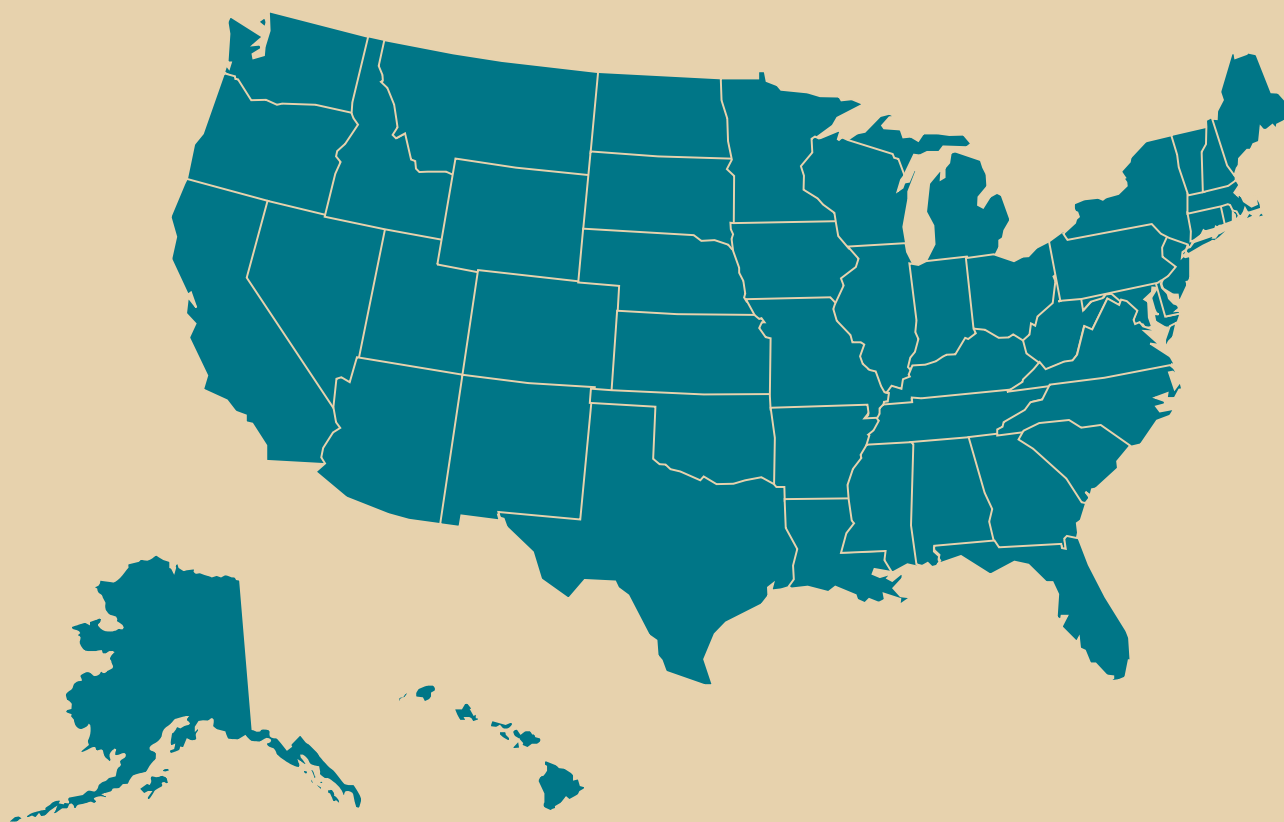


The State of the States in Family Caregiver Support:

A 50-State Study



November 2004



FAMILY CAREGIVER ALLIANCE®
National Center on Caregiving



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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.



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Funding for this project was provided in part by a grant, number 90-CG-2631 from the Administration on Aging, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration on Aging policy. OMB approval number 0985-0016.

PREFACE

This report focuses attention on a growing issue facing the nation: how to support and sustain those who are the cornerstone of our long-term care system—the dedicated families and informal caregivers of older people and adults with disabilities.

This 50-state study is the first to examine publicly funded caregiver support programs throughout the country. It focuses on caregiver support provided through the Older Americans Act's National Family Caregiver Support Program (NFCSP), Aged/Disabled Medicaid waiver programs, and state-funded programs.

The report identifies key findings, describes state approaches to providing caregiver support services, offers state-by-state profiles, pinpoints needs and challenges, and expands recognition of family caregiver needs as distinct from the needs of care receivers (i.e., older people and adults with disabilities). The report also identifies emerging themes and the relationship of caregiver support to other home and community-based programs.

Through this first nationwide study of caregiver support services in the U.S., we hope to:

- ♦ inform policy discussions among federal and state leaders in caregiving and long-term care throughout the nation; and
- ♦ advance the public debate about the explicit provision of family support within the context of long-term care systems development.

This report builds on in-depth case studies of ten states' caregiver support programs undertaken by FCA's National Center on Caregiving in 2002 with funding from the U.S. Administration on Aging. As such, it is designed to serve as a reference point for examining future progress and anticipating emerging issues that are likely to shape the future.

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ACKNOWLEDGEMENTS

The authors thank the U.S. Administration on Aging (AoA) for its funding of this two-year project and Rick Greene, in particular, whose support and enthusiasm were invaluable throughout the study.

This report is the result of a collaborative process involving many individuals and organizations. Our national advisory committee provided invaluable assistance in defining the issues to be covered in the 50-state survey and offered important guidance and support throughout the two-year project: Diane Braunstein, National Governors Association; Richard Browdie, Benjamin Rose; Elinor Ginzler; AARP; Gail Hunt, National Alliance for Caregiving; Kathy Kotula, National Association of State Medicaid Directors; Robert Mollica, National Academy for State Health Policy; and Lynda Terry, California Department of Aging.

We sincerely acknowledge the many staff at Family Caregiver Alliance (FCA) who contributed to the research and production components of this project: Steve Czerniak, Angela Hernandez, Melania Jusuf, Bonnie Lawrence, Lana Sheridan and Heather Whitmore. Kathleen Kelly, FCA's executive director, provided vital support and encouragement throughout the project. We are also grateful to our colleagues at the National Conference of State Legislatures (NCSL) who made important contributions to this study: Barbara Coleman, Donna Folkemer and Eboni Morris. Sincere appreciation also goes to Virginia Dize, National Association of State Units on Aging (NASUA), for her assistance in sample selection and her support of this 50-state study.

This project could not have been completed without the expert work of Brad Silen and his team at Quality Process, particularly Paul Quinones, in developing the web-based survey and online display mechanism. Special thanks are extended to Carol Van Steenberg for her skilled editorial assistance and ongoing support.

We especially are grateful to the 150 state program administrators in all 50 states and the District of Columbia who provided the information for this study, responded to follow-up questions and reviewed their respective state profiles. These state officials gave generously of their time and expertise to provide us with their perspectives and the information that allowed us to conduct this 50-state study. This report could not have been prepared without their cooperation and support.

LIST OF FIGURES AND TABLES

Figures

1. Eighteen States are Relatively “New” to Providing Support Services for Family Caregivers.....	12
2. NFCSP Programs in the States Have Transitioned from Program Development to Delivering More Services.....	15
3. State are Beginning to Utilize Single Entry Points (SEP) for all HCBS Programs and Include Access to Caregiver Support Services.....	16
4. Major Sources of Program Funding, FY 2003.....	18
5. Who is Considered the Client?.....	21
6. State Programs with Age Eligibility Criteria.....	22
7. Who is Assessed?.....	24
8. Assessment in Programs with Family Caregiver as Main Client.....	25
9. Assessment in Programs in Both Family Caregiver and Care Receiver as Clients.....	25
10. Caregiver Assessment: Top Five Areas Addressed.....	25
11. Type of Caregiver Support Services Provided by State Programs.....	27
12. Selected Services Provided to Caregivers, by Program Type.....	27
13. States Offer a Variety of Types of Respite Care.....	29
14. Use and Amount of Respite Cost Caps by State Programs.....	30
15. Caregivers Can Access State Programs in a Variety of Ways.....	31
16. State Programs Offer a Range of Consumer-Directed Options.....	33
17. Perception of Level of Integration of States’ HCBS Systems Varies by Program Type.....	36
18. States Have Mixed Views on the Importance of Olmstead to Caregiver Support.....	38
19. Barriers that Limit/Prevent Coordination with Other HCBS Programs.....	38
20. Top Three Long-Term Care Priorities in States by Program Type.....	39
21. Top Five Unmet Needs of Caregivers in the States.....	41
22. Top Five Identified Technical Assistance & Training Areas for Staff Who work with Family Caregivers.....	42
23. Top Five Challenges to Implementing Family Caregiver Support Programs in the States.....	42
24. Major Lessons Learned by State Programs in Providing Family Caregiver Support Services.....	43
25. Top Five Recommendations to Other States.....	44
26. 23 States have Enacted Caregiver Legislation.....	45

Tables

1. Program Client Designation.....	267
2. Program Eligibility Criteria: Age and Functional Status.....	273
3. Uniform Caregiver Assessment and Areas Assessed.....	278
4. Caregiver Support Services.....	283
5. Respite Care.....	291
6. Training on Caregiving.....	298

EXECUTIVE SUMMARY

Background

The need to strengthen families in their caregiving role, and to sustain them as the backbone of our long-term care system, is a central issue in our aging society. As more long-term care is provided at home and in the community, rather than through institutions, reliance on family and informal caregivers grows.

The federal government's increased role in financing services to caregivers of older people is evidenced by the National Family Caregiver Support Program (NFCSP) enacted under the Older Americans Act Amendments of 2000. Before passage of the NFCSP, state general revenues financed explicit caregiver services in relatively few states. Some states have also covered respite care, an important benefit for family caregivers, under their Medicaid home and community-based services (HCBS) waiver programs. Today, the NFCSP, Medicaid waivers and state-funded programs provide the bulk of public financing to support family caregiving.

States approach the design of home and community-based programs, including those to support caregivers, in different ways. Some states view caregiver support as a component of programs that serve frail elders or adults with disabilities. Others see caregiver support as a separate program with distinct eligibility criteria; they seek to ensure the explicit recognition of family and informal caregivers as individuals with rights to their own services and supports. Despite the importance of state-administered programs in the everyday lives of families, we know relatively little about how these programs operate in the 50 states or the differences in their philosophy or structure.

Purpose of Study

This report profiles the experience of all 50 states and the District of Columbia since the passage of the NFCSP in providing publicly funded support services to family and informal caregivers of older people and adults with disabilities. The report arises from a two-year project to provide an understanding of the range and scope of federal and state-funded caregiver support programs in each of the 50 states and across states. The study was designed to take a broad focus; it examines policy choices and approaches to caregiver support through state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid HCBS waiver programs, and state-funded programs that have either a caregiver-specific focus or include a family caregiving component in their service package. Through this first 50-state study of caregiver support services in the U.S., we hope to inform policy discussions among federal and state leaders in caregiving and long-term care throughout the nation.

Method

This study used the survey method, with written surveys and telephone interviews, to profile federal and state caregiver support programs in the 50 states and the District of Columbia. We obtained supplemental information from public documents, public agency and research databases, state websites and a literature review. We collected programmatic data

from state program administrators for fiscal year 2003 and collected or obtained fiscal and legislative data for fiscal years 2001-2003.

We chose a three-part approach to data collection because of the range of information to be obtained and the national scope of the study. Family Caregiver Alliance's (FCA) National Center on Caregiving staff fielded Part 1 (written survey) and Part 2 (follow-up semi-structured telephone interviews) of the survey. Part 3 consisted of a fiscal and legislative analysis. The National Conference of State Legislatures, under a subcontract with FCA, conducted that part of the study.

Responses to the Part 1 survey were received from 150 out of 154 identified state programs from all 50 states and the District of Columbia, representing a 97% response rate overall. We received responses from 69 state agencies and the District of Columbia, including all 51 administrators of the NFCSP (100% response); 49 Aged/Disabled Medicaid waiver programs (94% response); and 50 state-funded programs (98% response). A total of 148 of the 150 (99%) initial state respondents participated in the Part 2 follow-up telephone interview. NFCSP program administrators in 43 states and the District of Columbia responded to the Part 3 fiscal survey. These administrators also completed Part 3 surveys for an additional 16 state-funded family caregiver programs.

Key Findings

Program Administration

- ♦ More than one in three (36%) states began providing support to caregivers of older people for the first time as a result of the federal funds through the NFCSP.
- ♦ Most caregiver support and home and community-based services (HCBS) programs are administered at the state level by State Units on Aging and are available statewide.
- ♦ Area Agencies on Aging (AAAs) are the most common agency to have administrative responsibility for local programs providing caregiver support.
- ♦ In 15 states all respondents agree that the state has a single entry point (SEP) for consumers, providing better access to all HCBS programs. In 11 of these states, the SEP includes access to caregiver support.

Funding

- ♦ State program administrators use a range of definitions and data collection methods to track expenditures and caregiver service delivery, resulting in much variability across the states.
- ♦ Most state programs report multiple sources of funding, with the majority of funding coming from four main sources: State general funds, NFCSP, Aged/Disabled Medicaid HCBS waivers, and client contributions.
- ♦ Aged/Disabled Medicaid HCBS waiver programs are a significant source of funds for services helping family caregivers of beneficiaries, typically for respite care.

Eligibility and Assessment

- ♦ Client designation varies by funding source, with half the programs in this survey recognizing either the family or informal caregiver as the primary client (30%), or *both* the person with disability and the care-

giver as the client population (21%).

- ♦ Programs use a range of criteria, including age, functional state and/or income to determine eligible populations, with most state-administered programs focused on care-receiver characteristics.
- ♦ Less than half of the programs in this study uniformly assess caregiver needs.

Services

- ♦ Programs offer an array of services to support family and informal caregivers.
- ♦ Respite is the service strategy most commonly offered to caregivers and is available in all 50 states and the District of Columbia, although the amount of respite to family members varies substantially from state to state and program to program within states.
- ♦ The NFCSP is emerging both as a key program to enhance the scope of services available to caregivers and as fuel for innovation.
- ♦ Access to program information or services varies by program type; even within the same state, caregivers typically do not find the same package of services to be available.

Consumer Direction

- ♦ States and programs within states differ in the extent to which they offer consumer-directed options to family members. The NFCSP appears to be speeding the adoption of consumer direction in family caregiving programs.
- ♦ Most states (all but six) pay families to provide care in at least one of their programs.

Systems Development

- ♦ About one-fourth of the states use a uniform assessment tool for all HCBS programs for the elderly and adults with disabilities; family caregiving is a component in just five states' uniform assessments.
- ♦ The top barriers to coordinating caregiver support programs with other HCBS programs in the states are differing eligibility requirements and service complexity and fragmentation.
- ♦ Expanding Medicaid HCBS waivers, integrating long-term care services and implementing or expanding consumer-directed care are the top long-term care issues identified by the states.
- ♦ States are beginning to establish task forces or commissions to examine family caregiving.

Other Issues

- ♦ State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options in particular as the top unmet needs of family caregivers in the states.
- ♦ About half the state programs offer training for staff who work with family caregivers.
- ♦ Three of the five current training topics match those training and technical assistance areas almost all respondents say would benefit staff: best practices in service delivery, outreach/public awareness and caregiver assessment.

- States identify inadequate funding as the main challenge to implementing caregiver support services.
- The major lesson learned by the states in providing family caregiver support is “one size does not fit all” – so programs should increase the choices that families have.
- To strengthen caregiving programs, state officials recommend more innovation in program design to provide a broader array of services, better coordination and integration of caregiver support into HCBS, and more local collaboration.
- State legislatures, recognizing family caregivers’ role, are enacting laws to fund caregiver support services, expand family and medical leave, and include family caregiving in state long-term care efforts.

Conclusions

States play a large role in supporting family caregivers. This 50-state study of caregiver support services in the U.S. leads to the following main conclusions:

- *There is both an increasing availability of publicly funded caregiver support services, as well as a great unevenness of services and service options for family caregivers across the states and within states.* All states now provide some explicit caregiver support services as a result of the passage of the NFCSP in 2000. Yet, similar to HCBS, in general the availability of caregiver support services varies greatly across the U.S. due to differences in philosophy, program eligibility criteria, funding, and approaches to design and administration of the services. At a practical level, such service gaps and variations can pose challenges for caregivers by limiting choices for needed support services that may not be available where they live. Service inequities may also place more pressure on already strained caregiving families and compromise the caregivers’ abilities to care for their loved one.
- *The NFCSP is emerging as a key program to enhance the scope of caregiver support services and is fueling innovation in the states, but is inadequately funded.* The modest level of NFCSP funding to the states (\$138.7 million in 2003) leaves gaps in caregiver support services that vary substantially from state to state. As a result, most states in this study continue to rely on their own general revenues to provide caregiver support services, and utilize Aged/Disabled Medicaid waivers, a significant source of funds, to finance respite care for family caregivers of Medicaid waiver beneficiaries.
- *While there is great variation among states and programs within states in their approach to caregiver assessment, there is broad recognition of the value of uniformly assessing caregiver needs and the importance of training and technical assistance in this area.* Only five states that use a uniform assessment tool for all HCBS programs for older people and adults with disabilities were found to include a family caregiving component as part of systematic assessment practice. Yet, systematic assessment of the caregiver’s needs as distinct from, but related to the needs of the care receiver, is central to systems change and to improving policy and practice in HCBS.
- *States have mixed views on approaches to systems development, the importance of caregiver support services within home and community-based care, and integrating family caregiving programs into HCBS.* It is not surprising that in a time of major organizational and systems

change efforts, there may be different levels of understanding and perspectives of how states can and should accomplish the policy goal of reforming long-term care by expanding HCBS.

Issues for the Future

From this study, we can identify important issues for the future. Following are five initial steps towards achieving a better caregiver support system across the nation:

1. Raise the funding level of the NFCSP to reduce gaps in caregiver support services and provide meaningful support to caregiving families.
2. Improve data collection and reporting under the NFCSP and other state programs that provide caregiver support services.
3. Strengthen and expand uniform assessment of caregiver needs in all HCBS programs that provide some component of caregiver support.
4. Conduct a national public awareness campaign on family caregiving.
5. Invest in innovation, promising practices and technical assistance.

This first 50-state study on caregiving provides new insights into the ways states provide caregiver support services and their approaches to family caregiving issues in the context of HCBS. As such, it provides a starting point to further examine the policy choices and state approaches to caregiver support, as well as changes over time.

INTRODUCTION

In our aging society, the challenges of family care are an increasing reality of daily life for America's families. An estimated 44.4 million Americans provide care for adult family members and friends who, because of disabling illnesses or conditions, cannot carry out basic activities of daily living, such as bathing, preparing meals or managing medications (National Alliance for Caregiving & AARP, 2004). In 2000, informal caregiving had an estimated national economic value of \$257 billion per year, greatly exceeding the combined costs of nursing home care (\$92 billion) and home health care (\$32 billion) (Arno, 2002).

Contrary to popular belief, most people who need long-term care depend on help from family and friends, not on paid service providers or institutions. The vast majority (78%) of adults in the U.S. who receive long-term care at home get *all* their care exclusively from unpaid family and friends, mostly wives and adult daughters. Another 14 percent receive some combination of family care and paid assistance; only eight percent rely on formal care alone (Thompson, 2004).

The need to strengthen families in their caregiving role, and to sustain them as the backbone of our long-term care system, is a central issue in our aging society. At both federal and state levels, debate is mounting about policy choices to support family and informal care and increase the capacity of families and friends to provide such care.

The need to strengthen families in their caregiving role, and to sustain them as the backbone of our long-term care system, is a central issue in our aging society.

Families often undertake caregiving willingly and as a source of great personal satisfaction. However, caregiving can exact a high cost. Families commonly face health risks, financial burdens, emotional strain, mental health problems, workplace issues, retirement insecurity and lost opportunities. Research shows that support services effectively reduce the burden, strain and depression of caregiving responsibilities (Mittleman, Roth, Haley, & Zarit, 2004; Montgomery & Borgatta, 1989; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Zarit, Stephens, Townsend, & Greene, 1998), allow family caregivers to remain in the workforce (Wagner, 2001), and can even delay the institutionalization of a loved one (Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996). Keeping family caregivers healthy and able to provide care helps families remain together with their loved ones, thus avoiding more costly nursing homes. That is what most Americans value and want.

In recent years, changes in our health care delivery system—including shorter hospital stays—have transferred cost and responsibility for ongoing care onto families. As more and more long-term care is provided through home and community-based service programs rather than institutions, reliance on family and informal caregivers grows. Health care worker shortages, a highly fragmented and confusing array of programs, and soaring health and long-term care costs all limit families' access to helpful formal services such as in-home care or adult day services. We can expect the psychological and other costs of caregiving to rise as everyday care continues to shift to families.

The federal government's increased role in financing caregiver support services to older people is evidenced by the National Family Caregiver Support Program (NFCSP) passed under the Older Americans Act (OAA) Amendments of 2000. States, however, still lead the effort to increase recognition of the caregiving role, and its demands, in order to strengthen and support families. Despite the importance of state-administered programs in the everyday lives of families, we know relatively little about how these programs operate in each of the 50 states, or how the programs differ in philosophy or structure.

Background

States approach the design of home and community-based programs, including those to support caregivers, in different ways. Some states view caregiver support as part of their programs that serve frail elders or adults with disabilities. Others see caregiver support as a separate program with distinct eligibility criteria; they seek to ensure the explicit recognition of family and informal caregivers as individuals with rights to their own services and supports.

The availability, range and scope of publicly funded home and community-based programs vary greatly across the U.S.

Family caregiver support in general, and respite care in particular, first appeared in the statutes of several states in the 1970s, primarily focusing on family support for the developmentally disabled (Petty, 1990). Most state-funded programs, particularly those targeting caregivers of persons with Alzheimer's disease or other dementing illnesses, began in the mid-to-late 1980s (Feinberg & Pilisuk, 1999). Until

recently, just a few states had created distinct caregiver support programs or included some degree of caregiver support services in their strategies for frail elders or adults with disabilities.

The availability, range and scope of publicly funded home and community-based programs vary greatly across the U.S. (Kassner & Williams, 1997; Weiner, Tilly, & Alecxih, 2002). These programs have multiple funding sources and each source has its own terminology, eligibility criteria and services, often constraining systems development. States, therefore, face a challenge to administer and coordinate programs, develop integrated systems of care and improve access to services for older people or adults with disabilities, as well as their family caregivers (Feinberg & Pilisuk, 1999; Mollica, 2003; Weiner et al., 2002).

Before passage of the NFCSP in 2000, state general revenues paid for most publicly funded caregiver support services. However, some states have covered respite care, an important benefit for family caregivers, under their Medicaid home and community-based services (HCBS) waiver programs. Today the NFCSP, Medicaid waivers and state-funded programs provide the bulk of public financing for family caregiving.

National Family Caregiver Support Program (NFCSP)

The NFCSP signifies national recognition of and commitment to providing direct support services to caregivers. It is the first major nationwide program initiative under the Older Americans Act since the 1970s (Lewin Group, 2002). Under broad federal guidelines, the NFCSP calls for the states, working in partnership with area agencies on aging (AAAs) and local

service providers, to develop multifaceted systems of support for family and informal caregivers within five basic service categories:

- information to caregivers about available services;
- assistance to caregivers in gaining access to supportive services;
- individual counseling, support groups and caregiver training to assist caregivers in making decisions and solving problems related to their roles;
- respite care to temporarily relieve caregivers from their responsibilities;
- supplemental services (e.g., emergency response systems, home modifications), on a limited basis, to complement the care provided by caregivers.

Congress appropriated \$125 million for the NFCSP in fiscal year 2001, \$141.5 million for 2002 and \$155.2 million for 2003. State Units on Aging (SUAs) receive over 90 percent of these funds, allocated through a congressionally mandated formula based on a proportionate share of the state's over-70 population.¹ Funds also support a National Innovations Program,² the goal of which is to conduct activities of national significance. Grants, awarded on a competitive basis, foster the development and testing of new approaches to supporting caregivers (Administration on Aging [AoA], 2004).

Under the NFCSP, the states use federal funds to offer direct support services to family caregivers of persons age 60 and older.³ All income groups are eligible for services, but states must give priority to those providing care to older individuals in the greatest social or economic need with particular attention to low-income individuals.⁴ Functional eligibility criteria vary by type of service: individuals 60 years and older must have two or more limitations in activities of daily living (ADLs) (e.g., bathing, dressing) or a cognitive impairment for the caregiver to be eligible for respite or supplemental services. Other service categories (e.g., counseling, support groups) are available to family caregivers regardless of the care receiver's functional status.

Medicaid Home and Community-Based Services (HCBS) Waiver Programs

Medicaid, mainly through its waiver programs, supplies the majority 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 (Feinberg, Newman, & Van Steenberg, 2002).

Within broad federal guidelines, states have considerable flexibility in determining who is eligible and what services to cover in their Medicaid program (U.S. General Accounting Office [GAO], 2002). While federal Medicaid services must address the beneficiary's needs, Medicaid HCBS waiver programs permit states to provide a wide variety of services

¹ Another portion, approximately \$5 million in fiscal year 2001, \$5.5 million in fiscal year 2002, and \$6.2 million in fiscal year 2003, supported grants to Indian Tribal Organizations.

² \$6.2 million in fiscal year 2001, \$6.8 million in fiscal year 2002, and \$7.5 million in fiscal year 2003.

³ States also have the flexibility to reserve up to a maximum of 10% of their funding to provide support services to grandparents and relative caregivers of children age 18 and younger.

⁴ Priority consideration for services is also given to older individuals providing care and support to persons 18 and under with mental retardation and related developmental disabilities.

not otherwise covered under Medicaid, including respite care and other caregiver support services such as education and training. Although Medicaid services focus directly on the beneficiary, they indirectly sustain families in their caregiving role (Feinberg & Newman, in press). The federal government does not require states to maintain records on or report whether or not a waiver beneficiary also receives help from a family member.

To qualify for a waiver program, beneficiaries must be at risk of institutional care and meet state residency and financial requirements. Each state sets its own guidelines and defines the particular level of care required for a person to be nursing-home eligible, such as medical diagnosis or number of ADL limitations (Smith et al., 2000). Although Medicaid financial eligibility criteria are quite restrictive (Kassner & Williams, 1997), Medicaid HCBS waiver programs allow beneficiaries to have somewhat higher incomes, generally incomes at or below 300 percent of the federal Supplemental Security Income (SSI) level.

HCBS waiver programs do not have to provide the same services to similar beneficiaries across the state. Thus, states may target specific geographic areas or population groups (e.g., people with traumatic brain injuries, frail elders, people with developmental disabilities). A common waiver type, known as the “aged” or “aged/disabled” waiver program, provides services to aged or aged and disabled Medicaid beneficiaries.

Medicaid waiver expenditures have grown dramatically over the last decade as a share of Medicaid’s community-based service benefits, increasing from 37 percent in 1992 to 66 percent in 2001 (Reester, Missmar, & Tumlinson, 2004). In 2001, waiver programs for the aged and disabled population served over half of all waiver participants, but accounted for only 21 percent of waiver program spending. In contrast, HCBS waivers for persons with mental retardation or developmental disabilities served 38 percent of total waiver participants and used almost three-quarters of total waiver funds in 2001 (Reester et al., 2004).

State-Funded Programs

State funds generally pay for the home and community-based service programs having the most flexible eligibility criteria.⁵ These programs usually offer services that Medicaid will not cover or are more liberal and expand eligibility to people who do not qualify for Medicaid HCBS waivers, OAA services, or other programs (Summer, 2003). State-funded programs need not be bound by federal Medicaid and OAA regulations and can provide specific services (e.g., respite care) to distinct populations (e.g., family caregivers). One example is Connecticut’s state-funded Alzheimer’s Respite Care Program. Its eligibility requirements focus on the income and assets of the care receiver, who can be of any age; income cannot exceed \$30,000 per year and assets cannot total more than \$80,000.

Impact of Recent Federal Initiatives on States

States’ efforts to support family caregivers, particularly with the added resources from the NFCSP, take place in the context of the federal government’s New Freedom Initiative. Established by executive order in 2001, the initiative outlines a plan to assist states and local communities

⁵ Note that in this report “home and community-based services” (or HCBS) refers to the aggregate of programs that may be delivered in the home or community to support persons in need of long-term care and their caregivers. These programs include, but are not limited to, the programs funded through Medicaid HCBS waivers.

in responding to the U.S. Supreme Court's decision in *Olmstead v. L.C.* In this landmark decision, the Court ruled that states must provide services in community, rather than institutional, settings for certain persons with disabilities who receive assistance in publicly funded programs (Rosenbaum, 2001). The New Freedom Initiative identifies lack of family support as a major barrier to community living for persons with disabilities, underscoring the need for greater assistance to families and informal caregivers (U.S. Department of Health and Human Services, 2002). Support of caregiving families will be crucial in assisting frail elders and persons with disabilities to remain in or transition back to the community.

Despite the NFCSP and *Olmstead* major policy developments, viewing family caregivers as a "consumer" or "client" population is a relatively new concept for many state program administrators. Recent case studies of 10 states (since passage of the NFCSP) found that providing explicit support for family caregivers under the NFCSP represented a sometimes challenging paradigm shift in philosophy and program operations. Some state administrators of the NFCSP, Aged/Disabled Medicaid waivers and state-funded programs identified the tension between serving the older person (i.e., care receiver), who is the traditional client in the long-term care system, and the new mandate of the NFCSP to address the family caregivers' needs as distinct from but related to the needs of the care receiver (Feinberg et al., 2002).

These 10 case studies also reveal that state administrators (directors of state units on aging and Medicaid waiver programs) believe that caregiver support can reduce the strain on Medicaid and other state-funded programs by keeping individuals in the home or community longer. A greater understanding of federal and state-funded caregiver support programs in and across the 50 states will help federal and state leaders react more effectively to emerging issues in implementing the NFCSP and state-funded programs, expanding Medicaid waivers and providing coordinated and quality services for people with disabilities and their family caregivers.

Purpose of Study

This report profiles the experience of all 50 states and the District of Columbia since the passage of the NFCSP in providing support services to family and informal caregivers to older people and adults with disabilities. It arises from a comprehensive two-year study designed to:

- 1) provide an understanding of the range and scope of federal and state-funded caregiver support programs in each of the 50 states and across states; and
- 2) assist the aging network and other program administrators in areas of program development and best practice, facilitating the implementation of the NFCSP and its coordination with other caregiver policy initiatives in the states.

We collected information from state agencies responsible for the administration of the NFCSP; Aged/Disabled Medicaid waiver programs; and state-funded programs that either have a caregiver-specific focus or include a family caregiving component (e.g., respite care) in their home and community-based service offerings. The information obtained will be used to establish a searchable online database of caregiver support policies, programs and services in the 50 states and the District of Columbia.

Organization of Report

Following a description of the study methodology, we summarize the key findings, identify crosscutting themes, address issues for the future and present individual profiles for each of the 50 states and the District of Columbia.

To identify the study's major findings: the key findings section presents findings for these topics:

- ♦ program administration
- ♦ funding
- ♦ eligibility/Assessment
- ♦ services
- ♦ consumer direction
- ♦ systems development
- ♦ other issues.

To find data on a particular state: Review the state profiles, organized alphabetically by state. Each profile includes:

- ♦ selected background characteristics (e.g., census data, caregiving and long-term care data) for the state and the U.S.
- ♦ data about the state's home and community-based services as they relate to family caregiving
- ♦ key program-level information about programs and services to support caregivers (i.e., administrative structure, funding and caseload, eligibility, assessment and consumer direction).

Sources of data for the state profiles, in addition to the survey responses, appear in the Data Documentation section on page 264 of this report.

To compare how programs within a state respond to key survey questions: Review the data tables. These tables follow the state profiles section and highlight key descriptive information about programs within states.

The appendices follow the data tables and include the survey instruments used in this study as well as a list of state programs participating in this 50-state study.

Throughout the report, the terms "respondents" "state program administrators" and "state officials" are used interchangeably to refer to the individuals interviewed for this study. The term "care receiver" is used to describe the frail elder or adult with disabilities.

METHODS

This study used the survey method, with written surveys and telephone interviews, to profile federal and state caregiver support programs in the 50 states and the District of Columbia. A national Advisory Committee of selected experts in the field and stakeholders guided our efforts. We obtained supplemental information from public documents, public agency and research databases, state websites and a literature review. We collected programmatic data for fiscal year 2003 and collected or obtained fiscal and legislative data for fiscal years 2001-2003.

For purposes of the study, the term *family caregiver* includes care provided by relatives, friends or neighbors to persons 60 years or older or adults aged 18-59 with physical and/or adult-onset cognitive disabilities (e.g., Huntington's disease, traumatic brain injury). The persons giving care could be primary or secondary caregivers, provide full or part-time help, and live with or separately from the person receiving care.

To be included in the 50-state study, a program had to be administered by the state and provide support services to family caregivers under: (1) the Older Americans Act's National Family Caregiver Support Program (NFCSP); (2) the Aged/Disabled Medicaid home and community-based services (HCBS) waivers; or (3) state general funds. State-funded programs could be caregiver-specific or have a family caregiver component (e.g., respite care) as part of a home and community-based program aimed at care receivers.

State general fund programs with a "caregiver-specific" focus had these characteristics:

- primarily state funded and administered according to state rules
- provide one or more services (e.g., respite care, family counseling) explicitly to families or friends who care for older people or younger adults with disabilities in need of long-term care.

State-funded HCBS programs with a family caregiver component had these characteristics:

- primarily state funded and administered according to state rules
- target older people or younger adults with disabilities with long-term care needs, *and*
- provide one or more services (e.g., respite care, family counseling) to support family caregivers of the eligible population.

We did not attempt to detail all the publicly funded programs that states administer through which family caregivers may receive some support. Within the array of caregiver support services across the lifespan, we focused on programs for caregivers of the elderly and younger adults with physical and/or adult-onset cognitive disabilities. Consequently, this study did not look at some programs known to be important to family caregivers and people with disabilities, but beyond the study's scope. We did not:

- survey programs serving the target populations of family caregivers of persons with developmental disabilities or grandparents raising grandchildren, or

- ♦ examine programs in states funded by the federal Alzheimer's Disease Demonstration Grants to States that were considered "stand alone" rather than integrated into a larger caregiver support program.

Identification of Programs and State Contacts

We identified programs and state contacts to include in the study using the following process:

- ♦ based on a literature review, examination of state agency websites and discussions with the project's Advisory Committee, created an initial list of state programs within the 50 states and the District of Columbia (January-March 2003).
- ♦ compiled a list of key state contacts with knowledge and insights about their state's program operations and practice, and an understanding of family caregiving issues (January-March 2003).
- ♦ made calls to agency officials responsible for administering the NFCSP, Aged/Disabled Medicaid waivers and state-funded programs to inform them of the study, seek their participation, obtain their contact information and query the existence of any additional state-funded programs that met the study inclusion criteria (April-July 2003).

In all, we identified 154 programs in 71 state agencies in the 50 states and the District of Columbia, an average of three programs per state. We classified each program based on its major source of funding and provisionally assigned it a code:

- ♦ NFCSP (FC)
- ♦ Aged/Disabled Medicaid waivers (MC)
- ♦ state-funded programs with either a caregiver-specific focus, or HCBS programs with a caregiver component (SC).

Several state programs were reclassified later, based on survey responses.

Survey Development

The study's national Advisory Committee and previous state studies conducted by Family Caregiver Alliance's National Center on Caregiving (NCC) guided survey development. We chose a three-part approach because of the range of information to be collected and the national scope of the study. FCA's NCC staff fielded the first two parts of the survey, focusing on programmatic information. Parts 1 and 2 of the 50-state survey were pre-tested with state officials in Alabama and Hawaii. For the third part, FCA's NCC subcontracted with the National Conference of State Legislatures (NCSL). Part 3 was pretested in New Jersey and Pennsylvania.

- ♦ **Part 1** was a written survey, developed so it could be completed in printed form or electronically, then returned by mail, fax or electronically. We mailed the written survey and cover letter to program officials and also sent them the same material via email with hyperlink access to the Web-based survey instrument. Respondents were asked to complete the survey for each identified program that met the study inclusion criteria. The survey included 30 questions: 29 fixed-choice and one open-ended. The questions addressed program background, program eligibility/assessment process, program administration, services, consumer direction, systems development and other issues. (See Appendix A for a copy of the survey instrument).
- ♦ **Part 2** was a semi-structured telephone interview with state

respondents, conducted after receipt of their Part 1 written surveys. The Part 2 interview guide included 17 questions: three fixed-choice and 14 open-ended. Our aim in the Part 2 interview was to allow respondents as much freedom as possible in their responses. The interview guide had two sections, the first (8 questions) asked specifically about the program; the second (9 questions) gathered impressions about family caregivers within the state, and about the state's system of HCBS generally. Within the first section, two questions applied only to NFCSP respondents. (See Appendix B for a copy of the interview guide).

- ♦ **Part 3** consisted of a fiscal and legislative analysis for the 50 states and the District of Columbia to identify and analyze new and expanded policies, programs and appropriations since the NFCSP's passage in 2000. FCA's NCSL selected the NCSL to collect and analyze these data because of NCSL's relationships with the states and familiarity with their data. The NCSL developed the Part 3 instrument in consultation with project staff. It included eight questions addressing caseloads; federal, state, local, private, in-kind and other funding levels; funds used to meet the federally mandated match requirements under the NFCSP; state legislation related to family caregiving; and anticipated funding in future years for family caregiver programs. (See Appendix C for the Part 3 instrument).

Data Collection

We collected data using the following steps:

- ♦ sent written survey (Part 1) and cover letter to each identified program to obtain background information on the program and services and identify emerging issues; and assisted, by telephone or e-mail, respondents who reported difficulties with the Web-based format to complete survey on-line (July 2003)
- ♦ made up to two follow-up contacts with states by mail, e-mail and telephone to encourage participation (August-October 2003)
- ♦ entered Part 1 data received via paper into the Web-based application (October-December 2003)
- ♦ sent all Part 1 respondents the Part 2 interview guide (September-October 2003)
- ♦ conducted semi-structured telephone interviews (Part 2) to explore more fully the program's successes and challenges, and the relationship to other HCBS programs in the state (September-December 2003)
- ♦ provided NCSL with list of Part 1 program contacts (September 2003)
- ♦ fielded the fiscal and legislative survey (Part 3) by e-mail and postal mail (October-December 2003, by NCSL)
- ♦ sent second copy of Part 3 survey to non-responders (January-February 2004, by NCSL)
- ♦ developed codebook and cleaned data (February-April 2004)
- ♦ made follow-up calls to state respondents, when necessary, to clarify data or responses for all three parts of the data collection (April-June 2004)
- ♦ provided each respondent with a draft of their state's profile to verify the accuracy of the data included in this report (August 2004).

Part 1: Written Survey Response

Of the 154 identified state programs, 150 responded to the written survey in all 50 states and the District of Columbia, representing a 97% response rate overall (See Appendix D). We received responses from 69 state agencies and the District of Columbia, including all 51 administrators of the NFCSP (100% response); 49 Aged/Disabled Medicaid waiver programs (94% response); and 50 state-funded programs (98% response). Over half (57%) of the respondents used the electronic format.

Part 2: Follow-Up Telephone Interview Response

The telephone interviews lasted, on average, 34 minutes. When a respondent was responsible for more than one state program meeting the study criteria, one interview covered all qualifying programs. In some telephone interviews, multiple respondents representing a single program participated.

Of the 150 respondents to the Part 1 survey, 148 (99%) participated in the Part 2 follow-up telephone interview. This response included all 51 administrators of the NFCSP (100%); 48 of the 49 responding waiver programs (98%); and 49 of the 50 state-funded programs (98%).

Part 3: Fiscal and Legislative Trend Analysis Response

NCSL decided to exclude Aged/Disabled Medicaid waiver programs from the Part 3 survey. While Medicaid HCBS waivers are important funding sources for older people, persons with disabilities and their family caregivers, states deliver and pay for services based on the eligibility of the client. The federal government does not require states to track whether a waiver client is also served by a family caregiver. Given the size and scope of many of the HCBS waivers, NCSL determined that asking state officials to separate waiver clients according to the availability of a family caregiver would be very challenging for states and would likely result in inconsistent or incomplete data.

In many cases, state program administrators for the NFCSP forwarded the surveys to fiscal counterparts within their agencies. NCSL researchers conducted follow-up telephone interviews when clarification was needed. To augment survey data, NCSL also used its Health Policy Legislative Tracking Service, the National Association of State Units on Aging's "Promoting Systemic Development of State Family Caregiver Support Programs: State Profiles" from 2002, as well as various online state resource documents.

Program administrators in 43 states and the District of Columbia responded to the Part 3 survey. Responses were received from 43⁶ NFCSP program administrators (84%), and administrators also completed Part 3 surveys for an additional 16 state-funded family caregiver programs (32%).

Data Analysis

We used SPSS for Windows, version 11.0, to analyze the data. Part 1 and Part 2 data were analyzed by the total sample and separately by the three program types (i.e., NFCSP, Medicaid waivers and state general fund programs). We used descriptive statistics, including frequency distributions and cross-tabulations of selected questions, to characterize closed-ended questions. For selected questions that addressed state (rather than program) issues, we examined the responses from each of the respondents within a state for congruence. Congruence is defined as the level of

⁶ The 7 states that did not respond to the Part 3 survey were Alaska, Missouri, Ohio, Rhode Island, South Carolina, South Dakota and Wisconsin.

agreement among the state respondents within a state in their perceptions or assessment of certain state-level questions in this study. For those questions in which respondents within a state disagreed, we report a “lack of agreement” on the state profile. Any other reported state-level finding indicates all respondents within the state gave the same response.

The project team developed a set of codes to analyze questions with open-ended responses. All questions with an “other” response were coded so that the “other” category included less than 15 percent of all responses for that question. These data were then re-entered into the Web-based application prior to data analysis by SPSS.

For the Part 2 telephone interviews, the project team developed an initial codebook by question based on past surveys conducted by FCA. A qualitative, grounded theory (Glaser & Strauss, 1967) approach was used throughout analysis. The 148 interviews were divided into groups of 10 interviews, and coded two times daily in two-hour periods for nine weeks. Coding teams consisted of two project staff, who each coded the same interview simultaneously, then had a short discussion of the interview and coding scheme to ensure coder reliability.

To determine if any additional codes were necessary, 20 surveys were initially selected at random and analyzed. During this process, we clarified, expanded or narrowed the codes. For data verification, we reanalyzed the first 30 interviews to insure that the data and codes reflected any changes in the codebook. Upon completion of coding, we chose 15 surveys at random and analyzed them by question to ensure no themes were missed. We then calculated frequencies by program type and for the entire sample. We also incorporated data taken from other sources (e.g., legislative and bill information from the NCSL Health Policy Tracking Service) into the database used for the Part 1 and Part 2 data analyses.

For Part 3, NCSL analyzed data using Microsoft Excel. Certain Part 3 data, specifically NFCSP expenditures and NFCSP caseloads, have not been analyzed and are not included in this report. We excluded caseload data from the analysis because of the wide variance of state data reported and the lack of comparable data. For example, some states reported caseloads using a duplicated count, others an unduplicated count. We excluded the NFCSP fiscal data collected based on variance in state fiscal years, carryover of funds from one year to the next, and different reporting and accounting systems.

Fiscal information used in this report is based on data obtained from the following sources:

- ♦ for all years cited, we obtained federal allocations to the states for the NFCSP from the U.S. Administration on Aging
- ♦ we obtained expenditures for state-funded programs from either NCSL’s Part 3 survey or from the state program respondent during the data verification process, where available
- ♦ for fiscal years 2001 and 2002, we obtained Medicaid waiver data from CMS Form 372 for respite participants and expenditures, and total participants and expenditures. For fiscal year 2003, we obtained waiver data from CMS 64 quarterly reports of total expenditures for Aged/Disabled waivers. (For full citations, please see page 264.)

KEY FINDINGS

Program Administration

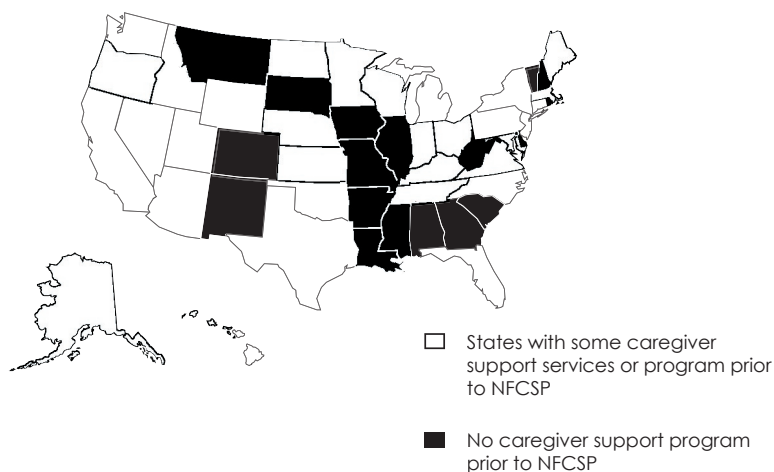
To understand what is taking place in the states in administering caregiver programs, we posed a number of questions for analysis: Did the infusion of federal funds through the National Family Caregiver Support Program (NFCSP) enable any states to serve family caregivers for the first time? How are states administering their caregiver support programs? Are local agencies involved in program administration? Is promoting a statewide identity for caregiver programs a priority in the states? Are intra-state collaborations, including pooling of funds, occurring among agencies or programs? How have caregiver programs changed since 2001, when the NFCSP implementation started?

We explored the impact of the NFCSP on caregiver program growth by looking at the programs funded primarily through state general funds and identifying states that had no state-funded programs serving caregivers before the passage of NFCSP in 2000.

More than one in three (36%) states began providing support to caregivers of older people for the first time as a result of the federal funds through the National Family Caregiver Support Program.

- ♦ Before the NFCSP, 18 states and the District of Columbia had no state program primarily funded through state general funds that served family or informal caregivers—neither a caregiver-specific statewide program nor a caregiver component within a broader HCBS program (see Figure 1).
- ♦ In 32 states, 50 state-funded programs serving family and informal caregivers had predated the NFCSP. Usually these programs were part of state-funded home and community-based services, where one or more components, e.g., respite, helped family caregivers of older people or adults with physical and/or adult-onset cognitive disabilities such as Alzheimer’s disease. A few states had state-funded programs with a “caregiver-specific” focus.
- ♦ Just seven state-funded programs, operating in six states (California, Nevada, Oklahoma, Oregon, Virginia and Washington), had recognized family caregivers as the explicit client population before the NFCSP. Another 16 programs identified both the care receiver and the family caregiver as the client population in the HCBS program (see Table 1).

Figure 1. Eighteen States are Relatively “New” to Providing Support Services for Family Caregivers



Most caregiver support and home and community-based services programs are administered at the state level by State Units on Aging and are available statewide.

States administer their caregiver support and HCBS programs in a variety of ways.

- ♦ About two-thirds of the states⁷ (34) centralize administrative responsibilities for caregiver support and HCBS programs in one state agency serving the elderly and their family caregivers, typically the SUA.
- ♦ The District of Columbia and 14 states⁸ administer caregiver support programs through two agencies: typically the SUA, which oversees the NFCSF and some state-funded programs, and the Medicaid agency, which oversees services within the Aged/Disabled HCBS waiver program.
- ♦ Two states (California and Virginia) spread administrative responsibility for caregiver support and HCBS programs among three or more state agencies.

Many SUAs also have responsibility for other state HCBS programs which often have a caregiving component as well.

- ♦ In 31 states⁹, the SUA has lead responsibility for managing the Aged or the Aged/Disabled Medicaid waiver program. In 26 states¹⁰ the SUA administers state-funded HCBS programs for older people and/or younger adults with disabilities.
- ♦ Three states (California, Maryland and Virginia) administer some state-funded caregiver support programs outside either the SUA or the state Medicaid agency.
- ♦ Virtually all (96%) the programs in this study operate statewide, providing access to caregivers in all regions of their state. Only six programs (2 Medicaid waivers, 4 state-funded) did not provide services statewide by 2003.

Overseeing caregiver programs merits special focus in most states and for most programs. According to more than three out of four (77%) program respondents, an organizational unit or a person specifically designated for caregiver programs or activities exists within their state agency.

- ♦ All but three (94%) of the SUAs that administer the NFCSF designate a lead unit or staff for caregiver programs. (Michigan, New Jersey and Texas do not.)

⁷ Alaska, Arkansas, Connecticut, Delaware, Florida, Georgia, Indiana, Kansas, Kentucky, Maine, Massachusetts, Minnesota, Missouri, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming.

⁸ Alabama (shares administrative responsibility with the SUA), Arizona, Colorado, District of Columbia, Hawaii, Iowa, Idaho, Illinois, Louisiana, Maryland, Michigan, Mississippi, New Mexico, North Carolina, Texas.

⁹ Arkansas, California, Delaware, Florida, Georgia, Illinois, Indiana, Kansas, Maine, Maryland, Massachusetts, Minnesota, Missouri, Montana, Nevada, New Hampshire, New Jersey, North Dakota, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Utah, Vermont, Washington, West Virginia, Wisconsin, Wyoming.

¹⁰ Arizona, California, Connecticut, Florida, Hawaii, Idaho, Indiana, Kansas, Kentucky, Maine, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Nevada, New Jersey, New York, North Carolina, North Dakota, Oklahoma, Pennsylvania, Tennessee, Utah, Virginia, Washington, Wyoming.

- ♦ The great majority (80%) of the state-funded programs and over half (57%) of the Aged/Disabled Medicaid waiver programs have an organizational unit or person for caregiving programs within their agency as well. Most of the waiver programs with caregiver specialists (23 of 28) are administered by the SUA.

Among the 34 programs in 22 states that do not have a designated unit or person for caregiving, most are linked to the Aged/Disabled Medicaid waivers, a program targeted to the older person or adult with disabilities.

Area Agencies on Aging (AAAs) are the most common agency to have administrative responsibility for local programs providing caregiver support.

- ♦ AAAs have administrative responsibility for three-fifths of the programs (92 of the 150, or 61%).
- ♦ Other local entities most frequently involved in administering the programs are nonprofit agencies (16%), other government agencies (13%), county health departments (5%), county human/social services departments (3%), and private for-profit agencies (2%).
- ♦ About one in six of the 150 programs (7 NFCSP, 12 Medicaid waivers and 7 state-funded programs), in 16 states, use the SUA as the administrative entity. Nine states¹¹ and the District of Columbia operate as single state planning and service areas without AAAs where the SUA administers all programs under the OAA, including the NFCSP.
- ♦ In 18 states the single state agency for Medicaid has local administrative responsibility for some programs, covering five state-funded and 19 Medicaid waiver programs.

As to the priority placed on promoting a statewide identity for their caregiver support program, state program administrators divide fairly evenly in their responses. About one-third (35%) see statewide identity as a “high” priority, slightly fewer (32%) rate it as a “medium” priority, and one-third (33%) assign it a “low” priority. This variation is consistent across program type.

- ♦ All program respondents from seven states (Alabama, Delaware, Massachusetts, Pennsylvania, Rhode Island, South Dakota, and Vermont) report that their state agencies place a “high” priority on promoting a statewide identity for caregiver support programs. All seven states also designate a specific unit or person for caregiving programs, allowing for a focused and consistent effort in promoting caregiver support services.

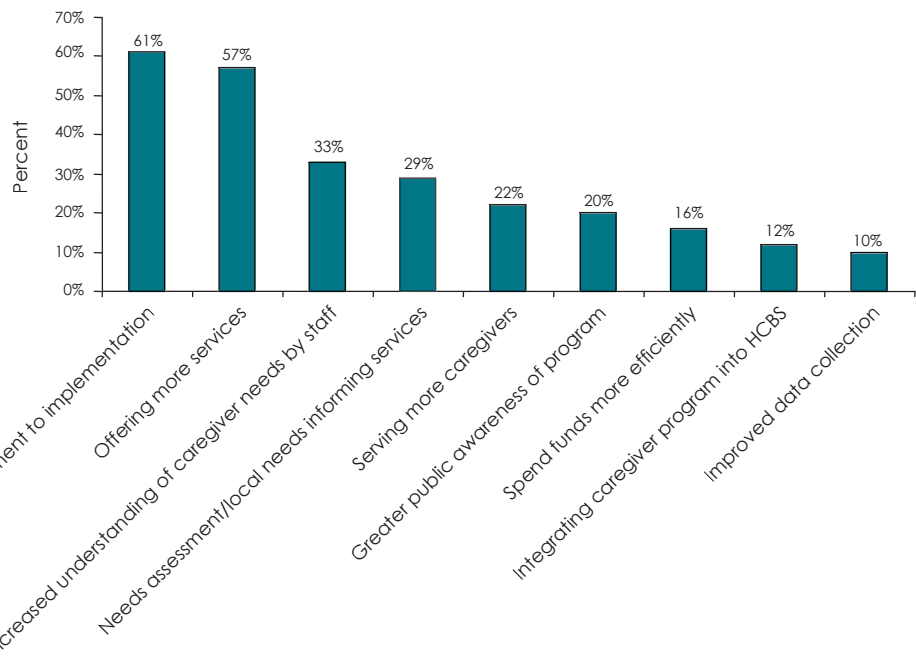
About one-third (34%) of all state programs report collaboration initiatives and pool funding for joint activities. The top three joint efforts are outreach/advertising/marketing (74%), education and training (44%), and toll-free telephone numbers (40%) to improve access to the program.

State NFCSP programs have transitioned from program development to delivering more services to caregivers.

As shown in Figure 2, NFCSPs report that in 2003, as compared to 2001, they were offering more services to caregivers (57%) and serving more caregivers (22%), having transitioned from start-up and program

¹¹Alaska, Delaware, District of Columbia, Nevada, New Hampshire, North Dakota, Rhode Island, South Dakota, Wyoming.

Figure 2. NFCSP Programs in the States Have Transitioned from Program Development to Delivering More Services (n = 51)



development in 2001 to implementation of more programs and services in 2003 (the year of this survey). One-third (33%) of the NFCSPs say their staff has an increased awareness of caregiver needs, and one in five (20%) report greater public awareness of the NFCSP. Eight states (16%) report spending their funds more effectively and six states (12%) say they are integrating the caregiver program into their state's system of HCBS.

In 15 states all respondents agree that the state has a single entry point (SEP) for consumers, providing better access to all HCBS programs. In 11 of these states, the SEP includes access to caregiver support.

Some states have created SEP systems to help individuals and their families find and simplify access to the most appropriate long-term care and supportive services for their needs. Broadly, these organizations carry out a range of functions that include, but are not limited to, information and assistance, screening, assessment, care planning, service authorization, monitoring and reassessment using one or more funding sources. These functions may be combined in a single agency or split among agencies (Mollica & Gillespie, 2003). We asked all program respondents (i.e., NFCSP, Medicaid waivers and state-funded programs) whether or not their state has a SEP for all HCBS programs.

The presence of SEPs varies across the states, as do the perceptions of program administrators, in some states, as to whether their state has a SEP and, if so, whether it provides access to all HCBS programs and includes access to caregiver support.

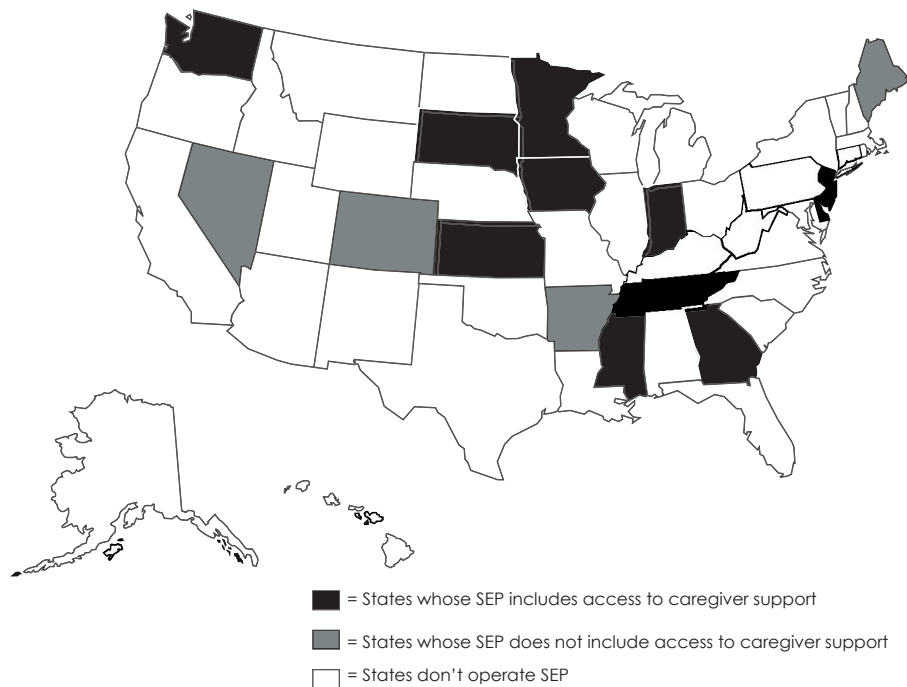
- ♦ In 19 states and the District of Columbia all respondents agree that they do not operate SEPs.
- ♦ Respondents from 68 programs (45%) in 31 states report SEPs, including 57 respondents from 27 states who say the SEP includes access to

the state's caregiver support program. However, in more than half of these states (16) respondents within the state disagree.

- ♦ In just 15 states do all respondents within that state say that the state has a SEP for all HCBS programs.
- ♦ In these 15 states, respondents from all but four agree that the SEP for all HCBS includes access to caregiver programs. Only administrators in Arkansas, Colorado, Maine and Nevada vary in their opinions as to whether their state's SEP provides access to caregiver support.

Figure 3 shows the states that reported SEPs for all HCBS programs. It also indicates which state's SEPs provide access to caregiver support.

