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Consumer Direction and Family Caregiving: Results from a National Survey

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Consumer Direction and Family Caregiving: Results from a National Study

Introduction

Over the past decade, the philosophy and practice of “consumer direction” has shifted how we deliver home and community-based services (HCBS) in the U.S. Consumer direction is not a single method; rather it is an array of approaches designed to increase choice and control by those who need services or supports. Most consumer-directed models focus on the traditional “consumer” or care recipient; fewer approaches focus on the family caregiver or the family as the unit of care.

In its broadest sense, consumer direction enables people to make meaningful choices regarding their care or the care they are providing (Sciegaj, 2001). 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 or services. At the other is traditional service delivery, sometimes called the “medical model,” where the provider or payer decides what is needed and will be covered.

The Role of the Family in Consumer Direction

The work of family caregivers is central to the care of older people and adults with disabilities. Family caregivers provide the bulk of support and direct assistance that persons with disabilities receive at home, and third-party payers and formal service providers increasingly recognize their major role in enabling persons with disabilities to remain at home (Doty, 2004). In fact, the availability of family and informal (i.e., friends, neighbors) caregivers often determines whether an individual can keep living at home or must turn to the more costly, less preferable, long-term care option of nursing home care (Feinberg, 1997). Increasingly, many caregiving families see consumer-directed approaches in HCBS as attractive because families can “custom-tailor” services to complement and support the care they are giving (Doty, 2004).

Although some older people and younger adults with disabilities insist on “self” direction and person-centered care, family and informal caregivers are often key partners in consumer-directed programs. In fact, many policymakers and program administrators think of the “consumer” in consumer-directed care not as the individual with the disability, but the dyad -- that is, the care recipient *and* his or her family (Ditto, 2004; Doty, 2004; Feinberg, Whitlatch, & Tucke, 2000).

Within consumer-directed programs family members can assume a variety of roles: from information-gatherer and coordinator of care, to representative or surrogate decision-maker for persons with cognitive impairments, to the person paid to provide care. When allowed to do so, persons needing care often choose to hire family members as paid workers in the home (Doty, 2004). In states that enable consumers to direct their own services, program participants value the freedom to hire a family member, friend or neighbor as a meaningful feature of choice and control (Feinberg & Newman, 2004).

Purpose of Study

Although consumer direction is a growing trend in publicly supported HCBS programs across the states, we know relatively little about how this approach is implemented in the states. This national study aims to describe the role of consumer direction in publicly funded family caregiver support services and HCBS programs with a family caregiving component.

This effort stems from a two-year research project, funded by the U.S. Administration on Aging, that examines the range and scope of 150 state-administered programs in and across the 50 states and the District of Columbia. These programs all receive federal or state funds and either provide explicit caregiver services, for example through the Older Americans Act's (OAA) National Family Caregiver Support Program (NFCSP), or support family caregivers indirectly through HCBS programs. The research project collected information from the state agencies that administer three types of programs: the NFCSP, Aged or Aged/Disabled Medicaid HCBS waiver programs¹ and state-funded programs with a caregiver-specific focus or a family caregiving component, such as respite care (Feinberg et al., 2004).

With the intent of informing policy discussions about consumer direction and family caregiving, the research presented in this report addresses three main questions:

- 1) What range and scope of consumer-directed options do the states offer family caregivers?
- 2) How do states configure services when they provide payment to family caregivers?
- 3) What is the perception among state program administrators of the importance of consumer-directed options in long-term care?

Organization of the Report

Following the presentation of background information and a description of the study methodology, we summarize the key findings, offer conclusions and address issues for the future. To compare responses to key questions related to consumer direction, we also provide two data tables displaying program-specific data. Table 1 identifies the consumer-directed options available in the surveyed programs. Table 2 illustrates which services family members can be paid to provide by each program and any restrictions on payment to family providers.

Background

One model of consumer direction is known as “cash and counseling”. Using a controlled experimental design, three states (Arkansas, Florida and New Jersey) have been testing “cash and counseling” approaches under the Medicaid program to promote consumer direction, including paying family members to provide care. Funded in 1995 by the Robert Wood Johnson Foundation (RWJF) and The Assistant Secretary for Planning and Evaluation (ASPE), through the Medicaid 1115 demonstration and research authority, these states utilized funds from Medicaid state plan personal care services or Medicaid HCBS waiver programs. Consumers have had the alternative of managing flexible allowances to design and purchase the goods and

¹ In this report, we use the terms “Medicaid waivers” and “A/D Medicaid waivers” to refer to Aged or Aged/Disabled Medicaid HCBS 1915(c) waivers that allow states to expand home and community services as an alternative to nursing facility care. These programs target frail elders or combined elderly and working-age persons with disabilities. More generally “home and community-based services” or HCBS refers to the aggregate of programs, delivered in the home or community, that support persons who need long-term services and their families. Thus, HCBS is a broader term, including not only waiver-supported services in the states, but also programs that reach people who are not eligible for Medicaid and/or offer services that may not be available under the Medicaid program.

services needed to stay at home (Phillips et al., 2003). Evaluations of the Arkansas program have documented high satisfaction, comparable costs and significantly positive outcomes for family caregivers who help consumers the most (Dale et al., 2003, Foster et al., 2003).

The early success of the original demonstration led to the replication of the model. RWJF, ASPE and the Administration on Aging (AoA) in 2004 extended the cash and counseling model to another 11 states, and one additional state has joined this replication with private funds (Mollica & Reinhard, 2005). Concurrently, The Centers for Medicare & Medicaid Services (CMS) has launched its "Independence Plus" initiative within the Medicaid 1915(c) and 1115 waiver authorities to allow consumers within the Medicaid program greater involvement, control and choice in accessing and managing their care (Crowley, 2003). CMS also has funded 12 "Independence Plus" grantee states under the Real Choices Systems Change initiative to develop the state infrastructure for consumer direction (Mollica & Reinhard, 2005).

