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Consumer Enrollment and Experiences in the Cash and Counseling Program

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Study Context. Consumer direction of Medicaid supportive services raises concerns about who should be permitted to self-direct, whether consumers should be allowed to pay family members, whether a self-directed option increases demand for services, and how to ensure quality. The Cash and Counseling programs contained features designed to address these concerns.

Demonstration Enrollment. Many consumers used representatives to manage the allowance on their behalf and others chose to disenroll, suggesting that beneficiaries were capable of deciding for themselves whether the programs were suitable for them. Participation among eligible beneficiaries during the demonstration was modest, suggesting that consumer direction did not itself substantially increase the demand for services.

Consumer Experiences. Most consumers were able to assume the role of employer without difficulty, many hiring relatives or acquaintances as workers. In each state, more than 85 percent reported they would recommend the program to others seeking more control over their care, and more than half said the program had "improved their lives a great deal."

Key Words. Consumer direction, consumer choice, long-term care, personal care, home- and community-based care

Medicaid supportive services, traditionally prescribed by physicians and provided by home care agencies under nurse supervision, help recipients with activities such as bathing, using the toilet, meal preparation, and light housework. The traditional system of care, while adequate for many recipients, has been criticized for overmedicalizing services and not being flexible enough to effectively meet recipient needs. Consumer-directed care, as an alternative to agency-delivered services, offers a "constellation of services, assistive technologies, and other supports" over which recipients (or their representatives) have control. These include: (1) deciding the types of assistance needed, and (2) if human help is desired, hiring, training, supervising, and paying

workers, and defining workers' duties and how and when they are performed. Consumer direction is based on the premise that, because personal assistance is low tech and nonmedical, it does not require the intervention of medical professionals. Rather, consumers should be empowered to make informed choices about assistance and provided with supports to take control of it (Doty, Kasper, and Litvak 1996; Eustis 2000; Stone 2000, 2001; Benjamin 2001).

Consumer-directed care in a publicly funded program like Medicaid raises many concerns. These include (1) whether consumer direction should be available to people with cognitive deficits or elderly people, (2) whether offering an allowance in lieu of agency services itself increases the demand for services, (3) whether hiring family members results in a reduction in unpaid care, and (4) in the absence of agency oversight, how to assure care quality, minimize abuse of the benefit, and ensure that workers are treated fairly (Doty, Kasper, and Litvak 1996; Kapp 2000; Benjamin 2001; Kane and Kane 2001; Donlin 2002). On the other hand, supporting choice and control over personal assistance resonates strongly with "basic American values," as well as having the potential to better meet individual needs. Moreover, consumer direction could address the perennial shortage of personal assistance workers by enlarging the worker pool; it also might be less costly because agencies would not be responsible for hiring, training, and supervising directly hired workers (Eustis 2000; Stone 2000).

This paper describes the experiences of Medicaid beneficiaries who were eligible for and volunteered to participate in the Cash and Counseling demonstration and who subsequently were randomly assigned to the evaluation's treatment group (referred to below as "consumers"). The paper addresses the following questions about consumer experiences with enrollment and key program features: Who enrolled? Who went on to receive the allowance and how promptly? How did they spend the allowance? How satisfied were consumers with the program? It concludes by examining how program features addressed key policy concerns about consumer direction in the Medicaid program.

Data for this paper come from several sources. Evaluation telephone surveys, program records, and Medicaid data quantify consumer experiences in the program. The evaluation conducted a baseline interview and two fol-

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low-up telephone interviews with consumers. The follow-up interviews were at 4–6 months and at 9 months after enrollment; they asked about experiences in and satisfaction with Cash and Counseling. (Before random assignment, baseline interviews were conducted with the 3,285 beneficiaries who ultimately were assigned to the treatment group. Their rates of response to the follow-up interviews were between 88 and 93 percent; Carlson and Phillips 2003.) Records kept by each program contained consumers' dates of enrollment and disenrollment, reasons for disenrollment, and uses of the allowance during month 8 after enrollment, as well as limited demographic information. Program staff also interviewed beneficiaries who inquired about the program to determine why they chose to participate or not to participate. Medicaid data were the source of estimates of Medicaid spending before program enrollment, indicators of Medicare coverage, and program participation rates. (The interested reader is referred to the "Source" note on each table, which identifies individual data sources for each estimate presented.)

