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Cash and Counseling:
Consumers' Early Experiences in Florida
Part II: Uses of Cash and
Satisfaction at Nine Months

Interim Memo

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This memorandum describes the experiences of 231 early clients in Florida’s Cash and Counseling Demonstration, the Consumer-Directed Care (CDC) program.¹ The description is based on clients’ responses to a telephone survey conducted about nine months after they applied to the program and were randomly assigned to the demonstration’s treatment group to receive a monthly budget (the program’s term for the cash benefit). Mathematica Policy Research, Inc. (MPR), the demonstration evaluator, administered the survey.

After briefly describing the Florida program, our data and analytic approach, and client characteristics, we present findings in four areas: (1) program participation; (2) use of services, goods, and cash; (3) hiring of caregivers and performance of other employer responsibilities; and (4) satisfaction with care and quality of life. The following findings are particularly interesting:

- The cohort used in this analysis, which is roughly the same one we described in our memorandum on responses to the six-month survey, is dominated by children (47 percent) and nonelderly adults (36 percent). Elderly adults make up only 17 percent of the cohort.
- Nine months after random assignment, 91 percent of children were still enrolled in the CDC program, compared with 53 percent of elderly adults.
- Three-quarters of all clients—and 90 percent of enrolled clients—said they had received the monthly budget by the time of the nine-month interview.
- Of the clients who received the monthly budget, 81 percent used it to hire caregivers, 50 percent used it to pay for personal care supplies, and 16 percent used it to purchase care-related equipment.
- About 20 percent of clients who hired caregivers hired former agency workers.
- Almost all clients (99 percent) who used the monthly budget to hire caregivers were satisfied with their relationship with their caregivers. Of those who were satisfied, 96 percent described themselves as “very satisfied.”

¹Cash and Counseling is a national demonstration jointly funded by The Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, and administered by the Centers for Medicare & Medicaid Services. The national program office for Cash and Counseling is the Center on Aging at the University of Maryland.

- Many clients modified their original purchasing plans between the time of the six- and nine-month interviews, and about half changed caregivers' hours, wages, or tasks while they were recruiting or after they hired.
- Most clients (88 percent) who received the monthly budget said the budget improved their quality of life. The most commonly cited improvements were the ability to choose their own caregivers and obtain the right types of personal care services.
- Despite their overwhelming satisfaction with the program, about one-third of budget recipients needed more help with meal preparation or housework.
- Ninety-seven percent of clients who used the monthly budget to hire caregivers would recommend the CDC program to others wanting more control over their personal care.

A. CASH AND COUNSELING IN FLORIDA

Florida's CDC program gives beneficiaries who are eligible for Medicaid Home- and Community-Based Services (HCBS) waiver programs a chance to receive a monthly budget in lieu of traditional services. CDC draws participants from four HCBS waiver programs, those for: (1) frail elderly adults, (2) nonelderly adults with physical disabilities, (3) nonelderly adults with developmental disabilities, and (4) children with developmental disabilities. The CDC program enrolls children in all 67 Florida counties, but enrolls adults in only 19 counties in central and south Florida.

As part of the evaluation of the demonstration, eligible beneficiaries interested in receiving the monthly budget are randomly assigned by the evaluator to the treatment group (whose members receive the monthly budget) or to the control group (whose members continue to receive traditional HCBS waiver program services). Throughout this memorandum, we refer to treatment group members as "clients" of the program.²

²For the sake of brevity, we refer to all survey respondents in the treatment group as "clients" of the Cash and Counseling program, even though parents responded for children, proxies responded for some adults, and some clients disenrolled from or never actively participated in the program.

CDC clients may use the monthly budget to hire caregivers and to purchase services, supplies, or equipment related to their need for long-term care or community support. Adult clients who are unable to manage their monthly budget (for example, are unable to make decisions about whom to hire and how much to pay) may have a representative manage it for them. Representatives may be a family member, friend, guardian, or other individual. Parents or guardians manage the monthly budgets of clients who are younger than age 18.

In addition to the monthly budget, the demonstration provides consulting and bookkeeping services to clients in the treatment group. In Florida, consultants help clients (or their parents/guardians) develop purchasing plans to manage their monthly budget and provide materials and assistance on recruiting and training caregivers. Most consultants are also case managers or support coordinators for Florida's Medicaid waiver programs, so they play multiple roles. As case managers or support coordinators in the Medicaid waiver programs, they play a key role in making decisions about client care and bear responsibility for those decisions. As consultants, in contrast, they advise CDC clients about their care options, but the clients are responsible for making care decisions and bearing their consequences. Finally, most CDC clients elect to have the project bookkeeper maintain an account for their monthly budget, perform all payroll activities, and pay invoices on their behalf.³ Clients pay \$5 per check (up to a maximum monthly amount of \$25).