Figure 3. States are Beginning to Utilize Single Entry Points (SEP) for all HCBS Programs and Include Access to Caregiver Support Programs



The organization that most frequently functions as the SEP is the AAA (56%). The other SEP options are state agency field offices (e.g., Medicaid agency, SUA) (22%), county health or human service departments (13%), community-based nonprofit agencies (10%), other government agencies (e.g., social services) (10%), other organizations (e.g., home health agency (7%) and private for-profit agencies (4%).

FUNDING

Caregiver support services are financed through a variety of public and private funding sources. In this study, we wanted to gain an understanding of the sources and amount of federal and state funding for caregiver support in the 50 states since the enactment of the NFCSP. We also wanted to identify general trends and issues in spending by the state-administered programs. We expected these trends would provide insight into broader spending patterns for caregiver support.

In all programs included in this study (i.e., NFCSP, Medicaid waivers, state-funded), states have enormous flexibility in determining what services are provided to best meet locally identified needs, how they are delivered, and how services and expenditures are reported. However, this flexibility at the state level poses challenges: without comparable data, cross-state comparisons cannot be made and we cannot obtain a clear picture of spending, across all the states, for caregiver support services.

During the study period, the NFCSP, in particular, was in a developmental stage: states have been identifying needs, building programs and services, and creating reporting systems to meet the new client mandate under the OAA. Data are available on the federal allocations to the states, but variance in fiscal years among the states and in treatment of carryover funds results in inconsistent reporting of actual state program expenditures. Beginning in FY 2005, states will use a new version of the National Aging Program Information System (NAPIS). As part of NAPIS, SUAs will complete utilization and expenditure profiles for the NFCSP to provide more consistent programmatic and expenditure data across the states.

State program administrators use a range of definitions and data collection methods to track expenditures and caregiver service delivery, resulting in much variability across the states.

Due to data limitations, we could not obtain consistent and accurate information on expenditures (and persons served) for programs providing caregiver support services. Indeed, many states have no uniform system in use across their own state's HCBS programs. Thus it was not possible to consistently identify total funding (or the total number of families served) for programs in this study. On the other hand, study respondents give us insights into the sources of funding, how these vary across states and how the sources and funding levels are changing over time, especially with the advent of the NFCSP. In addition, data reported for the Medicaid waiver programs allow us to see expenditure trends for one service of significant help to caregivers, respite.

Most states continue to rely primarily on their own general revenues to provide caregiver support services.

We asked state program administrators to identify the major sources of public funding that their program receives for fiscal year 2003. Most state programs report multiple sources of funding, with the majority of funding

Figure 4. Major Sources of Program Funding, FY 2003

	# of programs receiving funding from this source*	% of programs receiving funding from this source
State general fund	86	57%
NFCSP	55	37%
Medicaid HCBS waiver	49	33%
Client contribution	36	24%
Tobacco settlement fund	11	7%
Local/county fund	10	7%
AD** grants to states	7	5%
Social Services Block Grant (Title XX)	5	3%
Lottery fund	3	2%
Private foundation	2	1%
Other sources	20	13%

Note. Many programs identified more than one source of funding. *N = 150.

**AD = Alzheimer's disease.

coming from four main sources: State general funds; NFCSP; Aged/Disabled Medicaid HCBS waivers; and client contributions. Figure 4 shows the range of funding sources.

State general revenues are a source of funding for the majority (57%) of programs in this study. State general funds allow states to develop programs that are generally not constrained by federal rules and regulations. States also use their general revenues to match federal funds (NFCSP or Medicaid waiver programs). Some "over-match" by supplying more state money than

required for federal funding.

- Among respondents for Medicaid waiver programs, more than two-fifths (43%) identify state general funds as a major source of funding for their program.
- About one-third (39%) of respondents for the state NFCSPs say state general funds are a major funding source.
- In California, Florida, New Jersey and Pennsylvania state coffers have significantly funded caregiver support programs.

In this study, some state-funded programs provided expenditure data for fiscal years 2001-2003. In all, 22 of the 50 state-funded programs in 14 states¹² (44% of programs of this type in these states) provided expenditure data, with the most complete data for fiscal years 2002 and 2003. These identified expenditures represent less than half of the state-funded programs in this study. Based on previous research (Feinberg & Pilisuk, 1999; Feinberg et al., 2002), as well as data limitations and reporting variances, these expenditures clearly under-report the amount of state funding for caregiver support across all states. (See State Profiles for expenditure data).

- These 22 state-funded programs (a combination of explicit caregiver support programs and HCBS programs with a caregiver component) expended approximately \$132.4 million in state general funds in fiscal year 2002 and \$128.5 million in fiscal year 2003.
- In fiscal year 2003, state funding varied from a high of \$42.3 million in Florida's HCBS program, Community Care for the Elderly, and \$11.7 million in California's Caregiver Resource Centers, to a low of \$250,971 in Minnesota's Alternative Care Program and \$238,407 in Nevada's Community-Based Caregiving Training Program.

The NFCSP (Title III-E) is the funding source that state officials cite second most frequently (by 37% of study respondents). Through this relatively new funding source, explicit family caregiver support services now operate in all 50 states and the District of Columbia. Where caregiver

¹² California, Connecticut, Florida, Maine, Michigan, Minnesota, Nevada, New Jersey, North Carolina, North Dakota, Pennsylvania, Texas, Washington, Wisconsin.

support programs existed before the NFCSP, these funds expand the range and scope of services to families. In the other states, the NFCSP serves as the major funding source for a range of caregiver support services not available previously.

- Federal data on the NFCSP show the AoA provided the 50 states and the District of Columbia with about \$110.9 million in fiscal year 2001, \$126.6 million in 2002 and \$138.7 million in 2003.
- In fiscal year 2003, federal funding varied from \$13.9 million in California and \$11.1 in Florida to a low of \$705,756 in 11 states¹³ and the District of Columbia.
- Between fiscal years 2001 and 2003, the NFCSP federal allocations to the states increased 25 percent. (See State Profiles for allocation data).

Aged/Disabled Medicaid HCBS waiver programs are a significant source of funds for services that help family caregivers of beneficiaries, typically for respite care.

- According to data reported to the Centers for Medicare and Medicaid Services (CMS), the Aged/Disabled 1915(c) waivers¹⁴ provided an estimated \$84.5 million for respite care alone in FY 2001.
- Respite care expenditures under these waivers grew to \$101.4 million (a 20% increase) in fiscal year 2002, the most recent year for which these data are available. (See State Profiles for expenditure data).¹⁵

Client contributions are a funding source for about one-fourth (24%) of program respondents. These funds are more likely to contribute some support to state-funded programs (36%) or the NFCSPs (28%) rather than those offered through Medicaid waivers (8%).

Tobacco settlement funds, study respondents report, support 11 programs in seven states¹⁶ including four Medicaid waivers, six state-funded programs and one state NFCSP. These monies have typically been used to expand services to more older people or adults with disabilities or to support specific services, such as respite care for family caregivers.

State officials report several other funding sources:

- Revenue from *state lotteries* supports two Pennsylvania programs (OPTIONS and NFCSP) and West Virginia's Aged/Disabled Medicaid waiver.
- *Casino revenue* contribute to New Jersey's state-funded Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias.
- *Escheat*¹⁷ monies benefit Michigan's State/Escheat Respite program.

¹³ Alaska, Delaware, District of Columbia, Hawaii, Idaho, Montana, New Hampshire, North Dakota, South Dakota, Rhode Island, Vermont, Wyoming.

¹⁴ Source: CMS Form 372 (Annual Report on HCBS Waivers), with data analysis performed by Kitchener, M., Ng, T. & Harrington, C., UCSF Department of Social and Behavioral Sciences, 2004.

¹⁵ Source: CMS Form 372 (Annual Report on HCBS Waivers), with data analysis performed by CMS Center for Medicaid and State Operations, 2004.

¹⁶ Medicaid waivers in Georgia, Iowa, Nevada and Pennsylvania; state-funded programs in Florida (RELIEF and Community Care for the Elderly), Nevada (Independent Living Grant), Michigan (Caregiver Respite Program), Nebraska (Respite Subsidy Across the Lifespan), Pennsylvania (BRIDGE program); and the Pennsylvania NFCSP.

¹⁷ "Escheat" refers to unclaimed reimbursements or payments made by Blue Cross/Blue Shield for insurance in Michigan. The unclaimed payments revert back to the state and the funds are then set aside for designated health-related programs.

- ♦ Arizona and Wyoming use federal *OAA Title III-B* social services funds for state-funded programs (Non-Medical Home and Community Based Services Program in Arizona and Community Based In-Home Services Program in Wyoming).
- ♦ Alaska's Innovative Respite Program uses *Mental Health Trust Authority* authorized receipts.

Although most states experienced severe budget crises between 2001 and 2003, funding levels for family caregiver programs generally held their own—either increased or remained about the same.

Program administrators in Alabama, Arizona, Connecticut, Delaware, the District of Columbia and Florida (for the NFCSP), and Iowa, Massachusetts, Montana, New Mexico, Oklahoma, Pennsylvania, Utah, Virginia, Washington, West Virginia and Wyoming (for the state-funded program in general or the state respite program in particular) report either stable funding or slight increases between fiscal years 2002 and 2003 and project increases for fiscal year 2004. For many, modest increases in federal NFCSP allocations account for the growth. Program respondents also expect to see an increase in demand for services from family and informal caregivers due to budget pressures on other aging and disability supportive services.

ELIGIBILITY AND ASSESSMENT

"The aging network now recognizes the family caregiver as a valued consumer in need of support services in their own right. Other HCBS programs don't yet share this philosophy."

--Medicaid waiver respondent

Eligibility criteria determine who will have access to caregiver support, further define service priorities, and vary by source of program funding. Most HCBS programs focus solely on the functional limitations of frail elders or persons with disabilities. The programs usually do not address the "family unit" together as the client system, the range of informal caregivers' needs or the complexity of caregiving responsibilities (Feinberg et al., 2002; Levine, C., Reinhard, S., Feinberg, L. F., Albert, S., & Hart, A., 2004).

State officials generally define family caregiving programs as those that specifically serve families who are providing care to a relative. Although states vary, they typically do not consider programs targeted to serve an older person or younger adult with disabilities as caregiver support programs, even if they provide important and often significant benefits to families.

Who is the Program Client?

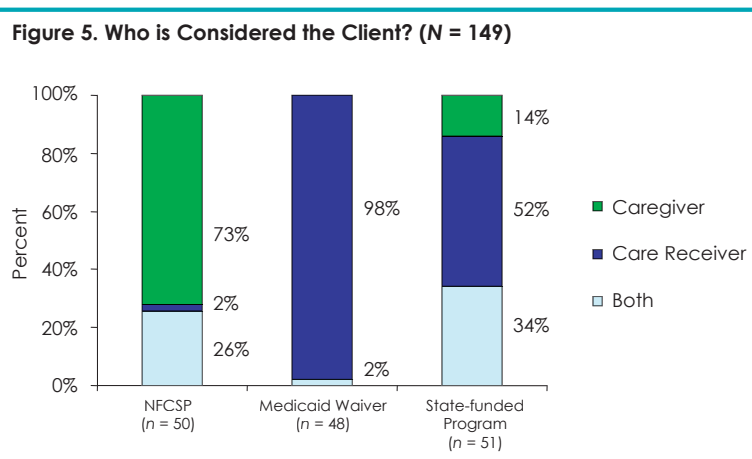
Client designation varies by funding source, with half of the programs in this survey recognizing either the family or informal caregiver as the primary client (30%), or both the person with disability and the caregiver as the client population (21%).

A program's client designation impacts eligibility and shapes how program services are configured and delivered. As shown in Table 1 and Figure 5 the three types of programs examined in this study (i.e., NFCSP, Medicaid waiver and state-funded) differ considerably in whom they see to be program clients.

- Across all three types of programs, half the respondents (74 or 50%) say they consider the person with disease/disability (i.e., the care receiver) the client.
- All but one of the Medicaid HCBS waiver programs (48 out of 49) identified the individual with disability as the client, as did more than half of state-funded programs (52%) and one state NFCSP (Virginia).

Among programs focused on the care receiver, a sizeable proportion (44%) cannot say whether or not their clients have a family caregiver because they do not collect these data.

We found that the family or informal caregiver is the primary client in nearly one-third (30%) of the programs studied



(44 programs in 38 states and the District of Columbia). *"I think we 'get' it now,"* says one state NFCSP administrator, *"but that was one of the biggest challenges and one of the lessons learned. The focus [of the program] is the caregiver, the client is the caregiver, and the recipient is the caregiver too. That is quite a switch from how we think, especially in the HCBS world."*

- NFCSPs make up the great majority of programs (37 out of 44; 84%) designating the caregiver as primary client. They have an explicit requirement under the OAA to serve caregivers of older people. Nevertheless, a sizeable number of NFCSPs (those in 13 states¹⁸) view both the family caregiver and the person with disease/disability as the primary client group.
- Only a few state-funded programs (seven in six states¹⁹) identify the family caregiver as their primary client. These programs typically have explicit state mandates to serve family and informal caregivers.

Overall, 31 programs in 23 states (21%) including New Hampshire's Medicaid waiver program and 17 of the 50 state-funded programs in this study, take a more "family centered" approach to service eligibility and consider *both* the person with a disability (i.e., the care receiver) and the caregiver to be clients.

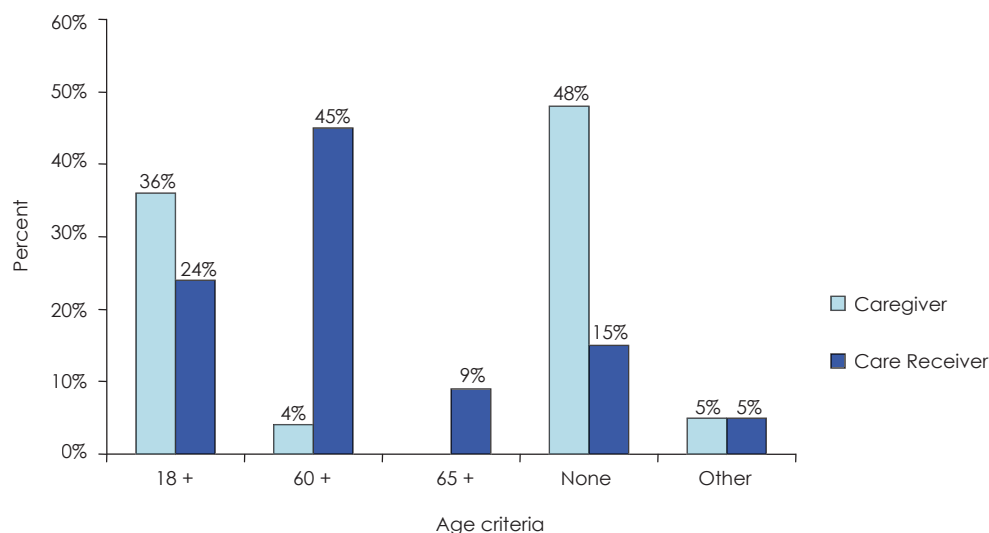
Eligibility Criteria

The programs in this study serve a range of disease/disability groups.

Eligible populations most commonly include persons 60 years and older

with physical disabilities (79%) and/or persons 60+ with Alzheimer's disease or a related cognitive impairment (73%). Younger adults (i.e., age 18-64) with physical disabilities are eligible for more than one-third (38%) of the programs, generally Medicaid HCBS waiver (52%) or state-funded (49%) programs. State-funded programs in only nine states²⁰ focus solely on persons with dementia.

Figure 6. State Programs with Age Eligibility Criteria (N = 150)



¹⁸ Arizona, Connecticut, Florida, Hawaii, Idaho, Missouri, Montana, New Mexico, Nevada, New York, Pennsylvania, Rhode Island, Texas.

¹⁹ California (Caregiver Resource Centers); Nevada (Community-Based Caregiving Training); Oklahoma (Respite Resource Network); Oregon (Lifespan Respite Care); Virginia (Caregiver Grant Program); and Washington (Family Caregiver Support Program; Respite Care Services).

²⁰ Alaska, California, Florida, Kentucky, Maine, New Jersey, Ohio, Pennsylvania, Texas.

Programs use a range of criteria, including age, functional status and/or income to determine eligible populations, with most state-administered programs focused on care-receiver characteristics.

Age: As shown in Figure 6 the vast majority of programs have age eligibility criteria for care receivers (85%) and fewer have age criteria for the caregiver (52%). Not surprisingly, given the OAA mandate, NFCSPs were the most likely of all program types to serve caregivers of persons age 60 and older.

- ♦ The most common age requirement for care receivers are age 60+ (68 programs; 45%) and age 18+ (36 programs; 24%).
- ♦ The most common age requirement for caregivers is 18+ (53 programs; 36%); just a few programs require the caregiver to be age 60 or older (6 programs, 4%).

Functional Status: Most programs use some type of criteria related to the functional status or diagnostic category of the care receiver to determine program eligibility. As shown in Table 2, functional eligibility requirements vary by source of funding and type of service.

- ♦ The most common functional requirements for eligibility are based on the status of the care receiver:
- ♦ Nursing home eligible (50 programs²¹, 33%);
- ♦ Limitations in two ADLs (33 programs, 22%);
- ♦ Diagnosed with Alzheimer’s disease or a related cognitive impairment (28 programs, 19%).
- ♦ A few programs (16, 11%) report no functional status requirements.

Income: Like functional status and age, states vary widely in financial eligibility requirements depending on funding source and type of service provided. Most publicly funded programs restrict the income eligibility of the care receiver to target those most in need.

- ♦ A total of 61 of 146 (42%) programs responding report no income requirements for their program. These are the NFCSPs (79%) and state-funded programs (21%).
- ♦ Programs with financial requirements typically look at the care receiver’s income and/or assets. Although amounts allowed vary widely, SSI-eligibility is the most common.

Assessment

Less than half of the programs in this study uniformly assess caregiver needs.

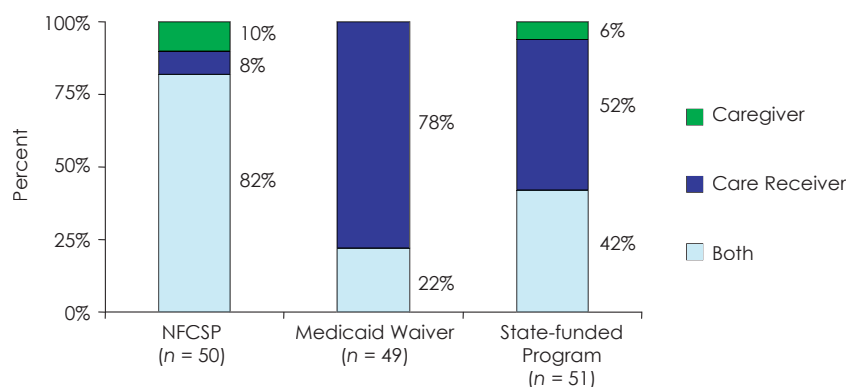
Caregiver assessments may establish eligibility for explicit caregiver programs or for support services from broader HCBS programs. Although understanding the role, multiple stressors and particular situation of the family caregiver is viewed as essential to any care plan developed for the care receiver (Baxter, 2000; Feinberg, 2004; Gaugler, Kane, & Langlois,

²¹ 90% of the Aged/Disabled Medicaid waiver programs.

2000), few state programs uniformly assess the family caregiver's well-being and his or her own service needs. *"Caregivers need a formalized assessment system,"* advocated one Medicaid waiver respondent. *"They need a tool that asks them what they need, that is unified and formalized and can be used across the health care continuum."*

As shown in Table 3, about half of the state administrators (49%, 74 programs) say they assess needs, in some way, of both the older adult or person with disabilities and the family caregiver. This approach to dual assessment is much more common among the NFCSPs (82%), compared to Medicaid waiver (22%) or state-funded programs (42%).

Figure 7. Who is Assessed? (N = 150)



Medicaid waiver and state-funded programs most commonly assess only the person with disease or disability (in 78% of waiver and 52% of state-funded programs). In all, 68 programs (45%), including four NFCSPs (Iowa, Louisiana, New Hampshire and Virginia), report they assess only the person with disease or disability.

Eight²² programs (5%) in seven states and the District of Columbia assess only the family caregiver's needs.

Despite the variation among programs in their assessment

targets, there is broad recognition of the value of uniformity in program assessment instruments. The more established the program, the more likely it is to use a uniform tool. Among all 150 programs surveyed, the majority (69%; 104 programs) use a statewide, uniform assessment tool in their program, rather than instruments that differ from one locality to another. Moreover, programs with a uniform assessment process often include the family caregiver's situation in their assessment.

- ♦ Almost all Medicaid waivers (94%) report using a uniform tool, as compared to state-funded programs (64%) and the NFCSPs (51%).
- ♦ More than two-thirds (68%; 71 programs) of programs with a uniform assessment tool say they assess the family caregiver's needs and situation, too.

Still, fewer than half (47%) of all state administrators in this survey say their state program uniformly assesses the family caregiver's needs and situation in addition to the care receiver. The programs that most typically utilize a uniform assessment process for the care receiver but do not conduct a caregiver assessment are the Medicaid HCBS waivers (44%). *"We don't have caregiver issues built into the assessment process,"* comments one Medicaid waiver respondent. *"This would be a whole new way of thinking about support and services."*

As shown in Figures 8 and 9, client designation appears to influence

²² NFCSPs in Alaska, District of Columbia, Maine, Minnesota, and North Dakota; state-funded programs in California (Caregiver Resource Centers); Nevada (Community-Based Caregiving Training); and Oklahoma (Oklahoma Respite Resource Network).

assessment policies. Programs that are “caregiver-specific” or view both the care receiver and the family caregiver as their clients, generally assess both members of the dyad to better understand the care situation.

- Among the 44 programs (37 NFCSPs and 7 state-funded) that consider the family caregiver the client (Figure 8), eight programs (18%) assess the family or informal caregiver only and 32 (73%) assess both the caregiver and the care receiver.
- Of the 31 programs that consider both the care receiver and the family caregiver as clients (Figure 9), the great majority (81%, 25 programs) assess both family members.

Table 3, shows how the domains used to assess a family caregiver’s needs and situation vary greatly among states and programs. Figure 10 illustrates the top five areas found in uniform assessment tools used by programs to assess caregivers.

- For the NFCSPs, the top five areas of caregiver assessment are: “ability to provide care” (76%); “basic demographics” (71%); “caregiver strain” (67%); “care frequency”; and “caregiver physical health” and “caregiver depression” (57% each).
- For the Medicaid waiver programs, the top five areas of caregiver assessment are: “willingness to provide care” (92%); “ability to provide care” (88%); “care frequency” (84%); “caregiver strain” (72%); and “care duration” and “physical health” (56% each).
- For the state-funded programs, the top five areas of caregiver assessment are: “ability to provide care” (80%); “caregiver strain” (76%); “basic demographics” (64%); and “caregiver physical health”, “care frequency” and “caregiver depression” (56% each).

In their responses, state officials frequently observe that the Medicaid waiver assessment of caregivers focuses on whether or not the family caregiver is willing and available to provide care to the individual, not on the caregiver’s own particular needs and support.

Figure 8. Assessment in Programs with Family Caregiver as Main Client (n = 44)

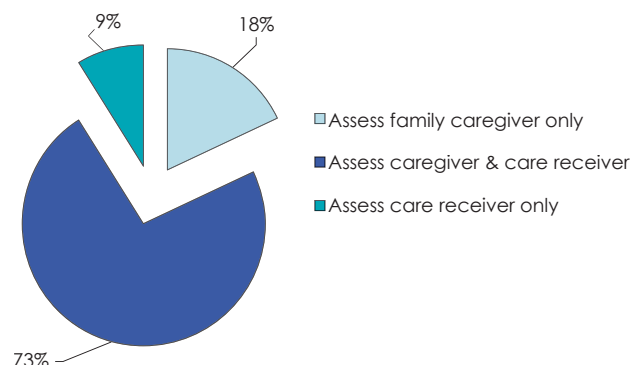


Figure 9. Assessment in Programs with Both Family Caregiver and Care Receiver as Main Client (n = 31)

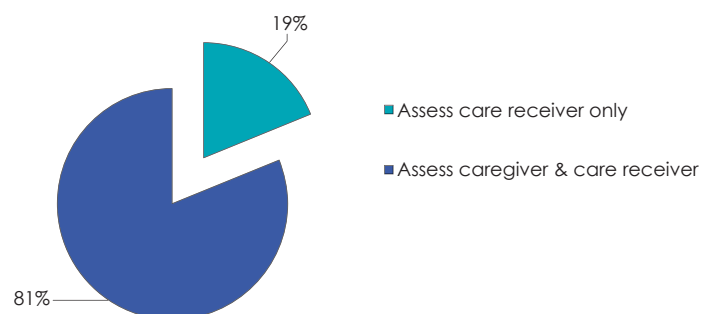
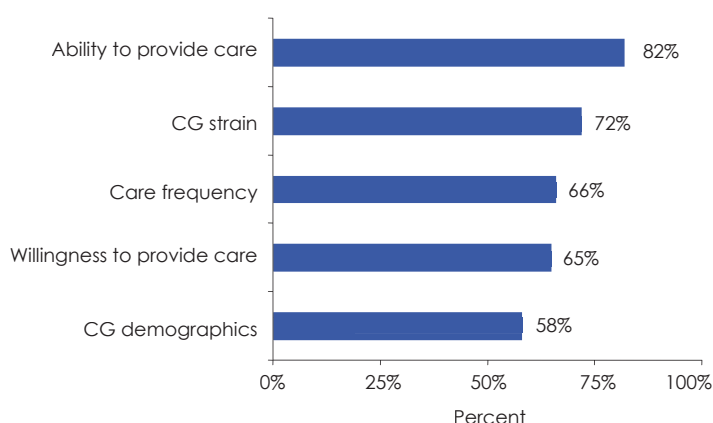


Figure 10. Caregiver Assessment: Top 5 Areas Addressed (n = 71)



Note. CG = caregiver

Services

"There is a growing recognition within the policy arena of the importance of caregiver support services as a preventive service. The more you provide in terms of services and infrastructure for caregiver support, the better off the state will be in future expenditures."

--Medicaid waiver respondent

"Respite is frequently identified as the number one need, but once the family caregiver starts having regular respite, there is usually the recognition that they need information, support and links to other services and supports."

--State-funded program respondent

Family members and friends may have different needs and preferences at different times during their caregiving experience. A variety of services can bolster them in providing care to a loved one. We asked state program administrators to identify each service that their program provides specifically to family caregivers. The programs in this survey offer a broad array of services that either directly or indirectly assist caregivers. Table 4 shows which of 18 services each program in this survey provides to caregivers.

Definitions for services vary across programs and across states. Because service categories, names and availability fluctuate, they challenge efforts to track and classify them. At a practical level, these variations make it more difficult for a caregiver to access needed help. For example, under the NFCSP, states can provide the service category of "supplemental services", as defined by the state, to complement the care provided by caregivers. By definition, supplemental services are intended to benefit caregivers and be flexible enhancements to the caregiver support programs (Lewin Group, 2002). Services can include home modifications, assistive technology, emergency alarm response systems, consumable supplies, or any service or service option as defined by the state. Neither the Medicaid waiver nor the state-funded programs have such a broad service category.

Similarly, definitions of the term "respite" vary widely from program to program. As one state-funded program respondent said, *"Respite means different things to different people."* Some program administrators view respite as a specific service; others view it as an outcome of providing other out-of-home or in-home services, such as personal care or homemaker/chore services. Some state-funded and Medicaid waiver programs consider in-home services such as homemaker/chore and personal care to be "respite" for the family caregiver, even though it is often not tracked as such and this care directly benefits the older person or adult with disabilities.

Caregiver Support Services

Figure 11 illustrates the types of services provided by programs in this study to support family and informal caregivers. Figure 12 shows the percentage of state programs surveyed by program type providing selected caregiver support services.

State-administered programs offer an array of services to support family and informal caregivers; respite care tops the list.

- At least half of all programs in this survey (76 out of 150 programs) provide one or more of the following eight services: respite care (95%), information and assistance (69%), education and training (62%), care management/family consultation (58%), homemaker/chore/personal care (58%), assistive technology/emergency response systems (54%), individual and/or family counseling (52%), and home modifications (51%).
- Most, but not all, programs in this survey offer multiple services to caregivers, generally respite care and one or more other services. In 14 programs²³ in ten states (six state-funded programs; eight Medicaid waivers) respite care is the only service identified specifically for family caregivers.

The NFCSP is emerging both as a key program to enhance the scope of services available to caregivers and fueling innovation.

Many services now available to support caregivers come mainly through the NFCSPs, as shown below.

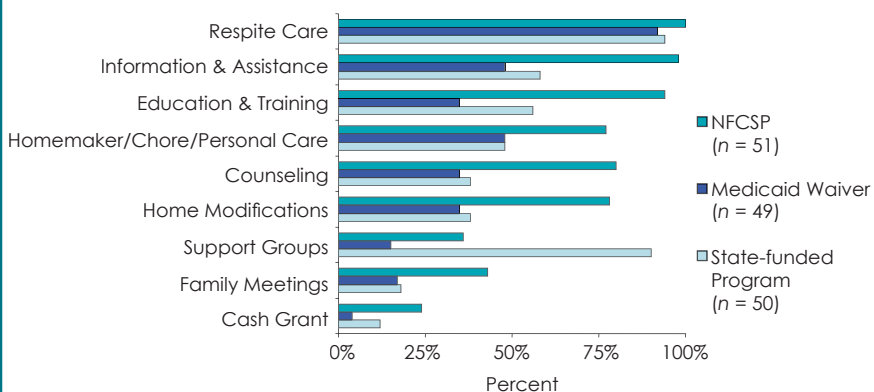
- Caregiver education and training is offered by nearly two out of three (62%) programs surveyed. Education and training can include conferences or classes covering a broad range of topics of interest to family caregivers, or can teach caregivers “hands-on” skills and knowledge to improve confidence and competence in

Figure 11. Types of Caregiver Support Services Provided by State Programs

	Program responses*	
	n	%**
Respite Care	143	95%
Information & Assistance	102	69%
Education & Training	93	62%
Care Management/Family Consultations	87	58%
Homemaker/Chore/Personal Care	86	58%
Assistive Technology/Emergency Response	80	54%
Counseling (individual and/or family)	77	52%
Home Modifications	76	51%
Support Groups	71	48%
Transportation	66	44%
Consumable Supplies	51	34%
Legal/Financial Consultations	48	32%
Family Meetings	39	26%
Other Services	22	15%
Cash Grant	20	13%
eHealth Applications (excluding read-only websites)	10	7%

Note. *N=150. **Percentages are based on total number of responses.

Figure 12. Selected Services Provided to Caregivers, by Program Type



²³ State-funded programs (California's Adult Day Health Care, Michigan's State/Escheat Respite, Nebraska's Respite Subsidy Across the Lifespan, Oklahoma's Respite Resource Network, Washington's Respite Care Services and Wyoming's Community-Based In-Home Services Program). Medicaid waivers in Arkansas, California, Illinois, Nebraska, Oklahoma, Texas, Vermont and Wyoming.

the caregiving role (e.g., training for lifting or bathing a person, techniques for managing behavioral problems, methods of coping with stress). Caregiver education and training is much more commonly offered by the NFCSPs (94%) than the state-funded (56%) or Medicaid waiver programs (35%).

- ♦ *Care management or family consultations* are covered by well over half (58%) the programs in this study, and are considerably more common among the NFCSPs (84%), as compared to the Medicaid waiver (47%) or state-funded programs (42%). These services assist families in making a care plan, identifying and arranging needed services, locating other resources, and assisting caregivers with both everyday and long-term choices and decisions.
- ♦ *Individual and/or family counseling* to address specific caregiving needs and psychological well-being are offered by over half (52%) of the programs surveyed. Counseling is twice as likely to be a covered service under the NFCSP as compared to the other programs in the study (NFCSP, 80%; state-funded, 38%; and Medicaid waiver programs, 35%).
- ♦ *Caregiver support groups* are available through fewer than half (48%) of the programs. Support groups are provided by almost all the NFCSPs (90%). Support groups are especially uncommon among Medicaid waivers (15%) and offered by a little over one-third of the state-funded programs (36%).

In several emerging, or innovative, service areas the NFCSP is leading the way:

- ♦ *Family meetings*, offered by only 26 percent of programs in this study, help resolve caregiving issues and improve communication among family members about difficult subjects. NFCSPs are twice as likely to offer this service (43%) as compared to the state-funded (18%) or Medicaid waiver programs (17%).
- ♦ *Cash grants* to purchase goods (e.g., incontinence products, ramps, grab bars) and/or services (e.g., respite care) help offset the often high costs of providing care and, for some, may enable the family to continue to provide care. Cash grants are available through only 20 of the programs surveyed (13%) in 18 states and the District of Columbia, mostly through the “supplemental services” category of the NFCSPs. The NFCSPs are at least twice as likely to offer this option as are the other programs in this study (24% NFCSP, versus 12% of state-funded programs and just 4% of waiver programs, i.e., those in Alabama and Minnesota).
- ♦ *eHealth applications* (e.g., telemedicine, interactive websites) include information and services delivered or enhanced through the Internet and related technologies. Although this offering for family caregivers is still rare (by just 10 programs²⁴ in eight states overall), NFCSPs account for more than half.

²⁴ NFCSPs (Arkansas, Idaho, Maine, Missouri, New York and Oregon); state-funded programs (California Caregiver Resource Centers, Minnesota Alternative Care Program) and Medicaid waivers (Minnesota, Oregon).

Respite Care

Respite care addresses one of the most pressing needs identified by caregiving families. Although some programs consider “respite” to be a broad concept that includes almost anything if it improves the caregiver’s quality of life (Feinberg & Pilisuk, 1999), respite care is generally defined as temporary, short-term help provided to the care receiver that enables caregivers to take a break.

In this survey, we found that respite is offered in varying degrees, by all types of programs and in all 50 states. It is provided under the NFCSP; as a state-funded, single purpose program; as part of state-funded HCBS multi-component programs; and also as a specific benefit under Medicaid HCBS waiver programs. In the NFCSP, respite is a specific part of the core package of services to caregivers. In Medicaid waiver and state-funded HCBS programs, however, respite may not be an explicitly covered benefit or service. Administrators of these programs often see respite as a by-product of other in-home (e.g., homemaker/chore/personal care) or out-of-home services (e.g., adult day services). Some say that cash grants to care receivers to purchase in-home services or home modifications, for example, provide respite and relief for the family caregiver, although their purpose is to benefit the care receiver.

Respite is the service strategy most commonly offered to support caregivers and is available in all 50 states, although the amount of respite to family members varies substantially from state to state and program to program within states.

- Nearly all (95%) of the programs in this survey (143 out of 150) report providing respite care, regardless of funding source.
- All states and the District of Columbia (100%) offer respite care to caregivers under the NFCSP.
- All but four states²⁵ report including respite as an explicit service under their Aged/Disabled Medicaid HCBS waiver.
- In two states, Tennessee and Nevada, a state-funded HCBS program does not offer respite or other in-home services.

As shown in Table 5, respite care takes many forms. The most common types of respite offered in the state programs surveyed are in-home respite, adult day services and overnight respite in a facility. Figure 13 shows the prevalence of various types of respite service options available in the states.

- The great majority (71%) of the programs offering respite assistance do not require that the caregiver live with the care receiver, enabling adult children or other relatives to qualify for respite services even if they live in separate households.
- This broader eligibility criteria exists more often in the NFCSPs (80%) and the state-funded programs (75%), than in the Medicaid waiver programs (58%) (see Table 5).

Figure 13. States Offer a Variety of Types of Respite Care

	Program responses*	
	<i>n</i>	%**
In-home	136	91%
Adult Day Services	131	87%
Overnight in Facility	113	75%
Weekend/Camp	86	57%
Other	17	11%

Note. *N=150. **Percentages are based on total number of responses.

²⁵ The Aged/Disabled Medicaid HCBS waiver programs in Alaska, Kentucky and New York did not respond to this survey. The waiver programs that do not report including respite as an explicit service are located in Louisiana, Rhode Island, Washington and West Virginia, although the waiver in Louisiana includes homemaker/chore/personal care that can provide some respite to family caregivers.

To control costs and distribute services equitably, given limited program budgets, programs cap cost or service utilization. We were particularly interested in better understanding how caps are used for respite care in the states and who decides how to formulate the caps.

Figure 14. Use and Amount of Respite Cost Caps by State Programs

Use and Amount of Respite Cost Caps by State Programs	Number of Programs
None	73
\$100 - \$200/mo	1
\$501 - \$600/mo	3
\$1,000/mo	1
< \$500/yr	3
\$501 - \$1,000/yr	7
\$1,001 - \$2,000/yr	5
\$2,000 - \$3,000/yr	1
\$3,001 - \$4,000/yr	6
> \$4,000/yr	1

- ♦ Sixty-six programs (46%) in 38 states and the District of Columbia that offer respite assistance utilize a respite cap of some type to contain costs. Considerable variation exists within the limits imposed. In a majority of these programs (49 out of 66; 74%), the respite cap is applied uniformly across each program site, with Medicaid waiver (96%) and state-funded programs (88%) most likely and the NFCSPs least likely (48%) to do so.
- ♦ In nearly two-thirds (62%) of these 66 programs, the administering state agency decides how to formulate the cap. Medicaid waivers (91%) and state-funded programs (71%) are much more likely than the NFCSPs (33%) to set policy through the state agency.
- ♦ Less than one-third (30%) of the respite caps overall are set by local administering agencies. However, where the NFCSP has a cap for respite, the majority (59%) rely on their AAAs to set it. In contrast, a minority of state-funded (18%) and Medicaid waiver programs (5%) let the local agency do this.
- ♦ Half (50%) of the programs with a respite cap utilize a cost cap. Nearly as many (47%) use a utilization cap, typically a ceiling on the number of allowable hours of respite per year.
- ♦ Caps vary widely. Some use monthly limits, while others calculate caps on an annual basis.
 - In the NFCSPs, most capped programs (19, 70%) refer to dollars, not utilization. The caps range from \$250-\$500 per year (Colorado) to \$4,000 per year (District of Columbia) and average \$1,300 per year.
 - Medicaid waiver programs more often use a utilization cap, with these ranging from 168 hours per year (Maryland) to 6,480 hours per year (South Dakota) and averaging 937 hours annually.
 - State-funded programs are slightly more likely to use cost (59%) than utilization (41%) caps. These caps range from \$1,500 per year (Nebraska's Lifespan Respite) to \$7,200 per year (New Jersey's Assistance for Community Caregiving) and average \$3,844 annually. The average utilization cap across state-funded programs was 300 hours per year.
- ♦ Among the programs reporting dollar amounts for their respite caps, Colorado's Family Caregiver Support Program has the lowest

(\$250-\$500 per year) and New Jersey's Enhanced Community Options (ECO) Medicaid waiver program the highest (\$1,000 per month). The variation in the 29 programs reporting the amount of their respite caps is shown in Figure 14.

Access to Information and Services

Access to program information or services varies by program type; even within the same state, caregivers typically do not find the same package of services to be available.

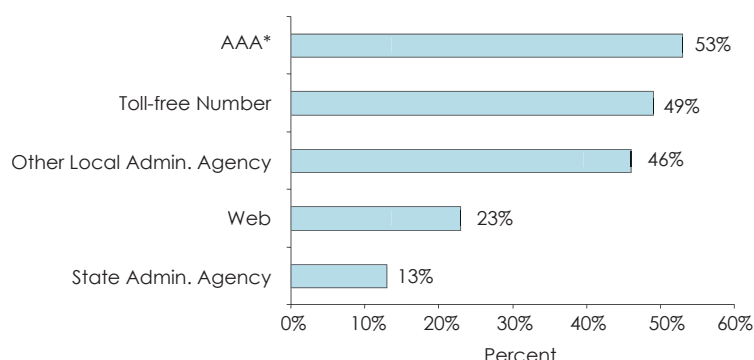
Fragmented services, confusing service delivery systems, and inaccessible information about community resources can compromise the family member's ability to care for their relative and adversely affect the caregiver's own health and quality of life. We asked state program administrators to describe the best way for a caregiver to access their program either for information or for services. As shown in Figure 15, over half (53%) of the program respondents, regardless of type of program, point to the local AAA. Nearly half (49%) indicate the state's toll-free telephone number. Programs in this survey suggest various ways for caregivers to access information or services:

- for the NFCSP, officials cite first the local AAA (69%), then the state's toll-free telephone number (55%)
- for the Medicaid waivers, respondents see the top method to be the local administrative toll-free number (40% each)
- for state-funded programs, respondents say to call the toll-free number or the local AAA (51%)
- relatively few program administrators mention the Web as a way to access programs (31%, state-funded; 25%, NFCSP; 13%, Medicaid waiver).

We asked respondents whether or not family caregivers in their state have access to the same package of services within their program. In about half (49%) the programs, respondents said "No." The NFCSPs were the least likely of all three program types to respond affirmatively; more than three out of four (77%) report that caregivers in their state don't have access to the same program services, followed by state-funded programs (44%) and the Medicaid waivers (18%).

- Under the NFCSP, only 21 states²⁶ (42%) report that all of their state's AAAs offer each of the five specified service components (information, assistance, counseling/support groups/education and training, respite and supplemental services).

Figure 15. Caregivers Can Access State Programs in a Variety of Ways (N = 148)



Note. *Area Agency of Aging.

²⁶ Alabama, Connecticut, Florida, Georgia, Hawaii, Kentucky, Louisiana, Massachusetts, Maryland, Maine, Michigan, New Hampshire, New York, Ohio, Pennsylvania, South Dakota, Tennessee, Texas, Utah, Washington, Wyoming. Note: 4 states (Alaska, Delaware, Rhode Island, Wisconsin) and the District of Columbia responded "not applicable." All but Wisconsin do not have AAAs; the state or district acts as the single planning and service area.

CONSUMER DIRECTION

The philosophy and practice of “consumer direction” is an emerging trend in HCBS programs. Consumer direction is not a single method; rather it is a philosophical approach to paying for services or supports. It shifts the locus of decision-making and control from service providers and payers to consumers and families (Benjamin, 2001; Doty, 2004). At one end of the spectrum the consumer has total control over how the care dollar is spent, from hiring a relative to paying for goods. At the other

is traditional service delivery, where the provider or payer decides what is needed and will be covered. In between is a family-centered approach, such as the NFCSP’s “supplemental services” category: giving family caregivers a menu of services from which to choose and taking a flexible approach to approving services. For example, NFCSP funds can pay for a car battery needed for a family member to drive a relative to the doctor’s office.

States are grappling with ways to improve quality of care, address the shortage of direct care workers and increase consumer choice. One method of achieving these goals is to pay family members who provide vital care to their elderly or disabled relatives.

States are grappling with ways to improve quality of care, address the shortage of direct care workers and increase consumer choice. One method of achieving these goals is to pay family members who provide vital care to their elderly or disabled relatives. However, the practice of paying relatives is subject to debate in the U.S. (Blaser, 1998; Kunkel, Applebaum, & Nelson, 2004). In states that enable consumers to direct their own services, the freedom to hire a family member, friend or neighbor is viewed as a meaningful feature of choice and control (Feinberg & Newman, in press).

The NFCSP, Medicaid HCBS waivers and some state-funded programs permit consumer-directed approaches depending upon each state’s rules and regulations. For example, under the NFCSP, states may make direct payments to family caregivers or provide a voucher or budget for goods and services (e.g., grab bars, respite care) to meet their needs and those of the care receiver. Thus, a state’s NFCSP may give families maximum control as to how, when and to whom respite is provided, or the goods or services to buy directly (Feinberg & Newman, in press). States may also let each individual AAA (the local administering agency) set policy for this option.

States and programs within states differ in the extent to which they offer consumer-directed options to family members. The NFCSP appears to be speeding the adoption of consumer direction in family caregiving programs.

All but two states (Delaware and New York²⁷) report at least one program with a consumer-directed option for family caregivers; 106 programs

²⁷ New York’s Aged/Disabled Medicaid waiver program did not respond to this survey.

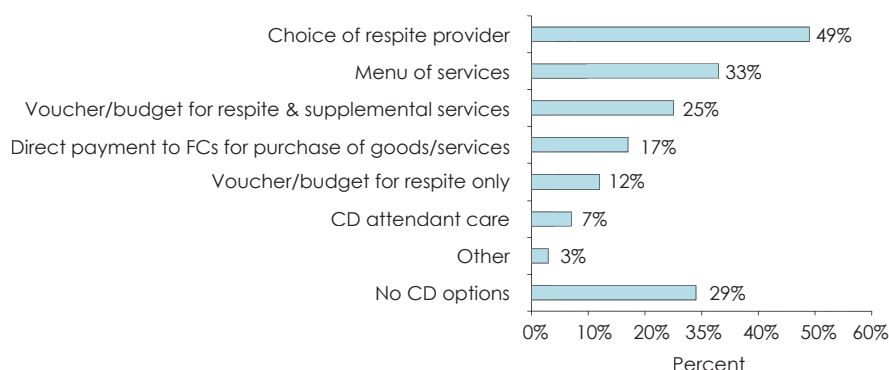
nationwide (71% of sample) say they offer consumer direction of some kind. But consumer direction is far from universally available.

- In 43 programs²⁸ (29% of the sample) in 29 states and the District of Columbia, family caregivers have no consumer-directed options.
- The NFCSPs are more likely than the Medicaid waiver or state-funded programs to say they have a consumer-directed option for family caregivers. Just seven NFCSPs (14%) report no consumer directed option in their service package compared to 17 Medicaid waiver (35%) and 19 state-funded (38%) programs.

We asked state program administrators to identify the types of consumer-directed options, if any, their program provides for family caregivers. Direct payments to families to hire, supervise or fire workers, including other family members, or vouchers/budgets for respite and supplemental services give families the most choice and

control to select the options that work best for them and their relative. As shown in Figure 16, programs in this survey offer a range of choices.

Figure 16. State Programs Offer a Range of Consumer-Directed Options (N = 149)



Note. CD = consumer-directed; FC = family caregiver

- Most commonly, programs give the family a choice of respite providers, (e.g., between contract agencies such as home care agencies or independent providers), effectively allowing families to hire their own worker. Overall, 73 programs (49%) in 43 states have this option, including two-thirds of the NFCSPs (67%) but less than half of state-funded (42%) or Medicaid waiver (38%) programs.
- One-third of all programs (49 in 35 states, 33%) provide caregivers a menu of services from which to choose those that best fit their needs. Nearly half the NFCSPs (49%) do so, compared to about one-fourth of state-funded and Medicaid-waiver programs (26% and 23% respectively).
- Fewer programs (37 in 29 states, 25%) offer a voucher or budget for respite care and supplemental services (e.g., consumable supplies, assistive devices, yard maintenance). Again, NFCSPs lead the way, with more than half (51%) offering supplemental services, one of the five statutory service components under the NFCSP. Relatively few state-funded (16%) or Medicaid-waiver (6%) programs provide this option.
- Direct payments to family members to buy goods or services also are more likely from the NFCSPs (31%) than the state-funded (16%) or Medicaid waiver (4%) programs. Overall, 26 programs (17%) in 20 states and the District of Columbia permit such payments to families.
- A respite-only voucher or budget appears as an option in 17 programs

²⁸ The South Dakota Medicaid waiver program did not respond to this question.

(12%) in 14 states, more often in state-funded programs (18%) and less frequently in NFCSPs (12%) or Medicaid-waiver (4%) programs.

Most states (all but six) pay families to provide care in at least one of their state-administered programs.

We asked state program administrators: “Can family members be paid to provide care in your program?”

- ♦ Over half (57%), or 86 out of 150, in 44 states and the District of Columbia) say they do. Only Alaska, Delaware, Mississippi, Nevada, Pennsylvania and Tennessee do not allow payments to family members.
- ♦ A higher proportion of Medicaid waiver programs (36, 74%) than NFCSPs (59%) or state-funded programs (40%) report they allow payment to family members (other than spouses or parents/guardians of minors).

The practice of paying families to provide care may be perceived by some state administrators as a consumer-directed option for the individual beneficiary or consumer (i.e., the care receiver) without directly aiding the family caregiver. Nine of the Medicaid waivers and five of the state-funded programs reporting no consumer-directed option for family caregivers say they do permit beneficiaries to pay family members to provide care.

SYSTEMS DEVELOPMENT

"I think that this is the most important program that the aging network has done in the last 20 years in terms of crossing boundaries and starting to think of older people in terms of their families and those who support them. We are moving toward supporting families as opposed to making people fit into categorical age criteria, and recognizing that older people are part of larger family systems. If we are successful... it will change the way that we deliver social services. This is working to break down some of the silos that we talk about. We are becoming more responsive as a result of supporting caregivers."

--NFCSP respondent

State System of Home and Community-Based Services (HCBS)

In the absence of a national, cohesive long-term care system, states have developed their own systems, primarily funded by Medicaid and state general revenues. Currently, a key policy goal in most states is reforming long-term care by expanding HCBS (Weiner et al., 2002). States face growing needs for long-term care services and supports due to an aging population, consumer preference for HCBS and constrained federal and state resources. Many states seek to develop more responsive community systems of long-term care, including family caregiver supports.

State approaches to systems development in HCBS and family care vary greatly due to differing administrative structures, funding sources and levels, program eligibility requirements, service definitions and distinct services, and other factors. For example, a respondent in this study (an administrator of a state-funded program) notes a major challenge: *"Differences in the definition of ADLs and IADLs from one funding stream to the next [NFCSP and Medicaid waiver, primarily]. This creates an organizational barrier because it leads to staff inconsistencies and not being able to translate the same assessment information from two different tools."*

States also differ in the degree to which they integrate their family caregiver support programs into other HCBS programs, and state officials' views about this issue vary, too (Feinberg & Newman, in press). The NFCSP may be helping states to advance their system development efforts. One study respondent, for example, tells of collaboration between the Medicaid waiver administration and the family caregiver support program to educate waiver service staff about the needs of the state's family caregivers.

Program administrators within a state often have differing views about the level of integration of their states' HCBS system for the elderly and adults with physical disabilities.

In this study, we asked state program administrators to choose one statement that best characterizes the level of integration of their state's HCBS system for the elderly and adults with physical disabilities. We gave them three choices:

- ♦ integrated through intake, assessment, care planning and data collection
- ♦ part of a larger program, but separate assessment and data collection

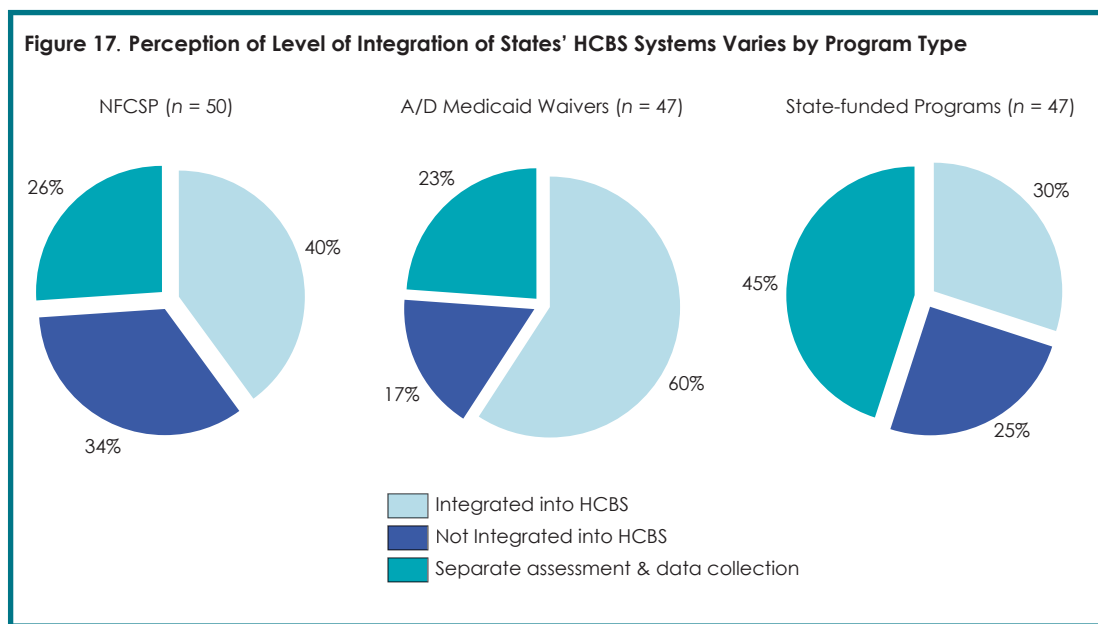
- ♦ not integrated into the state's home and community-based service system.

In only 21 states do all program administrators within the state agree on this issue.

- ♦ More than four in 10 (43%) or 62 programs (in 33 states and the District of Columbia) report that their state's HCBS system is integrated through intake, assessment, care planning and data collection.
 - In 14 states²⁹ all program respondents within the state agree on the level of integration.
- ♦ Nearly one-third (31%) of state administrators for 45 programs (in 21 states) say they are part of a larger program, but have separate assessment and data collection.
 - In three states (Florida, New Jersey and Pennsylvania) all respondents within these states are in agreement on this issue.
- ♦ About one in four (26%) respondents for 37 programs (in 23 states) characterize their program as not integrated into the state's HCBS system.
 - In four states (Kentucky, Massachusetts, New York and Rhode Island) the program respondents within these states are in agreement on this issue.

As shown in Figure 17, the perception of level of integration varies by type of program.

- ♦ Medicaid waiver respondents are the most likely to view their state's HCBS system as integrated (60% Medicaid waivers, 40% NFCSPs, 30% state-funded programs).
- ♦ State-funded program respondents are the most likely to view their



²⁹ Arizona, Delaware, Iowa, Indiana, Kansas, Maine, Minnesota, Mississippi, North Dakota, New Hampshire, South Dakota, Washington, West Virginia, Wisconsin.

programs as part of a larger program, but with separate assessment tools and data collection requirements (45% state-funded, 26% NFCSPs, 23% Medicaid waivers).

- The NFCSPs are the most likely of the three program types to view their program as not integrated into their state's HCBS system (34% NFCSPs, 25% state-funded, 17% Medicaid waiver programs).

About one-fourth of the states use a uniform assessment tool for all HCBS programs for the elderly and adults with disabilities; family caregiving is a component in just five states' uniform assessments.

A uniform assessment tool and protocol for all HCBS programs is one method that states utilize to develop support systems that are more responsive to consumer needs and preferences and to coordinate eligibility and care across various state programs that serve frail elders, adults with physical disabilities and their family caregivers. As discussed in earlier findings (see Eligibility and Assessment section), we asked state program administrators if their specific program uses a uniform assessment tool. We also asked administrators whether their state has a uniform assessment tool for *all* its HCBS programs for the elderly and adults with physical disabilities, and if the state does, whether this tool includes a family caregiving component.

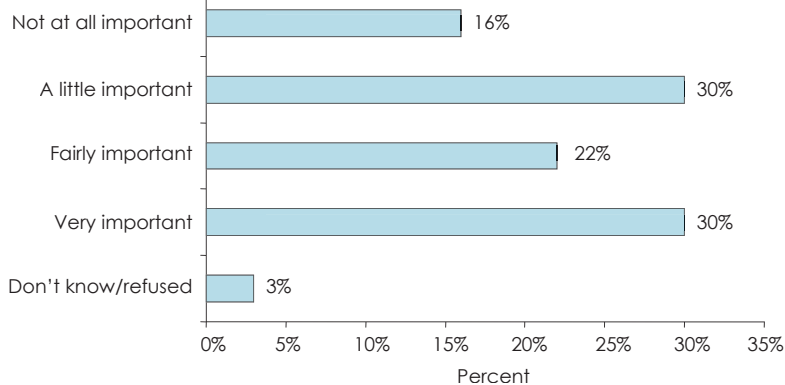
- A total of 60 programs (41%) in 30 states and the District of Columbia report a uniform assessment tool for all HCBS programs in their state.
- Of these, only half (31 of 60 programs) in 17 states indicate their state's tool includes a caregiving component.

Not surprisingly, given that administrators in the majority of states have differing perceptions about the level of integration they see in their state's HCBS system, there is also a general lack of agreement among state program administrators about the adoption of a uniform HCBS assessment tool in their state.

- In just 12 states³⁰ do all program administrators within the state agree that a uniform assessment tool is used for all HCBS programs for the elderly and adults with disabilities.
- Of those 12 states, respondents in only five (Delaware, Louisiana, Minnesota, South Dakota and Washington) report their state's tool includes a caregiving component.

Several Medicaid waiver respondents from states that have uniform assessment protocols but do not assess the needs and situation of the caregiver, commented that their state does not have caregiver issues built into the assessment process. One Medicaid waiver respondent remarked: *"Sometimes we don't know who is the significant other in a client's life. A major barrier to looking at program outcomes is trying to assess how well the program is meeting the family caregiver's needs too."*

³⁰ Colorado, Delaware, Indiana, Louisiana, Maine, Minnesota, Mississippi, North Dakota, Oregon, South Dakota, Washington, West Virginia.

Figure 18. States Have Mixed Views on the Importance of *Olmstead* to Caregiver Support (N = 148)

States have mixed views on the importance of *Olmstead* to caregiver support.

As required by the *Olmstead* decision, each state has worked to develop an *Olmstead* plan and is engaged in ongoing activities to expand community services for individuals with disabilities and promote community integration. A recent analysis of state *Olmstead* plans found that some states developed specific strategies slated for implementation over a number of years; some identified key priorities for more immediate actions;

some set forth broad policy recommendations to guide future action; and others anticipated frequent plan updates and revisions in what they consider to be working documents (Fox-Grage, Folkemer, & Lewis, 2003).