This paper uses qualitative information from two sources to provide context for consumer experiences. The evaluation included site visits with state program staff and counselors conducted about 18 months after enrollment began. (More detailed descriptions of program operations and site visit methodology can be found in Phillips and Schneider 2002, 2003, 2004.) Information from the site visits cited in this paper include descriptions of: program eligibility criteria and reasons programs declined to use appropriateness screening; the use of purchasing plans to initiate the receipt of the monthly allowance; the roles of consumer representatives, program counselors, and fiscal intermediaries; and program procedures to limit consumer abuse and neglect, and misuse of the allowance. The site visits were supplemented by a mail survey of counselors approximately 18 months after each program began to gather information about their experiences with and impressions of the program. (Surveys were completed by 224 of 272 active counselors; Carlson and Phillips 2003.)

Who Enrolled in Cash and Counseling?

Consumer direction has its roots in the disability movement, which historically has been the domain of nonelderly adults with physical disabilities. Because consumer direction requires an active role in decision making and planning, some have questioned its suitability for elderly adults and people

with cognitive disabilities. The evaluation examined the proportion and types of eligible individuals who chose to enroll in the Cash and Counseling programs, as these provide some guidance on the level of demand for the option and on the types of support participants may need to accommodate different disabilities. This section describes the types of consumers who decided to enroll, first presenting program eligibility criteria and enrollment rates as background.

Eligibility Criteria

Program eligibility criteria were a basic determinant of the types of beneficiaries who enrolled in the programs. The Florida Cash and Counseling program required its consumers (adults and children) to be *current service recipients* in one of several Medicaid home- and community-based waiver programs (including such a program for beneficiaries with developmental disabilities). New Jersey required its consumers to be adults who were *current users* of (or who had assessments for) the state's personal care benefit. Arkansas required adults only *to be eligible* for its personal care benefit. The three programs did not screen interested eligible beneficiaries for "appropriateness," as that would have been antithetical to the model. Rather, they allowed consumers and their representatives to decide whether to participate, with the understanding that they could return to agency care at any time.

Enrollment Targets and Rates

A preference study conducted by the demonstration national program office during program planning suggested that up to one-third of beneficiaries were interested in Cash and Counseling (Mahoney et al. 2004). After setting initial enrollment targets for a 12-month intake period and discovering recruitment was more difficult than anticipated, the program office extended the intake period and reduced the target sample sizes to 2,000 adults in each state, plus 1,000 children in Florida. Arkansas, which started enrolling in December 1998, nearly 1 year before New Jersey (November 1999) and 18 months before Florida (June 2000), reached its enrollment target in April 2001 (after 28 months of intake). The Florida program met its enrollment target for children by August 2001 (after 14 months) and for nonelderly adults by November 2001 (after 17 months). Intake for Florida's elderly beneficiaries and all New Jersey beneficiaries was terminated in July 2002 (after 25 and 32 months, respectively) to allow the evaluation to proceed.

Participation rates among eligibles suggested that Cash and Counseling did not itself substantially increase the number of Medicaid beneficiaries using the Florida waiver programs or the New Jersey personal care benefit, but did increase benefit receipt somewhat in Arkansas. Florida and New Jersey attempted to minimize such an effect by requiring enrollees to be current program users; Arkansas required them to say they would pursue personal care from an agency if they were assigned to the control group. In addition, federal requirements specified that the proportions of demonstration enrollees who were new to the programs were not to exceed historic state-specific values.

The proportions of new enrollees never exceeded these historic values, and relatively modest proportions (5–10 percent) of the eligible adults (and 16 percent of Florida children) enrolled. For example, in Arkansas, just under 9 percent of elderly adults enrolled among an estimated 16,523 eligibles (Brown et al. 2005). Nevertheless, it appears that some enrollees were interested in the flexibility of consumer direction, but not in agency-delivered care. In Arkansas, which did not require beneficiaries to already be using the personal care benefit, two-thirds of the control group members not receiving that benefit when they enrolled also did not receive any during the year after enrollment (Dale and Brown 2005). This proportion seems too high to be due entirely to Arkansas's worker shortage at the time. In fact, among 46 control group members who reported on the follow-up survey having no paid care during the 9 months after enrollment, more than half said they had not sought care from an agency (not shown).

Consumer Characteristics

Although it was believed that consumer direction would be most attractive to nonelderly adults with physical disabilities, roughly equal (although modest) proportions of eligible elderly and nonelderly adults enrolled (Brown et al. 2005). The majority of consumers in all three programs (between 50 and 78 percent) identified themselves as white (Table 1). The New Jersey program had the highest proportion of consumers identifying themselves as Hispanic (roughly a third). Representatives for Florida's nonelderly adult consumers and children (many of whom were their parents) had high levels of education: more than half (53–67 percent) had attended college. Under 10 percent of consumers themselves in Arkansas and about a fifth in New Jersey had done so; these percentages were higher for nonelderly than elderly consumers.

