

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 majority of adults in the U.S. who receive long-term care at home get all their care exclusively from unpaid family and friends (Thompson, 2004).

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. Half the programs in this

survey recognize 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%).

- ♦ 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 may 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. When compared to Aged/Disabled 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. 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 both to further examine and to track policy choices and state approaches to caregiver support, as well as changes over time.