Family and informal support are essential to the successful transition of those with disabilities back into the community. We asked state program administrators how important the *Olmstead* decision is in influencing the development of caregiver support services in their state. As shown in Figure 18, states have mixed views on this issue, although over half (52%) of program respondents say that *Olmstead* is “fairly” or “very” important in influencing the development of caregiver support in their state. Medicaid waiver respondents are somewhat more likely (59%) than those representing state-funded programs (53%) and the NFCSPs (46%) to report that *Olmstead* is either “fairly” or “very” important to caregiver support.

We also asked each state respondent to indicate what priority is placed on implementing an *Olmstead* plan, among all long-term care issues in their state. Nearly half (48%) report a “high” priority, one-third (33%) say “medium,” a few (6%) report “low” and two programs believe that *Olmstead* is not a priority at all. Some (12%) say they “don’t know.”

Figure 19. Barriers That Limit/Prevent Coordination with Other State HCBS Programs*

	Program responses**	
	n	%***
Different eligibility requirements	70	50%
Complexity and fragmentation of services	60	43%
Different client population than in other programs	55	39%
Different reporting requirements/ capabilities	37	26%
Organizational cultural differences	31	22%
Federal regulatory or statutory requirements	30	21%
Staff have too many responsibilities	29	21%
State regulatory or statutory requirements	23	16%
Lack of access to adequate computer technology and support	16	11%
Lack of knowledge of opportunities for coordination	16	11%
Low priority given to caregiver support services	14	10%
Other	9	6%

Note. *Excludes funding. **N=140.

***Percentages are based on total number of responses.

The top barriers to coordinating caregiver support programs with other HCBS programs in the states are differing eligibility requirements and service complexity and fragmentation.

We asked program administrators to identify the three most important organizational, programmatic, geographic or political barriers (other than funding) that limit or prevent coordination of the caregiver support program with other HCBS programs in their state. Eligibility issues (50%) take the lead as shown in Figure 19. One Medicaid waiver respondent identified the need to change eligibility and the service package to better support family caregivers: “We must move beyond the care receiver as the focus of care,” a waiver

respondent explains. *"No one looks at the caregiver when we look at eligibility or when they are seeking to deter institutionalization. Overall, it is the stress of the family caregiver as well as the care receiver status that puts someone in a nursing home. If we were able to look at factors outside the care receiver's status that would be helpful, and we would do a better job of truly assessing risk of institutionalization."*

The next two most important barriers are complexity and fragmentation of services (43%), and different client population (i.e., informal caregivers) than in other programs (39%). No major differences were found among the three groups in this study (i.e., NFCSP, Medicaid waivers, state-funded programs).

Top Long-Term Care Issues; Caregiver Support Priority

Expanding Medicaid HCBS waivers, integrating long-term care services and implementing or expanding consumer-directed care are the top long-term care issues identified in the states.

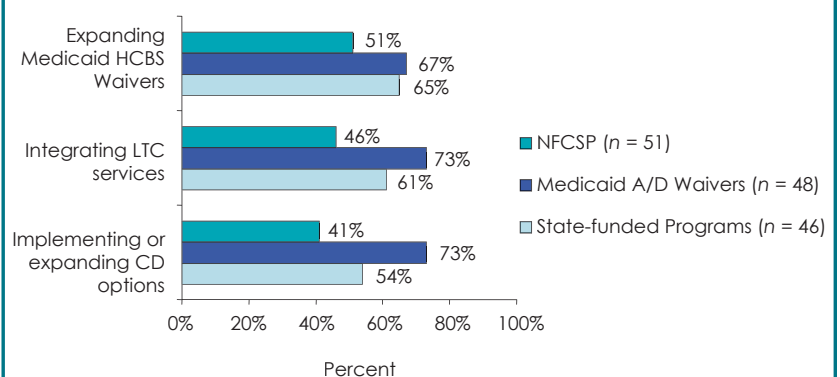
We asked state program administrators their opinion about the state's priority (high, medium, low) for 11 long-term care issues. The top priorities among respondents, include:

- expanding Medicaid HCBS waivers for the elderly and people with disabilities (61%)
- integrating long-term care services (60%)
- implementing or expanding consumer-directed options (56%).

Figure 20 shows the top long-term care priorities in the states by program type. Not surprisingly, given the economic downturn in most states at the time of this survey, lowest priority is given to expanding programs and services or creating other financial supports at the state level. Issues most frequently ranked as a low priority are:

- expansion of state-funded caregiver support programs (33%)
- expansion of state-funded home and community-based services for the elderly and adults with disabilities (32%)
- establishment of tax credits for caregiving (29%).

Figure 20. Top Three Long-Term Care Priorities in States by Program Type



Note. HCBS = home and community-based services; LTC = long-term care; CD = consumer-directed.

State program administrators have mixed views about the importance of caregiver support within home and community-based care; the majority perceive caregiver services as a medium priority.

We asked respondents to indicate what priority (high, medium, low) their state places on family caregiver support services within all of the state's home and community-based care programs. No differences emerge among program groups. Overall, program administrators view the importance of caregiver support in HCBS as follows:

- ♦ "high" priority (26%)
- ♦ "medium" priority (56%)
- ♦ "low" priority (18%)

As with other opinion questions in this survey, respondents within a state often have different views of the priority placed in their state on caregiver support. In 27 states there was no consensus. In the 23 states with consensus, we see:

- ♦ "high" priority given to caregiver support within six states (Illinois, Louisiana, Massachusetts, Montana, North Dakota and Pennsylvania)
- ♦ "medium" priority in 13 states³¹
- ♦ "low" priority in four states (Alabama, Colorado, Kansas and West Virginia).

States are beginning to establish task forces or commissions to examine family caregiver issues.

In response to the NFCSP, some states have formed task forces or commissions on family caregiving issues. Other states have established task forces or commissions to highlight the central role that family caregivers play in long-term care as states move toward more responsive and coordinated systems of care. In still other states, informal caregiving issues are being addressed as part of broader state task forces on long-term care in general or HCBS in particular.

In this study, 15 states³² report either a task force or commission on family caregiving. These entities range in scope and objective. Examples include:

- ♦ The *Connecticut LifeSpan Respite Coalition*, a grassroots coalition of individuals, is seeking to identify gaps in respite services and to coordinate existing services available to families across the lifespan.
- ♦ *Hawaii's Family Caregiver Network* is bringing together family caregivers by providing a coordinated system to disseminate information to family caregivers on a range of issues, serving as a vehicle for families to comment on and respond to caregiving needs and policies, and serving as a resource for researchers.
- ♦ The *Maryland Caregivers Support Coordinating Council*, operated through the Maryland Department of Human Resources, is working to improve support services for unpaid family caregivers in the states, including the need for additional resources for respite care.

³¹ Arkansas, Arizona, Delaware, Florida, Iowa, Maryland, Minnesota, New Hampshire, Oregon, Rhode Island, South Carolina, Vermont, Wyoming.

³² Alabama, Colorado, Connecticut, Hawaii, Illinois, Indiana, Louisiana, Maryland, Michigan, North Carolina, New York, Oklahoma, Oregon, Utah, Virginia.

OTHER ISSUES

*"Supporting family caregivers is family-friendly state policy."
--Medicaid waiver respondent*

As state administrators work to strengthen and enhance services in the home and community, they face complex issues. We asked respondents for their opinions about key policy and programmatic issues for caregiver support and long-term care in their state. What do they see as unmet needs for caregivers? What are their views about training and technical assistance to better meet the needs of family and informal caregivers? What are their major challenges, what have they learned about providing caregiver support services and what would they recommend to other states pursuing similar goals? What new legislation has been enacted in the states to support caregiving families?

Top Unmet Needs of Caregivers

State program administrators see the lack of resources to meet caregiver needs in general and limited respite care options as the top unmet needs of family caregivers in the states.

When we asked respondents this open-ended question, "What would you say is the major unmet need of family caregivers in your state?" we received many different answers, but definite themes emerge. As Figure 21 shows, about half of all respondents in the states identify as unmet needs the overall lack of resources for a range of caregiver services (e.g., services for working caregivers, culturally appropriate services, family counseling) and the limitation in respite options. Although a minority of respondents identify other unmet needs in the top five, their concerns reveal the challenges officials are facing in the states as they implement caregiver support programs: lack of public awareness about caregiver issues and programs, shortage of workers to provide help to caregivers, and access to services in rural areas.

Figure 21. Top Five Unmet Needs of Caregivers in the States

	Program responses*	
	n	%**
Lack of resources to provide a range of services	69	50%
Limited respite care/options	66	47%
Lack of public awareness about caregiver issues/programs	38	27%
Shortage of providers (workforce)	23	17%
Limited access to services in rural areas	13	9%

Note. *N=139. **Percentages are based on total number of responses.

Program Support Needs: Training and Technical Assistance

About half the state programs offer training for staff who work with family caregivers.

Well-trained staff can reduce the stress of the family caregiver (Levine, 2004). As shown in Table 6, 69 programs or about half (47%) of programs surveyed provide training for staff who work with family caregivers. Another six programs (4%) say they are developing training on caregiving topics.

- ♦ The top five training areas are:
 - caregiver assessment (60%)
 - best practices in service delivery (54%)
 - data collection and reporting (50%)

- outreach and public awareness (47%)
- caregiver intake issues (47%)
- ♦ NFCSP respondents (61%) are, not surprisingly, more likely than state-funded (40%) or Medicaid waiver programs (39%) to provide caregiver-related training to program staff.

Three of the top five current training topics match those training and technical assistance areas almost all respondents say would benefit staff: best practices in service delivery, outreach/public awareness and caregiver assessment.

Figure 22. Top Five Identified Technical Assistance & Training Areas for Staff Who Work with Family Caregivers*

	% Responding “Strongly Agree” or “Agree” **
Best practices in service delivery	99%
Culturally/ethnically appropriate services	97%
Program evaluation/outcome measures	96%
Outreach/public awareness	92%
Caregiver assessment issues	91%

Note. *N = 139. **Percentages are based on total number of responses.

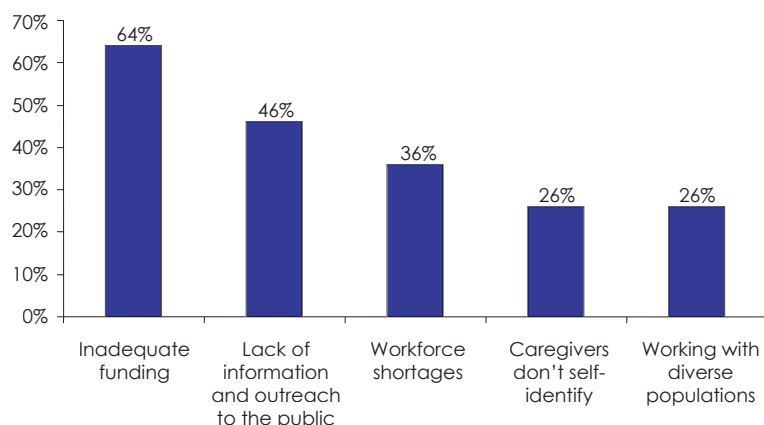
We asked respondents to share their views about the benefit to their staff of technical assistance and training on 11 specified topics. Figure 22 shows the five areas where state program administrators see the most likely benefit. Interestingly, two of the top three areas for technical assistance are *not* among the topics that actual training programs most often address: culturally/ethnically appropriate services and program evaluation/outcome measures.

Top Challenges, Lessons Learned and Recommendations

States identify inadequate funding as the main challenge to implementing caregiver support services.

In telephone follow-up interviews we asked program respondents this question, “What are the three main challenges to implementing family caregiver support services in your state?” The majority of program respondents (64%) report “inadequate funding.” As Figure 23 shows, many of the other recurring themes match the officials’ views on unmet caregiver needs:

Figure 23. Top 5 Challenges to Implementing Family Caregiver Support Program in the States (N = 145)



- ♦ **Lack of information and outreach to the public.** Nearly half (46%) feel that many families who might benefit from their services do not know where to go for help. More outreach is needed to educate families about caregiving needs and available services.
- ♦ **Workforce shortages.** More than one in three (36%) respondents face a shortage of qualified service providers (e.g., social workers) or direct care workers (e.g., nurses aides). Low wages and turnover are often cited as a big part of this challenge.

- **Caregivers don't self-identify.** One in four (26%) respondents say it is often difficult to provide services when many caregivers don't identify with the term "family caregiver." Rather, family members view themselves as the husband, wife or daughter and may not recognize their own support needs or that programs could assist them in the care of their loved one. Increased public awareness campaigns can help alleviate this challenge.
- **Working with diverse populations.** One in four (26%) cite the challenge of providing targeted services to support ethnically diverse caregivers and meeting the needs of working, long-distance and other caregivers with particular care concerns.

Among just the NFCSP respondents specifically, one in four (25%) note the challenge of the "paradigm shift" in serving a new constituency, family members and friends, along with supporting the older person, the traditional client in the long-term care system.

The major lesson learned by the states in providing family caregiver support is 'one size does not fit all'—so increase the choices that families have.

We asked in our follow-up interviews with state program administrators, "What is the major lesson you've learned in providing family caregiver support services?" (see Figure 24). Among the many lessons that they share, the one that comes up most often is maximizing flexibility and choice for families. *Support is different for each family – there's no one size fits all for families,*" one Medicaid waiver respondent puts it. *"Sometimes the support is more for the caregiver themselves than for the care receiver."*

Figure 24. Major Lessons Learned by State Programs in Providing Family Caregiver Support Services	Program responses*	
	n	%**
Maximize flexibility and choice for families	47	33%
Allow caregivers to tell you what they need	37	26%
Provide a range of support services to meet caregiver needs	25	18%
Focus on consumer education and outreach to general public	22	16%
Caregivers don't self-identify	14	10%

Note. *N=141. **Percentages are based on total number of responses.

Other lessons that multiple respondents report are that it is important to focus on consumer education and outreach to the general public and that caregivers often need help to self-identify with the term "caregiver." One NFCSP respondent explains, *"No one knows the stress and need (emotional, mental, and physical) of caregivers. Once you start talking about it people understand, but until you start that dialogue they can't conceptualize the need."*

To strengthen caregiving programs, state officials recommend more innovation in program design to provide a broader array of services, better coordination and integration of caregiver support into HCBS, and more local collaboration.

When asked what recommendations they would make to other states that are implementing caregiver programs, respondents have many suggestions. As Figure 25 shows, the top recommendations are these:

- ♦ **Ensure innovative programs and a flexible array of caregiver support services to meet the diverse needs of families and the individuals for whom they care.** Respondents emphasize the importance of finding new ways for delivering services (e.g., through enhanced use of technology and on-line support groups, or providing mobile respite in rural areas) as well as the importance to caregivers of flexibility, especially for those who may be hard to reach (e.g., rural, working and long-distance caregivers).
- ♦ **Coordinate and integrate caregiver support into HCBS.** Respondents call attention to the fragmented nature of long-term care services and stress the need to integrate caregiver support into the HCBS system, making the delivery of caregiver services an everyday practice in family-centered home and community-based care. *"Don't look at caregiver programs in a silo,"* recommends one NFCSP respondent. *"Integrate caregiver support into other HCBS programs."*
- ♦ **Collaborate with local stakeholders.** Respondents suggest collaboration with local consumer groups to build consensus, develop programs and deliver services. One state-funded respondent notes, *"Tapping into community resources is a key element to a successful program."*

Figure 25. Top Five Recommendations to Other States	Program responses*	
	n	%**
Ensure innovative programs and a flexible array of caregiver support to meet the diverse needs of families	57	40%
Coordinate and integrate caregiver support into HCBS	42	29%
Collaborate with local consumer groups/agencies to build consensus, develop programs, and provide services	32	22%
Maximize family and consumer involvement in service planning and delivery	28	19%
Conduct strategic planning/needs assessment prior to program implementation	27	19%
Promote consumer-directed models of care	26	18%

Note. *N=144. **Percentages are based on total number of responses.

- ♦ **Maximize family and consumer involvement in service planning and delivery.** Respondents underscore the importance of recognizing families and care receivers as partners in long-term care. *"Delegate flexibility all the way down to the consumer level. It is not enough just to give it to the AAA, or to the provider,"* recommends one NFCSP respondent. Instead:
 - Listen to, assess, and take into account the caregiver's individual needs and situation.
 - Develop a vocal constituency base and have families participate in advocacy efforts to build partnerships at the community and state levels.
- ♦ **Conduct strategic planning.** Respondents recommend advance planning and a thorough needs assessments prior to program implementation. *"We did four public hearings around the state [prior to the start of the NFCSP] to hear from individuals and families to see what they needed,"* shares one NFCSP state administrator. *"This was great for us, and helped us get the input from people providing care."*
- ♦ **Promote consumer direction.** Respondents say that consumer-directed models of care allow for a more family-centered approach to support and services, including payment to families to provide care. One Medicaid waiver respondent advises, *"Make caregiver support an integral part of any type of personal care program, also allowing the families to be paid providers. Making sure families can be paid will help with funding issues, because it's built-in support for families."*

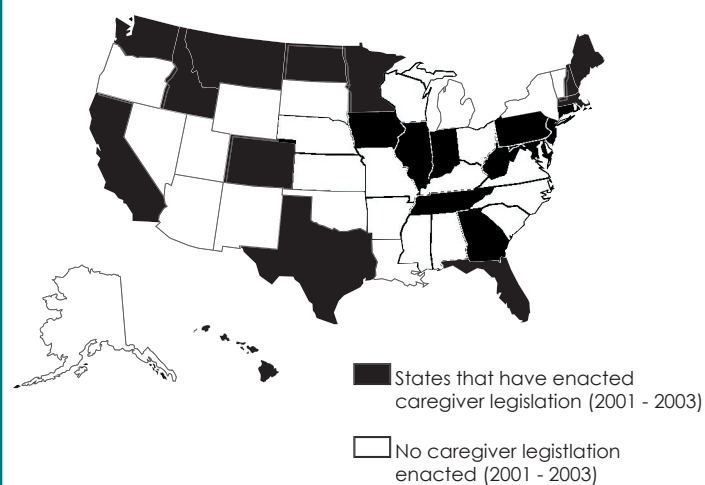
New Legislation in the States

State legislatures, recognizing family caregivers' important role, are enacting laws to fund caregiver support services, expand family and medical leave, and include family caregiving in state long-term care efforts.

From 2001 through 2003, 23 states enacted legislation that was relevant to family caregiving (see Figure 26 and State Profiles).

- In 11³³ states, legislation funded family caregiver support programs, many enacting these changes as a direct result of the NFCSP.
- California, Hawaii and Washington enacted legislation that expanded the minimum requirements of the federally prescribed Family and Medical Leave Act (FMLA).
 - California enacted the most comprehensive paid family leave bill in the nation in 2002. It provides up to six weeks of partial wage replacement (100% employee-funded) for workers caring for a new child or seriously ill family member.
- Maryland, New Hampshire and Washington established work groups, councils or commissions to study and coordinate family caregiver support services.
- Connecticut, Hawaii and Iowa enacted legislation to ensure that family caregivers are central to long-term care programs and policies.
 - In 2001, the Connecticut legislature required state agencies to include provisions that support family caregivers in any program that assists or supports people with long-term care needs.
 - In 2001, the Hawaii legislature established support for family caregivers of adults with disabilities as a long-term goal of the state.
 - The 2003 session of the Iowa legislature added "support for caregivers" to the state's objectives for serving older individuals.

Figure 26. 23 States Have Enacted Caregiver Legislation (2001 - 2003)



³³ California, Colorado, Florida, Idaho, Illinois, Indiana, Maine, Massachusetts, New Jersey, North Dakota, Pennsylvania.

CONCLUSIONS AND ISSUES FOR THE FUTURE

This study illuminates the large role states play in the nation's support of family caregivers. The study profiled the experience of all 50 states and the District of Columbia in providing publicly funded support services to caregivers of older people and younger adults with disabilities since the passage of the NFCSP. Designed to take a broad focus, the study examined policy choices and state approaches to caregiver support through state agencies responsible for the administration of the NFCSP, Aged/Disabled Medicaid waiver programs, and state-funded programs that have either a caregiver-specific focus or include a family caregiving component in their service package. This wide-ranging report of caregiver support services in the U.S. revealed the following:

While there is increasing availability of publicly funded caregiver support services, there is also great unevenness in services and service options for family caregivers across the states and within states.

All states now provide some explicit caregiver support services as a result of the passage of the NFCSP in 2000. Yet, similar to HCBS in general, the availability of caregiver support services varies greatly across the U.S. due to differences in philosophy, program eligibility criteria, funding and

approaches to program design and administration of services. For example, although respite care is the service strategy most commonly offered to help caregivers, and is available in all 50 states, our findings suggest that the goal of respite (i.e., whether

In this study, state program administrators identified the lack of resources to meet the range of caregiver needs in general, and limited respite care options in particular, as the top unmet needs of caregivers in the states.

it is targeted toward the care receiver or viewed as a service to sustain the family caregiver), its definitions, and the amount of respite assistance available to family members varies substantially from state to state and programs within states.

In this study, state program administrators identified the lack of resources to meet the range of caregiver needs in general, and limited respite care options in particular, as the top unmet needs of caregivers in the states. At a practical level, such service gaps and variations pose challenges for caregivers by limiting choices for needed support services that may not be available where they live. Service inequities may also place more pressure on already strained caregiving families and compromise the ability to care for a loved one.

The NFCSP is emerging as a key program to enhance the scope of caregiver support services and is fueling innovation in the states, but is inadequately funded.

In this study, the NFCSP was found to expand the range and scope of services to caregivers of older people in states where caregiver support services existed before the establishment of the NFCSP. In other states, the NFCSP now serves as an important resource for the provision of

services not available previously. Caregiver education and training, care management and family consultation, individual and/or family counseling, and support groups are offered by the majority of the states to some degree under the NFCSP, in addition to respite care.

The NFCSP also appears to be speeding the adoption of consumer direction in explicit family caregiving programs. However, the modest level of NFCSP funding leaves gaps in caregiver support services and also results in substantial variation in service availability across the states. As a consequence, most states in this study continue to rely on their own general revenues to provide caregiver support services, and utilize Aged/Disabled Medicaid waivers, a significant source of funds, to finance respite care for family caregivers of Medicaid waiver beneficiaries. When compared to spending for Medicaid waiver funds spent on respite care alone, the NFCSP funding appears even more limited.

While there is great variation among states and programs within states in their approach to caregiver assessment, there is broad recognition of the value of uniformly assessing caregiver needs and the importance of training and technical assistance in this area.

Only five states that use a uniform assessment tool for all HCBS programs for older people and adults with disabilities were found to include a family caregiving component as part of systematic assessment practice. The majority of state-funded and Medicaid waiver programs in this study assess only the person with disabilities, not the needs and situation of the family caregiver. Yet, systematic assessment of the caregiver's needs as distinct from, but related to the needs of the care receiver, is central to systems change and to improving policy and practice in HCBS. Indeed, identifying and meeting the specific needs of family caregivers is often a deciding factor in determining whether an individual can remain at home or must turn to more costly nursing home care. Without uniform, aggregated assessment information on the caregiver, it is difficult to measure the impact of services on family caregivers and to assure quality of care for frail elders and adults with disabilities.

Systematic assessment of the caregiver's needs as distinct from, but related to the needs of the care receiver, is central to systems change and to improving policy and practice in HCBS.

States have mixed views on approaches to systems development, the importance of caregiver support services within home and community-based care, and integrating family caregiving programs into HCBS.

On the one hand, state program administrators in this study often had different perspectives on these issues and, more frequently than not, respondents within a state lacked agreement. On the other hand, during the time of this survey, states were facing an economic downturn while they were attempting to develop plans to rebalance long-term care by expanding HCBS options. In addition, the advent of the NFCSP created a paradigm shift with its new mandate to explicitly provide services to family caregivers of older people. Recognizing the legitimate needs of family caregivers as a "consumer" or "client population" has been found to be a relatively new concept for many states (Feinberg et al., 2002). Therefore,

it is not surprising that in a time of major organizational and systems change, there may be different levels of understanding and perspectives of how states can and should accomplish the policy goal of reforming long-term care by expanding HCBS.

Our current HCBS system relies heavily on family and informal caregivers. Families need help more than ever as they struggle to balance competing demands of work, family and caregiving. Caregiver support services can help ease the burden on families, increasing confidence and competence in everyday care tasks and providing needed respite care to sustain them in their caregiving role. Without recognition of the legitimate needs of family and informal caregivers and additional investments in caregiver support services, the reforms underway in HCBS may not be as effective and meaningful to American families. If we are serious about reducing

fragmentation in home and community-based care and recognizing the legitimate needs of informal caregivers, then assessment of caregiver needs and caregiver support services should be integrated into HCBS. A family-centered approach to HCBS should be considered as states continue to pursue the goal of reforming the long-term care system to strengthen integrated systems of home and community-based care.

If we are serious about reducing fragmentation in home and community-based care and recognizing the legitimate needs of informal caregivers, then assessment of caregiver needs and caregiver support services should be integrated into HCBS.

Issues for the Future

From this study, we can identify important issues for the future. The following are five initial steps towards achieving a better caregiver support system across the nation:

- 1. Raise the funding level of the NFCSP to reduce gaps in caregiver support services and provide meaningful support to caregiving families.** The level of NFCSP funding is too low to meet the multifaceted needs of family caregivers. Increasing funds for the NFCSP will help promote systems change and ease the burdens on family caregivers, in turn preventing much higher expenditures in Medicaid and HCBS programs that might be necessitated if the informal caregivers became incapacitated or unavailable (Vladack, 2004).
- 2. Improve data collection and reporting under the NFCSP and other state programs that provide caregiver support services.** As part of the development process for the NFCSP, the Administration on Aging should partner and work closely with states on the uniform reporting requirements that will take effect in fiscal year 2005. Accountability is critical to the success of the NFCSP and other caregiver support programs. However, because many states do not have uniform reporting systems in use across their own HCBS programs, including those providing caregiver services, it is impossible to report on caseloads and funding across all programs providing some component of family caregiver support services at this time. Federal, state and local policymakers and program administrators must make decisions based on outcomes. Uniform data collection is essential for programs to achieve a more consistent understanding of the scope of services across the country and to ensure that federal and state funding remain viable.

3. **Strengthen and expand uniform assessment of caregiver needs in all HCBS programs that provide some component of caregiver support.** Currently, there is no consensus about how to assess family care or what should be included in a uniform caregiver assessment tool. Developing such a consensus should be a high priority (Gould, 2004). Establishing guidelines for caregiver assessment, based on an outcome-driven knowledge management system, would be a worthwhile investment to develop better data to support and drive decision making. Ultimately, consistent approaches to caregiver assessment will enable family caregivers to obtain needed support, strengthen their ability to ensure optimal outcomes and quality of care for the care receiver, remain in their caregiving role as long as appropriate, and provide solid information to policymakers and program administrators intent on improving the effectiveness and efficiency of HCBS.
4. **Conduct a national public awareness campaign on family caregiving.** Outreach to informal caregivers specifically, and to the public in general, is crucial to ensuring that families and friends access information and services early in the caregiving process, and have the supports they need to adequately sustain them in the caregiving role. In this study, lack of public awareness about caregiver issues and programs—including the notion that caregivers don’t self-identify with the term “caregiver”—was a recurring theme, as a top unmet need of caregivers, as a topic for training and technical assistance, and as a challenge to implementing caregiver support services in the states.
5. **Invest in innovation, promising practices and technical assistance.** States want to know about and learn from the successes and challenges of other states’ efforts to support and strengthen family and informal caregivers. State administrators of the NFCSP, Medicaid waiver and state-funded programs were particularly interested in program design to provide a broader array of services, develop consumer direction to maximize flexibility and choice for families, and to use technology with those caregivers who may be difficult to reach (e.g., rural, working and long-distance caregivers). Over 90 percent of respondents in this study viewed five topics as the top training and technical assistance areas most likely to benefit their staff: best practices in service delivery; culturally/ethnically appropriate services; program evaluation/outcome measures; outreach/public awareness; and caregiver assessment.

This first 50-state study on caregiving offers new insights into the ways states provide caregiver support services and approach family caregiving issues in the context of HCBS. As such, it provides a starting point for further examination of the policy choices and state approaches to caregiver support, as well as changes over time. We hope that this report, and subsequent papers and issue briefs emanating from this study, will help to stimulate continued development of policies and programs to support family and informal caregivers of older people and adults with disabilities.

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HOW TO READ THE STATE PROFILES

The state profiles in this report are organized alphabetically by state. Each profile includes:

- ♦ Selected state background characteristics (e.g., census data, caregiving and long-term care data) for the state and the U.S.
- ♦ Data about the state's home and community-based services as they relate to family caregiving, derived from this study
- ♦ Key program-level information from the study respondents and other sources about programs and services to support caregivers (i.e., administrative structure, funding and caseload, eligibility, assessment, services and consumer direction)

To determine the original data source for "Selected State Background Characteristics", go to the "Data Documentation" section that follows the state profiles on page 264.

In the "State System of Home and Community-Based Services" section of the profiles, level of agreement among program respondents within a state was examined for responses to questions on single point of entry and the availability of a uniform assessment tool for all home and community-based programs in a state. All program respondents within a state had to be in agreement for data to be reported as either "yes" or "no." For those data points in which program respondents within a state disagreed, we report that there was a "lack of agreement."

To identify sources for fiscal and caseload data used in "State Program Information", go to the "Data Documentation" section that follows the state profiles on page 264.

In certain cases, data were not applicable (N/A), not available (n/a) from the data sources utilized, or "no response" was provided by the survey respondent.

Abbreviations Used in State Profiles

FC=National Family Caregiver Support Program

MC=Aged or Aged/Disabled Medicaid HCBS waiver

SC=State-funded program

AAA=Area Agency on Aging

AD=Alzheimer's Disease

ADL=Activity of Daily Living

Adult day svcs.=Adult day services

Care mgt.=Care management

Consum. supplies=Consumable supplies

Dept.=Department

Educ. & training=Education & training

Emerg. response=Emergency response

Family Consult.=Family consultation

Gov't=Government

HCBS=Home and Community-Based Services

IADL=Instrumental Activity of Daily Living

Info. & assistance=Information & Assistance

OAA=Older Americans Act

OAA guidelines=the care receiver must have two or more ADL limitations or a cognitive impairment for the caregiver to be eligible for respite or supplemental services¹

SUA=State Unit on Aging

Title XX=Social Services Block Grant funds

¹ Alecxih, L., Zeruld, S., Linkins, K., Bush, S., Olearczyk, B. & Neill, C. (2002). The National Family Caregiver Support Program Resource Guide. Falls Church, Virginia: The Lewin Group.

State Profile: **Alabama**

Selected State Background Characteristics

	AL	US		AL	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	4.4	281.4	# of Caregivers (<i>millions</i>)	0.4	27.2
Pop. 60+ (<i>thousands</i>)	769.9	45,797.2	Caregiving Hours (<i>millions</i>)	465.2	29,182.0
% 60+	17.3	16.3	Value of Caregiving (<i>millions</i>)	\$4,099.0	\$257,096.0
National Ranking 60+	14	N/A	% Grandchildren living w/grandparents age 65+	4.5	4.4
% White (60+)	79.6	82.3			
% 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	■ Care Receivers ■		
% American Indian/ Alaska Native (60+)	0.2	0.4	% Pop. 21-64 Years w/Disability	23.2	19.2
Pop. 65+ (<i>thousands</i>)	579.8	34,991.8	% Pop. 65+ w/Disability	49.5	41.9
% Pop. 65+	13.0	12.4	% 65+ by Type of Disability		
National Ranking 65+	21	N/A	Sensory	17.0	14.2
Pop. 85+ (<i>thousands</i>)	67.3	4,239.6	Physical	35.5	28.6
% Pop. 85+	1.5	1.5	Self-care	13.0	9.5
National Ranking 85+	26	N/A	Mental	14.6	10.8
			Difficulty Going Outside Home	25.1	20.4
■ Economic Indicators ■					
Per Capita Income	\$26,338	\$31,632	■ Long-Term Care ■		
Median Household Income	\$37,603	\$42,409	Certified Nursing Facilities	218	15,162
% of Pop. 65+ Below Poverty	15.7	10.4	Certified Nursing Facility Beds (<i>thousands</i>)	24.9	1,574.0
			Average Cost Per Day in a Nursing Home	\$128	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	40	3,407
Households with Individuals 65+ (<i>millions</i>)	0.4	24.7	Home Health Aides	6,490	N/A
% Persons Age 65+ Living Alone	33.1	30.1			
% Pop. 65+ in Major Cities	23.5	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	37.6	50.1			

State Profile: **Alabama** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Department of Senior Services Support for Caregivers
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Administering State Agency	AL Department of Senior Services	AL Medicaid Agency
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Dept. of Public Health & Dept. of Senior Services are operating agencies

■ **Funding & Caseload** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	Medicaid HCBS waiver
FY 2001 Expenditures	\$1,739,242	\$5,148,710 (<i>respite only</i>)
FY 2002 Expenditures	\$1,996,374	\$5,676,620 (<i>respite only</i>)
FY 2003 Expenditures	\$2,187,095	\$52,919,759 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	1,704
FY 2002 A/D Waiver Respite Participants	N/A	1,776

State Profile: **Alabama** (cont'd)■ **Eligibility** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Caregiver Age Requirement	None	None
Care Receiver Age Requirement	60+	None
Care Receiver Functional Status Requirement	2 IADLs	Nursing home level of care
Client Population	Family Caregiver	Care Receiver

■ **Assessment** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care Receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	N/A
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver social support network ▪ Financial situation 	N/A

■ **Services** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. Response ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Support groups ▪ Transportation ▪ Other 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Counseling ▪ Home modification/repairs
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ In-home

State Profile: **Alabama** (cont'd)■ **Services** (cont'd) ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	\$500 - \$1200/year	720 hours/year
Uniform Respite Cap Across Program Sites	No	Yes
Entity that Formulates the Respite Cap	Administering local agency	Operating agencies

■ **Consumer Direction** ■

Program Name	Alabama CARES (FC)	Elderly & Disabled Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care

State Profile: **Alaska**

Selected State Background Characteristics

	AK	US		AK	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	0.6	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	53.0	45,797.2	Caregiving Hours (<i>millions</i>)	60.6	29,182.0
% 60+	8.5	16.3	Value of Caregiving (<i>millions</i>)	\$533.8	\$257,096.0
National Ranking 60+	51	N/A	% Grandchildren living w/grandparents age 65+	8.8	4.4
% White (60+)	73.4	82.3			
% African American (60+)	2.1	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.8	5.4	% Pop. 21-64 Years w/Disability	15.6	19.2
% Asian (60+)	4.7	2.5	% Pop. 65+ w/Disability	46.2	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.2	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	15.3	0.4	Sensory	20.7	14.2
Pop. 65+ (<i>thousands</i>)	35.7	34,991.8	Physical	32.1	28.6
% Pop. 65+	5.7	12.4	Self-care	10.4	9.5
National Ranking 65+	51	N/A	Mental	12.3	10.8
Pop. 85+ (<i>thousands</i>)	2.6	4,239.6	Difficulty Going Outside Home	20.2	20.4
% Pop. 85+	0.4	1.5			
National Ranking 85+	51	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$33,568	\$31,632	Certified Nursing Facilities		
Median Household Income	\$52,774	\$42,409		12	15,162
% of Pop. 65+ Below Poverty	N/A	10.4	Certified Nursing Facility Beds (<i>thousands</i>)	0.6	1,574.0
■ Socio-Demographics ■			Average Cost Per Day in a Nursing Home	\$457	\$158
Households with Individuals 65+ (<i>millions</i>)	0.0	24.7	Licensed Adult Day Facilities	11	3,407
% Persons Age 65+ Living Alone	26.0	30.1	Home Health Aides	1,180	N/A
% Pop. 65+ in Major Cities	39.9	40.1			
Average Household Size	2.7	2.6			
Average Family Size	3.3	3.1			
% Households with Internet Access	64.1	50.1			

State Profile: **Alaska** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
Administering State Agency	AK Department of Health and Social Services, Division of Senior & Disabilities Services	AK Department of Health & Social Services, Commission on Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	Grantees	SUA

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
Major Sources of Program Funding	OAA, Title III-E	Mental Health Trust Authority Authorized Receipts
FY 2001 Expenditures	\$564,300	n/a
FY 2002 Expenditures	\$644,212	n/a
FY 2003 Expenditures	\$705,756	n/a
FY 2001 A/D Waiver Respite Participants	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	N/A

State Profile: **Alaska** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
Caregiver Age Requirement	None	None
Care Receiver Age Requirement	60+	No response
Care Receiver Functional Status Requirement	No functional status requirement	No functional status requirement
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
Program Assesses	Family caregiver	Care receiver
Uniform Assessment Tool	No	No
Includes Caregiver Assessment	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Family consult. ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups 	<ul style="list-style-type: none"> ▪ Homemaker/chore/personal care ▪ Respite Care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home 	<ul style="list-style-type: none"> ▪ In-home ▪ Other
Caregiver Must Live with Care Receiver to Receive Respite	Yes	No
Respite Cap	No cap	40 hours/month
Uniform Respite Cap Across Program Sites	N/A	No
Entity that Formulates the Respite Cap	N/A	Administering local agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Innovative Respite (SC)
Consumer-Directed Options	Families have a choice of respite providers	None
Family Members Can Be Paid to Provide Care	No	Yes (with program approval)
Types of Services Families Can Be Paid to Provide	N/A	N/A

State Profile: **Arizona**

Selected State Background Characteristics

	AZ	US		AZ	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.1	281.4	# of Caregivers (<i>millions</i>)	0.5	27.2
Pop. 60+ (<i>thousands</i>)	871.5	45,797.2	Caregiving Hours (<i>millions</i>)	522.9	29,182.0
% 60+	17.0	16.3	Value of Caregiving (<i>millions</i>)	\$4,606.6	\$257,096.0
National Ranking 60+	21	N/A	% Grandchildren living w/grandparents age 65+	3.2	4.4
% White (60+)	85.3	82.3			
% African American (60+)	1.6	8.4			
% Hispanic (60+)	9.2	5.4			
% Asian (60+)	1.0	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	■ Care Receivers ■		
% American Indian/ Alaska Native (60+)	2.2	0.4	% Pop. 21-64 Years w/Disability	19.4	19.2
			% Pop. 65+ w/Disability	39.7	41.9
			% 65+ by Type of Disability		
Pop. 65+ (<i>thousands</i>)	0.7	34,991.8	Sensory	14.1	14.2
% Pop. 65+	13.0	12.4	Physical	27.3	28.6
National Ranking 65+	22	N/A	Self-care	7.8	9.5
			Mental	9.7	10.8
Pop. 85+ (<i>thousands</i>)	68.5	4,239.6	Difficulty Going Outside Home	17.4	20.4
% Pop. 85+	1.3	1.5			
National Ranking 85+	38	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$26,838	\$31,632	Certified Nursing Facilities	131	15,162
Median Household Income	\$39,734	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	15.0	1,574.0
% of Pop. 65+ Below Poverty	6.0	10.4	Average Cost Per Day in a Nursing Home	\$161	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	22	3,407
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Home Health Aides	10,510	N/A
% Persons Age 65+ Living Alone	26.3	30.1			
% Pop. 65+ in Major Cities	51.1	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	51.9	50.1			

State Profile: **Arizona** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
Administering State Agency	AZ Department of Economic Security	AZ Health Care Cost Containment System	AZ Department of Economic Security
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency	AAA

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid 1115 (c) Waiver	<ul style="list-style-type: none"> ▪ OAA, Title III-B ▪ State general fund ▪ Title XX
FY 2001 Expenditures	\$1,956,318	n/a	n/a
FY 2002 Expenditures	\$2,337,035	n/a	n/a
FY 2003 Expenditures	\$2,560,300	n/a	n/a

State Profile: **Arizona** (cont'd)

■ Funding & Caseload (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
FY 2001 A/D Waiver Respite Participants	N/A	n/a	N/A
FY 2002 A/D Waiver Respite Participants	N/A	n/a	N/A

■ Eligibility ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
Caregiver Age Requirement	None	18+	None
Care Receiver Age Requirement	60+	None	60+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ 2 IADLs ▪ Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> ▪ Nursing home level of care 	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ 2 IADLs
Client Population	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver

■ Assessment Process ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	No	Yes
Includes Caregiver Assessment	Yes	N/A	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver strain 	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver strain

State Profile: **Arizona** (cont'd)■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Family consult. Home modification/repairs Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Emerg. response Family meetings Homemaker/chore/personal care Home modification/repairs Info. & assistance Respite care Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Family consult. Home modification/repairs Info. & assistance Respite care Support groups Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	No cap	720 hours/year	No cap
Uniform Respite Cap Across Program Sites	N/A	Yes	N/A
Entity that Formulates the Respite Cap	N/A	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	AZ Long-Term Care System (ALTCS) (MC)	Non-Medical Home and Community Based Services (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A voucher or budget for respite only Families have a choice of respite providers 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose 	None
Family Members Can Be Paid to Provide Care	Yes	Yes	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Personal care Respite care 	N/A

State Profile: **Arkansas**

Selected State Background Characteristics

	AR	US		AR	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (millions)	2.7	281.4	# of Caregivers (millions)	0.3	27.2
Pop. 60+ (thousands)	491.4	45,797.2	Caregiving Hours (millions)	279.0	29,182.0
% 60+	18.4	16.3	Value of Caregiving (millions)	\$2,457.8	\$257,096.0
National Ranking 60+	7	N/A	% Grandchildren living w/grandparents age 65+	3.7	4.4
% White (60+)	88.1	82.3			
% African American (60+)	9.8	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.7	5.4	% Pop. 21-64 Years w/Disability	23.4	19.2
% Asian (60+)	0.3	2.5	% Pop. 65+ w/Disability	48.9	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.3	0.4	Sensory	17.6	14.2
			Physical	14.2	10.8
Pop. 65+ (thousands)	374.0	34,991.8	Self-care	35.7	28.6
% Pop. 65+	14.0	12.4	Mental	12.3	9.5
National Ranking 65+	9	N/A	Difficulty Going Outside Home	22.9	20.4
Pop. 85+ (thousands)	46.5	4,239.6			
% Pop. 85+	1.7	1.5			
National Ranking 85+	16	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$24,289	\$31,632	Certified Nursing Facilities	239	15,162
Median Household Income	\$32,387	\$42,409	Certified Nursing Facility Beds (thousands)	24.1	1,574.0
% of Pop. 65+ Below Poverty	16.6	10.4	Average Cost Per Day in a Nursing Home	\$108	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	33	3,407
Households with Individuals 65+ (millions)	0.3	24.7	Home Health Aides	3,230	N/A
% Persons Age 65+ Living Alone	30.9	30.1			
% Pop. 65+ in Major Cities	16.1	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	36.9	50.1			

State Profile: **Arkansas** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
Administering State Agency	AR Department of Human Services	AR Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Division of Aging RNs

■ **Funding & Caseload** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver
FY 2001 Expenditures	\$1,125,177	\$6,802,943 (<i>respite only</i>)
FY 2002 Expenditures	\$1,303,240	\$7,628,574 (<i>respite only</i>)
FY 2003 Expenditures	\$1,427,743	\$30,834,306 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	2,832
FY 2002 A/D Waiver Respite Participants	N/A	3,020

State Profile: **Arkansas** (cont'd)■ **Eligibility** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
Caregiver Age Requirement	18+	18+
Care Receiver Age Requirement	60+	65+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> Nursing home eligible
Client Population	Family caregiver	Care receiver

■ **Assessment Process** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Cash grant Consumer ehealth applications Counseling Educ. & training Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	\$1000/year (average)	600 hours (in-home)
Uniform Respite Cap Across Program Sites	N/A	Yes
Entity that Formulates the Respite Cap	N/A	Administering state agency

State Profile: **Arkansas** (cont'd)■ **Consumer Direction** ■

Program Name	Caring for the Caregiver Arkansas Caregivers (FC)	ElderChoices Medicaid Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Direct payments to family members for the purchase of goods or services 	<ul style="list-style-type: none"> ▪ Agency personal care can be exchanged for monthly cash allowance
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	Personal care	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Respite care

State Profile: **California**

Selected State Background Characteristics

	CA	US		CA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	33.9	281.4	# of Caregivers (<i>millions</i>)	3.2	27.2
Pop. 60+ (<i>thousands</i>)	4,742.5	45,797.2	Caregiving Hours (<i>millions</i>)	3,411.5	29,182.0
% 60+	14.0	16.3	Value of Caregiving (<i>millions</i>)	\$30,055.6	\$257,096.0
National Ranking 60+	46	N/A	% Grandchildren living w/grandparents age 65+	7.6	4.4
% White (60+)	67.9	82.3			
% African American (60+)	5.3	8.4	■ Care Receivers ■		
% Hispanic (60+)	14.3	5.4	% Pop. 21-64 Years w/Disability	20.0	19.2
% Asian (60+)	10.2	2.5	% Pop. 65+ w/Disability	42.2	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.2	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.4	0.4	Sensory	14.5	14.2
Pop. 65+ (<i>thousands</i>)	3,595.7	34,991.8	Physical	28.4	28.6
% Pop. 65+	10.6	12.4	Self-care	9.9	9.5
National Ranking 65+	46	N/A	Mental	12.2	10.8
Pop. 85+ (<i>thousands</i>)	425.7	4,239.6	Difficulty Going Outside Home	20.8	20.4
% Pop. 85+	1.3	1.5			
National Ranking 85+	43	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$33,749	\$31,632	Certified Nursing Facilities	1,190	15,162
Median Household Income	\$47,437	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	110.2	1,574.0
% of Pop. 65+ Below Poverty	8.9	10.4	Average Cost Per Day in a Nursing Home	\$164	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	467	3,407
Households with Individuals 65+ (<i>millions</i>)	2.6	24.7	Home Health Aides	38,590	N/A
% Persons Age 65+ Living Alone	27.9	30.1			
% Pop. 65+ in Major Cities	62.0	40.1			
Average Household Size	2.9	2.6			
Average Family Size	3.4	3.1			
% Households with Internet Access	55.3	50.1			

State Profile: **California** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	<p>SB 723 (Enacted 2003) Provided conforming, clarifying and technical changes to SB 1661.</p> <p>SB 1661 (Enacted 2002) Expanded on the federal FMLA by providing up to six weeks paid leave (100% employee-funded) for workers caring for a new child or a seriously ill family member.</p> <p>SB 739 (Enacted 2001) Required the Department of Aging to establish guidelines for the use of NFCSP funds to ensure the quality of services provided with those funds.</p>
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FCSP) (FC)	Multipurpose Senior Services Program (MSSP) (MC)	Adult Day Health Care Program (ADHC) (SC)	Alzheimer's Day Care Resource Center (ADCRC) (SC)	Caregiver Resource Centers (CRCs) (SC)	In-Home Supportive Services (IHSS) (SC)
Administering State Agency	CA Department of Aging	CA Department of Aging	CA Department of Aging	CA Department of Aging	CA Department of Mental Health	CA Department of Social Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes	Yes	Yes	No

State Profile: **California** (cont'd)■ **Administrative Structure** (cont'd) ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Geographic Region Served	Statewide	Statewide	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA County Health Dept. Non-profit agency Other gov't. agency 	<ul style="list-style-type: none"> State Dept. of Health Services licenses ADHC centers; Dept of Aging certifies for Medi-Cal to reimburse; both monitor for compliance. 	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> Caregiver Resource Centers (CRCs) 	<ul style="list-style-type: none"> County Departments of Social Services Non-profit consortium Public Authority

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> Client contribution Foundation State general fund Title XIX (Medicaid) 	<ul style="list-style-type: none"> Local/county funds State general fund 	<ul style="list-style-type: none"> Client contribution OAA, Title III-E State general fund 	<ul style="list-style-type: none"> State general fund Title XIX (Medicaid) Title XX
FY 2001 Expenditures	\$11,359,851	\$1,595,565 (respite only)	\$177,075*	\$4,293,000*	\$11,747,000*	n/a
FY 2002 Expenditures	\$12,657,601	\$1,988,822 (respite only)	\$242,279**	\$4,189,000**	\$11,747,000**	n/a
FY 2003 Expenditures	\$13,866,825	\$42,937,460 (total waiver)	\$305,264***	\$4,191,000***	\$11,747,000***	n/a
FY 2001 A/D Waiver Respite Participants	N/A	1,582	N/A	N/A	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	1,674	N/A	N/A	N/A	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Caregiver Age Requirement	18+	N/A	N/A	Other	None	Legally eligible to work under state law
Care Receiver Age Requirement	60+	65+	18+	18+	18+	None
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care	Other	Diagnosis of dementia or related disorder/requires supervision	Adult-onset cognitive disorder	<ul style="list-style-type: none"> 1 ADL 1 IADL
Client Population	Family caregiver	Care receiver	Care receiver	Both family caregiver and care receiver	Family caregiver	Care receiver

Note:*=FY 2000/2001 state general funds only; **=FY 2001/2002; ***=FY 2002/2003

State Profile: **California** (cont'd)■ **Assessment Process** ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver	Care receiver	Family caregiver	Care receiver
Uniform Assessment Tool	No	Yes	No	Yes	Yes	Yes
Includes Caregiver Assessment	N/A	No	N/A	No	Yes	No
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A	N/A	<ul style="list-style-type: none"> ▪ Caregiver demographic information ▪ Care duration ▪ Care frequency ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Caregiver social support network ▪ Need for education/ training 	N/A

■ **Services** ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	N/A	Yes	Yes	No

State Profile: **California** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consultation Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Counseling Educ. & training Family consultation Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Care mgt. Consumer ehealth applications Counseling Educ. & training Family consultation Family meetings Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Educ. & training Info. & assistance Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. 	<ul style="list-style-type: none"> Adult day svcs. 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> In-home
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A	No	No	Yes	No
Respite Cap	No cap	No cap	No cap	No cap	\$3600/year	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A	N/A	Yes	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A	N/A	Administering local agency	N/A

State Profile: **California** (cont'd)■ **Consumer Direction** ■

Program Name	FCSP (FC)	MSSP (MC)	ADHC (SC)	ADCRC (SC)	CRCs (SC)	IHSS (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose 	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> None 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite only Direct payments to family members for the purchase of goods or services Families have a choice of respite providers 	<ul style="list-style-type: none"> Direct payments to family members for the purchase of goods or services
Family Members Can Be Paid to Provide Care	Yes	No	No	No	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Personal care Respite care Any service needed 	N/A	N/A	N/A	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Personal care Respite care

State Profile: Colorado

Selected State Background Characteristics

	CO	US		CO	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. <i>(millions)</i>	4.3	281.4	# of Caregivers <i>(millions)</i>	0.4	27.2
Pop. 60+ <i>(thousands)</i>	560.6	45,797.2	Caregiving Hours <i>(millions)</i>	443.9	29,182.0
% 60+	13.0	16.3	Value of Caregiving <i>(millions)</i>	\$3,911.0	\$257,096.0
National Ranking 60+	49	N/A	% Grandchildren living w/grandparents age 65+	4.0	4.4
% White (60+)	85.8	82.3			
% African American (60+)	2.6	8.4			
% Hispanic (60+)	8.9	5.4			
% Asian (60+)	1.5	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.3	0.4			
Pop. 65+ <i>(thousands)</i>	416.1	34,991.8			
% Pop. 65+	9.7	12.4			
National Ranking 65+	48	N/A			
Pop. 85+ <i>(thousands)</i>	48.2	4,239.6			
% Pop.85+	1.1	1.5			
National Ranking 85+	47	N/A			
■ Economic Indicators ■			■ Care Receivers ■		
Per Capita Income	\$34,283	\$31,632	% Pop. 21-64 Years w/Disability	15.9	19.2
Median Household Income	\$48,294	\$42,409	% Pop. 65+ w/Disability	40.0	41.9
% of Pop. 65+ Below Poverty	9.8	10.4	% 65+ by Type of Disability		
			Sensory	15.1	14.2
			Physical	26.9	28.6
			Self-care	8.0	9.5
			Mental	9.8	10.8
			Difficulty Going Outside Home	18.1	20.4
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ <i>(millions)</i>	0.3	24.7	Certified Nursing Facilities	213	15,162
% Persons Age 65+ Living Alone	27.0	30.1	Certified Nursing Facility Beds <i>(thousands)</i>	19.1	1,574.0
% Pop. 65+ in Major Cities	51.4	40.1	Average Cost Per Day in a Nursing Home	\$144	\$158
Average Household Size	2.5	2.6	Licensed Adult Day Facilities	42	3,407
Average Family Size	3.1	3.1	Home Health Aides	N/A	N/A
% Households with Internet Access	58.5	50.1			

State Profile: **Colorado** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 1067 & HB 1420 (Enacted 2002) HB 1067 created the family caregiver support program to provide funding to AAAs for caregiver support services. HB 1420 appropriated funds to the program.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Caregiver Taskforce
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	No
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Administering State Agency	CO Department of Human Services	CO Department of Health Care Policy & Finance
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA County Dept. of Human or Social Services County Health Dept. Private for-profit agency Private non-profit case management agencies

State Profile: **Colorado** (cont'd)

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver
FY 2001 Expenditures	\$1,245,978	\$563,011 (<i>respite only</i>)
FY 2002 Expenditures	\$1,429,311	\$618,698 (<i>respite only</i>)
FY 2003 Expenditures	\$1,565,858	\$94,162,799 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	361
FY 2002 A/D Waiver Respite Participants	N/A	374

■ Eligibility ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Caregiver Age Requirement	18+	18+
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	▪ 2 ADLs	▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision
Client Population	Family caregiver	Care receiver

■ Assessment ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ Services ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No

State Profile: **Colorado** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. Supplies Counseling Educ. & training Family consultation Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care 	<ul style="list-style-type: none"> Assistive technology Care mgt. Emerg. Response Home modification/repairs Homemaker/chore/personal care Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A
Respite Cap	\$250 - \$500/year (average)	30 days/year
Uniform Respite Cap Across Program Sites	No	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Home and Community-Based Services for the Elderly, Blind and Disabled (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	Personal care

State Profile: **Connecticut**

Selected State Background Characteristics

	CT	US		CT	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	3.4	281.4	# of Caregivers (<i>millions</i>)	0.3	27.2
Pop. 60+ (<i>thousands</i>)	601.8	45,797.2	Caregiving Hours (<i>millions</i>)	361.5	29,182.0
% 60+	17.7	16.3	Value of Caregiving (<i>millions</i>)	\$3,184.6	\$257,096.0
National Ranking 60+	10	N/A	% Grandchildren living w/grandparents age 65+	5.1	4.4
% White (60+)	89.9	82.3			
% African American (60+)	5.2	8.4	■ Care Receivers ■		
% Hispanic (60+)	3.0	5.4	% Pop. 21-64 Years w/Disability	16.8	19.2
% Asian (60+)	1.0	2.5	% Pop. 65+ w/Disability	37.0	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	12.2	14.2
Pop. 65+ (<i>thousands</i>)	470.2	34,991.8	Physical	23.6	28.6
% Pop. 65+	13.8	12.4	Self-care	8.3	9.5
National Ranking 65+	10	N/A	Mental	8.4	10.8
Pop. 85+ (<i>thousands</i>)	64.3	4,239.6	Difficulty Going Outside Home	18.8	20.4
% Pop. 85+	1.9	1.5			
National Ranking 85+	9	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$43,173	\$31,632	Certified Nursing Facilities	239	15,162
Median Household Income	\$53,387	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	29.3	1,574.0
% of Pop. 65+ Below Poverty	5.9	10.4	Average Cost Per Day in a Nursing Home	\$267	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	68	3,407
Households with Individuals 65+ (<i>millions</i>)	0.3	24.7	Home Health Aides	9,680	N/A
% Persons Age 65+ Living Alone	30.8	30.1			
% Pop. 65+ in Major Cities	73.7	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	55.0	50.1			

State Profile: **Connecticut** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 291 (Enacted 2003) Established a kinship foster care program. HB 6909 (Enacted 2001) Required state agencies to include provisions that support family caregivers in any program that provides assistance or support to people with long-term care needs.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Connecticut Lifespan Respite Coalition
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Administering State Agency	CT Department of Social Services	CT Department of Social Services	CT Department of Social Services	CT Department of Social Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	No
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency	AAA	Dept. of Social Services

State Profile: **Connecticut** (cont'd)

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Major Sources of Program Funding	OAA, Title III-E	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Client contribution State general fund 	State general fund
FY 2001 Expenditures	\$1,509,874	\$117,131 (<i>respite only</i>)	\$1,120,000	n/a
FY 2002 Expenditures	\$1,709,384	\$131,664 (<i>respite only</i>)	\$1,140,000	n/a
FY 2003 Expenditures	\$1,872,687	\$79,013,906 (<i>total waiver</i>)	\$1,064,181	n/a
FY 2001 A/D Waiver Respite Participants	N/A	42	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	37	N/A	N/A

■ Eligibility ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Caregiver Age Requirement	18+	None	None	18+
Care Receiver Age Requirement	60+	65+	None	65+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> 1 ADL Nursing home level of care 	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> 2 ADLs
Client Population	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver	Care receiver

■ Assessment ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes	Yes

State Profile: **Connecticut** (cont'd)■ **Assessment** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver mental health/depression Caregiver physical health Caregiver strain If family caregivers are providing long-distance caregiving Willingness of caregiver to provide care Other 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver mental health/depression Caregiver physical health Caregiver strain If family caregivers are providing long-distance caregiving Willingness of caregiver to provide care Other 	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver physical health Other

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Educ. & training Emer. response Counseling Homemaker/chore/personal care Home modification/repairs Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Counseling Emerg. response Homemaker/chore/personal care Home modification/repairs Info. & assistance Respite care Transportation 	<ul style="list-style-type: none"> Educ. & training Family consult. Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Counseling Emerg. response Family meetings Homemaker/chore/personal care Home modification/repairs Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp Other 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Other 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp

