the formal home and community-based care system to recognize family caregivers as something other than reduced spending on home care services.” A state official commented that the needs of consumers and their families are changing and that “some of the assumptions that we made 20 years ago don't hold today; it is now a ‘new generation’ of older people, and their caregivers and families are more likely to seek out and use services.”

Maine has two programs that specifically address the needs of persons with Alzheimer's disease and their families, a state-funded Alzheimer's Respite Program and a federal Alzheimer's Demonstration grant. Maine has received two federal demonstration grants to states for Alzheimer's disease. The first, awarded in 1993, developed models of respite, and the state has now replicated one of the models through the state-funded Alzheimer's respite program. The second grant, funded at \$255,000, focuses on Alzheimer's coordination and information. The state was in the second year of the three-year grant at the time of the site visit. This federal demonstration is considered a stand-alone program, functioning apart from other Older Americans Act programs at the state and local levels in terms of funding, eligibility and assessment but coordinated at the service delivery level with other state programs through the AAAs, each with a respite coordinator on staff.

With the advent of the new NFCSP funds to support family caregivers, the state's goal is to reach a broader population than Alzheimer's disease and dementia caregivers and to provide support beyond respite care. One way to achieve this, according to some respondents, is to establish new referral sources, particularly with the medical and health communities. For example, Maine's Eastern Agency on Aging and the Center on Aging at the University of Maine are presently conducting a three-year project to forge partnerships among primary care practitioners, the university and the AAAs to develop referral relationships between physicians and other health care providers and the caregiver coordinators at Maine's AAAs.^d

State leaders noted that they want the emerging family caregiver support program, as a new program in the start-up phase, to maintain its own identity rather than to be integrated into Maine's home and community-based care system. That system has different eligibility requirements, provides services based on functional ability of the care recipient and requires a co-payment. Although the state has a well-coordinated and centrally administered long-term care system, the new caregiver support program is not integrated into Maine's other long-term care programs administered by the BEAS. Rather, the intent, according to state officials, is to coordinate with the existing long-term care system so that family caregivers are served earlier in the caregiving process and are aware of the range of long-term care services available in the state when they are needed.

PROGRAM BACKGROUND/DEVELOPMENT

The original impetus for Maine's family caregiver support program was the passage in 2000 of the Older Americans Act Amendments, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. State officials commented that "it was not a program that we would have been able to set up without the federal mandate and funding." Prior to the passage of the NFCSP, Maine supported family caregivers by providing respite care from a variety of funding sources administered by BEAS (i.e., Medicaid waivers, state-funded home based and Alzheimer's respite programs, federal Alzheimer's demonstration grants). Respondents noted that the modest federal funding through the NFCSP allows the state to broaden service delivery to family caregivers beyond respite care.

Maine's BEAS began planning for the establishment of the new program prior to the passage of the NFCSP in June 2000. The BEAS convened a roundtable of key stakeholders across the state, including family caregivers, to identify both caregiver needs and ways in which the proposed NFCSP could enhance Maine's existing caregiver support efforts beyond respite care. Once the Older Americans Act was reauthorized, including the creation of the NFCSP, BEAS convened a meeting with Maine's five AAAs to brainstorm and identify what this new program "would look like" in the state. The BEAS was interested not only in how much federal funding would come to Maine for family caregiver support and how the AAAs would use the funds, but also in how the new funds would complement what the state was already doing in long-term care.

BEAS established several core requirements for the AAAs:

1. Use the NFCSP funds to *expand* efforts to newly identified caregivers, not to supplant services to family caregivers already receiving services from other publicly funded programs.

^d This project is funded under a three-year NFCSP demonstration grant.

2. Submit a plan with AAA draft contract for state FY 2002 and identify the caregiver program as a separate item in the budget to the BEAS.
3. Set aside a portion of the base allocation to each AAA for joint activities with statewide impact: (a) development of an informational packet and promotional items (e.g., jar openers) that can be distributed to doctors' offices, hairdressers, pharmacies and so on; (b) website development; (c) statewide collaboration with specific disease associations and AARP and (d) data collection and evaluation. Each AAA pooled \$5,000 of its funds (\$25,000 total) for joint activities.
4. Set aside a portion of funds for grants/contracts to local community agencies or businesses, rather than just take the federal funds and use them for services provided only by the AAAs.
5. Add staff at each AAA to (a) organize and run support groups; (b) work with employers to identify caregivers working outside of the home and their needs, including offering on-site caregiver education; (c) make home visits to evaluate and support individual needs and requests of caregivers; (d) provide in-person counseling, information, assistance and referrals; and (e) demonstrate effective initiatives to reach caregivers earlier in their caregiving experience.
6. Collect data as required for monitoring and evaluation.

Beyond these requirements, the state gave the AAAs considerable flexibility in designing their caregiver support programs, particularly with respect to respite care and supplemental services. Maine's AAAs prioritize services to family caregivers of older persons who are not currently receiving caregiver support services under the Alzheimer's respite or home based care programs. If the care recipient is eligible for state or Medicaid waiver respite services, the caregiver is referred first to these services. A family caregiver can receive NFCSP respite if the care recipient is on a waiting list for respite through other state or Medicaid waiver respite services. The state encouraged the AAAs to work closely with Maine's federal Alzheimer's Disease Demonstration Grant to States so that the new caregiver support program could build on the federal demonstration but not duplicate services. The BEAS encouraged the AAAs to be creative and innovative in program development and to make the maximum use of limited federal funds.

The BEAS elected not to hire a statewide caregiver coordinator, in part because of the state's lack of administrative funds under the federal funding formula to run the program. Because of the small number of AAAs in the state, the respondents did not view this as a major challenge to statewide program implementation. The manager of BEAS's community programs unit was assigned the role of managing the family caregiver support program.

When developing policies and standards for the program, the state utilized the U.S. Administration on Aging (AoA) website and listserv. Respondents commented that the AoA-sponsored conference in September 2001 also was extremely helpful in designing the program. The state released the federal funds to the AAAs in July 2001, the start of Maine's fiscal year.

Most rewarding: The flexibility of the program's design was considered the most rewarding aspect of program development. Respondents commented that family caregiver issues are gaining increasing levels of support in Maine.

Biggest challenge: State officials raised two major challenges of the program's development in the first year of start-up. First, the aging network had to "change their mind-set to thinking about the family caregiver, not just the older person, as consumer," said several respondents. Concerns were expressed that "this is how our systems are set up in Maine; this is how we have always done it—to look at the older person as consumer, and now we must look at the caregiver, too." Respondents acknowledged that although they have some experience with the concept of family support and a family systems orientation from their state-funded Alzheimer's Respite Program and the federal Alzheimer's Disease Demonstration Grant to States, these programs are small in scope.

Second, respondents said that reporting issues were the biggest challenge, particularly in trying to figure out what information they needed to collect, because the client population of family caregivers was a new focus of the state's data collection. Respondents were concerned that AAAs and service providers would face requests to collect more or different caregiver data in a few years. They said that it is always easier to build data collection systems from the start, rather than to build in more data collection over time.

FUNDING

In FY 2001, the first year of federal funding under the NFCSP, Maine received \$564,300 in federal funds. In FY 2002, the federal share of NFCSP was increased to \$641,505, or only about 2% of the BEAS \$35 million budget (excluding Medicaid waivers).

In contrast, Maine's expenditures in FY 2001 for the state-funded Home Based Care Program (including consumer-directed home care) was \$15.5 million; for state-funded Alzheimer's Respite Care, \$754,600; and for the Aged and Disabled Medicaid waivers, about \$19 million.¹⁵ Respondents did not provide data on the proportion of state or waiver funds for respite care specifically.

Maine received \$63 million in tobacco settlement funds during FY 2000. In FY 2001, Maine used \$11.7 million of these revenues for prescription drug coverage for the elderly and \$3.7 million to expand Medicaid services. The bulk of revenues (\$25 million) has been used to fund the Healthy Maine Program established to serve as a reserve for future health care activities. No funds have been appropriated specifically for caregiver support services.

Key informants noted that while Maine has a budget shortfall, compared to other states, there have been no major cuts to date in health or social services programs. The economic downturn has not affected the new caregiver support program. The state-funded Alzheimer's respite funds, administered through the AAAs, are being used to meet 80% of the required match requirement for the NFCSP, as long as there is not a waiting list. AAAs are required to provide 20% of the match with local funds.

PROGRAM ADMINISTRATION

The BEAS considers its role in developing and implementing the state's first caregiver support program to be oversight, policy development, funding, data collection and technical assistance. State officials commented that policy development to date has been broad in scope, emphasizing uniform data collection and flexibility in service delivery. Policies for the program are developed at the state level. Because Maine has limited experience serving family caregivers, state officials continue to encourage AAAs to be flexible and creative in meeting caregiver needs with the limited federal dollars coming to Maine.

Housed in one agency, BEAS staff administer all home and community-based care programs and support for family caregivers. State staff coordinate regularly with the AAAs' family caregiver coordinators and the Alzheimer's coordinators through an on-line listserv and regular meetings. The manager of community services also administers the new family caregiver program; a project director housed in the BEAS manages the state Alzheimer's project; and the program manager for long-term care administers care coordination for MaineCare and the state-funded Home Based Care Program.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for Maine's family caregiver support program is consistent with federal requirements under the Older Americans Act; the program is for family or informal caregivers of any age who provide care to persons 60 years and older, as well as caregivers ages 60 and older who are caring for children ages 18 or younger.^e For respite and supplemental services, the older person (age 60 or older) must need help with at least two activities of daily living (ADLs) or have cognitive or other mental impairment.

Consistent with federal policy, the family caregiver is considered the client in the program. Respondents acknowledged that this has been confusing at times to both state officials and local service providers, however, because Maine has always focused on the older adult or person with disabilities as the "consumer."

Unlike for Maine's state-funded Home Based Care Program and Medicaid and waiver services, currently there are no uniform assessment standards for the family caregiver support program. Because of the limited federal funds for caregiver support, BEAS is not yet requiring that family caregivers go through a uniform assessment process. At intake, however, when a caregiver first contacts an agency for help, the BEAS requires all AAAs to utilize a common intake form. The form was adapted from the Alzheimer's respite intake, developed by the AoA and utilized by Maine's AAAs. It focuses on both the caregiver and the care recipient. Some intakes are conducted on the telephone and some in a caregiver's home. The form includes 24 questions about the caregiver, focusing on basic demographic information (age, race, income level, employment status), length of time caregiving, number of caregiving hours per week and so on. Ten additional questions are asked about the care recipient, including how much help the care recipient needs with ADLs. None of the questions on the intake form directly ask the caregiver about his or her needs and ability to provide care. The intake data are collected by AAAs at the local level. Data are not yet aggregated at the state level, although state officials expect to do this.

^e This includes caregivers ages 60+ who are caring for children ages 18 or younger who are affected with mental retardation or who have developmental disabilities.

The care recipient is the identified client in all of Maine's state-funded home and community-based care programs, as well as in MaineCare waiver programs. Eligibility for Maine's state-funded Home Based Care Program for older persons and adults with disabilities is based on the care recipient's functional ability (i.e., help needed with one ADL plus two other ADLs, instrumental activities of daily living (IADL) or nursing). For the state-funded Alzheimer's Respite Program, a dementia diagnosis is required. Cost-sharing is mandated for all state-funded programs, based on the care recipient's income, except for the Alzheimer's Respite Program, which has no income requirements but for which the consumer must co-pay 20% of cost-of-services.

Eligibility for the Aged and Disabled Medicaid (MaineCare) waivers is based on age (60+ for the elderly waiver; 18 to 59 for the people with physical disabilities waiver), income (225% of poverty level), assets and functional criteria (Medicaid nursing home level of care). For the Consumer Directed waiver, the care recipient must also demonstrate the ability to self-direct.

In 1995, the Maine legislature adopted a policy of universal preadmission assessment for all long-term care services, including nursing facility care, specialized adult family care homes, Medicaid waivers and state-funded home and community-based care services. Key informants pointed out that the use of a standardized assessment instrument with uniform definitions and a single point of entry into Maine's long-term care system provides consumers with a comprehensive system for determining services needs and leads to more consistent assessments statewide. Maine utilizes a centralized approach to assessment and care coordination through a two-agency system: One agency conducts assessments, and another coordinates care.

The BEAS contracts with one agency, Goold Health Systems, to conduct assessments under Maine's home and community-based care system. Under state regulations, this agency may not be a provider of in-home services. Trained nurses, meeting with the consumer (i.e., client), conduct the assessment using an automated, uniform assessment tool, 'establish functional eligibility' and authorize a service plan. The in-person assessments take two and one half to three hours on average to complete. Assessment data are kept in a central data warehouse so that information can be easily accessed for policy and programmatic analyses. Bureau of Family Independence (BFI) staff determine financial eligibility for the Aged and Disabled Medicaid waivers.

Although respondents acknowledged that there is no formal assessment of the caregiver, the assessment tool does include questions on social supports available to the consumer (i.e., care recipient), including:

- ✧ Extent of help (in hours) provided to the consumer from family, friends and neighbors
- ✧ Names of two informal helpers most relied on for help with ADLs or IADLs
- ✧ Caregiver status, (e.g., primary caregiver receives help from other family/friends in caring for the consumer; caregiver is unable to continue in caring activities because of a decline in health status
- ✧ Caregiver's extent of knowledge about care

Respondents noted that the focus of the assessment in all of Maine's long-term care programs is the care recipient. The extent of informal care (i.e., whether or not the consumer has a family caregiver) is taken into account in the authorization of paid services for the consumer to supplement but not to duplicate caregiver support.

In the BEAS-administered programs, after the completion of the assessment, the nurse assessors inform the consumer of which programs he or she may qualify for. Elder Independence of Maine then arranges, pays for and manages home and community-based services statewide. Elder Independence oversees services delivered through agencies.^f Key Informants pointed out that consolidating the administration of care management for home and community-based services has saved the state about \$800,000 annually since 1996.

SERVICES

Maine offers a wide range of home and community-based services and options through its state-funded home based care and MaineCare (Medicaid) waiver programs and through the Alzheimer's respite program. Services are delivered through a network of home health, adult day services, personal care agencies and independent nurse contractors. Consumers also have the choice of hiring their own direct care worker rather than using an agency. Services include, but are not limited to, meals and shopping; housekeeping; help with bathing, dressing and eating; transportation; nursing care; physical, speech and occupational therapy; respite care; adult day services; and other services to help maintain independence.

Two of the MaineCare waivers (Aged and Disabled) offer respite care; the Consumer Directed waiver does not. Key informants noted that Maine's Aged and Disabled waivers also cover other services that can help the family caregiver, such as home modifications and adult day services. A registered nurse can provide home health services such as counseling the consumer and family on addressing nursing and related needs at home, and a social worker may provide medical social services to support the family as well as the consumer when the needs are more complex than the home care coordination agency can provide.

Family caregiver support program: The state does not mandate that each AAA provide all caregiver support services given the very limited federal NFCSP funds in Maine. Maine's AAAs are emphasizing services that the state had not provided specifically to caregivers before the passage of the NFCSP: information, assistance, counseling and training. Most of the state's five AAAs opted to provide limited respite or supplemental services under the NFCSP to augment other state funding sources that cover these service options primarily for dementia caregivers. At the time of the site visit, Maine's AAAs were utilizing various approaches to provide support to family caregivers. All of the state's AAAs opted to provide information, assistance and counseling/support groups/training.

With limited NFCSP funds and other sources of respite care funding in the state, only three of the five AAAs are offering respite reimbursement up to a cap of \$500 per year, one time only. (Each AAA determined the amount of the cap; it was not state mandated.) Two of these AAAs have annual allocations for respite of \$3,000 and \$10,000, which fund respite for only six to 20 family caregivers. In contrast, the state-funded Alzheimer's respite program caps the amount of respite per family caregiver at \$3,800 per year for respite provided in the home, by adult day services or through short-term overnight placement options. Up to \$2,000 can be used for home modifications.

^f Alpha One manages the consumer-directed programs. That agency utilizes a different system, conducting both assessments and care coordination.

AAAs also varied in their policies and procedures for supplemental services. One AAA set aside \$2,000 for one-time funding assistance for caregivers to receive skills training in personal care such as proper lifting or bathing, to purchase assistive devices (e.g., grab bars), or to obtain nutrition counseling. Two other AAAs offered limited individualized services that include home modifications, other safety needs and handyman services. Two AAAs did not offer any supplemental services as part of their package of caregiver support.

State respondents noted that federal funds for caregiver support enabled the AAAs to hire designated caregiver coordinators and to expand service delivery to family caregivers beyond respite care. Program officials are interested to see what the demand for respite care will be beyond the state funds.

Major services needed by caregivers: The ability of family members to self-identify as caregivers “so they don’t suffer in silence” was viewed as a major need. Other major service needs identified by state officials included education and training on caregiver issues, emotional support for the caregiver and, to a lesser extent, respite care. Several observers pointed out that due to Maine’s labor shortage, home care agencies have problems finding staff, especially well-trained and consistent direct care workers. Stakeholders noted the major services needed by family caregivers were information, emotional support and care management. One respondent commented that “family caregivers need validation in a way that is meaningful to them.” Other stakeholders noted that families also have the difficult challenge of finding trained and consistent workers to offer them some relief.

Regarding service delivery, at the time of the site visit (April 2002), the following services had been provided:

- ✧ About 12,330 family caregivers had received information on caregiver support and services
- ✧ 150 caregivers had received assistance in gaining access to caregiver support services
- ✧ 128 caregivers had received counseling or participated in a support group or training session
- ✧ Only one family caregiver had received respite care under this program

Table 2. Family Caregiver Support Services in Maine

Program	Family Caregiver Support Program	Alzheimer's Respite	Home Based Care ^a	Aged & Disabled Medicaid Waivers
State Administrative Responsibility	Bureau of Elder & Adult Services, Department of Human Services (DHS)	Bureau of Elder & Adult Services, DHS	Bureau of Elder & Adult Services, DHS	Bureau of Elder & Adult Services, DHS
Local Service Delivery	AAAs ^b Service providers/ contractors	AAAs Service providers/ contractors/family/ neighbors/friends	Elder Independence of Maine—case management only Service providers/ contractors	Elder Independence of Maine—case coordination only Service providers/ contractors
Funding Source	Older Americans Act, Title III-E	State general fund	State general fund	Medicaid 1915 (c) waiver
Expenditures FY 2001	\$564,300 (for all caregiver support services)	\$754,609	\$15.5 million ^c	\$19.1 million
Client Population	Family informal caregiver	Care recipient & family caregiver	Care recipient	Care recipient
Eligibility Criteria				
Age	60+ care recipient Family caregivers of any age of persons 60+ Family caregivers of children ages 18 and under if the caregiver is age 60+	18+ care recipient	18+ care recipient	60+—elderly care recipient 18–59—disabled care recipient
Income	None	No income limit Assets <\$50,000 for 1, <\$75,000 for 2	No income limit	222% of poverty levels (\$1,635/month) <Assets \$2,000
Functional Ability	For respite & supplemental services only—at least 2 ADLs or cognitive impairment for care recipient	Dementia diagnosis	1 ADL + 2 other ADLs, IADLs or nursing	Nursing home level of care

a Maine also has a small, state-funded adult day services program, funded at \$304,000 in FY 2001, that serves 119 clients.

b AAAs = Area Agencies on Aging

c About \$3.1 million, or 20% of funds, were expended for consumer-directed home care.