Overall, consumers in all three programs had high levels of physical disability and required substantial help with daily living activities. Only a

Table 1: Characteristics of Treatment Group Consumers at Enrollment (Percent, Unless Otherwise Noted)

	Nonelderly Consumers			*Elderly Consumers*			*Children*
	Arkansas	*Florida*	*New Jersey*	*Arkansas*	*Florida*	*New Jersey*	*Florida*
Sociodemographic*							
Self-identified race							
White only	66.8	77.3	50.4	59.0	69.1	55.2	78.4
Black only or black and some other race	26.0	18.6	42.7	35.6	27.8	33.8	16.9
Some other race	7.2	4.1	6.9	5.4	3.0	11.1	4.7
Hispanic	1.1	18.9	30.3	1.4	33.1	39.9	17.8
Education†							
Less than high school	54.9	19.0	46.1	84.0	30.5	70.0	11.4
High school graduate	25.4	27.8	26.7	12.9	21.4	13.3	21.9
Some college	19.7	53.2	27.2	3.2	48.1	16.7	66.7
Living arrangement							
Lives alone	37.3	9.4	35.9	30.1	26.9	34.7	0.0
Lives only with spouse	7.5	0.9	7.7	8.7	12.4	11.1	0.0
Lives with others	55.2	89.9	56.4	61.2	60.9	54.2	100.0
Health and functioning							
Functional independence‡							
Transfer	36.9	51.9	34.1	34.1	35.2	32.5	39.7
Bathing	12.5	23.7	13.9	9.5	11.5	13.5	7.8
Using toilet	36.6	38.6	32.2	32.5	33.1	33.8	16.6
Used proxy respondent§	24.7	76.5	28.7	57.4	59.6	49.7	99.8
Health status							
Excellent or good	20.1	62.4	22.3	22.1	23.6	18.0	59.3
Fair	29.9	23.5	30.8	31.3	37.6	39.0	28.5
Poor	50.0	14.1	46.9	46.5	38.9	43.1	12.2
Total Medicaid expenditures prior year (mean dollars)	$11,547	$19,473	$24,677	$7,605	$12,970	$16,740	$18,838
Medicaid personal care/waiver program expenditures prior year (mean dollars)	$2,348	$13,863	$7,466	$2,142	$8,433	$8,648	$7,319
Had Medicare coverage	38.7	44.1	41.5	95.7	94.3	90.0	0.0

continued

Table 1. *Continued*

	Nonelderly Consumers			*Elderly Consumers*			*Children*
	Arkansas	*Florida*	*New Jersey*	*Arkansas*	*Florida*	*New Jersey*	*Florida*
Use of paid and unpaid care							
Had unpaid caregiver[‡]	91.4	92.7	84.6	90.5	82.5	83.9	99.8
Had paid caregiver[‡]	55.9	60.1	82.4	72.3	88.5	83.5	60.7
Was receiving publicly funded home care[¶]	60.6	64.7	43.5	79.1	70.6	46.2	59.1
Number of consumers	279	456	404	725	453	467	501

*The age distribution in each state was:

	Nonelderly Adults	*Elderly Adults*	*Children*
Arkansas	27.8	72.3	Not eligible
Florida	32.2	32.1	35.6
New Jersey	46.4	53.7	Not eligible

In Arkansas and New Jersey, elderly adults are age 65 or older; in Florida, they are age 60 or older.

[†]Education is meant to capture that of the primary decision maker for the program. For Florida children education is that of their parents. Education for adults in all three programs is that of the consumer, unless the consumer's representative completed the baseline interview; in that case, it is the representative's education. In particular, 90 percent of nonelderly adults in the Florida program had developmental disabilities, and more than 80 percent of nonelderly adults in that program used representatives. As a result, level of education for Florida's nonelderly adults (and for children) is relatively high. (See Table 2 for the percentages using a representative for all groups.)

[‡]Reference period for functioning and presence of caregivers was the week before the baseline survey. Consumers are categorized as functioning independently if they performed the activities without direct or standby assistance.

[§]A proxy respondent is one who answered the majority of baseline survey questions for the consumer.

[¶]For Arkansas, the percentages reflect whether consumers were receiving publicly funded home care at baseline, regardless of how long they had been receiving it. For Florida and New Jersey, the percentages reflect whether consumers were receiving publicly funded home care for 6 months or longer at baseline. The measures differ because the Florida and New Jersey programs required beneficiaries to be receiving agency services (or, in New Jersey, to be assessed to receive them) when they enrolled; Arkansas did not have this requirement.