Consumer direction is not limited to the Medicaid program, however. It is being implemented in a range of federal and state-funded HCBS programs. For example, in California, consumer direction has a long history, notably in the state's *In-Home Supportive Services* (IHSS) program funded by both the Medicaid (Medi-Cal) personal assistance benefit and state general funds, and in the respite program of the state-funded *Caregiver Resource Centers* for family and informal caregivers of persons with adult-onset cognitive impairment.

Many programs in this study, namely the OAA's NFCSP, Aged/Disabled Medicaid HCBS waivers and some state-funded programs, permit consumer-directed approaches. However, each state's rules and regulations are unique.

National Family Caregiver Support Program

The creation of the NFCSP in the 2000 reauthorization of the OAA has enabled each state to develop services for family caregivers of persons age 60 and older.² Under broad federal guidelines, the NFCSP calls for State Units on Aging (SUAs), working in partnership with local area agencies on aging (AAAs) and service providers, to develop multifaceted systems of support for family and informal caregivers within five basic service categories: 1) information to caregivers about available services; 2) assistance to caregivers in gaining access to supportive services; 3) individual counseling, support groups and caregiver training to assist caregivers in making decisions and solving problems related to their roles; 4) respite care to provide temporary relief for caregivers from their care responsibilities; and 5) supplemental services (e.g., emergency response systems, home modifications), on a limited basis, to complement the care provided by eligible caregivers.³

All income groups are eligible for NFCSP 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 the family caregiver regardless of the older person's functional status.

² 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.

³ Older Americans Act, Title III, Part E, Section 373(b).

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.

The NFCSP neither precludes nor explicitly permits consumer direction. Thus states, and NFCSP-funded services within states, have the flexibility to offer consumer-directed options for family caregivers. For example, respite services to give family members a break from care demands, can be provided through direct payments to families, vouchers or a budget, enabling more choice and control of respite providers. The NFCSP also provides flexibility, on a limited basis, within the “supplemental services” category, allowing such options as providing funds for a car battery needed for a family member to drive a relative to the doctor’s office (Feinberg et al., 2004).⁵ States may set the policy for consumer direction, or allow each AAA to determine the availability of such an option.

Aged/Disabled Medicaid HCBS Waiver Programs

Medicaid, mainly through its waiver programs, supplies the majority of public funding in the U.S. for home and community-based care. Within broad federal guidelines, states have considerable flexibility in determining who is eligible and what services to cover in their Medicaid program (US Government Accountability 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 not otherwise covered under Medicaid, including respite care and other caregiver support services such as education and training.

The HCBS waiver program was established in 1981 under the Omnibus Reconciliation Act (OBRA) of the Social Security Act for the Medicaid Program (Harrington et al., 2000). To qualify for a waiver program, beneficiaries must meet an institutional level of 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, Doty, & O’Keeffe, 2000). Although Medicaid financial eligibility criteria are narrow, 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.

Although states may offer consumer-directed options under the waiver program, federal guidelines preclude providing individuals money directly; payments to providers must be made by the Medicaid Agency or another eligible entity. Thus, individuals may arrange services but a third party (under contract with the state and generally known as a “fiscal intermediary”) provides financial management (Kitchener, Willmott, & Harrington, 2004).

State-Funded Programs

HCBS programs funded primarily through state coffers generally have the most flexible eligibility criteria. These programs may 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 members of persons with dementia). States may, and increasingly do, offer consumer-directed options within these general revenue funded programs. State funds can also be used to fund consumer-directed options that may be precluded by federal regulations.

⁵ No more than 20% of the federal funds can be used under the supplemental services category.

Methods

This study used written surveys and telephone interviews to collect programmatic information for fiscal year 2003. To be included in the study, a program had to be administered by the state and provide support services to family caregivers⁶ under: 1) the OAA's NFCSP; 2) Aged or Aged/Disabled Medicaid 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 an HCBS program aimed at care recipients. Programs and program administrators were identified through calls to state agencies, input from the project's national advisory committee of selected experts and stakeholders in the field, and information provided by respondents from the larger study.

The project's advisory committee and previous state studies conducted by the authors guided survey development. We collected data in two parts:

- In July 2003, we sent a cover letter and the written (Part 1) survey to the agency director of the qualifying program. We also sent the written survey and cover letter to the same program officials via email with hyperlink access to the Web-based survey instrument.
- Between September and December 2003, after we received responses to the Part 1 survey, we conducted semi-structured telephone interviews (Part 2) with state respondents. We made follow-up calls to the state respondents, when necessary, to clarify data or responses.

We received written survey responses from 150 out of 154 identified programs (97% response rate). They were located in all 50 states and the District of Columbia. The responses came from all 51 administrators of the NFCSP (100% response); 49 Aged and Aged/Disabled Medicaid waiver programs (94% response); and 50 state-funded programs (98% response). Almost all of the survey respondents (148 of the 150, or 99%) participated in the Part 2 follow-up telephone interview.

Copies of the instruments are available from the authors. For more detailed information about the study's methodology, see Feinberg et al., 2004.

Key Findings

Consumer-Directed Options among Family Caregiver and HCBS Programs

The availability of consumer-directed options for family caregivers varies by state and also by programs within states.

Most states offer some consumer direction, but the extent to which consumers and their family caregivers have real choice and control varies by state and also by programs within states. A 2001 inventory of consumer-directed programs across the life span⁷ identified 139 such programs operating in the states (Doty & Flanagan, 2002). Only Tennessee and the District of Columbia did not offer at least one HCBS program with a consumer direction component. Just

⁶ In this study, the term "family caregiver" includes relatives, friends or neighbors who provide care to persons 60 years or older or adults (age 18-59) with physical and/or adult-onset cognitive disabilities (e.g., traumatic brain injury). These persons may be primary or secondary caregivers, provide full or part-time help and live with or separately from the person being cared for.