Table 2. Family Caregiver Support Services in Maine (continued)

Program	Family Caregiver Support Program	Alzheimer's Respite	Home Based Care ^a	Aged & Disabled Medicaid Waivers
Uniform, Statewide Caregiver Assessment	No (Uniform intake only)	No (Uniform intake only)	No (Uniform care recipient assessment only)	No (Uniform care recipient assessment only)
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies) ^d	Respite care Information Assistance Counseling Education Referrals Home modification	Respite care	Respite care
Respite Cap	Varies by AAA up to \$500/year	\$3,800 per year	No	No
Consumer Direction	Yes	Yes	Yes	Yes
Family Caregivers Paid as Respite Providers	Yes	Yes	Yes	Yes

Source: Key Informant interviews and *State of Maine – State and Medicaid Long-Term Care Expenditures*, www.state.me.us/dhs/beas/lc/lc-exp-97-01.htm.

^d All services are provided in Maine. Not all AAAs offer all services, however. All AAAs provide information, assistance and counseling/support groups/training.

CONSUMER DIRECTION

Maine has a long tradition of offering consumer direction in both its state-funded and waiver programs, allowing consumers to choose and hire their own personal care attendant or respite worker, including family or friends. One key informant noted that 67% of in-home respite care under the state-funded Alzheimer's respite program is provided by family, friends or neighbors.

Family members can be paid to care for their elderly or disabled relatives at home in Maine's Aged and Disabled Medicaid waivers ^a as well as in the state-funded home based and Alzheimer's respite program with the following restrictions: Spouses or parents of minor children cannot be paid under the Medicaid waivers in keeping with federal regulations.

In Maine, family caregivers do not have to live with the consumer to be paid to provide care. Maine has neither established qualifications for family members to be paid that differ from formal caregivers (i.e., personal care assistants) nor required criminal background checks for family caregivers when the consumer hires the family member directly.

Under the state's MaineCare Aged and Disabled waivers only, the state also allows home care agencies to hire the consumer's relatives or friends to provide care, under limited circumstances, such as when the family lives in a rural area. In this option, families are paid through the agency, which is their employer, and the family member is required to have the same training as a regular personal care assistant hired through an agency and to undergo a criminal background check.

Under the new NFCSP-funded family caregiver support program, the state permits direct payments to family caregivers. Family caregivers can be paid regardless of whether they live with the older person or not. Spouses are not permitted to be paid, however, to be consistent with other programs.

QUALITY ASSURANCE AND EVALUATION

To date, the state is utilizing only AoA's data collection requirements for the family caregiver support program: type of service to caregiver (e.g., information, counseling), number of caregivers served by type of service, units of service provided (e.g., information contact, respite hours) and expenditures per service type. While state officials would like AAAs to report on the time spent providing services to family caregivers in each service category, this reporting item is currently optional, except for respite and supplemental services, to be consistent with current federal reporting requirements. Key informants noted that Maine is minimizing what the AAAs now collect and expressed concerns about future data collection requirements, "switching gears" and the impact on their automated client tracking system.

^a Under the Consumer Directed waiver, family members can be paid only to provide personal care. Respite care for caregivers is not covered.

Performance measures are collected once a year by surveys. Maine's legislature requires that all state social service programs collect outcome data. Given the early stages of development of the caregiver support program and the lack of overall guidance nationally, state leaders acknowledged that they don't yet have a clear method for evaluating the program or examining caregiver outcomes. Bureau of Elder and Adult Services respondents commented that, as the program gets off the ground at the local level, they will, at a minimum, be examining level of demand for caregiver support services.

Under the Medicaid waivers, no data are collected on caregiver outcomes. One respondent commented that Maine is a small state and that consumers themselves often call the state or home care coordination agency to express their satisfaction or dissatisfaction with services. (See also the section on Program Eligibility/Assessment Process for specific caregiver information collected by the state-funded programs, Medicaid waivers and new family caregiver support program.)

SYSTEMS DEVELOPMENT

Although the state has a history of long-term care reform, family caregiver needs have not been part of this debate. State leaders and stakeholders view the family caregiver support program as a new initiative with a new constituency group. At the time of the site visits, Maine had not yet completed the first year of program implementation.

One state agency, BEAS, administers Maine's long-term care system and family caregiver support program. The relatively small-scale Alzheimer's Respite Program and the even smaller new federally funded family caregiver support program are being operated separately from the long-term care system, however. For example, these programs are not required to utilize the state's standard in-home assessment, mandated for the other home and community-based programs, including Medicaid waivers. Respondents commented that they could in this way preserve local flexibility and eliminate often complicated issues such as incompatible service definitions, reporting requirements or client identification (i.e., the care recipient or family caregiver).

Some observers noted that family caregiver support services and services under the Alzheimer's Respite Program are integrated in a few of the AAAs; in others they are separate. Another respondent commented that the new family caregiver support program has not been consistently implemented at all of Maine's AAAs. When the family caregiver support program was initiated, respondents indicated that there was not so much concern about competition between the two programs, but rather there was an attempt to avoid confusion because the programs are tied so closely in terms of purpose and mission. State leaders acknowledged that their intent is to build on the Alzheimer's programs and not to overlap or duplicate efforts. To encourage systems development of caregiver support services at the local level, the state has strongly recommended that in each AAA, the family caregiver coordinator and the Alzheimer's coordinator work together. If a person has Alzheimer's disease, for example, staff are to direct the consumer and his or her family caregiver first to the state-funded Alzheimer's Respite Program and then to the more limited resources under the new federally funded family caregiver support program.

Maine does not have a body whose mission is coordination of family caregiver support services across state departments. All support to families of older persons is administered through the BEAS. At the local level, AAAs are viewed as the service coordinators for caregiver support.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

Maine's *Olmstead* initiative has been a collaborative process through the Plan Development Workgroup for Community-Based Living, involving representatives from five state departments (Human Services, Behavioral and Developmental Services, Education, Labor and Corrections) and a broad cross-section of consumer representatives, including some family caregivers. The goal is to develop a community integration plan that fills the gaps in the existing community services system. The workgroup has been meeting for two years, and a report is expected to be prepared in the fall of 2002. Maine's Real Choice Systems Change grant will attempt to implement the recommendations from this interdepartmental planning effort. Key informants were uncertain as to how much attention would be paid to family caregiver issues in the state plan.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, "Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?" As shown here, the key informants interviewed felt that overall, Maine tended to place a "low-medium" priority on caregiver support services. State officials agreed that there was a "low-medium" priority, while one stakeholder indicated a "low" priority and the other a "low-medium" priority. One stakeholder did not respond.

Number of Key Informants	Priority on Caregiver Support
1	No response
1	→ Low
3	→→→ Low - Medium
1	→→→→→ Medium

Benefits and challenges: Maine's key informants identified three aspects of their program that are most beneficial to family caregivers:

1. Having a funding source (i.e., NFCSP) with a broader range of services focused on the caregiver rather than just respite care (e.g., counseling, support groups)
2. Being able to publicize the issue of family caregiving so that families can recognize that they are caregivers
3. Having a contact person at the local level to whom the caregivers can talk about their needs

When asked to identify the three main challenges for implementing family caregiver support programs in the state, Maine key informants noted the following:

- ❖ Making the new federal program "fit in" with other state-funded programs (i.e., Alzheimer's respite and state-funded home based care)
- ❖ Helping family caregivers understand that they *are* caregivers and asking for help earlier in the disease process

- ✧ Identifying outcomes measures to see if the program is making a difference
- ✧ Identifying equitable ways to allocate support to family caregivers—that is, assessing the needs of caregivers while maintaining the interests and needs of the consumer (i.e., older person or adult with disabilities)
- ✧ Dealing with a labor shortage resulting in a lack of trained direct care providers

Major lesson learned: The view of Maine’s state leaders is that the “best interests” of the consumer do not always align with those of the family caregiver. As the state expands its program of caregiver support, the challenge, as expressed by one observer, will be to keep in mind “who is the customer.” In Maine, the state has traditionally sided with the older person or the adult with disabilities, and this perspective has “not always endeared us to the family or other agencies,” said one state leader.

Other lessons learned in the first year of program implementation identified by the respondents included the needs to try to maintain flexibility as the program grows and to recognize that family caregiver support cannot be provided using volunteers. One respondent from the Medicaid waiver program pointed to the need to put parameters on respite care, either by limiting the number of hours or by requiring that the caregiver live with the consumer to receive benefits.

Opportunity for expanding caregiver support: In general, Maine respondents did not view their state as expanding state-funded programs to support and strengthen family caregivers over the next three to five years. Maine, like most states, is experiencing another budget crisis. This makes program expansion with state revenues unlikely. One observer noted that another budget crisis began Maine’s process of long-term care reform a decade ago, however. With rising expectations, baby boomers will demand good-quality care for their parents and themselves. Respondents believed that caregiver issues will be addressed in the longer term.

Recommendations for other states: When asked what recommendations they would make to other states that are developing programs to support family caregivers, Maine’s respondents had many suggestions, including:

- ✧ Involve all stakeholders from the beginning to get their input and ideas.
- ✧ Ensure flexibility in service design and delivery at the local level, while maintaining consistency in assessment, eligibility and data collection across the state.
- ✧ Think through the parameters of the program before implementation.
- ✧ At the state level, identify a lead person to manage the program who has a history of good relationships with the AAAs; at the local level, hire caregiver coordinators with excitement and “fresh eyes.”
- ✧ Have a system in place to accommodate the demand for services (i.e., address workforce issues).

NOTES

- 1 State of Maine, www.state.me.us/legis/senate/statehouse/facts/facts.htm.
- 2 U.S. Census, www.census.gov/stateab/www/ranks.html.
- 3 AARP, *Reforming the Health Care System: State Profiles, 2001* (Washington, D.C.: AARP, Public Policy Institute, 2000).
- 4 U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrel/spi0401.htm (2001).
- 5 MapStats-Maine, www.fedstats.gov (June 2002).
- 6 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.
- 7 Maine Development Foundation, 2001 Survey of Maine Citizens.
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- 9 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusxrace-ho.html.
- 10 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html (2000).
- 11 P. Arno and M. Memmott, *Estimated Value of Informal Caregiving: Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
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- 13 State of Maine, www.state.me.us/bms/admin/sfy2001.pdf.
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PENNSYLVANIA

OVERVIEW

Pennsylvania is a moderately sized, densely populated mid-Atlantic state with less racial and ethnic diversity than the country as a whole. The Commonwealth of Pennsylvania is relatively unique in that it has the largest rural population of any state, yet it is the sixth most populous state in the nation.¹ In addition, Pennsylvania has the third-highest percentage of older persons in the country. The state's long-term care system has emphasized the provision of home and community-based services and has recently focused on expanding access to these services. State-only-funded programs for the elderly and for persons with disabilities have existed since 1987 and have received significant funding increases in recent years.

Pennsylvania's state-funded program to provide caregiver support began in 1987 with a demonstration program that went statewide in 1991. It was one of the models on which the National Family Caregiver Support Program (NFCSP) was based. When the program was first developed, it was a separate initiative, but it evolved over time into a more integrated system of caregiver support. While the infusion of federal funds has allowed the state to serve more caregivers, it has also allowed them to serve a broader range of needs that complement existing core services. The state's caregiver support services are characterized by:

- ❖ Centralized policymaking and administration with statewide policies and standards to ensure a consistent approach to caregiver support
- ❖ Fully integrated programs and services that are seamless to consumers (i.e., family caregivers and care recipients)
- ❖ Flexibility to meet the individual needs of family caregivers at the local level

Pennsylvania respondents noted that the major service needs of family caregivers are (1) respite care, (2) supplemental services (e.g., consumable supplies, home modification) and (3) personal care (e.g., hands-on help with activities of daily living, or ADLS).

INTRODUCTION

Pennsylvania is an "old" state, meaning that it had a long-time state general fund program providing caregiver support before the passage of NFCSP. The project team conducted a site visit between May 2 and 3, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies interviewed include:

Pennsylvania Department of Aging, Division of Quality Management and Long-Term Care

- ❖ Caregiver Support Program (NFCSP funded and state funded)
- ❖ OPTIONS (State lottery funds)
- ❖ Bridge (Tobacco settlement funds)
- ❖ Aged Medicaid waiver

Pennsylvania Department of Public Welfare, Bureau of Long-Term Care

- ✧ Aged Medicaid waiver

Stakeholders interviewed were from:

- ✧ Pennsylvania Association of Area Agencies on Aging
- ✧ Alzheimer's Association, Greater Pennsylvania Chapter

Five programs are featured, all of which are administered by the Pennsylvania Department of Aging:

1. Pennsylvania Family Caregiver Support Program
2. National Family Caregiver Support Program
3. Bridge program
4. OPTIONS program
5. Aged Medicaid waiver

BACKGROUND

Pennsylvania is a moderately sized, densely populated mid-Atlantic state with a population of 12.3 million residing in 67 counties.²

The state has a mix of major metropolitan and rural areas, with fewer minorities and low-income populations than the nation as a whole. Pennsylvania has 14.6% its of residents living in nonmetropolitan areas, compared to 21.8% in the nation as a whole, although it has in absolute terms the largest rural population.³ In 2000, personal income per capita was \$29,504, nearly the same as the national average of \$29,676.⁴ About 10.9% of Pennsylvania's population live below the federal poverty level (vs. 13.3% U.S.).⁵ Pennsylvania ranks 29th nationally in percentage of households with Internet access.⁶ Although the state's African-American population does not vary significantly compared to that of the U.S. (10.0% vs. to 12.3% U.S.), Pennsylvania has less racial and ethnic diversity than the nation as a whole (85.4% Caucasian compared to 75.1% U.S.)⁷ (table 1).

An estimated 2,430,821 persons in Pennsylvania, or 19.8% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Pennsylvania ranks third nationally in the number of older persons (ages 60+) residing in the state.⁸ The state's lower racial and ethnic diversity is also present in the 60+ population. African Americans ages 60+ are 6.7% of the population (vs. 8.4% U.S.). For Hispanics, however, the percentage drops to 0.9% (vs. 5.4% U.S.).⁹

Pennsylvania ranks seventh nationally in the proportion of its population ages 85 and older. In 2000, 237,567 persons, or 1.9% of Pennsylvania's population, were ages 85+.¹⁰ While Pennsylvania already ranks high in the percentage of older persons, that percentage is likely to increase because of the state's faster-than-average growth in the aging population. This trend may be explained by the state's relatively slow population growth as compared to that of the nation as a whole (0.1% vs. 5.2% U.S.).¹¹

An estimated 1,202,411 family caregivers reside in Pennsylvania. These family caregivers provide about 1,119 million hours of caregiving per year at an estimated value in 1997 of \$9.16 billion.¹²

Pennsylvania has a relatively well funded system of home and community-based services, using a variety of resources to pay for program implementation and expansion. Of note are the significant funding increases—more than \$100 million each year from FY 1996 to FY 2001—that Medicaid waiver programs have received.¹³ The legislature appropriated \$45 million in tobacco settlement funds to expand the number of Medicaid waiver slots and fund other home and community-based services.¹⁴ Additionally, Pennsylvania is the only state in the nation to have earmarked all proceeds from its state lottery exclusively for services assisting older persons.

Table 1. Selected Characteristics of PENNSYLVANIA and the UNITED STATES, 2000 ^a

	Pennsylvania	United States
Total Population Characteristics		
Total Pop. ^b	12,281,054	281,421,906
% African American ^c	10.0%	12.3%
% Hispanic ^d	3.2%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	2,430,821	45,797,200
% 60+ ^f	19.8%	16.3%
National ranking 60+ ^g	3	NA
Pop. 65+ ^h	1,919,165	34,991,753
% 65+ ⁱ	15.6%	12.4%
National ranking 65+ ^j	2	NA
Pop. 85+ ^k	237,567	4,239,587
% 85+ ^l	1.9%	1.5%
National ranking 85+ ^m	7	NA
% increase 1990–2000 60+ pop. ⁿ	-0.2%	9.4%
% White (60+) ^o	91.2%	82.4%
% African American (60+)	6.7%	8.4%
% Hispanic (60+)	0.9%	5.4%
% Asian (60+)	0.7%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.1%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	1,202,411	25,798,370
Caregiving hours (millions) (1997)	1,119.2	24,013.1
Value of caregiving (millions) (1997)	\$9,155.1	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$29,539	\$29,676
% of pop. below poverty (1997) ^r	10.9%	13.3%
Internet		
% of households w/Internet access (2001) ^s	40.1%	41.5%
Nat'l ranking of households w/Internet access	29	NA

a Unless otherwise noted, all data are from 2000.

b Mapstats-Pennsylvania, *www.fedstats.gov* (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r Mapstats-Pennsylvania.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two agencies: the Pennsylvania Department on Aging (PDA) and the Pennsylvania Department of Public Welfare (PDPW). Programs administered by PDA make use of several sources of funding, including federal matching funds, state general revenue, state lottery and tobacco settlement dollars. The Pennsylvania Family Caregiver Support Program is the only PDA program funded through state general funds; however, a significant portion of PDA's budget is financed through the state lottery.¹⁵ Pennsylvania has also committed 13% of its tobacco settlement to fund home and community-based services.

The PDA is a freestanding department, serving as the State Unit on Aging and administering the provisions of the federal Older Americans Act, including the new NFCSP, as well as the state-funded Family Caregiver Support Program (FCSP). The governor appoints the secretary, who has cabinet-level status.

The infrastructure of Pennsylvania's aging network is a statewide system of 52 Area Agencies on Aging (AAAs) that serve Pennsylvania's 67 counties. The state's AAAs provide assessment and case management for all PDA programs, including the Aged Medicaid waiver, NFCSP, state-funded FCSP, OPTIONS, Bridge and other Older Americans Act programs. AAAs may also provide directly or by subcontract services such as transportation, legal assistance, home support, home-delivered meals and long-term care ombudsmen. AAAs are either units of county government or private, nonprofit corporations.¹⁶

The PDPW is responsible for oversight of Medicaid programs and services as the single state agency for Medicaid. Of Pennsylvania's 11 home and community-based Medicaid waivers, the PDPW administers 10.^a The PDPW contracts with the PDA to administer the Aged Medicaid waiver,^b which provides services to about 7,300 aged beneficiaries in the state (7,400 total slots). In addition to receiving federal funds, the state has funded an expansion of 1,000 waiver slots with tobacco settlement monies.

In 2002, the PDPW was awarded a \$1.4 million Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The goal of the grant is to expand or improve community-integrated services for the disabled or for those with a long-term illness.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT^c

Pennsylvania has both an integrated and a well-developed system of home and community-based services. Other PDA-administered programs that provide some services to support family and informal caregivers include OPTIONS, Bridge and the Aged Medicaid waiver.

Pennsylvania's FCSP was developed in 1987 as a result of inclusion in the campaign platform of former Governor Bob Casey (D).^d The demonstration was expanded to nine additional sites in 1989 and went statewide in 1991. The support for this program and other aging services continued through the term of Tom Ridge (R), who left office in 2001, and the term of current Governor Mark Schweiker (R). Key informants indicated that the FCSP "is, hands down, the most popular program we've ever had."

Pennsylvania has fully integrated the FCSP, initially conceived as a stand-alone program, into its other long-term care programs. Noted one key informant, "Family caregiver programs are integral parts of the long-term care system, and they shouldn't be held separate from the rest of the long-term care system."