³Alternatively, clients may choose to maintain their own account and therefore handle payroll, taxes, and check-writing activities on their own. Clients who choose this option must first pass the program's test on bookkeeping skills. In addition, the project bookkeeper performs a monthly "desk review" of the client's records. Clients pay \$10 per month for this reduced level of bookkeeping services.

B. DATA AND ANALYTIC APPROACH

The data for this analysis were drawn from computer-assisted, precoded telephone interviews with demonstration clients who were randomly assigned to receive the monthly budget. As noted, MPR conducts the interviews about nine months after random assignment. For clients younger than age 18, we interview a parent or guardian. To obtain a complete picture of clients' experiences, we also conduct nine-month interviews with disenrolled clients and with the proxies of deceased clients. The interviews included in this analysis were conducted between late March and late November 2001. (Clients were randomly assigned to the treatment group between June 2000 and February 2001.)

Questions in the nine-month interview refer to a variety of periods, including the day of the interview, the most recent two weeks during the last two months the client was at home (as opposed to in a hospital, nursing home, or long-term-care facility), the entire nine months since random assignment, and the period between the nine-month interview and the interview that had been conducted about six months after random assignment. For example, we asked about clients' *present* quality of life and unmet needs because that is what clients can report most accurately. We used the recent two-week reference period for questions about daily activities because the interview day may have been atypical, and use of a two-week reference period should not lead to serious recall error. By contrast, we asked clients about their use of community services or equipment purchases during the entire nine months since random assignment because these events were likely to be relatively infrequent and easy to recall. Finally, questions about changes in clients' activities as employers and purchasers of goods and services refer to the period between the six- and nine-month interviews.

The tables in this memorandum present percentage distributions, frequencies, and cross-tabulations of selected survey responses. Our goal is simply to describe clients' experiences, so

we do not present standard errors, confidence intervals, or tests of hypotheses. Many of the tables categorize clients by subgroups defined by clients' age and by how long they had been using waiver program services at the time of random assignment (referred to hereafter as "preenrollment HCBS use").⁴ The age subgroups consist of elderly adults aged 65 or older, nonelderly adults aged 18 to 64, and children aged 3 to 17. Similarly, clients who used waiver program services for three months or longer prior to random assignment are distinguished from those who used services for fewer than three months. Given the relatively small sample available for this analysis, we note only subgroup differences that are 15 percentage points or larger, and that involve at least 15 respondents.⁵ Smaller differences, or those involving very few respondents, may well be due to chance.

As noted, 231 clients in the treatment group completed nine-month interviews by the cut-off date for this analysis, yielding a response rate of 96 percent (see Table 1).⁶ Nearly half (47 percent) of the 231 sample members are children, 36 percent are nonelderly adults, and 17 percent are elderly adults. Because the distribution of clients across age groups is uneven, the experiences of children and nonelderly adults drive the overall sample statistics presented in this memorandum. In addition, 82 percent of clients (including all children and all but four

⁴The CDC program provided data on clients' age and preenrollment use of waiver program services.

⁵In several instances, fewer than 15 elderly adults answered a particular survey question. We present their responses as a group in the tables but do not note them in the text of the memorandum, as they are too few for meaningful analysis.

⁶We calculated this response rate as of November 27, 2001. The rate equals the number of respondents who completed interviews divided by the number of sample members who were about nine months past random assignment. The rate excludes sample members we could not locate or for whom we were still pursuing a completed interview.

TABLE 1
DISTRIBUTION OF CLIENTS ELIGIBLE FOR INTERVIEW AND RESPONDENTS,
BY AGE AND HCBS USE

Subgroup	Clients Eligible for Interview ^a		Respondents		Response Rate (Percent)
	Number	Percent	Number	Percent	
Age					
65 or older	42	17.5	38	16.5	90.5
18 to 64	86	35.8	84	36.4	97.7
3 to 17	112	46.7	109	47.2	97.3
Preenrollment HCBS Use					
Three months or longer	162	67.5	156	67.5	96.3
Fewer than three months	78	32.5	75	32.5	96.2
Total	240	100.0	231	100.0	96.3

SOURCE: Consumer-Directed Care program and Mathematica Policy Research, Inc. CATI reports.

^aRefers to the pool of 240 sample members who were eligible for a nine-month interview as of November 27, 2001, the cut-off date for responses from completed interviews to be included in this analysis. The pool excludes 4 individuals we could not locate and 37 cases we were still pursuing as of November 27.