⁷ Across the life span includes programs serving children, adults or older people with physical or developmental disabilities, cognitive impairment or mental illness.

over half (51%) of the identified programs targeted elders. More recently, a 2004 survey of state aging directors and Medicaid directors about consumer direction for older persons found that 40 states operated a total of 62 consumer-directed programs (National Association of State Units on Aging and the National Council on the Aging, 2004).

In this study, all but two states (Delaware and New York⁸) report at least one program with a consumer-directed option for family caregivers. As Table 1 shows, 106 programs nationwide (71% of sample) say they offer a consumer-directed option of some kind for family caregivers. But consumer direction is far from universally available. For instance:

- ◆ In 43 programs⁹ (29% of the sample) in 29 states and the District of Columbia, family caregivers of older people and adults with disabilities have no consumer-directed options.

The NFCSP appears to be speeding the adoption of consumer direction in family caregiving programs.

The NFCSPs are more likely than the Medicaid waiver or state-funded programs to report a consumer-directed option for family caregivers. Just seven NFCSPs (14%) report their service package has no consumer-directed option, compared to 17 A/D Medicaid waiver (35%) and 19 state-funded (38%) programs.

The NFCSPs are the most likely program to offer a range of consumer-directed approaches, including choice in respite providers, a menu of services, vouchers and direct payments.

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 Table 1 and Figure 1, this survey reveals that programs offer a range of choices:

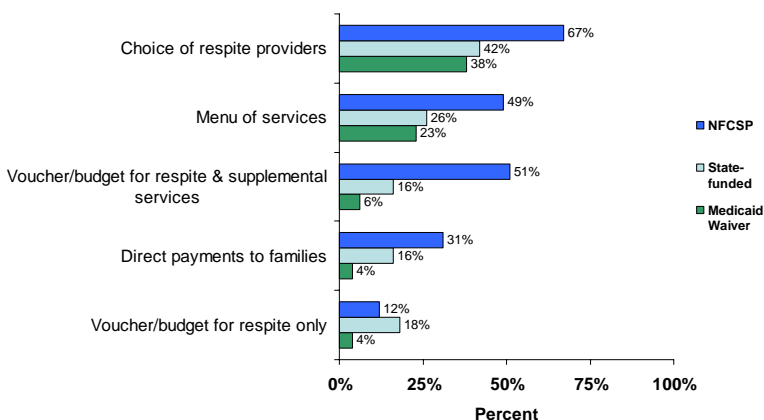
- ◆ Most commonly, programs give the family a choice of respite providers, (e.g., between contract agencies such as home care agencies or independent providers), effectively allowing families to hire their own worker. Overall, 73 programs (49%) in 43 states have this option, including two-thirds of the 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.

⁸ New York's Aged/Disabled Medicaid waiver program did not respond to this survey.

⁹ The South Dakota Medicaid waiver program did not respond to this question.

- ◆ A respite-only voucher or budget appears as an option in 17 programs (12%) in 14 states, more often in state-funded programs (18%) and less frequently in NFCSPs (12%) or Medicaid-waiver (4%) programs.

Figure 1. Consumer-Directed Options by Program Type (n = 106)



Note: CG = caregiver. Figure is based on the State of the States in Family Caregiver Support Survey (Part 1, Question 21), National Center on Caregiving, Family Caregiver Alliance, San Francisco, CA, 2004.

Client designation using a family-centered, rather than a person-centered, model appears to impact consumer-directed options for family caregivers.

A program’s client designation impacts eligibility and shapes how program services are configured and delivered. Programs that explicitly target the family caregiver often identify their client as the family caregiver, although some programs consider the client to be both the family caregiver and the person for whom they care. In contrast, consumer-oriented HCBS programs target the person with disease or disability, even though some take a more family-systems approach, considering both the family caregiver and the care recipient as clients in the program.

In this study, of the 73 programs that identify the person with disease/disability as the primary client, 44 (60%) report a consumer-directed option. In contrast, of the 44 programs that identify the family caregiver as their client, 39 (89%) offer a consumer-directed option. In the 31 programs identifying the family caregiver *and* the person with disease/disability as the client population or unit of care, 22 programs (71%) provide a consumer-directed option.

Payment to Family Caregivers

A central way of empowering consumers is to give them control over who provides their direct care. Given this choice and control, consumers often select family members as providers (Doty, 2004).

Most states (all but six) allow families to be paid providers of care in at least one of their state-administered caregiver support or HCBS programs serving older persons or adults with disabilities.

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

- ◆ Over half (86 out of 150, or 57%) of the programs in this study, in 44 states and the District of Columbia say family members can be paid to provide care (see Table 2). Viewed another way, the vast majority of programs that offer some component of consumer direction, allow payment to relatives to provide care (86 out of 106 programs, or 81%). Only six states (Alaska, Delaware, Mississippi, Nevada, Pennsylvania, Tennessee) did not allow payments to family members in any of their programs at the time of the study.
- ◆ A/D Medicaid waivers are the most likely program to allow payment to family members: Almost three-quarters of Medicaid waiver programs (36 programs, 74%) embrace this practice (although spouses and parents/guardians of minors may not be paid).
- ◆ Comparatively fewer NFCSPs (30 programs, 59%) or state-funded programs (20 programs, 40%) report they allow relatives to be paid providers.

Personal care and respite care are the most likely services that families can be paid to provide.

Of the 86 programs that allow relatives to be paid providers, program administrators report that families can be paid to provide the following services:

- ◆ Personal care (73%)
- ◆ Respite care (70%)
- ◆ Homemaker/Chore (20%)
- ◆ Other (9%)
- ◆ Any service needed (6%)

NFCSPs lead the way in allowing payment to family caregivers to provide respite services, but are less likely to pay families for personal care or homemaker/chore services.