Source: Program records for age and use of publicly funded home care for Florida and New Jersey; Medicaid records for Medicaid expenditures and Medicare coverage; and MPR baseline survey of consumers for all other characteristics (including use of publicly funded home care for Arkansas).

minority of consumers (8–14 percent) could bathe independently, although the proportion was somewhat higher among Florida's nonelderly adults (Table 1). Roughly two-thirds of adults required assistance using the toilet; 85 percent of Florida children required such help. Most consumers in the Arkansas and New Jersey programs and most elderly consumers in the Florida program (roughly 80 percent) considered their health to be fair or poor (Table 1). In contrast, only 20 percent of children and nonelderly adult consumers in the Florida program reported their health to be fair or poor, the lower rate in Florida likely due to the high proportion of enrollees whose program eligibility was based on participation in the developmental disability waiver program, rather than on physical health problems.

Consumers' poor health and need for help with daily living activities each contributed to high total Medicaid expenditures in the year before enrollment. The actual amounts varied widely, from about $7,600 per elderly consumer in Arkansas to more than $24,000 for nonelderly consumers in New Jersey (Table 1), reflecting in part sizable differences in the cost of living and in the proportions who also had Medicare to cover the costs of medical care. Many of the Medicaid expenditures were for assistance with daily living activities. Mean Medicaid spending for waiver program services or personal care benefits, the generosity of which also varied across states, ranged from just over $2,000 in Arkansas during the year to nearly $14,000 for nonelderly adults in Florida.

Again, because of poor health or the need for personal care, nearly all adult consumers (between 85 and 93 percent) had at least one unpaid caregiver at enrollment, as did all children (Table 1). The majority of elderly consumers also had paid caregivers (between 72 and 89 percent); however, only between about 55 and 60 percent of nonelderly consumers in Arkansas and Florida and children in Florida had paid help with personal care when they enrolled.

Who Received the Allowance and How Promptly?

Perhaps the most critical implementation issue is what proportion of treatment group members received the monthly allowance, the cornerstone of the Cash and Counseling intervention. Beneficiaries who enrolled and were randomly assigned to the treatment group *had the opportunity* to receive the allowance. Before actually receiving it, however, consumers had to develop purchasing

plans and begin to make arrangements for implementing them (e.g., by identifying workers). It is thus also important to know how long it took them to start receiving it. For those who took relatively longer to start or who never did, knowing some of the barriers could inform future consumer-directed options.

Proportion Receiving the Allowance

The proportion of consumers who began receiving the allowance during the first year after enrollment ranged from roughly 40 percent of elderly Florida consumers to about 90 percent of nonelderly Arkansans (Table 2). Nonelderly consumers in all three programs were more likely than their elderly counterparts to receive the allowance during the year. In Florida, more than 70 percent of children started receiving the allowance during the year. In addition, consumers who reported at enrollment that it was very important to pay family or friends to help them were more likely than other consumers to receive the allowance, other things being equal (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b). In two of the programs, consumers who identified themselves as black or Hispanic were less likely to receive the allowance, while those who required more care and thus, whose allowances were greater, were more likely to receive it.

A variety of program features contributed to the differences across states and age groups in the proportion of consumers who received the allowance (and how long it took to get it). Arkansas required counselors to help establish purchasing plans for consumers within 45 days of enrollment (unless prevented by health problems). In contrast, New Jersey's process for getting consumers started on an allowance was fairly complex initially, requiring many steps, and approvals that led to long delays for many consumers and discouraged some from continuing. The low rate of allowance receipt among elderly Florida adults was due in part to counselors' uncertainty about how much assistance to offer consumers, and to their belief that consumers who needed a lot of help were inappropriate for consumer direction. Florida limited enrollment in their program to consumers who were receiving agency services when they enrolled; therefore, unless consumers were quite unhappy with their care, they may have felt little urgency to develop purchasing plans. Elderly consumers, who typically had more trouble with program budgeting and paperwork than did the representatives developing plans for nonelderly adults with developmental disabilities, were especially unlikely to ever receive allowances.

