
Consumer-Directed Home Care: *Effects on Family Caregivers*

POLICY BRIEF

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National Center on Caregiving

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By Pamela Doty, PhD

INTRODUCTION

“Consumer direction” is a philosophical approach to paying for services to support elders and younger persons with disabilities living in their own or relatives’ homes that is very different from the way “third parties”—public programs or private insurers—typically pay for any other kind of medical or related services. Consumer-directed models of care shift the locus of decision-making and control away from payers and providers toward program participants or policyholders. Although some elders and younger adults with disabilities insist on “self” direction, family caregivers’ participation is so widespread that many policymakers and program administrators think of the “consumer” in consumer-directed care not as an individual but as a dyad consisting of the program participant or insured beneficiary *and* his or her family (Ditto, 2004; Feinberg, Whitlatch, & Tucke, 2000).

What it means for consumers to be in charge is illustrated by Mrs. Lillian Brannon, who was 88 years old when she became one of the first Medicaid beneficiaries to enroll in Arkansas’ *Independent Choices* program. Arkansas is one of three states that pioneered the “cash and counseling” model of consumer-directed care. Mrs. Brannon had multiple chronic diseases and conditions as well as very severe physical disabilities, but no cognitive impairment. Explaining why she chose to participate in the demonstration program, Mrs. Brannon said she had already “escaped” four times from nursing homes. Before enrolling in *Independent Choices*, Mrs. Brannon received Medicaid-funded in-home services in the traditional way, through licensed

agencies. Her case manager, a nurse, tried to persuade Mrs. Brannon that she really needed to be in a nursing home. Mrs. Brannon was determined to continue to live alone in a low-income senior housing project where she had many friends. Mrs. Brannon’s children could not provide much informal care because most lived out-of-state. One son helped on a weekly basis, but was limited in what he could do both because he lived an hour away and had physical disabilities himself. Mrs. Brannon used her cash and counseling allowance primarily to hire and supervise directly her own home care aides, two “regular” aides (one for weekdays and one for weekends) and two “back-up” aides. She also used some of her funds to purchase personal care supplies and to pay uncovered prescription and over-the-counter drug costs. After having been an *Independent Choices* participant for over a year, Mrs. Brannon said she liked it because “I’m the boss.” (Larson, n.d.; Squillace, 2002).

OVERVIEW

This policy brief describes currently available opportunities for consumer direction of care in public programs and private insurance plans, including opportunities for family caregivers to take on roles as representative decision-makers and paid caregivers. Evaluation research findings will be discussed, with an emphasis on recent findings from the cash and counseling demonstrations. Using a controlled experimental design to compare outcomes for service users and their family caregivers who participated in the consumer-directed care model with those in the control group receiving traditional services, the

evaluation found that outcomes for both elderly and disabled program participants and their family caregivers were at least the same and often significantly improved in the cash and counseling alternative to traditional services.

The brief concludes by addressing some concerns that have been expressed about the role of family caregivers in consumer direction and by assessing the prospects for expansion of consumer-directed alternatives to traditional modes of financing and service delivery.

BACKGROUND

Three Models of Consumer Direction

The amount of choice and control consumers and their families can exercise is greater in some consumer-directed care models than in others. The most common option limits consumer-directed services covered by a public program or private insurance policy to personal assistance from an aide or attendant who is hired/fired and supervised directly by service users or their families (instead of being an employee of a licensed home care agency).

A newer option—currently available only in some public programs—broadens the amount of choice and control available to service users and families by giving them an individualized monthly budget. The funds may be used to purchase a broad range of services and supports, which include but are not limited to individually hired aides. For example, consumers might choose to purchase assistive technologies or make home modifications to decrease dependence on human assistance from paid or unpaid helpers. This approach is often called *cash and counseling* because it was tested on a broad scale in a three-state Medicaid demonstration of that name, first implemented in Arkansas in 1998. Participants in cash and counseling programs (including those with a similar design that wear other labels such as “self-determination” or “Independence Plus”)

do not literally receive cash payments. Although program participants make their own decisions about disability services and supports, they manage their budgets via a book-keeping service or fiscal intermediary which assures the third party payer of an independent accounting of how the allowances are being spent (Mahoney, Simone, & Simon-Rusinowitz, 2000).

