A Study of 10 States Since Passage of the National Family Caregiver Support Program: Policies, Perceptions, and Program Development

Lynn Friss Feinberg, MSW, and Sandra L. Newman, MPH

Purpose: This study describes the preliminary experiences of 10 states in providing support services to family or informal caregivers of elderly adults and adults with disabilities; it focuses on the newly created National Family Caregiver Support Program, state general funds, Medicaid-waiver programs, and other state-funding streams. Design and Methods: Case studies were conducted, between March and July 2002, through in-person interviews with state officials and stakeholders in Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas, and Washington. Results: States were in the start-up phase of implementing the National Family Caregiver Support Program and varied greatly in program design and integration of caregiver support into their home- and community-based care system. Viewing family caregivers as a client population was a paradigm shift for many state officials. Implications: Heavy reliance is currently placed on family and informal caregivers in home- and community-based care, without adequate support services. Family support should be an explicit goal of long-term-care system reform.

Key Words: State policy, Consumer-directed care, Home- and community-based care, Family care

Family and informal caregiving has emerged as a prominent public-policy issue associated with aging and long-term care. A body of research has well documented that families provide the vast majority of support and direct care to frail elders and people with disabilities, yet they receive little support and assistance themselves, and they often face health risks, emotional strain, mental health problems, workplace issues, and financial insecurity (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Brody, 1985; Kiecolt-Glaser et al., 2003; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Scharlach & Boyd, 1989; Schultz et al., 1997; Stone, 2000; Whitlatch & Noelker, 1996).

Although state and federal policy discussions have begun to address the role of family support within the debate on financing and delivering long-term care, very little research has focused on how states are grappling with issues related to the direct provision of services to support family caregivers. These issues cover a wide array of policy choices and philosophies, and they include program design and eligibility, administrative structure, coordination, service-delivery options, and systems integration. Our major objective in the present study is to begin to fill that gap by examining policy issues related to caregiver-support services within the context of home- and community-based care.

Until recently, federal public policy has neither acknowledged nor explicitly recognized the service needs of caregiving families. The passage of the National Family Caregiver Support Program (NFCS), under the Older Americans Act (OAA) Amendments of 2000, stands as the first federally funded program implemented at the state level designed specifically to support the service needs of family caregivers of older people (Fox-Grage, Coleman, & Blancato, 2001). The program, administered by the U.S. Administration on Aging, authorizes state units on aging, working in partnership with local area...
agencies on aging and service providers, to develop multifaceted systems of support for family and informal caregivers of older people, including five basic service categories: (a) information about available services; (b) assistance to caregivers in gaining access to services; (c) individual counseling, support groups, and caregiver training; (d) respite care; and (e) supplemental services (e.g., home modifications and assistive devices) on a limited basis to complement the care provided by family members. For the NFCSP, Congress appropriated $125 million for fiscal year 2001, $141.5 million for 2002, and $155.2 million for 2003. In fiscal year 2002, when this study was conducted, state units on aging received $128 million in federal grant funds, allocated through a congressionally mandated formula based on a proportionate share of a state’s over-70 population. Another $5.5 million was allocated to Indian tribal organizations. The remaining funds supported grants for innovative caregiver projects and programs of national significance for training, technical assistance, and research (U.S. Department of Health and Human Services [USDHHS], 2003).

The implementation of the new NFCSP takes place within the context of an emerging policy direction in states to address support to family caregivers. In June 1999, the U.S. Supreme Court ruled in the landmark case Olmstead v. L.C. that states are required to provide services to certain individuals with disabilities in community settings rather than in institutions (Rosenbaum, 2001). The federal government’s New Freedom Initiative, established by executive order in 2001, outlines a plan to assist states and localities to implement the Olmstead decision. Lack of family caregiver support and the need for greater assistance to families and informal caregivers is identified in the federal plan as a major barrier to community living for those with disabilities (USDHHS, 2002). A key policy goal in most states is the creation of a balanced long-term-care system by expanding home- and community-based services (HCBS; Weiner, Tilly, & Alexxih, 2002). In January 2001, the Centers for Medicare and Medicaid Services announced a new program of $125 million, awarded over a 2-year period, to include Real Choice Systems Change grants designed to help states improve community long-term-support systems for people with disabilities and their families. Another $33.5 million was awarded to states in 2003. States also have used state general revenue funds for delivering HCBS to frail elders and people with disabilities as they attempt to gain greater flexibility and control over program design, services delivered, and spending (Kassner & Williams, 1997). State-funded programs generally either offer services that Medicaid will not cover or expand eligibility to people who do not qualify for Medicaid HCBS waiver programs (Summer, 2003). Family caregivers can benefit from these programs, some of which provide a caregiver component, such as respite care or family consultation (Kassner & Williams, 1997; Summer, 2003).