HCBS = Home- and Community-Based Waiver Program Services; CATI = computer-assisted telephone interview.

nonelderly adults) have developmental disabilities, rather than physical disabilities (not shown).⁷ Finally, only 27 percent of the 122 adult clients in this sample completed interviews themselves; representatives or other proxies responded for 73 percent of the cases (not shown). Of the 89 adult clients who had proxy respondents, 58 (65 percent) have developmental disabilities. As noted, we routinely interviewed a parent or guardian of clients younger than age 18; no proxies responded on a parent's or guardian's behalf.

C. CLIENT CHARACTERISTICS AND UNPAID HELP

More than half the sample members (52 percent) said they were in good or excellent health, but the majority (79 percent) required care for at least one chronic condition or help with one or more daily activities (75 percent) (Table 2; daily activities shown separately). Health and functioning levels varied somewhat by age. For example, elderly adults were more likely than younger adults or children to be in poor health (40 percent compared with about 17 percent). In addition, 9 in 10 elderly adults had a chronic condition that required care, compared with about 7 in 10 younger adults. Finally, more than half the elderly adults, but only one-third of younger adults or children, would have found it very difficult or impossible to get in or out of bed without help.

On average, elderly adults lived in smaller households and had fewer unpaid caregivers than did younger sample members. Specifically, 23 percent of elderly clients lived alone, and 51 percent lived with just one other person (Table 3). In contrast, most younger adults (68 percent) lived in households with one or two other people, and most children (65 percent) lived with at least three other people. The number of clients' unpaid caregivers, including live-in unpaid

⁷We identified clients with developmental disabilities as those who are eligible for waiver program services under Florida's Developmental Disabilities Program (DDP). Data on DDP eligibility were provided by the CDC program.

TABLE 2
HEALTH AND FUNCTIONING, BY AGE AND HCBS USE
(Percentages)

Characteristic	All Clients	Age			Preenrollment HCBS Use	
		65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Self-Rated Relative Health Status (A2)						
Excellent	16.3	2.9	16.9	20.2	13.6	22.2
Good	36.1	8.6	36.1	45.0	32.9	43.1
Fair	26.9	48.6	30.1	17.4	29.7	20.8
Poor	20.7	40.0	16.9	17.4	23.9	13.9
Has Chronic Condition that Requires Care (A16)	79.1	91.4	72.0	80.6	80.7	75.7
Activity Would Be Very Difficult or Impossible Without Help						
Bathing (A19)	73.2	77.2	63.4	79.6	71.1	77.5
Getting in or out of bed (A20)	38.0	54.3	31.3	37.9	36.0	42.3
Toileting (A21)	44.5	42.9	37.8	50.5	41.6	50.7
Number of Clients^a	227	35	83	109	155	72

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

^aIncludes clients who were living at the time of the nine-month interview. Sample sizes vary slightly (from 220 to 227) from measure to measure because of item nonresponse and skip patterns.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 3
HOUSEHOLD SIZE AND NUMBER OF UNPAID CAREGIVERS, BY AGE AND HCBS USE
(Percentages)

Characteristic	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Number of People in Client's Household, Including Client (B5 and B12)						
1	8.9	22.9	14.8	0.0	11.8	2.8
2	21.9	51.4	30.9	5.6	24.2	16.9
3	30.4	17.1	37.0	29.6	32.7	25.4
4 or more	38.8	8.6	17.3	64.8	31.4	54.9
Number of Unpaid Caregivers (C4)						
0	13.3	20.0	18.3	7.3	16.2	6.9
1	29.7	51.4	28.1	23.9	30.5	27.8
2	24.8	11.4	29.3	25.7	21.4	31.9
3 or more	32.3	17.1	24.4	43.1	31.8	33.3
Among Clients with Unpaid Caregivers, Number of Live-In Unpaid Caregivers (C4, C24, and C26)						
0	15.3	39.3	23.9	3.0	18.6	9.0
1	35.7	50.0	31.3	34.7	36.4	34.3
2	34.7	7.1	35.8	41.6	33.3	37.3
3 or more	14.3	3.6	9.0	20.8	11.6	19.4
Number of Clients Overall^a	226	35	82	109	154	72
Clients with Unpaid Caregivers	196	28	67	101	129	67

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to a two-week period within the two months before the interview.

^aIncludes respondents who were home for a recent two-week period.

HCBS = Home- and Community-Based Waiver Program Services.

caregivers, was similarly distributed across age groups. Overall, 93 percent of clients' unpaid caregivers were family members (not shown).