- ◆ Among the programs paying families to provide care, nearly all of the NFCSPs (28 programs or 93%) pay for respite care. An equal number of state-funded programs and A/D Medicaid waiver programs pay families for respite care (16 programs each), but the respective proportions differ (80% of state-funded programs, 44% of waiver programs).
- ◆ Payment to family members for personal care (i.e., assistance with tasks of daily living such as dressing, bathing, feeding) is common among Medicaid waiver programs (34 programs, or 94%) and state-funded programs (15 programs, or 75%), but not among NFCSPs (14 out of 30 programs, or 47%).
- ◆ Homemaker/chore services are equally uncommon under programs of any type -- state-funded and Medicaid waiver programs (25% each), as well as the NFCSPs (10%).
- ◆ Very few programs have no restrictions on the type of services families can be paid to provide (“any service needed”) -- three state-funded programs, one NFCSP and one Medicaid waiver program fall into this category.

Some state administrators may not perceive the practice of paying families to provide care as a consumer-directed option that directly aids the family caregiver. Of programs reporting no consumer-directed option for family caregivers, 14 say they do permit beneficiaries to pay family members to provide care (9 Medicaid waivers, 5 state-funded).

Spouses are the most likely family member not allowed to be paid to provide care.

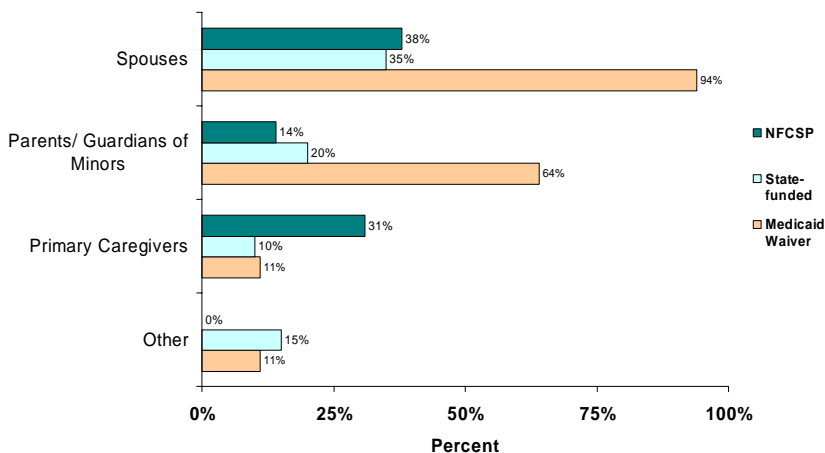
We asked respondents if their programs that pay relatives to provide care have any restrictions on the types of family members who could be paid (see Table 2).

- ◆ Among these 86 programs, nearly two-thirds (61%) do not permit spouses to be paid providers. Other family members who cannot be paid by some programs are parents/guardians (37%); primary caregivers (18%); legal guardians (8%); children 18 and under (6%); and other relatives (4%).
- ◆ Among the programs paying family members, 40% of state-funded programs and 28% of the NFCSPs have no restrictions as to who can get paid, while all of the Medicaid waiver programs have some restriction.

As Figure 2 indicates, programs vary with respect to prohibitions on payment. Prior to May 2003, federal payment to spouses and parents for HCBS waiver services was allowed only in rare instances, so it is not surprising that almost all of the Medicaid waiver programs (94%) report they cannot pay spouses. However, more than a third of the NFCSPs (38%) and state-funded programs (35%) that permit payment to relatives also exclude spouses. Medicaid waiver programs often prohibit payment to parents/guardians (64%); few NFCSPs (14%) and state-funded programs (20%) have this restriction.

Some programs prohibit primary caregivers from being paid (31% of NFCSP respondents, 11% of Medicaid waivers, and 10% of state-funded programs). All the NFCSPs that pay family members allow legal guardians to be paid, but few Medicaid waiver and state-funded programs do (11% and 15% respectively).

Figure 2. Types of Family Members Prohibited from Being Paid Providers of Care (n = 85)



Note: CG = caregiver. Missing data for one program. Figure is based on the State of the States in Family Caregiver Support Survey (Part 1, Question 22b), National Center on Caregiving, Family Caregiver Alliance, San Francisco, CA, 2004.

Programs impose few special requirements upon family members to qualify for payment.

Of the 86 programs that allow relatives to be paid providers, we asked what special requirements they have, if any. Most had none, but there were exceptions (see Table 2). A little

over one-third (36%) of the programs require a criminal background check, followed by training (33%), “other” requirements (13%) and physician approval (4%).

Medicaid waiver programs are the most likely program type with special requirements for family payees:

- ◆ The majority requires criminal background checks (57%) and training (54%). Just 10% of NFCSPs have either requirement; among state-funded programs, 37% require criminal background checks and 26% require training of the family provider.
- ◆ “Other” restrictions also are more common among Medicaid waivers (23%) than state-funded programs (11%) or NFCSPs (3%), as is physician approval (Medicaid waivers, 6%; state-funded programs, 5%; and NFCSPs, none).

Technical Assistance and Training Issues

Staff who work in programs that offer consumer-directed options can benefit from training and technical assistance. We asked state respondents whether they provide such training for their program staff who work with family caregivers and if so, its focus.

Of the 76 programs (51%) that provide or were developing training for staff who work with caregiving families, a good number cover issues related to consumer direction:

- ◆ Nearly half (34 programs, 45%) focus on the role of staff in assisting families with consumer-directed options (e.g., concepts of autonomy, choice, decision making and self-determination). Proportionately more Medicaid waiver programs with training have this focus (67% compared to 42% of the NFCSPs and 29% of state-funded programs).
- ◆ Close behind are programs that provide training on the technical aspects of administering consumer-directed options (e.g., vouchers, cash payments or fiscal intermediaries). In these 31 programs are 49% of the NFCSPs, 43% of Medicaid waiver programs and 29% of state-funded programs that offer or are developing such training.
 - ◆ Across 18 states, 23 programs report that they provide training in both areas of consumer direction.