Examining the provision of respite, however, can be a challenge because some state-funded programs consider the term “respite” to be such a broad concept that almost anything can be included if it improves the caregiver’s quality of life (Feinberg & Pilisuk, 1999).

Most HCBS programs are focused on the needs of frail elders or individuals with disabilities, not on the needs of informal caregivers, who are mainly relatives (Feinberg, 2004; Weiner, 2003). Federal Medicaid policy does not allow services under the traditional program to be provided directly to benefit the family or informal caregiver (Smith, Doty, & O’Keefe, 2000). Through Medicaid HCBS waivers, however, states can offer respite and other services (e.g., home modifications and caregiver training) that, although they do not explicitly target the caregivers’ need for assistance, indirectly support and sustain them in their caregiving role. Research suggests that about 72% of state waivers cover respite assistance for frail elders or combined elderly and disabled populations (Miller, Ramsland, & Harrington, 1999). Current Medicaid policy limits respite care for family caregivers to HCBS-waiver programs only (Summer, 2003; USDHHS, 2002), even though it is the service that is most often requested by family caregivers to keep frail elders and individuals with disabilities at home (Feinberg & Kelly, 1995; Montgomery, Marquis, Schaefer, & Kosloski, 2002).

Consumer-directed care options also are expanding under Medicaid HCBS-waiver and state-funded programs, some of which allow the care recipient to pay family and informal caregivers to provide respite and personal assistance services. Consumer direction is not a single approach. Rather, it is a range of models that can vary by how much decision making, control, and autonomy are shifted from service providers to consumers (Benjamin, 2001). In states that enable consumers to direct their own services, the freedom to hire a family member, friend, or neighbor is considered an important aspect of consumer choice and control.

Although states that have created caregiver-support services have typically funded them with state general revenues (Coleman, 2000; Feinberg & Pilisuk, 1999), the new NFCSP, Medicaid HCBS-waiver programs, and other funding streams have emerged as public-funding sources to support family and informal caregivers of elderly adults and people with disabilities. Little is known about states’ experiences in providing family caregiver support, whether in states that have well-developed systems of caregiver services funded largely with state general revenues or in states that have just begun to create programs as a result of the new federal resources through the NFCSP.
Purpose of the Study

Our aim in this article is to describe the preliminary experiences of 10 states in providing services to family and informal caregivers since passage of the NFCSP. The qualitative study, using a case-study approach, focused on programs administered under the newly created NFCSP, state general funds, Medicaid HCBS-waiver programs, and other state funding streams. We address five policy issues from the larger study (Feinberg, Newman, & Van Steenberg, 2002): program design; administrative structure; assessment; consumer direction; and systems integration. We frame these policy issues around the following key questions: (a) Do states view family and informal caregivers as a central component of a long-term-care system and perceive family caregivers as “consumers” in their own right? (b) What approaches are states taking to the designing of systems of caregiver-support services? (c) How do states administer programs that provide caregiver-support services at the state and local levels, and coordinate diverse funding streams? (d) What approaches are states taking in utilizing caregiver assessment to address the multifaceted needs and situations of family caregivers? (e) Do states permit family caregivers to have consumer-directed options? (f) How do states view the integration of caregiver support into other HCBS programs? (g) Are states addressing family and caregiver support within the context of implementing the Olmstead decision?

Methods

To collect the information for this study, we used the key informant method through extensive in-person interviews with state officials and major stakeholders in 10 states. Our goal was to gather the views and opinions of key informants in a range of states: those at the forefront in caregiver policies and services, and those states just beginning to provide caregiver support as a result of the creation of the NFCSP. We also obtained supplemental information from public documents, state Web sites, and an extensive literature review.