State Profile: **Connecticut** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No	No
Respite Cap	\$3500/year	No cap	\$3500/year	\$4067/month
Uniform Respite Cap Across Program Sites	Yes	N/A	Yes	N/A
Entity that Formulates the Respite Cap	Administering state agency	N/A	Administering state agency	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Home Care Program for Elders (MC)	Statewide Respite Care Program (SC)	Personal Care Assistance State-Funded Pilot Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A voucher or budget for respite and/or supplemental services Families have a choice of respite providers 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose 	Other	Other
Family Members Can Be Paid to Provide Care	No	Yes	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> Personal care 	N/A	<ul style="list-style-type: none"> Homemaker/chore Personal care

State Profile: Delaware

Selected State Background Characteristics

	DE	US
■ Population ■		
Total Pop. (<i>millions</i>)	0.8	281.4
Pop. 60+ (<i>thousands</i>)	133.9	45,797.2
% 60+	17.1	16.3
National Ranking 60+	19	N/A
% White (60+)	85.3	82.3
% African American (60+)	11.6	8.4
% Hispanic (60+)	1.2	5.4
% Asian (60+)	1.1	2.5
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1
% American Indian/ Alaska Native (60+)	0.3	0.4
Pop. 65+ (<i>thousands</i>)	101.7	34,991.8
% Pop. 65+	13.0	12.4
National Ranking 65+	23	N/A
Pop. 85+ (<i>thousands</i>)	10.5	4,239.6
% Pop. 85+	1.3	1.5
National Ranking 85+	37	N/A

■ Economic Indicators ■

Per Capita Income	\$32,810	\$31,632
Median Household Income	\$49,650	\$42,409
% of Pop. 65+ Below Poverty	6.0	10.4

■ Socio-Demographics ■

Households with Individuals 65+ (<i>millions</i>)	0.1	24.7
% Persons Age 65+ Living Alone	28.7	30.1
% Pop. 65+ in Major Cities	9.0	40.1
Average Household Size	2.5	2.6
Average Family Size	3.0	3.1
% Households with Internet Access	52.5	50.1

	DE	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	0.1	27.2
Caregiving Hours (<i>millions</i>)	82.3	29,182.0
Value of Caregiving (<i>millions</i>)	\$725.0	\$257,096.0
% Grandchildren living w/grandparents age 65+	4.4	4.4

■ Care Receivers ■

% Pop. 21-64 Years w/Disability	18.0	19.2
% Pop. 65+ w/Disability	37.7	41.9
% 65+ by Type of Disability		
Sensory	12.7	14.2
Physical	25.9	28.6
Self-care	7.4	9.5
Mental	8.5	10.8
Difficulty Going Outside Home	17.3	20.4

■ Long-Term Care ■

Certified Nursing Facilities	33	15,162
Certified Nursing Facility Beds (<i>thousands</i>)	3.5	1,574.0
Average Cost Per Day in a Nursing Home	\$162	\$158
Licensed Adult Day Facilities	15	3,407
Home Health Aides	N/A	N/A

State Profile: **Delaware** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	No

State Program Information■ **Administrative Structure** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
Administering State Agency	DE Department of Health & Social Services	DE Department of Health and Social Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	SUA	SUA

■ **Funding & Caseload** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	Medicaid HCBS waiver
FY 2001 Expenditures	\$564,300	\$160,778 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	\$105,994 (<i>respite only</i>)
FY 2003 Expenditures	\$705,756	\$10,962,500 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	86
FY 2002 A/D Waiver Respite Participants	N/A	108

State Profile: **Delaware** (cont'd)■ **Eligibility** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
Caregiver Age Requirement	None	None
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	2 ADLs	Nursing home level of care
Client population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care frequency ▪ Caregiver demographic information ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver strain ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Educ. & training ▪ Emerg. response ▪ Homemaker/chore/personal care ▪ Home modification/repairs ▪ Info. & assistance ▪ Respite care ▪ Support groups 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	250 hours/year	336 hours/year
Uniform Respite Cap Across Program Sites	Yes	Yes
Entity that Formulates the Respite Cap	Administering state agency	Administering state agency

■ **Consumer Direction** ■

Program Name	CARE Delaware (FC)	Elderly & Disabled Waiver (MC)
Consumer-Directed Options	None	None
Family Members Can Be Paid to Provide Care	No	No
Types of Services Families Can Be Paid to Provide	N/A	N/A

State Profile: **District of Columbia**

Selected State Background Characteristics

	DC	US		DC	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	0.6	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	91.9	45,797.2	Caregiving Hours (<i>millions</i>)	62.8	29,182.0
% 60+	16.1	16.3	Value of Caregiving (<i>millions</i>)	\$553.6	\$257,096.0
National Ranking 60+	32	N/A	% Grandchildren living w/grandparents age 65+	6.0	4.4
% White (60+)	26.3	82.3			
% African American (60+)	67.6	8.4			
% Hispanic (60+)	3.0	5.4			
% Asian (60+)	1.6	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.2	0.4			
Pop. 65+ (<i>thousands</i>)	69.9	34,991.8	■ Care Receivers ■		
% Pop. 65+	12.2	12.4	% Pop. 21-64 Years w/Disability	21.9	19.2
National Ranking 65+	31	N/A	% Pop. 65+ w/Disability	42.5	41.9
			% 65+ by Type of Disability		
Pop. 85+ (<i>thousands</i>)	9.0	4,239.6	Sensory	11.1	14.2
% Pop. 85+	1.6	1.5	Physical	28.1	28.6
National Ranking 85+	23	N/A	Self-care	11.2	9.5
			Mental	11.2	10.8
			Difficulty Going Outside Home	23.7	20.4
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$48,342	\$31,632	Certified Nursing Facilities	20	15,162
Median Household Income	\$39,070	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	3.1	1,574.0
% of Pop. 65+ Below Poverty	N/A	10.4	Average Cost Per Day in a Nursing Home	\$227	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	40	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	1,190	N/A
% Persons Age 65+ Living Alone	38.6	30.1			
% Pop. 65+ in Major Cities	100.0	40.1			
Average Household Size	2.2	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	41.4	50.1			

State Profile: **District of Columbia** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
Administering State Agency	DC Office on Aging	DC Department of Health, Medical Assistance & Administration
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> ▪ AAA ▪ SUA 	Medical Assistance Administration

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> ▪ OAA, Title III-E ▪ State general fund 	<ul style="list-style-type: none"> ▪ Medicaid HCBS waiver ▪ Real Choice Systems Change Grants ▪ State general fund
FY 2001 Expenditures	\$564,300	\$219 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	\$1,288 (<i>respite only</i>)
FY 2003 Expenditures	\$705,756	\$2,933,176 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	2
FY 2002 A/D Waiver Respite Participants	N/A	3

State Profile: **District of Columbia** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
Caregiver Age Requirement	None	No response
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	No functional status requirement	<ul style="list-style-type: none"> 2 ADLs 3+ IADLs Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
Program Assesses	Family caregiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Care mgt. Cash grant Consum. supplies Counseling Educ. & training Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Counseling Educ. & training Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes
Respite Cap	No cap	6480 hours/year
Uniform Respite Cap Across Program Sites	N/A	Yes
Entity that Formulates the Respite Cap	N/A	Administering state agency

State Profile: **District of Columbia** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Physical Disabilities Waiver (MC)
Consumer-Directed Options	Direct payments to family members for the purchase of goods or services	None
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: **Florida**

Selected State Background Characteristics

	FL	US		FL	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	16.0	281.4	# of Caregivers (<i>millions</i>)	1.6	27.2
Pop. 60+ (<i>thousands</i>)	3,545.1	45,797.2	Caregiving Hours (<i>millions</i>)	1,738.9	29,182.0
% 60+	22.2	16.3	Value of Caregiving (<i>millions</i>)	\$15,319.7	\$257,096.0
National Ranking 60+	1	N/A	% Grandchildren living w/grandparents age 65+	4.2	4.4
% White (60+)	81.2	82.3			
% African American (60+)	6.6	8.4	■ Care Receivers ■		
% Hispanic (60+)	10.7	5.4	% Pop. 21-64 Years w/Disability	21.9	19.2
% Asian (60+)	0.7	2.5	% Pop. 65+ w/Disability	39.5	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	13.0	14.2
Pop. 65+ (<i>thousands</i>)	2,807.6	34,991.8	Physical	26.2	28.6
% Pop. 65+	17.6	12.4	Self-care	8.0	9.5
National Ranking 65+	1	N/A	Mental	9.6	10.8
Pop. 85+ (<i>thousands</i>)	331.3	4,239.6	Difficulty Going Outside Home	18.6	20.4
% Pop. 85+	2.1	1.5			
National Ranking 85+	4	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,446	\$31,632	Certified Nursing Facilities	646	15,162
Median Household Income	\$38,024	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	74.7	1,574.0
% of Pop. 65+ Below Poverty	11.3	10.4	Average Cost Per Day in a Nursing Home	\$165	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	165	3,407
Households with Individuals 65+ (<i>millions</i>)	1.9	24.7	Home Health Aides	25,910	N/A
% Persons Age 65+ Living Alone	26.7	30.1			
% Pop. 65+ in Major Cities	29.4	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	52.8	50.1			

State Profile: **Florida** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 27e (Enacted 2002) Appropriated funds for Alzheimer's caregiver support programs.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Aged & Disabled Adult Medicaid HCBS Waiver (A/D Waiver) (MC)	Respite for Elders Living in Everyday Families (RELIEF) (SC)	Home Care for the Elderly (HCE) (SC)	Community Care for the Elderly (CCE) (SC)	Alzheimer's Disease Initiative (ADI) (SC)
Administering State Agency	FL Department of Elder Affairs	FL Department of Elder Affairs	FL Department of Elder Affairs	FL Department of Elder Affairs	FL Department of Elder Affairs	FL Department of Elder Affairs
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Multi-county	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA	AAA	AAA	AAA	AAA

State Profile: **Florida** (cont'd)

■ Funding & Caseload ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Major sources of program funding	<ul style="list-style-type: none"> ▪ OAA, Title III-E ▪ Client contribution 	<ul style="list-style-type: none"> ▪ Medicaid HCBS waiver 	<ul style="list-style-type: none"> ▪ State general fund ▪ Tobacco fund 	<ul style="list-style-type: none"> ▪ State general fund 	<ul style="list-style-type: none"> ▪ Client contribution ▪ State general fund ▪ Tobacco fund 	<ul style="list-style-type: none"> ▪ Client contribution ▪ State general fund
FY 2001 Expenditures	\$8,721,584	\$9,047,970 (respite only)	n/a	n/a	\$42,364,370	n/a
FY 2002 Expenditures	\$10,083,438	\$11,273,116 (respite only)	\$1,330,044	\$9,529,461	\$42,364,370	\$12,025,763
FY 2003 Expenditures	\$11,046,746	\$100,620,265 (total waiver)	\$1,330,044	\$9,529,461	\$42,364,370	\$11,394,025
FY 2001 A/D Waiver Respite Participants	N/A	2,739	N/A	N/A	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	3,635	N/A	N/A	N/A	N/A

■ Eligibility ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Caregiver Age Requirement	19+	None	None	18+	None	None
Care Receiver Age Requirement	None	18+	60+	60+	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/ requires supervision 	<ul style="list-style-type: none"> ▪ Nursing home level of care 	<ul style="list-style-type: none"> ▪ Homebound 	<ul style="list-style-type: none"> ▪ Nursing home level of care 	<ul style="list-style-type: none"> ▪ Nursing home level of care 	<ul style="list-style-type: none"> ▪ Diagnosis of dementia or related disorder/ requires supervision
Client Population	Both family caregiver and care receiver	Care receiver	Care receiver	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver

■ Assessment ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	No	Yes	Yes	Yes
Includes Caregiver Assessment	N/A	Yes	N/A	Yes	Yes	Yes

State Profile: **Florida** (cont'd)■ **Assessment** (cont'd) ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver demographic information Caregiver mental health/ depression Caregiver physical health Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> N/A 	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver demographic information Caregiver mental health/ depression Caregiver physical health Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver demographic information Caregiver mental health/ depression Caregiver physical health Caregiver strain Care duration Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Caregiver demographic information Caregiver mental health/ depression Caregiver physical health Caregiver strain Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No	No	No	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups 	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Emerg. response Home modification/ repairs Homemaker/ chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation

State Profile: **Florida** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ In-home 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	Yes	Yes	No	No
Respite Cap	No cap	No cap	4 hours/week	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	Yes	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	Administering state agency	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	A/D Waiver (MC)	RELIEF (SC)	HCE (SC)	CCE (SC)	ADI (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Direct payments to family members for the purchase of goods or services 	None	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	None	None
Family Members Can Be Paid to Provide Care	Yes	Yes	No	Yes	No	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	N/A	<ul style="list-style-type: none"> ▪ Any service needed ▪ Personal care ▪ Respite care 	N/A	N/A

State Profile: **Georgia**

Selected State Background Characteristics

	GA	US		GA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	8.2	281.4	# of Caregivers (<i>millions</i>)	0.8	27.2
Pop. 60+ (<i>thousands</i>)	1071.1	45,797.2	Caregiving Hours (<i>millions</i>)	833.9	29,182.0
% 60+	13.1	16.3	Value of Caregiving (<i>millions</i>)	\$7,346.8	\$257,096.0
National Ranking 60+	48	N/A	% Grandchildren living w/grandparents age 65+	6.0	4.4
% White (60+)	77.1	82.3			
% African American (60+)	19.8	8.4			
% Hispanic (60+)	1.2	5.4			
% Asian (60+)	1.1	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.1	0.4			
Pop. 65+ (<i>thousands</i>)	785.3	34,991.8	■ Care Receivers ■		
% Pop. 65+	9.6	12.4	% Pop. 21-64 Years w/Disability	19.9	19.2
National Ranking 65+	49	N/A	% Pop. 65+ w/Disability	47.5	41.9
Pop. 85+ (<i>thousands</i>)	87.9	4,239.6	% 65+ by Type of Disability		
% Pop. 85+	1.1	1.5	Sensory	15.9	14.2
National Ranking 85+	48	N/A	Physical	33.9	28.6
			Self-care	11.8	9.5
			Mental	14.2	10.8
			Difficulty Going Outside Home	24.2	20.4
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,442	\$31,632	Certified Nursing Facilities	323	15,162
Median Household Income	\$42,939	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	35.2	1,574.0
% of Pop. 65+ Below Poverty	10.7	10.4	Average Cost Per Day in a Nursing Home	\$118	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	62	3,407
Households with Individuals 65+ (<i>millions</i>)	0.6	24.7	Home Health Aides	5,300	N/A
% Persons Age 65+ Living Alone	26.9	30.1			
% Pop. 65+ in Major Cities	32.3	40.1			
Average Household Size	2.7	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	46.7	50.1			

State Profile: **Georgia** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 318 (Enacted 2003) Created the Adult Day Center for Aging Adults Licensure Act.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community Care Services Program (CCSP) (MC)
Administering State Agency	GA Department of Human Resources	GA Department of Human Resources
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	CCSP (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Client contribution Indigent Care Trust Fund (until SFY 2003) Medicaid HCBS waiver State general fund Tobacco fund
FY 2001 Expenditures	\$2,305,333	\$2,592 (<i>respite only</i>)
FY 2002 Expenditures	\$2,659,575	\$1,575,550 (<i>respite only</i>)
FY 2003 Expenditures	\$2,913,654	\$76,742,607 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	5
FY 2002 A/D Waiver Respite Participants	N/A	319

State Profile: **Georgia** (cont'd)■ **Eligibility** ■

Program Name	FCSP (FC)	CCSP (MC)
Caregiver Age Requirement	18+	N/A
Care Receiver Age Requirement	60+	None
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	CCSP (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Caregiver demographic information ▪ Caregiver eligibility ▪ Caregiver strain 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	CCSP (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Emerg. response ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Other
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp ▪ Other 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A

State Profile: **Georgia** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	CCSP (MC)
Entity that Formulates the Respite Cap	Administering local agency	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	CCSP (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	Yes	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	N/A

State Profile: **Hawaii**

Selected State Background Characteristics

	HI	US		HI	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.2	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	207.0	45,797.2	Caregiving Hours (<i>millions</i>)	128.1	29,182.0
% 60+	17.1	16.3	Value of Caregiving (<i>millions</i>)	\$1,128.5	\$257,096.0
National Ranking 60+	20	N/A	% Grandchildren living w/grandparents age 65+	13.4	4.4
% White (60+)	22.7	82.3			
% African American (60+)	0.4	8.4	■ Care Receivers ■		
% Hispanic (60+)	2.6	5.4	% Pop. 21-64 Years w/Disability	17.7	19.2
% Asian (60+)	60.6	2.5	% Pop. 65+ w/Disability	40.6	41.9
% Native Hawaiian/ Pacific Islanders (60+)	5.5	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	13.8	14.2
Pop. 65+ (<i>thousands</i>)	160.6	34,991.8	Physical	24.8	28.6
% Pop. 65+	13.3	12.4	Self-care	8.6	9.5
National Ranking 65+	16	N/A	Mental	12.3	10.8
Pop. 85+ (<i>thousands</i>)	17.6	4,239.6	Difficulty Going Outside Home	22.0	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	30	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,913	\$31,632	Certified Nursing Facilities	31	15,162
Median Household Income	\$47,303	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	2.6	1,574.0
% of Pop. 65+ Below Poverty	9.4	10.4	Average Cost Per Day in a Nursing Home	\$232	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	27	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	2,480	N/A
% Persons Age 65+ Living Alone	19.4	30.1			
% Pop. 65+ in Major Cities	41.3	40.1			
Average Household Size	2.9	2.6			
Average Family Size	3.4	3.1			
% Households with Internet Access	55.2	50.1			

State Profile: **Hawaii** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 389 (Enacted 2003) Allowed caregivers during working hours to attend to a child, parent, spouse, or reciprocal beneficiary with a serious health condition. Employers who provide sick leave must permit employees to use up to 10 days of accrued and available sick leave for these family leave purposes. SB 597 (Enacted 2001) Established support for family caregivers of adults with disabilities as a long-term goal of the state.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Hawaii Family Caregiver Network Hawaii Caregiver Coalition (in development)
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FCSP) (FC)	Nursing Home Without Walls (NHWW) (MC)	Kupuna Care (SC)
Administering State Agency	HI Executive Office on Aging	HI Department of Human Services	HI Executive Office on Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Multi-county	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA Contracted service providers 	<ul style="list-style-type: none"> Medicaid agency 	<ul style="list-style-type: none"> AAA

■ Funding & Caseload ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E State general fund 	Medicaid HCBS waiver	State general fund
FY 2001 Expenditures	\$564,300	\$239,675 (<i>respite only</i>)	n/a

State Profile: **Hawaii** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
FY 2002 Expenditures	\$644,212	\$236,106 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$705,756	\$18,497,541 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	57	N/A
FY 2002 A/D Waiver Respite Participants	N/A	56	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
Caregiver Age Requirement	60+	None	N/A
Care Receiver Age Requirement	60+	None	60+
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care	Other
Client Population	Both family caregiver and care receiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes	Yes
Includes Caregiver Assessment	N/A	Yes	Yes
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care frequency ▪ Caregiver demographic information ▪ Emergency plan ▪ Type of care (provided)

■ **Services** ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No

State Profile: **Hawaii** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Cash grant Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Counseling Respite care 	<ul style="list-style-type: none"> Care mgt. Homemaker/chore/personal care Respite care Transportation Other
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp Other 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home
Caregiver Must Live with Care Receiver to Receive Respite	N/A	Yes	N/A
Respite Cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	NHWW (MC)	Kupuna Care (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services Direct payments to family members for the purchase of goods or services Families have a choice of respite providers 	<ul style="list-style-type: none"> Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	No	Yes	No
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> Personal care Other 	N/A

State Profile: Idaho

Selected State Background Characteristics

	ID	US		ID	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.3	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	193.4	45,797.2	Caregiving Hours (<i>millions</i>)	128.1	29,182.0
% 60+	14.9	16.3	Value of Caregiving (<i>millions</i>)	\$1,128.9	\$257,096.0
National Ranking 60+	44	N/A	% Grandchildren living w/grandparents age 65+	3.9	4.4
% White (60+)	95.8	82.3			
% African American (60+)	0.1	8.4	■ Care Receivers ■		
% Hispanic (60+)	2.0	5.4	% Pop. 21-64 Years w/Disability	16.7	19.2
% Asian (60+)	0.6	2.5	% Pop. 65+ w/Disability	42.5	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.7	0.4	Sensory	17.7	14.2
Pop. 65+ (<i>thousands</i>)	145.9	34,991.8	Physical	28.8	28.6
% Pop. 65+	11.3	12.4	Self-care	8.3	9.5
National Ranking 65+	42	N/A	Mental	10.7	10.8
Pop. 85+ (<i>thousands</i>)	18.1	4,239.6	Difficulty Going Outside Home	17.6	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	35	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$25,911	\$31,632	Certified Nursing Facilities	71	15,162
Median Household Income	\$37,715	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	5.4	1,574.0
% of Pop. 65+ Below Poverty	3.6	10.4	Average Cost Per Day in a Nursing Home	\$128	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	4	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	2,510	N/A
% Persons Age 65+ Living Alone	25.9	30.1			
% Pop. 65+ in Major Cities	24.3	40.1			
Average Household Size	2.7	2.6			
Average Family Size	3.2	3.1			
% Households with Internet Access	52.7	50.1			

State Profile: **Idaho** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 1481 (Enacted 2002) Appropriated the National Family Caregiver Support Program federal grant to the state Commission on Aging.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Administering State Agency	ID Commission on Aging	ID Department of Health & Welfare	ID Commission on Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Regional Medicaid units	AAA

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver	State general fund
FY 2001 Expenditures	\$564,300	\$82,963 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$644,212	\$97,758 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$705,756	\$50,782,660 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	47	N/A
FY 2002 A/D Waiver Respite Participants	N/A	55	N/A

State Profile: **Idaho** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Caregiver Age Requirement	60+	18+	60+
Care Receiver Age Requirement	None	18+	60+
Care Receiver Functional Status Requirement	2 ADLs	Nursing home level of care	1 ADL
Client Population	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	No	No	No
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Consumer ehealth applications ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Family consult. ▪ Respite care 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Educ. & training ▪ Family consult. ▪ Family meetings ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Transportation

State Profile: **Idaho** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight
Caregiver Must Live with Care Receiver to Receive Respite	Yes	Yes	Yes
Respite Cap	No cap	\$52/day (in-home)	No cap
Uniform Respite Cap Across Program Sites	N/A	Yes	N/A
Entity that Formulates the Respite Cap	N/A	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	HCBS Aged & Disabled Waiver (MC)	Senior Services Act, Respite Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	No	Yes	No
Types of Services Families Can Be Paid to Provide	N/A	Personal care	N/A

State Profile: Illinois

Selected State Background Characteristics

	IL	US		IL	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	12.4	281.4	# of Caregivers (<i>millions</i>)	1.2	27.2
Pop. 60+ (<i>thousands</i>)	1,962.9	45,797.2	Caregiving Hours (<i>millions</i>)	1278.0	29,182.0
% 60+	15.8	16.3	Value of Caregiving (<i>millions</i>)	\$11,258.9	\$257,096.0
National Ranking 60+	35	N/A	% Grandchildren living w/grandparents age 65+	4.5	4.4
% White (60+)	82.2	82.3			
% African American (60+)	11.1	8.4			
% Hispanic (60+)	3.8	5.4			
% Asian (60+)	2.1	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.1	0.4			
Pop. 65+ (<i>thousands</i>)	1,500.0	34,991.8	■ Care Receivers ■		
% Pop. 65+	12.1%	12.4	% Pop. 21-64 Years w/Disability	17.1	19.2
National Ranking 65+	34	N/A	% Pop. 65+ w/Disability	40.5	41.9
Pop. 85+ (<i>thousands</i>)	192.0	4,239.6	% 65+ by Type of Disability		
% Pop. 85+	1.5%	1.5	Sensory	12.9	14.2
National Ranking 85+	25	N/A	Physical	27.8	28.6
			Self-care	9.1	9.5
			Mental	9.5	10.8
			Difficulty Going Outside Home	20.1	20.4
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$33,690	\$31,632	Certified Nursing Facilities	799	15,162
Median Household Income	\$42,710	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	94.8	1,574.0
% of Pop. 65+ Below Poverty	8.1	10.4	Average Cost Per Day in a Nursing Home	\$148	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	88	3,407
Households with Individuals 65+ (<i>millions</i>)	1.1	24.7	Home Health Aides	13,140	N/A
% Persons Age 65+ Living Alone	32.3	30.1			
% Pop. 65+ in Major Cities	35.5	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.2	3.1			
% Households with Internet Access	46.9	50.1			

State Profile: **Illinois** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 3774 (Enacted 2003) Appropriated funds for Senior Caregivers of Adult Disabled Children.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Illinois Caregiver Advisory Committee
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Administering State Agency	IL Department on Aging	IL Department on Aging	IL Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	No
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	SUA	Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Major Sources of Program Funding	OAA, Title III-E	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund
FY 2001 Expenditures	\$4,732,281	n/a	n/a
FY 2002 Expenditures	\$5,344,843	n/a	n/a
FY 2003 Expenditures	\$5,855,455	\$36,066,462 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	n/a	n/a
FY 2002 A/D Waiver Respite Participants	N/A	n/a	n/a

State Profile: **Illinois** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Caregiver Age Requirement	18+	N/A	18+
Care Receiver Age Requirement	60+	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> OAA guidelines 	<ul style="list-style-type: none"> ADL/IADL combination Nursing home level of care 	<ul style="list-style-type: none"> ADL/IADL combination Physically disabled
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	Yes
Includes Caregiver Assessment	N/A	No	No
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	N/A	<ul style="list-style-type: none"> Assistive technology Care mgt. Counseling Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. 	<ul style="list-style-type: none"> Adult day svcs. In-home

State Profile: **Illinois** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A	No
Respite Cap	Varies	N/A	Respite cap varies by need
Uniform Respite Cap Across Program Sites	No	N/A	No
Entity that Formulates the Respite Cap	Administering local agency	N/A	Administering local agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Community Care Program (CCP) (MC)	Home Services Program (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes (in one Planning and Service Area)	Yes (but must meet certain requirements)	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore 	<ul style="list-style-type: none"> ▪ Personal care

State Profile: Indiana

Selected State Background Characteristics

	IN	US		IN	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	6.1	281.4	# of Caregivers (<i>millions</i>)	0.6	27.2
Pop. 60+ (<i>thousands</i>)	988.5	45,797.2	Caregiving Hours (<i>millions</i>)	627.8	29,182.0
% 60+	16.3	16.3	Value of Caregiving (<i>millions</i>)	\$5,531.2	\$257,096.0
National Ranking 60+	29	N/A	% Grandchildren living w/grandparents age 65+	3.0	4.4
% White (60+)	92.0	82.3			
% African American (60+)	5.9	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.1	5.4	% Pop. 21-64 Years w/Disability	18.5	19.2
% Asian (60+)	0.4	2.5	% Pop. 65+ w/Disability	42.6	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	14.9	14.2
Pop. 65+ (<i>thousands</i>)	752.8	34,991.8	Physical	29.6	28.6
% Pop. 65+	12.4	12.4	Self-care	9.1	9.5
National Ranking 65+	28	N/A	Mental	10.0	10.8
Pop. 85+ (<i>thousands</i>)	91.6	4,239.6	Difficulty Going Outside Home	19.6	20.4
% Pop. 85+	1.5	1.5			
National Ranking 85+	28	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$28,783	\$31,632	Certified Nursing Facilities	489	15,162
Median Household Income	\$41,047	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	45.6	1,574.0
% of Pop. 65+ Below Poverty	9.3	10.4	Average Cost Per Day in a Nursing Home	\$150	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	66	3,407
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Home Health Aides	9,550	N/A
% Persons Age 65+ Living Alone	30.5	30.1			
% Pop. 65+ in Major Cities	51.8	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	47.3	50.1			

State Profile: **Indiana** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 493 (Enacted 2003) Established a caretaker support program.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Caregiver Program Advisory Committee
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Administering State Agency	IN Family & Social Services Administration	IN Family & Social Services Administration	IN Family & Social Services Administration
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	<ul style="list-style-type: none"> ▪ SUA ▪ Medicaid agency 	<ul style="list-style-type: none"> ▪ AAA ▪ SUA ▪ Medicaid agency

■ **Funding & Caseload** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver	<ul style="list-style-type: none"> ▪ Children's CHOICE/TANF funds ▪ State general fund
FY 2001 Expenditures	\$2,331,599	\$7,888,128 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$2,661,771	\$8,618,508 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$2,916,060	\$27,133,940 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	1,308	N/A
FY 2002 A/D Waiver Respite Participants	N/A	1,365	N/A

State Profile: **Indiana** (cont'd)■ **Eligibility** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Caregiver Age Requirement	18+	18+	18+
Care Receiver Age Requirement	60+	None	60+
Care Receiver Functional Status Requirement	2 ADLs	<ul style="list-style-type: none"> 2 ADLs Nursing home level of care 	2 ADLs
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	Yes
Includes Caregiver Assessment	N/A	No	Yes
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A

■ **Services** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Cash grant Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Emerg. response Home modification/repairs Homemaker/chore/personal care Respite care Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Educ. & training Emerg. response Home modification/repairs Homemaker/chore/personal care Legal and/or financial consultation Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> In-home Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No

State Profile: **Indiana** (cont'd)■ **Services** (cont'd) ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Respite Cap	\$1,000/year	No cap	No cap
Uniform Respite Cap Across Program Sites	Yes	N/A	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A	N/A

■ **Consumer Direction** ■

Program Name	Caring and Compassion (FC)	Aged & Disabled Medicaid Waiver (MC)	CHOICE (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	None	<ul style="list-style-type: none"> ▪ Consumer-directed attendant care
Family Members Can Be Paid to Provide Care	Yes	Yes	No
Types of Services Families Can Be Paid to Provide	Respite care	Personal care	N/A

State Profile: Iowa

Selected State Background Characteristics

	IA	US		IA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (millions)	2.9	281.4	# of Caregivers (millions)	0.3	27.2
Pop. 60+ (thousands)	554.6	45,797.2	Caregiving Hours (millions)	305.9	29,182.0
% 60+	19.0	16.3	Value of Caregiving (millions)	\$2,695.1	\$257,096.0
National Ranking 60+	4	N/A	% Grandchildren living w/grandparents age 65+	3.1	4.4
% White (60+)	97.7	82.3			
% 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	■ Care Receivers ■		
% American Indian/ Alaska Native (60+)	0.1	0.4	% Pop. 21-64 Years w/Disability	15.2	19.2
Pop. 65+ (thousands)	436.2	34,991.8	% Pop. 65+ w/Disability	37.8	41.9
% Pop. 65+	14.9	12.4	% 65+ by Type of Disability		
National Ranking 65+	4	N/A	Sensory	13.1	14.2
Pop. 85+ (thousands)	65.1	4,239.6	Physical	25.4	28.6
% Pop. 85+	2.2	1.5	Self-care	7.0	9.5
National Ranking 85+	2	N/A	Mental	7.6	10.8
			Difficulty Going Outside Home	16.2	20.4
■ Economic Indicators ■					
Per Capita Income	\$29,043	\$31,632	■ Long-Term Care ■		
Median Household Income	\$41,049	\$42,409	Certified Nursing Facilities	442	15,162
% of Pop. 65+ Below Poverty	11.8	10.4	Certified Nursing Facility Beds (thousands)	32.1	1,574.0
			Average Cost Per Day in a Nursing Home	\$115	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	71	3,407
Households with Individuals 65+ (millions)	0.3	24.7	Home Health Aides	6,420	N/A
% Persons Age 65+ Living Alone	32.7	30.1			
% Pop. 65+ in Major Cities	22.8	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	51.0	50.1			

State Profile: **Iowa** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 386 (Enacted 2003) Added "support for caregivers" to the state's objectives for serving older individuals.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
Administering State Agency	IA Department of Elder Affairs	IA Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA SUA 	<ul style="list-style-type: none"> Medicaid agency

■ Funding & Caseload ■

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
Major Sources of Program Funding	OAA, Title III-E	<ul style="list-style-type: none"> Medicaid HCBS waiver Tobacco fund
FY 2001 Expenditures	\$1,391,731	\$702,563 (<i>respite only</i>)
FY 2002 Expenditures	\$1,594,075	\$714,081 (<i>respite only</i>)
FY 2003 Expenditures	\$1,746,362	\$26,846,176 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	366
FY 2002 A/D Waiver Respite Participants	N/A	357

State Profile: **Iowa** (cont'd)

■ Eligibility ■

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
Caregiver Age Requirement	None	18+
Care Receiver Age Requirement	60+	65+
Care Receiver Functional Status Requirement	2 ADLs	2 ADLs
Client Population	Family caregiver	Care receiver

■ Assessment ■

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
Program Assesses	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ Services ■

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Educ. & training ▪ Respite care ▪ Other
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes
Respite Cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A

State Profile: **Iowa** (cont'd)■ **Consumer Direction** ■

Program Name	Iowa Family Caregiver (FC)	Elderly Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care

State Profile: **Kansas**

Selected State Background Characteristics

	KS	US		KS	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	2.7	281.4	# of Caregivers (<i>millions</i>)	0.3	27.2
Pop. 60+ (<i>thousands</i>)	454.8	45,797.2	Caregiving Hours (<i>millions</i>)	274.8	29,182.0
% 60+	16.9	16.3	Value of Caregiving (<i>millions</i>)	\$2,420.6	\$257,096.0
National Ranking 60+	23	N/A	% Grandchildren living w/grandparents age 65+	1.5	4.4
% White (60+)	92.7	82.3			
% African American (60+)	3.5	8.4	■ Care Receivers ■		
% Hispanic (60+)	2.0	5.4	% Pop. 21-64 Years w/Disability	16.8	19.2
% Asian (60+)	0.7	2.5	% Pop. 65+ w/Disability	41.5	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.4	0.4	Sensory	14.1	14.2
Pop. 65+ (<i>thousands</i>)	356.2	34,991.8	Physical	28.6	28.6
% Pop. 65+	13.3	12.4	Self-care	8.2	9.5
National Ranking 65+	17	N/A	Mental	9.0	10.8
Pop. 85+ (<i>thousands</i>)	51.8	4,239.6	Difficulty Going Outside Home	18.3	20.4
% Pop. 85+	1.9	1.5			
National Ranking 85+	8	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,935	\$31,632	Certified Nursing Facilities	360	15,162
Median Household Income	\$42,619	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	23.4	1,574.0
% of Pop. 65+ Below Poverty	10.2	10.4	Average Cost Per Day in a Nursing Home	\$113	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	19	3,407
Households with Individuals 65+ (<i>millions</i>)	0.2	24.7	Home Health Aides	3,920	N/A
% Persons Age 65+ Living Alone	32.4	30.1			
% Pop. 65+ in Major Cities	29.2	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	50.9	50.1			

State Profile: **Kansas** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Administering State Agency	KS Department on Aging	KS Department on Aging	KS Department on Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	<ul style="list-style-type: none"> AAA SUA 	AAA

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Client contribution Local/county funds State general fund
FY 2001 Expenditures	\$1,139,251	\$17,210 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$1,290,151	\$17,210 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$1,413,404	\$50,520,551 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	24	N/A
FY 2002 A/D Waiver Respite Participants	N/A	24	N/A

State Profile: **Kansas** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Caregiver Age Requirement	18+	18+	60+
Care Receiver Age Requirement	60+	65+	60+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> OAA guidelines 	<ul style="list-style-type: none"> 2 ADLs 3+ IADLs ADL/IADL combination Nursing home level of care 	<ul style="list-style-type: none"> 2 ADLs 3+ IADLs ADL/IADL combination
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	Yes
Includes Caregiver Assessment	N/A	Yes	No
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Care frequency Caregiver strain Willingness of caregiver to provide care 	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Consum. supplies Counseling Educ. & training Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Info. & assistance Respite care 	<ul style="list-style-type: none"> Assistive technology Care mtg. Consum. supplies Emerg. response Home modification/repairs Homemaker/chore/personal care Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No

State Profile: **Kansas** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Respite Cap	Respite cannot be provided for more than 7 consecutive days	180 hours/year	No cap
Uniform Respite Cap Across Program Sites	Yes	Yes	N/A
Entity that Formulates the Respite Cap	Administering state agency	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Home & Community Based Frail Elder Waiver (MC)	Senior Care Act Program (SC)
Consumer-Directed Options	A menu of services from which caregivers can choose	Families have a choice of respite providers	Consumer-directed attendant care
Family Members Can Be Paid to Provide Care	No	Yes	Yes
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care ▪ Other 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care

State Profile: **Kentucky**

Selected State Background Characteristics

	KY	US		KY	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	4.0	281.4	# of Caregivers (<i>millions</i>)	0.4	27.2
Pop. 60+ (<i>thousands</i>)	672.9	45,797.2	Caregiving Hours (<i>millions</i>)	425.8	29,182.0
% 60+	16.6	16.3	Value of Caregiving (<i>millions</i>)	\$3,751.2	\$257,096.0
National Ranking 60+	26	N/A	% Grandchildren living w/grandparents age 65+	3.5	4.4
% White (60+)	93.4	82.3			
% African American (60+)	0.1	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.5	5.4	% Pop. 21-64 Years w/Disability	24.0	19.2
% Asian (60+)	0.3	2.5	% Pop. 65+ w/Disability	49.3	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	17.7	14.2
Pop. 65+ (<i>thousands</i>)	504.8	34,991.8	Physical	35.8	28.6
% Pop. 65+	12.5	12.4	Self-care	12.4	9.5
National Ranking 65+	27	N/A	Mental	14.2	10.8
Pop. 85+ (<i>thousands</i>)	58.3	4,239.6	Difficulty Going Outside Home	23.9	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	31	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$26,252	\$31,632	Certified Nursing Facilities	261	15,162
Median Household Income	\$36,762	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	21.7	1,574.0
% of Pop. 65+ Below Poverty	10.9	10.4	Average Cost Per Day in a Nursing Home	\$140	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	119	3,407
Households with Individuals 65+ (<i>millions</i>)	0.4	24.7	Home Health Aides	5,100	N/A
% Persons Age 65+ Living Alone	32.5	30.1			
% Pop. 65+ in Major Cities	14.4	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	44.2	50.1			

State Profile: **Kentucky** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
Administering State Agency	KY Cabinet for Health Services	KY Cabinet for Health Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	<ul style="list-style-type: none"> State general fund
FY 2001 Expenditures	\$1,516,043	n/a
FY 2002 Expenditures	\$1,745,716	n/a
FY 2003 Expenditures	\$1,912,491	n/a
FY 2001 A/D Waiver Respite Participants	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	N/A

State Profile: **Kentucky** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
Caregiver Age Requirement	None	60+
Care Receiver Age Requirement	60+	None
Care Receiver Functional Status Requirement	No functional status requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ 3+ ADLs ▪ Diagnosis of dementia or related disorder/requires supervision
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	No
Includes Caregiver Assessment	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Educ. & training ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	Varies	No cap
Uniform Respite Cap Across Program Sites	No	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A

State Profile: **Kentucky** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Adult Day/Alzheimer's Respite (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> • A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Respite care ▪ Other 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: Louisiana

Selected State Background Characteristics

	LA	US		LA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	4.5	281.4	# of Caregivers (<i>millions</i>)	0.4	27.2
Pop. 60+ (<i>thousands</i>)	687.2	45,797.2	Caregiving Hours (<i>millions</i>)	452.1	29,182.0
% 60+	15.4	16.3	Value of Caregiving (<i>millions</i>)	\$3,983.2	\$257,096.0
National Ranking 60+	40	N/A	% Grandchildren living w/grandparents age 65+	5.9	4.4
% White (60+)	73.4	82.3			
% African American (60+)	23.2	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.7	5.4	% Pop. 21-64 Years w/Disability	22.1	19.2
% Asian (60+)	0.6	2.5	% Pop. 65+ w/Disability	48.1	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.3	0.4	Sensory	16.4	14.2
Pop. 65+ (<i>thousands</i>)	516.9	34,991.8	Physical	34.3	28.6
% Pop. 65+	11.6	12.4	Self-care	12.4	9.5
National Ranking 65+	40	N/A	Mental	13.5	10.8
Pop. 85+ (<i>thousands</i>)	58.7	4,239.6	Difficulty Going Outside Home	23.7	20.4
% Pop. 85+	1.3	1.5			
National Ranking 85+	39	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$26,100	\$31,632	Certified Nursing Facilities	313	15,162
Median Household Income	\$34,008	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	37.5	1,574.0
% of Pop. 65+ Below Poverty	13.6	10.4	Average Cost Per Day in a Nursing Home	\$98	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	12	3,407
Households with Individuals 65+ (<i>millions</i>)	0.4	24.7	Home Health Aides	5,720	N/A
% Persons Age 65+ Living Alone	28.8	30.1			
% Pop. 65+ in Major Cities	34.2	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.2	3.1			
% Households with Internet Access	40.2	50.1			

State Profile: **Louisiana** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	DSS Planning Group and Consumer Task Force
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Administering State Agency	LA Governor's Office of Elderly Affairs	LA Department of Health & Hospitals
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA Parish Councils on Aging 	Medicaid agency

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver Real Choice Systems Change grants
FY 2001 Expenditures	\$1,535,025	n/a
FY 2002 Expenditures	\$1,788,389	n/a
FY 2003 Expenditures	\$1,959,241	\$13,221,098 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	n/a
FY 2002 A/D Waiver Respite Participants	N/A	n/a

State Profile: **Louisiana** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Caregiver Age Requirement	None	21+
Care Receiver Age Requirement	60+	65+
Care Receiver Functional Status Requirement	None	<ul style="list-style-type: none"> ▪ Nursing home level of care ▪ Physically disabled
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Program Assesses	Care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Support groups ▪ Transportation
Types of Respite Care Offered	In-home	None
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A

State Profile: **Louisiana** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Respite Cap	96 hours/year	N/A
Uniform Respite Cap Across Program Sites	Yes	N/A
Entity that Formulates the Respite Cap	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Home and Community-Based Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	Personal care

State Profile: **Maine**

Selected State Background Characteristics

	ME	US		ME	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.3	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	238.1	45,797.2	Caregiving Hours (<i>millions</i>)	137.6	29,182.0
% 60+	18.7	16.3	Value of Caregiving (<i>millions</i>)	\$1,212.4	\$257,096.0
National Ranking 60+	5	N/A	% Grandchildren living w/grandparents age 65+	1.4	4.4
% White (60+)	98.6	82.3			
% 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			
% American Indian/ Alaska Native (60+)	0.2	0.4			
Pop. 65+ (<i>thousands</i>)	183.4	34,991.8	■ Care Receivers ■		
% Pop. 65+	14.4	12.4	% Pop. 21-64 Years w/Disability	19.2	19.2
National Ranking 65+	7	N/A	% Pop. 65+ w/Disability	41.1	41.9
			% 65+ by Type of Disability		
Pop. 85+ (<i>thousands</i>)	23.3	4,239.6	Sensory	16.0	14.2
% Pop. 85+	1.8	1.5	Physical	28.2	28.6
National Ranking 85+	11	N/A	Self-care	8.4	9.5
			Mental	9.7	10.8
			Difficulty Going Outside Home	17.2	20.4
■ Economic Indicators ■					
Per Capita Income	\$28,831	\$31,632			
Median Household Income	\$36,853	\$42,409			
% of Pop. 65+ Below Poverty	12.0	10.4			
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Certified Nursing Facilities	113	15,162
% Persons Age 65+ Living Alone	35.2	30.1	Certified Nursing Facility Beds (<i>thousands</i>)	7.0	1,574.0
% Pop. 65+ in Major Cities	4.9	40.1	Average Cost Per Day in a Nursing Home	\$199	\$158
Average Household Size	2.4	2.6	Licensed Adult Day Facilities	42	3,407
Average Family Size	2.9	3.1	Home Health Aides	4,360	N/A
% Households with Internet Access	53.3	50.1			

State Profile: **Maine** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 1441 (Enacted 2002) Authorized the Department of Human Services to use money from the Respite Care Fund to carry out purposes of the NFCSP. HB 1441 (Enacted 2002) & HB 655 (Enacted 2001) Allocated funding for FY 2001 and FY 2002 to implement the NFCSP within the Bureau of Elder and Adult Services.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
Administering State Agency	ME Department of Human Services	ME Department of Human Services	ME Department of Human Services	ME Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	▪ AAA	▪ AAA ▪ Private for-profit agency	▪ AAA	▪ AAA

State Profile: **Maine** (cont'd)■ **Assessment** (cont'd) ■

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver mental health/depression Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver mental health/depression Caregiver strain Social support network Type of care (provided) Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Care duration Care frequency Caregiver demographic information Caregiver mental health/depression Caregiver strain

■ **Services** ■

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Consumer ehealth applications Educ. & training Family consult. Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Assistive technology Care mgt. Educ. & training Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	Yes	No	No	No
Respite Cap	\$500/year	\$4340/year	\$3800/year	\$3800/year
Uniform Respite Cap Across Program Sites	No	Yes	Yes	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency	Administering state agency	Administering state agency

State Profile: **Maine** (cont'd)■ **Assessment** (cont'd) ■

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver mental health/depression Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver mental health/depression Caregiver strain Social support network Type of care (provided) Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Care duration Care frequency Caregiver demographic information Caregiver mental health/depression Caregiver strain

■ **Services** ■

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Consumer ehealth applications Educ. & training Family consult. Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Assistive technology Care mgt. Educ. & training Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	Yes	No	No	No
Respite Cap	\$500/year	\$4340/year	\$3800/year	\$3800/year
Uniform Respite Cap Across Program Sites	No	Yes	Yes	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency	Administering state agency	Administering state agency

State Profile: **Maine** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Program (FC)	MaineCare (MC)	Home-Based Care (SC)	Partners in Caring (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: **Maryland**

Selected State Background Characteristics

	MD	US		MD	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.3	281.4	# of Caregivers (<i>millions</i>)	0.5	27.2
Pop. 60+ (<i>thousands</i>)	801.0	45,797.2	Caregiving Hours (<i>millions</i>)	553.9	29,182.0
% 60+	15.1	16.3	Value of Caregiving (<i>millions</i>)	\$4,880.2	\$257,096.0
National Ranking 60+	42	N/A	% Grandchildren living w/grandparents age 65+	5.3	4.4
% White (60+)	75.3	82.3			
% African American (60+)	19.4	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.6	5.4	% Pop. 21-64 Years w/Disability	17.2	19.2
% Asian (60+)	2.8	2.5	% Pop. 65+ w/Disability	39.8	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	12.5	14.2
Pop. 65+ (<i>thousands</i>)	599.3	34,991.8	Physical	26.8	28.6
% Pop. 65+	11.3	12.4	Self-care	9.1	9.5
National Ranking 65+	41	N/A	Mental	10.0	10.8
Pop. 85+ (<i>thousands</i>)	66.9	4,239.6	Difficulty Going Outside Home	20.3	20.4
% Pop. 85+	1.3	1.5			
National Ranking 85+	42	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$37,331	\$31,632	Certified Nursing Facilities	229	15,162
Median Household Income	\$56,407	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	27.9	1,574.0
% of Pop. 65+ Below Poverty	11.0	10.4	Average Cost Per Day in a Nursing Home	\$176	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	40	3,407
Households with Individuals 65+ (<i>millions</i>)	0.4	24.7	Home Health Aides	5,770	N/A
% Persons Age 65+ Living Alone	28.7	30.1			
% Pop. 65+ in Major Cities	27.7	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	57.8	50.1			

State Profile: **Maryland** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 567 & HB 513 (Enacted 2001) Established the Maryland Family Caregivers Support Coordinating Council in the Department of Human Resources to coordinate statewide planning, development and implementation of family caregiver support services.
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Maryland Caregiver Support Coordinating Council
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Administering State Agency	MD Department of Aging	MD Department of Aging	MD Department of Human Resources
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA	MD Department of Human Resources

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Major Sources of Program Funding	▪ OAA, Title III-E	▪ Medicaid HCBS waiver ▪ State general fund	▪ State general fund
FY 2001 Expenditures	\$1,843,229	\$576 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$2,089,617	\$14,363 (<i>respite only</i>)	n/a

State Profile: **Maryland** (cont'd)

■ Funding & Caseload (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
FY 2003 Expenditures	\$2,289,246	\$43,074,185 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	1	N/A
FY 2002 A/D Waiver Respite Participants	N/A	31	N/A

■ Eligibility ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Caregiver Age Requirement	None	50+	18+
Care Receiver Age Requirement	60+	Other	18+
Care Receiver Functional Status Requirement	▪ OAA guidelines	▪ Nursing home level of care	▪ 3+ ADLs
Client Population	Family caregiver	Care receiver	Both family caregiver and care receiver

■ Assessment ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	No
Includes Caregiver Assessment	N/A	Yes	N/A
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	N/A

■ Services ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	No	No

State Profile: **Maryland** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Cash grant Consum. supplies Counseling Educ. & training Emerg. response Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Care mgt. Consum. supplies Educ. & training Emerg. response Family consult. Home modification/repairs Homemaker/chore/personal care Respite care 	<ul style="list-style-type: none"> Care mgt. Counseling Educ. & training Emerg. response Family consult. Family meetings Homemaker/chore/personal care Info. & assistance Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	\$599/year	168 hours/year	164 hours/year
Uniform Respite Cap Across Program Sites	No	Yes	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver for Older Adults (MC)	Respite for Caregivers of Adults with Functional Disabilities (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services Direct payments to family members for the purchase of goods or services Families have a choice of respite providers 	<ul style="list-style-type: none"> Families have a choice of respite providers 	<ul style="list-style-type: none"> Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Personal care Respite care 	N/A

State Profile: **Massachusetts**

Selected State Background Characteristics

	MA	US		MA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (millions)	6.3	281.4	# of Caregivers (millions)	0.6	27.2
Pop. 60+ (thousands)	1,096.6	45,797.2	Caregiving Hours (millions)	678.7	29,182.0
% 60+	17.3	16.3	Value of Caregiving (millions)	\$5,979.0	\$257,096.0
National Ranking 60+	17	N/A	% Grandchildren living w/grandparents age 65+	3.4	4.4
% White (60+)	92.2	82.3			
% African American (60+)	2.9	8.4			
% Hispanic (60+)	1.9	5.4			
% Asian (60+)	1.7	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.1	0.4			
Pop. 65+ (thousands)	860.2	34,991.8			
% Pop. 65+	13.5	12.4			
National Ranking 65+	12	N/A			
Pop. 85+ (thousands)	116.7	4,239.6			
% Pop. 85+	1.8	1.5			
National Ranking 85+	10	N/A			
■ Economic Indicators ■			■ Care Receivers ■		
Per Capita Income	\$39,815	\$31,632	% Pop. 21-64 Years w/Disability	17.9	19.2
Median Household Income	\$49,855	\$42,409	% Pop. 65+ w/Disability	37.8	41.9
% of Pop. 65+ Below Poverty	10.9	10.4	% 65+ by Type of Disability		
			Sensory	13.0	14.2
			Physical	24.8	28.6
			Self-care	8.6	9.5
			Mental	8.8	10.8
			Difficulty Going Outside Home	18.8	20.4
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ (millions)	0.6	24.7	Certified Nursing Facilities	461	15,162
% Persons Age 65+ Living Alone	32.0	30.1	Certified Nursing Facility Beds (thousands)	49.6	1,574.0
% Pop. 65+ in Major Cities	37.8	40.1	Average Cost Per Day in a Nursing Home	\$240	\$158
Average Household Size	2.5	2.6	Licensed Adult Day Facilities	133	3,407
Average Family Size	3.1	3.1	Home Health Aides	11,590	N/A
% Households with Internet Access	54.7	50.1			

State Profile: **Massachusetts** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 4004 (Enacted 2003) Appropriated funds from the NFCSP to the Executive Office on Elder Affairs. HB 5300 (Enacted 2002) No bill information available. HB 5300 (Enacted 2002) No bill information available.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Home and Community-Based Waiver (HCBW) (MC)	Home Care Program (HCP) (SC)
Administering State Agency	MA Executive Office of Elder Affairs	MA Executive Office of Elder Affairs	MA Executive Office of Elder Affairs
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA Aging services access points 	<ul style="list-style-type: none"> Aging services access points 	<ul style="list-style-type: none"> Aging services access points

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Federal A/D grants to states Foundation OAA, Title III-E Private donations State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Client contribution State general fund
FY 2001 Expenditures	\$2,766,510	\$345,030 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$3,120,206	\$386,194 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$3,418,290	\$12,324,152 (<i>total waiver</i>)	n/a

State Profile: **Massachusetts** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
FY 2001 A/D Waiver Respite Participants	N/A	245	N/A
FY 2002 A/D Waiver Respite Participants	N/A	286	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
Caregiver Age Requirement	18+	None	None
Care Receiver Age Requirement	60+	60+	60+
Care Receiver Functional Status Requirement	No functional status requirement	Nursing home level of care	4+ ADLs and/or IADLs
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	Yes	Yes
Includes Caregiver Assessment	N/A	Yes	Yes
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver physical health Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver strain Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Family consult. Family meetings Home modification/ repairs Homemaker/chore/ personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Home modification/ repairs Homemaker/chore/ personal care Respite care Transportation 	<ul style="list-style-type: none"> Care mgt. Emerg. response Home modification/ repairs Homemaker/chore/ personal care Info. & assistance Respite care Transportation

State Profile: **Massachusetts** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	\$500 - \$1000/year	No cap	No cap
Uniform Respite Cap Across Program Sites	No	N/A	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	HCBW (MC)	HCP (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	None	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Consumer-directed attendant care
Family Members Can Be Paid to Provide Care	Yes	No	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care 	N/A	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care

State Profile: **Michigan**

Selected State Background Characteristics

	MI	US		MI	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	9.9	281.4	# of Caregivers (<i>millions</i>)	1.0	27.2
Pop. 60+ (<i>thousands</i>)	1,596.2	45,797.2	Caregiving Hours (<i>millions</i>)	1,026.8	29,182.0
% 60+	16.1	16.3	Value of Caregiving (<i>millions</i>)	\$9,045.7	\$257,096.0
National Ranking 60+	33	N/A	% Grandchildren living w/grandparents age 65+	3.1	4.4
% White (60+)	87.0	82.3			
% African American (60+)	10.0	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.2	5.4	% Pop. 21-64 Years w/Disability	18.1	19.2
% Asian (60+)	0.8	2.5	% Pop. 65+ w/Disability	17.1	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.3	0.4	Sensory	14.1	14.2
Pop. 65+ (<i>thousands</i>)	1,219.0	34,991.8	Physical	10.4	10.8
% Pop. 65+	12.3	12.4	Self-care	28.8	28.6
National Ranking 65+	30	N/A	Mental	9.4	9.5
Pop. 85+ (<i>thousands</i>)	142.5	4,239.6	Difficulty Going Outside Home	20.4	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	32	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,439	\$31,632	Certified Nursing Facilities	410	15,162
Median Household Income	\$42,715	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	45.2	1,574.0
% of Pop. 65+ Below Poverty	11.5	10.4	Average Cost Per Day in a Nursing Home	\$155	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	85	3,407
Households with Individuals 65+ (<i>millions</i>)	0.9	24.7	Home Health Aides	21,800	N/A
% Persons Age 65+ Living Alone	32.7	30.1			
% Pop. 65+ in Major Cities	37.3	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	51.2	50.1			

State Profile: **Michigan** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	n/a
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Administering State Agency	MI Office of Services to the Aging	MI Department of Community Health	MI Office of Services to the Aging	MI Office of Services to the Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	No	No	No	No
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Individual contractors 	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Approved HCBS/ED Medicaid Waiver agents

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Blue Cross/Blue Shield Escheat funds 	<ul style="list-style-type: none"> Tobacco fund

State Profile: **Michigan** (cont'd)

■ Funding & Caseload (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
FY 2001 Expenditures	\$3,848,418	\$9,175,034 (<i>respite only</i>)	\$1,870,501	\$3,997,001
FY 2002 Expenditures	\$4,315,224	\$10,063,820 (<i>respite only</i>)	\$2,544,862	\$4,912,537
FY 2003 Expenditures	\$4,727,473	\$62,105,775 (<i>total waiver</i>)	\$2,442,565	\$4,972,401
FY 2001 A/D Waiver Respite Participants	N/A	3,169	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	2,674	N/A	N/A

■ Eligibility ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Caregiver Age Requirement	None	18+	None	None
Care Receiver Age Requirement	60+	None	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> Nursing home level of care 	<ul style="list-style-type: none"> No functional status requirement 	<ul style="list-style-type: none"> No functional status requirement if over 60¹
Client Population	Family caregiver	Care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver

■ Assessment ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver	Care receiver
Uniform Assessment Tool	No	Yes	No	No
Includes Caregiver Assessment	N/A	Yes	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Care frequency Willingness of caregiver to provide care 	N/A	N/A

¹ 18+ with a medical disability

State Profile: **Michigan** (cont'd)■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Counseling Educ. & training Respite care 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No	No
Respite Cap	No cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A voucher or budget for respite and/or supplemental services Families have a choice of respite providers 	None	<ul style="list-style-type: none"> A voucher or budget for respite only Families have a choice of respite providers 	<ul style="list-style-type: none"> A voucher or budget for respite only Families have a choice of respite providers

State Profile: **Michigan** (cont'd)■ **Consumer Direction** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	MI Choice (MC)	State/Escheat Respite (SC)	Caregiver Respite Program (SC)
Family Members Can Be Paid to Provide Care	No	Yes	No	No
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care 	N/A	N/A

State Profile: **Minnesota**

Selected State Background Characteristics

	MN	US		MN	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	4.9	281.4	# of Caregivers (<i>millions</i>)	0.5	27.2
Pop. 60+ (<i>thousands</i>)	772.3	45,797.2	Caregiving Hours (<i>millions</i>)	506.1	29,182.0
% 60+	15.7	16.3	Value of Caregiving (<i>millions</i>)	\$4,458.6	\$257,096.0
National Ranking 60+	37	N/A	% Grandchildren living w/grandparents age 65+	2.1	4.4
% White (60+)	96.5	82.3			
% African American (60+)	1.0	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.6	5.4	% Pop. 21-64 Years w/Disability	14.0	19.2
% Asian (60+)	1.0	2.5	% Pop. 65+ w/Disability	36.9	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.5	0.4	Sensory	12.6	14.2
Pop. 65+ (<i>thousands</i>)	594.3	34,991.8	Physical	24.2	28.6
% Pop. 65+	12.1	12.4	Self-care	7.0	9.5
National Ranking 65+	33	N/A	Mental	7.8	10.8
Pop. 85+ (<i>thousands</i>)	85.6	4,239.6	Difficulty Going Outside Home	17.1	20.4
% Pop. 85+	1.7	1.5			
National Ranking 85+	15	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$34,443	\$31,632	Certified Nursing Facilities	368	15,162
Median Household Income	\$54,622	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	34.6	1,574.0
% of Pop. 65+ Below Poverty	6.9	10.4	Average Cost Per Day in a Nursing Home	\$155	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	68	3,407
Households with Individuals 65+ (<i>millions</i>)	0.4	24.7	Home Health Aides	19,460	N/A
% Persons Age 65+ Living Alone	30.7	30.1			
% Pop. 65+ in Major Cities	23.4	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	55.6	50.1			

State Profile: **Minnesota** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB6a (Enacted 2003) Increased reimbursement limits for Medigap coverage and removed the exclusion for coverage for care provided by a family member.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Administering State Agency	MN Department of Human Services	MN Department of Human Services	MN Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide AAA	Statewide	Statewide
Local Program Administrative Responsibility	AAA	County Dept. of Human or Social Services	County Dept. of Human or Social Services

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Federal A/D grants to states Medicaid HCBS waiver OAA, Title III-E State funded grants 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> State general fund
FY 2001 Expenditures	\$1,875,522	\$399,516 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$2,138,248	\$428,623 (<i>respite only</i>)	\$250,971
FY 2003 Expenditures	\$2,342,523	\$95,451,136 (<i>total waiver</i>)	\$255,889

State Profile: **Minnesota** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
FY 2001 A/D Waiver Respite Participants	N/A	220	N/A
FY 2002 A/D Waiver Respite Participants	N/A	195	N/A

■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Caregiver Age Requirement	None	18+	18+
Care Receiver Age Requirement	60+	65+	65+
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care	Nursing home level of care
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Program Assesses	Family caregiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Caregiver needs/preferences ▪ Caregiver social support network 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Caregiver needs/preferences ▪ Caregiver social support network ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Caregiver needs/preferences ▪ Caregiver social support network ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Do all family caregivers eligible for your program have access to the same package of services?	Yes	No	Yes

State Profile: **Minnesota** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Services provided specifically to family caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Counseling Educ. & training Family consult. Home modification/repairs Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Cash grant Consumer ehealth applications Counseling Educ. & training Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Cash grant Consumer ehealth applications Counseling Educ. & training Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Other 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Other
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Elderly Waiver (MC)	Alternative Care Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> Families have a choice of respite providers 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose Families have a choice of respite providers 	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services Families have a choice of respite providers Other
Family Members Can Be Paid to Provide Care	Yes	No ¹	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Personal care Respite care 	N/A	<ul style="list-style-type: none"> Personal care Respite care

¹ Effective October 1, 2004 this program will allow family members to be paid providers of care.