We also asked state program administrators their views about the benefit to their staff of technical assistance and training on 11 specified topics. Included in these topics were the role of staff in assisting families with consumer-directed options, and the technical aspects of administering the programs.

- ◆ Across all three program types, most respondents (88%) “strongly agreed” or “agreed” that both topics would be of benefit. Respondents from Medicaid HCBS waiver programs were slightly more likely to see the benefits of such training and technical assistance.

Views on Consumer Direction and Long-Term Care

Implementing or expanding consumer-directed options is one of the top three long-term care issues identified by the states.

We asked state program administrators their opinion about the state’s current priority (high, medium, low) for 11 long-term care issues. Implementing or expanding consumer-directed options (56%) ranked third, behind expanding Medicaid waivers for the elderly and people with disabilities (61%), and integrating long-term care services (60%).

Among all respondents, over half (56%) place consumer direction as a current “high” state priority. Of the rest, the largest group (30%), calls it a “medium” priority (7% say it is “low” and 2% of no priority; 6% “don’t know”). Some differences emerged among program types, however.

- ♦ Medicaid waivers (73%) are the most likely program type to view implementing or expanding consumer direction in long-term care as a “high” priority, followed by the state-funded programs (54%) and the NFCSPs (41%).

Respondents had many suggestions for other states about implementing caregiver programs.

Several themes emerged:

- ♦ Four in 10 (40%) respondents say other states should ensure innovative programs and a flexible array of caregiver support to meet the diverse needs of families.
- ♦ Some (19%) recommend maximizing family and consumer involvement in service planning and delivery. Respondents underscore the importance of recognizing families and care recipients as partners in long-term care.
- ♦ Others (18%) specifically cite promotion of consumer-directed models of care.
- ♦ These models 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.”*

Conclusions

Consumer direction in HCBS has surged over the past decade as consumers and their families voice their desire to shape and direct their own support services. While most states offer at least one consumer-directed option to family caregivers of the elderly or adults with disabilities, considerable variation exists among states and programs within states in how much choice and control they give families to manage care.

This nationwide study of 150 programs funded by either the Older Americans Act’s NFCSP, Aged/Disabled Medicaid HCBS waivers or state revenues identified 106 (71%) programs that offer consumer-directed options for family caregivers. We found the relatively new NFCSPs to be speeding the adoption of consumer direction models in explicit family caregiving programs. Of the three programs studied, the Aged/Disabled Medicaid waiver program was the least likely to offer one or more consumer-directed options. State-administered programs with a family-centered approach (i.e., identify either the family caregiver as the program’s client or *both* the person with disease/disability and the family caregiver), rather than person-centered programs, are more likely to offer some component of consumer direction.

Paying family caregivers directly for providing services calls into question fundamental assumptions about care and work and raises a host of policy issues (Kunkel, Applebaum, & Nelson, 2004). State administrators view paying family caregivers as one way to give families maximum choice and control to meet their needs and daily living. Although not all consumer-directed programs permit relatives to be paid providers, the programs that do pay family members have relatively few restrictions overall. The most common is that spouses cannot be compensated to provide care.

In this study, state respondents show a high level of interest in consumer-directed approaches. Program administrators identify consumer direction as a top long-term care priority in their states and generally see a need for training and technical assistance in this area, both to help staff in assisting families with consumer-directed options, and to better understand the technical aspects of administering these programs.

Our current HCBS system relies heavily on family and informal caregivers who also take on central roles in consumer-directed models operated in the home. We found growing recognition of the need to be more responsive to caregiving families through services and supports, including consumer direction.

Issues for the Future

1. Federal Medicaid policy could recognize the work of family caregivers more by encouraging more consumer-directed options that benefit the family unit.

Although a sizeable number of Medicaid waiver respondents (35%) report no consumer-directed option for family caregivers in their program, Medicaid waiver programs are the most likely of the three programs in this study to allow payment to family caregivers to provide services. These programs could provide consumers and their family caregivers with more flexible options, for example vouchers for goods and services. Then consumers could choose from an array of services that would best sustain their family unit. "Another way to ease caregiver burden," suggest Foster et al. (2003), "is to give interested Medicaid beneficiaries more control over their personal care services" (p. 31). Beneficiaries allowed to direct their own funds and pay families could reduce the numbers who are forced into nursing homes for want of sufficient services at home. The recent success of the cash and counseling demonstration program shows individualized budgets and the ability to hire families and friends as care providers brings equal, if not better, outcomes for Medicaid consumers. States should consider making this flexibility a central part of their Aged or Aged/Disabled Medicaid HCBS waiver program.

2. Consumer direction in general, and payment to family caregivers in particular, are key ways to address worker shortages, improve outcomes for consumers and their families, and enable family caregivers to continue to provide care.

State efforts to provide adequate resources to meet consumers' preferences to remain in the home have produced significant shifts in state policy (Mollica & Reinhard, 2005). One shift is the expansion of consumer direction among HCBS programs. While facing uneven budgetary climates and increasingly complex systems of long-term care and HCBS, state and federal policymakers continue to look for the best ways to meet family needs. As Doty (2004) explains, "This can only be accomplished by offering family caregivers, along with elderly and younger adult service users, more choice, more control and more flexibility to tailor formal services and supports to meet their needs and preferences" (p. 12). Ultimately, most families want and prefer this flexible approach to service delivery, and public policy and practice should both recognize and meet these needs.