Within the array of caregiver-support services across the life span, we chose to focus on services to caregivers of elderly adults (those aged 60 years or older) and younger individuals with physical disabilities or with adult-onset cognitive impairment (e.g., Huntington’s disease or traumatic brain injury). Consequently, in this study we do not address support services for two specific caregiver populations targeted under the NFCSP: grandparents who are raising grandchildren, or family caregivers who are caring for those with developmental disabilities.

For purposes of the study, we use the term “family caregiver” to define care provided by family, friends, or neighbors. These people may be primary or secondary caregivers, provide full-time or part-time help, and live with the person being cared for or live separately.

Identification of States, Programs, and Key Informants

Project staff identified potential case-study states through a literature review and discussions with the project’s advisory committee. In selecting the sample of states for the study, we used several criteria: largest populations of older adults; mix of urban and rural states; geographical representation of U.S. regions; and substantial as well as limited previous involvement in caregiver-support services. We also examined states’ Medicaid HCBS-waiver programs to identify expenditures, caseloads, and services related to family caregivers. We chose to include states’ Medicaid HCBS-waiver programs in the study because all states have established these programs, and waiver programs allow coverage for respite and other services that cannot be covered under the regular state Medicaid plan (Summer, 2003). Finally, we looked at the use of state general funds for caregiver services as well as how states were tapping tobacco settlement revenues for HCBS in general or for caregiver support in particular. The states that met the inclusion criteria and were included in the study were Alabama, California, Florida, Hawaii, Indiana, Iowa, Maine, Pennsylvania, Texas, and Washington. Together, these 10 states represent about 37% of the total U.S. population.

In each state, project staff contacted key informants who were either state government officials or key stakeholders. The state officials were responsible for administering the NFCSP, Medicaid HCBS-waiver programs, state general funds, or other funding streams. These state officials were generally, but not always, located within the state unit on aging or the Medicaid agency. The stakeholders represented agencies and groups seen as having the most knowledge of and interest in caregiver-support programs (e.g., area agencies on aging and Alzheimer’s Association chapters). Project staff made every effort to identify informants who had involvement in and insights about the history and actual program operations, and who understood caregiving issues in their state. In addition, each informant who agreed to be interviewed was asked to nominate other state officials or stakeholders whom he or she considered to be knowledgeable about the state’s caregiver-support system. In total, 140 individuals contributed their views to this study.

Data Collection

We developed open-ended, structured, site-visit protocols with input from the project’s advisory committee (copies of the interview protocols are available from the authors on request). Project staff conducted interviews in each state to gather information on the state’s caregiver-support policies and services, and the key stakeholders who had involvement in and insights about the history and actual program operations. In each state, project staff selected two to five key informants (either state government officials or stakeholders) who were knowledgeable about the state’s caregiver-support system. Once key informants were selected, project staff contacted them by telephone to verify their interest in and availability for the interview. Project staff also requested that key informants submit names of other people they knew who might be knowledgeable about the state’s caregiver-support system. These names were used to find additional key informants. If a key informant declined to be interviewed, project staff tried to contact another key informant. In all, 140 individuals contributed their views to this study.
available from us). State officials and stakeholders in every selected state agreed to participate in the in-person interviews. Prior to the site visits, each key informant received a copy of the interview protocol. Two-person project teams conducted site visits to the 10 states between March and July 2002. Because of scheduling conflicts, staff conducted several interviews by telephone, and two interviews could not be scheduled during the data-collection period. On average, the interviews with state officials took 2 hr each to complete, whereas stakeholders’ interviews took, on average, between 30 and 45 min each. In all, 61 interviews took place in 10 states, 31 involving state officials and 30 with key stakeholders. In most cases, more than one state official or stakeholder representative participated in an interview. When this occurred, we considered their responses as one.