The third model is a no-strings-attached cash benefit. Currently, it is available almost exclusively from private insurers, who typically refer to it as the “disability insurance model” because, unlike most private long-term care insurance, its design is based on the insurance industry’s experience with disability rather than medical insurance (Cohen, Weinrobe, & Miller, 1999; Hancock, 2004; Ruddock, 2004).

Why is Consumer Direction an Attractive Alternative to Traditional Services?

Proponents of consumer-directed care typically contrast this approach with what they refer to as “provider-driven” care, also termed the “medical model” because it is based on traditional, fee-for-service medical insurance principles and practices. The traditional approach emphasizes professional decision-making and oversight (e.g., physicians’ orders, nurse supervision, and case management by nurses or social workers). The traditional approach is also characterized by a proliferation of coverage rules that define and restrict, often in quite considerable detail, the amount, duration, and scope of services that will be paid for, as well as reimbursement rates.

These complex bureaucratic systems can confuse and frustrate people with disabilities and their family caregivers. This is why many advocates argue that professionals and service providers (e.g., case managers) who know the rules need to

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be in charge. Proponents of consumer direction argue that what people with disabilities and their families really need is rule simplification, which becomes possible when benefits take the form of individualized budgets or monthly cash allowances rather than covered services from approved service providers.

Traditional medical insurance principles and practices reflect a pre-existing, highly professionalized and regulated service system (e.g., physicians, hospitals) to which third party payers deferred in developing coverage rules, service definitions and payment policies. Until recently, long-term care at home was provided almost exclusively by informal caregivers (i.e., family, friends and neighbors) and, even now, is provided only secondarily by paid, mostly low-wage, nonprofessional personnel. To a considerable extent, third party payers—especially Medicare and Medicaid—are responsible for creating today’s home health industry (e.g., certified home health agencies, licensed personal care agencies) via their provider qualifications.

According to a federally sponsored, nationally representative sample of all chronically disabled elders living in the community, 96 percent receive at least some unpaid family care and two-thirds rely exclusively on such help. Eighty-six percent of those at greatest risk of nursing home placement (i.e., those who require help with three or more personal care tasks such as bathing, dressing, transferring from bed to chair, using the toilet, and eating) live with others. They receive, on average, slightly under 75 hours of human assistance per week, of which approximately 60 hours are provided by unpaid family caregivers and a little over 14 hours per week are provided by paid helpers. It is very rare for elders whose level of disability puts them at risk of nursing home admission to depend primarily on formal home care: only four percent

live alone and receive more paid than unpaid hours of care per week (Assistant Secretary for Planning and Evaluation [ASPE] & Administration on Aging [AoA], 1998).

Home care is so labor-intensive that paid services are seldom a cost-effective alternative to residential care for individuals with severe physical disabilities and/or cognitive impairment except when subsidized by unpaid family care. Third-party payers’ home care coverage is rarely sufficient to pay for round-the-clock supervision, unscheduled assistance (such as dealing with incontinence), and help with regular, routine, but very frequent tasks (such as taking multiple medications several times a day). Third party payers—government programs in particular—explicitly design and limit home care coverage to supplement or complement but not to substitute for unpaid care from family, friends, and neighbors. The cost of replacing all family caregiving with paid help would be prohibitively high (Arno, Levine, & Memmott, 1999).

Recent research in three states found that disabled elders enrolled in traditional (i.e., non-consumer-

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directed) Medicaid-funded home care programs received from 13 to 22 percent of their weekly hours of human assistance with basic and instrumental activities of daily living from paid helpers. In a study of private long-term care insurance claimants, family caregivers reported that insurance paid for slightly less than half the

total weekly hours of human assistance their elderly relatives received while informal family care supplied the remainder (Cohen, Weinrobe, & Miller, 2000a; Cohen, Weinrobe, & Miller, 2000b).