When the NFCSP was implemented, Pennsylvania used the program to supplement and expand access to services under its state-funded programs. According to key informants, the state and federally funded programs are administered to "appear as if they are one program out in the field." That is, consumers are "blind" as to the funding source of the services they are receiving. This historical focus on integrated, flexible programs within the state's home and community-based services was a common theme cited by many respondents.

a Pennsylvania has 11 home and community-based service waivers, including Infants, Toddlers, and Families Waiver; Consolidated Waiver for Individuals with Mental Retardation; Person/Family Directed Support Waiver; Attendant Care Waiver; Independence Waiver; OBRA Waiver; AIDS Waiver; Michael Dallas Waiver; Elwyn Waiver; Aging Waiver; and Long-Term Care Capitated Assistance Program.

b In Pennsylvania, the Aged Medicaid waiver is referred to as the Pennsylvania Department of Aging (PDA) waiver.

c The overview of the State system of caregiver support includes information on Program Background and Development. Additional background information on Pennsylvania's programs serving family and informal caregivers can be found in Family Caregiver Alliance's October 1999 study *Survey of Fifteen States' Caregiver Support Programs: Final Report*.

d See the Family Caregiver Alliance 1999 study *Survey of Fifteen States' Caregiver Support Programs: Final Report* for further details on development of caregiver support in Pennsylvania.

Pennsylvania also provides some caregiver support services, such as respite care, through its OPTIONS and Bridge programs. OPTIONS, created in 1989, provides a wide range of both facility-based and home and community-based services, mostly to older, frail Pennsylvanians. There is no income eligibility requirement for OPTIONS; however, there is a sliding-scale cost-share requirement. The Bridge program, which began providing services in January 2002, provides home and community-based services to those who need a nursing home level of care but do not meet the asset test associated with the state's Aged Medicaid waiver. Consumers are required to make a 50% cost-share, with the expectation that they will draw down their assets and eventually qualify for waiver services.

Pennsylvania's Aged Medicaid waiver began in 1995 as a way to slow the growth in nursing homes and includes respite care as one of its benefits. Respondents indicated that other benefits, such as home support, environmental modifications and personal care, also help family and informal caregivers, although this may not be explicitly stated.

When asked if family and informal caregivers are recognized as a central component of a comprehensive long-term care system, key informants agreed that they are, citing the wide variety of programs providing services to family caregivers as evidence of this. Further, family and informal caregivers are explicitly recognized in Pennsylvania statute, the legislation that created the state's caregiver support program, and in a set of regulations that are a part of Pennsylvania code.^e The PDA also employs a staff person whose responsibilities include coordinating the NFCSP and the state-funded FCSP.

Most rewarding: Key informants cited the reward of seeing families benefit from services but also noted that flexibility built into the new federal program was very positive. According to one key informant, the U.S. Administration on Aging (AoA) was "so respectful of our program in the design of the federal program...it's effectively allowed us to do the kind of things that we wanted to localize the program without having to reopen the state legislation, which is a major act within itself...[We] used the federal program to empower us to do things that we couldn't do before." Respondents also noted the ability to allow people to live out more of their lives at home and the cost-savings associated with supporting home and community-based care, as opposed to nursing home care, as rewarding program aspects.

Biggest challenge: Key informants indicated three challenges: (1) the difficulty in implementing and processing a system of cash payments when the FCSP program began, (2) Medicaid estate recovery provision and (3) the difficulty in keeping the number of Medicaid waiver slots ahead of demand. Regarding cash payments, state officials noted that AAA staff encountered some complications when implementing the system. They ascribed the difficulty to the shift in the way AAAs had traditionally provided services and also to the responsibility to provide the necessary education to consumers about how to invoice for services.

^e The Pennsylvania code referencing the state-funded caregiver support program can be found in Pennsylvania Code Title 6, Chapter 20.

FUNDING

For FY 2001–02, Pennsylvania expended \$9.3 million on the state-funded FCSP. In FY 2002, the state received \$6.9 million for the NFCSP with the PDA contributing \$2.1 million for the required state match. Combined, the FCSP and NFCSP provide less than 3% of the PDA’s overall budget. The PDA does not provide specific funding levels for their other home and community-based programs, such as OPTIONS and Bridge. The PDA block grants funds for these services and then requires that the AAAs spend a certain amount of the funds for in-home services. For FY 2001–02, the PDA block grant to the AAAs is \$288 million. Of this, AAAs were required to spend at least \$158 million, or about 22% of PDA’s total budget, providing in-home services.

Exhibit 1. FY 2000–01 PDA Block Grant Expenditures by Service ^a

	Expenditure	Consumers Served
Adult Day Care	\$11.51 million	3,747
Attendent Care	\$3.02 million	174
Consumer Reimbursement	\$8.70 million	5,554
Environmental Modifications	\$1.83 million	1,697
Home Support	\$4.87 million	10,313
Overnight Supervision	\$242,677	208
Personal Assistance Services	\$5.86 million	1,722
Personal Care Services	\$42.24 million	22,417

For FY 2000–01, total expenditures for the Aged Medicaid waiver were \$63.7 million, serving a total of 7,464 consumers. PDA does not specifically break down expenditures for respite care. Instead, it accounts for services in categories that include attendant care, adult day health and overnight supervision. (No data were available for FY 2001-02 expenditures.)

Exhibit 2. FY 2001–02 Aged Medicaid Waiver Expenditures by Service

	Expenditure	Consumers Served
Adult Day Care	\$3.47 million	1,127
Attendent Care	\$5.91 million	1,372
Environmental Modifications	\$266,024	192
Home Support	\$2.54 million	1,090
Overnight Supervision	\$2.44 million	809
Personal Assistance Services	\$361,000	2,280
Personal Care Services	\$26.89 million	4,366

^a Services funded through the block grant may also receive funding from other sources, such as cost-sharing.

Pennsylvania has made use of a variety of funding sources for its home and community-based services. In FY 2001, the state received about \$398 million in tobacco settlement funds. Of these funds, the legislature appropriated almost \$45 million (13% of annual tobacco settlement revenue) in new, annual funding for home and community-based services.¹⁷ In FY 2002, Pennsylvania received nearly \$478 million in tobacco funds, again earmarking 13% for home and community-based services. Pennsylvania is also the only state in the nation that exclusively targets state lottery fund proceeds to pay for services supporting older persons. OPTIONS is exclusively funded by the Pennsylvania state lottery, whereas the Bridge program is funded by tobacco settlement monies.

Key informants described the current budget situation in Pennsylvania as “not bad.” Challenges due to the economy include a leaner budget (no cost-of-living adjustment included for the current budget year) and difficulty growing programs, particularly in expanding home and community-based services. Key informants cited utilization of tobacco funds for long-term care as one reason that short-term financial problems were not as dire in Pennsylvania as in other states. Another reason is that savings in Medicaid due to reduced nursing facility utilization have been significant.

PROGRAM ADMINISTRATION

In Pennsylvania’s current system of support, the 52 AAAs coordinate caregiver services at the local level. At the state level, services are coordinated through regulations, directives, training and periodic inquiries to AAAs regarding resource reallocation. State officials identified two major roles that the PDA plays with regard to caregiver support services. The first is to administer the state and federal caregiver programs, in addition to administering the Aged Medicaid waiver. The second is to “feed” families into the waiver where appropriate. Policy development and program administration are centralized at the state level, with a strong focus on integrated assessment, service delivery and single point of entry at the AAA level. According to key informants, the agency has worked “to redirect the program...to make it more like a part of the long-term care system rather than a freestanding program.” PDA officials described their relationship with the AAAs as a democratic one and indicated that they work “hand-in-glove” with the Pennsylvania Association of AAAs (P4A). State officials indicated that they intentionally keep policies and standards broad to allow AAAs to meet local and individual needs. They noted, however, that some AAAs occasionally narrow the parameters set by the PDA. Whereas the PDA encourages any service that will prolong or enhance the caregiver relationship (i.e., purchasing a washer and dryer for an arthritic caregiver who was hand washing clothes; allowing a caregiver to bank respite benefits and go on vacation), some AAAs have preferred “stricter” program guidelines. One key informant ascribed the narrowing of parameters to accounting challenges or simple disagreements over the “politics” of providing so much flexibility for consumers.

The OPTIONS and Bridge programs are administered by the PDA and the AAAs. Home health agencies and other service providers have contracts with the AAAs to provide services.

With regard to the Aged Medicaid waiver, the PDA is responsible for administering the program. Officials of the PDA indicated that they try to get “buy-in” from the various stakeholders and usually assist PDPW and the AAAs in achieving consensus in the process of developing guidelines and policies. Respondents from the PDA stated that they see themselves in the role of policy brokers, rather than as policymakers.

The PDA has focused resources on publicizing caregiver support services by creating two websites—a comprehensive long-term care site as well as the PDA site. Additional publicity includes speaking engagements throughout the state to increase awareness of caregiver needs and the NFCSP. With regard to the Aged Medicaid waiver, state officials have focused on marketing home and community-based services as a product line, rather than as a set of stand-alone services.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Pennsylvania's caregiver support and home and community-based programs are based on an integrated care management model at the AAA level. In this effort, the PDA uses programs to complement each other, and a consumer who does not meet eligibility for one program often may use similar services from another program with different eligibility criteria.

Regarding assessment, Pennsylvania incorporates caregiver information as part of its comprehensive assessment instrument used for all of the home and community-based care programs administered by PDA.¹⁸ The assessment includes measures of caregiver burden and stress, as well as of the ability and capability of the caregiver to assist the care recipient.

Each AAA administers the uniform assessment instrument directly, although state officials cited the possibility that a small number of AAAs may contract out this service. Assessments are conducted in person, usually in the home. Reassessment is generally done every six months, although the standard is “as needed.” The PDA is currently in the process of revising its assessment instrument.

The care plan is based on the assessor's determination of need. Once needs have been established, the assessor determines which of the PDA's home and community-based service programs is most appropriate for the situation. The intent of the care plan and the resulting services is to enhance, preserve and prolong the caregiving relationship. Key informants noted that there was at one time in the state-funded FCSP a movement to exclude assessing the care recipient at all and to focus only on the caregiver. This changed, however, as the program moved from a stand-alone set of services to a more integrated part of the state's long-term care system as a whole.

Eligibility for PDA programs are as follows:

State-funded FCSP: Family or informal caregivers of any age who provide care to persons 60 years or older or to persons of any age with a diagnosis of dementia. The care recipient must have one ADL deficit. Although the NFCSP requires that the care recipient be unable to complete two ADLs rather than only one ADL, as in the state program, a PDA respondent noted that “It is a distinction without a difference...My experience is that ADLs come in pairs, usually.” The respondent also pointed out that, in addition to the ADL deficits of the care recipients, many of the caregivers served have some instrumental activities of daily living (IADL) deficits.

There are no income requirements for “soft,” or core, services (i.e., support groups, caregiver education and training, etc.). Income requirements do exist for “hard” services (i.e., respite and consumable supplies). If income exceeds 380% of poverty level, no reimbursement for hard services is provided. For incomes between 380 and 200% of poverty level, Pennsylvania uses a sliding scale. Consumers below 200% of poverty level are entitled to reimbursement for the full amount of services, within a \$200 cap.

The assessment is uniform, and both the family caregiver and the care recipient are considered the client in the program.

NFCSP: Family or informal caregivers of any age who provide care to persons 60 years or older, as well as caregivers ages 60 and over who care for children ages 18 or younger.^f The care recipient must have at least two ADL deficits. There are no income requirements for “soft,” or core, services. The same sliding scale used for the FCSP is used for the NFCSP.

OPTIONS: Care recipients ages 60 or older who have “some frailty” in their physical or mental health status.¹⁹ There are no financial eligibility requirements for OPTIONS; however the program has a sliding-scale cost-sharing component. The assessment is uniform across the state, and the care recipient is the identified client in the program.

Bridge: Care recipients ages 60 or older who require a nursing facility level of care. Net incomes must be less than \$1,635 per month, with assets of at least \$2,000 but not more than \$40,000.

The assessment is uniform across the state, and the care recipient is the identified client in the program.

Aged Medicaid waiver: Care recipients ages 60 or older, disabled (according to the AAA functional review) or meeting the medical criteria for Medicaid nursing home level of care. The care recipient cannot exceed \$2,000 in resources, and income is limited to 300% of the Federal Benefit Rate (\$1,593 per month as of August 2001).

Consistent with Medicaid policy in general, respondents noted that the care recipient is the identified client, and the extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. The assessment instrument maximizes informal supports to the extent possible before including other services in a care plan. Respondents acknowledged that utilizing informal care is an important part of staying within the Medicaid waiver cost cap (80% of nursing home costs). Further, they noted that a family caregiver’s needs and ability to provide care are formally assessed, as are the needs of the care recipient, although they acknowledged that the assessment tool is focused more on the care recipient.

The PDA recently implemented a system of cost-sharing. Before the system was implemented, cost-sharing had always been included in the FCSP but not required in other community-based long-term care programs, such as OPTIONS. AAAs did have the flexibility to apply cost-sharing to their programs, and 26 of the AAAs had some level of cost-sharing. As of January 1, 2002, the PDA required that all AAAs cost-share—using the same standard—for consumers whose income is above 125% of the federal poverty level, currently \$923 for one person or \$1,244 for a couple. PDA staff noted that two-thirds of the people they serve are under 125% of the poverty level.

^f This includes caregivers ages 60+ who are caring for children affected with mental retardation or with developmental disabilities.

SERVICES

Rather than focus on one specific service category within the FCSP or NFCSP, the state emphasizes the flexibility that each AAA has to meet individual consumer needs. Consumers determine what they need and are then reimbursed for everything from respite care to consumable supplies. Reimbursement is typically limited to \$200 per month, but AAAs can reimburse for costs as high as \$500 as long as their caseload average does not exceed \$300. Describing the program, one state official said that “there is no menu [of services]. It’s what the consumer wants. The program can literally be reinvented every time it goes into a new family...That’s the beauty and the secret of our program.” The program does strictly prohibit reimbursement for prescription drugs because of the recent enactment of a state-subsidized prescription drug program.

Some of Pennsylvania’s AAAs provide direct services, whereas others contract out these services. Typically the services AAAs provide include information and assistance, assessment and case management. PDA staff indicate that “soft,” or core, services—such as counseling and support groups—are not as highly utilized as “hard” services, such as reimbursement for respite care. In addition to the \$200 monthly cap, reimbursements are available for home modifications and assistive technology, with a lifetime maximum of \$2,000. Key informants stated that “We don’t want to be a housing program, but we do want to incorporate technology where it’s appropriate, and...[we] do so a little more liberally than the federal [NFCSP] program.”

Respondents indicated that if a particular AAA overspends its caregiver support program funds, then that AAA will put clients on a waiting list. State officials said this is relatively rare, however. Further, if a consumer needs additional services above the cap, other programs may provide some assistance. In fact, key informants said that they have “many arrows in their quiver” that allow them to replicate family caregiver support services in other programs.

For respite care, caregivers can purchase services in any setting they choose and can hire friends (but not family members) as providers. Caregivers also have the option of banking respite benefits in order to take a vacation or for other reasons.

With regard to the Aged Medicaid waiver, many of the same services are available as in other PDA programs. Key informants indicated that caregiver education and training could be provided under the “care management” component. The only service cap that exists relates to the overall requirement that Medicaid waiver services must be no more than 80% of nursing home costs; it is not a cap on a specific service, such as respite care. Covered respite services include in-home respite assistance, adult day health services, overnight respite in a facility and access to respite weekends. Key informants described the program as having more statewide standards than under the state and federal family caregiver support programs administered in Pennsylvania. Waiting lists do not exist for Medicaid waiver services.

Services provided within PDA programs include the following:

NFCSP: \$200 monthly reimbursement for caregiver-identified services and supplies; \$2,000 reimbursement (lifetime maximum) for home modification or assistive technology; caregiver education and training; support groups and other “soft” services.

State-funded FCSP: \$200 monthly reimbursement for caregiver-identified services and supplies; \$2,000 reimbursement (lifetime maximum) for home modification or assistive technology; caregiver education and training; support groups and other “soft” services.

OPTIONS: Respite care; home modifications; home support activities.

Bridge: Respite care; home modifications; home support activities.

Aged Medicaid waiver: Respite care; home modifications; home support activities.

Major services needed by caregivers: At PDA, respite was identified as the major service category needed by family caregivers. Medicaid officials indicated that personal care, such as hands-on help with ADLs, was the major service needed.

Table 2. Family Caregiver Support Services in Pennsylvania

Program	Pennsylvania FCSP and NFCSP	OPTIONS	BRIDGE Program	Aged/Disabled Medicaid Waiver
State Administrative Responsibility	Pennsylvania Department of Aging	Pennsylvania Department of Aging	Pennsylvania Department of Aging	Pennsylvania Department of Aging
Local Service Delivery	AAAs ^a —information, education, assistance, assessment & case management	AAAs—information, education, assistance, assessment & case management	AAAs—information, education, assistance, assessment & case management	AAAs—assessment & case management only
Funding Source	State general funds, ^b Older Americans Act, Title III-E	State lottery funds	Tobacco settlement funds	Medicaid 1915 (c) waiver
Expenditures FY 2001-02	FCSP—\$9.3 million NFCSP—\$6.9 million	NA ^c	NA ^d	\$63.7 million ^e
Client Population	Family caregiver, care recipient	Care recipient	Care recipient	Care recipient
Eligibility Criteria				
Age	Family caregivers of any age of persons 60+ ^f	60+ care recipient	60+ care recipient	60+ care recipient
	Family caregivers of care recipient of any age with dementia diagnosis (FCSP only)			
Income	None	No income eligibility	\$1,635 or less in income; assets between \$2,000 and \$40,000	\$2,000 (assets) 300% of federal poverty rate ^g
Functional Ability	1 ADL need (FCSP) 2 ADLs needs (NFCSP)	Nursing home level of care	ADL or IADL deficiency	Disabled ^h or nursing home level of care
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes	Yes

a AAAs = Area Agencies on Aging.

b These funds are for Pennsylvania's state family caregiver support program.

c Pennsylvania does not budget specifically for this program but rather block grants the funds to the AAAs, which allocate among various programs providing home and community-based services.

d Ibid.

e FY 2000-01.

f Eligibility for the NFCSP also includes caregivers ages 60 and older who are caring for children 18 or younger, including those affected by mental retardation or with developmental disabilities.

g Federal poverty level was \$1,593/month as of August 2001.

h Disability must be assessed according to AAA functional review.

Table 2. Family Caregiver Support Services in Pennsylvania (continued)

Program	Pennsylvania FCSP and NFCSP	OPTIONS	BRIDGE Program	Aged/Disabled Medicaid Waiver
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite care Home modifications Home support activities	Respite care Home modifications Home support activities	Respite care Home modifications Home support activities
Respite Cap	\$200 per month ⁱ	No	No	No specific cap— total expenditures per recipient must be less than 80% of nursing home cost
Consumer Direction	Yes	Yes	Yes	Yes
Family Caregivers Paid as Respite Providers	No	Yes (not spouses)	Yes (not spouses)	Yes (not spouses)

ⁱ PDA uses \$200 as a guideline for capping services, although this is not an absolute cap. AAAs may reimburse for as much as \$500 per month, as long as the caseload average does not exceed \$300.

CONSUMER DIRECTION

Both the national and state-funded caregiver support programs and the Aged Medicaid waiver allow for consumer direction. For the NFCSP and FCSP, the PDA emphasized the importance of informal caregivers as providers, rather than more formal, agency-provided services. State officials indicated that this works better, both because it is less expensive and because the relationship between the caregiver and the provider is “much more comfortable.” In addition to hiring their own respite providers, consumers can receive reimbursement for almost any service (with the direct exclusion of prescription drug reimbursement). Friends and neighbors can be paid to provide personal care; however, all relatives are specifically prohibited from being reimbursed for this service. The basis for the regulation, the PDA respondents indicated, is the assumption that “family members, whether primary or otherwise, are going to give the services...and we’re supporting that noble initiative.”