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

Results

Program Design

We asked all key informants, both state officials and stakeholders, whether family and informal caregivers were recognized as a central component of a comprehensive long-term-care system, through state statute, in other state policies (e.g., family and medical leave laws), or in the provision of other HCBS programs. In all but one case-study state (Pennsylvania), key informants within the state disagreed substantially on this question (see Table 1). State officials generally believed that family caregivers were recognized, whereas most stakeholders did not believe this was the case. Stakeholders typically held the view that family caregivers were neither adequately recognized nor supported in their state’s long-term-care system. One stakeholder commented that her state’s entire HCBS system was “built upon the presumption that informal caregivers could provide day-to-day care to complement formal services.” Another observer commented that the “entire system takes family caregivers for granted.”

We found explicit policy attention to caregiver-support services to emerge only recently, with the passage of the NFCSP, in 6 of the 10 case-study states (Alabama, Hawaii, Iowa, Indiana, Maine, and Texas). Through state law and state funding, other case-study states (California, Florida, Pennsylvania, and Washington) had well-established and multifaceted caregiver-support programs prior to the enactment of the NFCSP. As well, all states in this study had Medicaid HCBS-waiver programs for the elderly population only or elderly adults and younger adults with disabilities that covered some respite care for the informal caregivers of the service recipients, although most states did not track respite expenditures as a distinct waiver-service category. Nevertheless, all case-study states were immersed in the early stages of policy and program development or expansion as a result of the new federally funded caregiver-support program.

Who a program designates as its client provides insight into how programs are designed and services are delivered. In this study, we found key informants to disagree about whether or not informal caregivers should be considered “clients” or “consumers” in the long-term-care system and whether they should have access to their own support services. Nearly half (47%) of the respondents who were state officials considered the care recipient (i.e., the elderly individual or person with disabilities) the client. Not surprisingly, the majority of these responses came from administrators of Medicaid HCBS-waiver programs, because under Medicaid, the care recipient is considered the beneficiary or client. Approximately 27% of state officials in the case-study states considered both the care recipient and the caregiver to be clients, taking a more “family systems” approach to service eligibility. Only 23% of state officials identified the caregiver as the primary client; the programs they administered were typically state funded with explicit mandates to serve family caregivers. Surprisingly, only half (50%) of the state unit on aging respondents (Alabama, California, Florida, Hawaii, and Maine) identified family caregivers as the primary client under the NFCSP, despite the new federal caregiver-support program explicitly targeting services to family caregivers of older people. Stakeholders, in contrast to state officials, uniformly embraced the notion of the family caregiver as the consumer or client.

Viewing family caregivers as a consumer or client population was found to be a relatively new concept for many state units on aging, area agencies on aging, and Medicaid HCBS-waiver programs, representing a paradigm shift. In case-study states that were beginning to provide a range of caregiver-support services only as a direct result of the NFCSP, family caregivers were typically viewed as a “new constituency.” Some state units and area agencies on aging (Hawaii, Maine, and Texas) found this paradigm shift challenging. They identified the tension between serving the older person (i.e., the care recipient), who is the traditional client in the long-term-care system, and specifically addressing the family caregivers’ needs as distinct but related to the needs of the care recipient, which is the new mandate under the NFCSP.

With the advent of the federal funds under the NFCSP, states generally were faced with two fundamental choices regarding how to design new or expanded caregiver-support services with limited
resources: (a) using the NFCSP funds to supplement services in existing public programs targeting family caregivers, or (b) creating a separate program to serve caregivers of individuals eligible for existing HCBS programs, as well as new groups of caregivers who would not otherwise be getting any public support to sustain them in their caregiving role.

States differed in how they designed programs under the NFCSP. Three of the case-study states (California, Pennsylvania, and Washington), funded explicit caregiver-support programs from their state general revenues prior to the enactment of the NFCSP. Two of those states, Pennsylvania and Washington, augmented existing state-funded caregiver programs with the new federal funds, enabling them to broaden eligibility, expand the range and scope of existing caregiver-support services, and use the NFCSP funds to supplement existing publicly funded caregiver supports. Washington State, for example, began to offer counseling for family caregivers, a service not previously allowable under its state-funded program. In contrast, California, a state with a wide array of publicly funded programs, made the policy choice to administer the NFCSP outside of the established state-funded caregiver program. This statewide system is administered by the state’s Department of Mental Health and has been providing direct caregiver support to families of adults with cognitive impairment for nearly 20 years.