D. PROGRAM PARTICIPATION

Most clients (81 percent of the 231 sample members) were still enrolled in the CDC program nine months after random assignment; however, enrollment varied across age groups (Table 4). Children and nonelderly adults were more likely than elderly adults to still be enrolled (91 percent and 82 percent, respectively, compared with 53 percent). Of the 39 clients who disenrolled by the nine-month interview, 27 had already done so by the time of the six-month interview (not shown).

Three-quarters of all clients, and 90 percent of enrolled clients, had begun receiving their monthly budget by the time of the nine-month interview (Table 5). Of the clients who disenrolled (39 clients) or died (4 clients) a total of 6 had begun receiving their monthly budget.

E. USE OF SERVICES, GOODS, AND CASH

1. Personal Assistance Services

Most clients had recently received paid assistance, and many used the monthly budget to pay for it. Overall, 89 percent of clients who lived at home for at least two weeks during the two months before the interview received assistance from a paid caregiver during that two-week reference period (Table 6). Of those, two-thirds (133 clients) used their CDC budget to hire caregivers.⁸ Roughly equal percentages of the 133 clients who used the monthly budget to hire caregivers and who had paid assistance during the two-week reference period had one, two, or

⁸Of the remaining third (66 clients), 36 had not received the monthly budget, so it is likely they were still receiving paid help from their HCBS waiver program. The other 30 clients, who had received the budget, may have had caregivers paid for by another public program or with private funds.

TABLE 4
ENROLLMENT STATUS AND RECEIPT OF MONTHLY BUDGET AT NINE MONTHS, BY AGE AND HCBS USE
(Percentages)

	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Enrollment Status at Nine Months (A1a)						
Enrolled	81.4	52.6	82.1	90.8	78.8	86.7
Disenrolled	16.9	39.5	16.7	9.2	20.5	9.3
Deceased	1.7	7.9	1.2	0.0	0.6	4.0
Receipt of Monthly Budget (A1b) ^a						
Started before six-month interview	56.3	47.4	52.4	62.4	56.4	56.0
Started between six- and nine-month interviews	19.5	7.9	21.4	22.0	16.0	26.7
Not started by nine-month interview	24.2	44.7	26.2	15.6	27.6	17.3
Number of Clients	231	38	84	109	156	75

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

^aThese tabulations exclude two clients who did not answer a question about receipt of the monthly budget. We asked clients about the monthly budget regardless of their enrollment status.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 5

ENROLLMENT STATUS BY RECEIPT OF THE MONTHLY BUDGET

Enrollment Status at Nine Months (A1a)	Number of Respondents	Percentage That Ever Received Monthly Budget (A1b)
Enrolled	188	89.9
Disenrolled	39	7.7
Deceased	4	75.0
All Clients	231	75.8

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

TABLE 6
 USE OF PAID CAREGIVERS, BY AGE AND HCBS USE
 (Percentages)

Characteristic	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Had Paid Caregiver(s) (D1)	88.8	94.3	86.4	88.9	88.2	90.1
Among Those Who Had Paid Caregiver(s)						
Hired with Monthly Budget	66.8	42.4	62.9	78.1	65.9	68.8
Did not Hire with Monthly Budget	33.2	57.6	37.1	21.9	34.1	31.2
Among Those Who Had Paid Caregivers(s) and Hired with Monthly Budget						
Number of Paid Caregivers (D1)						
1	29.3	35.7	29.5	28.0	27.0	34.1
2	35.3	50.0	38.6	30.7	36.0	34.1
3 or more	35.3	14.3	31.8	41.3	37.0	31.8
Had Visiting Paid Caregiver(s) (B5, D1, and D30)	81.2	64.3	84.1	82.7	83.2	77.3
Had Live-in Paid Caregivers(s) (D28)	48.9	57.1	38.6	53.3	50.6	45.5
Had Related Paid Caregiver(s) (D3)	59.4	71.4	43.2	66.7	60.7	56.8
Number of Clients Overall^a	224	35	81	108	153	71
Clients Who Had Paid Caregivers	199	33	70	96	135	64
Clients Who Hired with the Monthly Budget^b	133	14	44	75	89	44

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to a two-week period within the two months before the interview.

^aIncludes clients who were home for a recent two-week period, excluding two clients in group homes.

^bIncludes clients who had paid assistance during a recent two-week period and hired with the monthly budget.

HCBS = Home- and Community-Based Waiver Program Services.

three or more paid caregivers (Table 6).⁹ About 80 percent of clients had visiting paid caregivers; almost half had live-in paid caregivers. A majority of clients (59 percent) who used the monthly budget to hire caregivers received paid assistance from a family member.