In both the OPTIONS and Bridge programs, family (except for spouses) and friends can be hired to provide both respite and personal care services.

Medicaid officials characterized consumer direction in the Aged Medicaid waiver as “informal.” Family members, excluding spouses, can be paid to provide personal care and respite care. Respondents cited empowering consumers and dealing with a workforce shortage as reasons for allowing the reimbursement of family members to provide personal care. Respondents further indicated that background checks for family caregivers providing personal care have been a big debate in Pennsylvania, although currently they are not required.

QUALITY ASSURANCE AND EVALUATION

Officials from the PDA stated that they currently do not collect any data on family caregivers and indicated that they will soon collect a “rudimentary” level of data. Data is not aggregated or mined at the state level. The PDA does, however, plan to automate its client-tracking system in the near future. The goal is to begin collecting, in an automated format, at least the information contained in the current assessment tool. Key informants indicated that there have been glitches in developing this automated system, including the challenge of designing a system that meets the needs of 52 AAAs, each with a distinct organizational structure and with varying data systems and equipment. While respondents identified the inability to do statewide analysis as a shortcoming, they felt that the system was functional in terms of assisting consumers. One state official indicated that “the system operationally knows the information about caregivers. We know it at the level where we can actually help the consumer, but knowing it at the level where you’re going to do statewide analysis is what we don’t have.”

Under the Aged Medicaid waiver, respondents stated, Pennsylvania’s family caregiver support programs collect more data on their consumers than PDPW does on waiver participants. Service utilization and spending by recipient were the example offered of data collected. Respondents also indicated that the current system, the Medical Assessment Management Information Systems, is being revised and should be more user friendly to operate and provide more flexibility with regard to data collection.

SYSTEMS DEVELOPMENT

Respondents noted that their family caregiver support programs have been very popular, that “they are everybody’s favorite program.” The program appears to be popular not just with caregivers and care recipients, but with AAA staff as well. State officials cited higher “payoffs” among caregiver support program consumers and believed this was in part due to the intense relationship that staff forms with them.

In terms of the impact of the federal program on the existing state program, a PDA official said,

“The NFCSP was basically used to expand what we were already doing and allow us to do things that we wanted to do that state law didn’t let us do. And it’s been a very positive experience as far as I know, down to the AAA level. [It’s] not a real hard program to implement once you learn how to pay consumers...It’s taken a really neat program and made it an almost perfect program.”

The official went on to say that the FCSP has

“incorporated an awareness of the caregiver and their needs into the overall long-term care structure. So even though it’s...probably 5% of our community-based long-term care budget, that caregiver section is in every assessment that’s done except for people who only want to go to a nursing home, who don’t even want to consider community-based care. If somebody’s even considering community-based care, the caregiver is now assessed, and their needs are assessed. So I think our whole system is more caregiver-friendly than it would have been had we not had the Family Caregiver Support Program.”

Pennsylvania does not have a body whose mission is coordination of family caregiver support services across state departments. Pennsylvania does have a long-term care project with a general focus on home and community-based care, rather than specifically on caregiver support. All respondents stated that Pennsylvania’s caregiver support program is integrated into the state’s other home and community-based services, as opposed to a stand-alone program.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In August 2000, the Home and Community-Based Care Project was launched to address issues related to *Olmstead* planning. Components of this project include the following teams: resource facilitation, assessment, tracking and data management, policy, program and operations, communications and quality management.²⁰ While consumers have been involved in the task force associated with the project, key informants did not believe that family caregivers were necessarily represented.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high, medium, low) is placed on caregiver support?” State officials agreed that the priority statewide was “medium,” but indicated that in specific programs the priority was much higher. Stakeholders’ perceptions varied, with one stakeholder indicating a “low-medium” priority, the other “medium-high.” A summary of all responses is provided here.

Number of Key Informants	Priority on Caregiver Support
1	→ Low - Medium
2	→→→ Medium
1	→→→→→ Medium - High

Benefits and challenges: Pennsylvania case study respondents identified two aspects of their program that are most beneficial to family caregivers:

- ✧ Flexibility, all the way down to the consumer level
- ✧ The Aged Medicaid waiver, which is the best program available for care recipients who need a high level of care

The following challenges were reported:

- ✧ Inflexibility at the federal level (regarding Medicaid)
- ✧ The need to keep resources flowing

Major lesson learned: Pennsylvania’s respondents cited flexibility as one of the keys to a successful program, recommending that state agencies work with AAAs in a way that doesn’t allow them to take away any flexibility. Informants also recommended that family caregiver support programs integrate the intake, assessment and service delivery system with the overall community-based long-term care system in a manner that facilitates usage across programs.

Referring to the PDA and PDPW, other case study respondents reported that “if incentives are aligned, two agencies with vastly different views and priorities can partner successfully.”

Opportunity for expanding caregiver support: All Pennsylvania respondents indicated optimism about expanding programs. The PDA is interested in expanding the grandparents-raising-grandchildren component of the caregiver support programs, in addition to components for older people taking care of adult children with mental retardation or developmental disabilities. The PDPW is interested in working internally to document the shift toward home and community-based care and the savings it generates to make the case for funding expansions.

Recommendations for other states: State respondents offered two recommendations based on their extensive experience:

- ✧ Ensure flexibility in the program.
- ✧ Integrate intake, assessment and service delivery within the overall long-term care system so that all services and funding needs are integrated.

NOTES

- 1 U.S. Census Bureau, population statistics, www.census.gov/population/cen2000/phc-t2/tab01.pdf (2000).
- 2 Mapstats-Pennsylvania, www.fedstats.gov (June 2002).
- 3 M. Birnbaum, *Health Policy for Low-Income People in Pennsylvania* (Washington, D.C.: The Urban Institute, 1998).
- 4 Mapstats-Pennsylvania.
- 5 Ibid.
- 6 Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.
- 7 Ibid.
- 8 U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group*, www.aoa.gov/aoa/stats/2000pop/percentxstate.html (April 1, 2000).
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- 10 U.S. Administration on Aging, *2000 Census Figures for the Older Population for States: Profile of General Demographic Characteristics for the United States*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html (2000).
- 11 M. Birnbaum.
- 12 P. Arno and M. Memmott, *Estimated Value of Informal Caregiving: Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- 13 National Conference of State Legislatures, *State Long-Term Care: Recent Developments and Policy Directions* (Washington, D.C.: National Conference of State Legislatures, 2002).
- 14 Ibid.
- 15 Pennsylvania State Unit on Aging, www.aging.state.pa.us (November 2001).
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- 17 National Conference of State Legislatures, *Major Health Care Policies: 50 State Profiles* (Washington, D.C.: Health Policy Tracking Services/National Conference of State Legislatures, 2002).
- 18 L. Friss Feinberg, *Recognizing the Work of Family and Informal Caregivers: The Case for Caregiver Assessment*, prepared for the United Hospital Fund, New York, 2002.
- 19 Pennsylvania Department of Aging, *Community-Based Long-Term Care Programs*, www.aging.state.pa.us (2002).
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OVERVIEW

Texas, the second-most populous state in the nation, is large and diverse, with nearly one in three persons of Hispanic origin. The southwestern state has the fourth-largest number of older persons in the United States, the second-largest population of older Hispanic persons and the third-largest population of older African Americans.

The state's current long-term care system serving older persons and adults with disabilities is complex and fragmented, with many programs that have differing eligibility requirements. Home and community-based services range widely. Partly because of the state's strong antitax sentiments, these services are funded largely through Medicaid waivers and relatively small state programs. Texas is, however, one of the only states to commit tobacco settlement revenues to caregiver support by appropriating funds for respite care.

Prior to passage of the National Family Caregiver Support Program (NFCSP), no comprehensive statewide caregiver support program existed in Texas. The state's developing caregiver support services are characterized by:

- ❖ Flexibility to meet the individual needs of family caregivers at the local level
- ❖ Variable program design and services throughout the state
- ❖ Decentralized policy development and program administration

Texas respondents noted that the major service needs of family caregivers are (1) caregiver education and training, (2) counseling, (3) help in navigating the system and (4) general support services.

As Texas develops its caregiver support program and seeks to streamline its home and community-based service infrastructure, the development of uniform assessment standards and a consistent statewide approach to accessing and delivering services will be a key consideration.

INTRODUCTION

Texas represents a "new" state that is explicitly providing a range of caregiver support services, beyond limited respite care through state funds, as a result of the passage of the NFCSP. The project team conducted a site visit on June 17 and 18, 2002, through in-person interviews with government officials and key stakeholders. State agencies and programs within those agencies that were interviewed include:

Texas Department on Aging

- ❖ Family Caregiver Support Program (NFCSP funded)

Texas Department of Health

- ❖ Texas Council on Alzheimer's Disease and Related Disorders (state funded)

Texas Department of Human Services

- ✧ Community Based Alternatives Aged/Disabled Medicaid waiver
- ✧ Consolidated Medicaid waiver
- ✧ Respite Care program (state funded)
- ✧ In-Home and Family Support voucher grant program (state funded)
- ✧ Consumer Managed Personal Assistance Services (Social Services Block Grant and state funded)
- ✧ Community Alzheimer's Resources and Education (CARE) program (federally and state funded)

Stakeholders interviewed were from:

- ✧ Texas Association of Area Agencies on Aging
- ✧ Alzheimer's Association, Austin Chapter
- ✧ Austin Independent Living

Six programs are featured in this profile:

1. Texas NFCSP
2. Aged/Disabled Medicaid waiver
3. Consolidated waiver
4. In-Home and Family Support program
5. Respite Care program
6. Community Alzheimer's Resources and Education program

BACKGROUND

Texas is a large, diverse southwestern state with a population of 29.9 million residing in 254 counties.¹ The state has substantial rural, low-income and minority populations. Although two-thirds of the population live in urban areas, 196 of the state's 254 counties are rural.² In 2000, personal income per capita was \$27,871, below the national average of \$29,676.³ About 16.7% of Texas's population live below the federal poverty level (vs. 13.3% U.S.).⁴ Texas ranks 35th nationally in percentage of households with Internet access.⁵ The racial makeup of the state's population also differs significantly from that of the United States as a whole. Compared to the national average, Texas has more than twice the proportion of Hispanic persons (32.0% vs. 12.5% U.S.) and a slightly smaller percentage of African Americans (11.5% vs. 12.3% U.S.)⁶ (table 1).

An estimated 2.8 million persons in Texas, or 13.3% of the state's population, were 60 years or older in 2000 (vs. 16.3% U.S.). Texas ranks fourth nationally in the number of older persons (ages 60+) residing in the state.⁷ Texas has more than three times the percentage of Hispanics ages 60+ as the nation on average (17.6% vs. 5.4% U.S.).⁸ In fact, Texas has the second largest population of Hispanic older persons in the United States.⁹ With almost the same proportion of African Americans ages 60+ as in the United States as a whole (8.6% vs. 8.4% U.S.),¹⁰ Texas also has the third highest proportion of African American elderly in the country.¹¹

Texas ranks 46th nationally in the proportion of its population ages 85 and older. In 2000, 238,000 persons, or 1.1% of Texas's population, were ages 85+. ¹²

An estimated 1,790,931 family caregivers reside in Texas. These family caregivers provide about 1.7 billion hours of caregiving per year at an estimated value in 1997 of \$13.6 billion. ¹³

Texas is traditionally a conservative, low-service state with a general philosophy that residents “take care of their own.” The state legislature takes an active role in enacting long-term care policies and programs. In addition, Texas has a strong network of effective advocates and has some history of offering limited support services for family caregivers through the Department of Human Services, rather than through the Department of Aging. In contrast, the “taking care of their own” philosophy might explain why state policy attention to caregiver issues has emerged only recently.

Table 1. Selected Characteristics of TEXAS and the UNITED STATES, 2000 ^a

	Texas	United States
Total Population Characteristics		
Total Pop. ^b	20,851,820	281,421,906
% African American ^c	11.5%	12.3%
% Hispanic ^d	32.0%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	2,774,201	45,797,200
% 60+ ^f	13.3%	16.3%
National ranking 60+ ^g	47	NA
Pop. 65+ ^h	2,072,532	34,991,753
% 65+ ⁱ	9.9%	12.4%
National ranking 65+ ^j	47	NA
Pop. 85+ ^k	237,940	4,239,587
% 85+ ^l	1.1%	1.5%
National ranking 85+ ^m	46	NA
% increase 1990–2000 60+ pop. ⁿ	18.3%	9.4%
% White (60+) ^o	71.2%	82.4%
% African American (60+)	8.6%	8.4%
% Hispanic (60+)	17.6%	5.4%
% Asian (60+)	1.5%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.0%	0.1%
% Amer. Indian/Alaska Native (60+)	0.2%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	1,790,931	25,798,370
Caregiving hours (millions) (1997)	1,667.0	24,013.1
Value of caregiving (millions) (1997)	\$13,636.0	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$27,871	\$29,676
% of pop. below poverty (1997) ^r	16.7%	13.3%
Internet		
% of households w/Internet access (2001) ^s	38.3%	41.5%
Nat'l ranking of households w/Internet access	35	NA

a Unless otherwise noted, all data are from 2000.

b MapStats-Texas, www.fedstats.gov (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r MapStats-Texas.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Caregiver support services for the elderly and for adults with physical disabilities are administered largely through two state agencies: the Department on Aging and the Department of Human Services. Most of the programs administered by these state agencies rely generally on federal funds with some state match; state-only-funded programs are limited.

The Texas Department on Aging (TDoA), small compared to other Texas state agencies, is a free-standing department that serves as the State Unit on Aging and administers the provisions of the federal Older Americans Act, including the new NFCSP. The governor appoints the executive director, who has cabinet-level status. TDoA consists of approximately 35 full-time staff members, who work with the Department of Health (TDH), and the Department of Human Services on various programs.

The infrastructure of Texas's aging network is a statewide system of 28 Area Agencies on Aging (AAAs), each covering a territory ranging from one to 10 counties. Twenty-five of the 28 AAAs are housed within their local council of government, a regional municipal governing body. Two others, the AAAs serving the Dallas and Houston areas, are located within city government. The local United Way chapter oversees the remaining AAA. The AAAs have also formed the Texas Association of Area Agencies on Aging (T4A), which holds quarterly meetings to report on best practices, among other activities.

The Health and Human Services Commission (HHSC) has oversight responsibility for designated health and human service agencies (including the TDoA, TDH and DHS). HHSC has been the "single state agency" for Medicaid since 1993. Historically, TDH has administered most Medicaid programs, with oversight by HHSC. Recently, however, Texas has reorganized the administration of Medicaid services, and in 2001, most of TDH Medicaid functions were shifted to other agencies under HHSC. Currently, Texas Medicaid programs are administered by various agencies, including

DHS (eligibility and long-term care programs), the Department of Mental Health and Mental Retardation (waiver services for mental retardation) and TDH (family planning and medical transportation).

Texas has nine Medicaid waivers providing home and community-based services.^a The two that specifically serve the elderly and persons with physical disabilities are the Aged/Disabled Medicaid waiver, known in Texas as the Community-Based Alternatives (CBA) waiver, and the Consolidated waiver, a pilot program providing services to many different populations. The CBA waiver was originally approved in 1994. DHS, under contract with HHSC, administers this waiver. In FY 2001, it delivered services to 26,337 beneficiaries,^b 70% of whom were older persons. DHS has projected that the Consolidated Medicaid waiver will serve 58 clients in 2002.

In addition to these waivers, the Division of Long-Term Care within DHS administers several other programs that provide services to older persons and their family caregivers. The Respite Care and In-Home and Family Support voucher programs (both state funded) and the Consumer Managed Personal Assistance Services program (CMPAS, funded through both the state and a Social Services Block Grant, Title XX) serve collectively more than 4,600 clients per month. CMPAS does not, however, provide any explicit caregiver support services. DHS also administers the Community Alzheimer's Resources and Education (CARE) program.

In 2002, HHSC was awarded a Real Choice Systems Change grant from the Centers for Medicare and Medicaid Services (CMS). Texas will use the almost \$1.4 million to try to make more accessible and better coordinate its system of long-term care services and to assist individuals in making the transition from institutions back into the community.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Texas has some state-funded programs serving the elderly, persons with disabilities and family caregivers, including a stand-alone respite benefit. The philosophy of "taking care of your own," however, seems to account for at least some of the limited growth of those programs. Budget shortfalls and a priority on developing programs for children are also contributing factors.

HHSC has identified caregiver support among the strategic priorities within its coordinated strategic planning effort for 2003–08. These priorities, known as "enterprise strategies," will provide the interagency focus for the HHSC coordinated strategic plan. The priority for caregiver support is to "improve support to families by expanding, developing and coordinating formal, informal and innovative supports for caregivers."¹⁴ The enterprise strategy should effectively raise the profile of caregiver support issues within the Texas long-term care system.

a Other Medicaid home and community-based waivers are the Medically Dependent Children Program, serving children under age 21 who qualify for nursing facility care; Home and Community-Based Services, providing in-home services to individuals with mental retardation; Community Living Assistance and Support Services, providing home and community-based services to people with severe disabilities, other than mental retardation, that originated before age 22; Home and Community-Based Services OBRA, providing services to persons with mental retardation or related conditions who are determined to be inappropriately residing in a nursing home; Deaf Blind/Multiple Disability waiver, serving people ages 18+ who have been determined legally blind and who have multiple disabilities; Star+Program, a pilot waiver for Community-Based Alternative waiver clients, providing managed care, acute and long-term care services in Harris County; and Mental Retardation-Local Authority, serving people with mental retardation/developmental disabilities in 29 counties.

b In FY 2001, Texas had approval for 26,337 waiver slots, and all slots filled.

Long-term care planning and expansion of home and community-based services has been a recent focus of the Texas legislature, which meets biannually. In the legislature's 2001 session, for example, home and community-based services received a boon from the tobacco settlement. Allocations in the amount of almost \$74 million for the state-funded Respite Care program and of another \$17.3 million earmarked for home and community-based care indicate recognition of the importance of these services.¹⁵ Despite this, the downturn in the state's economy will likely pose significant fiscal challenges to the legislature when it next meets in 2003.

Before enactment of the NFCSP, caregiver support was not a specifically identified policy issue of state leaders in Texas. Although Texas had some limited state-funded programs that provided ancillary benefits to caregivers, the NFCSP was the first program in Texas "to make it happen" in terms of directly targeting services to family caregivers, according to one respondent.

Housed in DHS, the CARE program, legislatively mandated in 1998, is funded through a mix of Alzheimer's Disease Demonstration Grant funds and state general funds. The program provides some measure of caregiver support through respite services, education, training and support of families. In fact, one state official indicated, although CARE is conceptually geared to serve the person with Alzheimer's, the program and its services "are about the caregivers" in reality.

Respondents gave mixed answers when asked if family and informal caregivers were recognized as a central component of a comprehensive long-term care system. Some state officials responded that family caregivers were essential to the Texas long-term care service delivery system and that Texas relies heavily on family, friends and neighbors to provide care. Another respondent indicated that families are relied on to provide care but are not recognized or supported. A common theme was the philosophy that "families take care of their own."