### Table 1. Selected Characteristics of Federal and State Programs Providing Family Caregiver Support in 10 States, 2002

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>AL</th>
<th>CA</th>
<th>FL</th>
<th>HI</th>
<th>IN</th>
<th>IA</th>
<th>ME</th>
<th>PA</th>
<th>TX</th>
<th>WA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family caregivers are recognized as central component of long-term-care system by state government officials and stakeholders</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>State funded caregiver-support program prior to the NFCSP</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>A/D Medicaid Waiver covers respite care</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Centralized State administrative structure (NFCSP, Medicaid waiver, state funded)</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>SUA has state administrative responsibility for A/D Medicaid Waiver</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Uniform, statewide caregiver assessment for the NFCSP</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Uniform assessment tool for all HCBS programs, including caregiving component</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Consumer direction permitted</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>A/D Medicaid Waiver</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>State-funded HCBS</td>
<td>N/A</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Family caregivers paid as respite providers</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Olmstead planning addresses family caregiving</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

Notes: NFCSP = National Family Caregiver Support Program; A/D = aged/disabled; SUA = state unit on aging; HCBS = home- and community-based services; N/A = not applicable.

*aCentralized approach for programs that serve older adults and their family caregivers only; these services are administered through the Pennsylvania Department of Aging. Services for adults with physical disabilities are administered through the Pennsylvania Department of Public Welfare.

*bUniform assessment standards.

*cUniform intake only.

*dAt the time of the site visit, state officials were working to include caregiver assessment into the state’s uniform assessment for all HCBS programs.

*eNot formally. Alabama’s NFCSP does have some elements of consumer direction, such as allowing caregivers to choose from a menu of services.

*fPermitted, but no area agency on aging was offering this option at the time of the site visit.

*gConsumer direction is permitted in the In-Home and Supportive Services (IHSS) Program, funded by state general funds (20%) and Medicaid (80%), and in the state-funded Caregiver Resource Centers (CRCs).

*hThe federal Cash and Counseling demonstration functions as the state’s A/D Medicaid Waiver consumer-directed option.

*iExcept in the Home Care for the Elderly program, which is a cash subsidy.

+jPilot project only at the time of the site visit.

+kConsumer direction is permitted in the In-Home and Family Support voucher program.

+lPermitted in IHSS and CRC programs.

+1Family caregivers can be paid in the In-Home and Family Support voucher program.

+2Pilot project only.
At the other extreme, Alabama focused explicit policy attention to caregiver services only following passage of the NFCSP. Interestingly, this state was able to provide a consistent, statewide approach to caregiver support, in part because it had no separate state-funded programs into which to integrate the NFCSP.

States that already had some component of caregiver support through state-funded HCBS programs utilized the NFCSP to expand the range and amount of services to family caregivers. For example, Florida and Maine used the NFCSP to broaden caregiver-support services beyond state-funded respite programs, to reach a new population besides a focus on dementia caregivers, and to work with families earlier in the process of caregiving. During the study period, five of the case-study states (Alabama, Florida, Iowa, Pennsylvania, and Texas) were utilizing tobacco settlement revenues to expand home- and community-based services. Two of those states (Iowa and Texas) were also using those funds to expand respite options for family caregivers. In addition, Pennsylvania earmarked proceeds from its state lottery for services assisting older people, including respite for family and informal caregivers.

**Administrative Structure**

The 10 states in this study used a variety of approaches to administer their caregiver support and HCBS programs. As shown in Table 1, we found three of the case-study states (Indiana, Maine, and Washington) to centralize all administrative responsibility for caregiver support and HCBS programs in one state department that served elderly adults, younger individuals with physical disabilities, and their family caregivers. Another state, Pennsylvania, utilized this centralized approach for its programs for elderly adults and their family caregivers only. In six of the case-study states (California, Florida, Indiana, Maine, Pennsylvania, and Washington), the state units on aging had lead responsibility for managing the Aged/Disabled HCBS Medicaid-Waiver Program. Other states (Alabama, Hawaii, and Iowa) generally administered programs through two agencies: typically the NFCSP and some state-funded programs were within the unit on aging, whereas the Aged/Disabled HCBS Medicaid Waiver was in the Medicaid agency. In the three largest states studied (California, Florida, and Texas), administrative responsibility for caregiver support and HCBS programs was spread across multiple state agencies. This state administrative structure made coordination and integration difficult, according to the majority of the state officials and stakeholders interviewed in this study.