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to be able to reside at home in safety, comfort and dignity. If they cannot personally provide the help, families will try to find some other way to meet the need, be it by another informal helper, paid worker, or some different approach such as technology. Family members do not refuse to meet a need because it is not in their job description or is not a covered service or an approved task under the definition of a covered service. If family caregivers “specialize” it is usually along gender lines. For example, intimate personal care is more often performed by female relatives or relatives of the same sex as the care recipient. In contrast, third party payers pay for discrete specialty services such as “home health,” “personal care,” “homemaker/chore,” “companion,” and “respite,” and define what kinds of assistance will be paid for (or not) in each category. Each of these services may be subject to separate billing requirements, reimbursement rates, coverage limits and provider qualifications.

In addition, “authorized” service providers often have their own rules and restrictions. For example, many home care agencies do not provide services outside the hours of 9 a.m. to 5 p.m. weekdays. Agencies’ concerns about liability and insurance costs may result in significant limitations on what tasks aides are allowed to perform. For example, agency workers are often prohibited from driving clients anywhere, including to medical appointments. In addition, agencies may prohibit their employees from performing any kind of “heavy” cleaning or chores, which may make it very difficult, for example, to control dust to the extent that a client with respiratory problems requires.

If a particular service or task is not covered or not provided by any authorized service providers, people with disabilities and their families still have to find a way to get the job done. Otherwise, disabled family members may be left with unmet needs for assistance that could adversely affect their quality of life and their health and safety.

Formal providers often reserve the right to change service schedules on short notice. This may cause significant inconvenience to clients and family caregivers—such as when an employed family caregiver needs to get to her job. Agencies also re-assign workers at will. This may mean, for example, that the client receives a bath from a different “stranger” at each visit and the family must cope with their disabled relative’s emotional distress. When third-party payers restrict coverage to a limited set of authorized providers, market forces are attenuated: dissatisfied consumers cannot seek better service elsewhere.

Because family caregivers do so much of the actual “work” of home care themselves, it seems only natural for them to want third-party payers and formal service providers to recognize the family’s central role in enabling their disabled relatives to remain at home. Family caregivers would like paid services to be responsive and adaptive to them, for example, by accommodating family caregivers’ schedules instead of the other way around. Family caregivers would also like payers and providers to acknowledge the family’s expertise about their relatives’ care needs and preferences. Although service users and their families may appreciate advice and assistance from professionals and formal service providers, this does not always mean that they see themselves as needing professionals and bureaucrats to take over all the executive functions of “care planning, care coordination and oversight” while families continue to provide most of the actual care (Squillace, 2002).

Medicaid law requires that states providing home and community-based services to individuals who qualify for institutional care under federally approved waivers “assure” their health and safety in home and community-based care settings. The implication is that it is the Medicaid-financed formal services that guarantee program participants’ health and safety. But family caregivers

who provide 75 percent or more of total care hours without pay know that, in reality, it is primarily their efforts that are responsible for keeping their relatives safe and healthy. At best, the government only assists the family because of the limited types and amount of services the state Medicaid program covers. If consumer-directed approaches to financing and delivering home care are attractive to many family caregivers, it is because these models have potential to help families access third party-financed care in ways that are “custom-tailored” by them, to complement unpaid family care and support family caregivers.

The Role of Family Caregivers in Consumer-Directed Care Models: Representatives and Paid Family Care

Much family involvement in consumer direction is implicit and informal: it just “happens” naturally, in keeping with how family members normally consult one another about decisions that affect them all and help each other get household chores and family “business” accomplished. However, some consumer-directed services programs and plans have made explicit, formal provisions to recognize

shared or surrogate decision-making by family caregivers. In the cash and counseling demonstration programs, family members who take on a decision-making role are termed “representatives.” This is similar to the Social Security concept of a “representative payee.”