Acknowledgements

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Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
ALABAMA							
FC	Alabama CARES	X	X		X		
MC	Elderly & Disabled Waiver						X
ALASKA							
FC	NFCSP				X		
SC	Innovative Respite						X
ARIZONA							
FC	NFCSP		X		X		
MC	AZ Long-Term Care System (ALTCS)	X					
SC	Non-Medical HCBS						X
ARKANSAS							
FC	Caring for the Caregiver Arkansas Caregivers	X		X			
MC	ElderChoices Medicaid Waiver					X	
CALIFORNIA							
FC	NFCSP	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			

Program Type: FC = National Family Caregiver Support Program; MC = Aged/Disabled Medicaid HCBS Waiver; SC = State-Funded Program
 Program Name: NFCSP= National Family Caregiver Support Program; HCBS=Home and Community-Based Services

Data source: Feinberg, L.F., Newman, S.L., Gray, L., Kolb, K.N., & Fox-Grage, W. (November 2004). *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
COLORADO							
FC	NFCSP	X	X		X		
MC	HCBS for the Elderly, Blind and Disabled						X
CONNECTICUT							
FC	NFCSP		X		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	NFCSP			X			
MC	Elderly & Physical Disabilities Waiver						X
FLORIDA							
FC	NFCSP		X	X	X		
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	X	X		
SC	Community Care for the Elderly						X
SC	Alzheimer's Disease Initiative						X
GEORGIA							
FC	NFCSP	X	X	X	X		
MC	Community Care Services Program (CCSP)						X

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
HAWAII							
FC	NFCSP	X	X	X	X		
MC	Nursing Home Without Walls				X		
SC	Kupuna Care						X
IDAHO							
FC	NFCSP		X	X	X		
MC	HCBS Aged & Disabled Waiver				X		
SC	Senior Services Act, Respite Program		X	X	X		
ILLINOIS							
FC	NFCSP	X	X	X	X		
MC	Community Care Program (CCP)				X		
MC	Home Services Program				X		
INDIANA							
FC	Caring and Compassion	X	X	X	X		
MC	Aged & Disabled Medicaid Waiver						X
SC	CHOICE					X	
IOWA							
FC	Iowa Family Caregiver	X	X	X	X		
MC	Elderly Waiver				X		
KANSAS							
FC	NFCSP	X					
MC	Home & Community-Based Frail Elder Waiver				X		
SC	Senior Care Act Program					X	
KENTUCKY							
FC	NFCSP		X		X		
SC	Adult Day/Alzheimer's Respite						X

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
LOUISIANA							
FC	NFCSP	X					
MC	Medicaid Home and Community-Based Waiver	X			X		
MAINE							
FC	Family Caregiver Program	X	X		X		
MC	MaineCare	X			X		
SC	Home-Based Care	X		X	X		
SC	Partners in Caring	X	X		X		
MARYLAND							
FC	NFCSP	X	X	X	X		
MC	Medicaid Waiver for Older Adults				X		
SC	Respite for Caregivers of Adults with Functional Disabilities				X		
MASSACHUSETTS							
FC	NFCSP	X	X		X		
MC	Home and Community-Based Waiver						X
SC	Home Care Program	X				X	
MICHIGAN							
FC	NFCSP		X		X		
MC	MI Choice						X
SC	State/Escheat Respite		X		X		
SC	Caregiver Respite Program		X		X		
MINNESOTA							
FC	NFCSP				X		
MC	Elderly Waiver	X			X		
SC	Alternative Care Program	X	X		X	X	

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
MISSISSIPPI							
FC	NFCSP	X	X		X		
MC	Elderly & Disabled Waiver	X					
MISSOURI							
FC	NFCSP		X	X	X		
MC	Aged & Disabled Waiver						X
MONTANA							
FC	Family Caregiving Support						X
MC	HCBS Program for Elderly & Physically Disabled	X					
NEBRASKA							
FC	NFCSP	X	X		X		
MC	Aged & Disabled Waiver		X		X		
SC	Respite Subsidy Program Across the Lifespan		X	X	X		
NEVADA							
FC	NFCSP						X
MC	Community Home-Based Initiatives Program	X			X		
SC	Independent Living Grant	X	X		X		
SC	Community-Based Care Caregiving Training						X
NEW HAMPSHIRE							
FC	NFCSP	X	X		X		
MC	Elderly and Chronically Ill Waiver		X				

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
NEW JERSEY							
FC	NFCSP				X		
MC	Community Care Program for the Elderly & Disabled						X
MC	Enhanced Community Options (ECO)	X	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	X		X		
NEW MEXICO							
FC	NFCSP		X		X		
MC	Disabled & Elderly HCBS Waiver						X
NEW YORK							
FC	Eldercare Family Support Program (EFSP)						X
SC	Respite Program						X
NORTH CAROLINA							
FC	NFCSP		X		X		
MC	Community Alternatives Program for Disabled Adults (CAP/DA)					X	
SC	Respite Care Program						X
NORTH DAKOTA							
FC	NFCSP	X			X		
MC	Aged & Disabled Waiver		X		X		
SC	Family Home Care		X		X		

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of consumer-directed options provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
OHIO							
FC	NFCSP	X	X	X	X		
MC	PASSPORT HCBS Waiver Program						X
SC	Alzheimer's Respite Program	X	X		X		
OKLAHOMA							
FC	NFCSP		X				
MC	Advantage Program						X
SC	Respite Resource Network	X	X		X		
OREGON							
FC	NFCSP	X	X				
MC	Medicaid Waiver/In-Home Care					X	
SC	Lifespan Respite Care Networks	X	X		X		
PENNSYLVANIA							
FC	NFCSP			X			
MC	PA Department of Aging 60+ Medicaid Waiver					X	
SC	PA FCSP	X			X		
SC	OPTIONS					X	
SC	BRIDGE					X	
RHODE ISLAND							
FC	Partners in CaRIing	X		X	X		
MC	Home & Community-Based Waiver						X
SOUTH CAROLINA							
FC	NFCSP	X	X		X		
MC	Elderly/Disabled Home and Community-Based Waiver	X			X		