Table 2: Treatment Group Consumer Allowance Receipt and Enrollment (Percent, Unless Otherwise Noted)

	Nonelderly Consumers			*Elderly Consumers*			*Children*
	Arkansas	*Florida*	*New Jersey*	*Arkansas*	*Florida*	*New Jersey*	*Florida*
Time to start of allowance receipt during year after enrollment							
3 months or less	86.0	13.8	31.7	79.3	19.0	31.3	21.8
4–6 months	1.5	29.0	27.0	2.2	16.5	23.7	32.1
7–12 months	1.8	15.1	10.9	1.7	5.3	9.0	17.2
Did not start	10.7	42.1	30.4	16.8	59.2	36.0	28.9
Disenrolled during year after enrollment	23.3	34.2	32.6	32.3	49.2	32.7	20.4
Died during year after enrollment	6.8	1.8	3.8	8.8	9.7	7.4	1.0
Among those disenrolled or died							
Did so before allowance started	39.3	90.9	69.7	45.3	86.9	76.0	87.9
Disenrolled after allowance started	42.9	7.9	22.5	37.6	6.4	15.3	11.2
Died after allowance started	17.9	1.2	7.7	17.1	6.7	8.7	0.9
Monthly allowance at enrollment (mean dollars)	$362	$1,641	$1,069	$302	$818	$1,056	$1,108
Used representative to manage allowance*	26.2	84.4	NA	46.5	69.5	66.0	97.4
Number of consumers with program records	279	456	404	725	453	467	501

In Arkansas and New Jersey elderly adults are age 65 or older; in Florida they are age 60 or older.

*Data on the use of representatives for Arkansas and Florida come from consumer-level program records. All children were required to use program representatives; however, for a few, none were designated at enrollment. New Jersey did not keep consumer-level data on representatives; however, staff reported during the site visit that about two-thirds of elderly consumers had a representative and that the proportion for nonelderly consumers was considerably smaller.

NA, not available.

Source: Program records.

Time to and Duration of Allowance Receipt

Most consumers took at least a couple of months to start receiving the allowance. Although a high proportion of Arkansas consumers (79–86 percent) started receiving the allowance within 3 months of enrollment, only about a third of New Jersey consumers and a fifth of Florida consumers started that quickly (Table 2). If a consumer disenrolled (or died) before the end of the year that would have also shorten the duration of allowance receipt and thus the intensity of the intervention. Between 23 and 49 percent of consumers disenrolled during the year after enrollment; mortality was between 2 and 10 percent, although higher for elderly consumers, as might be expected. In the Florida and New Jersey programs, among consumers who disenrolled or died, the majority did so before they started receiving the allowance (70–91 percent of those who disenrolled or died), compared with only 39–45 percent in Arkansas. The lower percentages for Arkansas are likely related to the fact that Arkansas consumers were more likely than those in Florida and New Jersey to start receiving the allowance within the first few months after enrollment.

Proportion Using a Representative to Manage the Allowance

Use of representatives was meant to allow people with all types of disabilities to participate in Cash and Counseling. Representatives—frequently family or friends who had been helping consumers before enrollment—typically assisted with developing purchasing plans, recruiting and training workers, and handling paperwork, among other tasks. (Program representatives are not the same as proxy respondents to evaluation interviews, although the same person might have filled both roles for some consumers.) The proportion of consumers using representatives varied across programs and age groups. The proportion was lowest among nonelderly Arkansas consumers (26 percent; Table 2). Among nonelderly adult consumers in Florida, 90 percent of whom had developmental disabilities, 84 percent used representatives.

How Did Consumers Spend the Allowance?

A key argument for consumer direction is that people with disabilities should be able to hire workers of their own choosing to help with intimate care, food preparation, and household tasks. Another argument is that personal care delivered on an agency's schedule is often not timely and thus inhibits individuals' ability to be as independent and productive as they would be if they could get care when they needed it. The evaluation examined how consumers

used their allowances to hire workers and set the conditions of their employment, and to make other purchases.

Hiring workers

Most Cash and Counseling consumers used their allowance to hire workers. Except for Florida's children and nonelderly adults, between roughly 80 and 90 percent of those receiving an allowance used part or all of it to hire workers (Table 3). Arkansas and New Jersey consumers used roughly three-quarters of the allowance, on average, to pay workers. In contrast, just over 60 percent of Florida children and nonelderly adults used their allowance to hire workers. The rates are lower primarily because not all consumers in these two groups needed or qualified for personal care. Florida's developmental disability waiver programs included a range of support services in addition to personal care, and some Florida consumers had care plans that included only supplies, equipment, or therapy. Nonelderly adults in Florida were also more likely than other groups to be able to perform personal care without help (see Table 1), and most children under a certain age, whether they have disabilities or not, typically receive help from their parents with bathing and dressing. Thus, no personal care was needed or authorized for them. They used just under half their allowances to pay workers, consistent with their lower rate of hiring.