Designation of a representative is necessary to enable individuals with cognitive impairments (e.g., adults with Alzheimer’s or other dementia disorders, traumatic brain injury, mental retardation and various other kinds of mental/behavioral dis-

orders) to participate in consumer-directed programs, although studies have shown that persons with mild to moderate cognitive impairment are capable of expressing their preferences for everyday living (Feinberg & Whitlatch, 2001). For example, Gregorio and Felicita Cruz, of Zephyrhills, Florida, who participate in Florida’s Consumer-Directed Care (CDC) program, would not have been able to direct their own care without designating a representative (their daughter Elsa Torres) because both had dementia as well as physical disabilities and other health problems. Although Elsa’s mother could still communicate her preferences to her daughter, her father’s dementia had already progressed so far that Elsa had to act as his surrogate (Burness Communications, n.d.).

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However, many participants, including those without cognitive impairments, who participate in cash and counseling programs elect to have family members serve as their representatives. For example, Mrs. Janice Maddox, a 75-year old resident of Pine Bluff, Arkansas, eligible for Medicaid-funded personal care services because she is physically frail and con-

finned to a wheelchair, was not required to name a representative to be allowed to join Arkansas’ Independent Choices program. However, she did not feel comfortable making her own arrangements for care: she wanted her family to do so for her. Mrs. Maddox, whom her loved ones call “Big Momma,” has an extensive natural support network of family and friends who make it possible for her to continue to live independently. She asked her eldest daughter Johnetta Thurman to be her representative. Johnetta is a “long-distance caregiver” who lives in Chicago but

travels frequently to Arkansas to oversee the arrangements she has made and make sure her mother's needs are being met. (Burness Communications, n.d.). Sizable minorities of cash and counseling program participants have representatives, especially older participants (e.g., 46 percent of elders in Arkansas' Independent Choices) and, of course, all children under age 18.

Participants in consumer-directed care options often choose to hire family members as paid home care workers. For example, a majority of program participants in all three cash and counseling demonstration states (Arkansas, New Jersey, and Florida) chose to hire family members as their paid home care aides. The preference for hiring family members was strongest among elders.

Prevalence of Consumer-Directed Care Options in Public Programs and Private Insurance

A 2001 inventory of consumer-directed public programs identified 139 programs, of which two-thirds were Medicaid-funded. There was at least one such program in every state except Tennessee and the District of Columbia. However, all but a handful limited consumer-direction to the hiring, firing and supervision of individual aides. About 80 percent of these programs permitted participants to hire family caregivers as aides, although Medicaid-funded programs prohibit spouses and parents (of minors) from being paid workers except under research and demonstration waivers (Doty & Flanagan, 2002). The single largest—and among the oldest—public programs permitting clients to hire their own individual personal care attendants is California's *In-Home Supportive Services (IHSS)* Program which currently serves about 310,000 persons with disabilities of all ages (Amaral, 2004).

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A handful of public programs give participants access to a regular dollar amount (i.e., a monthly budget) in lieu of covered services. Five of these program operate under Medicaid "1115" research and demonstration waivers. They include the three original cash and counseling programs in Arkansas, New Jersey and Florida, which, collectively, have enrolled more than 7000 participants, and two similar but much smaller demonstration programs operating in Oregon and Colorado. The average monthly allowance varied by target population (elderly as compared to disabled children) and across states (from a low of \$350 per month in Arkansas to a high of \$1400 in New Jersey for elders and adults with disabilities). Because Medicaid law prohibits direct payments to beneficiaries, Medicaid beneficiaries who participate in cash and counseling or related programs may receive cash directly only under special research waivers. Participants in the cash and counseling demonstration states were given the choice to manage their funds via a "fiscal intermediary" (bookkeeping service) or receive a direct cash payment if, after training, they passed a financial skills test. Only about a dozen or so participants in all three states elected to take the training, pass the skills test, and manage their own

funds (Phillips, B., Mahoney, K., Simon-Rusinowitz, L., Schore, J., Barrett, S., Ditto, W., Reimers, T., & Doty, P. 2003).