During the start-up phase of the NFCSP, the case-study states faced a difficult balancing act: giving area agencies on aging the local flexibility that encouraged individualized approaches to meet caregiver needs while simultaneously setting statewide standards and uniformity so that family caregivers could access a core set of support services and service-delivery options regardless of where in the state they lived. Federal funding limitations and increasing state budget shortfalls played a key role in influencing states to make these policy decisions. For fiscal year 2002, NFCSP formula grants to the case-study states ranged from a high of $12.6 million in California to a low of $639,540 in Hawaii. In general, we found the balance that states had achieved to be tipped toward local flexibility, resulting in an inconsistent range of services varying by locality.

Because most states had a range of programs with different eligibility requirements, divergent funding sources, and varied funding levels, the majority of state officials and stakeholders viewed caregiver-support services as difficult to access at the local level. To help consumers navigate the complexity, some states had begun working to improve the service-delivery system so it was seamless for the consumer. Half the case-study states (Florida, Iowa, Indiana, Pennsylvania, and Washington) were using the local area agency on aging as a single point of entry for all of the states’ caregiver support and home- and community-based services, regardless of the administering agency or funding stream. In addition, at the time of the site visit, Indiana was exploring the “no wrong door” approach, whereby consumers (including family caregivers) could access all programs through the local office of any state agency, as well as through the local agency on aging.

**Caregiver Assessment**

Caregiver assessments may determine eligibility for caregiver-support services, both within explicit caregiver-support programs or in broader HCBS programs. Caregiver assessments can also be used as a basis for a care plan and services to support family caregivers as well as care recipients, thereby allowing family members and friends to remain in the caregiving role for as long as it is appropriate.

We found great variation to exist among and within the case-study states in their approaches to caregiver assessment (see Table 1). In particular, we found state and local implementation of caregiver-assessment policies, tools, and procedures under the NFCSP to be at very different stages. Typically, within state-funded and Medicaid HCBS-waiver programs, caregiver assessment was viewed as a minor part of the overall assessment of the care recipient, with a brief section of the assessment tool identifying whether the care recipient has a family caregiver, the type and frequency of help provided to the care recipient, and the willingness of the family member to continue in the caring role. Moreover, state respondents noted that what minimal information is collected on family caregivers is typically not aggregated and reported statewide.
Consumer Direction

Many federally and state-funded consumer-directed models have been established for the care recipient, but few states have developed consumer-directed programs that focus on the caregiver (The Lewin Group, 2002). Because the NFCSP neither precludes nor mandates consumer-directed approaches, a state may allow direct payments to family caregivers or a voucher system for services (e.g., respite and supplemental services) that gives families maximum control as to how, when, and by whom respite is to be provided, or the option of purchasing goods or services that directly meet their needs. We found states to differ considerably in the extent to which their family caregivers had consumer-directed options (see Table 1).

Pennsylvania’s family caregiver-support program (state funded and NFCSP) allowed for consumer direction. Families were able to hire their own respite providers or be reimbursed for the purchase of almost any goods or services except prescription drugs (covered under another state-funded program). Friends and neighbors could be paid to provide care, although family caregivers could not be. In contrast, the state’s other HCBS programs, including the Aged Medicaid-Waiver Program, allowed payment to family members (except spouses) to provide care.

In California, although the Aged Medicaid-Waiver Program did not offer a consumer-directed option, the state’s In-Home Supportive Services Program (funded by the optional Medicaid personal assistance benefit and state funds) did. The state placed no restrictions on the hiring of and payment to family members for in-home supportive services; use of state funds allowed any family member, including a parent or spouse, to be a paid care provider. California’s state-funded caregiver program also allowed for consumer direction. Primary family caregivers were able to choose from a range of respite options, including the hiring of other family or friends to provide respite care. In contrast, their NFCSP-funded program had no statewide policy on consumer direction; no area agency on aging had implemented this option at the time of the site visit.

Florida was not found to permit consumer direction under its traditional Aged/Disabled Medicaid-Waiver Program. Florida’s federal Cash and Counseling Demonstration and the state’s recently enacted state-funded consumer-directed care project served that purpose, however. Also, area agencies on aging in Florida had a consistent statewide policy supporting the utilization of consumer direction in their NFCSP.