Nearly all consumers who hired workers (89–100 percent) received assistance with personal care or housework (Table 3). Somewhat fewer (73–93 percent) received help with routine health care, such as taking medications. Between 46 and 76 percent had workers who provided transportation. The latter two tasks are of particular interest because agency workers are typically precluded from transporting clients or helping them with health care or medications. Many consumers reported that their workers helped them on weekends and evenings, times when agency workers often are unavailable (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b). As noted, a key criticism of agency-delivered personal care has been its inability to provide consumers with care at the times it is needed.

Many consumers hired family members, often parents or adult children. Among nonelderly adult consumers who hired workers, between 14 and 36 percent hired a parent; similarly, 29 percent of children with paid workers had at least one who was a parent (Table 3). Many elderly consumers who hired workers hired an adult child (47–59 percent). Despite a general tendency toward hiring relatives, 22–38 percent of adult consumers who hired workers employed at least one who was unrelated to them. Most of these unrelated workers were friends or neighbors of the consumers (Schore and Phillips 2004;

Table 3: Treatment Group Consumer Uses of the Allowance (Percent)

	Nonelderly Consumers			*Elderly Consumers*			*Children*
	Arkansas	*Florida*	*New Jersey*	*Arkansas*	*Florida*	*New Jersey*	*Florida*
Hiring workers							
Used allowance to pay worker, among consumers with allowance in month 8	87.7	63.4	86.7	88.6	78.9	85.8	62.4
Percent of allowance used to pay workers among consumers with allowance in month 8	71.6	45.4	79.1	76.0	64.3	81.4	48.0
Tasks performed by workers, among consumers who reported hiring during first 9 months*							
Personal care	95.2	88.6	97.3	94.7	95.8	98.1	97.9
Housework and chores	98.4	94.3	99.5	97.6	99.2	99.5	97.1
Routine health care	78.5	72.6	90.3	78.4	80.7	93.2	77.7
Transportation	75.8	76.4	70.8	51.0	46.2	63.3	70.6
Among consumers who reported hiring during first 9 months, at least one worker:							
Was consumer's parent	13.9	36.3	22.2	0.2	0.0	0.5	28.6
Was consumer's child	28.9	1.9	24.3	52.9	47.1	59.4	NA
Was unrelated to consumer	30.5	33.8	33.0	24.3	37.8	22.2	41.6
Lived with consumer	28.9	49.7	41.6	43.7	48.7	45.4	40.8
Attempts by consumers to hire during first 9 months							
Hired a worker	85.4	42.2	56.7	77.0	35.2	57.7	59.0
Tried to hire, but did not	9.5	21.2	30.3	11.5	22.2	19.8	14.7
Did not try	5.1	36.6	13.1	11.5	42.6	22.5	26.3
Among consumers who reported hiring during first 9 months, found hiring hard	20.7	38.7	30.9	19.1	35.3	27.0	46.0
Other purchases in month 8†							
Personal care supplies	51.8	14.5	2.5	47.4	5.4	0.0	23.8
Cash for incidentals	38.6	31.9	55.6	35.5	59.0	47.2	40.2

Community services	18.6	31.5	2.9	13.5	3.0	2.2	10.0
Equipment	8.2	2.6	10.9	2.6	1.2	4.5	4.5
Number of consumers with bookkeeper data for month 8	220	235	239	498	166	267	311
Number of consumers responding to 9-month survey	243	399	345	642	373	402	441

Note: In Arkansas and New Jersey elderly adults are age 65 or older; in Florida they are age 60 or older.

*Personal care includes bathing, transfer from bed, eating, and using the toilet. Housework and chores include light housework, yard work, meal preparation, shopping, and, for children, help with homework. Routine health care includes taking medications, checking vital signs, and doing exercises. Transportation includes trips for medical and nonmedical reasons. Consumers reported that workers conducted these tasks; however, workers also provided substantial amounts of care for which they were not paid. The survey did not distinguish between paid and unpaid tasks.

†Personal care supplies include incontinence products, ostomy supplies, and feeding equipment. Arkansas and New Jersey limited cash for incidentals to 10 percent of total allowance; Florida limited it to 20 percent. Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, prepared food from commercial vendors, congregate meals, grocery delivery, and laundry services. Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.

Source: Measures during month 8 come from records kept by program bookkeepers; measures during first 9 months after enrollment come from follow-up telephone survey responses.

Foster, Phillips, and Schore 2005a, b). Among children with workers, just over 40 percent had workers who were unrelated, some of whom were actually professionals, such as therapists (Table 3). A substantial proportion of consumers (29–50 percent) hired workers with whom they lived.

Between 10 and 30 percent of consumers reported that they tried to hire workers but were unable to do so (Table 3). Among those who eventually succeeded in hiring a worker, between 19 and 46 percent said they found hiring difficult.