About 40 percent of clients who used the monthly budget to hire caregivers paid for 15 to 42 hours of care during the two-week reference period (roughly 1 to 3 hours per day; Table 7). Fifteen percent purchased 43 to 70 hours of care (roughly 3 to 5 hours per day), and 33 percent paid for more than 71 hours (or an average of more than 5 hours per day). Clients purchased nearly equal amounts of care from visiting caregivers and from live-in caregivers. Furthermore, clients who used their monthly budget to hire caregivers received help with many types of care, including routine health care, personal care, and household activities. At least half the clients—and as many as 87 percent—paid someone who helped them with each of the specific activities we asked about, such as taking medicine, bathing, and preparing meals (Table 8).

2. Goods and Community Services

In addition to (or instead of) purchasing personal assistance, CDC clients (or their families, in the case of children) may use the monthly budget to buy supplies or equipment related to their personal care needs or to modify their homes or vehicles. During our interviews, many clients said they purchased supplies, equipment, or home modifications since enrolling in the CDC program, and substantial proportions used the monthly budget to do so. For example, 60 percent of the 175 clients who received the monthly budget bought personal care supplies (such as diapers and disposable gloves), and 50 percent used the monthly budget to make those purchases (Table 9). Fifty-seven percent of budget recipients obtained or repaired equipment for household

⁹We cannot assume from the survey responses that clients used the monthly budget to hire *all* their paid caregivers; some clients may have had an additional source of paid care.

TABLE 7
HOURS OF CARE PAID FOR WITH THE MONTHLY BUDGET
(Percentages)

Hours of Paid Care (D65, D41, and D46)	Total	From Visiting Paid Caregivers	From Live-In Paid Caregivers
14 or Fewer (less than 1 per day)	12.3	22.6	19.4
15 to 42 (1 to 3 per day)	39.2	39.6	40.3
43 to 70 (3 to 5 per day)	15.4	17.0	14.5
71 or More (more than 5 per day)	33.1	20.8	25.8
Number of Clients^a	130	106	62

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to a two-week period within the two months before the interview.

^aIncludes clients who hired with their monthly budget, used paid assistance during a recent two-week period, and answered questions about the hours of care they received from as many as three visiting and/or two live-in paid caregivers.

TABLE 8

TYPES OF PAID CARE RECEIVED BY CLIENTS WHO HIRED WITH THE MONTHLY BUDGET, BY AGE AND HCBS USE
(Percentages)

Received Paid Help with:	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Health Care						
Taking Medicine (D8)	55.6	71.4	61.4	49.3	64.0	38.6
Other Routine Health Care (D9)	63.2	78.6	56.8	64.0	62.9	63.6
Personal Care						
Bathing/Showering (D17)	75.9	85.7	68.2	78.7	75.3	77.3
Getting in or out of Bed (D15)	56.8	71.4	52.3	56.8	58.0	54.6
Eating (D14)	86.5	71.4	77.3	94.7	83.2	93.2
Toileting (D16)	67.7	64.3	59.1	73.3	65.2	72.7
Other (D18) ^a	87.2	100.0	77.3	90.7	88.8	84.1
Household/Community Chores						
Light Housework (D21)	80.5	100.0	79.6	77.3	83.2	75.0
Meals (D20)	85.0	92.9	79.6	86.7	86.5	81.8
Shopping (D22)	63.2	78.6	72.7	54.7	69.7	50.0
Transportation (D23)	72.2	35.7	65.9	82.7	70.8	75.0
Other (D24) ^b	83.5	78.6	81.8	85.3	86.5	77.3
Number of Clients^c	133	14	44	75	89	44

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to a two-week period within the two months before the interview.

^aOther personal care may include help dressing or getting around outside.

^bOther household/community chores may include yardwork or heavy housework, such as scrubbing floors.

^cIncludes clients who had paid assistance during a recent two-week period and hired with the monthly budget.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 9
 SUPPLIES, EQUIPMENT, AND MODIFICATIONS AMONG RECIPIENTS
 OF THE MONTHLY BUDGET
 (Percentages)

Activity	Client/Family Performed Activity	Used Monthly Budget to Do So
Obtained Personal Care Supplies ^a (F3 and G5)	60.3	50.0
Obtained/Repaired Equipment ^b (F7, F8, F9, G23, and G29)	56.9	16.2
Modified Home (F4 and G11)	27.2	7.6
Modified Vehicle (F5 and G17)	5.8	0.0
Number of Clients^c	175	175

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to the nine-month period since random assignment.

^aIncludes supplies such as diapers, disposable gloves, catheter bags, feeding and ostomy bags, and pads to protect bedding.