PROGRAM BACKGROUND/DEVELOPMENT

The impetus for the state's family caregiver support program was passage of the Older Americans Act Amendments of 2000, which created the NFCSP and provided federal funding (based on a congressionally mandated formula) to the State Units on Aging to provide caregiver support services. Prior to passage of the NFCSP, no comprehensive, statewide caregiver support program had existed in Texas. TDoA allocated funds to the AAAs in the same month that it received them from the U.S. Administration on Aging (AoA), in March 2001. As part of the NFCSP, TDoA also piloted a respite voucher in May 2002. In developing the voucher, and for other program design details, Texas looked to caregiver support programs in both Oklahoma and California.

In the design and start-up phases of the NFCSP in Texas, TDoA involved the AAAs, held public hearings, organized focus groups and partnered with the CARE program to identify providers. Officials from TDoA indicated significant challenges during these early phases, attributing some of the difficulties to a delay in policy development from the federal government. Integrating the new funds into existing services was also a challenge. TDoA has attempted to centralize some of the policymaking and administrative decisions, although the AAAs appear to play a sizable role at the local level. TDoA established an AAA caregiver task force in 2001 to have a forum to identify focus areas, such as policy and program development. TDoA sees the task force as a way to examine what is and is not working under the NFCSP in Texas. The task force, which meets on a quarterly basis, is comprised of AAA directors, caregiver specialists and TDoA staff.

Texas has been innovative in its use of administrative funds received under the NFCSP. TDoA has kept 5% to hire a caregiver coordinator, conduct trainings and increase awareness of caregiver issues through public information campaigns. The rest of the funds have been used in several ways. First, TDoA has contracted with a legal services center to provide a statewide hotline and provide services to grandparents raising grandchildren. At the time of the site visit, TDoA was also in the process of conducting a caregiver survey to obtain data on caregivers residing in the state. Finally, the agency has created a series of “caregiver capacity-building grants.” These funds provide seed money in the amount of \$15,000 each to build on informal infrastructures in the community. Responding to a request for proposals were AAAs, churches and other community organizations. A faith-based respite program is an example of a project funded through this grant program.

Most rewarding: Key informants noted that the most rewarding aspect of the program’s development has been having new funds to support family caregivers. Additionally, the ability for AAAs to bring on designated caregiver staff has been helpful. State officials also indicated that the innovation of AAAs in providing services has been rewarding.

Biggest challenge: Key informants cited some significant challenges in the start-up phase of the NFCSP. First, reporting requirements have posed problems. Although the caregiver is the identified client, eligibility for NFCSP-funded services—namely, respite and supplemental services—is based on activity of daily living (ADL) deficits of the care recipient. This has made it difficult to “get a handle on who is the client.” Worker shortages have also been problematic, particularly in vast rural areas of the state of Texas, where trained respite providers are sometimes difficult to find. The 25% match requirement mandated in the federal legislation was another challenging issue identified. Key informants noted that the required match was problematic because it was more than any other required under Title III Services. TDoA and the AAAs have worked to identify other sources of match, including in-kind.

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—Texas received \$6.2 million in federal funds. The majority of the federal funds were carried over to FY 2002. In FY 2002, the federal share of NFCSP funds was increased, with Texas receiving a total of \$7 million, or 9.1% of TDoA’s total budget.

DHS expenditures under the CBA Aged/Disabled Medicaid waiver were \$355.6 million in FY 2001. This waiver for Texas alone is nearly three times the entire federal appropriation for the NFCSP, which received \$125 million in FY 2001. The state Respite Care program was funded at \$1.13 million; the In-home and Family Support voucher program at \$6.5 million; the Consolidated Medicaid waiver at \$1.5 million;^c and the CARE program at \$2.5 million. Combined, these programs represent just under 10% of the total DHS budget.

Texas was one of four states to negotiate an independent settlement with the tobacco industry prior to and separate from the multistate agreement.¹⁶ Texas is scheduled to receive approximately \$17 billion over a 25-year period from its settlement. The legislature has established several endowments to provide for education and public health, although none of these funds is earmarked for home and

c Figures are for projected expenditures for FY 2002.

community-based care. In addition to these endowments, Texas has used a portion of its tobacco settlement revenues to shore up state spending on Medicaid and to support home and community-based care. Funds appropriated specifically for caregiver support services include \$73.9 million allocated in 2001 for respite care.¹⁷ In addition, \$17.3 million was provided to expand home and community-based care, and another \$61.3 million was for Medicaid simplification.¹⁸

Key informants described the current budget situation in Texas as “bleak” and expected that situation to continue to weaken. An across-the-board cut in state general revenue would have a broad impact on programs. Officials from the TDoA indicated that they are strategizing on ways to save funds, though with the influx of federal dollars under the NFCSP, the department’s funds have actually increased over the past two years. At the time of the site visits, some AAAs thought they might have to have return some of the federal NFCSP funds because they were concerned that they could not come up with the match required under federal rules. State officials indicated this was no longer an issue.

Medicaid officials expect a significant shortfall, with respondents predicting a shortfall of anywhere from \$5 billion to \$8 billion by the end of this year. Because of the biennial legislative session, key informants have predicted that the impact will be felt even more in the following two years when the legislature prepares its next two-year budget.

PROGRAM ADMINISTRATION

TDoA sees its role in developing and implementing the state’s first caregiver support program to be in the areas of service design and the development of rules and reporting standards. State officials commented that they have provided a lot of support to the AAAs in the implementation of this program, yet some stakeholders have expressed concern about what they considered to be limited state guidelines in this regard.

Publicizing the new Texas caregiver support program has been primarily the responsibility of the AAAs. TDoA is working with employee assistance personnel in the corporate sector, and is developing interdepartmental partnerships with agencies such as TDH to publicize services through its Council on Alzheimer’s Disease.

State Medicaid officials at DHS identified their role as administrators, policy developers and monitors for the state’s long-term care programs, including home and community-based Medicaid waivers, nonwaiver Medicaid services and state-funded long-term care programs. DHS is responsible for directly providing case management within the home and community-based waivers but has the flexibility to contract out this service. In addition to administering the CBA Aged/Disabled and Consolidated Medicaid waivers, DHS administers several programs that provide services to assist caregivers. Nonwaiver services include the Consumer Managed Personal Assistant Services (CMPAS), the In-Home and Family Support voucher program, CARE and the state-funded Respite Care program.

State officials observed that Texas has a complex and fragmented long-term care system, with many programs and services with different sources of funding for different age groups and disabilities. In recent years, under the leadership of HHSC, the state has attempted to address uniformity across departments and programs to reduce fragmentation. Both state officials and stakeholders commented that this goal is relatively recent and that Texas still has “a long way to go.”

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Eligibility for the state's family caregiver support program is consistent with federal requirements under the Older Americans Act: the program is open to family or informal caregivers of any age who provide care to persons age 60 or older, as well as caregivers ages 60 or over who care for children ages 18 or younger.^d For respite and supplemental services, the older person (age 60 or older) must need help with at least two ADLs or two instrumental activities of daily living (IADLs). In Texas, both the family caregiver and the care recipient are considered the client in the program. The new client population of family and informal caregivers has been a source of confusion among both TDoA officials and AAA staff, however.

Client assessment standards are not uniform across the state, although AAAs do use a standard intake form that is completed by phone or in-person. TDoA recently adopted the DHS community care assessment for its home and community-based programs, although questions regarding family caregivers are extremely limited. As part of this assessment process, informal care is taken into account in the authorization of paid services for the care recipient. Officials of TDoA described the goal of the assessment as first identifying any ADL impairment, however, and then determining whether the client has a family caregiver for support. Although the assessment tool focuses on both the care recipient and the caregiver, little information is asked about the family caregiver, and as respondents pointed out, some AAAs focus more on caregivers than others. One respondent characterized the assessment process as "highly variable."

Eligibility for the CBA Aged/Disabled Medicaid waiver is consistent with federal requirements: the waiver is for those who receive Supplemental Security Income (SSI) or meet income and resource limits (up to \$1,635 per month in income and less than \$2,000 in assets). Waiver recipients must also be 21 years of age or older and must meet the medical criteria for Medicaid nursing home level of care. Respondents noted that the care recipient is the identified client in the program, consistent with Medicaid policy.

Each of Texas's nine waivers has its own eligibility criteria for its specific target population and its own assessment process. HHSC is in the process of developing a uniform functional assessment tool, now being tested, to be used for all ages and types of disabilities across programs and services. Consistent with Medicaid policy generally, respondents noted, extent of informal care (i.e., whether or not the care recipient has a family caregiver) is taken into account in the authorization of paid services for the care recipient. Although the assessment focuses on the care recipient, respondents noted some emphasis on who the caregiver is; whether or not that person is willing, reliable and dependable to provide care; and what impact providing care could have on the caregiver's own work situation. Respondents indicated that services might be reduced for a care recipient with a high level of family support.

Texas also has implemented a program that allows families to self-screen for Medicaid eligibility. Known as the State of Texas Assistance and Referral System (STARS), the on-line tutorial offers care recipients and their families the option to self-screen as the first step in determining eligibility for Medicaid programs administered by DHS and other state agencies.

^d This includes caregivers ages 60+ who are caring for children who are affected with mental retardation or who have developmental disabilities.

SERVICES

All five of the permissible NFCSP service components are being provided in Texas, although not necessarily by each AAA. The AAAs either subcontract for caregiver support services or provide them directly. Services that AAAs provide directly include facilitating support groups, developing resource materials such as fact sheets, and conducting trainings.

Regarding respite care, the AAAs are authorized to provide in-home care, adult day services, overnight care in a facility and respite weekends. Not all types of respite services are always available, however. To help overcome the increasing lack of respite providers throughout the state, especially in rural areas, TDoA, in partnership with the AAAs, has been looking at the concept of mobile respite to bring respite care to underserved communities.

TDoA has also created a respite voucher so that families can contract directly for respite services on their own. The state has recommended a cap of \$300 per quarter, so as not to exceed federal tax guidelines, but AAAs have the flexibility to exceed this cap. Caregivers are allowed to bank respite benefits, but state officials indicated this is rarely necessary because of the flexibility in the program. Only a caregiver who does not live with the care recipient may receive a respite voucher. This is because the voucher is intended to serve families who are not eligible for respite through the state-funded In-home and Family Support program.

Respite care is a covered benefit in both the CBA Aged/Disabled and Consolidated Medicaid waivers. Respite care in the CBA waiver is capped at 30 days per year, whereas the Consolidated waiver has a 45-day cap. Although these caps exist, Medicaid officials emphasized the flexibility to authorize higher caps, citing a rider that DHS cannot deny services if the denial would be detrimental. Of 30,000 Aged/Disabled waiver clients, only 1,290 use respite care. Beneficiaries are more likely to utilize the most attractive feature of the Aged/Disabled waiver, the provision of access to unlimited prescription drugs with no co-payment. This benefit alone may motivate some to participate in the waiver, according to Medicaid officials.

DHS has also capped reimbursement based on provider type. Hospital-based respite has a \$67 per day maximum, for example, whereas in-home respite limits vary from \$35 to nearly \$50 per day. Adult day service provider reimbursements are capped at \$13 per half day.

Significant waiting lists also exist for Medicaid waiver services. One state official estimated that 60,000 to 70,000 people are on waiting lists (known as “interest lists”) to be assessed for waiver eligibility and indicated that some 10,000 people are added to these lists per year, with an average wait time of 11 months. Another respondent noted that those on the interest list for the state-funded In-Home and Family Support program could wait up to five years for services. Further, a respondent observed that “people that access waiver programs in Texas get a good package of services; those that don’t, don’t get much.” One qualifying factor for DHS non-Medicaid waiver services is the establishment of “unmet need,” for example. A care recipient who already has a caregiver may not qualify for state-funded programs that would provide services (i.e., respite care) that would assist that caregiver in remaining in the caregiving role.

Other DHS-administered programs also provide some services that support family caregivers. Additionally, the In-Home and Family Support program provides direct grants to individuals and/or their families for goods and services. These grants have a \$3,600 annual maximum. Consumers and/or their families can use the money to purchase a variety of goods and services, including respite, attendant care and chore services. The state-funded Respite Care program also serves family and informal caregivers. This program has a respite cap of 14 days (336 hours) per year. The CARE program provides respite services and home modifications to assist dementia caregivers.

Major services needed by caregivers: At TDoA, caregiver education, training, counseling and general support services were identified as the major services needed by caregivers. Respondents indicated that these services allow caregivers to make the decision to use respite care and to access services earlier. As other key informants indicated, “Everything we do in Texas is related to the care recipient, which indirectly benefits the family caregiver.” Stakeholders cited information, case management, in-home assessment and help in navigating the system as essential in supporting family and informal caregivers. Expanding on this, one respondent indicated that families do not know what services are available and how to access them.

Table 2. Family Caregiver Support Services in Texas

Program	Texas NFCSP	Aged/Disabled Medicaid Waiver^a	Consolidated Waiver	In-Home and Family Support Voucher Program	Respite Care Program	Community Alzheimer's Resources and Education (CARE)
State Administrative Responsibility	Texas Department on Aging	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services	Texas Department of Human Services
Local Service Delivery	AAAs ^b	DHS: care management Local service provider agencies: other services	DHS: care management Local service provider agencies: other services	No contract providers; written bids submitted by vendors to clients	Local service provider agencies	CARE sites throughout the state
Funding Source	Older Americans Act, Title III-E	Federal and state funds	Federal and state funds	State funds	State funds	State general funds, federal Alzheimer's Disease Demonstration Project
Expenditures FY 2001–02	\$7.0 ^c million	\$355.7 million	\$1.5 million ^d	\$6.5 million	\$1.1 million	\$2.5 million ^e
Client Population	Family & informal caregiver	Care recipient	Care recipient	Care recipient	Care recipient	Family caregiver & care recipient

a In Texas, this waiver is known as the Community-Based Alternatives (CBA) waiver.

b AAAs = Area Agencies on Aging.

c Funding is for FY 2002.

d Projected expenditures are for FY 2002.

e This funding level is for FY 2002 and is the source of the required matching funds under the federal Alzheimer's pilot program.

Table 2. Family Caregiver Support Services in Texas (continued)

Program	Texas NFCSP	Aged/Disabled Medicaid Waiver	Consolidated Waiver	In-Home and Family Support Voucher Program	Respite Care Program	Community Alzheimer's Resources and Education (CARE)
Eligibility Criteria:						
Age	60+ care recipient Family caregivers of persons age 60+	21+ care recipient	Any age care recipient	4+ care recipient	18+ care recipient	Any age family caregivers & care recipients
Income	None	\$1,635/month \$2,000 resource limit	\$1635/month \$2,000 resource limit	Co-payment beginning at 105% of state median income	\$1,635/month \$2,000 resource limit	400% of poverty level \$10,000 resource limit
Functional Ability	For respite & supplemental services, care recipient must have at least 2 ADLs or IADL needs	Nursing home eligible	Nursing home eligible	Physical disability that substantially limits ability to function independently	Care or supervision needed; unpaid caregiver needs relief from caregiver responsibilities	Diagnosis of Alzheimer's or dementia
Uniform, Statewide Caregiver Assessment	No	No	No	No	No	Yes
Services Provided to Family Caregivers	Information Assistance Counseling, support groups, training Respite care Supplemental services (e.g., consumable supplies)	Respite, home modifications	Respite	\$3,600 annual stipend for respite care and supplemental services; \$3,600 lifetime maximum for home modifications or assistive technology	Respite	Respite, home modifications
Respite Cap	\$300 per quarter (recommended)	30 days	45 days	\$3,600 annual	14 days (336 hours)	Cap varies by site
Consumer Direction	Yes	No	No	Yes	No	No
Family Caregivers Paid as Respite Providers	Yes	No	No	Yes	No	No

CONSUMER DIRECTION

Although Texas has a long history of consumer-directed care programs, services options for older persons and their caregivers are currently limited. Within the NFCSP, consumer-directed options are limited to the respite voucher previously described. Family members, except for spouses, can be paid respite providers.

Within DHS, a legislative mandate has required that all Medicaid waivers eventually have consumer direction as an option. Currently, the only two waivers that allow consumer direction are the Deaf/Blind and Community Living Assistance and Support Services (CLASS) waivers. DHS respondents indicated, however, that there is in Texas, “a consumer choice kind of philosophy.” The DHS-administered Consumer Managed Personal Assistance Service (CMPAS) program does allow family members to be paid to provide personal care but does not provide caregiver support services.

Texas was one of the first states to include consumer direction under its Medicaid waivers, although the CBA Aged/Disabled Medicaid waiver does not currently permit consumer direction. According to key informants, Texas has one of the largest consumer-directed waiver programs in the country.

With regard to other DHS-administered programs, the In-Home and Family Support program provides a cash grant to families to help pay for respite care, consumable supplies, home modifications and assistive technology. Family members can be paid respite providers, with no restrictions. The state-funded Respite Care program and the CARE program do not have consumer-directed options.

QUALITY ASSURANCE AND EVALUATION

TDoA has developed a uniform client enrollment (intake) form for all AAAs. The AAAs now utilize a standard assessment, the DHS community care assessment with limited data collected on family caregivers. TDoA requires that AAAs collect basic information about caregivers, such as expenditures and number of caregivers served, using the AoA’s minimal data collection requirements. The system is currently a mix of manual and automation systems.

Texas is not formally collecting data on caregiver outcomes, although officials indicated that they do receive feedback from the caregivers and care recipients that they serve. Although TDoA is required to do annual client satisfaction surveys, they have not so far included family caregivers in this process.

The only program in DHS that appears to be collecting data on caregiver outcomes is the CARE program, which includes caregiver information—such as measures of caregiver health—in its assessment. The department uses a new, web-based system and has not had time to evaluate the strengths and weaknesses of its data collection practices. In its state-funded programs, DHS is not collecting substantive data on the caregivers served through its various respite components. In the CMPAS care program, it does collect information on what the family caregiver is doing to help the care recipient—but not on what help the family caregiver may need. Medicaid officials indicated that their current system, the Texas Integrated Eligibility and Redesign System (TIERS), lags behind in automation. They do plan to implement a new system, called Service Authorization System (SAS) Wizards, which would be a more user friendly and technologically advanced system.

SYSTEMS DEVELOPMENT

Texas has a complex and fragmented system of support for the elderly, for persons with disabilities and for their family caregivers, administered largely by two state agencies. HHSC, however, is trying to streamline, integrate and coordinate the service system. HHSC, through its “enterprise strategy,” has come to recognize family caregivers as an independent constituency within long-term care.

TDoA and AAA respondents noted that their experience in implementing the NFCSP in Texas had been positive overall. They saw the program as an expansion of an existing goal, rather than as implementation of a completely new program. Although TDoA officials identified their role as one of statewide coordination and development of state standards, some stakeholders raised concerns that TDoA has not set standards. Key informants noted that the small size of TDoA staff, at 35 people, has left the department “stretched.” In turn, state officials have been concerned about the level of guidance coming from the federal government, indicating that they would like additional guidelines and feedback on policy issues.

Medicaid officials were largely unaware of the NFCSP and of implementation by TDoA and the AAAs. They did indicate, however, that the HHSC umbrella to both DHS and TDoA has identified caregiver support as one of its enterprise strategies, as previously noted. As part of its coordination effort, HHSC will provide a liaison to support the interagency development of consistent policies for caregiver support, and other state agencies will provide related activities. Noted one key informant, “Whether this strategy develops into something concrete will depend on funding.”

In the evolving NFCSP, caregiver services are coordinated at the local level by the 28 AAAs. Most of the AAAs have hired dedicated staff, known as “caregiver specialists” to implement the program. They meet informally to share experiences and information.