Other Uses of the Allowance

Cash and Counseling permitted consumers to use their allowances to purchase goods and services that would promote their independence or to purchase them more efficiently than Medicaid could. For some consumers, some types of equipment might take the place of human assistance. Other consumers might purchase less expensive services unencumbered by Medicaid rules (e.g., using a housecleaning service, rather than paying a personal care worker to clean house). Either would free up funds for additional goods or care.

According to program records, 8 months after enrollment, the rates at which consumers used their allowances to purchase goods or services varied markedly across age groups, states, and types of purchases. Roughly half of Arkansas consumers purchased personal care supplies (such as incontinence supplies), compared with between 5 and 24 percent of Florida consumers and about 1 percent of New Jersey consumers (Table 3). Nearly a third of nonelderly adult consumers in Florida used their allowance to purchase community services such as day care or housecleaning, but rates of use for this purpose were markedly lower for other groups. Eleven percent or fewer consumers purchased equipment to assist with mobility, communication, safety, or housework. Sizable proportions (32–59 percent) did, however, opt to take some of their allowance in cash for incidental expenses that were difficult to invoice (such as taxi services). Arkansas and New Jersey limited these amounts to 10 percent of the allowance; Florida's limit was 20 percent.

How Satisfied Were Consumers with Cash and Counseling?

Consumers were highly satisfied with Cash and Counseling and their care arrangements. The latter is particularly important because it was a major

program goal. Very few consumers or workers reported being exploited, and counselors reported that fraudulent use of the allowance was extremely rare.

Consumer Satisfaction with Program Services

Consumers made extensive use of program counseling and fiscal intermediary services and were very satisfied with them. Counselors provided a range of services, including advice on how to set up the purchasing plans and how to recruit and train workers. Younger and older consumers reported similar rates of use of counseling services. In all states and age groups, 80 percent or more of users of counseling services found them to be helpful. In particular, between 90 and 99 percent were satisfied with the counselors' help in preparing purchasing plans. Most consumers (more than 85 percent of allowance recipients) reported using fiscal intermediary services to perform bookkeeping functions, such as preparing paychecks and withholding employer taxes for workers hired with the allowance, complex tasks that require some knowledge of tax law. It is therefore not surprising that the majority of consumers preferred to let program fiscal intermediaries take responsibility for these tasks. Moreover, use of the fiscal intermediaries in no way limited consumer control over the funds, which were monitored and subject to the same program rules regardless of who performed bookkeeping. A high proportion of consumers (86–98 percent) were satisfied with the bookkeeping assistance they received (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b).

Consumer Satisfaction with Cash and Counseling

The overwhelming majority of consumers were highly satisfied with Cash and Counseling. Between 85 and 98 percent reported that they would recommend the program to others seeking more control over their care, and more than half of those who received the allowance said that the program had "improved their lives *a great deal*"—for example, by allowing them to choose personal care workers. Although most consumers were pleased with the programs, a substantial minority chose to leave them. Between 16 and 38 percent voluntarily disenrolled during the year after enrollment. In general, the most common reasons given for leaving were (1) the belief that the allowance was not enough to cover care needs, (2) difficulty managing employer responsibilities (such as hiring and firing workers), and (3) deciding they were satisfied with traditional agency care after all (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b).

Counselor Perceptions of Abuse, Neglect, and Fraud

A major concern expressed about consumer-directed home care is that consumers might be exploited or abused by family members or hired workers. Other concerns have centered on whether consumers would misuse the allowance, even though only expenditures consistent with their purchasing plans were allowed. To identify potential problems, counselors periodically contacted consumers and their representatives in person and by telephone, and both counselors and bookkeepers reviewed consumer spending. As a result, program counselors reported very few cases of abuse, neglect, or fraud. For example, only one of 37 New Jersey counselors reported any incidents of financial exploitation, and that incident was for a single consumer (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b). One other New Jersey counselor reported one case of self-neglect. (There was no independent verification of these low rates, however.) Counselors agreed that representatives selected by consumers acted in the consumers' best interest in all but a handful of cases (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b). Thus, it appears that consumers and their families, with assistance and oversight from counselors, fiscal agents, and representatives, were able to manage their own care responsibly and safely.

DISCUSSION

As noted, consumer-directed personal assistance in a publicly funded program raises some policy concerns. Cash and Counseling program features were meant to address these concerns; consumer experiences suggest the extent to which they succeeded.