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
SOUTH DAKOTA							
FC	Caregiver Program	X	X		X		
MC	Home & Community-Based Elderly Waiver						
TENNESSEE							
FC	NFCSP		X				
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities		X				
TEXAS							
FC	NFCSP		X				
MC	Community-Based Alternatives				X	X	
SC	Respite Care Program						X
SC	In-Home & Family Support Program			X			
UTAH							
FC	Caregiver Support Program	X			X		
MC	Medicaid Aging Waiver						X
SC	Home & Community-Based Alternatives						X
VERMONT							
FC	NFCSP	X	X	X	X		
MC	Home-Based Medicaid Waiver				X	X	
VIRGINIA							
FC	NFCSP						X
MC	Elderly & Disabled Waiver				X	X	
SC	Caregiver Grant Program						X
SC	Respite Care Initiative Grant						X
SC	Respite Care Grant Program 2003						X

Table 1: Consumer-Directed Options for Family Caregivers (cont'd)

Program		Types of Consumer-Directed Options Provided					
Type	Name	Menu of services	Voucher	Direct payments to family members	Choice of respite providers	Other	None
WASHINGTON							
FC	NFCSP		X		X		
MC	Community Options Program Entry System (COPES)						X
SC	WA FCSP		X		X		
SC	Respite Care Services				X		
WEST VIRGINIA							
FC	Family Caregiver Support						X
MC	Medicaid Aged & Disabled Waiver	X					
WISCONSIN							
FC	NFCSP		X	X	X		
MC	Community Options Program Waiver (COP-W)		X		X		
SC	Alzheimer's Family & Caregiver Support Program	X	X	X	X		
WYOMING							
FC	NFCSP						X
MC	HCBS Waiver for Elderly & Physically Disabled			X		X	
SC	Community Based In-Home Services Program (CBIHS)						X

Table 2: Payment of Family Members to Provide Care

Program		Services Family Members Can Be Paid to Provide ¹					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/chore	Any service needed	None	Spouses	Parents/guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
ALABAMA														
FC	Alabama CARES					X								
MC	Elderly & Disabled Waiver		X	X			X	X						
ALASKA														
FC	NFCSP					X								
SC	Innovative Respite					X								
ARIZONA														
FC	NFCSP	X											X	
MC	AZ Long-Term Care System (ALTCS)	X	X				X	X			X		X	
SC	Non-Medical HCBS					X								
ARKANSAS														
FC	Caring for the Caregiver Arkansas Caregivers		X				X	X						
MC	ElderChoices Medicaid Waiver	X		X			X	X						
CALIFORNIA														
FC	NFCSP	X	X		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	X				X			X				

¹ Eight programs additionally marked "Other" services that family members can be paid to provide: Hawaii Nursing Home Without Walls, Kansas Home & Community-Based Frail Elder Waiver, Kentucky NFCSP, Nebraska Aged & Disabled Waiver, New Jersey Enhanced Community Options (ECO), Jersey Assistance for Community Caregiving, Oregon Medicaid Waiver/In-Home Care, Wisconsin Community Options Program Waiver (COP-W).

Program Type: FC = National Family Caregiver Support Program; MC = Aged/Disabled Medicaid HCBS Waiver; SC = State-Funded Program
 Program Name: NFCSP= National Family Caregiver Support Program; HCBS=Home and Community-Based Services

Data source: Feinberg, L.F., Newman, S.L., Gray, L., Kolb, K.N., & Fox-Grage, W. (November 2004). *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
COLORADO														
FC	NFCSP					X								
MC	HCBS for the Elderly, Blind and Disabled		X				X						X	
CONNECTICUT														
FC	NFCSP					X								
MC	Home Care Program for Elders		X				X	X						
SC	Statewide Respite Care Program					X								
SC	Personal Care Assistance State-Funded Pilot Program		X	X			X			X				
DELAWARE														
FC	CARE Delaware					X								
MC	Elderly & Disabled Waiver					X								
DISTRICT OF COLUMBIA														
FC	NFCSP	X	X						X					
MC	Elderly & Physical Disabilities Waiver	X	X				X	X		X	X		X	
FLORIDA														
FC	NFCSP	X		X										
MC	Aged & Disabled Adult Medicaid HCBS Waiver	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
SC	Community Care for the Elderly					X								
SC	Alzheimer's Disease Initiative					X								

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
GEORGIA														
FC	NFCSP	X	X							X				
MC	Community Care Services Program (CCSP)					X								
HAWAII														
FC	NFCSP					X								
MC	Nursing Home Without Walls		X				X	X					X	
SC	Kupuna Care					X								
IDAHO														
FC	NFCSP					X								
MC	HCBS Aged & Disabled Waiver		X				X	X			X			X
SC	Senior Services Act, Respite Program					X								
ILLINOIS														
FC	NFCSP	X	X						X		X			
MC	Community Care Program (CCP)			X			X		X	X				X
MC	Home Services Program		X				X	X						
INDIANA														
FC	Caring and Compassion	X												
MC	Aged & Disabled Medicaid Waiver		X				X	X			X	X		
SC	CHOICE					X								
IOWA														
FC	Iowa Family Caregiver	X	X											
MC	Elderly Waiver		X				X	X					X	