In the case-study states with consumer direction for respite care, most families were found to choose relatives, friends, or other people they already knew. For example, in the Medicaid-waiver programs in Hawaii and Washington State, respondents indicated that about 90% and 50% of the respite workers, respectively, were family members.

We found all states to be looking for ways to meet caregivers’ needs and preferences, even if formal consumer direction was not yet an option. For example, Alabama did not permit direct payment to family caregivers under the NFCSP; however, we found some elements of consumer direction to be available. The state offered caregivers a menu of services, and it permitted area agencies on aging to use a voucher system, typically capped at $300 per year per family client, for respite and supplemental services. In this approach, family caregivers were able to choose their own providers from the list of voucher home-care agencies and could set the number of hours of help they needed. Allowable benefits under the supplemental services category included whatever goods and services the caregivers needed to keep their relatives at home.

Systems Integration

States differed in the degree to which their family caregiver-support programs were integrated with
other HCBS programs, as did state officials’ views about this issue. Officials in 5 of the 10 case-study states were in full agreement about the degree of integration. In four states (Florida, Hawaii, Iowa, and Pennsylvania), officials agreed that their caregiver-support programs were integrated into their states’ other HCBS programs. In Maine, in contrast, officials agreed the state had made the policy choice to maintain a “stand-alone” identity for the emerging NFCSP, rather than to integrate caregiver support into the state’s single point of entry to the long-term-care system. Maine took this approach because the NFCSP had different eligibility and reporting requirements and a “new” identified consumer (i.e., the family caregiver) that differed from the state’s centralized, integrated long-term-care system that centers on the older individual or the person with disabilities as the consumer. In the other five case-study states (Alabama, California, Indiana, Texas, and Washington), some state officials saw their programs as integrated, some as stand-alone, and some as having both elements.

Lastly, we found the aging network in general, and family caregivers of elderly adults in particular, not to be active participants to date in state Olmstead task forces. In planning documents, only two case-study states specifically identified the need to support family caregivers: California, in the preliminary values statement of its planning council for Olmstead, and Indiana, as one of six major policy directions to be pursued. Texas reported having a family caregiver of an older person as a member of its Olmstead task force (see Table 1). In most of the other case-study states, however, the family members on these task forces were parents of children with developmental disabilities. Further, we found that states’ Real Choice Systems Change grants did not address family caregiver issues. Although most of the state units on aging were involved in Systems Change-grant activities, only one case-study state (Indiana) identified family caregivers as an explicit target group under its grant.

Discussion

Our purpose in the present study was to describe the preliminary experiences of 10 states in providing services to family and informal caregivers since passage of the NFCSP. Our further aim was to examine key policy areas and identify issues for the future related to caregiver-support services within the context of other HCBS programs.

The results of the study suggest that, similar to research on home- and community-based services in general, there is great variation in philosophy and approaches to the design and administration of family caregiver-support services from state to state, and, in some cases, in programs within states. In addition, we found that state officials’ views of whether or not family caregivers should be considered legitimate consumers of services in their own right contributed to the policy choices states made in developing or expanding caregiver-support services. In general, the case-study states that were “new” to family caregiving issues opted to develop a separate program for family and informal caregivers, whereas the majority of states that already funded some component of caregiver support made the policy choice to augment existing programs to broaden eligibility and expand the range and scope of caregiver support in their states.

Because states have considerable flexibility in designing services under the NFCSP, it was not surprising to find that the case-study states varied greatly in their approaches to program development and service delivery. Caused in part by the modest level of NFCSP funding and the thrust toward local flexibility in service design, we found services to vary substantially from state to state, as well as within states. The results of this study suggest that the attempt to support this flexibility at the local level appears to have promoted a variability of service options that paradoxically limited, rather than enhanced, choices for caregivers. As a result, family caregivers did not have access to the same core support services in the majority of the case-study states. Stakeholders interviewed in this study asserted that the overall lack of consistency in states’ services was particularly frustrating for long-distance caregivers, who found that different services may be provided by different agencies in different states. We identified single point of entry and seamless service delivery across funding streams as promising approaches to reduce the greatest frustration of family caregivers, which is locating and accessing help.