Although Texas does not have a body whose mission is coordination of family caregiver support services across state departments, many key informants cited the HHSC enterprise strategy as taking on that role. Texas appears to be in the beginning stages of systems development in both DHS and TDoA, which have identified this as a goal, but have not achieved this in the current program structure. One key informant indicated that there are “too many departments in Texas....Texas has a maze” of a long-term care system, and that informant would like to see movement toward a single state long-term care agency.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

In response to the recent Supreme Court *Olmstead* decision, the governor of Texas issued an executive order requiring the HHSC to review all services and supports for people with disabilities.¹⁹ HHSC, in turn, established the Promoting Independence Advisory Board, which evolved into the Interagency Task Force on Care Settings for Persons with Disabilities and serves as the state’s *Olmstead* task force.²⁰ Officials of DHS noted that two family caregivers serve on the panel; one provides care for an elderly parent and the other for a teenage son with cognitive disabilities.

OTHER POLICY ISSUES

Priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high/medium/low) is placed on caregiver support?” As shown here, the key informants interviewed varied in their estimation of the priority placed on caregiver support. Two stakeholders and one state official indicated the priority was “low.” One state official and two stakeholders agreed that there was a “medium” priority, and one state official cited a “high” priority on caregiver support.

Number of Key Informants	Priority on Caregiver Support
3	→ Low
3	→→→ Medium
1	→→→→→ High

Benefits and challenges: Texas case study respondents identified three aspects of their program that are most beneficial to family caregivers:

- ✧ Respite care
- ✧ Education and training
- ✧ Personal assistance services, which also provide some measure of caregiver relief

When asked to identify the challenges for implementing family caregiver support programs in Texas, respondents noted the following:

- ✧ Limited implementation guidelines from the federal government
- ✧ Challenges with reporting requirements; structuring the program around these requirements
- ✧ High caseloads; more staff needed in Medicaid waiver programs
- ✧ Too many “silos” in the state

Major lessons learned:

- ✧ Because the needs of families vary, families need options and flexibility
- ✧ Regarding caregiver support, “We don’t really provide caregiver support—we provide client services,” according to one Medicaid official
- ✧ “Families don’t feel the responsibility to care the way they used to,” another indicated
- ✧ In contrast, another DHS official expressed surprise at how much family caregivers are willing to take on, even when they are experiencing strain themselves, and also at how vital the family caregiver is to the overall health of the client’s situation and how fragile the caregiver’s own physical and mental health can be

Opportunity for expanding caregiver support: All Texas respondents were pessimistic about new initiatives or the expansion of state-funded programs to support and strengthen family caregivers over the next three to five years. One state official said that caregiver support would not be expanded; another pointed out that efforts to strengthen family supports in Texas are focused on children. Despite this, the HHSC's upcoming focus on supporting family caregivers is promising.

Recommendations for other states: State officials in Texas had several recommendations for other states:

- ✧ Share best practices.
- ✧ Develop the trust of the community and agencies so they can work together to identify service needs.
- ✧ Ensure an adequate funding base.
- ✧ Offer more educational programs to help families navigate health and human services programs.
- ✧ Start with consolidated programs if you are starting from scratch. Don't create multiple programs and "silos."

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WASHINGTON

OVERVIEW

Washington is a northwestern state with more than three-fourths of its residents living in urban areas. State leaders have been committed to expanding home and community-based services and downsizing institutional care for decades. Today, Washington State has a single point of entry for all long-term care services needed by individuals ages 18 and older and for their family caregivers.

The passage of the National Family Caregiver Support Program (NFCSP) gave Washington State the opportunity to expand existing state-funded policies and programs for family caregivers. Changes in caregiver support resulting from the NFCSP include greatly increased funding, the addition of counseling for family caregivers and the inclusion of services for grandparents raising grandchildren. The state's caregiver support services are characterized by:

- ❖ Service to family caregivers ages 18 and older, regardless of conditions
- ❖ The targeting of underserved populations (e.g., ethnic communities)
- ❖ Program flexibility
- ❖ An emphasis on training, including widespread adoption of the “Powerful Tools” training program for caregivers, developed in Oregon, and specialty training on topics such as dementia care and mental health issues

Washington State respondents noted that the major service needs of family caregivers are (1) respite care, (2) specialized caregiver information, training and consultation with specialists and (3) support groups.

The NFCSP in Washington State, although delivered locally with unique features in each community, is moving toward statewide identification of the program through a uniform name, The Family Caregiver Support Program (FCSP), definitions and a common contact form to document caregiver needs. As Washington continues to build its caregiver support system, a key consideration will be how the state achieves one of its goals: integration of caregiver assessment into the state's uniform assessment tool for all long-term care programs.

INTRODUCTION

Washington represents an “old” state in this study since caregiver support policies and programs were already in place through state funds in Washington prior to passage of the NFCSP. The project team conducted a site visit on April 15 and 16, 2002, interviewing government officials and key stakeholders in Olympia and Seattle.

All government staff interviewed worked in one agency:

- ❖ Department of Social and Health Services, Aging and Adult Services Administration

The stakeholders held positions at the following agencies or associations:

- ✧ Washington Association of Area Agencies on Aging
- ✧ Pierce and Lewis-Mason-Thurston Area Agencies on Aging
- ✧ Senior Services (Seattle)
- ✧ Alzheimer's Association, Western and Central Washington Chapter (Seattle)

Three programs are featured:

1. Respite Care Program (state funded)
2. Washington State Family Caregiver Support Program (state funded)
3. National Family Caregiver Support Program (federally funded)

BACKGROUND

Washington is a northwestern state with a population of 5.9 million people who reside in 39 counties. More than three-fourths of the state's residents live in urban areas (76.4% in 1990).¹ The Cascade Range divides the state, geographically and politically. East of the Cascades lies the politically conservative, largely rural area predominated by agricultural crops such as wheat and apples. To the west are Seattle, Tacoma and Olympia; successful businesses such as Microsoft and Starbucks; and a relatively liberal population with a strong union history.²

In 2000, personal income per capita among Washingtonians was \$31,528, higher than the national average of \$29,676.³ About 10.2% of Washington's population live below the federal poverty level (vs. 13.3% U.S.).⁴ Washington ranks seventh nationally in percentage of households with Internet access (49.7% in 2001).⁵ The racial makeup of the state's population differs somewhat from that of the United States as a whole, with Washington having a smaller proportion of both African American (3.2% vs. 12.3% U.S.) and Hispanic persons (7.5% vs. 12.5% U.S.) and a higher proportion of Asian persons (5.8% vs. 4.1% U.S.)⁶ (table 1). Washington also is home to 26 federally recognized Native American tribes.

An estimated 873,223 persons in Washington were 60 years or older in 2000 (14.8%), a lower proportion than in the nation as a whole (16.3% U.S.). Washington ranks 45th nationally in the number of older persons (ages 60+) residing in the state.⁷ Compared to the national average, Washington's older population (ages 60+) has a much smaller proportion of African American (1.7% vs. 8.4% U.S.) and Hispanic (1.9% vs. 5.4% U.S.) persons and a larger share of Asian persons (4.1% vs. 2.5% U.S.) Washington also has twice the national proportion of older Native Americans (0.8% vs. 0.4% U.S.)⁸.

Washington ranks 34th nationally in the proportion of its population ages 85 and older. In 2000, 84,085 persons, or 1.4% of Washington's population, were ages 85+.⁹

An estimated 540,272 family caregivers reside in Washington. These family caregivers provide about 503 million hours of caregiving per year at an estimated value in 1997 of \$4.1 billion.¹⁰

Washington's state tax revenue in 2001 was \$12.7 billion, or \$2,117 per capita, placing the state 16th in the nation. Washington does not have a state income tax but relies upon property, sales and business taxes for its general revenues. A ballot initiative in 1994, I-601, imposed a stringent cap on general fund spending, limiting increases to a three-year average of inflation and population growth. During the economically robust mid-1990s, state budget surpluses grew because of this spending cap, setting the stage for tax cut initiatives, such as one in 1999 that replaced the state's motor vehicle excise tax with a \$30 annual fee and reduced state revenues by hundreds of millions of dollars. As a share of personal income, total state taxes dropped from 7.2% in 2000 to 6.8% in 2001.¹¹

Table 1. Selected Characteristics of WASHINGTON and the UNITED STATES, 2000 ^a

	Washington	United States
Total Population Characteristics		
Total Pop. ^b	5,894,121	281,421,906
% African American ^c	3.2%	12.3%
% Hispanic ^d	7.5%	12.5%
Older Population Characteristics		
Pop. 60+ ^e	873,223	45,797,200
% 60+ ^f	14.8%	16.3%
National ranking 60+ ^g	45	NA
Pop. 65+ ^h	662,148	34,991,753
% 65+ ⁱ	11.2%	12.4%
National ranking 65+ ^j	43	NA
Pop. 85+ ^k	84,085	4,239,587
% 85+ ^l	1.4%	1.5%
National ranking 85+ ^m	34	NA
% increase 1990–2000 60+ pop. ⁿ	14.2%	9.4%
% White (60+) ^o	90.2%	82.4%
% African American (60+)	1.7%	8.4%
% Hispanic (60+)	1.9%	5.4%
% Asian (60+)	4.1%	2.5%
% Native Hawaiian/Pacific Islanders (60+)	0.1%	0.1%
% Amer. Indian/Alaska Native (60+)	0.8%	0.4%
Informal Caregiver Characteristics^p		
# of caregivers (1997)	540,272	25,798,370
Caregiving hours (millions) (1997)	502.9	24,013.1
Value of caregiving (millions) (1997)	\$4,113.6	\$196,426.7
Economic Characteristics		
Per capita income ^q	\$31,528	\$29,676
% of pop. below poverty (1997) ^r	10.2%	13.3%
Internet		
% of households w/Internet access (2001) ^s	49.7%	41.5%
Nat'l ranking of households w/Internet access	7	NA

a Unless otherwise noted, all data are from 2000.

b Mapstats-Washington, *www.fedstats.gov* (June 2002).

c Ibid.

d Ibid.

- e U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S. and for States: 2000*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- f Ibid.
- g U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States: Population for States by Age Group: Rank*, / www.aoa.gov/aoa/stats/2000pop/rankxpercent.html.
- h U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- i Ibid.
- j U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- k U.S. Administration on Aging, *Summary Table of Age Characteristics of the Older Population in the U.S.*
- l Ibid.
- m U.S. Administration on Aging, *2000 Census Figures for the Older Population, for States*.
- n U.S. Administration on Aging, *Profile of General Demographic Characteristics for the U.S.: 2000 with 1990 Data*, www.aoa.gov/Census2000/stateprofiles/ageprofile-states.html.
- o All percentages for 60+ white, African American, Hispanic, Asian, Native Hawaiian/Pacific Islanders and American Indian/Alaska Native populations are from U.S. Administration on Aging, *Percent of Persons 60+ by Race and Hispanic Origin—by State—2000*, www.aoa.gov/stats/2000pop/percent60plusrace-HO.html.
- p Informal caregivers are family and friends of adults with disabilities or of older persons. Source: P. Arno and M. Memmott, *Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997* (Washington, D.C.: Alzheimer's Association, March 1999).
- q U.S. Department of Commerce, Bureau of Economic Analysis, "State Personal Income and State Per Capita Personal Income: 2000" (news release), www.bea.doc.gov/bea/newsrelarchive/2001/spi0401.htm (2001).
- r Mapstats-Washington.
- s Congressional Quarterly, *Governing's State and Local Sourcebook: 2002*, www.governing.com/source.htm. Source for Internet access is the National Telecommunications and Information Administration, 2001.

STATE ADMINISTRATIVE STRUCTURE

Unlike in most other states, caregiver support services and long-term care for the elderly and adults with physical disabilities are administered in Washington through the Aging and Adult Services Administration (AASA), a part of the Department of Social and Health Services (DSHS). AASA is responsible for virtually all financing, regulation, quality assurance and policy for long-term care, whether these services are delivered in nursing homes, in private dwellings in the community or in nonmedical residential facilities. DSHS serves as the "single state agency" for Medicaid and has assigned to AASA the tasks for Medicaid long-term care services. In addition, AASA has responsibility for community-based services and nursing home care (state and federally funded), a small chore services program (state funded), and the state's respite care and family caregiver support programs (state funded). Last, AASA also serves as the State Unit on Aging, administering the provisions and programs of the federal Older Americans Act, including the NFCSP.

Washington's aging network includes a statewide system of 13 Area Agencies on Aging (AAAs). Most of the AAAs are part of city or county government, although two are Tribal governments and one is under a nonprofit agency. AAAs' planning and service areas range in size from one county or reservation to six. The state's AAAs administer home and community-based care and caregiver support at the local level.

Washington has a single point of entry for all state-funded long-term care services needed by anyone age 18 or older. Employees of the AASA, organized into six regions that cover the state, assess each applicant, create a care plan and authorize services. If the consumer will receive services in a nursing home or a nonmedical residential facility (adult family home, adult residential care or assisted living), an AASA staff member continues as the ongoing case manager. If the consumer remains in his or her own home, however, the local AAA takes over the ongoing case management role, including reauthorization of services and payment of agency providers. DSHS reimburses the AAA for these expenses. The state, rather than the AAA, pays independent providers directly.

Washington officials have been committed to expanding community resources and downsizing institutional care for decades. About 85% of the aging, developmentally disabled and mentally ill populations are served today in the community. Washington has a lower-than-average supply of nursing home beds, with 27,204 beds in 285 facilities in 1998 (41.7 beds per 1,000 persons ages 65 and older, compared to an average of 52.5 beds nationally).¹² The number of nursing home beds has actually fallen in recent years, partly because of an expansion of alternative services, including adult family homes, adult residential care facilities and assisted living facilities.

Washington's Aged/Disabled 1915(c) Medicaid waiver for the elderly and for adults with disabilities is called "Community Options Program Entry System," or COPES. Implemented in 1983, COPES offers a range of home and community-based services to persons who would otherwise require care in a skilled or intermediate nursing care facility. Within its state Medicaid plan, Washington has a personal care benefit and provides reimbursement for assisted living.

In FY 2002, the DSHS was awarded a \$1.4 million Real Choice Systems Change grant by the Centers for Medicare and Medicaid Services (CMS). The grant is administered by the Department's Health and Rehabilitation Services Administration. The purpose of the grant is to integrate systems that support transition from institutional settings and direct payment systems.

OVERVIEW OF STATE SYSTEM OF CAREGIVER SUPPORT

Washington set the stage for caregiver support programs with its historic commitment to home and community-based services. Having long recognized the informal caregiver as a major provider of long-term care services, Washington State has built caregiver support services into existing infrastructures and state-funded programs. The state has been a leader in caregiver-specific policies and programs.

Washington's state officials identified one statute, Chapter 74.41 RCW, that recognizes family caregivers. Respite Care Services were enacted statewide in 1989. The Fred Mills Act, enacted in 2000, added to Chapter 74.41 RCW, broadening the array of services to create the state's Family Caregiver Support Program. In addition, Washington State's strategic plan for long-term care references family caregivers. A bill to take effect in January 2003, SSB 6426, requires the state to offer family and medical leave benefits beyond the federally prescribed minimum. Under that bill, employers must allow employees to use "sick leave or other paid leave to care for a spouse, parent, child, parent-in-law, or grandparent with a health condition requiring treatment or supervision or for emergency purposes."¹³ Washington, having no state income tax, does not have a caregiver tax credit. Through SHB 1397, passed in March 2002, a "kinship caregivers working group" was convened, within existing resources, to review the study conducted by the Washington State Institute for Public Policy and published in June 2002 and prepare a briefing for the legislature due November 1, 2002.

Washington has three statewide programs explicitly designed to help family caregivers: (1) the state-funded Respite Care Program, (2) the state-funded Washington State Family Caregiver Support Program (FCSP) and (3) the new federally funded NFCSP. AASA's goal for its family caregiver support programs is "to develop a coordinated caregiver support program, linking existing infrastructure and network services with new programs/services."¹⁴ With all three of these programs run through the AAAs, as are the state's other community-based long-term care programs, this goal

seems reasonable. For example, caregivers whose family member receives services through the COPES Medicaid waiver or other state programs are to be made aware of the AAA's Information and Assistance (I&A) number so that they may access additional services for themselves. The I&A programs also cross-refer to COPES, Medicaid personal care and chore services during caregiver screening.

Stakeholders agreed that family and informal caregivers are recognized as a central part of Washington's long-term care system. Some saw this as a work in progress, however. "More so now," said one: "For a long time family caregivers were taken for granted." Another felt that NFCSP is "opening a lot of eyes." Like state officials, stakeholders cited the state's Family Caregiver Support bill and said it had raised the awareness of legislators about caregivers' situations. Still, the main perspective has to do with the economic value to the state of family caregivers' services, rather than with the needs of this group. Several stakeholders mentioned that caregivers do not see themselves as caregivers eligible for services, making outreach a challenge. "A caregiver usually self-identifies as a son or a daughter who is doing what they are supposed to do—taking care of a parent who needs help." Ethnic minority caregivers, in particular, were reported to believe that caring for a relative is normal and not to see this service as a huge burden for which they should receive help. One informant wondered, "Do we need to make people, who are doing what they think is the right thing to do, be 'dependent'?"

The annual caregiver conference convened by DSHS/AASA, AARP, the Alzheimer's Association and others provides training on emotional health and well-being, along with hands-on training for care provision. State officials view the conference as a place to coalesce groups of providers for work on joint projects, and as a support service for caregivers. Some tribal areas now offer caregiver training, too, and some workshops take place in Spanish. The local coalitions created to carry out the workshops and conferences throughout the state proved to be useful for developing more sophisticated caregiver support services after the NFCSP passed.

State officials believed that the priority for caregiver support services in Washington was "somewhat low" among long-term care programs offered by DSHS because Medicaid programs, with a \$1 billion budget, drive the priorities. In comparison, family caregiver services are small. One observer considered this low priority ironic, given all the talk in the state about natural support systems, and felt that growing these resources was an evolutionary process.

PROGRAM BACKGROUND/DEVELOPMENT

Washington has built its caregiver support capacity through state-funded demonstrations, federal demonstration grants and foundation funds. Between 1993 and 2000, Washington received two federal Alzheimer's Disease Demonstration Grants to States, administered by AASA and funded first by the Health Resources and Services Administration (HRSA) and then by the Administration on Aging (AoA). The demonstration projects targeted four ethnic communities, (Chinese, Hispanic, Korean and Native American), as well as rural communities. Through the demonstration, 4,822 caregivers and others were trained, 387 families received culturally appropriate respite services, 268 persons received in-home diagnosis through the University of Washington/Alzheimer's Disease Research Center and various educational tools were developed.

Since 1993, Washington has had an annual regional training conference for caregivers, with the first conference launched as a collaborative effort of AASA, AARP, AoA and numerous community organizations. In 1998, the state developed the 57-page *Caregivers' Handbook*,¹⁵ it has distributed 45,000 copies of this guide to family and other unpaid caregivers of adults with disabilities. In 1998, the Brookdale Foundation awarded the state a Relatives as Parents Program (RAPP) State Initiative grant, making possible the creation of a state RAPP coalition of 40 public and private organizations, a RAPP website (parenting.wsu.edu/relative/index.htm), a training video, a resource guide, a state conference on laws and resources, and a statewide kinship caregiver survey.

Initially the state's Respite Care Program was a demonstration project operated by three AAAs; during its first two years, it served 1,408 caregivers with an appropriation of \$545,000. Legislation in 1989 made the Respite Care Program statewide. The program is designed to provide relief to unpaid caregivers who offer continuous care and/or supervision to persons ages 18 or older who have a functional disability.