Since May 2002, when the Centers for Medicare and Medicaid Services (CMS) announced that, under an initiative called *Independence Plus*, states could apply to offer cash and counseling options under the 1915(c) home and community-based alternatives to institutionalization waiver authority, four states (New Hampshire, Louisiana, South Carolina and North Carolina)

have sought and received approval. The largest of these Independence Plus waiver programs is approved to serve up to 900 Medicaid eligibles. All participants in Independence Plus programs must manage their funds via a financial management service.

Many of the new caregiver support programs administered by state units on aging and local area agencies on aging with Older Americans Act funding offer family caregivers the opportunity to access respite and other services through models patterned after cash and counseling. A small number of state general revenue funded programs give beneficiaries or families a cash benefit. Usually the dollar amounts that consumers or families can qualify for under these cash allowance programs are low compared to the individual budget amounts allocated in Medicaid cash and counseling or related programs.

Finally, approximately ten percent of private long-term care insurance policies currently in force are similar to disability insurance in paying benefits in the form of a monthly check which the beneficiary is free to spend however he or she chooses (Cohen et al., 1999). Monthly benefits for home care under private insurance policies in 1998-1999 averaged \$1500.

RESEARCH FINDINGS: EFFECTS OF CONSUMER DIRECTION ON FAMILY CAREGIVERS

Most research to date has focused on the effects of consumer-directed care as compared to traditional models of agency-delivered care or professionally case-managed service plans on public program participants with disabilities. These results have been quite positive, finding many outcomes to be significantly improved when services are consumer directed and no significant difference between consumer-directed and traditional services on other measures. (Brown et al., 2004; Dale, Brown, Phillips, Schore, & Carlson, 2003; Foster, Brown, Carlson, Phillips, & Schore, 2003a; Benjamin, Matthias, & Franke, 1998; Doty, Kasper, & Litvak, 1996).

Conceptually, we can readily differentiate between effects of consumer direction on care recipients and effects on their family caregivers, but, in practice, the distinction tends to blur. One reason is that research often requires family caregivers to serve as proxy respondents for care recipients who have cognitive impairments or who have died. This is typical of research on home and community-based long-term care generally, not just consumer-directed as compared to traditional services. There is no evidence that mortality increases when home care is consumer-directed.

A second factor that can make it difficult to separate effects on care recipients from effects on caregivers is that family caregivers' attitudes toward consumer-directed and traditional models of service financing and delivery (e.g., satisfaction measures) are, not surprisingly, very strongly affected by both care recipients' and their own perceptions about the benefits or shortcomings of these models for the care recipients. For example, if care recipients and caregivers perceive reductions in unmet needs for assistance, they will both report higher satisfaction and, conversely, if significant unmet needs persist, they will both report lower satisfaction.

Outcomes that are unique to family caregivers involve measuring work/care-giving conflict, caregiver stress and burden, and the number of hours that family members report that they give to caregiving. Here again, however, the perceived benefits of consumer-directed care to the care recipient are likely to influence caregivers' views of how consumer-directed care affects them. Similarly, because care recipients do not wish to be a burden to their family members, they are likely to be more satisfied with models of financing and service delivery that they perceive as benefiting family caregivers.

