

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.

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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.

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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.