State Profile: **Mississippi****Selected State Background Characteristics**

	MS	US		MS	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	2.8	281.4	# of Caregivers (<i>millions</i>)	0.3	27.2
Pop. 60+ (<i>thousands</i>)	457.1	45,797.2	Caregiving Hours (<i>millions</i>)	287.4	29,182.0
% 60+	16.1	16.3	Value of Caregiving (<i>millions</i>)	\$2,531.7	\$257,096.0
National Ranking 60+	31	N/A	% Grandchildren living w/grandparents age 65+	4.8	4.4
% White (60+)	73.5	82.3			
% African American (60+)	24.9	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.6	5.4	% Pop. 21-64 Years w/Disability	24.5	19.2
% Asian (60+)	0.3	2.5	% Pop. 65+ w/Disability	51.7	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	18.0	14.2
Pop. 65+ (<i>thousands</i>)	343.5	34,991.8	Physical	38.1	28.6
% Pop. 65+	12.1	12.4	Self-care	14.3	9.5
National Ranking 65+	35	N/A	Mental	16.3	10.8
Pop. 85+ (<i>thousands</i>)	42.9	4,239.6	Difficulty Going Outside Home	25.6	20.4
% Pop. 85+	1.5	1.5			
National Ranking 85+	27	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$23,448	\$31,632	Certified Nursing Facilities	191	15,162
Median Household Income	\$30,882	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	16.4	1,574.0
% of Pop. 65+ Below Poverty	19.1	10.4	Average Cost Per Day in a Nursing Home	\$120	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	12	3,407
Households with Individuals 65+ (<i>millions</i>)	0.2	24.7	Home Health Aides	1,920	N/A
% Persons Age 65+ Living Alone	32.2	30.1			
% Pop. 65+ in Major Cities	10.0	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	36.1	50.1			

State Profile: **Mississippi** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	No
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Administering State Agency	MS Department of Human Services	MS Office of the Governor
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver
FY 2001 Expenditures	\$1,031,878	\$2,230 (<i>respite only</i>)
FY 2002 Expenditures	\$1,189,322	\$28,707 (<i>respite only</i>)
FY 2003 Expenditures	\$1,302,942	\$48,592,126 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	3
FY 2002 A/D Waiver Respite Participants	N/A	22

State Profile: **Mississippi** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Caregiver Age Requirement	18+	21+
Care Receiver Age Requirement	60+	21+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 3+ ADLs 	<ul style="list-style-type: none"> 3+ ADLs Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	No
Includes Caregiver Assessment	Yes	N/A
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver demographic information Caregiver mental health/depression Caregiver physical health Caregiver strain Emergency plan If family caregivers are providing long-distance caregiving Willingness of caregiver to provide care 	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Consum. supplies Counseling Educ. & training Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Care mgt. Homemaker/chore/personal care Respite care Transportation Other
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes

State Profile: **Mississippi** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Respite Cap	32 hours/month	40 hours/month
Uniform Respite Cap Across Program Sites	Yes	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Disabled Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose
Family Members Can Be Paid to Provide Care	No	No
Types of Services Families Can Be Paid to Provide	N/A	N/A

State Profile: **Missouri**

Selected State Background Characteristics

	MO	US		MO	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.6	281.4	# of Caregivers (<i>millions</i>)	583.1	27.2
Pop. 60+ (<i>thousands</i>)	983.7	45,797.2	Caregiving Hours (<i>millions</i>)	0.6	29,182.0
% 60+	17.6	16.3	Value of Caregiving (<i>millions</i>)	\$5,136.8	\$257,096.0
National Ranking 60+	12	N/A	% Grandchildren living w/grandparents age 65+	3.9	4.4
% White (60+)	90.4	82.3			
% African American (60+)	7.4	8.4			
% Hispanic (60+)	0.8	5.4			
% Asian (60+)	0.5	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.2	0.4			
Pop. 65+ (<i>thousands</i>)	755.4	34,991.8	■ Care Receivers ■		
% Pop. 65+	13.5	12.4	% Pop. 21-64 Years w/Disability	18.2	19.2
National Ranking 65+	13	N/A	% Pop. 65+ w/Disability	42.6	41.9
			% 65+ by Type of Disability		
Pop. 85+ (<i>thousands</i>)	98.6	4,239.6	Sensory	14.3	14.2
% Pop. 85+	1.8	1.5	Physical	29.8	28.6
National Ranking 85+	13	N/A	Self-care	9.2	9.5
			Mental	10.3	10.8
			Difficulty Going Outside Home	19.8	20.4
■ Economic Indicators ■					
Per Capita Income	\$29,252	\$31,632			
Median Household Income	\$42,776	\$42,409			
% of Pop. 65+ Below Poverty	6.4	10.4			
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Certified Nursing Facilities	506	15,162
% Persons Age 65+ Living Alone	31.5	30.1	Certified Nursing Facility Beds (<i>thousands</i>)	47.3	1,574.0
% Pop. 65+ in Major Cities	24.6	40.1	Average Cost Per Day in a Nursing Home	\$115	\$158
Average Household Size	2.5	2.6	Licensed Adult Day Facilities	59	3,407
Average Family Size	3.0	3.1	Home Health Aides	9,750	N/A
% Households with Internet Access	49.9	50.1			

State Profile: **Missouri** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
Administering State Agency	MO Department of Health & Senior Services	MO Department of Health & Senior Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund Title XX
FY 2001 Expenditures	\$2,337,876	\$17,883,132 (<i>respite only</i>)
FY 2002 Expenditures	\$2,666,197	\$21,903,300 (<i>respite only</i>)
FY 2003 Expenditures	\$2,920,908	\$80,630,401 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	4,525
FY 2002 A/D Waiver Respite Participants	N/A	5,007

State Profile: **Missouri** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
Caregiver Age Requirement	18+	63+
Care Receiver Age Requirement	60+	63+
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care
Client Population	Both family caregiver and care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No response
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Consumer ehealth applications ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation ▪ Other 	<ul style="list-style-type: none"> ▪ Homemaker/chore/personal care ▪ Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A
Respite Cap	16-20 hours/month	No cap
Uniform Respite Cap Across Program Sites	No	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A

State Profile: **Missouri** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	Yes	No
Types of Services Families Can Be Paid to Provide	Respite care	N/A

State Profile: **Montana**

Selected State Background Characteristics

	MT	US
■ Population ■		
Total Pop. (millions)	0.9	281.4
Pop. 60+ (thousands)	158.9	45,797.2
% 60+	17.6	16.3
National Ranking 60+	11	N/A
% White (60+)	95.4	82.3
% African American (60+)	0.1	8.4
% Hispanic (60+)	0.8	5.4
% Asian (60+)	0.3	2.5
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1
% American Indian/ Alaska Native (60+)	2.6	0.4
Pop. 65+ (thousands)	120.9	34,991.8
% Pop. 65+	13.4	12.4
National Ranking 65+	14	N/A
Pop. 85+ (thousands)	15.3	4,239.6
% Pop. 85+	1.7	1.5
National Ranking 85+	14	N/A

■ Economic Indicators ■		
Per Capita Income	\$25,920	\$31,632
Median Household Income	\$34,835	\$42,409
% of Pop. 65+ Below Poverty	10.6	10.4

■ Socio-Demographics ■		
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7
% Persons Age 65+ Living Alone	34.5	30.1
% Pop. 65+ in Major Cities	23.3	40.1
Average Household Size	2.5	2.6
Average Family Size	3.0	3.1
% Households with Internet Access	47.5	50.1

	MT	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	0.1	27.2
Caregiving Hours (<i>millions</i>)	94.4	29,182.0
Value of Caregiving (<i>millions</i>)	\$831.9	\$257,096.0
% Grandchildren living w/grandparents age 65+	2.1	4.4

■ Care Receivers ■		
% Pop. 21-64 Years w/Disability	16.9	19.2
% Pop. 65+ w/Disability	39.6	41.9
% 65+ by Type of Disability		
Sensory	16.4	14.2
Physical	26.5	28.6
Self-care	6.9	9.5
Mental	8.8	10.8
Difficulty Going Outside Home	16.1	20.4

■ Long-Term Care ■		
Certified Nursing Facilities	74	15,162
Certified Nursing Facility Beds (<i>thousands</i>)	5.6	1,574.0
Average Cost Per Day in a Nursing Home	\$127	\$158
Licensed Adult Day Facilities	56	3,407
Home Health Aides	2,100	N/A

State Profile: **Montana** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SJR 18 (Enacted 2003) Requested a Medicaid waiver to allow greater flexibility with family caregiving.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
Administering State Agency	MT Department of Public Health & Human Services	MT Department of Public Health & Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Local/county funds OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver Real Choice Systems Change grants
FY 2001 Expenditures	\$564,300	\$325,861 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	\$207,183 (<i>respite only</i>)
FY 2003 Expenditures	\$705,756	\$18,935,410 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	160
FY 2002 A/D Waiver Respite Participants	N/A	106

State Profile: **Montana** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
Caregiver Age Requirement	None	18+
Care Receiver Age Requirement	None	None
Care Receiver Functional Status Requirement	No functional status requirement	Nursing home level of care
Client Population	Both family caregiver and care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	Yes
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Caregiver strain ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Educ. & training ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Family consult. ▪ Family meetings ▪ Respite care ▪ Support groups
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	Yes	No
Respite Cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A

State Profile: **Montana** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiving Support (FC)	Home and Community-Based Services Program for Elderly and Physically Disabled (MC)
Consumer-Directed Options	None	A menu of services from which caregivers can choose
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> ▪ Any service needed ▪ Personal care

State Profile: **Nebraska**

Selected State Background Characteristics

	NE	US		NE	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.7	281.4	# of Caregivers (<i>millions</i>)	0.2	27.2
Pop. 60+ (<i>thousands</i>)	296.1	45,797.2	Caregiving Hours (<i>millions</i>)	175.5	29,182.0
% 60+	17.3	16.3	Value of Caregiving (<i>millions</i>)	\$1,546.4	\$257,096.0
National Ranking 60+	15	N/A	% Grandchildren living w/grandparents age 65+	3.2	4.4
% White (60+)	95.5	82.3			
% African American (60+)	2.1	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.3	5.4	% Pop. 21-64 Years w/Disability	15.2	19.2
% Asian (60+)	0.5	2.5	% Pop. 65+ w/Disability	37.1	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.3	0.4	Sensory	12.8	14.2
Pop. 65+ (<i>thousands</i>)	232.2	34,991.8	Physical	24.2	28.6
% Pop. 65+	13.6	12.4	Self-care	7.3	9.5
National Ranking 65+	11	N/A	Mental	7.4	10.8
Pop. 85+ (<i>thousands</i>)	34.0	4,239.6	Difficulty Going Outside Home	17.0	20.4
% Pop. 85+	2.0	1.5			
National Ranking 85+	6	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,758	\$31,632	Certified Nursing Facilities	200	15,162
Median Household Income	\$42,796	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	13.2	1,574.0
% of Pop. 65+ Below Poverty	10.6	10.4	Average Cost Per Day in a Nursing Home	\$135	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	21	3,407
Households with Individuals 65+ (<i>millions</i>)	0.2	24.7	Home Health Aides	2,190	N/A
% Persons Age 65+ Living Alone	31.9	30.1			
% Pop. 65+ in Major Cities	29.9	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	45.5	50.1			

State Profile: **Nebraska** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Administering State Agency	NE Department of Health & Human Services	NE Department of Health & Human Services	NE Department of Health & Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Independent Living Centers Medicaid agency 	<ul style="list-style-type: none"> Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> State general fund Tobacco fund
FY 2001 Expenditures	\$732,458	\$4,022,528 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$837,679	\$3,509,695 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$917,706	\$29,557,464 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	868	N/A
FY 2002 A/D Waiver Respite Participants	N/A	896	N/A

State Profile: **Nebraska** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Caregiver Age Requirement	None	None	None
Care Receiver Age Requirement	60+	None	None
Care Receiver Functional Status Requirement	2 ADLs	Nursing home level of care	Other
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform, Statewide Assessment Tool	Yes	Yes	No
Includes Caregiver Assessment	Yes	No	N/A
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver mental health/depression Caregiver physical health Caregiver strain 	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Educ. & training Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp Other 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp

State Profile: **Nebraska** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes	Yes
Respite Cap	\$1000/year (average)	No cap	\$125/month
Uniform Respite Cap Across Program Sites	No	N/A	Yes
Entity that Formulates the Respite Cap	Administering local agency	N/A	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Aged and Disabled Waiver (MC)	Respite Subsidy Program Across the Lifespan (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite only ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Respite care ▪ Other 	<ul style="list-style-type: none"> ▪ Respite care

State Profile: Nevada

Selected State Background Characteristics

	NV	US
■ Population ■		
Total Pop. (<i>millions</i>)	2.0	281.4
Pop. 60+ (<i>thousands</i>)	304.1	45,797.2
% 60+	15.2	16.3
National Ranking 60+	41	N/A
% White (60+)	83.2	82.3
% African American (60+)	4.6	8.4
% Hispanic (60+)	6.2	5.4
% Asian (60+)	3.7	2.5
% Native Hawaiian/ Pacific Islanders (60+)	0.2	0.1
% American Indian/ Alaska Native (60+)	0.7	0.4
Pop. 65+ (<i>thousands</i>)	218.9	34,991.8
% Pop. 65+	11	12.4
National Ranking 65+	45	N/A
Pop. 85+ (<i>thousands</i>)	17.0	4,239.6
% Pop. 85+	0.9	1.5
National Ranking 85+	50	N/A

■ Economic Indicators ■

Per Capita Income	\$31,266	\$31,632
Median Household Income	\$44,958	\$42,409
% of Pop. 65+ Below Poverty	7.6	10.4

■ Socio-Demographics ■

Households with Individuals 65+ (<i>millions</i>)	0.2	24.7
% Persons Age 65+ Living Alone	27.4	30.1
% Pop. 65+ in Major Cities	74.3	40.1
Average Household Size	2.6	2.6
Average Family Size	3.1	3.1
% Households with Internet Access	52.5	50.1

	NV	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	0.2	27.2
Caregiving Hours (<i>millions</i>)	207.5	29,182.0
Value of Caregiving (<i>millions</i>)	\$1,828.2	\$257,096.0
% Grandchildren living w/grandparents age 65+	4.2	4.4

■ Care Receivers ■

% Pop. 21-64 Years w/Disability	21.8	19.2
% Pop. 65+ w/Disability	40.6	41.9
% 65+ by Type of Disability		
Sensory	13.8	14.2
Physical	28.6	28.6
Self-care	7.8	9.5
Mental	8.6	10.8
Difficulty Going Outside Home	17.3	20.4

■ Long-Term Care ■

Certified Nursing Facilities	44	15,162
Certified Nursing Facility Beds (<i>thousands</i>)	5.1	1,574.0
Average Cost Per Day in a Nursing Home	\$151	\$158
Licensed Adult Day Facilities	6	3,407
Home Health Aides	1,620	N/A

State Profile: **Nevada** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Administering State Agency	NV Department of Human Resources	NV Department of Human Resources	NV Department of Human Resources	NV Department of Human Resources
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	No
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	SUA	SUA	SUA	SUA

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> ▪ OAA, Title III-E 	<ul style="list-style-type: none"> ▪ Client contribution ▪ Medicaid HCBS waiver ▪ State general fund ▪ Tobacco fund 	<ul style="list-style-type: none"> ▪ Tobacco fund 	<ul style="list-style-type: none"> ▪ State general fund

State Profile: **Nevada** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
FY 2001 Expenditures	\$603,803	\$47,233 (<i>respite only</i>)	n/a	n/a
FY 2002 Expenditures	\$715,220	\$26,107 (<i>respite only</i>)	n/a	\$238,407
FY 2003 Expenditures	\$783,548	\$7,258,346 (<i>total waiver</i>)	n/a	\$261,183
FY 2001 A/D Waiver Respite Participants	N/A	39	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	47	N/A	N/A

■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Caregiver Age Requirement	None	None	None	None
Care Receiver Age Requirement	60+	65+	60+	None
Care Receiver Functional Status Requirement	No functional status requirement	Nursing home level of care	No functional status requirement	No functional status requirement
Client Population	Both family caregiver and care receiver	Care receiver	Care receiver	Family caregiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver	Family caregiver
Uniform Assessment Tool	Yes	Yes	No	No
Includes Caregiver Assessment	No	No	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes	Yes	Yes

State Profile: **Nevada** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore/personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Transportation 	<ul style="list-style-type: none"> ▪ Educ. & training
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ In-home 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	None
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No	N/A
Respite Cap	No cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Community Home-Based Initiatives Program (MC)	Independent Living Grant (SC)	Community-Based Care Caregiving Training (SC)
Consumer-Directed Options	None	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	No	No	No	No
Types of Services Families Can Be Paid to Provide	N/A	N/A	N/A	N/A

State Profile: **New Hampshire**

Selected State Background Characteristics

	NH	US		NH	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. <i>(millions)</i>	1.2	281.4	# of Caregivers <i>(millions)</i>	0.1	27.2
Pop. 60+ <i>(thousands)</i>	195.0	45,797.2	Caregiving Hours <i>(millions)</i>	130.1	29,182.0
% 60+	15.2	16.3	Value of Caregiving <i>(millions)</i>	\$1,146.3	\$257,096.0
National Ranking 60+	36	N/A	% Grandchildren living w/grandparents age 65+	2.1	4.4
% White (60+)	98.1	82.3			
% African American (60+)	0.3	8.4			
% Hispanic (60+)	0.5	5.4			
% Asian (60+)	0.5	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.1	0.4			
Pop. 65+ <i>(thousands)</i>	148.0	34,991.8			
% Pop. 65+	12.0	12.4			
National Ranking 65+	37	N/A			
Pop. 85+ <i>(thousands)</i>	18.2	4,239.6			
% Pop. 85+	1.3	1.5			
National Ranking 85+	29	N/A			
■ Economic Indicators ■			■ Care Receivers ■		
Per Capita Income	\$34,702	\$31,632	% Pop. 21-64 Years w/Disability	16.1	19.2
Median Household Income	\$55,321	\$42,409	% Pop. 65+ w/Disability	38.5	41.9
% of Pop. 65+ Below Poverty	7.1	10.4	% 65+ by Type of Disability		
			Sensory	14.5	14.2
			Physical	25.7	28.6
			Self-care	7.3	9.5
			Mental	8.4	10.8
			Difficulty Going Outside Home	16.3	20.4
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ <i>(millions)</i>	0.1	24.7	Certified Nursing Facilities	62	15,162
% Persons Age 65+ Living Alone	27.3	30.1	Certified Nursing Facility Beds <i>(thousands)</i>	6.2	1,574.0
% Pop. 65+ in Major Cities	16.1	40.1	Average Cost Per Day in a Nursing Home	\$199	\$158
Average Household Size	2.5	2.6	Licensed Adult Day Facilities	23	3,407
Average Family Size	3.0	3.1	Home Health Aides	1,530	N/A
% Households with Internet Access	61.6	50.1			

State Profile: **New Hampshire** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 831 (Enacted 2003) Created a study commission on end of life care. One of the goals of the commission included the education and training of caregivers. HB 569 (Enacted 2001) Established a committee to study the information, training and support needs of family caregivers.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
Administering State Agency	NH Department of Health & Human Services	NH Department of Health & Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	SUA	SUA

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> ▪ OAA, Title III-E ▪ State general fund 	<ul style="list-style-type: none"> ▪ Medicaid HCBS waiver ▪ State general fund
FY 2001 Expenditures	\$564,300	\$14,844 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	\$23,148 (<i>respite only</i>)
FY 2003 Expenditures	\$705,756	\$23,633,285 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	9
FY 2002 A/D Waiver Respite Participants	N/A	17

State Profile: **New Hampshire** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
Caregiver Age Requirement	None	18+
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> 1 ADL
Client Population	Family caregiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
Program Assesses	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	No
Includes Caregiver Assessment	No	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Consum. supplies Emerg. response Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Transportation Other
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	\$2000/year	480 hours/year
Uniform Respite Cap Across Program Sites	Yes	Yes
Entity that Formulates the Respite Cap	Administering state agency	Administering state agency

State Profile: **New Hampshire** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Elderly and Chronically Ill Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: **New Jersey****Selected State Background Characteristics**

	NJ	US		NJ	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	8.4	281.4	# of Caregivers (<i>millions</i>)	0.8	27.2
Pop. 60+ (<i>thousands</i>)	1,443.8	45,797.2	Caregiving Hours (<i>millions</i>)	891.2	29,182.0
% 60+	17.2	16.3	Value of Caregiving (<i>millions</i>)	\$7,851.4	\$257,096.0
National Ranking 60+	18	N/A	% Grandchildren living w/grandparents age 65+	4.2	4.4
% White (60+)	81.0	82.3			
% African American (60+)	9.2	8.4	■ Care Receivers ■		
% Hispanic (60+)	6.0	5.4	% Pop. 21-64 Years w/Disability	17.4	19.2
% Asian (60+)	2.8	2.5	% Pop. 65+ w/Disability	38.6	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	12.0	14.2
Pop. 65+ (<i>thousands</i>)	1,113.1	34,991.8	Physical	25.5	28.6
% Pop. 65+	13.2	12.4	Self-care	8.8	9.5
National Ranking 65+	18	N/A	Mental	9.2	10.8
Pop. 85+ (<i>thousands</i>)	136.0	4,239.6	Difficulty Going Outside Home	20.0	20.4
% Pop. 85+	1.6	1.5			
National Ranking 85+	22	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$40,427	\$31,632	Certified Nursing Facilities	338	15,162
Median Household Income	\$54,568	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	0.5	1,574.0
% of Pop. 65+ Below Poverty	9.1	10.4	Average Cost Per Day in a Nursing Home	\$219	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	114	3,407
Households with Individuals 65+ (<i>millions</i>)	0.8	24.7	Home Health Aides	18,240	N/A
% Persons Age 65+ Living Alone	29.4	30.1			
% Pop. 65+ in Major Cities	31.3	40.1			
Average Household Size	2.7	2.6			
Average Family Size	3.2	3.1			
% Households with Internet Access	57.2	50.1			

State Profile: **New Jersey** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 3000 (Enacted 2003) Appropriated funds for the New Jersey Ease for Caregivers—Building Support Systems project. SB 2003 (Enacted 2002) Appropriated funding from the National Family Caregiver Program to the state Department of Health and Senior Services. SB 2500 (Enacted 2001) No bill information available.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community Care Program for the Elderly & Disabled (CCPED) (MC)	Enhanced Community Options (ECO) (MC)	New Jersey Statewide Respite Care Program (SRCP) (SC)	Adult Day Svcs. Program for Persons with Alzheimer's Disease or Related Dementias (ADSP) (SC)	Jersey Assistance for Community Caregiving (JACC) (SC)
Administering State Agency	NJ Department of Health & Senior Services	NJ Department of Health & Senior Services	NJ Department of Health & Senior Services	NJ Department of Health & Senior Services	NJ Department of Health & Senior Services	NJ Department of Health & Senior Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	No	No	No	Yes	No	No
Geographic Region Served	Statewide	Statewide	Statewide	Statewide	Statewide	Statewide

State Profile: **New Jersey** (cont'd)■ **Administrative Structure** (cont'd) ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Medicaid agency 	<ul style="list-style-type: none"> AAA Adult Family Care Sponsor Agencies - Home Care or Social Service Agencies Care Mgt. 2000, Inc. (Adult Family Care Sponsor Agency) Medicaid agency 	<ul style="list-style-type: none"> AAA Board of Social Services Division of Disability Services Family and Children's Services Hospitals Visiting Health Service Visiting Nurses Assoc. 	<ul style="list-style-type: none"> County Health Dept. Hospitals Independent service organizations Nursing homes Private For Profit Agency Visiting Health Service Visiting Nurses Assoc. 	<ul style="list-style-type: none"> AAA County Welfare Agency/ Board of Social Services

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> State general fund 	<ul style="list-style-type: none"> Casino revenue Client contribution State general fund 	<ul style="list-style-type: none"> State general fund
FY 2001 Expenditures	\$3,496,629	\$302,716 (respite only)	\$30,516 (respite only)	\$7,705,856	\$2,338,000	\$5,227,861
FY 2002 Expenditures	\$3,974,716	\$351,900 (respite only)	\$39,061 (respite only)	\$6,818,000	\$2,436,000	\$10,366,956
FY 2003 Expenditures	\$4,354,435	\$42,697,404 (total waiver)	\$37,797,191 (total waiver)	\$5,918,000	\$2,483,000	\$10,000,000
FY 2001 A/D Waiver Respite Participants	N/A	180	38	N/A	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	185	40	N/A	N/A	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Caregiver Age Requirement	None*	None	None*	18+	18+	None*
Care Receiver Age Requirement	60+	None	21+	18+	18+	60+
Care Receiver Functional Status Requirement	Other	Nursing home level of care	Nursing home level of care	Physically disabled	Diagnosis of dementia or related disorder/ requires supervision	Nursing home level of care
Client Population	Family caregiver	Care receiver	Care receiver	Both family caregiver and care receiver	Care receiver	Care receiver

Note: * = Client employed provider must be 18+

State Profile: **New Jersey** (cont'd)■ **Assessment** ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	Yes	Yes	Yes	No	Yes
Includes Caregiver Assessment	N/A	Yes	Yes	Yes	N/A	Yes
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver physical health Caregiver strain If family caregivers are providing long-distance caregiving Need for education/training Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver physical health Caregiver strain Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver demographic information Caregiver mental health/depression Caregiver physical health Caregiver strain 	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver physical health Caregiver strain Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups 	<ul style="list-style-type: none"> Counseling Educ. & training Emerg. response Family consult. Family meetings Info. & assistance Respite care 	<ul style="list-style-type: none"> Counseling Educ. & training Emerg. response Family consult. Family meetings Info. & assistance Respite care 	<ul style="list-style-type: none"> Educ. & training Emerg. response Respite care 	<ul style="list-style-type: none"> Educ. & training Counseling Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Counseling Educ. & training Emerg. response Family consult. Family meetings Info. & assistance Respite care

State Profile: **New Jersey** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp ▪ Other 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp ▪ Other 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp ▪ Other
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No	No	Yes	No
Respite Cap	No cap	<ul style="list-style-type: none"> ▪ 30 days/year (skilled nursing facility) ▪ 336 hours/year (in-home) 	\$1000/month	\$3000/year	3 days/week	\$600/month
Uniform Respite Cap Across Program Sites	N/A	Yes	Yes	Yes	Yes	Yes
Entity that Formulates the Respite Cap	N/A	Administering state agency	Administering state agency	Administering state agency	Administering state agency	Administering state agency

■ **Consumer Direction** ■

Program Name	FCSP (FC)	CCPED (MC)	ECO (MC)	SRCP (SC)	ADSP (SC)	JACC (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ Families have a choice of respite providers 	None	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose 	None	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	No	No	Yes	No	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	N/A	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Other 	N/A	N/A	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Other

State Profile: **New Mexico**

Selected State Background Characteristics

	NM	US		NM	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.8	281.4	# of Caregivers (<i>millions</i>)	0.2	27.2
Pop. 60+ (<i>thousands</i>)	283.8	45,797.2	Caregiving Hours (<i>millions</i>)	183.1	29,182.0
% 60+	15.6	16.3	Value of Caregiving (<i>millions</i>)	\$1,612.9	\$257,096.0
National Ranking 60+	39	N/A	% Grandchildren living w/grandparents age 65+	5.1	4.4
% White (60+)	62.6	82.3	■ Care Receivers ■		
% African American (60+)	1.3	8.4	% Pop. 21-64 Years w/Disability	21.0	19.2
% Hispanic (60+)	29.6	5.4	% Pop. 65+ w/Disability	44.8	41.9
% Asian (60+)	0.6	2.5	% 65+ by Type of Disability		
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	Sensory	17.6	14.2
% American Indian/ Alaska Native (60+)	5.0	0.4	Physical	31.2	28.6
Pop. 65+ (<i>thousands</i>)	212.2	34,991.8	Self-care	9.8	9.5
% Pop. 65+	11.7	12.4	Mental	12.6	10.8
National Ranking 65+	39	N/A	Difficulty Going Outside Home	21.1	20.4
Pop. 85+ (<i>thousands</i>)	23.3	4,239.6	■ Long-Term Care ■		
% Pop. 85+	1.3	1.5	Certified Nursing Facilities	68	15,162
National Ranking 85+	41	N/A	Certified Nursing Facility Beds (<i>thousands</i>)	6.2	1,574.0
■ Economic Indicators ■			Average Cost Per Day in a Nursing Home	\$146	\$158
Per Capita Income	\$25,541	\$31,632	Licensed Adult Day Facilities	18	3,407
Median Household Income	\$35,457	\$42,409	Home Health Aides	4,970	N/A
% of Pop. 65+ Below Poverty	14.5	10.4	■ Socio-Demographics ■		
■ Socio-Demographics ■			Households with Individuals 65+ (<i>millions</i>)	0.2	24.7
Households with Individuals 65+ (<i>millions</i>)	0.2	24.7	% Persons Age 65+ Living Alone	28.2	30.1
% Persons Age 65+ Living Alone	28.2	30.1	% Pop. 65+ in Major Cities	36.8	40.1
% Pop. 65+ in Major Cities	36.8	40.1	Average Household Size	2.6	2.6
Average Household Size	2.6	2.6	Average Family Size	3.2	3.1
Average Family Size	3.2	3.1	% Households with Internet Access	43.1	50.1
% Households with Internet Access	43.1	50.1			

State Profile: **New Mexico** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Administering State Agency	NM State Agency on Aging	NM Human Services Department
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Federal A/D Grants to States OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund
FY 2001 Expenditures	\$594,433	\$597,733 (<i>respite only</i>)
FY 2002 Expenditures	\$709,061	\$833,334 (<i>respite only</i>)
FY 2003 Expenditures	\$776,799	\$36,206,362 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	606
FY 2002 A/D Waiver Respite Participants	N/A	657

State Profile: **New Mexico** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Caregiver Age Requirement	18+	18+
Care Receiver Age Requirement	60+	None
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> ▪ 3+ ADLs ▪ Nursing home level of care
Client Population	Both family caregiver and care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Financial situation ▪ If family caregivers are providing long-distance caregiving 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Educ. & training ▪ Info. & assistance ▪ Respite care

State Profile: **New Mexico** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	<ul style="list-style-type: none"> ▪ In-home
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes
Respite Cap	No cap	336 hours/year
Uniform Respite Cap Across Program Sites	N/A	Yes
Entity that Formulates the Respite Cap	N/A	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Disabled and Elderly Home and Community-Based Services Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal Care ▪ Respite Care 	<ul style="list-style-type: none"> ▪ Personal Care

State Profile: **New York**

Selected State Background Characteristics

	NY	US		NY	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	19.0	281.4	# of Caregivers (<i>millions</i>)	1.9	27.2
Pop. 60+ (<i>thousands</i>)	3,204.3	45,797.2	Caregiving Hours (<i>millions</i>)	2,000.4	29,182.0
% 60+	16.9	16.3	Value of Caregiving (<i>millions</i>)	\$17,623.7	\$257,096.0
National Ranking 60+	24	N/A	% Grandchildren living w/grandparents age 65+	4.9	4.4
% White (60+)	76.4	82.3			
% African American (60+)	11.0	8.4	■ Care Receivers ■		
% Hispanic (60+)	7.8	5.4	% Pop. 21-64 Years w/Disability	21.0	19.2
% Asian (60+)	3.4	2.5	% Pop. 65+ w/Disability	40.3	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	12.6	14.2
Pop. 65+ (<i>thousands</i>)	2,448.4	34,991.8	Physical	26.8	28.6
% Pop. 65+	12.9	12.4	Self-care	9.9	9.5
National Ranking 65+	24	N/A	Mental	10.3	10.8
Pop. 85+ (<i>thousands</i>)	311.5	4,239.6	Difficulty Going Outside Home	21.4	20.4
% Pop. 85+	1.6	1.5			
National Ranking 85+	21	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$36,574	\$31,632	Certified Nursing Facilities	645	15,162
Median Household Income	\$41,966	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	118.2	1,574.0
% of Pop. 65+ Below Poverty	12.4	10.4	Average Cost Per Day in a Nursing Home	\$252	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	175	3,407
Households with Individuals 65+ (<i>millions</i>)	1.8	24.7	Home Health Aides	108,210	N/A
% Persons Age 65+ Living Alone	32.8	30.1			
% Pop. 65+ in Major Cities	106.7	40.1			
Average Household Size	2.6	2.6			
Average Family Size	3.2	3.1			
% Households with Internet Access	50.2	50.1			

State Profile: **New York** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Caregiver Technical Advisory Group
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	No

State Program Information**■ Administrative Structure ■**

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Administering State Agency	NY Office for the Aging	NY Office for the Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Select geographic regions
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Determined by RFP/legislative initiatives

■ Funding & Caseload ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Local/county funds State general fund
FY 2001 Expenditures	\$7,612,334	n/a
FY 2002 Expenditures	\$8,680,794	n/a
FY 2003 Expenditures	\$9,510,102	n/a
FY 2001 A/D Waiver Respite Participants	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	N/A

State Profile: **New York** (cont'd)■ **Eligibility** ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Caregiver Age Requirement	60+	None
Care Receiver Age Requirement	60+	60+
Care Receiver Functional Status Requirement	None	Other
Client Population	Both family caregiver and care receiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	No
Includes Caregiver Assessment	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Cash grant ▪ Consum. supplies ▪ Consumer ehealth applications ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	No cap	100 hours/year

State Profile: **New York** (cont'd)■ **Services** (cont'd) ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Uniform Respite Cap Across Program Sites	N/A	Yes
Entity that Formulates the Respite Cap	N/A	State legislation/Section 536/ Executive Laws of New York State

■ **Consumer Direction** ■

Program Name	Eldercare Family Support Program (EFSP) (FC)	Respite Program (SC)
Consumer-Directed Options	Under consideration	None
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	Respite care

State Profile: **North Carolina**

Selected State Background Characteristics

	NC	US		NC	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	8.0	281.4	# of Caregivers (<i>millions</i>)	0.8	27.2
Pop. 60+ (<i>thousands</i>)	1,292.6	45,797.2	Caregiving Hours (<i>millions</i>)	848.1	29,182.0
% 60+	16.1	16.3	Value of Caregiving (<i>millions</i>)	\$7,471.9	\$257,096.0
National Ranking 60+	34	N/A	% Grandchildren living w/grandparents age 65+	4.0	4.4
% White (60+)	81.6	82.3			
% African American (60+)	15.9	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.7	5.4	% Pop. 21-64 Years w/Disability	20.9	19.2
% Asian (60+)	0.5	2.5	% Pop. 65+ w/Disability	45.7	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.7	0.4	Sensory	15.4	14.2
Pop. 65+ (<i>thousands</i>)	969.0	34,991.8	Physical	32.3	28.6
% Pop. 65+	12	12.4	Self-care	11.3	9.5
National Ranking 65+	36	N/A	Mental	13.2	10.8
Pop. 85+ (<i>thousands</i>)	105.5	4,239.6	Difficulty Going Outside Home	22.7	20.4
% Pop. 85+	1.3	1.5			
National Ranking 85+	40	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$28,235	\$31,632	Certified Nursing Facilities	375	15,162
Median Household Income	\$36,515	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	38.4	1,574.0
% of Pop. 65+ Below Poverty	10.6	10.4	Average Cost Per Day in a Nursing Home	\$138	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	107	3,407
Households with Individuals 65+ (<i>millions</i>)	0.7	24.7	Home Health Aides	22,950	N/A
% Persons Age 65+ Living Alone	31.4	30.1			
% Pop. 65+ in Major Cities	23.1	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	44.5	50.1			

State Profile: **North Carolina** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	State Family Caregiver Steering Team
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community Alternatives Program for Disabled Adults (CAP/DA) (MC)	Respite Care Program (SC)
Administering State Agency	NC Department of Health & Human Services, Division of Aging & Adult Services	NC Department of Health & Human Services, Division of Medical Assistance	NC Department of Health & Human Services, Division of Aging & Adult Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	No
Geographic Region Served	Statewide	Statewide	Other
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> County Health Dept. Other gov't. agency Other non-profit agency 	<ul style="list-style-type: none"> AAA Other gov't. agency

■ Funding & Caseload ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> Client contribution State general fund
FY 2001 Expenditures	\$2,916,628	\$181,744 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$3,326,460	\$223,341 (<i>respite only</i>)	\$563,640
FY 2003 Expenditures	\$3,644,249	\$183,297,444 (<i>total waiver</i>)	\$316,102

State Profile: **North Carolina** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
FY 2001 A/D Waiver Respite Participants	N/A	203	N/A
FY 2002 A/D Waiver Respite Participants	N/A	217	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
Caregiver Age Requirement	18+	18+	Either caregiver or care receiver must be 60+
Care Receiver Age Requirement	60+	18+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> OAA guidelines 	<ul style="list-style-type: none"> Nursing home level of care 	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision Physically disabled
Client Population	Family caregiver	Care receiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	Yes	No
Includes Caregiver Assessment	N/A	Yes	N/A
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver physical health Caregiver strain Willingness of caregiver to provide care 	N/A

■ **Services** ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No

State Profile: **North Carolina** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation ▪ Other 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care 	<ul style="list-style-type: none"> ▪ Counseling ▪ Educ. & training ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Support groups
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	No cap	30 days (or 720 hours)/year (in skilled nursing facility)	No cap
Uniform Respite Cap Across Program Sites	N/A	Yes	N/A
Entity that Formulates the Respite Cap	N/A	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	CAP/DA (MC)	Respite Care Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Family members can be paid providers if hired by licensed home care agency 	None
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Respite care

State Profile: **North Dakota**

Selected State Background Characteristics

	ND	US		ND	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	0.6	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	119.0	45,797.2	Caregiving Hours (<i>millions</i>)	66.8	29,182.0
% 60+	18.5	16.3	Value of Caregiving (<i>millions</i>)	\$588.1	\$257,096.0
National Ranking 60+	6	N/A	% Grandchildren living w/grandparents age 65+	1.9	4.4
% White (60+)	97.4	82.3			
% African American (60+)	0.1	8.4			
% Hispanic (60+)	0.3	5.4			
% Asian (60+)	0.2	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	■ Care Receivers ■		
% American Indian/ Alaska Native (60+)	1.7	0.4	% Pop. 21-64 Years w/Disability	15.4	19.2
Pop. 65+ (<i>thousands</i>)	94.5	34,991.8	% Pop. 65+ w/Disability	38.5	41.9
% Pop. 65+	14.7	12.4	% 65+ by Type of Disability		
National Ranking 65+	5	N/A	Sensory	13.8	14.2
Pop. 85+ (<i>thousands</i>)	14.7	4,239.6	Physical	24.1	28.6
% Pop. 85+	2.3	1.5	Self-care	6.4	9.5
National Ranking 85+	1	N/A	Mental	7.8	10.8
			Difficulty Going Outside Home	17.6	20.4
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,204	\$31,632	Certified Nursing Facilities	81	15,162
Median Household Income	\$36,200	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	6.4	1,574.0
% of Pop. 65+ Below Poverty	11.1	10.4	Average Cost Per Day in a Nursing Home	\$195	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	22	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	1,420	N/A
% Persons Age 65+ Living Alone	29.1	30.1			
% Pop. 65+ in Major Cities	17.7	40.1			
Average Household Size	2.4	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	46.5	50.1			

State Profile: **North Dakota** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 1012 (Enacted 2001) Specified that the Department of Human Services determine the requirements related to the acceptance of the federal family caregiver funds, including allowable uses, maintenance of effort and future funding projections.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	No
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Administering State Agency	ND Department of Human Services	ND Department of Human Services	ND Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	Regional Human Service Centers	County Social Service Office	County Social Service Office

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Major Sources of Program Funding	OAA, Title III-E	Medicaid HCBS waiver	State general fund
FY 2001 Expenditures	\$564,300	\$146,213 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$644,212	\$154,037 (<i>respite only</i>)	\$2,058,166
FY 2003 Expenditures	\$705,756	\$5,441,168 (<i>total waiver</i>)	\$779,728

State Profile: **North Dakota** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
FY 2001 A/D Waiver Respite Participants	N/A	73	N/A
FY 2002 A/D Waiver Respite Participants	N/A	80	N/A

■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Caregiver Age Requirement	18+	18+	18+
Care Receiver Age Requirement	60+	18+	18+
Care Receiver Functional Status Requirement	No functional status requirement	Nursing home level of care	3+ ADLs
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Program Assesses	Family caregiver	Care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	No	No
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver physical health ▪ Caregiver social support network ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care ▪ Other 	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes	Yes

State Profile: **North Dakota** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups 	<ul style="list-style-type: none"> ▪ Educ. & training ▪ Respite care 	<ul style="list-style-type: none"> ▪ Cash grant ▪ Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ In-home ▪ Overnight ▪ Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	Yes	Yes	Yes
Respite Cap	\$1900/year	\$550/month	\$550/month
Uniform Respite Cap Across Program Sites	Yes	Yes	Yes
Entity that Formulates the Respite Cap	Administering state agency	Administering state agency	Administering state agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Aged & Disabled Waiver (MC)	Family Home Care (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: **Ohio**

Selected State Background Characteristics

	OH	US		OH	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	11.4	281.4	# of Caregivers (<i>millions</i>)	1.1	27.2
Pop. 60+ (<i>thousands</i>)	1,963.5	45,797.2	Caregiving Hours (<i>millions</i>)	1,186.4	29,182.0
% 60+	17.3	16.3	Value of Caregiving (<i>millions</i>)	\$10,452.5	\$257,096.0
National Ranking 60+	16	N/A	% Grandchildren living w/grandparents age 65+	2.5	4.4
% White (60+)	89.7	82.3			
% African American (60+)	8.4	8.4			
% Hispanic (60+)	0.7	5.4			
% Asian (60+)	0.5	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	■ Care Receivers ■		
% American Indian/ Alaska Native (60+)	0.1	0.4	% Pop. 21-64 Years w/Disability	17.5	19.2
Pop. 65+ (<i>thousands</i>)	1,507.8	34,991.8	% Pop. 65+ w/Disability	41.0	41.9
% Pop. 65+	13.3	12.4	% 65+ by Type of Disability		
National Ranking 65+	15	N/A	Sensory	13.5	14.2
Pop. 85+ (<i>thousands</i>)	176.8	4,239.6	Physical	27.8	28.6
% Pop. 85+	1.6	1.5	Self-care	9.0	9.5
National Ranking 85+	24	N/A	Mental	9.6	10.8
			Difficulty Going Outside Home	19.9	20.4
■ Economic Indicators ■					
Per Capita Income	\$29,944	\$31,632	■ Long-Term Care ■		
Median Household Income	\$42,684	\$42,409	Certified Nursing Facilities	868	15,162
% of Pop. 65+ Below Poverty	7.5	10.4	Certified Nursing Facility Beds (<i>thousands</i>)	82.6	1,574.0
			Average Cost Per Day in a Nursing Home	\$153	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	106	3,407
Households with Individuals 65+ (<i>millions</i>)	1.1	24.7	Home Health Aides	27,220	N/A
% Persons Age 65+ Living Alone	32.1	30.1			
% Pop. 65+ in Major Cities	24.8	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	50.9	50.1			

State Profile: **Ohio** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Administering State Agency	OH Department of Aging	OH Department of Aging	OH Department of Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	No
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA SUA 	<ul style="list-style-type: none"> AAA

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Local/county funds OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Gambling (off-track betting) Medicaid HCBS waiver Nursing facility franchise fees State general fund 	<ul style="list-style-type: none"> Client contribution State general fund
FY 2001 Expenditures	\$4,739,721	n/a	n/a
FY 2002 Expenditures	\$5,358,995	n/a	n/a
FY 2003 Expenditures	\$5,868,769	n/a	n/a

State Profile: **Ohio** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
FY 2001 A/D Waiver Respite Participants	N/A	n/a	N/A
FY 2002 A/D Waiver Respite Participants	N/A	n/a	N/A

■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Caregiver Age Requirement	None	None	None
Care Receiver Age Requirement	60+	60+	None
Care Receiver Functional Status Requirement	▪ OAA guidelines	▪ Nursing home level of care	▪ Diagnosis of dementia or related disorder/requires supervision
Client Population	Family caregiver	Care receiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	Yes	No
Includes Caregiver Assessment	N/A	Yes	N/A
Areas Addressed by Caregiver Assessment	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care 	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No	No

State Profile: **Ohio** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Counseling Educ. & training Emerg. response Home modifications/repairs Homemaker/chore/personal care Info. & assistance Respite care Transportation Other 	<ul style="list-style-type: none"> Care mgt. Counseling Educ. & training Emerg. response Family consult. Family meetings Homemaker/chore/personal care Info. & assistance Respite care Support groups Other
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/Camp 	<ul style="list-style-type: none"> Adult day svcs. In-home 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	PASSPORT HCBS Waiver Program (MC)	Alzheimer's Respite Program (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services Direct payments to family members for the purchase of goods or services Families have a choice of respite providers 	None ¹	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite only Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	No	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Personal care Respite care 	N/A	<ul style="list-style-type: none"> Respite care

¹ As of July 1, 2004, Passport offers a consumer-directed option called Choices. Under this option, family members (excluding spouses and parents) can be paid providers of care.

State Profile: **Oklahoma**

Selected State Background Characteristics

	OK	US		OK	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	3.5	281.4	# of Caregivers (<i>millions</i>)	0.3	27.2
Pop. 60+ (<i>thousands</i>)	599.1	45,797.2	Caregiving Hours (<i>millions</i>)	356.7	29,182.0
% 60+	17.4	16.3	Value of Caregiving (<i>millions</i>)	\$3,142.3	\$257,096.0
National Ranking 60+	13	N/A	% Grandchildren living w/grandparents age 65+	3.1	4.4
% White (60+)	86.6	82.3			
% African American (60+)	4.5	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.3	5.4	% Pop. 21-64 Years w/Disability	21.5	19.2
% Asian (60+)	0.6	2.5	% Pop. 65+ w/Disability	46.7	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	4.4	0.4	Sensory	17.1	14.2
Pop. 65+ (<i>thousands</i>)	456.0	34,991.8	Physical	34.0	28.6
% Pop. 65+	13.2	12.4	Self-care	10.8	9.5
National Ranking 65+	19	N/A	Mental	12.4	10.8
Pop. 85+ (<i>thousands</i>)	57.2	4,239.6	Difficulty Going Outside Home	21.2	20.4
% Pop. 85+	1.7	1.5			
National Ranking 85+	19	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$26,656	\$31,632	Certified Nursing Facilities	364	15,162
Median Household Income	\$36,458	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	31.4	1,574.0
% of Pop. 65+ Below Poverty	10.5	10.4	Average Cost Per Day in a Nursing Home	\$112	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	25	3,407
Households with Individuals 65+ (<i>millions</i>)	0.3	24.7	Home Health Aides	6,410	N/A
% Persons Age 65+ Living Alone	33.0	30.1			
% Pop. 65+ in Major Cities	31.7	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	43.8	50.1			

State Profile: **Oklahoma** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Caregiver Communications Task Force
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Administering State Agency	OK Department of Human Services	OK Department of Human Services	OK Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> Medicaid agency SUA 	<ul style="list-style-type: none"> Medicaid agency SUA

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Local/county funds OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> OAA, Title III-E State general fund
FY 2001 Expenditures	\$1,388,901	\$921,164 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$1,586,096	\$1,105,079 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$1,737,621	\$70,751,956 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	764	N/A
FY 2002 A/D Waiver Respite Participants	N/A	755	N/A

State Profile: **Oklahoma** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Caregiver Age Requirement	None	N/A	18+
Care Receiver Age Requirement	60+	18+	60+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> Nursing home level of care 	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision
Client Population	Family caregiver	Care receiver	Family caregiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Family caregiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Caregiver demographic information Other 	<ul style="list-style-type: none"> Ability of caregiver to provide care Willingness of caregiver to provide care 	<ul style="list-style-type: none"> Ability of caregiver to provide care Caregiver demographic information

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Counseling Educ. & training Emerg. response Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No response	No

State Profile: **Oklahoma** (cont'd)■ **Services** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Respite Cap	\$200 - \$400/quarter	No cap	\$1600/year
Uniform Respite Cap Across Program Sites	No	N/A	Yes
Entity that Formulates the Respite Cap	Administering local agency	N/A	Administering local agency

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Advantage Program (MC)	Respite Resource Network (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> • A voucher or budget for respite only 	None	<ul style="list-style-type: none"> • A menu of services from which caregivers can choose ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	Respite care	Personal care	Respite care

State Profile: **Oregon**

Selected State Background Characteristics

	OR	US		OR	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	3.4	281.4	# of Caregivers (<i>millions</i>)	0.3	27.2
Pop. 60+ (<i>thousands</i>)	569.6	45,797.2	Caregiving Hours (<i>millions</i>)	360.4	29,182.0
% 60+	16.6	16.3	Value of Caregiving (<i>millions</i>)	\$3,175.6	\$257,096.0
National Ranking 60+	27	N/A	% Grandchildren living w/grandparents age 65+	3.2	4.4
% White (60+)	94.0	82.3			
% African American (60+)	0.9	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.6	5.4	% Pop. 21-64 Years w/Disability	18.0	19.2
% Asian (60+)	1.7	2.5	% Pop. 65+ w/Disability	41.5	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.1	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.6	0.4	Sensory	15.5	14.2
Pop. 65+ (<i>thousands</i>)	438.2	34,991.8	Physical	28.8	28.6
% Pop. 65+	12.8	12.4	Self-care	9.0	9.5
National Ranking 65+	25	N/A	Mental	11.2	10.8
Pop. 85+ (<i>thousands</i>)	57.4	4,239.6	Difficulty Going Outside Home	18.0	20.4
% Pop. 85+	1.7	1.5			
National Ranking 85+	18	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,340	\$31,632	Certified Nursing Facilities	135	15,162
Median Household Income	\$41,802	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	12.0	1,574.0
% of Pop. 65+ Below Poverty	6.2	10.4	Average Cost Per Day in a Nursing Home	\$144	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	20	3,407
Households with Individuals 65+ (<i>millions</i>)	0.3	24.7	Home Health Aides	6,700	N/A
% Persons Age 65+ Living Alone	30.8	30.1			
% Pop. 65+ in Major Cities	31.3	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	58.2	50.1			

State Profile: **Oregon** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Caregiver Coalition of Oregon
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Administering State Agency	OR Department of Human Services	OR Department of Human Services	OR Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA SUA 	<ul style="list-style-type: none"> AAA County Health Dept. County Mental Health & DD programs University Extension programs Varies by community

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E 	<ul style="list-style-type: none"> Client contribution Medicaid HCBS waiver State general fund 	<ul style="list-style-type: none"> Local/county funds State general fund
FY 2001 Expenditures	\$1,396,517	n/a	n/a
FY 2002 Expenditures	\$1,578,189	0	n/a

State Profile: **Oregon** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
FY 2003 Expenditures	\$1,728,959	\$264,997,488 (total waiver)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	n/a	N/A
FY 2002 A/D Waiver Respite Participants	N/A	0	N/A

■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Caregiver Age Requirement	None	N/A	None
Care Receiver Age Requirement	60+	18+	None
Care Receiver Functional Status Requirement	OAA guidelines	ADL/IADL combination	No functional status requirement
Client Population	Family caregiver	Care receiver	Family caregiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	No	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Ability of caregiver to provide care Willingness of caregiver to provide care 	N/A	<ul style="list-style-type: none"> Caregiver demographic information Care duration Care frequency

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No

State Profile: **Oregon** (cont'd)■ **Services (cont'd)** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Consum. supplies Consumer health applications Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Consumer health applications Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Cash grant Counseling Educ. & training Info. & assistance Respite care Support groups
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No response	N/A	No
Respite Cap	Varies	No cap	No cap
Uniform Respite Cap Across Program Sites	No	N/A	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Medicaid Waiver/ In-Home Care (MC)	Lifespan Respite Care Networks (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite and/or supplemental services 	Other	<ul style="list-style-type: none"> A menu of services from which caregivers can choose A voucher or budget for respite only Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	No	Yes	No
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> Personal care Respite care Other 	N/A

State Profile: **Pennsylvania**

Selected State Background Characteristics

	PA	US
■ Population ■		
Total Pop. (millions)	12.3	281.4
Pop. 60+ (thousands)	2,430.82	45,797.2
% 60+	19.8	16.3
National Ranking 60+	3	N/A
% White (60+)	91.2	82.3
% 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
% American Indian/ Alaska Native (60+)	0.1	0.4
Pop. 65+ (thousands)	1,919.2	34,991.8
% Pop. 65+	15.6	12.4
National Ranking 65+	2	N/A
Pop. 85+ (thousands)	237.6	4,239.6
% Pop. 85+	1.9	1.5
National Ranking 85+	7	N/A

■ Economic Indicators ■		
Per Capita Income	\$31,998	\$31,632
Median Household Income	\$42,498	\$42,409
% of Pop. 65+ Below Poverty	7.7	10.4

■ Socio-Demographics ■		
Households with Individuals 65+ (<i>millions</i>)	1.3	24.7
% Persons Age 65+ Living Alone	30.7	30.1
% Pop. 65+ in Major Cities	21.2	40.1
Average Household Size	2.5	2.6
Average Family Size	3.0	3.1
% Households with Internet Access	48.7	50.1

	PA	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	1.2	27.2
Caregiving Hours (<i>millions</i>)	1,316.7	29,182.0
Value of Caregiving (<i>millions</i>)	\$11,600.5	\$257,096.0
% Grandchildren living w/grandparents age 65+	2.8	4.4

■ Care Receivers ■		
% Pop. 21-64 Years w/Disability	17.5	19.2
% Pop. 65+ w/Disability	39.4	41.9
% 65+ by Type of Disability		
Sensory	12.8	14.2
Physical	25.9	28.6
Self-care	8.5	9.5
Mental	9.0	10.8
Difficulty Going Outside Home	19.7	20.4

■ Long-Term Care ■		
Certified Nursing Facilities	694	15,162
Certified Nursing Facility Beds (<i>thousands</i>)	85.4	1,574.0
Average Cost Per Day in a Nursing Home	\$181	\$158
Licensed Adult Day Facilities	208	3,407
Home Health Aides	23,150	N/A