The only cash and counseling report yet completed that focuses specifically on comparing the

effects of consumer-directed care and traditional services on family caregivers (Foster, Brown, Phillips, & Carlson, 2003b) found that, overall, family caregivers of consumer-directed participants reported greater well-being compared to family caregivers of those receiving traditional services. Specifically, the report found that, on average, family caregivers of consumer-directed demonstration program participants provided fewer hours of assistance than the caregivers of those receiving traditional services. Because this difference was small (i.e., only about five fewer hours of assistance per week) this effect is consistent with the goal of giving family members some respite as distinct from substituting paid for unpaid care. Caregivers of consumer-directed beneficiaries were less likely than caregivers of traditional service users to report high levels of physical, financial and emotional strain. They worried less about insufficient care and safety and were more likely to be very satisfied with recipients' overall care arrangements. Caregivers of consumer-directed beneficiaries were less likely to report that caregiving impinged on their privacy, social lives and job performance. Compared with control group caregivers, those who helped consumer-directed care participants also perceived their own health to be better and were less likely to report that caregiving responsibilities adversely affected their health. Finally, caregivers of consumer-directed program participants were also more likely than caregivers of traditional service users to say that they were very satisfied with their own lives.

Family caregivers often report that caregiving conflicts with paid employment outside the home. Cash and counseling evaluation findings suggest that this model of consumer direction does not eliminate such conflicts but does significantly reduce some of them. Equal percentages (slightly less than half) of the caregivers of consumer-directed

and nonconsumer-directed demonstration participants were employed (not including employment in the demonstration as a paid caregiver to the program participant). However, significantly fewer caregivers of consumer-directed participants reported that they had not looked for a job or another job even though they wanted to or had turned down a better job or promotion. Also, significantly fewer family caregivers of consumer-directed participants reported missing work or arriving late.

Because family caregivers could become paid caregivers after their care recipients became eligible to receive the cash and counseling intervention, whereas family caregivers of traditional service users remained unpaid, the evaluation also explored the extent to which the positive effects of consumer direction on family caregivers were primarily associated with those hired to provide care (Foster et al., 2003b; Simon-Rusinowitz, Mahoney, Loughlin, & Sadler, in press). In Arkansas, over half (56 percent) of

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the primary family caregivers of elderly and younger adult participants in the consumer-directed care program provided some paid hours. On average, paid family members provided 11 hours of paid care per week for which they received \$6 per hour. Independent Choices did not discernibly affect caregivers' household income. However, because family caregivers of consumer-directed program participants who were paid reported less financial strain than both unpaid caregivers of consumer-directed participants and unpaid caregivers of traditional service users, it appears that even relatively small payments had a positive effect on family caregivers' well-being.

In a majority of the caregiver outcomes examined (10 of 15 measures), family caregivers of consumer-directed program participants, including both those who became paid workers and those

who remained unpaid, scored significantly better than the family caregivers of traditional service users. However, the positive effects were greater for the paid caregivers than for the unpaid caregivers of consumer-directed care participants in all but two of these measures. On the remaining five satisfaction and well-being measures, only paid caregivers of consumer-directed care participants scored higher. That is, caregivers of consumer-directed participants who continued to provide only unpaid help and caregivers of traditional services users had similarly lower scores compared to the paid family caregivers. In sum, although the positive effects of consumer-directed services were not solely attributable to family caregivers being paid, becoming a paid caregiver made positive outcomes both more likely and of greater magnitude.

Primary family caregivers of treatment group members who remained unpaid cited a variety of reasons. The single most frequently cited reason was that they provided care out of love, devotion or family tradition; the second most common reason was that the family caregiver was serving as the program participant's representative and was therefore prohibited under program rules from also becoming a paid caregiver. Other caregivers who remained unpaid reported reasons such as:

- ◆ they could not do the work expected of a paid caregiver because they lived too far away or had other obligations;
- ◆ the care recipient chose to hire someone else; and
- ◆ the monthly benefit was not sufficient to pay the caregiver, or was needed for other things.

ADDRESSING CONCERNS ABOUT CONSUMER-DIRECTED CARE

Paying family caregivers has been controversial (Linsk, Keigher, Simone-Rusinowitz, & England, 1992). It is becoming less so as research evidence accumulates that paying family caregivers can be beneficial to both care recipients and caregivers

(Benjamin et al., 1998; Foster et al., 2003a; Foster et al., 2003b; Simon-Rusinowitz, Mahoney & Benjamin, 1998).