^bIncludes equipment for household chores, personal activities, communication, or safety.

^cIncludes clients who received the monthly budget. Sample sizes vary slightly from measure to measure because of item nonresponse and because questions were asked only of clients who met certain criteria. For example, we did not ask parents of clients younger than age 18 about equipment for household chores, such as meal preparation.

chores, personal activities, communication, or safety; 16 percent used the monthly budget for such a purpose.¹⁰ In addition, slightly more than one-quarter of budget recipients modified their homes during the nine months since random assignment, and eight percent used the budget to do so. Only six percent of budget recipients made vehicular modifications, and none used the budget to do so. Compared with elderly adults and (parents of) children, younger adults were less likely to buy personal care supplies or to modify their homes (Table 10). We see only small differences in these purchases between clients grouped by preenrollment use of waiver program services.

Recipients of the monthly budget used a variety of community services while participating in the CDC program (although we do not know whether they used the budget to pay for them). Specifically, some used special transportation services (42 percent), attended social or recreational programs (37 percent), or attended day care or sheltered workshops for adults or children (30 percent) (Table 11). Elderly adults had the lowest rates of use of such services. Children were more likely than nonelderly adults to attend social or recreational programs, but less likely to attend day care.

F. HIRING CAREGIVERS AND PERFORMING OTHER RESPONSIBILITIES

1. Hiring Caregivers

In addition to asking clients about the amounts and types of help they received from paid caregivers (described in the preceding section), we asked them about recruiting and training the caregivers they hired, or tried to hire, with the monthly budget. At the time of the nine-month interview, 72 percent of clients who were still enrolled successfully hired caregivers, 14 percent

¹⁰Parents of clients younger than age 18 were not asked whether they had purchased equipment for household chores, such as meal preparation.

TABLE 10
 SUPPLIES, EQUIPMENT, AND MODIFICATIONS AMONG RECIPIENTS
 OF THE MONTHLY BUDGET, BY AGE AND HCBS USE
 (Percentages)

Activity	All Clients	Age		Preenrollment HCBS Use		
		65 or Older	18 to 64	Three Months or Longer	Fewer than Three Months	
Obtained Personal Care Supplies (F3)	60.3	75.0	46.8	66.3	57.1	66.1
Obtained/Repaired Equipment (F7, F8, F9)	56.9	55.0	51.6	60.9	54.5	61.3
Modified Home (F4)	27.2	35.0	16.1	33.0	28.6	24.6
Modified Vehicle (F5)	5.8	5.0	3.2	7.6	4.5	8.1
Number of Clients^a	175	21	62	92	113	62

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to the nine-month period since random assignment.

^aIncludes clients who received the monthly budget. Sample sizes vary slightly from measure to measure because of item nonresponse and because questions were asked only of clients who met certain criteria. For example, we did not ask parents of clients younger than age 18 about equipment for household chores, such as meal preparation.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 11
 USE OF COMMUNITY SERVICES BY RECIPIENTS OF THE MONTHLY BUDGET, BY AGE AND HCBS USE
 (Percentages)

Characteristic	Age			Prenrollment HCBS Use		
	All Clients	65 or Older	Age 18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Received Special Transportation Services ^a (H7)	42.0	25.0	40.3	46.7	44.6	37.1
Attended Social or Recreational Programs (H5)	37.4	15.0	30.7	46.7	36.6	38.7
Attended Day Care ^b (H4)	29.9	10.0	43.6	25.0	32.1	25.8
Received Home-Delivered Meals (H6)	1.7	0.0	4.8	0.0	2.7	0.0
Number of Clients^c	175	21	62	92	113	62

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to the nine-month period since random assignment. Though the statistics in this table pertain to clients who received the monthly budget, they did not necessarily use the monthly budget to pay for the community services we asked about.

^aIncludes vans, buses, and school buses intended for the elderly or for people with disabilities

^bIncludes day care programs for adults and children and sheltered workshops.

^cIncludes clients who received the monthly budget. Sample sizes vary slightly from measure to measure because of item nonresponse.