Appropriateness Screening Did Not Appear to Have Been Necessary, although Use of Representatives Was Common

Use of representatives or surrogate decision makers is common in public consumer-directed programs (Flanagan 2001; Tilly and Wiener 2001). At least 40 percent of Cash and Counseling consumers in each state used representatives. Program staff also believed that people would self-select once they understood the responsibilities and risks. In fact, each of the programs experienced substantial rates of voluntary disenrollment. Consumers with a variety of disabilities who remained in the programs were highly satisfied with the care arranged and paid for with the allowance. The programs could also terminate consumers and return them to traditional Medicaid services if the

program seemed unsuitable, but this seldom happened (Schore and Phillips 2004; Foster, Phillips, and Schore 2005a, b).

Concerns about Increasing the Number of Beneficiaries Using Waiver Programs or Personal Care Benefits Appear to Have Been Largely Unfounded, in Part Due to Program Design

Two Cash and Counseling programs limited enrollment to beneficiaries who were already receiving (or had already been assessed to receive) services. The third did not have this constraint, but it had to abide by the federal demonstration requirement capping the proportion of enrollees who could be new service users. Participation rates among eligible beneficiaries during the demonstration period were relatively low, suggesting consumer direction may not increase waiver program or benefit use markedly in any case. However, the very low rate of agency care use following enrollment among Arkansas control group members new to the personal care benefit suggests some who were not interested in agency care, or who were not able to get it due to worker shortages or lack of nearby agencies, were attracted to the consumer-directed option.

Allowing Consumers to Hire Relatives Was Critical to the Success of the Program

There is a long-standing debate in community-based long-term care policy about whether it is appropriate to use public funds to pay family or others who would provide care without pay (Simon-Rusinowitz, Mahoney, and Benjamin 1998; Doty et al. 1999; Benjamin, Matthias, and Frank 2000; Tilly, Wiener, and Cuellar 2000; Benjamin and Matthias 2001). Those who consider it appropriate point to unpaid caregiver burnout and their foregone wages, while those who consider it inappropriate believe that it increases costs by substituting paid for unpaid care and diminishes traditional familial caregiving values. In 1999, more than 80 percent of the 139 publicly funded consumer-directed personal assistance programs in the United States allowed consumers to hire relatives other than those who are legally liable (e.g., spouses and parents of dependent children; Flanagan 2001). In each Cash and Counseling program, at least 60 percent of consumers who hired workers hired at least one relative. Family (and friends) represented a labor pool unavailable to agencies, many of which experienced severe worker shortages during the demonstration. Moreover, consumers who hired nonrelatives were more likely to report having difficulty hiring.

Concerns about Abuse or Neglect of Consumers, Fraudulent Use of the Allowance, or Abuse of Workers Did Not Appear to Materialize

Ensuring the health and safety of vulnerable consumers and the quality of their care without agency oversight is a major concern for consumer direction. Regulations for agency-delivered home care have been developed over many years to try to ensure care quality through requirements concerning agency structure and worker training and supervision (Doty, Kasper, and Litvak 1996; Kapp 2000). However, there is disagreement about how to define care quality in consumer-directed models and how to assess it. Should the uniform professional standards of agency-based care apply? Or are the consumer's opinions of how well care is provided more germane and appropriate to the nontechnical nature of personal assistance (Benjamin 2001)? In 1999, most U.S. consumer-directed personal assistance programs (74 percent) required workers to have specific qualifications; nearly half (45 percent) required some type of worker training; and most (88 percent) conducted quality monitoring activities, such as case management, consumer satisfaction reviews, and program evaluations (Flanagan 2001).

There was no evidence from consumers, counselors, or state program staff that participation in Cash and Counseling led to any adverse effects on consumers' health or safety. (This is consistent with the evaluation of the California In-Home Supportive Services program, which also found that consumer direction had no deleterious effect on care quality or consumer safety; Doty et al. 1999.) Cash and Counseling programs oversaw consumer safety and care quality primarily through regular counselor contacts with consumers by telephone and in person. Subtle behavior changes or other cues during telephone contact could prompt a home visit by a counselor. Reports of consumer abuse were rare, and consumers were highly satisfied with the program and their care arrangements. Moreover, another paper in this volume (Carlson et al. 2007) demonstrates that Cash and Counseling had no deleterious effect on objective, care-related outcomes for consumers (such as decubiti or injuries incurred while receiving care).

Critics of consumer direction are also concerned about the welfare of workers in the absence of collective bargaining and agency protection from abusive caregiving situations. Reports by program counselors of worker abuse were rare. (The programs did not, however, have formal procedures to receive worker complaints, so if workers did have complaints, they may have gone unreported.) On the other hand, workers themselves reported being very satisfied with their wage and working conditions (see Foster, Dale, and Brown 2007).

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