Nevertheless, skeptics voice concerns that consumer-directed care might encourage elder abuse because relatives are the most common perpetrators of elder abuse and these models allow family members to serve as representative decision-makers and paid caregivers. The cash and counseling programs in Arkansas, New Jersey and Florida have, to date, experienced no serious problems with abuse, neglect, mistreatment or financial exploitation of consumer-directed program participants by either family members serving as representatives or by directly-hired workers, whether family members or unrelated individuals (Phillips et al., 2003).

According to Arkansas officials, the Independent Choices program (which now has a five-year track record) has been able to build in multiple safeguards, without imposing “bureaucratic” quality assurance requirements that would have interfered with consumer/family direction, and, they believe, would have been less effective in detecting and resolving problems. The main safeguards are the counseling and fiscal intermediary services. A minimum amount of counseling is mandatory and—in the absence of a special research authority—so is use of the fiscal intermediary service.

According to state officials (and this is also documented in the formal evaluation), counselors and fiscal intermediaries have identified a handful of potential situations they feared could “go sour” and dealt with them—in most cases, still allowing the program participant to continue in the consumer-directed option. For example, in a very few instances, counselors became concerned that a representative might not have the participant's best interests at heart. By discussing the situation with the program participant and other family members, counselors were able to broker

a change of representative (Phillips et al., 2003). Arkansas state officials also report receiving some disturbing allegations against paid family caregivers that were investigated and disproved. In one instance, suspected physical abuse by a paid family caregiver (facial blotching that looked like bruising) was actually caused by an adverse drug reaction to two prescription medicines that conflicted. Another investigation was instigated by a displaced agency worker calling to complain that her former client's daughter, who had become the elderly program participant's paid caregiver, had spent her mother's funds to buy a television. Because the daughter used her wages as a paid worker to purchase the TV, she did not misuse program funds. Moreover, both mother and daughter benefited from the extra household income the daughter's role as paid caregiver brought in (i.e., both enjoyed the new TV). Meanwhile, the former worker was not harmed. She was still employed by the agency and available for re-assignment to another client who might otherwise have been on a waiting list or received less than the full quota of care plan-authorized service. To the state, paying family caregivers had become acceptable in large part because worker shortages were causing Arkansas' personal care agencies to have difficulty meeting demand for Medicaid-covered services.

Concerns have also been voiced that consumer-directed care may "exploit" family caregivers. For example, a Kaiser Foundation study (Crowley, 2003) recently red-flagged that "federal requirements and guidelines may be insufficient to ensure that individual budgets receive adequate funding."

Inadequate funding would imply, among other things, not enough paid help to keep informal caregivers from burning out. But does the very par-

ticular concern expressed about adequate funding for consumer-directed budgets presume that federal requirements currently ensure the adequacy of traditional "medical model" services?

The cash and counseling evaluation findings suggest that such a presumption may be false. In Arkansas, the evaluation found that traditional agency service users only received, on average, two thirds of authorized care plan hours. Also, a sizable minority of Medicaid beneficiaries newly eligible for personal care services who joined the demonstration but were assigned to receive traditional services did not receive any agency-delivered personal care during the nine-month study period. This appears to be because they lived in rural areas that authorized agencies were

unable to service or because agencies did not have sufficient workers to serve them (Dale et al., 2003).

Instead of finding individual budgets insufficient compared to traditional services, the evaluation found that consumer-directed participants and their caregivers were able to

stretch their funds to obtain more access to paid care and, often, more or more efficient assistance. Among the indicators of better, more efficient access to paid care were the reductions in unmet need reported by Medicaid beneficiaries themselves as well as reports by their primary family caregivers of worrying less about their relatives not receiving enough help, even as they personally provided slightly fewer hours of help per week.