HCBS = Home- and Community-Based Waiver Program Services.

tried to hire but failed, and 13 percent had not tried (Table 12). Forty-seven percent of the clients who hired or tried to hire said the process was somewhat or very difficult. Of the 141 clients who hired, 81 percent had done so by the time of their six-month interview (not shown).¹¹

On average, the 175 clients who *tried to hire* caregivers before the time of the nine-month interview used more than two recruiting methods (reflected by the fact that the percentages in Table 13 sum to more than 200 percent). Clients most commonly tried to hire people they already knew, including their family members (64 percent), friends and neighbors (48 percent), or agency workers (39 percent). In addition, about half the clients asked family or friends to recommend caregivers. Elderly adults were less likely than their younger counterparts to try to hire friends and neighbors or to seek recommendations. Some clients (but very few elderly adults) attempted to hire caregivers on their own. Their methods included posting or consulting advertisements (16 percent); contacting employment agencies (10 percent); seeking recommendations from contacts at schools or support groups (8 percent); and contacting home care agencies, hospitals, or schools that train home care workers (6 percent).

More than half the clients (55 percent) who *successfully hired* caregivers hired family members; 29 percent hired friends or neighbors, 21 percent hired agency workers, and 19 percent hired through recommendations (Table 14). Some clients had success with advertisements (13 percent) or with other methods (also 13 percent). Compared with others in the sample, elderly clients were more likely to hire family members and were less likely to hire friends or neighbors.

¹¹One hundred forty-one clients used the monthly budget to hire caregivers. The sample of 139 clients shown in Table 12 excludes 2 clients who hired but who did not say whether they were still enrolled in the program. Previous references to 133 clients who used the budget to hire pertain to a subset of clients who used the budget to hire *and* who received paid care during a recent two-week period.

TABLE 12

CAREGIVER HIRING BY ENROLLMENT STATUS AS OF THE NINE-MONTH INTERVIEW

Hiring Status	Enrolled (A2 and A1a)		Disenrolled/Deceased		Total	
	Number	Percent	Number	Percent	Number	Percent
Hired Caregiver (C2 and J3)	136	72.3	3	7.7	139	61.2
Did Not Hire Caregiver (D2 and J4)						
Tried to hire	27	14.4	5	12.8	32	14.1
Did not try	25	13.3	31	79.5	56	24.7
Number of Clients^a	188	100.0	39	100.0	227	100.0

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses (A2, C2, and D2 are from the six-month interview).

^aIncludes only clients who answered questions about enrollment status *and* caregiver hiring status.

TABLE 13
 RECRUITING METHODS ATTEMPTED AS OF THE NINE-MONTH INTERVIEW, BY AGE AND HCBS USE
 (Percentages)

Recruiting Method	All Clients	Age			Preenrollment HCBS Use	
		65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Tried to Hire (D5 and J6)						
Family member	64.0	69.6	59.0	65.9	64.6	62.9
Friend, neighbor, or church member	48.0	30.4	54.1	48.4	46.9	50.0
Agency worker	39.4	30.4	42.6	39.6	39.8	38.7
Asked Family or Friends for Recommendations (D5A and J6A)	49.1	30.4	49.2	53.8	46.9	53.2
Posted/Consulted Advertisement (D5B and J6B)	16.0	8.7	23.0	13.2	16.8	14.5
Contacted Employment Agency (D5C and J6C)	9.7	0.0	8.2	13.2	8.8	11.3
Asked Contacts at School or Support Group for Recommendations (D5D and J6D)	8.0	0.0	3.3	13.2	5.3	12.9
Contacted Home Care Agency, Hospital, or School for Home Care Workers (D5D and J6D)	5.7	0.0	6.6	6.6	3.5	9.7
Number of Clients^a	175	23	61	91	113	62

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses (D5, D5A, D5B, and D5C are from the six-month interview).

NOTE: Columns sum to more than 100 percent because many respondents attempted more than one recruiting method.

^aIncludes clients who answered questions about trying to hire a caregiver, regardless of whether they succeeded.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 14
 RECRUITING METHODS RESULTING IN HIRES AS OF THE NINE-MONTH INTERVIEW, BY AGE AND HCBS USE
 (Percentages)

	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Hired (D7 and J6E)						
Family Member	55.3	68.8	51.1	55.0	57.5	51.1
Friend, Neighbor, or Church Member	29.1	6.3	37.8	28.8	27.7	31.9
Former Agency Worker	21.3	18.8	22.2	21.3	22.3	19.2
Caregiver Recommended by Family or Friend	19.2	12.5	15.6	22.5	16.0	25.5
By Posting/Consulting Advertisement	12.8	6.3	20.0	10.0	12.8	12.8
Other	13.5	0.0	13.3	16.3	8.5	23.4
Number of Clients^a	141	16	45	80	94	47

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses (D7 is from the six-month interview).

NOTE: Columns sum to more than 100 percent because some respondents had success with more than one recruiting method.

^aIncludes clients who used their monthly budget to hire a caregiver.

HCBS = Home- and Community-Based Waiver Program Services.