Washington State's FCSP was a natural extension of the state-funded Respite Care Program. In 1999, the AAAs' Respite Care Program managers, the Washington Association of Area Agencies on Aging, caregiver organizations and AASA created a framework to provide unpaid caregivers supportive services. At the same time, State Representative Carolyn Edmonds and six other Washington State legislators attended a national policy conference on caregiving for state legislators in October 1999, sponsored by the San Francisco-based Family Caregiver Alliance. As a result of both efforts, SHB 2454, the Family Caregiver Support bill, (also known as the Fred Mills bill), was authored by Representative Edmonds, was introduced and received unanimous support. It passed during the 2000 legislative session with a modest \$610,000 appropriation, in a year when passage of any new programs was deemed most unlikely. The new state funds allowed Washington to enhance service delivery to caregivers beyond respite care, emphasizing specialized information and assistance, caregiver training and consultation, support groups and supplemental services.

Following passage of SHB 2454, AASA requested plans from the AAAs in the fall of 2000 to identify local family caregiver needs, current caregiver activities (those of the AAA and of other public/private local agencies), culturally relevant services, outreach strategies that would include those who do not recognize themselves as caregivers, collaboration with other agencies and core services to be implemented.

By the time the NFCSP was enacted at the end of 2000, the state of Washington had some experience in providing caregiver support services. Thus, both the AASA and the state's AAAs were primed to respond to the new federal caregiver support initiative and to further expand family caregiver support. Seeing its role as shaping local processes rather than as prescribing the exact way in which AAAs should provide services, AASA developed a framework for and facilitated discussions with the AAAs, distributed materials to them and made it clear that a multifaceted system was to be developed, rather than a system with a single-service focus. In addition, AASA required the AAAs to develop plans showing how NFCSP funding would result in something new and address each of the five core service categories. In March 2001, AASA asked the AAAs to present their NFCSP plans, addressing its requirements in addition to the requirements of the state FCSP, including counseling, targeting caregivers in the greatest social and economic needs and serving both older grandparents raising children and older caregivers of persons with a developmental disability.

Most rewarding: Respondents felt that the availability of a variety of services offered by the 13 AAAs was particularly rewarding in the development and implementation of Washington's family caregiver support services. "The beauty of it is that it's turned out so different in each place, that we see there was enough flexibility to allow it to sort of blend with whatever the community already had or didn't have," one said. "There's definitely flexibility. We like to say flexibility with accountability." Another rewarding aspect is that "people really like supplemental services, be they...technology or...giving a caregiver transportation if they don't have their own." Also noted were the energy and innovation seen across the state among the aging network and service providers.

Biggest Challenge: "A big challenge that we faced—in both the state-funded FCSP and the NFCSP—was discouraging the AAAs from simply focusing on respite services," reported one state official. "Respite is a wonderful service and caregivers really need it. It's hard when you recognize how important respite is to people," she explained, "to take that extra step and say now we've got to go move onto these other more important support services." The state initially limited the share of funds that could go to respite programs under the state FCSP to 25%, then increased it to 35% when the federal dollars came. "We had an expectation that all core services would be offered." Initially the AAAs felt that with such a small amount (around \$30,000 for most during the first year of the state FCSP), the funding should simply be incorporated into their current budgets. "We were saying, 'We really want you [the AAAs] to develop an in-depth plan, and tell us what will be done to meet the identified roles.' There was no guarantee that the federal dollars would come, but we were very hopeful," the state official said. "The AAAs really had to go on faith."

As a result of some of the state's policies, the AAAs developed programs that created "a lot more sophisticated presentation of specific information," especially about dementia and Alzheimer's disease. "Whereas respite focuses on relief, which is really important, these other activities focused on some real specific tools these caregivers could use," the official continued. "I've had a number of caregivers call me and say that they had been [respite] participants for a long time... and they really appreciated it. They thought it was wonderful, but the other...caregiver support activities sort of took them to a new level in terms of things that they could use to make their caregiving experience more successful."

Respondents indicated that reporting has been a "nightmare" with such flexibility and with the three different programs (i.e., the state-funded Respite Care Program and FCSP and the federally funded NFCSP). "Even the funding cycles are different," said one state official. A related challenge is the differing eligibility criteria for the state and federal programs: Whereas the federal program is only interested in caregivers of people age 60 and older, the state helps caregivers of any age who care for adults (age 18+). "So it's a lot" for the front line worker "to figure out where this person is going to be served."

FUNDING

In FY 2001—the first year of federal funding under the NFCSP—Washington State received \$2.1 million in federal funds. In FY 2002, the federal appropriation increased, so that Washington's share was nearly \$2.3 million. This past year, Washington had a budget of \$2.8 million for the Respite Care Program, \$610,000 for the state FCSP and \$2.3 million for the NFSCP. The sum of these funds represents just a bit over half of 1% of the agency's total budget of \$1 billion (including Medicaid expenditures) for FY 2001–02.

In the first two years of the state's FCSP, the AAAs have received an annual allocation ranging from a low of \$7,966 (for a tribal AAA) to a high of \$172,111; most AAAs received between \$30,000 and \$40,000. In the first year under the NFCSP, the AAAs received funds from a low of \$25,853 to a high of \$558,656, with most receiving allocations between \$100,000 and \$130,000.

The downturn in the economy has not yet had an impact on funding for family caregiver support services, but respondents were uncertain what would happen in the coming year. The state budget situation was described as “dismal,” “very sour,” “a crisis,” “bleak” and “horrible.” State officials and stakeholders all agreed that the recession had hit Washington very hard.

Adding to the woes of two major segments of the state's economy, technology and aerospace, are populist ballot initiatives that changed the way the state pays (or does not pay) for services. Initiative 601 capped expenditures based on a combination of inflation and demographics, but the “market basket” used for its calculation does not reflect the needs of the long-term care population. The demographic measure is a global one, not taking into account the mix (i.e., that the 85+ population is growing at twice the rate of the general population, while the overall numbers decline as younger people exit the state in a “down” economy.) This impacts the state by having fewer persons available to support children and older persons financially and through caregiving. Another recent initiative increased teachers' wages without a revenue source, putting stress on other programs because the budget cannot grow overall. With no income tax, the state must rely upon sales and property taxes, including an automobile excise tax. Initiative 695 cut the latter from an average of \$400 to \$30 per vehicle. Although I-695 was challenged and found by the courts to be unconstitutional, the legislature accepted its limits during the budget process anyway and enacted the cuts. The state has been betting on “Pro Share” (increased federal reimbursement for rural hospitals) to make the budget work.

Washington received about \$132 million in tobacco settlement funds during FY 2000 and another \$142 million in FY 2001. This year the tobacco settlement was used to balance the state budget, helping with the Basic Health Plan (BHP), the low-income insurance plan sponsored by the state. Washington State is pursuing tobacco securitization.

PROGRAM ADMINISTRATION

Respite Care Program: The 13 AAAs manage the Respite Care Program. AASA distributes funding to the AAAs using the Older Americans Act Title III allocation formula. A sliding fee scale is used, based on the income of the care recipient. “Banking” of respite is discouraged in this program and the family caregiver support programs, because past experience shows that caregivers may not use the banked services, resulting in the AAA having to return unspent respite funds to the state.

Washington State FCSP: AASA is charged with administration of the program, which is implemented at the local level by the AAAs. Funding is distributed to the AAAs based upon the state's funding formula. The state-funded FCSP is now used as the state match for the federally funded NFCSP. In implementing the FCSP, the state developed common core service definitions, reporting requirements and screening processes for use by the AAAs. State officials reported that the flexibility allowed by AASA has led to unique local programs. Since a strong state-funded respite program already existed,

AASA capped respite care expenditures at 25% during the first year of the state program, then increased it to 35% in the second year of program operation. The state does not impose an individual cap on the amount of respite, and the caps imposed by the AAAs are not uniform across the state.

NFCSP: AASA administers the NFCSP at the state level, and the AAAs implement the program at the local level. Again, funding is distributed to the AAAs by an allocation formula. AASA's role at the state level is to set policy for caregiver services and to establish requirements for developing services, reporting and setting up contracts. The state also coordinates sharing of information among the AAAs and provides training, administrative coordination and promotion of the program. AASA has imposed a 35% cap on respite care. A sliding fee scale is used for respite care and is optional for other services. One AAA is experimenting with cost-sharing for supplemental services. The state does not impose individual respite caps, but AAAs may set such for their locality. The NFCSP has been publicized in Washington through conferences, websites, AAAs' local outreach, caregiver kits, the Community of Faith program (and kit) and pharmacy bags. The NFCSP in Washington, although delivered locally and with unique features in each locality, is moving toward statewide identification. The state-funded FCSP is also moving toward statewide identification through a uniform name, The Family Caregiver Support Program (FCSP), definitions and a common contact form.

The state has set aside 5%, or \$130,000, of the administrative support provided by the federal funds as seed money for special projects to target underserved populations. This initiative is called "Innovations in Family Caregiver Support." In June 2002, 10 projects (four rural, five ethnic and one ethnic-kinship) were selected through a Request for Proposal (RFP) process and received one-time-only funding (e.g., up to \$15,000 each for ethnic and rural projects and up to \$10,000 for ethnic-kinship projects).

Some stakeholders felt that Washington does not provide strong oversight to ensure consistency across the state. These stakeholders believed that an increased level of consistency in eligibility requirements, similar to that of the Medicaid program, would be helpful. Additionally, standardization would help facilitate caregivers' access to services—knowing where to go for a particular service and who is in charge of what. Despite some concerns about statewide consistency, stakeholders agreed that the flexibility allowed the AAAs is good, because it enables AAAs to respond to local needs and to innovate.

PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

Respite Program: In this program, the caregiver may be of any age, but the care recipient must be age 18 years or older. The caregiver must be unpaid and provide continuous care and/or supervision. Respite eligibility is driven by daily time in caring (on average, at least 12 hours), rather than by the caregiver's perception of need, which are considered during the service priority process. The care recipient must need substantially continuous care or supervision and must be assessed as requiring placement in a long-term care facility in the absence of an unpaid caregiver.

Stakeholders pointed out that the 12-hour daily caregiving requirement means that working caregivers, including self-employed persons who work at home and give care while they work, are ineligible for services. The rules for eligibility are interpreted inconsistently across the state, stakeholders said. In one AAA, for example, respite is provided on a first-come, first-served basis, making it impossible for a caregiver to count on a standing respite period. Each month, the caregiver has to call to request respite, hoping that the limit has not been reached. This approach makes consistency of respite workers difficult, which is a problem for a person with dementia.

Washington State FCSP: As with the Respite Care Program, caregivers must be unpaid and can be of any age, but kinship caregivers are not eligible. The care recipient can be of any age 18 or older and must have a functional disability.

NFCSP: The entry point for the caregiver is usually through the AAA's I&A staff, although two-thirds of the AAAs have identified "family caregiver specialists." AAAs use the federal eligibility criteria under the Older Americans Act: informal caregivers of any age who provide care to persons age 60 or older, as well as caregivers age 60+ who are caring for grandchildren age 18 or younger, and older caregivers (age 60+) who are caring for children who are mentally retarded or have developmental disabilities. For respite and supplemental services, the care recipient must have two or more ADL limitations or cognitive impairment.

Washington has developed a uniform Family Caregiver Contact Form for use by AAA staff and service providers to document caregiver needs, primary health conditions of the care recipient, ethnicity and language; the form also includes referrals for caregiver support and long-term care services. Even more significant, caregiver assessment is being integrated into the state's Comprehensive Assessment (the uniform assessment tool for all long-term care programs). Currently, the Comprehensive Assessment tool focuses on the care recipient, taking the informal caregiver into account only when determining unmet needs of the care recipient. One respondent pointed out that the tool does not currently capture the need for emotional support. In the future, AASA plans to incorporate caregiver needs into the uniform assessment tool.

SERVICES

Caregivers' access to services varies by geographic area, according to several observers. In part, this is because of the lack of trained providers in some regions of the state. Generally, and increasingly, because of the infusion of federal funds through the NFCSP, services to caregivers are provided as part of a larger, multicomponent family caregiver support program.

Respite Program: In-home, out-of-home and institutional respite are covered, with all levels of care included (from supervision to nursing care), both on a planned and an emergency basis.

Washington State FCSP: Caregiver support services include information, assistance, promotion and implementation of support groups, caregiver training, respite care and supplemental services. Counseling services are *not* included. Despite the latitude granted to the AAAs, there is commonality across the state, including family caregiver conferences (offered in different languages depending upon the locality), family caregiver training ("Fundamentals in Caregiving," "Powerful Tools for Caregiving" and individualized training) and caregiver resource centers, with books, videos and CDs,

caregiver web pages and caregiver kits. The most common condition among care recipients is Alzheimer's disease or related dementias, and the most commonly used service (based on the number of calls) is the provision of specialized caregiver information.

During the first year of the FCSP (October 2000 through September 2001), the AAAs received 3,165 calls for specialized caregiver information, provided 135 group training sessions or presentations reaching 2,236 persons, gave one-on-one training by professionals to 193 caregivers, assisted 1,454 family caregivers in gaining access to long-term care services and provided 189 caregivers with 9,307 hours of respite. During the second year, three times as many calls were received in the first six months as in the entire first year: 4,114 between October and December 2001 and 6,002 between January and March 2002.

Examples of promising efforts of specific AAAs include:

1. A focus on "hidden" caregivers through work with the Community of Faith outreach services, with presentations and printed materials ("Community of Faith Caregiving" curriculum)
2. Targeted outreach and service delivery focusing on male caregivers
3. A peer mentoring program, in which former caregivers provide support to current caregivers
4. Caregiver resource libraries
5. Pharmacy bags and posters in physician offices
6. Caregiver kits, many being translated

NFCSP: All NFCSP core services are available in almost every AAA region. Following the standard assessment, the intent is to give caregivers a menu of services from which they may choose to help meet their needs: information; assistance; individual counseling, support groups, training; respite care; and supplemental services.

The COPES Aged/Disabled Medicaid waiver covers an array of home and community-based services for Medicaid-qualified care recipients who are eligible for nursing home care. Many COPES services also support the client's family caregivers. Key examples are help with personal care and household tasks in the home, adult day care, environmental modifications, home-delivered meals, home health aide services, personal response systems and training and transportation to meet a therapeutic goal.

Major service needed by caregivers: The major services needed by family caregivers, state agency respondents noted, were respite, specialized caregiver information, training and consultation with specialists (lawyers, rehabilitation therapists, registered nurses). One respondent believed that caregivers need a sense of community to minimize their isolation. One stakeholder identified a range of services, including home help, education, care consultation and ongoing support groups for emotional support and to relieve isolation.

Stakeholders agreed that respite is crucial to sustaining family caregivers. They also mentioned information and assessment by an expert with empathy who can help caregivers self-identify. Another key informant stressed the value of "listening, being there at the time when they need to make a difficult step" to provide counseling and help with negotiation of family roles. "This is not a cookie

cutter situation,” one key informant said. “Caregivers have unique needs. Some want to do the caring themselves, so what they need most is someone to do chores. Others are totally burned out and what they need is residential placement for their loved one.” Key informants also indicated that education and planning (e.g., learning the Medicaid eligibility rules) and both group and individual training are valuable, especially to people who already self-identify as caregivers.

Stakeholders identified several caregiver support services that would enhance the program. Some said that they would like to see more direct payments go to caregivers—“grants to remove the barriers to services.” A caregiver with a grant might try adult day health care and then decide it was well worth using, for example. Another need is for early-stage Alzheimer’s classes to educate the caregiver before the crisis occurs.

Table 2. Family Caregiver Support Services in Washington

Program	Respite Care Program	State Family Caregiver Support Program	National Family Caregiver Support Program
State Administrative Responsibility	Aging and Adult Services Administration, Department of Social and Health Services	Aging and Adult Services Administration, Department of Social and Health Services	Aging and Adult Services Administration, Department of Social and Health Services
Local Service Delivery	AAAs ^a —information, assistance, assessment & case management; AAAs are not direct service providers but contract for respite care services.	Most of the AAAs provide FCSP information and assistance in-house. Some contract out these services. AAAs also contract most of the training and support groups and all of respite and supplemental services.	Same as the FCSP. Under the NFCSP, the AAAs also contract out most of the counseling services.
Funding Source	State general funds	State general funds	Older Americans Act, III-E
Expenditures FY 2001–02	\$2.8 million	\$610,000	\$2.3 million
Client Population	Family & informal caregivers	Family & informal caregivers	Family & informal caregivers
Eligibility:			
Age	18+ care recipient	18+ care recipient	60+ care recipient
Income	Family and other unpaid caregivers of any age	Family and other unpaid caregivers of any age	Family and other unpaid adult caregivers of person 60+ ^b
Functional Ability	None	None	None
	Care recipient who needs substantially continuous care or supervision (at least 12 hours/day) and has been assessed as requiring placement in LTC facility in the absence of an unpaid caregiver	Caregiver who has primary responsibility for the care of an adult with a functional disability and does not receive financial compensation for the care	For respite and supplemental services, care recipient with at least 2 ADLs or cognitive impairment
Uniform, Statewide Caregiver Assessment	Yes	Yes	Yes
Services Provided to Family Caregivers	In-home respite Out-of-home respite Institutional respite	Information Assistance & consultation Support groups Training Respite care Supplemental services (e.g., consumable supplies)	Information Assistance Counseling, support groups, training Respite care Supplemental services
Respite Cap	Individual caps on amount of respite vary by AAA	35% cap on respite expenditures per AAA Individual caps on amount of respite vary by AAA	35% cap on respite expenditures per AAA Individual caps on amount of respite vary by AAA
Consumer Direction	No	No	No
Family Caregivers Paid as Respite Providers	No	No	No

a AAAs = Area Agencies on Aging.

b Also a caregiver age 60+ providing care to a person with a developmental disability or a grandparent caregiver raising a child.

CONSUMER DIRECTION

Washington has not yet adopted consumer direction in its caregiver services. Within the COPES Aged/Disabled Medicaid waiver, consumer direction is strong: anyone requiring 112 or more hours of service per month *must* use an independent provider (rather than an agency) for services. The state pays the independent provider directly, but the client (i.e., the care recipient) is considered the employer. Since the state, rather than the AAA, pays these independent providers, the AAA cannot build consumer direction into the caregiver support program based on local experience. Family members who are hired as providers for COPES or the Medicaid Personal Care program must have criminal history background checks and must complete required training. If the provider has not lived in the state of Washington for at least three years, an FBI check is done. As one respondent observed, however, many workers are immigrants from another country, so the FBI check is of little use. Parents can be paid as providers, but spouses cannot be. The impetus for consumer-directed care in these programs is the shortage of workers and the preference of many clients to have a family member provide the care. Washington has no restriction related to whether or not the provider lives with the care recipient. State officials commented that about half of the paid providers are family members.

Paid caregivers are required to have 22 hours of caregiver training (soon to be increased to 28 hours) and 10 hours of continuing education each year. The training is provided through contract with the AAAs. Some AAAs provide the training directly and some contract it out. State officials noted there is funding for a substitute caregiver while the independent provider is in training. Training is also available for COPES clients, on a one-to-one basis, to help them learn how to be more involved with their own care.

