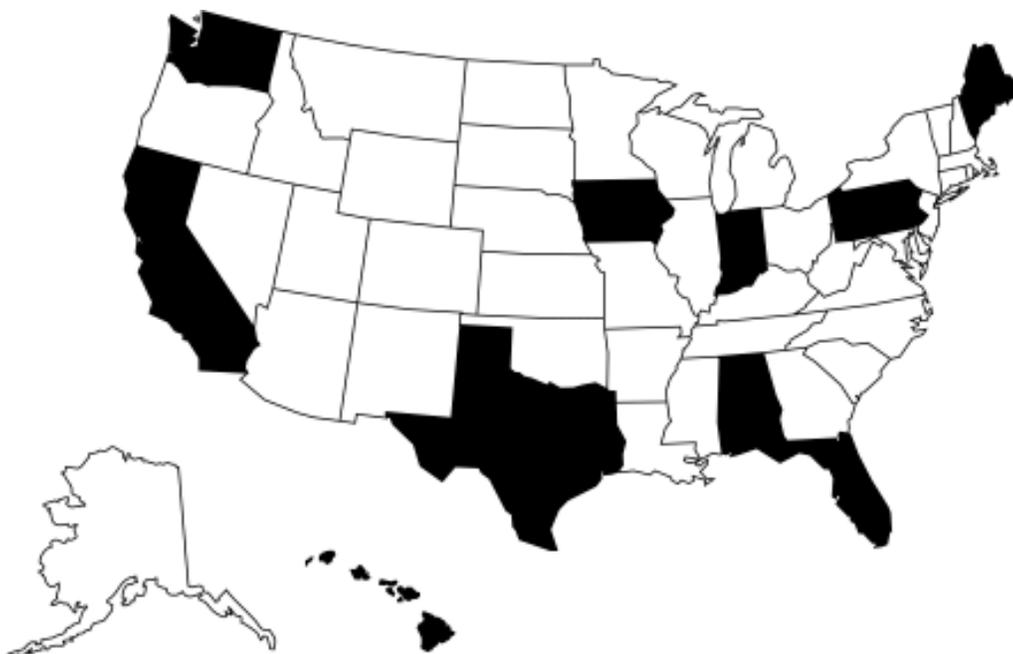


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**Family Caregiver Support:**  
*Policies, Perceptions and Practices in 10 States Since Passage  
of the National Family Caregiver Support Program*

November 2002



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## 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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**Family Caregiver Support:**  
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November 2002

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.

*Lynn Friss Feinberg  
Sandra L. Newman  
Carol Van Steenberg*

*National Center on Caregiving  
Family Caregiver Alliance*

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We sincerely want to acknowledge and thank many staff at Family Caregiver Alliance (FCA) for their numerous contributions. Kathleen Kelly, FCA's executive director, provided vital support and counsel throughout the project, and participated in site visits to two of the states. Sincere appreciation also goes to several staff for their invaluable help with a variety of project tasks: Lana Sheridan, Leslie Gray and Sara Adams. FCA's communications department worked diligently on the production of this report. Steve Czerniak, Julie Long and Bonnie Lawrence were notably crucial to this process.

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.<sup>1</sup>

Well into the 21<sup>st</sup> 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).<sup>2</sup>

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.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup>

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.<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup>

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.<sup>9</sup>
- ✧ 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.<sup>10</sup>

- ✧ 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.<sup>11</sup>
- ✧ 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.<sup>12, 13</sup>
- ✧ 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.<sup>14</sup> Medicaid spending on institutional care has grown more slowly, however, but still accounts for 70.5% of Medicaid long-term care.<sup>15</sup> 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,"<sup>16</sup> 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.<sup>17</sup> 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<sup>a</sup>, 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

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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.<sup>18</sup>

*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.<sup>19, 20</sup> Caregiver assessment legitimizes the needs of family caregivers themselves as distinct but related to those of the care recipient.<sup>21, 22</sup> 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.<sup>23</sup> As some researchers conclude, "The ultimate way to maximize choice is to ensure that people have the cash to purchase the services they prefer."<sup>24</sup> 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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