This study further shows that states are taking diverse approaches to utilizing caregiver assessment to address the multifaceted needs of family caregivers. Among the 10 states studied, caregiver-assessment policy and practice were in the very early stages of development, and they were highly variable across and within programs. Despite the emerging policy attention to caregiving, little consideration has been paid to the systematic assessment of the situation and well-being of the family caregiver to determine what direct assistance the caregiver may need, distinct from but related to the needs of the care recipient (Baxter, 2000; Feinberg, 2004). Interestingly, although the NFCSP was designed to promote a multifaceted approach to service provision for family caregivers specifically, there is no mandate for caregiver assessment. As a result, few of the case-study states that were new to providing caregiver-support services had developed consistent approaches to caregiver assessment. However, most state officials recognized that developing assessment standards and tools was key to effectively allocating limited resources and tailoring services to the specific needs of the caregiver. These findings suggest that
families may benefit from a common approach to caregiver assessment that: (a) identifies the particular needs of the caregiver as well as the care recipient; (b) approaches issues and the development of a plan of care from the caregiver’s perspective and culture; (c) focuses on the outcomes the caregiver wants for family support; and (d) ensures that the caregiver’s own health and well-being are maintained. Improving assessment tools in all HCBS programs to uniformly assess the needs of both the care recipient and the family caregiver is a promising approach to support a family systems perspective and to maintain the person with disabilities in the community.

Despite differences in the availability of consumer-directed options among case-study states, state officials in all programs expressed high interest in exploring consumer direction so that consumers may have greater control over their services. Because states can choose to offer consumer-directed options, the NFCSP presents an opportunity to expand caregivers’ choices in selecting goods or services that will benefit them and the care recipient directly.

The results of this study further suggest that state officials and stakeholders have mixed views about the integration of caregiver support into HCBS programs. Family caregiver-support services were not yet well integrated with states’ other HCBS programs, partially as a result of the relatively new emergence of the NFCSP and differences in terminology, funding levels, client populations, and reporting requirements. Nevertheless, most of the respondents in this study indicated that the new federal funding was a key factor in their developing or expanding caregiver-support services. In addition, many respondents suggested that the NFCSP was having a modest, though positive, impact on state long-term-care systems. The impacts of these policy shifts on family caregivers should be considered in the future.

Lastly, despite the broad goals of the Supreme Court’s Olmstead decision to “rebalance” the long-term-care system away from institutional care and toward community living (USDHHS, 2002), relatively few of the respondents in this study discussed the implications for family and informal caregivers of elderly adults and of individuals with disabilities or used their Systems Change grants to address family caregiving issues. As states grapple with reducing reliance on nursing homes and strengthening integrated HCBS systems, the impacts of these policy shifts on family caregivers should be considered. In the future, states may opt to use their Real Choice Systems Change grants to help offset the increased family responsibilities that will come with greater emphasis on and availability of HCBS options.

This study was limited by its focus on 10 states and the preliminary strategies and approaches they used to develop or expand caregiver services as a result of the NFCSP and within the context of other HCBS programs. The results of these case studies are currently being used to conduct a 50-state caregiving study to profile the experience of all states in providing family caregiver-support services to older people and younger adults with disabilities.

Long-term-care reform is complex, and it is the subject of considerable policy debate as states continue to struggle with major budget shortfalls. How policymakers and state program administrators choose to address family caregiving issues in the future will have important implications for enhancing individual choice, independence, and community living for older people, adults with disabilities, and their families.

References


Received March 31, 2003
Accepted January 27, 2004
Decision Editor: Linda S. Noelker, PhD

AgeLine Database
New books and articles in social gerontology

http://research.aarp.org/ageline
(also on Ovid, SilverPlatter, CSA, EbscoHost, Dialog, and NISC)

Other AARP resources: (link from AgeLine site)

- AgeSource Worldwide
  250 global aging resources from 24 countries

- AARP Research Center
  Complete text of publicly available AARP research

- Internet Resources on Aging
  700 web sites for or about older adults—search or browse

- AgeLine Research to Go
  New publications on high-interest topics—great for students!