State Profile: **Pennsylvania** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 648 (Enacted 2003) Appropriated funds to the Family Caregiver Support Program SB 5 (Enacted 2002) No bill information available. SB 1 (Enacted 2001) No bill information available.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	PA Department of Aging 60+ Medicaid Waiver (PDA Waiver) (MC)	PA Family Caregiver Support Program (PA FCSP) (SC)	OPTIONS (SC)	BRIDGE (SC)
Administering State Agency	PA Department of Aging	PA Department of Aging	PA Department of Aging	PA Department of Aging	PA Department of Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA	AAA	AAA	AAA

State Profile: **Pennsylvania** (cont'd)

■ Funding & Caseload ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Lottery funds OAA, Title III-E State general fund Title XX Tobacco fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver Tobacco fund 	<ul style="list-style-type: none"> Client contribution State general fund 	<ul style="list-style-type: none"> Client contribution Lottery funds OAA, Title III-E State general fund Title XX 	<ul style="list-style-type: none"> Client contribution Tobacco fund
FY 2001 Expenditures	\$6,097,763	\$2,450,901 (<i>respite only</i>)	\$11,461,000	n/a	n/a
FY 2002 Expenditures	\$6,973,272	\$3,461,069 (<i>respite only</i>)	\$11,461,000	n/a	n/a
FY 2003 Expenditures	\$7,639,454	\$111,035,656 (<i>total waiver</i>)	\$11,461,000	n/a	n/a
FY 2001 A/D Waiver Respite Participants	N/A	600	N/A	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	821	N/A	N/A	N/A

■ Eligibility ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
Caregiver Age Requirement	18+	18+	18+	18+	18+
Care Receiver Age Requirement	60+	60+	18+	18+	60+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 1 ADL 	<ul style="list-style-type: none"> Nursing home level of care 	<ul style="list-style-type: none"> 2 ADL Diagnosis of dementia or related disorder/ requires supervision (if under 60) 	<ul style="list-style-type: none"> No response 	<ul style="list-style-type: none"> Nursing home level of care
Client Population	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver	Care receiver	Care receiver

■ Assessment ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes	Yes	Yes

State Profile: **Pennsylvania** (cont'd)■ **Assessment** (cont'd) ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/ depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes	Yes	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Home modification/ repairs ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Counseling ▪ Educ. & training ▪ Home modification/ repairs ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Info. & assistance ▪ Respite care 	<ul style="list-style-type: none"> ▪ Info. & assistance ▪ Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/Camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	Yes	No	No
Respite Cap	No cap	No cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A	N/A	N/A

State Profile: **Pennsylvania** (cont'd)■ **Consumer Direction** ■

Program Name	FCSP (FC)	PDA Waiver (MC)	PA FCSP (SC)	OPTIONS (SC)	BRIDGE (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ Direct reimbursements to family members for the purchase of goods or services 	<ul style="list-style-type: none"> ▪ Consumer-directed attendant care 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Consumer-directed attendant care 	<ul style="list-style-type: none"> ▪ Consumer-directed attendant care
Family Members Can Be Paid to Provide Care	No	No	No	No	No
Types of Services Families Can Be Paid to Provide	N/A	N/A	N/A	N/A	N/A

State Profile: Rhode Island

Selected State Background Characteristics

	RI	US		RI	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.0	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	191.4	45,797.2	Caregiving Hours (<i>millions</i>)	111.6	29,182.0
% 60+	18.3	16.3	Value of Caregiving (<i>millions</i>)	\$982.8	\$257,096.0
National Ranking 60+	8	N/A	% Grandchildren living w/grandparents age 65+	3.3	4.4
% White (60+)	93.0	82.3			
% African American (60+)	2.0	8.4	■ Care Receivers ■		
% Hispanic (60+)	2.3	5.4	% Pop. 21-64 Years w/Disability	19.7	19.2
% Asian (60+)	0.9	2.5	% Pop. 65+ w/Disability	40.3	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	13.3	14.2
Pop. 65+ (<i>thousands</i>)	152.4	34,991.8	Physical	25.7	28.6
% Pop. 65+	14.5	12.4	Self-care	7.9	9.5
National Ranking 65+	6	N/A	Mental	8.9	10.8
Pop. 85+ (<i>thousands</i>)	20.9	4,239.6	Difficulty Going Outside Home	19.4	20.4
% Pop. 85+	2.0	1.5			
National Ranking 85+	5	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$31,916	\$31,632	Certified Nursing Facilities	83	15,162
Median Household Income	\$42,417	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	8.3	1,574.0
% of Pop. 65+ Below Poverty	12.6	10.4	Average Cost Per Day in a Nursing Home	\$190	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	18	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	N/A	N/A
% Persons Age 65+ Living Alone	33.0	30.1			
% Pop. 65+ in Major Cities	37.6	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	53.1	50.1			

State Profile: **Rhode Island** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Partners in CaRing (FC)	Home and Community-Based Waiver (MC)
Administering State Agency	RI Department of Elderly Affairs	RI Department of Elderly Affairs
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	Grantee agencies	SUA

■ **Funding & Caseload** ■

Program Name	Partners in CaRing (FC)	Home and Community-Based Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution Federal A/D Grants to States OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund
FY 2001 Expenditures	\$564,300	n/a
FY 2002 Expenditures	\$644,212	n/a
FY 2003 Expenditures	\$705,756	\$2,910,658 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	n/a
FY 2002 A/D Waiver Respite Participants	N/A	n/a

State Profile: **Rhode Island** (cont'd)■ **Eligibility** ■

Program Name	Partners in CaRIing (FC)	Home and Community-Based Waiver (MC)
Caregiver Age Requirement	None	None
Care Receiver Age Requirement	60+	65+
Care Receiver Functional Status Requirement	OAA guidelines	Nursing home level of care
Client Population	Both family caregiver and care receiver	Care receiver

■ **Assessment** ■

Program Name	Partners in CaRIing (FC)	Home and Community-Based Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Partners in CaRIing (FC)	Home and Community-Based Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Educ. & training ▪ Family consult. ▪ Family meetings ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Other 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Family consult. ▪ Info. & assistance
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight 	None
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A
Respite Cap	<ul style="list-style-type: none"> ▪ 120 units/year (for non-Alzheimer's disease caregivers) ▪ 240 units/year (for Alzheimer's disease caregivers) 	N/A
Uniform Respite Cap Across Program Sites	Yes	N/A
Entity that Formulates the Respite Cap	Administering local agency and SUA in partnership	N/A

State Profile: **Rhode Island** (cont'd)■ **Consumer Direction** ■

Program Name	Partners in CaRIing (FC)	Home and Community-Based Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	None
Family Members Can Be Paid to Provide Care	Yes	No
Types of Services Families Can Be Paid to Provide	Respite care	N/A

State Profile: South Carolina

Selected State Background Characteristics

	SC	US
■ Population ■		
Total Pop. (millions)	4.0	281.4
Pop. 60+ (thousands)	651.5	45,797.2
% 60+	16.2	16.3
National Ranking 60+	30	N/A
% White (60+)	76.8	82.3
% African American (60+)	21.5	8.4
% Hispanic (60+)	0.6	5.4
% Asian (60+)	0.4	2.5
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1
% American Indian/ Alaska Native (60+)	0.2	0.4
Pop. 65+ (thousands)	485.3	34,991.8
% Pop. 65+	12.1	12.4
National Ranking 65+	32	N/A
Pop. 85+ (thousands)	50.3	4,239.6
% Pop. 85+	1.3	1.5
National Ranking 85+	44	N/A

■ Economic Indicators ■		
Per Capita Income	\$26,132	\$31,632
Median Household Income	\$37,812	\$42,409
% of Pop. 65+ Below Poverty	14.7	10.4

■ Socio-Demographics ■		
Households with Individuals 65+ (<i>millions</i>)	0.3	24.7
% Persons Age 65+ Living Alone	31.1	30.1
% Pop. 65+ in Major Cities	8.3	40.1
Average Household Size	2.5	2.6
Average Family Size	3.0	3.1
% Households with Internet Access	45.0	50.1

	SC	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	0.4	27.2
Caregiving Hours (<i>millions</i>)	419.0	29,182.0
Value of Caregiving (<i>millions</i>)	\$3,691.5	\$257,096.0
% Grandchildren living w/grandparents age 65+	4.5	4.4

■ Care Receivers ■		
% Pop. 21-64 Years w/Disability	22.7	19.2
% Pop. 65+ w/Disability	45.8	41.9
% 65+ by Type of Disability		
Sensory	15.4	14.2
Physical	32.1	28.6
Self-care	11.6	9.5
Mental	13.4	10.8
Difficulty Going Outside Home	23.0	20.4

■ Long-Term Care ■		
Certified Nursing Facilities	163	15,162
Certified Nursing Facility Beds (<i>thousands</i>)	16.2	1,574.0
Average Cost Per Day in a Nursing Home	\$128	\$158
Licensed Adult Day Facilities	83	3,407
Home Health Aides	6,440	N/A

State Profile: **South Carolina** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
Administering State Agency	SC Department of Health & Human Services	SC Department of Health & Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA State fund grants to local entities 	<ul style="list-style-type: none"> Medicaid agency

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver State general fund
FY 2001 Expenditures	\$1,421,896	\$268,543 (<i>respite only</i>)
FY 2002 Expenditures	\$1,646,884	\$203,071 (<i>respite only</i>)
FY 2003 Expenditures	\$1,804,217	\$78,068,061 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	316
FY 2002 A/D Waiver Respite Participants	N/A	227

State Profile: **South Carolina** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
Caregiver Age Requirement	18+	None
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	2 ADLs	Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver physical health ▪ If family caregivers are providing long-distance caregiving ▪ Financial situation ▪ Other 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care frequency ▪ Caregiver social support network

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Access assistance ▪ Counseling ▪ Educ. & training ▪ Respite care ▪ Supplemental services 	<ul style="list-style-type: none"> ▪ Care mgt. ▪ Family consult. ▪ Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ Companion services ▪ Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	No
Respite Cap	<ul style="list-style-type: none"> ▪ \$500/year (average) 	<ul style="list-style-type: none"> ▪ 21 days/year (residential care facility) ▪ 14 days/year (skilled nursing facility)
Uniform Respite Cap Across Program Sites	No	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency

State Profile: **South Carolina** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Elderly/Disabled Home and Community-Based Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care

State Profile: **South Dakota**

Selected State Background Characteristics

	SD	US		SD	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	0.8	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	136.9	45,797.2	Caregiving Hours (<i>millions</i>)	76.8	29,182.0
% 60+	18.1	16.3	Value of Caregiving (<i>millions</i>)	\$676.9	\$257,096.0
National Ranking 60+	9	N/A	% Grandchildren living w/grandparents age 65+	0.8	4.4
% White (60+)	95.9	82.3			
% African American (60+)	0.1	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.4	5.4	% Pop. 21-64 Years w/Disability	15.6	19.2
% Asian (60+)	0.2	2.5	% Pop. 65+ w/Disability	39.5	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	3.0	0.4	Sensory	14.5	14.2
Pop. 65+ (<i>thousands</i>)	108.1	34,991.8	Physical	26.0	28.6
% Pop. 65+	14.3	12.4	Self-care	6.7	9.5
National Ranking 65+	8	N/A	Mental	7.6	10.8
Pop. 85+ (<i>thousands</i>)	16.1	4,239.6	Difficulty Going Outside Home	17.0	20.4
% Pop. 85+	2.1	1.5			
National Ranking 85+	3	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,234	\$31,632	Certified Nursing Facilities	101	15,162
Median Household Income	\$37,873	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	6.8	1,574.0
% of Pop. 65+ Below Poverty	14.4	10.4	Average Cost Per Day in a Nursing Home	\$119	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	6	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	760	N/A
% Persons Age 65+ Living Alone	36.3	30.1			
% Pop. 65+ in Major Cities	20.0	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	47.6	50.1			

State Profile: **South Dakota** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Administering State Agency	SD Department of Social Services	SD Department of Social Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> SUA 	<ul style="list-style-type: none"> Medicaid agency SUA

■ **Funding & Caseload** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver
FY 2001 Expenditures	\$564,300	\$111,403 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	n/a
FY 2003 Expenditures	\$705,756	\$3,330,821 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	212
FY 2002 A/D Waiver Respite Participants	N/A	n/a

State Profile: **South Dakota** (cont'd)■ **Eligibility** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Caregiver Age Requirement	None	N/A
Care Receiver Age Requirement	60+	65+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Other 	<ul style="list-style-type: none"> ▪ Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Care duration ▪ Care frequency ▪ Type of care (provided)

■ **Services** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	No response
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Educ. & training ▪ Emerg. response ▪ Family consult. ▪ Family meetings ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Legal and/or financial consultation ▪ Respite care ▪ Support groups ▪ Transportation ▪ Other 	<ul style="list-style-type: none"> ▪ Consum. supplies ▪ Emerg. response ▪ Homemaker/chore/personal care ▪ Respite care ▪ Other

State Profile: **South Dakota** (cont'd)■ **Services** (cont'd) ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp ▪ Other 	<ul style="list-style-type: none"> ▪ Adult Day svcs.
Caregiver Must Live with Care Receiver to Receive Respite	Yes	N/A
Respite Cap	\$4000/year	No cap
Uniform Respite Cap Across Program Sites	Yes	N/A
Entity that Formulates the Respite Cap	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	Caregiver Program (FC)	Home and Community-Based Elderly Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Families have a choice of respite providers 	No response
Family Members Can Be Paid to Provide Care	Yes	No
Types of Services Families Can Be Paid to Provide	Respite care	N/A

State Profile: **Tennessee**

Selected State Background Characteristics

	TN	US		TN	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.7	281.4	# of Caregivers (<i>millions</i>)	0.6	27.2
Pop. 60+ (<i>thousands</i>)	942.6	45,797.2	Caregiving Hours (<i>millions</i>)	600.4	29,182.0
% 60+	16.6	16.3	Value of Caregiving (<i>millions</i>)	\$5,289.2	\$257,096.0
National Ranking 60+	28	N/A	% Grandchildren living w/grandparents age 65+	2.3	4.4
% White (60+)	87.7	82.3			
% African American (60+)	10.6	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.5	5.4	% Pop. 21-64 Years w/Disability	21.9	19.2
% Asian (60+)	0.4	2.5	% Pop. 65+ w/Disability	47.8	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	16.5	14.2
Pop. 65+ (<i>thousands</i>)	703.3	34,991.8	Physical	34.3	28.6
% Pop. 65+	12.4	12.4	Self-care	12.1	9.5
National Ranking 65+	29	N/A	Mental	14.3	10.8
Pop. 85+ (<i>thousands</i>)	81.5	4,239.6	Difficulty Going Outside Home	17.0	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	33	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$28,455	\$31,632	Certified Nursing Facilities	314	15,162
Median Household Income	\$37,030	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	34.1	1,574.0
% of Pop. 65+ Below Poverty	14.4	10.4	Average Cost Per Day in a Nursing Home	\$125	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	28	3,407
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Home Health Aides	7,470	N/A
% Persons Age 65+ Living Alone	32.7	30.1			
% Pop. 65+ in Major Cities	47.4	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	44.8	50.1			

State Profile: **Tennessee** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	HB 448 (Enacted 2003) Power of attorney law to facilitate extended family members who are caring for related children and allows parents to delegate temporary authority for children to receive public benefits without terminating parental rights.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Home and Community-Based Long-Term Care for Non-Medicaid Elderly and Adults with Disabilities (HCB LTC) (SC)
Administering State Agency	TN Commission on Aging & Disability	TN Commission on Aging & Disability
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No response
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	HCB LTC (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Federal A/D Grants to States OAA, Title III-E 	<ul style="list-style-type: none"> State general fund
FY 2001 Expenditures	\$2,083,754	n/a
FY 2002 Expenditures	\$2,417,677	n/a
FY 2003 Expenditures	\$2,648,646	n/a
FY 2001 A/D Waiver Respite Participants	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	N/A

State Profile: **Tennessee** (cont'd)■ **Eligibility** ■

Program Name	FCSP (FC)	HCB LTC (SC)
Caregiver Age Requirement	None	18+
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision ▪ Physically disabled 	<ul style="list-style-type: none"> ▪ 1 ADL
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	HCB LTC (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	No	Yes
Includes Caregiver Assessment	N/A	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	FCSP (FC)	HCB LTC (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	No response
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> ▪ Assistive technology ▪ Care mgt. ▪ Consum. supplies ▪ Counseling ▪ Educ. & training ▪ Emerg. response ▪ Home modification/repairs ▪ Homemaker/chore/personal care ▪ Info. & assistance ▪ Respite care ▪ Support groups 	No response
Types of Respite Care Offered	<ul style="list-style-type: none"> ▪ Adult day svcs. ▪ In-home ▪ Overnight ▪ Weekend/camp 	None
Caregiver Must Live with Care Receiver to Receive Respite	N/A	N/A
Respite Cap	Varies by Planning and Service Area	N/A
Uniform Respite Cap Across Program Sites	No	N/A
Entity that Formulates the Respite Cap	Administering local agency	N/A

State Profile: **Tennessee** (cont'd)

■ **Consumer Direction** ■

Program Name	FCSP (FC)	HCBS LTC (SC)
Consumer-Directed Options	A voucher or budget for respite and/or supplemental services	A voucher or budget for respite and/or supplemental services
Family Members Can Be Paid to Provide Care	No	No
Types of Services Families Can Be Paid to Provide	N/A	N/A

State Profile: **Texas**

Selected State Background Characteristics

	TX	US		TX	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	20.9	281.4	# of Caregivers (<i>millions</i>)	1.9	27.2
Pop. 60+ (<i>thousands</i>)	2,774.2	45,797.2	Caregiving Hours (<i>millions</i>)	2,067.2	29,182.0
% 60+	13.3	16.3	Value of Caregiving (<i>millions</i>)	\$18,211.9	\$257,096.0
National Ranking 60+	47	N/A	% Grandchildren living w/grandparents age 65+	6.7	4.4
% White (60+)	71.2	82.3			
% African American (60+)	8.6	8.4	■ Care Receivers ■		
% Hispanic (60+)	17.6	5.4	% Pop. 21-64 Years w/Disability	19.9	19.2
% Asian (60+)	1.5	2.5	% Pop. 65+ w/Disability	44.8	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	15.4	14.2
Pop. 65+ (<i>thousands</i>)	2,072.5	34,991.8	Physical	31.5	28.6
% Pop. 65+	9.9	12.4	Self-care	11.2	10.8
National Ranking 65+	47	N/A	Mental	12.1	9.5
Pop. 85+ (<i>thousands</i>)	237.9	4,239.6	Difficulty Going Outside Home	22.0	20.4
% Pop. 85+	1.1	1.5			
National Ranking 85+	46	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$29,372	\$31,632	Certified Nursing Facilities	1,096	15,162
Median Household Income	\$40,149	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	106.6	1,574.0
% of Pop. 65+ Below Poverty	15.4	10.4	Average Cost Per Day in a Nursing Home	\$118	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	297	3,407
Households with Individuals 65+ (<i>millions</i>)	1.5	24.7	Home Health Aides	50,870	N/A
% Persons Age 65+ Living Alone	26.8	30.1			
% Pop. 65+ in Major Cities	46.6	40.1			
Average Household Size	2.7	2.6			
Average Family Size	3.3	3.1			
% Households with Internet Access	47.7	50.1			

State Profile: **Texas** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 297 (Enacted 2001) Lowered the age at which someone could qualify as a grandparent caregiver under the Temporary Assistance for Needy Families (TANF) from age 50 to age 45. The Legislature also raised the income eligibility criteria from 100 percent of the federal poverty level (FPL) to 200 percent of the FPL.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community-Based Alternatives (CBA) (MC)	Respite Care Program (RCP) (SC)	In-Home and Family Support Program (IHFS) (SC)
Administering State Agency	TX Department on Aging ¹	TX Department of Human Services	TX Department of Human Services	TX Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	No	No	Yes	No
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	▪ AAA	▪ Medicaid agency	▪ Medicaid agency ▪ Provider agencies	▪ Medicaid agency

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
Major Sources of Program Funding	▪ OAA, Title III-E ▪ State general fund	▪ Medicaid HCBS waiver ▪ State general fund	▪ State general fund ▪ FY 2004/2005 funding not appropriated by the legislature	▪ State general fund

¹ Effective September 1, 2004, the Texas Department of Aging will become the Texas Department of Aging and Disabilities.

State Profile: **Texas** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
FY 2001 Expenditures	\$6,147,379	\$1,789,864 (respite only)	n/a	n/a
FY 2002 Expenditures	\$7,087,631	\$2,205,063 (respite only)	\$1,328,781	n/a
FY 2003 Expenditures	\$7,764,738	\$460,761,123 (total waiver)	\$1,107,311	n/a
FY 2001 A/D Waiver Respite Participants	N/A	1,044	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	1,299	N/A	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
Caregiver Age Requirement	None	N/A	None	None
Care Receiver Age Requirement	60+	21+	18+	Other
Care Receiver Functional Status Requirement	▪ OAA guidelines	▪ Nursing home level of care	▪ Diagnosis of dementia or related disorder/requires supervision ▪ Other	▪ 1 ADL ▪ 1 IADL
Client Population	Both family caregiver and care receiver	Care receiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes	No	No
Includes Caregiver Assessment	No	No	N/A	N/A
Areas Addressed by Caregiver Assessment	N/A	N/A	N/A	N/A

■ **Services** ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A	Yes	Yes

State Profile: **Texas** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Homemaker/chore/personal care Respite care 	<ul style="list-style-type: none"> Cash grant
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	No	Yes	Yes
Respite Cap	No cap	720 hours/year	336 hours/year	No cap
Uniform Respite Cap Across Program Sites	N/A	Yes	Yes	N/A
Entity that Formulates the Respite Cap	N/A	Administering state agency	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	CBA (MC)	RCP (SC)	IHFSP (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A voucher or budget for respite only 	<ul style="list-style-type: none"> Consumer-directed attendant care Families have a choice of respite providers 	None	<ul style="list-style-type: none"> Direct payments to family members for the purchase of goods or services
Family Members Can Be Paid to Provide Care	Yes	Yes	No	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Personal care Respite care 	N/A	N/A

State Profile: **Utah**

Selected State Background Characteristics

	UT	US		UT	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	2.2	281.4	# of Caregivers (<i>millions</i>)	0.2	27.2
Pop. 60+ (<i>thousands</i>)	252.7	45,797.2	Caregiving Hours (<i>millions</i>)	204.7	29,182.0
% 60+	11.3	16.3	Value of Caregiving (<i>millions</i>)	\$1,803.4	\$257,096.0
National Ranking 60+	50	N/A	% Grandchildren living w/grandparents age 65+	4.5	4.4
% White (60+)	93.5	82.3			
% African American (60+)	0.4	8.4	■ Care Receivers ■		
% Hispanic (60+)	3.4	5.4	% Pop. 21-64 Years w/Disability	15.4	19.2
% Asian (60+)	1.3	2.5	% Pop. 65+ w/Disability	39.9	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.3	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.6	0.4	Sensory	15.4	14.2
Pop. 65+ (<i>thousands</i>)	190.2	34,991.8	Physical	26.8	28.6
% Pop. 65+	8.5	12.4	Self-care	7.9	9.5
National Ranking 65+	50	N/A	Mental	10.0	10.8
Pop. 85+ (<i>thousands</i>)	21.8	4,239.6	Difficulty Going Outside Home	17.9	20.4
% Pop. 85+	1.0	1.5			
National Ranking 85+	49	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$24,977	\$31,632	Certified Nursing Facilities	89	15,162
Median Household Income	\$47,861	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	7.2	1,574.0
% of Pop. 65+ Below Poverty	12.4	10.4	Average Cost Per Day in a Nursing Home	\$131	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	8	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	2,110	N/A
% Persons Age 65+ Living Alone	22.8	30.1			
% Pop. 65+ in Major Cities	31.6	40.1			
Average Household Size	3.1	2.6			
Average Family Size	3.6	3.1			
% Households with Internet Access	54.1	50.1			

State Profile: **Utah** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Utah Coalition for Caregiver Support
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Caregiver Support Program (CSP) (FC)	Medicaid Aging Waiver (MAW) (MC)	Home and Community-Based Alternatives (HCBA) (SC)
Administering State Agency	UT Department of Human Services	UT Department of Human Services	UT Department of Human Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	AAA	AAA

■ Funding & Caseload ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> ▪ OAA, Title III-E ▪ State general fund 	<ul style="list-style-type: none"> ▪ Medicaid HCBS waiver 	<ul style="list-style-type: none"> ▪ State general fund
FY 2001 Expenditures	\$573,563	\$208,287 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$658,988	\$191,248 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$721,945	\$2,623,436 (<i>total waiver</i>)	n/a
FY 2001 A/D Waiver Respite Participants	N/A	142	N/A
FY 2002 A/D Waiver Respite Participants	N/A	128	N/A

State Profile: **Utah** (cont'd)■ **Eligibility** ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
Caregiver Age Requirement	None	None	None
Care Receiver Age Requirement	60+	65+	18+
Care Receiver Functional Status Requirement	2 ADLs	Nursing home level of care	ADL/IADL combination
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
Program Assesses	Both family caregiver and care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver physical health ▪ Emergency plan ▪ Need for education/training ▪ Willingness of caregiver to provide care 	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care frequency ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	No

State Profile: **Utah** (cont'd)■ **Services** (cont'd) ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Home modification/repairs Homemaker/chore/personal care Info. & assistance Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Educ. & training Emerg. response Family consult. Homemaker/chore/personal care Home modification/repairs Info. & assistance Respite care Support groups
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	No	No
Respite Cap	\$1500/year	No cap	No response
Uniform Respite Cap Across Program Sites	Yes	N/A	N/A
Entity that Formulates the Respite Cap	Administering state agency	N/A	N/A

■ **Consumer Direction** ■

Program Name	CSP (FC)	MAW (MC)	HCBA (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A menu of services from which caregivers can choose Families have a choice of respite providers 	None	None
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Personal care Respite care 	<ul style="list-style-type: none"> Any service needed Personal care Respite care

State Profile: **Vermont**

Selected State Background Characteristics

	VT	US		VT	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	0.6	281.4	# of Caregivers (<i>millions</i>)	0.1	27.2
Pop. 60+ (<i>thousands</i>)	101.8	45,797.2	Caregiving Hours (<i>millions</i>)	64.8	29,182.0
% 60+	16.7	16.3	Value of Caregiving (<i>millions</i>)	\$571.0	\$257,096.0
National Ranking 60+	25	N/A	% Grandchildren living w/grandparents age 65+	3.2	4.4
% White (60+)	98.3	82.3			
% African American (60+)	0.2	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.4	5.4	% Pop. 21-64 Years w/Disability	16.2	19.2
% Asian (60+)	0.3	2.5	% Pop. 65+ w/Disability	38.6	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.2	0.4	Sensory	14.8	14.2
Pop. 65+ (<i>thousands</i>)	77.5	34,991.8	Physical	25.8	28.6
% Pop. 65+	12.7	12.4	Self-care	8.1	9.5
National Ranking 65+	26	N/A	Mental	9.6	10.8
Pop. 85+ (<i>thousands</i>)	10.0	4,239.6	Difficulty Going Outside Home	16.7	20.4
% Pop. 85+	1.6	1.5			
National Ranking 85+	20	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,740	\$31,632	Certified Nursing Facilities	37	15,162
Median Household Income	\$42,999	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	3.0	1,574.0
% of Pop. 65+ Below Poverty	8.4	10.4	Average Cost Per Day in a Nursing Home	\$187	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	20	3,407
Households with Individuals 65+ (<i>millions</i>)	0.1	24.7	Home Health Aides	1,500	N/A
% Persons Age 65+ Living Alone	31.3	30.1			
% Pop. 65+ in Major Cities	0.0	40.1			
Average Household Size	2.4	2.6			
Average Family Size	3.0	3.1			
% Households with Internet Access	53.4	50.1			

State Profile: **Vermont** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
Administering State Agency	VT Department of Aging & Disabilities	VT Department of Aging & Disabilities
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> AAA Certified home health agencies

■ Funding & Caseload ■

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Local/county funds OAA, Title III-E State general fund 	<ul style="list-style-type: none"> Medicaid HCBS waiver
FY 2001 Expenditures	\$564,300	\$688,713 (<i>respite only</i>)
FY 2002 Expenditures	\$644,212	\$1,016,930 (<i>respite only</i>)
FY 2003 Expenditures	\$705,756	\$23,441,790 (<i>total waiver</i>)
FY 2001 A/D Waiver Respite Participants	N/A	361
FY 2002 A/D Waiver Respite Participants	N/A	451

State Profile: **Vermont** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
Caregiver Age Requirement	None	N/A
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> Diagnosed with Alzheimer's or cognitive impairment and/or requiring supervision OAA guidelines 	Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	Yes	No
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Ability of caregiver to provide care Care frequency Caregiver mental health/depression Caregiver physical health Caregiver strain 	N/A

■ **Services** ■

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Care mgt. Cash grant Counseling Educ. & training Family meetings Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight
Caregiver Must Live with Care Receiver to Receive Respite	No	No response
Respite Cap	\$100 - \$1500+/year (average)	720 hours/year
Uniform Respite Cap Across Program Sites	No	Yes
Entity that Formulates the Respite Cap	Administering local agency	Administering state agency

State Profile: **Vermont** (cont'd)■ **Consumer Direction** ■

Program Name	Family Caregiver Support Program (FC)	Home-Based Medicaid Waiver (MC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite only ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ Consumer-directed attendant care ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Respite care 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: **Virginia**

Selected State Background Characteristics

	VA	US
■ Population ■		
Total Pop. (millions)	7.1	281.4
Pop. 60+ (thousands)	1,065.5	45,797.2
% 60+	15.1	16.3
National Ranking 60+	43	N/A
% White (60+)	80.1	82.3
% African American (60+)	0.2	8.4
% Hispanic (60+)	1.3	5.4
% Asian (60+)	2.1	2.5
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1
% American Indian/ Alaska Native (60+)	0.2	0.4
Pop. 65+ (thousands)	792.3	34,991.8
% Pop. 65+	11.2	12.4
National Ranking 65+	44	N/A
Pop. 85+ (thousands)	87.3	4,239.6
% Pop. 85+	1.2	1.5
National Ranking 85+	45	N/A

■ Economic Indicators ■		
Per Capita Income	\$33,671	\$31,632
Median Household Income	\$49,631	\$42,409
% of Pop. 65+ Below Poverty	9.8	10.4

■ Socio-Demographics ■		
Households with Individuals 65+ (<i>millions</i>)	0.6	24.7
% Persons Age 65+ Living Alone	30.5	30.1
% Pop. 65+ in Major Cities	29.2	40.1
Average Household Size	2.5	2.6
Average Family Size	3.0	3.1
% Households with Internet Access	54.9	50.1

	VA	US
■ Informal Caregivers ■		
# of Caregivers (<i>millions</i>)	0.7	27.2
Caregiving Hours (<i>millions</i>)	745.9	29,182.0
Value of Caregiving (<i>millions</i>)	\$6,571.2	\$257,096.0
% Grandchildren living w/grandparents age 65+	4.9	4.4

■ Care Receivers ■		
% Pop. 21-64 Years w/Disability	17.5	19.2
% Pop. 65+ w/Disability	42.1	41.9
% 65+ by Type of Disability		
Sensory	13.7	14.2
Physical	29.1	28.6
Self-care	10.1	9.5
Mental	11.1	10.8
Difficulty Going Outside Home	20.7	20.4

■ Long-Term Care ■		
Certified Nursing Facilities	239	15,162
Certified Nursing Facility Beds (thousands)	26.1	1,574.0
Average Cost Per Day in a Nursing Home	\$138	\$158
Licensed Adult Day Facilities	47	3,407
Home Health Aides	9,390	N/A

State Profile: **Virginia** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	Yes
Name of Task Force:	Virginia Caregiver Coalition
Single Point of Entry for State System of HCBS	Lack of agreement
Single Point of Entry Includes Access to State's Caregiver Support Program	Lack of agreement
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Lack of agreement
Assessment Includes Caregiver Component	Lack of agreement
At Least One State Program With Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Elderly and Disabled Waiver (EDW) (MC)	Caregiver Grant Program ¹ (CGP) (SC)	Respite Care Initiative Grant (RCIG) (SC)	Respite Care Grant Program 2003 (RCGP) (SC)
Administering State Agency	VA Department for the Aging	VA Department of Medical Assistance Services	VA Department of Social Services	VA Department for the Aging	VA Department for the Aging
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide	Other	Other
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA 	<ul style="list-style-type: none"> County Health Dept. 	<ul style="list-style-type: none"> Department of Social Services 	<ul style="list-style-type: none"> AAA Adult Care of Central Virginia Commonwealth Catholic Charities 	<ul style="list-style-type: none"> AAA Alz. Family Day Center Bedford Hospital

¹ Program operational during study period but no longer funded.

State Profile: **Virginia** (cont'd)■ **Funding & Caseload** ■

Program Name	FCSP (FC)	EDW (MC)	CGP (SC)	RCIG (SC)	RCGP (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver Real Choice Systems Change Grants State general fund 	<ul style="list-style-type: none"> State general fund 	<ul style="list-style-type: none"> Client contribution Local/county funds State general fund 	<ul style="list-style-type: none"> Client contribution State general fund Other public and/or private resources
FY 2001 Expenditures	\$2,354,500	\$1,423,711 (respite only)	n/a	n/a	n/a
FY 2002 Expenditures	\$2,728,115	\$3,098,046 (respite only)	n/a	n/a	n/a
FY 2003 Expenditures	\$2,988,742	\$73,720,666 (total waiver)	n/a	n/a	n/a
FY 2001 A/D Waiver Respite Participants	N/A	911	N/A	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	n/a	N/A	N/A	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	EDW (MC)	CGP (SC)	RCIG (SC)	RCGP (SC)
Caregiver Age Requirement	None	18+	18+	None	None
Care Receiver Age Requirement	60+	None	None	60+	Other
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> No functional status requirement 	<ul style="list-style-type: none"> Nursing home level of care 	<ul style="list-style-type: none"> 2 ADLs 	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/ requires supervision 	<ul style="list-style-type: none"> Nursing home level of care Physically disabled Other
Client Population	Care receiver	No response	Family caregiver	Both family caregiver and care receiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	EDW (MC)	CGP (SC)	RCIG (SC)	RCGP (SC)
Program Assesses	Care receiver	Care receiver	Care receiver	Care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes	No	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	N/A	Yes	No
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> Caregiver demographic information If family caregivers are providing long-distance caregiving Other 	<ul style="list-style-type: none"> Ability of caregiver to provide care Care duration Care frequency Caregiver demographic information Caregiver strain Willingness of caregiver to provide care 	N/A	<ul style="list-style-type: none"> Caregiver strain 	N/A

State Profile: **Virginia** (cont'd)■ **Services** ■

Program Name	FCSP (FC)	EDW (MC)	CGP (SC)	RCIG (SC)	RCGP (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes	Yes	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Consum. supplies Counseling Educ. & training Emerg. response Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Care mgt. Educ. & training Homemaker/chore/personal care Respite care 	<ul style="list-style-type: none"> Cash grant 	<ul style="list-style-type: none"> Homemaker/chore/personal care Respite care Other 	<ul style="list-style-type: none"> Respite care Transportation
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/Camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/Camp Other 	None	<ul style="list-style-type: none"> Adult day svcs. In-home Other 	<ul style="list-style-type: none"> Adult day svcs. Other
Caregiver Must Live with Care Receiver to Receive Respite	No	Yes	N/A	Yes	No
Respite Cap	No cap	720 hours/year	N/A	35 hours/month	No cap
Uniform Respite Cap Across Program Sites	N/A	Yes	N/A	Yes	N/A
Entity that Formulates the Respite Cap	N/A	Administering state agency	N/A	Administering state agency	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	EDW (MC)	CGP (SC)	RCIG (SC)	RCGP (SC)
Consumer-Directed Options	None	<ul style="list-style-type: none"> Consumer-directed attendant care Families have a choice of respite providers 	None	None	None
Family Members Can Be Paid to Provide Care	No	Yes	Yes	No	No
Types of Services Families Can Be Paid to Provide	N/A	<ul style="list-style-type: none"> Personal care Respite care 	<ul style="list-style-type: none"> Any service needed Personal care Respite care 	N/A	N/A

State Profile: **Washington**

Selected State Background Characteristics

	WA	US		WA	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.9	281.4	# of Caregivers (<i>millions</i>)	0.6	27.2
Pop. 60+ (<i>thousands</i>)	873.2	45,797.2	Caregiving Hours (<i>millions</i>)	611.2	29,182.0
% 60+	14.8	16.3	Value of Caregiving (<i>millions</i>)	\$5,385.1	\$257,096.0
National Ranking 60+	45	N/A	% Grandchildren living w/grandparents age 65+	2.7	4.4
% White (60+)	90.2	82.3			
% African American (60+)	1.7	8.4	■ Care Receivers ■		
% Hispanic (60+)	1.9	5.4	% Pop. 21-64 Years w/Disability	17.8	19.2
% Asian (60+)	4.1	2.5	% Pop. 65+ w/Disability	42.3	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.1	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.8	0.4	Sensory	16.8	14.2
Pop. 65+ (<i>thousands</i>)	662.1	34,991.8	Physical	28.9	28.6
% Pop. 65+	11.2	12.4	Self-care	9.4	9.5
National Ranking 65+	43	N/A	Mental	11.3	10.8
Pop. 85+ (<i>thousands</i>)	84.1	4,239.6	Difficulty Going Outside Home	18.8	20.4
% Pop. 85+	1.4	1.5			
National Ranking 85+	34	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$33,332	\$31,632	Certified Nursing Facilities	240	15,162
Median Household Income	\$45,183	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	21.8	1,574.0
% of Pop. 65+ Below Poverty	7.9	10.4	Average Cost Per Day in a Nursing Home	\$172	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	50	3,407
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Home Health Aides	11,270	N/A
% Persons Age 65+ Living Alone	29.6	30.1			
% Pop. 65+ in Major Cities	32.4	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	60.4	50.1			

State Profile: **Washington** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SSB 6426 (Enacted 2002) Required the state to offer family and medical leave benefits beyond the federally prescribed minimum and requires employers to 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. SHB 1397 (Enacted 2002) Established a kinship caregivers working group that would prepare a briefing for the legislature.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	Yes
Single Point of Entry Includes Access to State's Caregiver Support Program	Yes
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	Yes
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community Options Program Entry System (COPEs) (MC)	WA Family Caregiver Support Program (WA FCSP) (SC)	Respite Care Services (RCS) (SC)
Administering State Agency	WA State Department of Social & Health Services	WA State Department of Social & Health Services	WA State Department of Social & Health Services	WA State Department of Social & Health Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	AAA	Medicaid agency ¹	AAA	AAA

¹ Aging and Disability Services Administration

State Profile: **Washington** (cont'd)■ **Funding & Caseload** ■

Program Name	FCSP (FC)	COPES (MC)	WA FCSP (SC)	RCS (SC)
Major Sources of Program Funding	▪ OAA, Title III-E	▪ Medicaid HCBS waiver	▪ State general fund	▪ Client contribution ▪ State general fund
FY 2001 Expenditures	\$2,083,944	n/a	n/a	\$2,684,553
FY 2002 Expenditures	\$2,355,545	n/a	\$622,810	\$3,810,310
FY 2003 Expenditures	\$2,580,579	\$294,452,099 (total waiver)	\$631,652	\$3,700,941
FY 2001 A/D Waiver Respite Participants	N/A	n/a	N/A	N/A
FY 2002 A/D Waiver Respite Participants	N/A	n/a	N/A	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	COPES (MC)	WA FCSP (SC)	RCS (SC)
Caregiver Age Requirement	18+	18+	None	None
Care Receiver Age Requirement	60+	18+	18+	18+
Care Receiver Functional Status Requirement	▪ OAA guidelines	▪ 3+ ADLs ▪ Nursing home level of care	▪ Diagnosis of dementia or related disorder/requires supervision	▪ Diagnosis of dementia or related disorder/requires supervision ▪ Physically disabled
Client population	Family caregiver	Care receiver	Family caregiver	Family caregiver

■ **Assessment** ■

Program Name	FCSP (FC)	COPES (MC)	WA FCSP (SC)	RCS (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	Yes	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	Yes	Yes	Yes
Areas Addressed by Caregiver Assessment	▪ Ability of caregiver to provide care ▪ Caregiver demographic information ▪ Caregiver strain ▪ Emergency plan ▪ Need for education/training	▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care	▪ Ability of caregiver to provide care ▪ Caregiver demographic information ▪ Caregiver strain ▪ Emergency plan ▪ Need for education/training ▪ Other	▪ Ability of caregiver to provide care ▪ Care duration ▪ Caregiver demographic information ▪ Caregiver physical health ▪ Caregiver strain ▪ Emergency plan ▪ Need for education/training

State Profile: **Washington** (cont'd)■ **Services** ■

Program Name	FCSP (FC)	COPES (MC)	WA FCSP (SC)	RCS (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A	No	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Consum. supplies Counseling Educ. & training Family consult. Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	N/A	<ul style="list-style-type: none"> Assistive technology Consum. supplies Educ. & training Family consultation Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	None	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A	No	No
Respite Cap	No cap	N/A	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	COPES (MC)	WA FCSP (SC)	RCS (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> A voucher or budget for respite and/or supplemental services Families have a choice of respite providers 	None	<ul style="list-style-type: none"> A voucher or budget for respite and/or supplemental services Families have a choice of respite providers 	<ul style="list-style-type: none"> Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	No	Yes	No	No
Types of Services Families Can Be Paid to Provide	N/A	Personal care	N/A	N/A

State Profile: **West Virginia****Selected State Background Characteristics**

	WV	US		WV	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	1.8	281.4	# of Caregivers (<i>millions</i>)	0.2	27.2
Pop. 60+ (<i>thousands</i>)	362.8	45,797.2	Caregiving Hours (<i>millions</i>)	198.1	29,182.0
% 60+	20.1	16.3	Value of Caregiving (<i>millions</i>)	\$1,744.9	\$257,096.0
National Ranking 60+	2	N/A	% Grandchildren living w/grandparents age 65+	3.2	4.4
% White (60+)	96.2	82.3			
% African American (60+)	2.5	8.4	■ Care Receivers ■		
% Hispanic (60+)	0.4	5.4	% Pop. 21-64 Years w/Disability	23.8	19.2
% Asian (60+)	0.2	2.5	% Pop. 65+ w/Disability	48.6	41.9
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1	% 65+ by Type of Disability		
% American Indian/ Alaska Native (60+)	0.1	0.4	Sensory	17.5	14.2
Pop. 65+ (<i>thousands</i>)	276.9	34,991.8	Physical	35.3	28.6
% Pop. 65+	15.3	12.4	Self-care	12.4	9.5
National Ranking 65+	3	N/A	Mental	13.7	10.8
Pop. 85+ (<i>thousands</i>)	31.8	4,239.6	Difficulty Going Outside Home	24.3	20.4
% Pop. 85+	1.8	1.5			
National Ranking 85+	14	N/A			
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$24,379	\$31,632	Certified Nursing Facilities	123	15,162
Median Household Income	\$29,359	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	10.2	1,574.0
% of Pop. 65+ Below Poverty	11.6	10.4	Average Cost Per Day in a Nursing Home	\$139	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	6	3,407
Households with Individuals 65+ (<i>millions</i>)	0.2	24.7	Home Health Aides	4,620	N/A
% Persons Age 65+ Living Alone	33.1	30.1			
% Pop. 65+ in Major Cities	6.8	40.1			
Average Household Size	2.4	2.6			
Average Family Size	2.9	3.1			
% Households with Internet Access	40.7	50.1			

State Profile: **West Virginia** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	SB 626 (Enacted 2003) Provided an exception that relative caregivers who are providing in-home care are exempt from certain work requirements of the medical assistance program.
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	Yes
Assessment Includes Caregiver Component	No
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
Administering State Agency	WV Bureau of Senior Services	WV Bureau of Senior Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No
Geographic Region Served	Statewide	Mainly rural areas
Local Program Administrative Responsibility	<ul style="list-style-type: none"> AAA Local aging programs 	<ul style="list-style-type: none"> WV Bureau for Medical Services

■ **Funding & Caseload** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Federal A/D Grants to States OAA, Title III-E 	<ul style="list-style-type: none"> Lottery funds Medicaid HCBS waiver
FY 2001 Expenditures	\$854,259	n/a
FY 2002 Expenditures	\$974,517	n/a
FY 2003 Expenditures	\$1,067,616	\$62,220,120 (total waiver)
FY 2001 A/D Waiver Respite Participants	N/A	n/a
FY 2002 A/D Waiver Respite Participants	N/A	n/a

State Profile: **West Virginia** (cont'd)■ **Eligibility** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
Caregiver Age Requirement	None	None
Care Receiver Age Requirement	60+	18+
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision 	<ul style="list-style-type: none"> Nursing home level of care
Client Population	Family caregiver	Care receiver

■ **Assessment** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
Program Assesses	Both family caregiver and care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes
Includes Caregiver Assessment	No	No
Areas Addressed by Caregiver Assessment	N/A	N/A

■ **Services** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	Yes
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Educ. & training Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Info. & assistance
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Weekend/camp 	None
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A
Respite Cap	No cap	N/A
Uniform Respite Cap Across Program Sites	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A

■ **Consumer Direction** ■

Program Name	Family Caregiver Support (FC)	Medicaid Aged and Disabled Waiver (MC)
Consumer-Directed Options	None	A menu of services from which caregivers can choose
Family Members Can Be Paid to Provide Care	No	Yes
Types of Services Families Can Be Paid to Provide	N/A	Personal care

State Profile: **Wisconsin**

Selected State Background Characteristics

	WI	US		WI	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (<i>millions</i>)	5.4	281.4	# of Caregivers (<i>millions</i>)	0.5	27.2
Pop. 60+ (<i>thousands</i>)	907.6	45,797.2	Caregiving Hours (<i>millions</i>)	557.6	29,182.0
% 60+	16.9	16.3	Value of Caregiving (<i>millions</i>)	\$4,912.7	\$257,096.0
National Ranking 60+	22	N/A	% Grandchildren living w/grandparents age 65+	1.7	4.4
% White (60+)	95.3	82.3			
% African American (60+)	2.5	8.4			
% Hispanic (60+)	0.9	5.4			
% Asian (60+)	0.5	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	0.4	0.4			
Pop. 65+ (<i>thousands</i>)	702.6	34,991.8	■ Care Receivers ■		
% Pop. 65+	13.1	12.4	% Pop. 21-64 Years w/Disability	14.9	19.2
National Ranking 65+	20	N/A	% Pop. 65+ w/Disability	36.5	41.9
Pop. 85+ (<i>thousands</i>)	95.6	4,239.6	% 65+ by Type of Disability		
% Pop. 85+	1.8	1.5	Sensory	11.9	14.2
National Ranking 85+	12	N/A	Physical	24.1	28.6
			Self-care	7.5	9.5
			Mental	7.6	10.8
			Difficulty Going Outside Home	17.7	20.4
■ Economic Indicators ■			■ Long-Term Care ■		
Per Capita Income	\$30,898	\$31,632	Certified Nursing Facilities	386	15,162
Median Household Income	\$45,903	\$42,409	Certified Nursing Facility Beds (<i>thousands</i>)	41.0	1,574.0
% of Pop. 65+ Below Poverty	9.1	10.4	Average Cost Per Day in a Nursing Home	\$154	\$158
■ Socio-Demographics ■			Licensed Adult Day Facilities	111	3,407
Households with Individuals 65+ (<i>millions</i>)	0.5	24.7	Home Health Aides	12,020	N/A
% Persons Age 65+ Living Alone	33.1	30.1			
% Pop. 65+ in Major Cities	25.9	40.1			
Average Household Size	2.5	2.6			
Average Family Size	3.1	3.1			
% Households with Internet Access	50.2	50.1			

State Profile: **Wisconsin** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information**■ Administrative Structure ■**

Program Name	Family Caregiver Support Program (FCSP) (FC)	Community Options Program Waiver (COP-W) (MC)	Alzheimer's Family & Caregiver Support Program (AFCS) (SC)
Administering State Agency	WI Department of Health & Family Services	WI Department of Health & Family Services	WI Department of Health & Family Services
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	No	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> County Aging Office 	<ul style="list-style-type: none"> AAA County Dept. of Human or Social Services 	<ul style="list-style-type: none"> County Aging, Long-Term Support or Public Health Dept. County Health Dept.

■ Funding & Caseload ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Local/county funds OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> State general fund
FY 2001 Expenditures	\$2,203,655	\$1,609,989 (<i>respite only</i>)	\$2 million
FY 2002 Expenditures	\$2,522,840	\$1,561,025 (<i>respite only</i>)	\$1.9 million
FY 2003 Expenditures	\$2,763,856	\$144,252,932 (<i>total waiver</i>)	\$1.9 million
FY 2001 A/D Waiver Respite Participants	N/A	504	N/A
FY 2002 A/D Waiver Respite Participants	N/A	516	N/A

State Profile: **Wisconsin** (cont'd)■ **Eligibility** ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
Caregiver Age Requirement	18+	None	None
Care Receiver Age Requirement	60+	18+	No response
Care Receiver Functional Status Requirement	<ul style="list-style-type: none"> 2 ADLs 	<ul style="list-style-type: none"> Nursing home level of care Physically disabled 	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
Client Population	Family caregiver	Care receiver	Both family caregiver and care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Both family caregiver and care receiver
Uniform Assessment Tool	No	Yes	No
Includes Caregiver Assessment	N/A	No	N/A
Areas Addressed by Caregiver Assessment	N/A	Willingness of caregiver to provide care	N/A

■ **Services** ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	No	N/A	No
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Counseling Educ. & training Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation 	<ul style="list-style-type: none"> Educ. & training Info. & assistance Respite care 	<ul style="list-style-type: none"> Assistive technology Care mgt. Cash grant Consum. supplies Counseling Educ. & training Emerg. response Family consult. Family meetings Home modification/repairs Homemaker/chore/personal care Info. & assistance Legal and/or financial consultation Respite care Support groups Transportation Other
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp

State Profile: **Wisconsin** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
Caregiver Must Live with Care Receiver to Receive Respite	Yes	Yes	No
Respite Cap	116 hours/year	No cap	\$4,000/year
Uniform Respite Cap Across Program Sites	Yes	N/A	No
Entity that Formulates the Respite Cap	Administering state agency	N/A	County lead agency

■ **Consumer Direction** ■

Program Name	FCSP (FC)	COP-W (MC)	AFCS (SC)
Consumer-Directed Options	<ul style="list-style-type: none"> ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A voucher or budget for respite only ▪ Families have a choice of respite providers 	<ul style="list-style-type: none"> ▪ A menu of services from which caregivers can choose ▪ A voucher or budget for respite and/or supplemental services ▪ Direct payments to family members for the purchase of goods or services ▪ Families have a choice of respite providers
Family Members Can Be Paid to Provide Care	Yes	Yes	Yes
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care 	<ul style="list-style-type: none"> ▪ Homemaker/chore ▪ Personal care ▪ Respite care ▪ Other 	<ul style="list-style-type: none"> ▪ Personal care ▪ Respite care

State Profile: Wyoming

Selected State Background Characteristics

	WY	US		WY	US
■ Population ■			■ Informal Caregivers ■		
Total Pop. (millions)	0.5	281.4	# of Caregivers (millions)	0.0	27.2
Pop. 60+ (thousands)	77.3	45,797.2	Caregiving Hours (millions)	51.0	29,182.0
% 60+	15.7	16.3	Value of Caregiving (millions)	\$448.9	\$257,096.0
National Ranking 60+	38	N/A	% Grandchildren living w/grandparents age 65+	4.5	4.4
% White (60+)	94.1	82.3			
% African American (60+)	0.4	8.4			
% Hispanic (60+)	3.3	5.4			
% Asian (60+)	0.4	2.5			
% Native Hawaiian/ Pacific Islanders (60+)	0.0	0.1			
% American Indian/ Alaska Native (60+)	1.0	0.4			
Pop. 65+ (thousands)	57.7	34,991.8			
% Pop. 65+	11.7	12.4			
National Ranking 65+	38	N/A			
Pop. 85+ (thousands)	6.7	4,239.6			
% Pop. 85+	1.4	1.5			
National Ranking 85+	36	N/A			
■ Economic Indicators ■			■ Care Receivers ■		
Per Capita Income	\$32,808	\$31,632	% Pop. 21-64 Years w/Disability	16.8	19.2
Median Household Income	\$39,763	\$42,409	% Pop. 65+ w/Disability	39.3	41.9
% of Pop. 65+ Below Poverty	N/A	10.4	% 65+ by Type of Disability		
			Sensory	16.7	14.2
			Physical	26.1	28.6
			Self-care	6.8	9.5
			Mental	8.4	10.8
			Difficulty Going Outside Home	15.7	20.4
■ Socio-Demographics ■			■ Long-Term Care ■		
Households with Individuals 65+ (millions)	0.0	24.7	Certified Nursing Facilities	35	15,162
% Persons Age 65+ Living Alone	33.2	30.1	Certified Nursing Facility Beds (thousands)	2.7	1,574.0
% Pop. 65+ in Major Cities	12.7	40.1	Average Cost Per Day in a Nursing Home	\$141	\$158
Average Household Size	2.5	2.6	Licensed Adult Day Facilities	12	3,407
Average Family Size	3.0	3.1	Home Health Aides	620	N/A
% Households with Internet Access	51.0	50.1			

State Profile: **Wyoming** (cont'd)**State System of Home and Community-Based Services (HCBS)**

Legislation Enacted Within the Last Three Years (2001-2003) that Addresses Family Caregiving Issues	None
Task Force or Commission Specifically to Examine Family Caregiver Issues	No
Name of Task Force:	N/A
Single Point of Entry for State System of HCBS	No
Single Point of Entry Includes Access to State's Caregiver Support Program	N/A
Uniform Assessment Tool for All HCBS Programs for the Elderly and Adults with Disabilities	No
Assessment Includes Caregiver Component	N/A
At Least One State Program with Consumer-Directed Option for Family Caregivers	Yes

State Program Information■ **Administrative Structure** ■

Program Name	Family Caregiver Support Program (FCSP) (FC)	Home and Community-Based Services Waiver for Elderly and Physically Disabled (HCBS Waiver) (MC)	Community Based In-Home Services Program (CBIHS) (SC)
Administering State Agency	WY Department of Health	WY Department of Health	WY Department of Health
Organizational Unit or Person Specifically Designated for Caregiving Programs or Activities	Yes	Yes	Yes
Geographic Region Served	Statewide	Statewide	Statewide
Local Program Administrative Responsibility	<ul style="list-style-type: none"> Contracts with local senior centers for direct administration SUA 	<ul style="list-style-type: none"> SUA 	<ul style="list-style-type: none"> SUA (primary) Senior center projects, hospital/home health (secondary)

■ **Funding & Caseload** ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
Major Sources of Program Funding	<ul style="list-style-type: none"> Client contribution OAA, Title III-E 	<ul style="list-style-type: none"> Medicaid HCBS waiver 	<ul style="list-style-type: none"> Client contribution OAA, Title III-B State general fund
FY 2001 Expenditures	\$564,400	\$65,544 (<i>respite only</i>)	n/a
FY 2002 Expenditures	\$644,212	\$45,406 (<i>respite only</i>)	n/a
FY 2003 Expenditures	\$705,756	\$6,487,568 (<i>total waiver</i>)	n/a

State Profile: **Wyoming** (cont'd)■ **Funding & Caseload** (cont'd) ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
FY 2001 A/D Waiver Respite Participants	N/A	38	N/A
FY 2002 A/D Waiver Respite Participants	N/A	27	N/A

■ **Eligibility** ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
Caregiver Age Requirement	None	18+	18+
Care Receiver Age Requirement	60+	19+	18+
Care Receiver Functional Status Requirement	No functional status requirement	Nursing home level of care	1 ADL
Client Population	Family caregiver	Care receiver	Care receiver

■ **Assessment** ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
Program Assesses	Both family caregiver and care receiver	Care receiver	Care receiver
Uniform Assessment Tool	Yes	Yes	Yes
Includes Caregiver Assessment	Yes	No	Yes
Areas Addressed by Caregiver Assessment	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ Willingness of caregiver to provide care 	N/A	<ul style="list-style-type: none"> ▪ Ability of caregiver to provide care ▪ Care duration ▪ Care frequency ▪ Caregiver demographic information ▪ Caregiver mental health/depression ▪ Caregiver physical health ▪ Caregiver strain ▪ If family caregivers are providing long-distance caregiving ▪ Willingness of caregiver to provide care

■ **Services** ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
All Caregivers Eligible for Program Have Access to Same Package of Services	Yes	No response	No response

State Profile: **Wyoming** (cont'd)■ **Services** (cont'd) ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
Services Provided Specifically to Family Caregivers	<ul style="list-style-type: none"> Assistive technology Care mgt. Counseling Educ. & training Home modification/repairs Info. & assistance Respite care Support groups 	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Respite care
Types of Respite Care Offered	<ul style="list-style-type: none"> Adult day svcs. In-home Overnight Weekend/camp 	<ul style="list-style-type: none"> Adult day svcs. In-home 	<ul style="list-style-type: none"> Adult day svcs. In-home Other
Caregiver Must Live with Care Receiver to Receive Respite	No	N/A	No
Respite Cap	No cap	No cap	No cap
Uniform Respite Cap Across Program Sites	N/A	N/A	N/A
Entity that Formulates the Respite Cap	N/A	N/A	N/A

■ **Consumer Direction** ■

Program Name	FCSP (FC)	HCBS Waiver (MC)	CBIHS (SC)
Consumer-Directed Options	None	<ul style="list-style-type: none"> Consumer-directed attendant care Direct payments to family members for the purchase of goods or services 	None
Family Members Can Be Paid to Provide Care	Yes	Yes	No
Types of Services Families Can Be Paid to Provide	<ul style="list-style-type: none"> Respite care 	<ul style="list-style-type: none"> Homemaker/chore Personal care 	N/A

DATA DOCUMENTATION

Documentation for data used in two sections of the state profiles: "Selected State Background Characteristics" and "State Program Information" (Funding & Caseload table).