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
KANSAS														
FC	NFCSP					X								
MC	Home & Community-Based Frail Elder Waiver	X	X				X				X	X		
SC	Senior Care Act Program		X	X			X				X			
KENTUCKY														
FC	NFCSP	X					X							
SC	Adult Day/Alzheimer's Respite	X	X											
LOUISIANA														
FC	NFCSP					X								
MC	Medicaid Home and Community-Based Waiver		X				X	X		X	X		X	
MAINE														
FC	Family Caregiver Program	X					X							
MC	MaineCare	X	X				X				X		X	
SC	Home-Based Care	X	X							X	X		X	
SC	Partners in Caring	X	X											
MARYLAND														
FC	NFCSP	X												
MC	Medicaid Waiver for Older Adults	X	X				X				X		X	
SC	Respite for Caregivers of Adults with Functional Disabilities					X								
MASSACHUSETTS														
FC	NFCSP		X	X			X				X		X	
MC	Home and Community-Based Waiver					X								
SC	Home Care Program		X	X			X	X						

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
MICHIGAN														
FC	NFCSP					X								
MC	MI Choice		X	X			X					X	X	
SC	State/Escheat Respite					X								
SC	Caregiver Respite Program					X								
MINNESOTA														
FC	NFCSP	X	X						X			X		
MC	Elderly Waiver					X								
SC	Alternative Care Program	X	X				X	X			X	X		
MISSISSIPPI														
FC	NFCSP					X								
MC	Elderly & Disabled Waiver					X								
MISSOURI														
FC	NFCSP	X							X		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	NFCSP	X					X	X						
MC	Aged & Disabled Waiver	X		X			X	X	X	X	X			
SC	Respite Subsidy Program Across the Lifespan	X					X	X	X					

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
NEVADA														
FC	NFCSP					X								
MC	Community Home-Based Initiatives Program					X								
SC	Independent Living Grant					X								
SC	Community-Based Care Caregiving Training					X								
NEW HAMPSHIRE														
FC	NFCSP	X	X	X					X					
MC	Elderly and Chronically Ill Waiver	X	X				X	X			X		X	
NEW JERSEY														
FC	NFCSP					X								
MC	Community Care Program for the Elderly & Disabled					X								
MC	Enhanced Community Options (ECO)		X	X			X	X		X			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	X			X	X		X			X	

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/chore	Any service needed	None	Spouses	Parents/guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
NEW MEXICO														
FC	NFCSP	X	X				X							
MC	Disabled & Elderly HCBS Waiver		X				X	X			X			
NEW YORK														
FC	Eldercare Family Support Program (EFSP)					X								
SC	Respite Program	X												
NORTH CAROLINA														
FC	NFCSP	X	X											
MC	Community Alternatives Program for Disabled Adults (CAP/DA)	X	X	X			X				X		X	X
SC	Respite Care Program	X	X	X					X	X				X
NORTH DAKOTA														
FC	NFCSP	X												
MC	Aged & Disabled Waiver	X	X	X			X	X						X
SC	Family Home Care	X	X					X						
OHIO														
FC	NFCSP	X	X											
MC	PASSPORT HCBS Waiver Program					X								
SC	Alzheimer's Respite Program	X								X		X		
OKLAHOMA														
FC	NFCSP	X							X	X				
MC	Advantage Program		X				X	X						X
SC	Respite Resource Network	X							X					

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/chore	Any service needed	None	Spouses	Parents/guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
OREGON														
FC	NFCSP					X								
MC	Medicaid Waiver/In-Home Care	X	X								X			
SC	Lifespan Respite Care Networks					X								
PENNSYLVANIA														
FC	NFCSP					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					X		X					
MC	Home & Community-Based Waiver					X								
SOUTH CAROLINA														
FC	NFCSP	X	X				X	X	X					
MC	Elderly/Disabled Home and Community-Based Waiver		X				X	X	X			X		
SOUTH DAKOTA														
FC	Caregiver Program	X					X	X		X				
MC	Home & Community-Based Elderly Waiver					X								
TENNESSEE														
FC	NFCSP					X								
SC	Home & Community-Based Long-Term Care for Non-Medicaid Elderly & Adults with Disabilities					X								

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal back-ground checks	Doctor approval	Training	Other
TEXAS														
FC	NFCSP	X					X		X					
MC	Community-Based Alternatives	X	X				X				X		X	
SC	Respite Care Program					X								
SC	In-Home & Family Support Program					X								
UTAH														
FC	Caregiver Support Program	X					X							
MC	Medicaid Aging Waiver	X	X				X				X		X	X
SC	Home & Community-Based Alternatives	X	X		X		X				X		X	
VERMONT														
FC	NFCSP	X												
MC	Home-Based Medicaid Waiver	X	X				X				X			
VIRGINIA														
FC	NFCSP					X								
MC	Elderly & Disabled Waiver	X	X				X	X			X		X	
SC	Caregiver Grant Program	X	X		X									
SC	Respite Care Initiative Grant					X								
SC	Respite Care Grant Program 2003					X								

Table 2: Payment of Family Members to Provide Care (cont'd)

Program		Services Family Members Can Be Paid to Provide					Types of Family Members Who Cannot Be Paid to Provide Care				Special Requirements for Family Members Paid to Provide Care			
Type	Name	Respite care	Personal care	Home-maker/ chore	Any service needed	None	Spouses	Parents/ guardians of minors	Primary care-givers	Other	Criminal background checks	Doctor approval	Training	Other
WASHINGTON														
FC	NFCSP					X								
MC	Community Options Program Entry System (COPES)		X				X	X			X		X	
SC	WA FCSP					X								
SC	Respite Care Services					X								
WEST VIRGINIA														
FC	Family Caregiver Support					X								
MC	Medicaid Aged & Disabled Waiver		X				X							
WISCONSIN														
FC	NFCSP	X	X											
MC	Community Options Program Waiver (COP-W)	X	X	X			X	X						X
SC	Alzheimer's Family & Caregiver Support Program	X	X											
WYOMING														
FC	NFCSP	X												X
MC	HCBS Waiver for Elderly & Physically Disabled		X	X			X	X			X			
SC	Community Based In-Home Services Program (CBIHS)					X								