CONCLUSIONS

Family caregivers are confronted on a daily basis with the challenge of helping their relatives with

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significant disabilities meet the *totality* of their disability-related needs for assistance (which, as discussed above, typically reach or exceed 75 hours of one-to-one help per week or more for those eligible for nursing home placement). The assistance available from third-party payers—government and private insurance—is limited. As noted above, one study found that Medicaid-funded traditional home care programs in three states provided only 13 to 22 percent of the total hours of weekly help needed.

Trying to work within and around third-party payers' myriad and oft-changing home care coverage and reimbursement limits as well as "these-are-for-your-own-good" quality assurance requirements that limit choice among providers can be a frustrating experience for families whose members include people with disabilities. Consumer-directed services are not for everyone, but cash and counseling models, in particular, can offer people with disabilities and their family caregivers a way to cut through red tape. Although third-party payers do not throw away the rules, their rule books do shrink considerably when they offer consumer-directed alternatives.

Evidence from Arkansas's Independent Choices also indicates that these programs can be "budget neutral" (Dale et al., 2003). This is the primary question for third-party payers who want improved outcomes for program participants or policyholders and their families, but need to control expenditures. Medicaid personal care expenditures in Arkansas initially increased for Independent Choices participants because budgets were based on the cost of traditional services authorized in care plans whereas traditional agencies fell surprisingly short in delivering authorized services. But within two years these costs were offset by reductions in use of other Medicaid services—nursing home care, in particular. Moreover, according to Debby Ellis, project director for Arkansas' Independent

Choices, each hour of personal assistance delivered costs \$9.80 for consumer-directed beneficiaries, including fees paid to counselors and fiscal intermediaries—about 20 percent less than the \$12.36 per hour that Medicaid pays the traditional provider agencies.

Efforts Are Still Needed to Address Barriers

Within Medicaid, public policymakers and program administrators have sought to increase opportunities for cash and counseling models of consumer direction through the CMS Independence Plus Initiative, announced in May 2002. However, in many cases, legal barriers mean that states must still apply for research and demonstration waivers, which despite efforts to streamline federal approval processes, remain time-consuming and onerous to obtain. At the same time, there is clearly strong federal and state interest in expanding the scope of research and experimentation on consumer direction.

- ◆ In 2002, ASPE awarded Arkansas a Secretary's "State Innovations Grant" for "Next Choice," a program that will take the model pioneered in the "Independent Choices" program and adapt it for nursing home residents seeking to return to the community.
- ◆ CMS has encouraged more Medicaid programs to develop Independence Plus waiver applications and infrastructure necessary to meet federal approval (e.g. "health and safety" requirements) through "Real Choice Systems Grants" (specifically Independence Plus and CPAS grants) awarded in October 2003.
- ◆ The Robert Wood Johnson Foundation and the Department of Health and Human Services have expanded their partnership around cash and counseling to encourage diffusion of the model to additional states via grants and technical assistance.

Finally, there is bipartisan interest in and support for consumer-directed home care in Congress (House Committee on Energy and Commerce, 2003). In Medicare legislation enacted in the fall of 2003, Congress not only created prescription drug coverage but also included a lesser-known provision (“648”) directing the Secretary of Health and Human Services to implement a demonstration of consumer-directed care in Medicare.

In the private insurance sector as well, more remains to be done to remove barriers to consumer-directed care. Research indicates that both claimants and their family caregivers report greater satisfaction with consumer-directed policies patterned after disability rather than medical insurance models (Cohen et al., 1999). But because actuaries price disability model policies higher for equivalent dollar coverage limits, many purchasers who would prefer these policies settle for medical model coverage. More research is needed to deter-

mine whether or how companies could price consumer-directed policies more advantageously.

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their families. If third-party payers want to encourage home care—not just as an alternative to more costly nursing home care but as an alternative to newer, more attractive and perhaps less expensive assisted living facilities—they must find ways of supporting the primary providers of home care: family caregivers. 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.

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