State officials said that Washington is not yet looking at fiscal intermediaries for the family caregiver support program, and they did not think it made sense to handle consumer direction for respite through the state system, rather than at the AAA level, because the scale is so limited (i.e., handling a bill for 8 hours of respite vs. 184 hours of personal care). Providing caregivers with vouchers, along with a list of preferred providers, is the more likely option. AAAs have not yet developed this option but are considering it. One of the Innovation in Caregiver Support grants was awarded to the Olympia AAA. They are developing a pilot project to allow caregivers to employ independent providers for respite care. A service system will be developed, implemented and evaluated, resulting in a program that gives caregivers greater flexibility and control in how, when and to whom respite will be provided as well as serving as a model for others to replicate statewide.

A recent development reported by one state official was a voters' initiative to establish a Home Care Quality Authority, a statewide public authority that would cover any long-term care eligible person, including private pay and children. The official was not sure what impact this development might have on respite or family caregiver programs. With money in the budget, the governor was appointing nine members to the public authority, and funding was going to the Public Employees Negotiating Board to work with the union to implement this program. "We need to get better at consumer direction," commented one respondent. "We need to enable consumers to be equal partners with case managers in the design of services, as well as the hiring and firing of workers, etc."

QUALITY ASSURANCE AND EVALUATION

The AAAs collect data for care recipients through the Comprehensive Assessment instrument and for caregivers primarily through the Family Caregiver Support Program Contact Form. The Comprehensive Assessment instrument is currently undergoing revision and will include caregiver questions in the future; in the meantime, only the following “yes/no” items are included:

1. Primary caregiver who is unpaid
2. Primary caregiver paid privately (not DSHS paid)
3. Caregiver able and willing to continue care

The Family Caregiver Support Program Contact Form collects the following information:

1. Contact information (date, staff, nature of contact, how person heard about the program, caller’s relationship to care recipient, age of care recipient)
2. Caregiver information (name, address, telephone number, whether person is primary caregiver, gender, ethnicity, language used, under/over age 60, relationship to care recipient)
3. Care recipient information (name, address, telephone number, gender, ethnicity, primary health conditions, whether care recipient receives case management services and from whom, narrative)
4. Disposition (type of information provided—12 topics and “other”; assistance in gaining access to services—type/s of referral/s provided; type of support provided; other action; unmet needs or requests)
5. Progress notes
6. ADL screening for supplemental services (needs assistance with two or more ADLs, requires supervision due to cognitive impairment)

AASA requires the AAAs to submit quarterly reports for the caregiver support programs. Each AAA must report on:

1. Specialized caregiver information services (number of calls for state and national FCSP, callers’ relationship to care recipient, age of care recipient)
2. Assistance in gaining access to long-term care family caregiver services (number of caregivers assisted through the state and national FCSP; age, ethnicity and language of caregiver; health conditions of care recipients)
3. Group presentations (number of events and attendees, separated by state and national FCSP)
4. Counseling (individuals and hours—NFCSP only)
5. Training/consultation (number of events and attendees, separated by state and national FCSP)
6. Support groups (number of new and existing groups, facilitators and caregivers involved, separated by state and national FCSP)
7. Respite (number served and hours provided, separated by state and national FCSP)
8. Supplemental services (number of durable goods/assistive devices, one-on-one consultations with specialists, specialized transportation trips, interpreter services, other)

These reports have been in a paper based format, but the state is working on computerizing the report. According to state officials, the current data collection system gives Washington a better picture of caregiver needs than what AoA requires in their annual report. Two limitations respondents noted are that the database is not yet computerized and that some of the definitions provided by AoA are unclear or not useful. No data are being collected on caregiver outcomes.

To evaluate the success of the program, the state uses narrative and statistical reports on service utilization (both quarterly reports and case studies) and will be incorporating site visits in the near future, for which a tool was under development. Some, (but not all) AAAs do client satisfaction surveys, and satisfaction is assessed of caregivers who participate in the Powerful Tools training program.

SYSTEMS DEVELOPMENT

Both state officials and stakeholders said that the groundwork for implementing the NFCSP had been done through launching the state FCSP, so implementation of the federal program was relatively easy. State officials identified three main impacts of the first year of the NFCSP on future policy and program development:

1. Identification of problems in the referral process between the Medicaid programs and the family caregiver support programs
2. Recognition that the Comprehensive Assessment tool used for all community-based long-term care programs must assess caregiver needs
3. Growing use of the Powerful Tools training program for caregivers

Some stakeholders said that it was too soon to tell how the NFCSP would affect future policies and programs for family caregivers, especially with all the attention required to plug holes in the state budget. They underscored how important “nonsupplanting” language had been under such budgetary pressures. Others cited the launching of Caregiver Support Centers across the state and an increase in focus and visibility. One commented that this development stems from the cap on respite, which allowed funds to be channeled in other directions, encouraging the development of information and educational programs. These programs reach more caregivers than respite, but they may increase the demand for respite later. One respondent expressed concern as to whether implementation of the NFCSP distracts policymakers from the big money issue (i.e., Medicaid). That respondent hoped that there would be a big leap toward social insurance as family caregivers become involved and that the caregivers would galvanize support.

Washington does not have a body whose mission is coordination of family caregiver support services across state departments; AASA administers all long-term care services, including support for family caregivers. At the local level, AAAs are viewed as the coordinators for caregiver support.

STATE INVOLVEMENT OF FAMILY CAREGIVERS IN *OLMSTEAD* DECISION PLANNING

The governor has designated DSHS as the lead agency for *Olmstead* planning. Washington has an *Olmstead* task force with a family representative on it. The family caregiver is the parent of a developmentally disabled child, however. “There is no one from ‘our system,’” observed one state official. Because the vast majority of people needing long-term care in Washington are already receiving it in the community, the *Olmstead* plan is seen in the state as an effort to further coordinate and accelerate ongoing processes and programs. The Washington State Disability Initiative Advisory Committee serves as the main conduit for stakeholder input.

OTHER POLICY ISSUES

State priority on caregiver support: State officials and stakeholders were asked, “Within all the long-term care programs in your state, what priority (high, medium, low) is placed on caregiver support?” As shown here, the key informants interviewed varied in their estimation of the priority placed on caregiver support. One stakeholder indicated that the priority was “low-medium” while another said that it was “medium-high.” One state official believed the priority was “low.” Another state official and one stakeholder did not answer the question.

State officials commented that the legislature is interested in caregiver support, but budget problems have precluded action to expand services in the near future. One stakeholder believed that the priority had been “low” two years earlier but that it had climbed a little higher as recognition of and programs for caregivers in Washington State had increased.

Number of Key Informants	Priority on Caregiver Support
2	No response
1	→ Low
1	→→→ Low-Medium
1	→→→→→ Medium-High

Benefits and challenges: Key informants identified three aspects of their program that are most beneficial to family caregivers:

- ✧ Centralized access point for services for caregivers, with a consistent name for the program
- ✧ Training for caregivers
- ✧ Support groups

The following challenges were reported:

- ✧ Different funding sources for different populations; different funding cycles and reporting requirements
- ✧ Integration of respite for caregivers through the COPES Medicaid waiver and into the home and community-based long-term care system
- ✧ Difficulty reaching the underserved populations meaningfully
- ✧ Difficulty reaching caregivers earlier (many wait too long to use services)

Major lessons learned:

- ✧ The high level of innovation and interest at the AAA level
- ✧ Legislative support for family caregivers (“this was an easy sell,” one said)
- ✧ The need for better referrals between programs

Opportunities for expanding caregiver support: Respondents were not optimistic about the expansion of state-funded programs for family caregivers over the next three to five years. Two respondents noted the potential for Lifespan Respite, however, a concept that is gaining momentum in Washington State. One state official lamented that it is hard to get caregivers, who are tied down by caring for their loved ones, out to participate in educating policymakers and the public. One saw no increases for human services at all in the near future. Another thought that support for grandparents and relatives might be expanded, especially to reach younger grandparents who now are excluded. All key informants, however, emphasized a dismal budget picture over the next few years.

Recommendations for other states: State respondents offered several recommendations, based on their experience to date:

- ✧ Include caregivers of all ages, with no barriers tied to the care recipient’s condition.
- ✧ Create a comprehensive assessment that incorporates both the caregiver’s and the care recipient’s needs
- ✧ Build in flexibility, and focus on the caregiver in service delivery
- ✧ Give families a say in how money is spent on their behalf, whether through a cash-and-counseling approach or through a menu of services/providers from which they can choose
- ✧ Support thinking “out of the box”

As one key informant said, “Family caregiving is a critical public policy issue and we need to own it. We need to make clear that the caregiver, rather than the provider, should make the decisions. We need to invite them into the process. We all have a stake in the solution. Family caregivers are the ones to make that happen.”

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APPENDIX A
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Mark Buckley, Executive Director	Alzheimer's Association, Western and Central Chapter
Patricia Hunter, Family Services Director	Alzheimer's Association, Western and Central Chapter
Barbara Green, Care Consultant	Alzheimer's Association, Western and Central Chapter
Dennis Mahar, Director	Lewis-Mason-Thurston Area Agency on Aging

APPENDIX A

KEY INFORMANT LIST (CONTINUED)

NAME, TITLE	AGENCY/ASSOCIATION
Carrie Petit, Planner	Lewis-Mason-Thurston Area Agency on Aging
Sallie Nixon, Aging and Long Term Care Coordinator	Pierce County Aging and Long Term Care
Eileen Murphy, Associate Director, Information and Assistance	Senior Services
Toni Crutchfield, Outreach Support Advocate	Senior Services
Sally Friedman, Caregiver Advocate	Senior Services
Richard Dorsett, Executive Director	Washington Association of Area Agencies on Aging

APPENDIX B

SURVEY A: SITE VISIT PROTOCOL FOR STATE OFFICIALS

This survey is designed to profile the experience of 10 states in providing caregiver support services. Through in-person interviews with key informants, the survey will be administered to all state agencies and programs (within those agencies) that finance, deliver and regulate caregiver support services for older persons and adults with disabilities. This would include executive branch programs administering the National Family Caregiver Support Program (NFCSP), State General Funds, Medicaid waivers, and other state funding streams. The in-person interviews are expected to take between 1.5 to 2 hours each.

A. OVERVIEW OF STATE SYSTEM

1. In your state, are family and informal caregivers (i.e., friends, neighbors) recognized as a central component of a comprehensive long-term care system? How (e.g., in statute)?
2. What major legislation affecting family caregivers (FCs) exists in your state?
 - a. Expanded state family and medical leave laws?
 - b. Caregiver tax credit?
 - c. Support program financed through state general funds?
 - d. Other?
3. What are the key strengths/innovative aspects of your state's current caregiver support system?
4. To what degree has your state built caregiver support services into existing infrastructures or state-funded programs? Can you give an example?

B. PROGRAM BACKGROUND

1. What was the original impetus for the state program?
2. Briefly describe the history of the program.
 - a. In what year was it started?
3. What has been the most rewarding aspect of the program's development?
4. What has been the biggest challenge of the program's development?

PLANNING/DEVELOPMENT PROCESS - FOR "NEW" STATES ONLY ¹

1. Please give a brief history of the development of your FC support program.
2. Were there programs in other states that you looked at when developing your caregiver support program?
3. Describe the planning process your agency has taken with regard to developing your program.
 - a. Who are the critical players involved? What roles do they play?
 - b. How have caregivers been involved in the planning process?

¹ New states are those which were not profiled in Family Caregiver Alliance's *Survey of Fifteen States' Caregiver Support Programs*, 1999.

APPENDIX B

SURVEY A: SITE VISIT PROTOCOL FOR STATE OFFICIALS (CONTINUED)

C. PROGRAM ELIGIBILITY/ASSESSMENT PROCESS

1. Eligibility requirement: functional, age, diagnosis, income?
2. Who is considered the client in this program: care recipient, family caregiver or both?
3. Are there uniform assessment standards across the state?
4. As part of the program's assessment process, to what extent is informal care taken into account in the authorization of paid services for the care recipient?
5. Do you assess the family caregiver's needs and ability to provide care, or is the assessment just for the care recipient?
6. Does the assessment tool focus on the care recipient, caregiver or both?

D. PROGRAM ADMINISTRATION

1. What role does your agency play with regard to caregiver support services in your state?
2. How is your caregiver support program administered (state level, local level, etc.)?
3. How are policies developed for caregiver support services?
4. What is the state's role in developing these policies? [Probe: uniformity, flexibility, etc.]

E. SERVICES

1. What specific services does your program provide for FCs? (If respite is included, ask questions 2 - 4).
2. What types of respite services are offered through your program?
 - a. In-home
 - b. Adult day services
 - c. Overnight in a facility
 - d. Respite weekend, including camps
 - e. Other
3. Does your program cap the amount of respite for family caregivers?
 - a. If so, why? (e.g., state regulations, budget, etc.)?
 - b. If so, how is it done and what is the amount of the cap (e.g., per month, per year, other)?
4. Does your state allow caregivers to "bank" respite benefits and use the authorized amount whenever it is most needed?
5. Describe caregivers' access to these services (e.g., provider capacity; provider location; eligibility; availability; affordability; duration).
6. How are services delivered (statewide, locally, etc.)?
7. Are services generally provided as separate components (e.g., respite) or part of larger, multi-component family caregiver support programs?

APPENDIX B

SURVEY A: SITE VISIT PROTOCOL FOR STATE OFFICIALS (CONTINUED)

E. SERVICES (CONTINUED)

8. If your state has a Medicaid waiver for older persons, what does it provide to support FCs?
 - a. Paying FCs (consumer directed care)
 - b. Home modifications
 - c. Respite services
 - d. Caregiver Education and Training
 - e. Other family support services
9. Do waiting lists exist for caregiver support services?
 - a. If so, for which services?
 - b. If so, has the waiting list changed since the passage of the National Family Caregiver Support Program (NFCSP)?
10. Under the NFCSP, what service components are provided in your state?
 - a. Information to caregivers about available services
 - b. Assistance to caregivers in gaining access to supportive services
 - c. Individual counseling, organization of support groups, and caregiver training to assist the caregivers in making decisions and solving problems relating to their caregiving roles
 - d. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities
 - e. Supplemental services, on a limited basis, to complement the care provided by caregivers [Probe for examples.]
11. How is your state publicizing NFCSP services to FCs?
12. How have your FC Support services changed as a result of the NFCSP? [Probe]:
 - a. Funding
 - b. Program expansion or new program implementation
 - c. Expanded eligibility
 - d. Cost-sharing changes
13. Are there services that you think your agency should offer but currently does not?
14. In your view, what is the major service needed by family caregivers?

APPENDIX B

SURVEY A: SITE VISIT PROTOCOL FOR STATE OFFICIALS (CONTINUED)

F. CONSUMER DIRECTION

1. Does your program offer a consumer directed option?
 - a. If so, please describe.
 - b. If not, please explain why.
2. Does your program permit payment to FCs to provide personal care?
 - a. If so, what factors influenced this decision (e.g., shortage of workers to provide personal care)?
 - b. Under the NFCSP specifically, are direct payments to family caregivers allowed in your state? If so, are there any restrictions?
3. If family members are paid for caregiving, are there any restrictions (e.g., spouses cannot be paid, family caregivers can't be paid if they don't live with the care recipient)?
4. If your state permits payment to FCs, have you established qualifications for family members that differ from formal caregivers who provide such services?
5. Do you require criminal background checks for family caregivers to become personal care attendants (e.g., some states may exempt family members)?

G. FUNDING

1. What is your current budget (FY 2001–02) for caregiver support programs and how does this relate to your agency's overall budget?
2. What are the funding sources (Federal and State) for FC support services in your state?
3. How would you describe the current budget situation in your state?
4. What impact has the downturn in the economy had specifically on services to support FCs?
5. Have you been asked to reduce spending for caregiver support in FY 2002? If yes, what specific actions are you considering?
6. Has your state considered using tobacco settlement funds to shore up state spending on Medicaid? Caregiver support services?

H. QUALITY ASSURANCE AND EVALUATION

1. What information about FCs does your agency currently collect?
 - a. In what format (e.g., automated?)
2. What are the strengths and limitations of your current data collection practices?
3. Are you collecting data on caregiver outcomes? If so, in what areas? Can you give an example?
4. What criteria do you use to evaluate if the program is successful? [Probe:
 - a. Reporting on service utilization
 - b. Site visits
 - c. Client satisfaction surveys
 - d. Outcome measures
 - e. Cost-effectiveness studies
 - f. Other criteria
 - g. No program evaluation

APPENDIX B

SURVEY A: SITE VISIT PROTOCOL FOR STATE OFFICIALS (CONTINUED)

I. SYSTEMS DEVELOPMENT

1. Describe your experience in implementing the NFCSP in your state.
2. How has the first year of the NFCSP shaped future policy and program development for family caregivers in your state?
3. Are caregiver support services coordinated at the **local** level?
4. Are caregiver support services coordinated at the **state** level? If so, how?
5. Does your state have a coordinating body whose mission is coordination of family caregiver support services across state departments?
6. Is your caregiver support program integrated into your state's other long-term care programs or is it "stand-alone?"
7. If they are integrated, describe any challenges you have faced in coordinating these services.

J. OTHER POLICY ISSUES

1. What aspect of the program is the most beneficial to family caregivers?
2. Within all of the long-term care programs offered in your **agency**, what priority is placed on caregiver support services? [Probe: high, medium, low. Why?]
3. Within all of the long-term care programs offered in your **state**, what priority is placed on caregiver support services? [Probe: high, medium, low. Why?]
4. Describe your agency's partnerships with the private sector to support FC's. [Probe: businesses, disease-specific organizations, Chamber of Commerce.]
5. To your knowledge, are there any state programs in your state where the FC is considered the client?
6. Does your state have a task force addressing long-term issues including Olmstead? How has your state involved FCs in Olmstead planning?
7. What legislative or regulatory changes, if any, would enable your program to enhance its ability to support family caregivers? [Probe: Medicaid, NFCSP.]
8. What are the 3 main challenges for implementing FC support programs in your state?
9. What is the major lesson you've learned in providing caregiver support services?
10. Over the next 3-5 years, do you see your state expanding state-funded programs to support and strengthen FCs? [Probe: Other populations, such as younger disabled.]
11. What recommendations would you make to other states that are developing programs to support FCs?

APPENDIX C

SURVEY B: SITE VISIT PROTOCOL FOR STAKEHOLDERS

This study is designed to profile the experience of 10 states in providing caregiver support services. Through in-person interviews with key informants, a survey (Survey A) will be administered to all state agencies and programs (within those agencies) that finance, deliver and regulate caregiver support services for older persons and adults with disabilities. This would include executive branch programs administering the National Family Caregiver Support Program (NFCSP), State General Funds, Medicaid waivers, and other state funding streams.

Survey B will be administered to key informants associated with private organizations, consumer groups and other programs in a state that support family and informal caregivers. The in-person interviews are expected to take about 30 to 45 minutes.

1. What role does your organization or association play with regard to caregiver support services in your state?
2. In your view, what is the major service needed by family caregivers?
3. In your state, are family and informal caregivers (i.e., friends, neighbors) recognized as a central component of a comprehensive long-term care system? How (e.g., in statute)?
4. Within all of the long-term care programs offered in your state, what priority is placed on caregiver support services? [Probe: high, medium, low. Why?]
5. How would you describe the current budget situation in your state?
6. Has your state considered using tobacco settlement funds to shore up state spending on Medicaid? Caregiver support services?
7. How are caregiver support services coordinated at the **local** level?
8. Are caregiver support services coordinated at the **state** level? If so, how?
 - a. Does your state have a coordinating body whose mission is coordination of family caregiver support services across state departments?
9. How has the first year of the NFCSP shaped future policy and program development in your state?
 - a. In what way were you involved in the planning process for implementing the NFCSP?