■ Sources for Selected State Background Characteristics ■

Data Point	Data Year	Source
Population Characteristics		
Total Population	2000	US Census Bureau. (2000). <i>Census 2000 summary file 1</i> . Retrieved July 8, 2004, from http://www.fedstats.gov
Population 60+	2000	Ibid.
% Population 60+	2000	Ibid.
National Ranking 60+	2000	Ibid.
% White 60+	2000	US Census Bureau. (2000). <i>Percent of persons 60+ by race, Hispanic origin by state</i> . Retrieved July 8, 2004, from http://www.aoa.gov/prof/Statistics/Census2000/2000pop/number60plusrace-HO.asp
% African American 60+	2000	Ibid.
% Hispanic 60+	2000	Ibid.
% Asian 60+	2000	Ibid.
% Native Hawaiian/Pacific Islanders 60+	2000	Ibid.
% American Indian/Alaska Native 60+	2000	Ibid.
Population 65+	2000	US Census Bureau. (2000). <i>Census 2000 summary file 1</i> . Retrieved July 8, 2004, from http://www.fedstats.gov
% Population 65+	2000	Ibid.
National Ranking 65+	2000	Ibid.
Population 85+	2000	Ibid.
% Population 85+	2000	Ibid.
National Ranking 85+	2000	Ibid.
Economic Indicators		
Per capita personal income	2003	US Bureau of Economic Analysis. (2003). <i>Annual state personal income: Summary personal income estimates</i> . Retrieved June 25, 2004, from http://www.bea.doc.gov/bea/regional/spi/default.cfm
Median household income	2002	US Census Bureau. (2002). <i>Current population survey, annual demographic supplements: Table H-8 median household income by state: 1984 to 2003</i> . Retrieved June 29, 2004, from http://www.census.gov/hhes/income/histinc/h08.html
% 65+ (at 100% below poverty)	2002	US Census Bureau. (2003). <i>Current population survey, annual social and economic supplement</i> . Retrieved July 29, 2004, from http://ferret.bls.census.gov/macro/032003/pov/new46_100125_06.htm
Socio-Demographic Characteristics		
Households with individuals 65 years+	2000	US Census Bureau. (2000). <i>American fact finder US, profile of general demographic characteristics</i> . Retrieved July 30, 2004, from http://factfinder.census.gov
% Persons age 65+ living alone	2002	AARP Public Policy Institute. (2002). <i>Across the states: Profiles in long-term care</i> . Washington, DC: Author.
% 65+ population in major cities	2000	FCA calculations based on US Census Bureau. (2000). <i>American fact finder US, summary file 1</i> . Retrieved July 10, 2004, from http://factfinder.census.gov
Average household size	2000	Ibid.
Average family size	2000	Ibid.
% Households with Internet access	2001	National Telecommunications and Information Administration & the Economics and Statistics Administration. (2002). <i>A nation online: How Americans are expanding their use of the internet</i> . Retrieved July 11, 2004, from http://www.ntia.doc.gov/ntiahome/dn/hhs/TableH1.htm

■ Sources for Selected State Background Characteristics (cont'd) ■

Informal Caregivers Characteristics		
# of Caregivers (of persons 18+)	2000	Arno P. S., & Mintz S. (2004). <i>Prevalence and economic value of family caregiving, state analysis 2000</i> . Kensington, MD: National Family Caregivers Association.
Caregiving Hours (of persons 18+)	2000	Ibid.
Value of Caregiving (of persons 18+)	2000	Ibid.
% Grandchildren living w/grandparents age 65+	2000	AARP Public Policy Institute. (2002). <i>Across the states: Profiles in long-term care</i> . Washington, DC: Author.
Care Receiver Characteristics		
% Population 21-64 years with a disability	2000	US Census Bureau. (2000). <i>American fact finder US, profile of selected social characteristics: 2000</i> . Retrieved July 11, 2004, from http://factfinder.census.gov
% Population 65+ with a disability	2000	Ibid.
-% Sensory	2000	US Census Bureau. (2000). <i>American fact finder US, Characteristics of the Civilian Noninstitutionalized Population by Age, Disability Status, and Type of Disability: 2000</i> . Retrieved July 11, 2004 from http://factfinder.census.gov
-% Physical	2000	Ibid.
-% Self-care	2000	Ibid.
-% Mental	2000	Ibid.
-% Difficulty Going Outside Home	2000	Ibid.
Long-Term Care Providers		
Certified nursing facilities	2002	Harrington, C., Carrillo, H., Wellin, V., & Burdin, A. (2003, August) <i>Nursing, facilities, staffing, residents, and facility deficiencies, 1996 through 2002</i> . Department of Social and Behavioral Sciences, University of California: San Francisco. Retrieved July 9, 2004, from http://www.statehealthfacts.org
Certified nursing facility beds	2002	Ibid.
Average cost per day in a nursing home	2003	GE Financial. (2003, March). <i>GE long-term care insurance nursing home survey</i> . GE Financial, Long-Term Care Division: Waukesha, Wisconsin: Author. Data obtained from Kiplinger's Retirement Report. (2004, March). Retrieved July 11, 2004, from http://www.insurancenewsnet.net/article.asp?n=1&id=18108
Licensed adult day facilities	2001-2002	Wake Forest University School of Medicine. (2001 - 2002). <i>A national study of adult day services by partners in caregiving: The adult day services program</i> . Winston-Salem, North Carolina: Author.
Home health aides	2002	US Bureau of Labor Statistics. (2002). <i>State occupational employment and wage estimates</i> . Retrieved July 11, 2004, from http://www.bls.gov/oes/oes_dl.htm

■ Sources for Expenditure and Caseload Data ■

FY 2001 Expenditures: For Aged/Disabled Medicaid waivers, these amounts represent waiver expenditures for respite care only and were obtained from CMS Form 372 reports.³⁴ For the National Family Caregiver Support Program (NFCSP), this amount represents the U.S. Administration on Aging's (AoA's) allocation of NFCSP formula funds. For state-funded programs, data were provided by program respondents or by the National Conference of State Legislatures (NCSL).

³⁴ Kitchener M., Ng, T., & Harrington, C. (2004). *Medicaid home and community based services: Program data, 1992 - 2001*. San Francisco, CA: UCSF Department of Social and Behavioral Sciences.

■ **Sources for Expenditure and Caseload Data** (cont'd) ■

FY 2002 Expenditures: For Aged/Disabled Medicaid waivers, these amounts represent waiver expenditures for respite care only and were obtained from CMS Form 372 reports.³⁵ For the NFCSP, this amount represents the AoA's allocation of NFCSP formula funds. For state-funded programs, data were provided by program respondents or by NCSL.

FY 2003 Expenditures: For Aged/Disabled Medicaid waivers, these amounts represent total waiver expenditures and were obtained from CMS Form 64 reports.³⁶ Waiver expenditures for respite care only were not available at the time of this study. For the NFCSP, this amount represents AoA's allocation of NFCSP formula funds. For state-funded programs, data were provided by program respondents or by NCSL.

FY 2001 A/D Waiver Respite Participants: Data were obtained from CMS Form 372 reports.³⁷

FY 2002 A/D Waiver Respite Participants: Data were obtained from CMS Form 372 reports.³⁸

³⁵ Centers for Medicare & Medicaid Services, Center for Medicaid and State Operations. *Annual Report on Home and Community-Based Services Waivers* (CMS Form 372).

³⁶ Eiken, S., Burwell, B., & Schaefer, M. (2004). *Medicaid HCBS Waiver expenditures - FY 2003*. Retrieved July 9, 2004, from <http://www.hcbs.org>

³⁷ Kitchener M., Ng, T., & Harrington, C. (2004). *Medicaid home and community based services: Program data, 1992 - 2001*. San Francisco, CA: UCSF Department of Social and Behavioral Sciences.

³⁸ Centers for Medicare & Medicaid Services, Center for Medicaid and State Operations. *Annual report on Home and Community-Based Services Waivers* (CMS Form 372).

Table 1: Program Client Designation

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
ALABAMA				
FC	Alabama CARES		X	
MC	Elderly & Disabled Waiver	X		
ALASKA				
FC	FCSP		X	
SC	Innovative Respite	X		
ARIZONA				
FC	FCSP			X
MC	AZ Long-Term Care System (ALTCS)	X		
SC	Non-Medical HCBS			X
ARKANSAS				
FC	Caring for the Caregiver Arkansas Caregivers		X	
MC	ElderChoices Medicaid Waiver	X		
CALIFORNIA				
FC	FCSP		X	
MC	Multipurpose Senior Services Program (MSSP)	X		
SC	Adult Day Health Care Program	X		
SC	Alzheimer's Day Care Resource Center (ADCRC)			X
SC	Caregiver Resource Centers (CRCs)		X	
SC	In-Home Supportive Services (IHSS)	X		
COLORADO				
FC	FCSP		X	
MC	HCBS for the Elderly, Blind and Disabled	X		
CONNECTICUT				
FC	FCSP			X
MC	Home Care Program for Elders	X		
SC	Statewide Respite Care Program			X
SC	Personal Care Assistance State-Funded Pilot Program	X		
DELAWARE				
FC	CARE Delaware		X	
MC	Elderly & Disabled Waiver	X		
DISTRICT OF COLUMBIA				
FC	FCSP		X	
MC	Elderly & Physical Disabilities Waiver	X		
FLORIDA				
FC	FCSP			X

Note: Table is based on the Part 1 Survey (Question 7).
Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
NR=No Response

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
FLORIDA (cont'd)				
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X		
SC	Respite for Elders Living in Everyday Families (RELIEF)	X		
SC	Home Care for the Elderly			X
SC	Community Care for the Elderly	X		
SC	Alzheimer's Disease Initiative			X
GEORGIA				
FC	FCSP		X	
MC	Community Care Services Program (CCSP)	X		
HAWAII				
FC	FCSP			X
MC	Nursing Home Without Walls	X		
SC	Kupuna Care	X		
IDAHO				
FC	FCSP			X
MC	HCBS Aged & Disabled Waiver	X		
SC	Senior Services Act, Respite Program			X
ILLINOIS				
FC	FCSP		X	
MC	Community Care Program (CCP)	X		
MC	Home Services Program	X		
INDIANA				
FC	Caring and Compassion		X	
MC	Aged & Disabled Medicaid Waiver	X		
SC	CHOICE	X		
IOWA				
FC	Iowa Family Caregiver		X	
MC	Elderly Waiver	X		
KANSAS				
FC	FCSP		X	
MC	Home & Community-Based Frail Elder Waiver	X		
SC	Senior Care Act Program	X		
KENTUCKY				
FC	FCSP		X	
SC	Adult Day/Alzheimer's Respite	X		
LOUISIANA				
FC	FCSP		X	
MC	Medicaid Home and Community-Based Waiver	X		

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
MAINE				
FC	Family Caregiver Program		X	
MC	MaineCare	X		
SC	Home-Based Care	X		
	Partners in Caring			X
MARYLAND				
FC	FCSP		X	
MC	Medicaid Waiver for Older Adults	X		
SC	Respite for Caregivers of Adults with Functional Disabilities			X
MASSACHUSETTS				
FC	FCSP		X	
MC	Home and Community-Based Waiver	X		
SC	Home Care Program	X		
MICHIGAN				
FC	FCSP		X	
MC	MI Choice	X		
SC	State/Escheat Respite			X
SC	Caregiver Respite Program			X
MINNESOTA				
FC	FCSP		X	
MC	Elderly Waiver	X		
SC	Alternative Care Program	X		
MISSISSIPPI				
FC	FCSP		X	
MC	Elderly & Disabled Waiver	X		
MISSOURI				
FC	FCSP			X
MC	Aged & Disabled Waiver	X		
MONTANA				
FC	Family Caregiving Support			
MC	HCBS Program for Elderly & Physically Disabled	X		X
NEBRASKA				
FC	FCSP		X	
MC	Aged & Disabled Waiver	X		
SC	Respite Subsidy Program Across the Lifespan	X		
NEVADA				
FC	FCSP			X
MC	Community Home-Based Initiatives Program	X		

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
NEVADA (cont'd)				
SC	Independent Living Grant	X		
SC	Community-Based Care Caregiving Training		X	
NEW HAMPSHIRE				
FC	FCSP		X	
MC	Elderly and Chronically Ill Waiver			X
NEW JERSEY				
FC	FCSP		X	
MC	Community Care Program for the Elderly & Disabled	X		
MC	Enhanced Community Options (ECO)	X		
SC	New Jersey Statewide Respite Care Program (SRCP)			X
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	X		
SC	Jersey Assistance for Community Caregiving	X		
NEW MEXICO				
FC	FCSP			X
MC	Disabled & Elderly HCBS Waiver	X		
NEW YORK				
FC	Eldercare Family Support Program (EFSP)			X
SC	Respite Program			X
NORTH CAROLINA				
FC	FCSP		X	
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	X		
SC	Respite Care Program			X
NORTH DAKOTA				
FC	FCSP		X	
MC	Aged & Disabled Waiver	X		
SC	Family Home Care	X		
OHIO				
FC	FCSP		X	
MC	PASSPORT HCBS Waiver Program	X		
SC	Alzheimer's Respite Program			X
OKLAHOMA				
FC	FCSP		X	
MC	Advantage Program	X		
SC	Respite Resource Network		X	
OREGON				
FC	FCSP		X	

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
OREGON (cont'd)				
MC	Medicaid Waiver/In-Home Care	X		
SC	Lifespan Respite Care Networks		X	
PENNSYLVANIA				
FC	FCSP			X
MC	PA Department of Aging 60+ Medicaid Waiver	X		
SC	PA FCSP			X
SC	OPTIONS	X		
SC	BRIDGE	X		
RHODE ISLAND				
FC	Partners in Caring			X
MC	Home & Community-Based Waiver	X		
SOUTH CAROLINA				
FC	FCSP		X	
MC	Elderly/Disabled Home and Community-Based Waiver	X		
SOUTH DAKOTA				
FC	Caregiver Program			
MC	Home & Community-Based Elderly Waiver	X	X	
TENNESSEE				
FC	FCSP		X	
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities	X		
TEXAS				
FC	FCSP			X
MC	Community-Based Alternatives	X		
SC	Respite Care Program	X		
SC	In-Home & Family Support Program	X		
UTAH				
FC	Caregiver Support Program		X	
MC	Medicaid Aging Waiver	X		
SC	Home & Community-Based Alternatives	X		
VERMONT				
FC	FCSP		X	
MC	Home-Based Medicaid Waiver	X		
VIRGINIA				
FC	FCSP			
MC	Elderly & Disabled Waiver	NR	NR	NR
SC	Caregiver Grant Program		X	

Program		Who is the Client?		
TYPE	Name	Care Receiver	Family Caregiver	Both Care Receiver & Family Caregiver
VIRGINIA (cont'd)				
SC	Respite Care Initiative Grant			X
SC	Respite Care Grant Program 2003	X		
WASHINGTON				
FC	FCSP		X	
MC	Community Options Program Entry System (COPES)	X		
SC	WA FCSP		X	
SC	Respite Care Services		X	
WEST VIRGINIA				
FC	Family Caregiver Support		X	
MC	Medicaid Aged & Disabled Waiver	X		
WISCONSIN				
FC	FCSP		X	
MC	Community Options Program Waiver (COP-W)	X		
SC	Alzheimer's Family & Caregiver Support Program			X
WYOMING				
FC	FCSP		X	
MC	HCBS Waiver for Elderly & Physically Disabled	X		
SC	Community Based In-Home Services Program (CBIHS)	X		

Table 2: Program Eligibility Criteria: Age and Functional Status

Program		Caregiver Age	Care Receiver Age	Eligibility Requirements	
Type	Name				Care Receiver Functional Status
ALABAMA					
FC	Alabama CARES	None	60+	▪ 2 IADLs	
MC	Elderly & Disabled Waiver	None	None	▪ Nursing home level of care	
ALASKA					
FC	FCSP	None	60+	No functional status requirement	
SC	Innovative Respite	None	No response	No functional status requirement	
ARIZONA					
FC	FCSP	None	60+	▪ 2 ADLs ▪ 2 IADLs ▪ Diagnosis of dementia or related disorder/requires supervision	
MC	AZ Long-Term Care System (ALTCS)	18+	None	▪ Nursing home level of care	
SC	Non-Medical HCBS	None	60+	▪ 2 ADLs ▪ 2 IADLs	
ARKANSAS					
FC	Caring for the Caregiver Arkansas Caregivers	18+	60+	▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision	
MC	ElderChoices Medicaid Waiver	18+	65+	▪ Nursing home level of care	
CALIFORNIA					
FC	FCSP	18+	60+	▪ OAA guidelines	
MC	Multipurpose Senior Services Program (MSSP)	N/A	65+	▪ Nursing home level of care	
SC	Adult Day Health Care Program	N/A	18+	▪ Other	
SC	Alzheimer's Day Care Resource Center (ADCRC)	Other	18+	▪ Diagnosis of dementia or related disorder/requires supervision	
SC	Caregiver Resource Centers (CRCs)	None	18+	▪ Adult-onset cognitive disorder	
SC	In-Home Supportive Services (IHSS)	Legally eligible to work under state law	None	▪ 1 ADL ▪ 1 IADL	
COLORADO					
FC	FCSP	18+	60+	▪ 2 ADLs	
MC	HCBS for the Elderly, Blind and Disabled	18+	18+	▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision	
CONNECTICUT					
FC	FCSP	18+	60+	▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision	
MC	Home Care Program for Elders	None	65+	▪ 1 ADL ▪ Nursing home level of care	
SC	Statewide Respite Care Program	None	None	▪ Diagnosis of dementia or related disorder/requires supervision	
SC	Personal Care Assistance State-Funded Pilot Program	18+	65+	▪ 2 ADLs	
DELAWARE					
FC	CARE Delaware	None	60+	▪ 2 ADLs	
MC	Elderly & Disabled Waiver	None	18+	▪ Nursing home level of care	
DISTRICT OF COLUMBIA					
FC	FCSP	None	60+	No functional status requirement	
MC	Elderly & Physical Disabilities Waiver	n/a	18+	▪ 2 ADLs ▪ 3+ IADLs ▪ Nursing home level of care	

Note. Table is based on the Part 1 Survey (Question 5).

Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program

Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services

ADL=Activity of Daily Living; IADL=Instrumental Activity of Daily Living; OAA guidelines= Care receiver must have two or more ADL limitations or a cognitive impairment for the caregiver to be eligible for respite or supplemental services

Program		Eligibility Requirements		
Type	Name	Caregiver Age	Care Receiver Age	Care Receiver Functional Status
FLORIDA				
FC	FCSP	19+	None	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision Nursing home level of care Other
MC	Aged & Disabled Adult Medicaid HCBS Waiver	None	18+	
SC	Respite for Elders Living in Everyday Families (RELIEF)	None	60+	
SC	Home Care for the Elderly	18+	60+	<ul style="list-style-type: none"> Nursing home level of care
SC	Community Care for the Elderly	None	60+	<ul style="list-style-type: none"> Nursing home level of care
SC	Alzheimer's Disease Initiative	None	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
GEORGIA				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Community Care Services Program (CCSP)	N/A	None	<ul style="list-style-type: none"> Nursing home level of care
HAWAII				
FC	FCSP	60+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Nursing Home Without Walls	None	None	<ul style="list-style-type: none"> Nursing home level of care
SC	Kupuna Care	N/A	60+	<ul style="list-style-type: none"> Other
IDAHO				
FC	FCSP	60+	None	<ul style="list-style-type: none"> 2 ADLs
MC	HCBS Aged & Disabled Waiver	18+	18+	<ul style="list-style-type: none"> Nursing home level of care
SC	Senior Services Act, Respite Program	60+	60+	<ul style="list-style-type: none"> 1 ADL
ILLINOIS				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Community Care Program (CCP)	N/A	60+	<ul style="list-style-type: none"> Nursing home level of care ADL/IADL combination
MC	Home Services Program	18+	18+	<ul style="list-style-type: none"> Physically disabled ADL/IADL combination
INDIANA				
FC	Caring and Compassion	18+	60+	<ul style="list-style-type: none"> 2 ADLs
MC	Aged & Disabled Medicaid Waiver	18+	None	<ul style="list-style-type: none"> 2 ADLs Nursing home level of care
SC	CHOICE	18+	60+	<ul style="list-style-type: none"> 2 ADLs
IOWA				
FC	Iowa Family Caregiver	None	60+	<ul style="list-style-type: none"> 2 ADLs
MC	Elderly Waiver	18+	65+	<ul style="list-style-type: none"> 2 ADLs
KANSAS				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Home & Community-Based Frail Elder Waiver	18+	65+	<ul style="list-style-type: none"> 2 ADLs 3+ IADLs Nursing home level of care, ADL/IADL combination
SC	Senior Care Act Program	60+	60+	<ul style="list-style-type: none"> 2 ADLs 3+ IADLs ADL/IADL combination
KENTUCKY				
FC	FCSP	None	60+	<ul style="list-style-type: none"> No functional status requirement
SC	Adult Day/Alzheimer's Respite	60+	None	<ul style="list-style-type: none"> 2 ADLs 3+ ADLs Diagnosis of dementia or related disorder/requires supervision
LOUISIANA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> No functional status requirement Nursing home level of care Physically disabled
MC	Medicaid Home and Community-Based Waiver	21+	65+	

Program		Eligibility Requirements		
Type	Name	Caregiver Age	Care Receiver Age	Care Receiver Functional Status
MAINE				
FC	Family Caregiver Program	60+	60+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care
MC	MaineCare	None	18+	<ul style="list-style-type: none"> ▪ ADL/IADL combination
SC	Home-Based Care	18+	18+	<ul style="list-style-type: none"> ▪ Diagnosis of dementia or related disorder/requires supervision
SC	Partners in Caring	N/A	None	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ 3+ ADLs
MARYLAND				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ 3+ ADLs
MC	Medicaid Waiver for Older Adults	50+	Other	<ul style="list-style-type: none"> ▪ 3+ ADLs
SC	Respite for Caregivers of Adults with Functional Disabilities	18+	18+	<ul style="list-style-type: none"> ▪ 3+ ADLs
MASSACHUSETTS				
FC	FCSP	18+	60+	No functional status requirement
MC	Home and Community-Based Waiver	None	60+	<ul style="list-style-type: none"> ▪ Nursing home level of care ▪ 3+ ADLs ▪ 3+ IADLs
SC	Home Care Program	None	60+	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision ▪ Nursing home level of care
MICHIGAN				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision ▪ Nursing home level of care
MC	MI Choice	18+	None	No functional status requirement
SC	State/Escheat Respite	None	60+	<ul style="list-style-type: none"> ▪ Other
SC	Caregiver Respite Program	None	18+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ Nursing home level of care
MINNESOTA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ Nursing home level of care
MC	Elderly Waiver	18+	65+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ Nursing home level of care
SC	Alternative Care Program	18+	65+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care ▪ Nursing home level of care
MISSISSIPPI				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> ▪ 3+ ADLs ▪ 3+ ADLs ▪ Nursing home level of care
MC	Elderly & Disabled Waiver	Other	21+	<ul style="list-style-type: none"> ▪ 3+ ADLs ▪ Nursing home level of care
MISSOURI				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care
MC	Aged & Disabled Waiver	63+	63+	<ul style="list-style-type: none"> ▪ OAA guidelines ▪ Nursing home level of care
MONTANA				
FC	Family Caregiving Support	None	None	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care
MC	HCBS Program for Elderly & Physically Disabled	18+	None	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care
NEBRASKA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Nursing home level of care ▪ Other
MC	Aged & Disabled Waiver	None	None	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Nursing home level of care ▪ Other
SC	Respite Subsidy Program Across the Lifespan	None	None	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care ▪ No functional status requirement
NEVADA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care ▪ No functional status requirement
MC	Community Home-Based Initiatives Program	None	65+	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care ▪ No functional status requirement
SC	Independent Living Grant	None	60+	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care ▪ No functional status requirement
SC	Community-Based Care Caregiving Training	None	None	<ul style="list-style-type: none"> ▪ No functional status requirement ▪ Nursing home level of care ▪ No functional status requirement
NEW HAMPSHIRE				
FC	FCSP	None	60+	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision ▪ 1 ADL
MC	Elderly and Chronically Ill Waiver	18+	18+	<ul style="list-style-type: none"> ▪ 2 ADLs ▪ Diagnosis of dementia or related disorder/requires supervision ▪ 1 ADL

Program		Eligibility Requirements		
Type	Name	Caregiver Age	Care Receiver Age	Care Receiver Functional Status
NEW JERSEY				
FC	FCSP	None	60+	<ul style="list-style-type: none"> Other
MC	Community Care Program for the Elderly & Disabled	None	None	<ul style="list-style-type: none"> Nursing home level of care
MC	Enhanced Community Options (ECO)	None	21+	<ul style="list-style-type: none"> Nursing home level of care
SC	New Jersey Statewide Respite Care Program (SRCP)	18+	18+	<ul style="list-style-type: none"> Physically disabled
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	18+	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
SC	Jersey Assistance for Community Caregiving	None	60+	<ul style="list-style-type: none"> Nursing home level of care
NEW MEXICO				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision
MC	Disabled & Elderly HCBS Waiver	18+	None	<ul style="list-style-type: none"> 3+ ADLs Nursing home level of care
NEW YORK				
FC	Eldercare Family Support Program (EFSP)	60+	60+	No functional status requirement
SC	Respite Program	None	60+	<ul style="list-style-type: none"> Other
NORTH CAROLINA				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	18+	18+	<ul style="list-style-type: none"> Nursing home level of care
SC	Respite Care Program	Either caregiver or care receiver must be 60+	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision Physically disabled
NORTH DAKOTA				
FC	FCSP	18+	60+	No functional status requirement
MC	Aged & Disabled Waiver	18+	18+	<ul style="list-style-type: none"> Nursing home level of care
SC	Family Home Care	18+	18+	<ul style="list-style-type: none"> 3+ ADLs
OHIO				
FC	FCSP	None	60+	<ul style="list-style-type: none"> OAA guidelines
MC	PASSPORT HCBS Waiver Program	None	60+	<ul style="list-style-type: none"> Nursing home level of care
SC	Alzheimer's Respite Program	None	None	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
OKLAHOMA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision
MC	Advantage Program	N/A	18+	<ul style="list-style-type: none"> Nursing home level of care
SC	Respite Resource Network	18+	60+	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision
OREGON				
FC	FCSP	None	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Medicaid Waiver/In-Home Care	N/A	18+	<ul style="list-style-type: none"> ADL/IADL combination
SC	Lifespan Respite Care Networks	None	None	No functional status requirement
PENNSYLVANIA				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> 1 ADL
MC	PA Department of Aging 60+ Medicaid Waiver	18+	60+	<ul style="list-style-type: none"> Nursing home level of care
SC	PA FCSP	18+	18+	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision
SC	OPTIONS	18+	18+	No response
SC	BRIDGE	18+	60+	<ul style="list-style-type: none"> Nursing home level of care
RHODE ISLAND				
FC	Partners in CaRing	None	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Home & Community-Based Waiver	None	65+	<ul style="list-style-type: none"> Nursing home level of care
SOUTH CAROLINA				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> 2 ADLs
MC	Elderly/Disabled Home and Community-Based Waiver	None	18+	<ul style="list-style-type: none"> Nursing home level of care

Program		Eligibility Requirements		
Type	Name	Caregiver Age	Care Receiver Age	Care Receiver Functional Status
SOUTH DAKOTA				
FC	Caregiver Program	None	60+	<ul style="list-style-type: none"> 2 ADLs Other
MC	Home & Community-Based Elderly Waiver	N/A	65+	<ul style="list-style-type: none"> Nursing home level of care
TENNESSEE				
FC	FCSP	None	60+	<ul style="list-style-type: none"> 2 ADLs Diagnosis of dementia or related disorder/requires supervision Physically disabled
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities	18+	18+	<ul style="list-style-type: none"> 1 ADL
TEXAS				
FC	FCSP	None	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Community-Based Alternatives	N/A	21+	<ul style="list-style-type: none"> Nursing home level of care
SC	Respite Care Program	None	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision Other
SC	In-Home & Family Support Program	None	Other	<ul style="list-style-type: none"> 1 ADL 1 IADL
UTAH				
FC	Caregiver Support Program	None	60+	<ul style="list-style-type: none"> 2 ADLs
MC	Medicaid Aging Waiver	None	65+	<ul style="list-style-type: none"> Nursing home level of care
SC	Home & Community-Based Alternatives	None	18+	<ul style="list-style-type: none"> ADL/IADL combination
VERMONT				
FC	FCSP	None	60+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision OAA guidelines
MC	Home-Based Medicaid Waiver	N/A	18+	<ul style="list-style-type: none"> Nursing home level of care
VIRGINIA				
FC	FCSP	None	60+	<ul style="list-style-type: none"> No functional status requirement Nursing home level of care
MC	Elderly & Disabled Waiver	18+	None	<ul style="list-style-type: none"> 2 ADLs
SC	Caregiver Grant Program	18+	None	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
SC	Respite Care Initiative Grant	None	60+	<ul style="list-style-type: none"> Nursing home level of care Physically disabled Other
SC	Respite Care Grant Program 2003	None	Other	
WASHINGTON				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> OAA guidelines
MC	Community Options Program Entry System (COPES)	18+	18+	<ul style="list-style-type: none"> 3+ ADLs Nursing home level of care
SC	WA FCSP	None	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
SC	Respite Care Services	None	18+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision Physically disabled
WEST VIRGINIA				
FC	Family Caregiver Support	None	60+	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
MC	Medicaid Aged & Disabled Waiver	None	18+	<ul style="list-style-type: none"> Nursing home level of care
WISCONSIN				
FC	FCSP	18+	60+	<ul style="list-style-type: none"> 2 ADLs
MC	Community Options Program Waiver (COP-W)	None	18+	<ul style="list-style-type: none"> Nursing home level of care Physically disabled
SC	Alzheimer's Family & Caregiver Support Program	None	No response	<ul style="list-style-type: none"> Diagnosis of dementia or related disorder/requires supervision
WYOMING				
FC	FCSP	None	60+	<ul style="list-style-type: none"> No functional status requirement
MC	HCBS Waiver for Elderly & Physically Disabled	18+	19+	<ul style="list-style-type: none"> Nursing home level of care
SC	Community Based In-Home Services Program (CBHS)	18+	18+	<ul style="list-style-type: none"> 1 ADL

Table 3: Uniform Caregiver Assessment and Areas Assessed

Program		Uniform CG Assess. Tool		Areas Assessed												
Type	Name	Yes	No	Ability to Provide Care	Care Duration	Care Frequency	Demo. Info.	Emergency Plan	Info./Educ. Needs	Long-Distance Care	Mental Health	Physical Health	Social Support	Strain	Willing to Provide Care	Other
ALABAMA																
FC	Alabama CARES	X		X	X	X	X				X		X			X
MC	Elderly & Disabled Waiver		X													
ALASKA																
FC	FCSP		X													
SC	Innovative Respite		X													
ARIZONA																
FC	FCSP	X		X	X		X				X			X		
MC	AZ Long-Term Care System (ALICS)		X													
SC	Non-Medical HCBS	X		X	X		X				X			X		
ARKANSAS																
FC	Caring for the Caregiver Arkansas Caregivers		X													
MC	ElderChoices Medicaid Waiver		X													
CALIFORNIA																
FC	FCSP		X													
MC	Multipurpose Senior Services program (MSSP)		X													
SC	Adult Day Health Care Program		X													
SC	Alzheimer's Day Care Resource Center (ADCRC)		X													
SC	Caregiver Resource Centers (CRCs)	X			X	X	X		X	X	X	X	X	X		
SC	In-Home Supportive Services (IHSS)		X													
COLORADO																
FC	FCSP		X													
MC	HCBS for the Elderly, Blind and Disabled		X													
CONNECTICUT																
FC	FCSP	X		X	X	X				X	X	X		X	X	X
MC	Home Care Program for Elders	X		X		X									X	
SC	Statewide Respite Care Program	X		X	X	X				X	X	X		X	X	X
SC	Personal Care Assistance State-Funded Pilot Program	X		X								X				X
DELAWARE																
FC	CARE Delaware	X		X		X	X								X	
MC	Elderly & Disabled Waiver	X		X	X	X								X	X	
DISTRICT OF COLUMBIA																
FC	FCSP		X													
MC	Elderly & Physical Disabilities Waiver		X													

Notes: Table is based on the Part 1 Survey (Question 10).
Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
Assess.=Assessment; CG=Caregiver; Demo.=Demographic; Educ.=Education; Info.=Information

Note.

Program		Uniform CG Assess. Tool		Areas Assessed												
Type	Name	Yes	No	Ability to Provide Care	Care Duration	Care Frequency	Demo. Info.	Emergency Plan	Info./Educ. Needs	Long-Distance Care	Mental Health	Physical Health	Social Support	Strain	Willing to Provide Care	Other
FLORIDA																
FC	FCSP		X													
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X		X			X				X	X		X	X	
SC	Respite for Elders Living in Everyday Families (RELIEF)		X													
SC	Home Care for the Elderly	X		X			X				X	X		X	X	
SC	Community Care for the Elderly	X		X	X		X				X	X		X	X	
SC	Alzheimer's Disease Initiative	X		X	X		X				X	X		X	X	
GEORGIA																
FC	FCSP	X					X							X		X
MC	Community Care Services Program (CCSP)	X		X	X	X	X			X	X	X		X	X	
HAWAII																
FC	FCSP		X													
MC	Nursing Home Without Walls	X		X	X	X	X			X	X	X		X	X	
SC	Kupuna Care	X		X		X	X	X								X
IDAHO																
FC	FCSP		X													
MC	HCBS Aged & Disabled Waiver		X													
SC	Senior Services Act, Respite Program		X													
ILLINOIS																
FC	FCSP		X													
MC	Community Care Program (CCP)		X													
MC	Home Services Program		X													
INDIANA																
FC	Caring and Compassion		X													
MC	Aged & Disabled Medicaid Waiver		X													
SC	CHOICE	X														
IOWA																
FC	Iowa Family Caregiver		X													
MC	Elderly Waiver		X													
KANSAS																
FC	FCSP		X													
MC	Home & Community-Based Frail Elder Waiver	X				X								X	X	
SC	Senior Care Act Program		X													
KENTUCKY																
FC	FCSP		X													
SC	Adult Day/Alzheimer's Respite		X													
LOUISIANA																
FC	FCSP	X		X	X	X	X				X	X		X	X	
MC	Medicaid Home and Community-Based Waiver	X		X	X	X	X			X		X		X	X	
MAINE																
FC	Family Caregiver Program		X													
MC	MaineCare	X		X		X					X			X	X	
SC	Home-Based Care			X		X							X	X	X	
SC	Partners in Caring	X			X	X	X				X			X	X	X

Program		Uniform CG Assess. Tool		Areas Assessed												
Type	Name	Yes	No	Ability to Provide Care	Care Duration	Care Frequency	Demo. Info.	Emergency Plan	Info./Educ. Needs	Long-Distance Care	Mental Health	Physical Health	Social Support	Strain	Willing to Provide Care	Other
MARYLAND																
FC	FCSP		X													
MC	Medicaid Waiver for Older Adults	X		X	X	X	X					X		X	X	
SC	Respite for Caregivers of Adults with Functional Disabilities		X													
MASSACHUSETTS																
FC	FCSP		X													
MC	Home and Community-Based Waiver	X		X		X						X		X	X	
SC	Home Care Program	X		X		X								X	X	
MICHIGAN																
FC	FCSP		X													
MC	MI Choice	X				X									X	
SC	State/Escheat Respite		X													
SC	Caregiver Respite Program		X													
MINNESOTA																
FC	FCSP	X											X			X
MC	Elderly Waiver	X		X									X		X	X
SC	Alternative Care Program	X		X									X		X	X
MISSISSIPPI																
FC	FCSP	X		X	X	X	X	X		X	X	X		X	X	
MC	Elderly & Disabled Waiver		X													
MISSOURI																
FC	FCSP		X													
MC	Aged & Disabled Waiver		X													
MONTANA																
FC	Family Caregiving Support		X													
MC	HCBS Program for Elderly & Physically Disabled	X		X										X	X	
NEBRASKA																
FC	FCSP	X		X							X	X		X		
MC	Aged & Disabled Waiver		X													
SC	Respite Subsidy Program Across the Lifespan		X													
NEVADA																
FC	FCSP		X													
MC	Community Home-Based Initiatives Program		X													
SC	Independent Living Grant		X													
SC	Community-Based Care Caregiving Training		X													
NEW HAMPSHIRE																
FC	FCSP		X													
MC	Elderly and Chronically Ill Waiver		X													

Program		Uniform CG Assess. Tool		Areas Assessed												
Type	Name	Yes	No	Ability to Provide Care	Care Duration	Care Frequency	Demo. Info.	Emergency Plan	Info./Educ. Needs	Long-Distance Care	Mental Health	Physical Health	Social Support	Strain	Willing to Provide Care	Other
NEW JERSEY																
FC	FCSP		X													
MC	Community Care Program for the Elderly & Disabled	X		X	X	X			X	X		X		X	X	
MC	Enhanced Community Options (ECO)	X		X	X	X						X		X	X	
SC	New Jersey Statewide Respite Care Program (SRCP)	X		X	X	X	X				X	X		X		
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias		X													
SC	Jersey Assistance for Community Caregiving	X		X	X	X						X		X	X	
NEW MEXICO																
FC	FCSP	X		X			X			X	X	X		X		X
MC	Disabled & Elderly HCBS Waiver	X		X	X	X	X			X	X	X		X	X	
NEW YORK																
FC	Eldercare Family Support Program (EFSP)		X													
SC	Respite Program		X													
NORTH CAROLINA																
FC	FCSP		X													
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	X		X		X						X		X	X	
SC	Respite Care Program		X													
NORTH DAKOTA																
FC	FCSP	X		X	X	X	X			X		X	X	X	X	X
MC	Aged & Disabled Waiver		X													
SC	Family Home Care		X													
OHIO																
FC	FCSP		X													
MC	PASSPORT HCBS Waiver Program	X		X	X	X	X			X	X	X		X	X	
SC	Alzheimer's Respite Program		X													
OKLAHOMA																
FC	FCSP	X					X								X	
MC	Advantage Program	X		X											X	
SC	Respite Resource Network	X		X			X									
OREGON																
FC	FCSP	X		X											X	
MC	Medicaid Waiver/In-Home Care		X													
SC	Lifespan Respite Care Networks	X			X	X	X									
PENNSYLVANIA																
FC	FCSP	X		X	X	X	X			X	X	X		X	X	
MC	PA Department of Aging 60+ Medicaid Waiver	X		X	X	X	X				X	X		X	X	
SC	PA FCSP	X		X	X	X	X				X	X		X	X	
SC	OPTIONS	X		X	X	X	X				X	X		X	X	
SC	BRIDGE	X		X	X	X	X				X	X		X	X	
RHODE ISLAND																
FC	Partners in CaRing		X													
MC	Home & Community-Based Waiver		X													

Program		Uniform CG Assess. Tool		Areas Assessed												
Type	Name	Yes	No	Ability to Provide Care	Care Duration	Care Frequency	Demo. Info.	Emergency Plan	Info./Educ. Needs	Long-Distance Care	Mental Health	Physical Health	Social Support	Strain	Willing to Provide Care	Other
SOUTH CAROLINA																
FC	FCSP	X			X	X	X			X		X				X
MC	Elderly/Disabled Home and Community-Based Waiver	X		X		X							X			
SOUTH DAKOTA																
FC	Caregiver Program	X		X	X	X	X			X	X	X		X	X	
MC	Home & Community-Based Elderly Waiver	X			X	X										X
TENNESSEE																
FC	FCSP		X													
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities		X													
TEXAS																
FC	FCSP		X													
MC	Community-Based Alternatives		X													
SC	Respite Care Program		X													
SC	In-Home & Family Support Program		X													
UTAH																
FC	Caregiver Support Program	X		X	X	X	X			X	X	X		X	X	
MC	Medicaid Aging Waiver	X		X	X	X		X	X			X			X	
SC	Home & Community-Based Alternatives	X		X		X					X	X		X	X	
VERMONT																
FC	FCSP	X		X		X					X	X		X		
MC	Home-Based Medicaid Waiver		X													
VIRGINIA																
FC	FCSP	X					X			X						X
MC	Elderly & Disabled Waiver	X		X	X	X	X							X	X	
SC	Caregiver Grant Program		X													
SC	Respite Care Initiative Grant	X												X		
SC	Respite Care Grant Program 2003		X													
WASHINGTON																
FC	FCSP	X		X			X	X	X					X		
MC	Community Options Program Entry System (COPES)	X		X	X	X	X				X	X		X	X	
SC	WA FCSP	X		X			X	X	X					X		X
SC	Respite Care Services	X		X	X		X	X	X			X		X		
WEST VIRGINIA																
FC	Family Caregiver Support		X													
MC	Medicaid Aged & Disabled Waiver		X													
WISCONSIN																
FC	FCSP		X													
MC	Community Options Program Waiver (COP-W)		X												X	
SC	Alzheimer's Family & Caregiver Support Program		X													
WYOMING																
FC	FCSP	X		X	X	X					X	X		X	X	
MC	HCBS Waiver for Elderly & Physically Disabled		X													
SC	Community Based In-Home Services Program (CBHS)	X		X	X	X	X			X	X	X		X	X	

Table 4: Caregiver Support Services

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmklr/ Chore/ Personal Care	Home Mods.	I & A	Legal/ Financial Consult.	Respite Care	Support Groups	Trans.	Other services
ALABAMA																			
FC	Alabama CARES	X	X		X	X		X	X			X	X	X		X	X	X	Hydro-therapy; Home-delivered meals
MC	Elderly & Disabled Waiver	X	X	X		X							X						
ALASKA																			
FC	FCSP		X			X		X		X				X	X	X	X		
SC	Innovative Respite											X				X			
ARIZONA																			
FC	FCSP	X	X		X	X		X		X			X	X		X	X	X	
MC	AZ Long-Term Care System (ALICS)	X	X		X	X			X		X		X	X		X		X	
SC	Non-Medical HCBS	X	X		X	X		X		X			X	X		X	X	X	
ARKANSAS																			
FC	Caring for the Caregiver Arkansas	X	X	X		X	X	X				X	X	X	X	X	X	X	
MC	ElderChoices Medicaid Waiver															X			
CALIFORNIA																			
FC	FCSP	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	AAAs identify local needs & request new svcs
MC	Multipurpose Senior Services Program (MSSP)															X			
SC	Adult Day Health Care Program															X			
SC	Alzheimer's Day Care Resource Center (ADCRC)					X		X		X				X		X	X		
SC	Caregiver Resource Centers (CRCs)		X			X	X	X	X	X	X			X	X	X	X	X	
SC	In-Home Supportive Services (IHSS)							X						X		X			

Note. Table is based on the Part 1 Survey (Question 18).
Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
Consum.=Consumable; Consult.=Consultation; Educ.=Education; eHealth=Consumer eHealth Applications (excluding read-only websites); Emerg.=Emergency; Hmkr=Homemaker; I&A=Information & Assistance; Mgt.=Management; Supp=Supplemental; Svcs=Services; Tech.=Technology; Trans.=Transportation

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/ Chore/ Personal Care	Home Mods.	I & A	Legal/ Financial Consult.	Respite Care	Support Groups	Trans.	Other services
COLORADO																			
FC	FCSP	X	X		X	X		X		X	X	X	X	X		X			
MC	HCBS for the Elderly, Blind and Disabled	X	X						X			X	X	X		X		X	
CONNECTICUT																			
FC	FCSP	X	X		X	X		X	X			X	X	X	X	X	X	X	
MC	Home Care Program for Elders		X			X			X			X	X	X		X		X	
SC	Statewide Respite Care Program							X		X				X		X			
SC	Personal Care Assistance State-Funded Pilot Program					X			X		X	X	X			X			
DELAWARE																			
FC	CARE Delaware		X					X	X			X	X	X		X	X		
MC	Elderly & Disabled Waiver	X										X	X			X			
DISTRICT OF COLUMBIA																			
FC	FCSP		X	X	X	X		X		X	X	X	X	X		X	X	X	
MC	Elderly & Physical Disabilities Waiver		X			X		X	X			X	X	X		X		X	
FLORIDA																			
FC	FCSP	X			X	X		X	X			X	X	X	X	X	X	X	
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X			X	X		X	X			X	X	X	X	X	X	X	
SC	Respite for Elders Living in Everyday Families (RELIEF)	X			X	X		X	X			X	X	X	X	X	X		
SC	Home Care for the Elderly	X			X	X		X	X			X	X	X	X	X	X	X	
SC	Community Care for the Elderly	X			X	X		X	X			X	X	X	X	X	X	X	
SC	Alzheimer's Disease Initiative	X			X	X		X	X			X	X	X	X	X	X	X	
GEORGIA																			
FC	FCSP	X	X	X	X	X		X				X	X	X	X	X	X		Adult day health; Home-delivered meals; Skilled nursing
MC	Community Care Services Program (CCSP)		X						X			X		X		X			

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkt/ Chore/ Personal Care	Home Mods.	I & A	Legal/ Financial Consult.	Respite Care	Support Groups	Trans.	Other services
HAWAII																			
FC	FCSP	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	Yard service; Massage Therapy; Haircuts
MC	Nursing Home Without Walls					X										X			
SC	Kupuna Care		X									X				X		X	Attendant care; Home-delivered meals
IDAHO																			
FC	FCSP	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
MC	HCBS Aged & Disabled Waiver									X						X			
SC	Senior Services Act, Respite Program		X					X		X	X	X		X		X		X	
ILLINOIS																			
FC	FCSP	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	
MC	Community Care Program (CCP)																		
MC	Home Services Program	X	X			X			X		X	X	X	X	X	X			
INDIANA																			
FC	Caring and Compassion	X	X	X	X	X		X	X	X	X	X	X	X		X	X	X	
MC	Aged & Disabled Medicaid Waiver	X	X						X			X	X			X		X	
SC	CHOICE	X	X					X	X			X	X		X	X		X	
IOWA																			
FC	Iowa Family Caregiver	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	Provider training
MC	Elderly Waiver	X						X								X			
KANSAS																			
FC	FCSP				X	X		X				X	X	X		X	X	X	Nutritional counseling
MC	Home & Community-Based Frail Elder Waiver													X		X			
SC	Senior Care Act program	X	X		X				X			X	X			X		X	
KENTUCKY																			
FC	FCSP	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	
SC	Adult Day/ Alzheimer's Respite	X	X					X				X	X	X		X		X	
LOUISIANA																			
FC	FCSP											X		X		X			
MC	Medicaid Home and Community-Based Waiver	X	X			X		X	X	X	X	X	X	X	X		X	X	

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/Chore/Personal Care	Home Mods.	I & A	Legal/Financial Consult.	Respite Care	Support Groups	Trans.	Other services
MAINE																			
FC	Family Caregiver Program						X	X		X				X		X	X		
MC	MaineCare													X		X	X		
SC	Home-Based Care													X		X	X		
SC	Partners in Caring	X	X					X		X		X	X	X		X			
MARYLAND																			
FC	FCSP	X	X	X	X	X		X	X	X		X	X	X	X	X	X	X	Other services identified by families
MC	Medicaid Waiver for Older Adults		X		X			X	X	X		X	X			X			
SC	Respite for Caregivers of Adults with Functional Disabilities		X			X		X	X	X		X		X		X			
MASSACHUSETTS																			
FC	FCSP	X	X		X	X		X	X	X		X	X	X	X	X	X		Alz. coaching; Stress mgmt; End-of-life planning
MC	Home and Community-Based Waiver											X	X			X			
SC	Home Care Program		X						X			X	X	X		X		X	
MICHIGAN																			
FC	FCSP	X			X	X		X		X		X	X	X		X	X	X	
MC	MI Choice					X		X								X			
SC	State/Escheat Respite															X			
SC	Caregiver Respite Program															X		X	
MINNESOTA																			
FC	FCSP	X	X			X		X		X			X	X	X	X	X	X	
MC	Elderly Waiver		X	X		X	X	X		X	X	X	X	X	X	X	X	X	
SC	Alternative Care Program		X	X		X	X			X	X	X	X	X	X	X	X	X	
MISSISSIPPI																			
FC	FCSP				X	X		X		X	X	X	X	X		X	X		Home-delivered meals
MC	Elderly & Disabled Waiver		X									X				X		X	
MISSOURI																			
FC	FCSP	X	X	X	X	X	X	X	X	X			X	X	X	X	X	X	Home-delivered meals
MC	Aged & Disabled Waiver											X				X			

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/ Chore/ Personal Care	Home Mods.	I & A	Legal/ Financial Consult.	Respite Care	Support Groups	Trans.	Other services
MONTANA																			
FC	Family Caregiving Support	X						X				X		X		X	X	X	
MC	HCBS Program for Elderly & Physically Disabled		X			X		X		X						X	X		
NEBRASKA																			
FC	FCSP Aged & Disabled Waiver	X	X		X			X	X			X	X	X		X	X	X	
MC	Respite Subsidy Program Across the Lifespan															X			
NEVADA																			
FC	FCSP Community Home-Based Initiatives Program													X		X			
MC	Independent Living Grant	X	X			X		X				X	X	X	X	X		X	
SC	Community-Based Care Carving Training							X											
NEW HAMPSHIRE																			
FC	FCSP	X			X				X	X		X	X	X		X	X	X	Home-delivered meals; Nursing, assisted living, or residential care
MC	Elderly and Chronically Ill Waiver	X	X		X	X			X			X	X	X		X		X	
NEW JERSEY																			
FC	FCSP		X		X	X		X	X			X	X	X	X	X	X		
MC	Community Care Program for the Elderly & Disabled					X		X	X	X				X		X			
MC	Enhanced Community Options (ECO)					X		X	X	X				X		X			
SC	New Jersey Statewide Respite Care Program (SRCP)							X	X							X			
	Adult Day Services																		
SC	Program for Persons with Alzheimer's Disease or Related Dementias					X		X						X		X	X		
SC	Jersey Assistance for Community Caregiving					X		X	X	X	X			X		X			

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/ Chore/ Personal Care	Home Mods.	I & A	Legal/ Financial Consult.	Respite Care	Support Groups	Trans.	Other services
NEW MEXICO																			
FC	FCSP		X	X	X	X		X			X	X	X	X	X	X	X	X	
MC	Disabled & Elderly HCBS Waiver							X						X		X			
NEW YORK																			
FC	Eldercare Family Support Program (EFSP)	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
SC	Respite Program	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	
NORTH CAROLINA																			
FC	FCSP	X	X		X	X		X	X	X		X	X	X	X	X	X	X	Supp. svcs
MC	Community Alternatives Program for Disabled Adults (CAP/DA)		X		X	X			X	X	X	X	X	X	X	X			
SC	Respite Care Program					X		X				X		X		X	X		
NORTH DAKOTA																			
FC	FCSP		X			X		X				X		X	X	X	X		
MC	Aged & Disabled Waiver							X								X			
SC	Family Home Care			X												X			
OHIO																			
FC	FCSP	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	
MC	PASSPORT HCBS Waiver Program	X				X		X	X			X	X	X		X		X	Home-delivered meals
SC	Alzheimer's Respite Program		X			X		X	X	X	X	X		X		X	X		Safe return Scholarship
OKLAHOMA																			
FC	FCSP					X		X	X			X		X	X	X	X	X	Equipment
MC	Advantage Program															X			
SC	Respite Resource Network															X			
OREGON																			
FC	FCSP	X			X	X	X	X	X	X	X	X	X	X	X	X	X	X	
MC	Medicaid Waiver/In-Home Care	X	X		X		X	X	X	X	X	X	X	X	X	X	X	X	
SC	Lifespan Respite Care Networks			X		X		X						X		X	X		
PENNSYLVANIA																			
FC	FCSP	X	X			X		X					X	X		X			
MC	PA Department of Aging 60+ Medicaid Waiver													X		X			
SC	PA FCSP	X	X			X		X					X	X		X			
SC	OPTIONS													X		X			
SC	BRIDGE													X		X			

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/Chore/Personal Care	Home Mods.	I & A	Legal/Financial Consult.	Respite Care	Support Groups	Trans.	Other services
RHODE ISLAND																			
FC	Partners in CarIng	X	X					X		X	X			X	X	X	X		Supp. svcs (tangible supplies)
MC	Home & Community-Based Waiver		X							X				X					
SOUTH CAROLINA																			
FC	FCSP					X		X								X			Access assistance; Supp. svcs
MC	Elderly/Disabled Home and Community-Based Waiver		X							X						X			
SOUTH DAKOTA																			
FC	Caregiver Program	X	X		X			X	X	X	X	X	X	X	X	X	X	X	Home-delivered meals
MC	Home & Community-Based Elderly Waiver				X				X			X				X			Home-delivered meals; Nursing & assisted living for medication admin.
TENNESSEE																			
FC	FCSP	X	X		X	X		X	X			X	X	X		X	X		
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities																		
TEXAS																			
FC	FCSP		X		X	X		X	X	X	X	X	X	X	X	X	X	X	Home-delivered meals; Hospice
MC	Community-Based Alternatives															X			
SC	Respite Care Program											X				X			
SC	In-Home & Family Support Program			X															
UTAH																			
FC	Caregiver Support Program	X	X		X	X		X	X	X	X	X	X	X	X	X	X	X	
MC	Medicaid Aging Waiver	X	X		X	X		X	X			X	X	X		X	X	X	
SC	Home & Community-Based Alternatives		X					X	X	X		X	X	X		X	X		
VERMONT																			
FC	FCSP		X	X		X		X			X			X	X	X	X	X	
MC	Home-Based Medicaid Waiver															X			

Program		Services Provided to Support Family Caregivers																	
Type	Name	Assistive Tech.	Care Mgt.	Cash Grant	Consum. Supplies	Counseling	eHealth	Educ. & Training	Emerg. Response	Family Consult.	Family Meetings	Hmkr/Chore/Personal Care	Home Mods.	I & A	Legal/Financial Consult.	Respite Care	Support Groups	Trans.	Other services
VIRGINIA																			
FC	FCSP	X	X		X	X		X	X			X	X	X	X	X	X	X	
MC	Elderly & Disabled Waiver		X					X				X				X			
SC	Caregiver Grant Program			X															
SC	Respite Care Initiative Grant											X				X			Hospice
SC	Respite Care Grant Program 2003															X		X	
WASHINGTON																			
FC	FCSP	X			X	X		X		X		X	X	X	X	X	X	X	
MC	Community Options Program Entry System (COPES)																		
SC	WA FCSP	X			X			X		X		X	X	X	X	X	X	X	
SC	Respite Care Services															X			
WEST VIRGINIA																			
FC	Family Caregiver Support							X						X		X	X		
MC	Medicaid Aged & Disabled Waiver													X					
WISCONSIN																			
FC	FCSP	X	X			X		X		X	X	X	X	X	X	X	X	X	
MC	Community Options Program Waiver (COP-W)							X						X		X			
SC	Alzheimer's Family & Caregiver Support Program	X	X	X	X	X		X	X	X	X	X	X	X	X	X	X	X	Any svc needed to keep the person in community
WYOMING																			
FC	FCSP	X	X			X		X					X	X		X	X		
MC	HCBS Waiver for Elderly & Physically Disabled															X			
SC	Community Based In-Home Services Program (CBHS)															X			

Table 5: Respite Care

Program		Provide Respite		Types of Respite Care Offered						CG Must Live with CR to Receive Respite		Respite Cap		Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	Yes	No	Yes	No	N/A
ALABAMA																
FC	Alabama CARES	X		X	X		X				X	X			X	
MC	Elderly & Disabled Waiver	X			X						X	X				
ALASKA																
FC	Family Caregiver Support Program	X		X	X					X			X			X
SC	Innovative Respite	X			X			Special activities			X				X	
ARIZONA																
FC	Family Caregiver Support Program	X		X	X		X				X		X			X
MC	AZ Long-Term Care System (ALTCS)	X		X	X						X	X				
SC	Non-Medical Home and Community Based Services	X		X	X		X				X		X			X
ARKANSAS																
FC	Caring for the Caregiver	X		X	X						X	X				X
MC	Arkansas Caregivers ElderChoices Medicaid Waiver	X		X	X		X				X	X		X		
CALIFORNIA																
FC	Family Caregiver Support Program	X		X	X		X				X		X			X
MC	Multipurpose Senior Services Program (MSSP)	X		X	X								X			X
SC	Adult Day Health Care Program	X		X							X		X			X
SC	Alzheimer's Day Care Resource Center (ADCRC)	X		X							X		X			X
SC	Caregiver Resource Centers (CRCs)	X		X	X		X			X		X		X		
SC	In-Home Supportive Services (IHSS)	X			X						X		X			X
COLORADO																
FC	Family Caregiver Support Program	X		X	X		X				X	X			X	
MC	Home and Community-Based Services for the Elderly, Blind and Disabled	X		X	X							X		X		

Note: Table is based on the Part 1 Survey (Question 20).
Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
CG=Caregiver; CR=Care Receiver; N/A=Not Applicable; NR=No Response; Svcs.=Services

Program		Provide Respite		Types of Respite Care Offered							CG Must Live with CR to Receive Respite		Respite Cap		Respite Cap Uniform across Program Sites	
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	N/A
CONNECTICUT																
FC	Family Caregiver Support Program	X		X	X	X	X	Live-in home health aide			X		X			
MC	Home Care Program for Elders	X		X	X	X	X				X			X		X
SC	Statewide Respite Care Program	X		X	X	X		Live-in home health aide			X		X			
SC	Personal Care Assistance State-Funded Pilot Program	X		X	X	X	X				X		X			X
DELAWARE																
FC	CARE Delaware	X		X	X	X	X				X		X			
MC	Elderly & Disabled Waiver	X		X	X	X					X		X			
DISTRICT OF COLUMBIA																
FC	Family Caregiver Support Program	X		X	X	X	X				X			X		X
MC	Elderly and Physical Disabilities Waiver	X			X	X	X			X			X			
FLORIDA																
FC	Family Caregiver Support Program	X		X	X	X	X				X					X
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X		X	X	X	X				X					X
SC	Respite for Elders Living in Everyday Families (RELIEF)	X			X					X			X			
SC	Home Care for the Elderly	X		X	X	X	X			X						X
SC	Community Care for the Elderly	X		X	X	X	X				X					X
SC	Alzheimer's Disease Initiative	X		X	X	X	X				X					X
GEORGIA																
FC	Family Caregiver Support Program	X		X	X	X	X	Extended respite (more than one weekend)			X					X
MC	Community Care Services Program (CCSP)	X		X	X	X	X				X			X		X
HAWAII																
FC	Family Caregiver Support Program	X		X	X	X	X	Weekend support groups				X				X
MC	Nursing Home Without Walls	X		X	X	X	X			X						X
SC	Kupuna Care	X		X	X							X				X
IDAHO																
FC	Family Caregiver Support Program	X		X	X	X				X				X		X
MC	HCBS Aged & Disabled Waiver	X		X	X					X			X		X	
SC	Senior Services Act, Respite Program	X		X	X	X				X				X		X

Program		Provide Respite		Types of Respite Care Offered								CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/ Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A		
ILLINOIS																				
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X				
MC	Community Care Program (CCP)	X		X								X			X			X		
MC	Home Services program	X		X	X						X		X			X		X		
INDIANA																				
FC	Caring and Compassion	X		X	X		X				X		X			X				
MC	Aged & Disabled Medicaid Waiver	X		X	X	X	X				X		X					X		
SC	CHOICE	X			X		X							X				X		
IOWA																				
FC	Iowa Family Caregiver	X		X	X	X					X			X				X		
MC	Elderly Waiver	X		X	X	X	X			X				X				X		
KANSAS																				
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X				
MC	Home & Community Based Frail Elder Waiver	X		X	X	X					X		X			X				
SC	Senior Care Act Program	X		X	X		X				X			X				X		
KENTUCKY																				
FC	Family Caregiver Support Program	X		X	X						X		X				X			
SC	Adult Day / Alzheimer's Respite	X		X	X		X				X			X				X		
LOUISIANA																				
FC	Family Caregiver Support Program	X			X						X		X			X				
MC	Medicaid Home and Community-Based Waiver		X						X			X			X			X		
MAINE																				
FC	Family Caregiver Program	X		X	X	X				X			X				X			
MC	MaineCare	X		X	X	X					X		X			X				
SC	Home-Based Care	X		X	X	X					X		X			X				
SC	Partners in Caring	X		X	X	X	X				X		X			X				
MARYLAND																				
FC	Family Caregiver Support Program	X		X	X	X	X				X		X				X			
MC	Medicaid Waiver for Older Adults	X		X	X	X					X		X			X				
SC	Respite for Caregivers or Adults with Functional Disabilities	X		X	X	X	X				X		X			X				
MASSACHUSETTS																				
FC	Family Caregiver Support Program	X		X	X	X	X				X		X				X			
MC	Home and Community-Based Waiver	X		X	X	X	X							X				X		
SC	Home Care Program	X		X	X	X	X				X			X				X		

Program		Provide Respite		Types of Respite Care Offered							CG Must Live with CR to Receive Respite			Respite Cap			Respite Cap Uniform across Program Sites		
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/ Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	Yes	No	N/A	
MICHIGAN																			
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X	
MC	MI Choice	X		X	X	X					X			X				X	
	SC State / Escheat Respite	X		X	X	X	X				X			X				X	
SC	Caregiver Respite Program	X		X	X	X	X				X			X				X	
MINNESOTA																			
FC	Family Caregiver Support Program	X		X	X	X	X				X			X				X	
MC	Elderly Waiver	X		X	X	X		Out of home care provided by neighbor, friend, or family			X			X				X	
SC	Alternative Care Program	X		X	X	X		Out of home care provided by neighbor, friend, or family			X			X				X	
MISSISSIPPI																			
FC	Family Caregiver Support Program	X		X	X	X	X				X			X		X			
MC	Elderly and Disabled Waiver	X		X	X	X				X				X		X			
MISSOURI																			
FC	Family Caregiver Support Program	X		X	X		X				X			X			X		
MC	Aged and Disabled Waiver	X		X	X	X						X						X	
MONTANA																			
FC	Family Caregiving Support	X		X	X	X				X								X	
MC	Home and Community-Based Services Program for Elderly and Physically Disabled	X		X	X	X	X				X			X				X	
NEBRASKA																			
FC	Family Caregiver Support Program	X		X	X	X	X				X			X			X		
MC	Aged and Disabled Waiver	X		X	X	X	X	Individualized services		X				X				X	
SC	Respite Subsidy Program Across the Lifespan	X		X	X	X	X			X				X					
NEVADA																			
FC	Family Caregiver Support Program	X			X						X			X				X	
MC	Community Home-Based Initiatives Program	X		X	X	X	X				X			X				X	
SC	Independent Living Grant	X		X	X	X	X				X			X				X	
SC	Community-Based Care Caregiving Training		X						X			X				X		X	

Program		Provide Respite		Types of Respite Care Offered							CG Must Live with CR to Receive Respite		Respite Cap		Respite Cap Uniform across Program Sites	
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	Yes	N/A
NEW HAMPSHIRE																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X		X	
MC	Elderly and Chronically Ill Waiver	X		X	X	X	X				X		X		X	
NEW JERSEY																
FC	Family Caregiver Support Program	X		X	X						X		X			X
MC	Community Care Program for the Elderly and Disabled	X		X	X	X	X	Assisted living			X		X		X	
MC	Enhanced Community Options (ECO)	X		X	X	X	X	Assisted living			X		X		X	
SC	New Jersey Statewide Respite Care Program (SRCP)	X		X	X	X	X				X		X		X	
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	X		X						X			X			
SC	Jersey Assistance for Community Caregiving	X		X	X	X	X	Assisted living			X		X		X	
NEW MEXICO																
FC	Family Caregiver Support Program	X		X	X	X					X		X			X
MC	Disabled and Elderly Home and Community-Based Services Waiver	X			X					X			X		X	
NEW YORK																
FC	Eldercare Family Support Program (EFSP)	X		X	X	X					X		X			X
SC	Respite Program	X		X	X	X	X				X		X		X	
NORTH CAROLINA																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	X		X	X	X	X				X		X		X	
SC	Respite Care Program	X		X	X						X		X			X
NORTH DAKOTA																
FC	Family Caregiver Support Program	X		X	X	X	X			X			X		X	
MC	Aged & Disabled Waiver	X		X	X	X	X			X			X		X	
SC	Family Home Care	X			X	X	X			X			X		X	
OHIO																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X
MC	PASSPORT HCBS Waiver Program	X		X	X						X		X			X
SC	Alzheimer's Respite Program	X		X	X	X	X				X		X			X

Program		Provide Respite		Types of Respite Care Offered							CG Must Live with CR to Receive Respite		Respite Cap		Respite Cap Uniform across Program Sites	
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	Yes	N/A
OKLAHOMA																
FC	Family Caregiver Support Program	X		X	X	X					X		X		X	
MC	Advantage Program	X			X	X				NR	NR	NR		X		X
SC	Respite Resource Network	X		X	X	X	X				X		X		X	
OREGON																
FC	Family Caregiver Support Program	X		X	X	X	X			NR	NR	NR	X			X
MC	Medicaid Waiver / In-Home Care	X		X	X	X						X		X		X
SC	Lifespan Respite Care Networks	X		X	X	X	X				X			X		X
PENNSYLVANIA																
FC	Family Caregiver Support Program	X		X	X	X	X				X			X		X
MC	PA Department of Aging 60+ Medicaid Waiver	X		X	X	X	X				X			X		X
SC	PA Family Caregiver Support Program	X		X	X	X	X			X				X		X
SC	OPTIONS	X		X	X	X	X				X			X		X
SC	BRIDGE	X		X	X	X	X				X			X		X
RHODE ISLAND																
FC	Partners in Caring	X		X	X	X			X		X		X			X
MC	Home and Community-Based Waiver		X									X				
SOUTH CAROLINA																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X
MC	Elderly / Disabled Home and Community-Based Waiver	X		X		X		Companion services			X		X			
SOUTH DAKOTA																
FC	Caregiver Program	X		X	X	X	X			X			X			
MC	Home and Community-Based Elderly Waiver	X		X								X		X		X
TENNESSEE																
FC	Family Caregiver Support Program	X		X	X	X	X					X	X		X	
SC	Home and Community-Based Long-Term Care for Non-Medicaid Elderly and Adults with Disabilities		X						X			X				X
TEXAS																
FC	Family Caregiver Support Program	X		X	X	X					X		X			X
MC	Community-Based Alternatives	X			X	X					X		X		X	
SC	Respite Care Program	X		X	X	X				X			X		X	
SC	In-Home and Family Support Program	X		X	X	X				X				X		X

Program		Provide Respite		Types of Respite Care Offered							CG Must Live with CR to Receive Respite		Respite Cap		Respite Cap Uniform across Program Sites	
Type	Name	Yes	No	Adult Day Svcs.	In-home	Overnight	Weekend/Camp	Other Respite	N/A	Yes	No	N/A	Yes	No	N/A	
UTAH																
FC	Caregiver Support Program	X		X	X	X	X				X		X			
MC	Medicaid Aging Waiver	X		X	X	X								X		X
SC	Home and Community-Based Alternatives	X		X	X	X	X						NR	NR		X
VERMONT																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X		X	
MC	Home-Based Medicaid Waiver	X		X	X	X				NR	NR		X			
VIRGINIA																
FC	Family Caregiver Support Program	X		X	X	X	X				X			X		X
MC	Elderly and Disabled Waiver	X		X	X	X	X			X			X			
SC	Caregiver Grant Program		X						X			X				X
SC	Respite Care Initiative Grant	X		X	X			Companion services; Hospice		X			X			
SC	Respite Care Grant Program 2003	X		X				Transportation to adult day care			X					X
WASHINGTON																
FC	Family Caregiver Support Program	X		X	X	X	X				X			X		X
MC	Community Options Program Entry System (COPES)		X						X			X			X	
SC	WA Family Caregiver Support Program	X		X	X	X	X				X			X		X
SC	Respite Care Services	X		X	X	X	X				X			X		X
WEST VIRGINIA																
FC	Family Caregiver Support	X		X	X		X				X		X			X
MC	Medicaid Aged and Disabled Waiver		X						X			X			X	
WISCONSIN																
FC	Family Caregiver Support Program	X		X	X	X	X			X			X		X	
MC	Community Options Program Waiver (COP-W)	X		X	X	X	X			X				X		X
SC	Alzheimer's Family & Caregiver Support Program	X		X	X	X	X				X			X		X
WYOMING																
FC	Family Caregiver Support Program	X		X	X	X	X				X		X			X
MC	Home and Community-Based Services Waiver for Elderly and Physically Disabled	X		X	X						X		X			X
SC	Community Based In-Home Services Program (CBHS)	X		X	X			Chore services; Hospice			X			X		X

Table 6: Training on Caregiving

Program		Training Provided?			Focus of Training											
Program Type	Program Name	Yes	No	In process	Best Practices	CD – Role of Staff	CD - Technical Issues	CG Assessment Issues	CG Intake Issues	CR Disabilities	Cultural Issues	Data & Reporting	Outreach/ Public Awareness	Program Evaluation	Rural Issues	Other
ALABAMA																
FC	Alabama CARES		X													
MC	Elderly & Disabled Waiver		X													
ALASKA																
FC	FCSP		X													
SC	Innovative Respite		X													
ARIZONA																
FC	FCSP		X													
MC	AZ Long-Term Care System (ALTCs)		X													
SC	Non-Medical HCBS		X													
ARKANSAS																
FC	Caring for the Caregiver Arkansas Caregivers	X				X	X	X	X	X	X	X	X	X	X	
MC	Arkansas Caregivers ElderChoices Medicaid Waiver	X														
CALIFORNIA																
FC	FCSP		X													
MC	Multipurpose Senior Services Program (MSSP)		X													
SC	Adult Day Health Care Program		X													
SC	Alzheimer's Day Care Resource Center (ADCRC)		X													
SC	Caregiver Resource Centers (CRCs)	X					X					X		X		
SC	In-Home Supportive Services (IHSS)			X												
COLORADO																
FC	FCSP		X													
MC	HCBS for the Elderly, Blind and Disabled		X													
CONNECTICUT																
FC	FCSP		X													
MC	Home Care Program for Elders	X			X	X	X				X	X			X	
SC	Statewide Respite Care Program	X														
SC	Personal Care Assistance State-Funded Pilot Program		X													
DELAWARE																
FC	CARE Delaware	X														
MC	Elderly & Disabled Waiver		X													
DISTRICT OF COLUMBIA																
FC	FCSP		X					X		X	X	X			X	
MC	Elderly & Physical Disabilities Waiver				X											

Notes: Table is based on Part 1 Survey (Question 13)
Program Type: FC=National Family Caregiver Support Program; MC=Aged/Disabled Medicaid HCBS Waiver; SC=State-Funded Program
Program Name: FCSP=Family Caregiver Support Program; HCBS=Home and Community-Based Services
CD=Consumer Direction; CG=Caregiver; CR=Care Receiver; In process=In process of developing trainings

Program			Training Provided?			Focus of Training										
Program Type	Program Name	Yes	No	In process	Best Practices	CD – Role of Staff	CD - Technical Issues	CG Assessment Issues	CG Intake Issues	CR Disabilities	Cultural Issues	Data & Reporting	Outreach/ Public Awareness	Program Evaluation	Rural Issues	Other
FLORIDA																
FC	FCSP	X														X
MC	Aged & Disabled Adult Medicaid HCBS Waiver	X											X			
SC	Respite for Elders Living in Everyday Families (RELIEF)		X													X
SC	Home Care for the Elderly	X														X
SC	Community Care for the Elderly	X														X
SC	Alzheimer's Disease Initiative	X								X						X
GEORGIA																
FC	FCSP	X					X	X		X	X			X		
MC	Community Care Services Program (CCSP)	X			X											X
HAWAII																
FC	FCSP		X													
MC	Nursing Home Without Walls	X			X	X	X	X								
SC	Kupuna Care		X													
IDAHO																
FC	FCSP	X			X			X				X			X	
MC	HCBS Aged & Disabled Waiver		X													
SC	Senior Services Act, Respite Program	X			X	X		X				X			X	
ILLINOIS																
FC	FCSP	X			X	X	X	X	X	X	X	X	X			
MC	Community Care Program (CCP)	X														X
MC	Home Services Program	X				X	X									
INDIANA																
FC	Caring and Compassion			X								X		X	X	
MC	Aged & Disabled Medicaid Waiver		X													
SC	CHOICE	X				X	X	X	X	X	X		X		X	
IOWA																
FC	Iowa Family Caregiver		X													
MC	Elderly Waiver	X			X		X		X			X		X		
KANSAS																
FC	FCSP		X													
MC	Home & Community-Based Frail Elder Waiver		X													
SC	Senior Care Act Program		X													
KENTUCKY																
FC	FCSP	X			X	X	X	X	X			X	X	X		
SC	Adult Day/Alzheimer's Respite		X													
LOUISIANA																
FC	FCSP	X											X			
MC	Medicaid Home and Community-Based Waiver	X			X	X	X	X	X	X	X	X	X	X	X	X
MAINE																
FC	Family Caregiver Program	X			X			X	X			X	X			
MC	MaineCare		X													
SC	Home-Based Care		X													
SC	Partners in Caring	X			X				X	X		X				X
MARYLAND																
FC	FCSP	X			X	X	X	X			X	X	X	X		
MC	Medicaid Waiver for Older Adults			X	X	X		X			X	X		X		
SC	Respite for Caregivers of Adults with Functional Disabilities	X														X

Program			Training Provided?			Focus of Training										
Program Type	Program Name	Yes	No	In process	Best Practices	CD – Role of Staff	CD - Technical Issues	CG Assessment Issues	CG Intake Issues	CR Disabilities	Cultural Issues	Data & Reporting	Outreach/ Public Awareness	Program Evaluation	Rural Issues	Other
MASSACHUSETTS																
FC	FCSP	X			X			X	X	X	X	X	X		X	X
MC	Home and Community-Based Waiver		X													
SC	Home Care Program		X													
MICHIGAN																
FC	FCSP		X													
MC	MI Choice		X													
SC	State/Escheat Respite		X													
SC	Caregiver Respite Program		X													
MINNESOTA																
FC	FCSP	X			X	X	X	X								X
MC	Elderly Waiver	X			X	X	X	X	X	X	X		X		X	
SC	Alternative Care Program	X			X	X	X	X	X	X	X		X		X	
MISSISSIPPI																
FC	FCSP	X			X			X	X	X	X	X	X			
MC	Elderly & Disabled Waiver		X													
MISSOURI																
FC	FCSP		X													
MC	Aged & Disabled Waiver		X													
MONTANA																
FC	Family Caregiving Support	X						X								
MC	HCBS Program for Elderly & Physically Disabled	X			X					X	X	X	X	X	X	
NEBRASKA																
FC	FCSP		X													
MC	Aged & Disabled Waiver		X													
SC	Respite Subsidy Program Across the Lifespan		X													
NEVADA																
FC	FCSP		X													
MC	Community Home-Based Initiatives Program		X													
SC	Independent Living Grant	X								X			X		X	
SC	Community-Based Care (Caregiving Training)		X													
NEW HAMPSHIRE																
FC	FCSP	X			X	X	X	X	X	X	X	X	X	X	X	X
MC	Elderly and Chronically Ill Waiver		X													
NEW JERSEY																
FC	FCSP			X												
MC	Community Care Program for the Elderly & Disabled	X			X	X	X	X	X		X	X	X	X		
MC	Enhanced Community Options (ECO)	X			X	X	X	X	X			X	X	X		
SC	New Jersey Statewide Respite Care Program (SRCP)	X						X	X			X				
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	X								X						X
SC	Jersey Assistance for Community Caregiving	X			X	X	X	X	X			X		X		
NEW MEXICO																
FC	FCSP	X			X		X	X	X	X	X	X	X	X	X	
MC	Disabled & Elderly HCBS Waiver		X													
NEW YORK																
FC	Eldercare Family Support Program (EFSP)			X	X	X	X	X	X		X	X	X	X	X	
SC	Respite Program		X													

Program		Training Provided?			Focus of Training											
Program Type	Program Name	Yes	No	In process	Best Practices	CD – Role of Staff	CD - Technical Issues	CG Assessment Issues	CG Intake Issues	CR Disabilities	Cultural Issues	Data & Reporting	Outreach/ Public Awareness	Program Evaluation	Rural Issues	Other
NORTH CAROLINA																
FC	FCSP	X			X				X	X	X	X	X	X		
MC	Community Alternatives Program for Disabled Adults (CAP/DA)		X													
SC	Respite Care Program		X													
NORTH DAKOTA																
FC	FCSP	X						X	X			X	X			
MC	Aged & Disabled Waiver		X													
SC	Family Home Care	X					X					X				
OHIO																
FC	FCSP	X			X			X	X					X		
MC	PASSPORT HCBS Waiver Program			X		X										
SC	Alzheimer's Respite Program		X													
OKLAHOMA																
FC	FCSP			X	X	X							X			X
MC	Advantage Program		X													
SC	Respite Resource Network		X													
OREGON																
FC	FCSP	X			X		X	X	X		X	X	X	X	X	
MC	Medicaid Waiver/In-Home Care	X			X	X		X	X		X		X		X	
SC	Lifespan Respite Care Networks	X			X		X				X	X	X			
PENNSYLVANIA																
FC	FCSP	X			X	X	X	X	X	X	X	X	X	X	X	
MC	PA Department of Aging 60+ Medicaid Waiver		X													
SC	PA FCSP	X			X	X	X	X	X	X	X	X	X		X	
SC	OPTIONS		X													
SC	BRIDGE		X													
RHODE ISLAND																
FC	Partners in Caring	X				X	X	X	X		X		X			
MC	Home & Community-Based Waiver		X													
SOUTH CAROLINA																
FC	FCSP	X			X	X	X	X	X	X	X	X	X	X	X	X
MC	Elderly/Disabled Home and Community-Based Waiver	X				X	X		X	X	X			X		
SOUTH DAKOTA																
FC	Caregiver Program	X					X	X	X			X	X		X	
MC	Home & Community-Based Elderly Waiver	X				X		X	X			X	X			
TENNESSEE																
FC	FCSP		X													
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities		X													
TEXAS																
FC	FCSP	X			X	X	X	X								
MC	Community-Based Alternatives		X													
SC	Respite Care Program		X													
SC	In-Home & Family Support Program	X														X
UTAH																
FC	Caregiver Support Program	X							X	X	X	X	X		X	
MC	Medicaid Aging Waiver	X			X	X	X	X			X				X	
SC	Home & Community-Based Alternatives		X													

Program			Training Provided?			Focus of Training										
Program Type	Program Name	Yes	No	In process	Best Practices	CD – Role of Staff	CD – Technical Issues	CG Assessment Issues	CG Intake Issues	CR Disabilities	Cultural Issues	Data & Reporting	Outreach/ Public Awareness	Program Evaluation	Rural Issues	Other
VERMONT																
FC	FCSP	X			X			X		X						X
MC	Home-Based Medicaid Waiver		X													
VIRGINIA																
FC	FCSP	X			X			X	X	X	X		X			
MC	Elderly & Disabled Waiver	X			X											X
SC	Caregiver Grant Program		X													
SC	Respite Care Initiative Grant		X													
SC	Respite Care Grant Program 2003		X													
WASHINGTON																
FC	FCSP	X						X		X						X
MC	Community Options Program Entry System (COPES)		X													
SC	WA FCSP	X						X		X						X
SC	Respite Care Services	X						X		X						
WEST VIRGINIA																
FC	Family Caregiver Support		X													
MC	Medicaid Aged & Disabled Waiver		X													
WISCONSIN																
FC	FCSP	X			X			X	X					X		X
MC	Community Options Program Waiver (COP-W)		X													
SC	Alzheimer's Family & Caregiver Support Program	X			X	X		X		X				X		
WYOMING																
FC	FCSP	X														X
MC	HCBS Waiver for Elderly & Physically Disabled		X													
SC	Community Based In-Home Services Program (CBIHS)		X													

OMB Approval Number: 0985-0016
Expiration Date: 7/31/04

State of the States in Family Caregiver Support 50-State Survey (Part 1)

Under a contract with the U.S. Department of Health and Human Services, Administration on Aging, the National Center on Caregiving at Family Caregiver Alliance (FCA) is gathering information to examine family caregiver programs in all 50 states, with a focus on caregiver services under the National Family Caregiver Support Program (NFCSP), Aged/Disabled Medicaid waivers, state general fund programs that are caregiver-specific, and state-funded home and community-based service (HCBS) programs with a family caregiver component. As required under P.L. 104-13:

- 1) The information is being collected to profile the experience of states in providing family caregiver support services to older people and younger adults with disabilities;
- 2) The information will be used to establish a searchable online database of caregiver support policies, programs and services in the 50 states, and to identify promising practices to support family caregivers;
- 3) An estimated 30 minutes will be required to complete the survey (part 1) and an estimated 30 minutes will be required to complete the follow-up telephone interview (part 2);
- 4) Responses to the collection of information are voluntary; and
- 5) An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a valid approval number.

Instructions:

For this study, the term "family caregiver" is used to define care provided by family, friends or neighbors to persons 60 years or older or adults (aged 18-59) with physical and/or adult-onset cognitive disabilities (e.g., Huntington's disease, traumatic brain injury). These persons can be primary or secondary caregivers, provide full or part-time help, and can live with the person being cared for or live separately.

Not included in this survey are programs serving family caregivers of persons with developmental disabilities or grandparents raising grandchildren.

For state general fund programs that are "caregiver-specific" or state-funded HCBS programs with a family caregiver component please see below.

*If your state agency administers more than one program that meets the definitions below, copy the survey and complete it for **each** program.*

State general fund programs with a "caregiver-specific" focus are those that:

- Are primarily state funded and administered according to state rules;
- Provide one or more support services (e.g., respite care, family counseling) explicitly to families or friends who care for older people or younger adults with disabilities in need of long-term care.

State funded HCBS programs with a family caregiver component are those that:

- Are primarily state funded and administered according to state rules;
- Target older people or younger adults with disabilities with long-term care needs, **and**
- Provide one or more support services (e.g., respite care, family counseling) to support family caregivers of the eligible population.

Please complete the survey by **August 15, 2003** and send to:
Lynn Friss Feinberg, Project Director, National Center on Caregiving,
Family Caregiver Alliance, 690 Market St., Suite 600,
San Francisco, CA 94104.
Phone: 800/445-8106; fax: 415/434-3508, email: lfeinberg@caregiver.org

If you prefer to respond to the survey electronically, you will be receiving an email within one week with instructions on how to fill out the survey online. The electronic version of the survey is exactly the same as the attached paper copy, therefore you should either complete the attached survey or respond to the online version, but you do not need to do both. If you choose to respond electronically, your answers will be automatically forwarded to FCA.

After we receive your completed survey, we will contact you or your designated representative to schedule the part 2 follow-up telephone interview.

*Thank you for your timely response.
Your contribution to this 50-state survey is greatly appreciated.*

National Center on Caregiving
Family Caregiver Alliance
Page 1 of 9

State of the States in Family Caregiver Support (Part 1)**A. Program Background**

1. What is the name of your state program?

2. Indicate which option best describes the geographic region that your program serves. (check one)

- ☐ a. City
☐ b. Single county
☐ c. Multi-county
☐ d. Major metropolitan areas within the state
☐ e. Mainly rural areas
☐ f. Statewide
☐ g. Other (please describe)

3. For Fiscal Year 2003, what are the major sources of funding that your program receives? (check all that apply)

- ☐ a. Alzheimer's Demonstration Grants to States (U.S. Administration on Aging)
☐ b. Client contribution
☐ c. Lottery funds
☐ d. Medicaid HCBS waiver
☐ e. National Family Caregiver Support Program (U.S. Administration on Aging)
☐ f. Private foundation
☐ g. Real Choice Systems Change grant funds (Centers for Medicare and Medicaid Services)
☐ h. Social Services Block Grant (Title XX)
☐ i. State general funds
☐ j. Tobacco settlement funds
☐ k. Other (please specify)

4. If your state funded this caregiver support program prior to the National Family Caregiver Support Program (NFCSP), what was the funding source(s) for the program before the implementation of the NFCSP? (check all that apply)

- ☐ a. Primarily state funds
☐ b. Primarily federal funds
☐ c. Tobacco settlement funds
☐ d. Lottery funds
☐ e. Did not fund this caregiver support program prior to the NFCSP
☐ f. Other (please describe)

B. Program Eligibility/Assessment Process

5. For the following eligibility criteria (age and functional status), specify which apply to your caregiver support program.

- 5a. *Caregiver Age Requirement:* To be eligible for your program, caregivers must be age: (check all that apply)

- ☐ a. 18+
☐ b. 60+
☐ c. 65+
☐ d. No age requirement
☐ e. Other (please describe)

- 5b. *Care Recipient Age Requirement:* To be eligible for your program, the care recipient must be age: (check all that apply)

- ☐ a. 18+
☐ b. 60+
☐ c. 65+
☐ d. No age requirement
☐ e. Other (please describe)

OMB Approval Number: 0985-0016

Expiration Date: 7/31/04

- 5c. *Functional Status (e.g., ADL limitation):* To be eligible for your caregiver support program, the care recipient must be: (check all that apply)
- ☐ a. Unable to complete at least 1 Activity of Daily Living (ADL)
 - ☐ b. Unable to complete at least 2 ADLs
 - ☐ c. Unable to complete 3 or more ADLs
 - ☐ d. Unable to complete at least 1 Instrumental Activity of Daily Living (IADL)
 - ☐ e. Unable to complete at least 2 IADLs
 - ☐ f. Unable to complete 3 or more IADLs
 - ☐ g. Nursing home eligible
 - ☐ h. Diagnosed with Alzheimer's or related dementia
 - ☐ i. No functional status requirement
 - ☐ j. Other (please describe)
-
6. Indicate if caregivers for each of the following disability groups are eligible for your program. (check all that apply)
- ☐ a. Older persons with physical disabilities age 60+
 - ☐ b. Older persons with physical disabilities age 65+
 - ☐ c. Working age persons (i.e. age 18-64) with physical disabilities
 - ☐ d. Persons with Alzheimer's disease or other forms of cognitive impairment age 18+
 - ☐ e. Persons with Alzheimer's disease or other forms of cognitive impairment age 60+
 - ☐ f. Persons with Alzheimer's disease or other forms of cognitive impairment age 65+
7. Who is considered the client in this program? (check one)
- ☐ a. Person with disease/disability
 - ☐ b. Family caregiver
 - ☐ c. Both
8. If the family caregiver is not considered the client in the program, approximately what percentage of your clients have a family caregiver? (check one)
- ☐ a. Less than 25%
 - ☐ b. 25% - 50%
 - ☐ c. 50% - 75%
 - ☐ d. 75% - 100%
 - ☐ e. Agency/program does not collect these data
9. In your program, who is assessed? (check one)
- ☐ a. Person with disease/disability
 - ☐ b. Family caregiver
 - ☐ c. Both
10. Does your program use a uniform assessment tool? (If no, skip to Section C, question 11)
- ☐ a. Yes
 - ☐ b. No
- 10a. If yes, does the uniform assessment tool assess the family caregiver's needs and situation? (If no, skip to Section C, question 11)
- ☐ a. Yes
 - ☐ b. No
 - ☐ c. Not applicable
- 10b. If yes, which of the following areas address the caregiver's needs and situation? (check all that apply)
- ☐ a. Ability of caregiver to provide care
 - ☐ b. Caregiver demographic information (e.g., age, gender, etc.)
 - ☐ c. Caregiver depression
 - ☐ d. Caregiver physical health
 - ☐ e. Caregiver strain
 - ☐ f. Care duration
 - ☐ g. Care frequency
 - ☐ h. If family caregivers are providing long-distance caregiving
 - ☐ i. Willingness of caregiver to provide care
 - ☐ j. Other caregiver information (please describe)
-
- ☐ k. Not applicable

C. Program Administration

- 11.** Does your state have a single point-of-entry¹ for all home and community-based care programs? (If no, skip to question 12)
- ☐ a. Yes
- ☐ b. No
- 11a.** If yes, which agency or organization functions as the single point-of-entry? (check all that apply)
- ☐ a. Area Agency on Aging
- ☐ b. County Health Department
- ☐ c. Other government agency (please specify)
- _____
- ☐ d. Non-profit agency (please specify)
- _____
- ☐ e. Other (please specify)
- _____
- ☐ f. Not applicable
- 11b.** If yes, does the single point-of-entry **include** or **exclude** access to the caregiver support program? (check one)
- ☐ a. Include
- ☐ b. Exclude
- ☐ c. Not applicable
- 12.** What local entities have administrative responsibility for your program? (check all that apply)
- ☐ a. Area Agency on Aging
- ☐ b. County Health Department
- ☐ c. Other government agency (please specify)
- _____
- ☐ d. Non-profit agency (please specify)
- _____
- ☐ e. Other (please specify)
- _____
- 13.** Are you currently providing training for staff who work with family caregivers in your program? (If no, skip to question 14)
- ☐ a. Yes
- ☐ b. No
- ☐ c. In the process of developing trainings

¹ By single point-of-entry, we mean systems that enable consumers and their families to access home and community-based services through one agency or organization. Broadly, these organizations carry out a range of functions that include, but are not limited to, information and assistance, screening, assessment, care planning, service authorization, monitoring and reassessment using one or more funding sources. These functions may be combined in a single agency or split among agencies. This definition was adapted with permission from the National Academy for State Health Policy.

OMB Approval Number: 0985-0016
Expiration Date: 7/31/04

13a. If yes, please indicate the focus of the training. (check all that apply)

- ☐ a. Best practices in service delivery
☐ b. Caregiver assessment issues
☐ c. Caregiver intake issues
☐ d. Care recipient disabling conditions
☐ e. Culturally/ethnically appropriate services
☐ f. Data collection and reporting
☐ g. Outreach/public awareness
☐ h. Program evaluation/outcome measures
☐ i. Role of staff in assisting families with consumer directed options (e.g., concepts of autonomy, choice, decision making and self-determination)
☐ j. Rural issues
☐ k. Technical aspects of administering consumer directed options (e.g., vouchers, cash payments or fiscal intermediaries)
☐ l. Other (please describe) _____
☐ m. Not applicable

14. There are numerous areas in which technical assistance and training might assist your staff to more effectively address the needs of family caregivers in your state. How strongly do you feel that each of the following training and technical assistance areas would benefit your staff? (check which box **best** describes your level of agreement)

	Strongly Agree	Agree	Disagree	Strongly Disagree
a. Best practices in service delivery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Caregiver assessment issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Caregiver intake issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Care recipient disabling conditions	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Culturally/ethnically appropriate services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Data collection and reporting	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Outreach/public awareness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Program evaluation/outcome measures	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Role of staff in assisting families with consumer directed options (e.g., concepts of autonomy, choice, decision making and self-determination)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Rural issues	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Technical aspects of administering a consumer directed option (e.g., vouchers, cash payments or fiscal intermediaries)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
l. Other (please describe)	_____ _____ _____ _____			

15. Within your agency, is there an organizational unit or person specifically designated for caregiving programs or activities?

- ☐ a. Yes
☐ b. No

16. Rank the priority (high, medium or low) that is placed by your agency on promoting a statewide identity (e.g. consistent logo, tagline, etc.) for the caregiver support program. (check one)

- ☐ a. High
☐ b. Medium
☐ c. Low

D. Services

17. For those programs funded through the NFCSP, do all of your state's AAAs offer **each** of the five services components (Information, Assistance, Counseling, Respite and Supplemental Services)?

☐ a. Yes
☐ b. No
☐ c. Not applicable

18. Please check all of the following services that your program provides **specifically** to family caregivers. (check all that apply)

☐ a. Assistive Technology
☐ b. Care Management
☐ c. Cash Grant
☐ d. Consumer eHealth Applications (excluding read-only websites)
☐ e. Consumable Supplies
☐ f. Education & Training
☐ g. Emergency Response
☐ h. Family Consultation
☐ i. Family Counseling
☐ j. Family Meetings
☐ k. Homemaker/Chore Service
☐ l. Home Modification/Repairs
☐ m. Individual Counseling
☐ n. Information & Assistance
☐ o. In-Home Assessment
☐ p. Legal and/or Financial Consultation
☐ q. Personal Care
☐ r. Respite Care
☐ s. Support Groups
☐ t. Transportation
☐ u. Other services (please describe)

19. Do all family caregivers eligible for your program have access to the same package of services?

☐ a. Yes
☐ b. No

20. What types of respite services are offered through your program? (check all that apply)

☐ a. Do not provide respite services (if no to respite, go to Section E, question 21)
☐ b. Adult day services
☐ c. In-home
☐ d. Overnight in a facility
☐ e. Respite weekend, not including camps
☐ f. Respite weekend, including camps
☐ g. Other (please describe)

- 20a. Must the caregiver live with the care recipient to be eligible for respite assistance?

☐ a. Yes
☐ b. No
☐ c. Not applicable

- 20b. If your program caps respite care, complete the following to describe the cap (If no cap, go to Section E, question 21):

Cap is by (check one): ☐ Hour ☐ Dollar

Amount of cap (fill-in blank): _____ (whole numbers only)

Cap is applied (check one): ☐ Monthly ☐ Yearly

- 20c. If your program caps respite benefits, is the cap uniform across each program site?

☐ a. Yes
☐ b. No
☐ c. Not applicable

OMB Approval Number: 0985-0016

Expiration Date: 7/31/04

20d. If your program caps respite benefits, which entity decides how to formulate the cap?

- ☐ a. Administering local agency
☐ b. Administering state agency
☐ c. Local service provider
☐ d. Other (please describe)
-

- ☐ e. Not applicable

E. Consumer Direction

21. What types of consumer directed options, if any, does your program provide for family caregivers? (check all that apply)

- ☐ a. A menu of services from which caregivers can choose the services that best fit their needs
☐ b. A voucher or budget for respite only
☐ c. A voucher or budget for respite and supplemental services (e.g., consumable supplies, home modifications, etc.)
☐ d. Direct payments to family members for the purchase of goods or services
☐ e. Families have a choice of respite providers (e.g., between contract agencies and independent providers)
☐ f. Other (please describe)
-

- ☐ g. No consumer directed option in program

22. Can family members be paid to provide care in your program? (If no, skip to Section F, question 23)

- ☐ a. Yes
☐ b. No

22a. If yes, what types of services can they provide? (check all that apply)

- ☐ a. Respite care
☐ b. Personal care
☐ c. Other (please describe)
-

- ☐ d. Not applicable

22b. If yes, are there any types of family members who **cannot** be paid? (check all that apply)

- ☐ a. Spouses
☐ b. Parents/guardians of minors
☐ c. Other (please describe)
-

- ☐ d. Not applicable

22c. If yes, what types of special requirements are necessary for family members who are paid to provide care? (check all that apply)

- ☐ a. Criminal background checks
☐ b. Physician approval
☐ c. Training
☐ d. Other (please describe)
-

- ☐ e. No special requirements
☐ f. Not applicable

F. Systems Development

- 23.** Please identify other state agencies/public programs involved in (or responsible for) family and informal caregiving activities in your state. (check all that apply)
- ☐ a. State Unit on Aging
 - ☐ b. Department of Developmental Disabilities
 - ☐ c. Department of Health
 - ☐ d. Department of Human Services
 - ☐ e. Department of Mental Health
 - ☐ f. Department of Social Services
 - ☐ g. Other (please describe)
-
-
- 24.** Choose **one** statement that best characterizes the level of integration of your state's home and community-based service system for the elderly and adults with physical disabilities. (check one)
- ☐ a. Integrated through intake, assessment, care planning and data collection
 - ☐ b. Part of a larger program, but separate assessment and data collection
 - ☐ c. Not integrated into the state's home and community-based service system
- 25.** Does your state have a uniform assessment tool for **all** its home and community-based care programs for the elderly and adults with physical disabilities? (If no, skip to question 26)
- ☐ a. Yes
 - ☐ b. No
- 25a. If yes, does it include a caregiver component?
- ☐ a. Yes
 - ☐ b. No
 - ☐ c. Not applicable
- 26.** Check which are the **three** most important organizational, programmatic, geographic or political barriers (other than funding) that limit or prevent coordination of this caregiver support program with other home and community-based programs in your state. (check three)
- ☐ a. Complexity and fragmentation of services
 - ☐ b. Different client population than in other programs
 - ☐ c. Different eligibility requirements
 - ☐ d. Different reporting requirements
 - ☐ e. Federal regulatory or statutory requirements
 - ☐ f. Lack of access to adequate computer technology and support
 - ☐ g. Lack of knowledge of opportunities for coordination
 - ☐ h. Low priority given to caregiver support services
 - ☐ i. Organizational cultural differences
 - ☐ j. Staff have too many responsibilities
 - ☐ k. State regulatory or statutory requirements
 - ☐ l. Other (please describe)
-
-
-
- 27.** Does your state have a task force or commission specifically to examine family caregiver issues? (If no, skip to Section G, question 28)
- ☐ a. Yes
 - ☐ b. No
- 27a. If yes, what is the name and contact information for this entity?
-
-
-
-

OMB Approval Number: 0985-0016

Expiration Date: 7/31/04

G. Other Issues

28. In your opinion, what priority is currently placed on caregiver support services within all of the home and community-based care programs in your state? (check one)

- ☐ a. High
☐ b. Medium
☐ c. Low

29. Give one example of a family caregiver support program or activity in your state that you would nominate as a "best practice" for caregiver support. Provide the name of the program, a description and how outcomes were evaluated, if they were.

30. In your opinion, what priority is currently placed on **each** of the following long-term care issues in your state?

	High	Medium	Low	Don't know	Not a priority at all
a. Expanding Medicaid home and community-based waivers for the elderly and people with disabilities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Expanding state-funded home and community-based care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Expanding federally-funded family caregiver support programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Expanding state-funded family caregiver support programs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Establishing tax credits for caregiving	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Reducing worker shortages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Implementing an <i>Olmstead</i> plan	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Integrating long-term care services	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Implementing or expanding consumer directed options	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
j. Establishing a single point-of-entry for all home and community-based programs, including caregiver support	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
k. Reducing nursing home beds	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

H. Contact Information

Your Name _____
 Title _____
 State Department _____
 Mailing Address _____
 Telephone _____
 Fax _____
 Email address _____

Program contact (if different from person completing survey)

Name _____
 Title _____
 Telephone _____
 Email Address _____

*Thank you again for your timely response.
 Your contribution to this 50-state survey is greatly appreciated.*

State of the States in Family Caregiver Support 50-State Telephone Interview Follow-Up (Part 2)

1. Please describe the best way for a caregiver to access your program either for information or services.
2. How does this caregiver support program differ from other home and community-based care programs in your state?
3. Describe any income or asset eligibility requirements for your caregiver support program (e.g., SSI eligibility level, 200% of poverty, etc.) and indicate whether they apply to the family caregiver, the care recipient, or both.
4. If your program caps respite care, what factors went into the decision to formulate a respite cap?
5. Do any agencies or organizations that are involved in administering or delivering services in your program (i.e., Area Agencies on Aging) pool funding for joint activities such as advertising/marketing, toll-free phone numbers, or other initiatives?
 - a. Yes (please explain)
 - b. No
6. What legislative or regulatory changes, if any, would enable your program to enhance its ability to support family caregivers?
7. **[NFCSP only]** For programs funded through the NFCSP, how difficult is it to meet the federal match requirements for the NFCSP? Would you say:
 - a. Not at all difficult
 - b. Somewhat difficult
 - c. Quite a bit difficult
 - d. Extremely difficult
8. **[NFCSP only]** For programs funded through the NFCSP, how has your caregiver support program changed since implementation?
9. What would you say is the major unmet need of family caregivers in your state?
 - a. Describe what factors would enable you to help meet that need.
10. What effect has the state fiscal condition had on services to support family caregivers and/or state initiatives to explicitly assist family caregivers? Would you say:
 - a. No effect at all
 - b. A little effect
 - c. A moderate effect
 - d. A great deal of an effect
11. How important is the *Olmstead* decision in influencing development of caregiver support services in your state? Is it:
 - a. Not at all important
 - b. A little important
 - c. Fairly important
 - d. Very important
12. What collaboration efforts, if any, have been undertaken by any state agencies and other organizations to improve services and programs for family caregivers?
13. What are the 3 main challenges to implementing family caregiver support programs in your state?
14. In Part 1 of the survey (Question 28), you indicated the current priority on caregiver support services within all of the home and community-based care programs in your state. What factors or conditions contributed to your priority ranking?
15. What recommendations would you make to other states that are implementing caregiver support programs?
16. What is the major lesson you've learned in providing family caregiver support services?
17. Regarding your state's caregiver support program or system of home and community-based services, do you have any additional comments or information that you would like to share?

Thank you!
Your contribution to this effort is greatly appreciated.

National Center on Caregiving
Family Caregiver Alliance
Page 1 of 1

State of the States in Family Caregiver Support NCSL Family Caregiver Program Survey (Part 3)

1. Please identify the funding levels and caseloads for your family caregiving program that includes National Caregiving Support Program dollars. Please give the amounts of funding as well as total numbers of families served for FY 2002-2004.

	Caseloads	Federal Funding	State Funding	Local & Private Funds	In-Kind or Other
FY 2002		\$	\$	\$	\$
FY 2003		\$	\$	\$	\$
FY 2004 (projected)		\$	\$	\$	\$

2. Of the caseloads noted above, please indicate the percent of family caregivers who care for older adults age 60 and older and/or the percent of family caregivers who care for adults age 18-64 with physical and cognitive disabilities. (Note: This survey excludes families who are caring for people with developmental disabilities.)

	% of Family Caregivers Caring for Older Adults	% of Family Caregivers Caring for Adults Age 18-64	Total
FY 2002			100%
FY 2003			100%

3. Of the federal funds listed in column 3 of question 1, does your program include federal funding from sources other than the National Family Caregiver Support Program (e.g. other Older Americans Act funds)? If so, please break out the total amount of federal funds from FY 2002 to FY 2004 according to source.
4. Of the state funds listed in column 4 of question 1, are any state funds from a source other than general revenue? If so, please specify the amount and source of such funds—lottery, tobacco settlement funds or other sources—from FY 2002 to FY 2004.
5. The National Family Caregiver Support Program requires a 25 percent state match. In your state, what state program funds are used as the state match for FY 2002 - FY 2004? Is the match cash or in-kind?
6. Of the funds listed in column 5 of question 1, does your program include local funds or funds from private sources? If so, please specify the amount and source of such funds—local government revenue, foundation funds, sliding scale fees from caregivers or other sources—from FY 2002 to FY 2004.
7. Did your state enact legislation during the 2001, 2002 and/or 2003 legislative sessions related to family caregiving? If so, please provide the bill number, the year of enactment and a brief description of the legislation.
8. Do you anticipate more, less or the same amount of state funding for your program in FY 2004-FY 2005? Please explain any expected changes and the reasons for the change.

Please fax this guide back to Wendy Fox-Grage at the National Conference of State Legislatures at 202-737-1069. If you have questions, please contact her at 202-624-3572 or wendy.fox-grage@ncsl.org.

▪ State Respondent List ▪

Program Type	Program Name	Administering State Agency
■ ALASKA ■		
FC	Family Caregiver Support Program	AK Department of Health & Social Services
SC	Innovative Respite	AK Department of Health & Social Services
■ ALABAMA ■		
FC	Alabama CARES	AL Department of Senior Services
MC	Elderly & Disabled Waiver	AL Medicaid Agency
■ ARKANSAS ■		
FC	Caring for the Caregiver Arkansas Caregivers	AR Department of Human Services
MC	ElderChoices Medicaid Waiver	AR Department of Human Services
■ ARIZONA ■		
FC	Family Caregiver Support Program	AZ Department of Economic Security
MC	AZ Long-Term Care System (ALTCS)	AZ Health Care Cost Containment System
SC	Non-Medical Home & Community Based Services	AZ Department of Economic Security
■ CALIFORNIA ■		
FC	Family Caregiver Support Program	CA Department of Aging
MC	Multipurpose Senior Services Program (MSSP)	CA Department of Aging
SC	Adult Day Health Care Program	CA Department of Aging
SC	Alzheimer's Day Care Resource Center (ADCRC)	CA Department of Aging
SC	Caregiver Resource Centers (CRCs)	CA Department of Mental Health
SC	In-Home Supportive Services (IHSS)	CA Department of Social Services
■ COLORADO ■		
FC	Family Caregiver Support Program	CO Department of Human Services
MC	Home & Community-Based Services for the Elderly, Blind & Disabled	CO Department of Health Care Policy & Finance
■ CONNECTICUT ■		
FC	Family Caregiver Support Program	CT Department of Social Services
MC	Home Care Program for Elders	CT Department of Social Services
SC	Statewide Respite Care Program	CT Department of Social Services
SC	Personal Care Assistance State-Funded Pilot Program	CT Department of Social Services
■ DISTRICT OF COLUMBIA ■		
FC	Family Caregiver Support Program	DC Office on Aging
MC	Elderly & Physical Disabilities Waiver	DC Department of Health, Medical Assistance & Administration
■ DELAWARE ■		
FC	CARE Delaware	DE Department of Health & Social Services
MC	Elderly & Disabled Waiver	DE Department of Health & Social Services
■ FLORIDA ■		
FC	Family Caregiver Support Program	FL Department of Elder Affairs
MC	Aged & Disabled Adult Medicaid HCBS Waiver	FL Department of Elder Affairs
SC	Respite for Elders Living in Everyday Families (RELIEF)	FL Department of Elder Affairs
SC	Home Care for the Elderly	FL Department of Elder Affairs
SC	Community Care for the Elderly	FL Department of Elder Affairs
SC	Alzheimer's Disease Initiative	FL Department of Elder Affairs
■ GEORGIA ■		
FC	Family Caregiver Support Program	GA Department of Human Resources
MC	Community Care Services Program (CCSP)	GA Department of Human Resources

Note. FC=National Family Caregiver Support Program. MC=Aged/Disabled Medicaid waiver. SC=State-funded program with either a caregiver-specific focus, or HCBS program with a caregiver component.

■ **State Respondent List (cont'd)** ■

■ HAWAII ■		
FC	Family Caregiver Support Program	HI Executive Office on Aging
MC	Nursing Home Without Walls	HI Department of Human Services
SC	Kupuna Care	HI Executive Office on Aging
■ IOWA ■		
FC	Iowa Family Caregiver	IA Department of Elder Affairs
MC	Elderly Waiver	IA Department of Human Services
■ IDAHO ■		
FC	Family Caregiver Support Program	ID Commission on Aging
MC	HCBS Aged & Disabled Waiver	ID Department of Health & Welfare
SC	Senior Services Act, Respite Program	ID Commission on Aging
■ ILLINOIS ■		
FC	Family Caregiver Support Program	IL Department on Aging
MC	Community Care Program (CCP)	IL Department on Aging
MC	Home Services program	IL Department of Human Services
■ INDIANA ■		
FC	Caring & Compassion	IN Family & Social Services Administration
MC	Aged & Disabled Medicaid Waiver	IN Family & Social Services Administration
SC	CHOICE	IN Family & Social Services Administration
■ KANSAS ■		
FC	Family Caregiver Support Program	KS Department on Aging
MC	Home & Community Based Frail Elder Waiver	KS Department on Aging
SC	Senior Care Act Program	KS Department on Aging
■ KENTUCKY ■		
FC	Family Caregiver Support Program	KY Cabinet for Health Services
SC	Adult Day/Alzheimer's Respite	KY Cabinet for Health Services
■ LOUISIANA ■		
FC	Family Caregiver Support Program	LA Governor's Office of Elderly Affairs
MC	Medicaid Home & Community-Based Waiver	LA Department of Health & Hospitals
■ MASSACHUSETTS ■		
FC	Family Caregiver Support Program	MA Executive Office of Elder Affairs
MC	Home & Community-Based Waiver	MA Executive Office of Elder Affairs
SC	Home Care Program	MA Executive Office of Elder Affairs
■ MARYLAND ■		
FC	Family Caregiver Support Program	MD Department of Aging
MC	Medicaid Waiver for Older Adults	MD Department of Aging
SC	Respite for Caregivers of Adults with Functional Disabilities	MD Department of Human Resources
■ MAINE ■		
FC	Family Caregiver Program	ME Department of Human Services
MC	MaineCare	ME Department of Human Services
SC	Home-Based Care	ME Department of Human Services
SC	Partners in Caring	ME Department of Human Services
■ MICHIGAN ■		
FC	Family Caregiver Support Program	MI Department of Community Health
MC	MI Choice	MI Department of Community Health
SC	State / Escheat Respite	MI Department of Community Health
SC	Caregiver Respite Program	MI Department of Community Health

■ State Respondent List (cont'd) ■

■ MINNESOTA ■		
FC	Family Caregiver Support Program	MN Department of Human Services
MC	Elderly Waiver Program	MN Department of Human Services
SC	Alternative Care Program	MN Department of Human Services
■ MISSOURI ■		
FC	Family Caregiver Support Program	MO Department of Health & Senior Services
MC	Aged & Disabled Waiver	MO Department of Health & Senior Services
■ MISSISSIPPI ■		
FC	Family Caregiver Support Program	MS Department of Human Services
MC	Elderly & Disabled Waiver	MS Office of the Governor
■ MONTANA ■		
FC	Family Caregiving Support	MT Department of Public Health & Human Services
MC	Home & Community-Based Services Program for Elderly & Physically Disabled	MT Department of Public Health & Human Services
■ NORTH CAROLINA ■		
FC	Family Caregiver Support Program	NC Department of Health & Human Services
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	NC Department of Health & Human Services
SC	Respite Care Program	NC Department of Health & Human Services
■ NORTH DAKOTA ■		
FC	Family Caregiver Support Program	ND Department of Human Services
MC	Aged & Disabled Waiver	ND Department of Human Services
SC	Family Home Care	ND Department of Human Services
■ NEBRASKA ■		
FC	Family Caregiver Support Program	NE Department of Health & Human Services
MC	Aged & Disabled Waiver	NE Department of Health & Human Services
SC	Respite Subsidy Program Across the Lifespan	NE Department of Health & Human Services
■ NEW HAMPSHIRE ■		
FC	Family Caregiver Support Program	NH Department of Health & Human Services
MC	Elderly & Chronically Ill Waiver	NH Department of Health & Human Services
■ NEW JERSEY ■		
FC	Family Caregiver Support Program	NJ Department of Health & Senior Services
MC	Community Care Program for the Elderly & Disabled	NJ Department of Health & Senior Services
MC	Enhanced Community Options (ECO)	NJ Department of Health & Senior Services
SC	New Jersey Statewide Respite Care Program (SRCP)	NJ Department of Health & Senior Services
SC	Adult Day Services Program for Persons with Alzheimer's Disease or Related Dementias	NJ Department of Health & Senior Services
SC	Jersey Assistance for Community Caregiving	NJ Department of Health & Senior Services
■ NEW MEXICO ■		
FC	Family Caregiver Support Program	NM State Agency on Aging
MC	Disabled & Elderly Home & Community-Based Services Waiver	NM Human Services Department

■ **State Respondent List** (cont'd) ■

■ NEVADA ■		
FC	Family Caregiver Support Program	NV Department of Human Resources
MC	Community Home-Based Initiatives Program	NV Department of Human Resources
SC	Independent Living Grant	NV Department of Human Resources
SC	Community-Based Care Caregiving Training	NV Department of Human Resources
■ NEW YORK ■		
FC	Eldercare Family Support Program (EFSP)	NY Office for the Aging
SC	Respite Program	NY Office for the Aging
■ OHIO ■		
FC	Family Caregiver Support Program	OH Department of Aging
MC	PASSPORT HCBS Waiver Program	OH Department of Aging
SC	Alzheimer's Respite Program	OH Department of Aging
■ OKLAHOMA ■		
FC	Family Caregiver Support Program	OK Department of Human Services
MC	Advantage Program	OK Department of Human Services
SC	Respite Resource Network	OK Department of Human Services
■ OREGON ■		
FC	Family Caregiver Support Program	OR Department of Human Services
MC	Medicaid Waiver/In-Home Care	OR Department of Human Services
SC	Lifespan Respite Care Networks	OR Department of Human Services
■ PENNSYLVANIA ■		
FC	Family Caregiver Support Program	PA Department of Aging
MC	PA Department of Aging 60+ Medicaid Waiver	PA Department of Aging
SC	PA Family Caregiver Support Program	PA Department of Aging
SC	OPTIONS	PA Department of Aging
SC	BRIDGE	PA Department of Aging
■ RHODE ISLAND ■		
FC	Partners in CaRIing	RI Department of Elderly Affairs
MC	Home & Community-Based Waiver	RI Department of Elderly Affairs
■ SOUTH CAROLINA ■		
FC	Family Caregiver Support Program	SC Department of Health & Human Services
MC	Elderly/Disabled Home & Community-Based Waiver	SC Department of Health & Human Services
■ SOUTH DAKOTA ■		
FC	Caregiver Program	SD Department of Social Services
MC	Home & Community-Based Elderly Waiver	SD Department of Social Services
■ TENNESSEE ■		
FC	Family Caregiver Support Program	TN Commission on Aging & Disability
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities	TN Commission on Aging & Disability
■ TEXAS ■		
FC	Family Caregiver Support Program	TX Department on Aging
MC	Community-Based Alternatives	TX Department of Human Services
SC	Respite Care Program	TX Department of Human Services
SC	In-Home & Family Support Program	TX Department of Human Services
■ UTAH ■		
FC	Caregiver Support Program	UT Department of Human Services
MC	Medicaid Aging Waiver	UT Department of Human Services
SC	Home & Community-Based Alternatives	UT Department of Human Services

■ **State Respondent List** (cont'd) ■

■ VIRGINIA ■		
FC	Family Caregiver Support Program	VA Department for the Aging
MC	Elderly & Disabled Waiver	VA Department of Medical Assistance Services
SC	Caregiver Grant Program	VA Department of Social Services
SC	Respite Care Initiative Grant	VA Department for the Aging
SC	Respite Care Grant Program 2003	VA Department for the Aging
■ VERMONT ■		
FC	Family Caregiver Support Program	VT Department of Aging & Disabilities
MC	Home-Based Medicaid Waiver	VT Department of Aging & Disabilities
■ WASHINGTON ■		
FC	Family Caregiver Support Program	WA State Department of Social & Health Services
MC	Community Options Program Entry System (COPES)	WA State Department of Social & Health Services
SC	WA Family Caregiver Support Program	WA State Department of Social & Health Services
SC	Respite Care Services	WA State Department of Social & Health Services
■ WISCONSIN ■		
FC	Family Caregiver Support Program	WI Department of Health & Family Services
MC	Community Options Program Waiver (COP-W)	WI Department of Health & Family Services
SC	Alzheimer's Family & Caregiver Support Program	WI Department of Health & Family Services
■ WEST VIRGINIA ■		
FC	Family Caregiver Support	WV Bureau of Senior Services
MC	Medicaid Aged & Disabled Waiver	WV Bureau of Senior Services
■ WYOMING ■		
FC	Family Caregiver Support Program	WY Department of Health
MC	Home & Community-Based Services Waiver for Elderly & Physically Disabled	WY Department of Health
SC	Community Based In-Home Services Program (CBIHS)	WY Department of Health