With the exception of that difference, successful hiring methods were quite evenly distributed across subgroups defined by age or by preenrollment use of waiver program services.

2. Performing Other Employer Responsibilities and Satisfaction with Bookkeeping Services

In addition to hiring caregivers, clients may perform other responsibilities as employers, sometimes with the help of a consultant or peer counselor. For example, clients may revise their purchasing plans in order to purchase a different combination of services. Clients might also decide to change their caregiver's job description, wages, or fringe benefits after they have had some experience recruiting and being cared for by the people they hired.

In this early cohort, 35 percent of all clients revised their purchasing plans with the help of a consultant between the time of the six- and nine-month interviews (Table 15). Clients with relatively little waiver program experience were more likely than others to have made revisions (45 percent versus 30 percent). In addition, the parents of clients younger than age 18 were more likely than elderly adults to have done so (41 percent versus 22 percent).

While they were recruiting or after hiring, nearly half the clients (47 percent) who hired or who tried to hire between interviews changed the wages, hours, or types of work with which they wanted help (Table 15). Of those who used the monthly budget to hire, seven clients (five percent) provided their paid caregivers with fringe benefits, such as paid sick days, as of the nine-month interview (not shown). Twelve percent of clients who were still enrolled at nine months said they received support or advice from their peers in the CDC program between interviews (not shown). No elderly clients received peer support.

In addition, 84 percent of the 166 clients who used the program's bookkeeping services to manage their fiscal responsibilities were satisfied with those services (not shown). Sixty-nine percent of satisfied clients were "very satisfied."

TABLE 15
 REVISING PURCHASING PLANS, BY AGE AND HCBS USE
 (Percentages)

Characteristic	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Consultant Helped Client Revise Plan (J1) ^a	35.0	21.7	31.5	40.6	30.0	44.8
Among Those Who Hired or Tried to Hire						
Changed wages, hours, or type of work (J16, J17, and J18) ^b	46.6	43.8	49.0	45.7	47.5	44.9
Number of Clients Overall^a	197	23	73	101	130	67
Clients Who Hired or Tried to Hire^b	148	16	51	81	99	49

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: The questions used in this table refer to the period between the six- and nine-month interviews.

^aIncludes clients who answered a question about revising their purchasing plan and who had not died or disenrolled before the six-month interview.

^bIncludes clients who hired or who tried to hire between the six- and nine-month interviews and who had not died or disenrolled before the six-month interview.

HCBS = Home- and Community-Based Waiver Program Services.

G. SATISFACTION WITH CARE AND UNMET NEEDS

Most CDC clients in this early cohort were highly satisfied with their paid care (including care purchased with the monthly budget as well as other paid care). Nine in 10 clients were satisfied with their overall care arrangements, and 8 in 10 were satisfied with their ability to obtain help with transportation as needed (Table 16). Ninety-nine percent of the clients who used the monthly budget to hire caregivers were satisfied with their relationship with their caregivers. Of those, 96 percent said they were very satisfied (as opposed to somewhat satisfied; not shown). All or nearly all clients who used the monthly budget to hire caregivers were satisfied with the way their caregivers fulfilled various duties (Table 16), and at least 8 in 10 of the satisfied clients reported being very satisfied (not shown). More than half the clients (59 percent) who hired said it would be difficult to change their caregiver's schedule if they needed to, but 99 percent were satisfied with the times of day they received help (Table 16). Finally, nearly 9 in 10 clients said their caregivers always or almost always completed their tasks.

A full 90 percent of clients who received the monthly budget said they were satisfied with their lives, although some reported unmet needs in specific areas (Table 17). Roughly 30 percent of clients who received the budget were not receiving enough help with personal care, meals and housework, or transportation. About 20 percent needed more help with routine health care or needed more personal care supplies. In addition, health problems or lack of assistance limited clients' recreational or social activities in more than half the cases (57 percent). Forty-three of the clients (84 percent) who were 18 to 74 years old and who received the monthly budget were limited in their ability to do paid work because of health problems or lack of assistance; 32 (62 percent) were limited in their educational pursuits for these reasons.

TABLE 16
SATISFACTION WITH PAID CARE, BY AGE AND HCBS USE
(Percentages)

Characteristic	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Currently Satisfied with:						
Overall Care Arrangements (E14)	92.4	95.7	91.7	92.0	91.9	93.2
Help with Transportation (E16) ^a	79.6	77.3	83.6	77.5	77.9	83.0
Among Those Who Hired with the Monthly Budget						
Relationship with Caregiver Is Satisfying (E28)	99.0	100.0	100.0	98.3	100.0	97.1
Satisfied with How Caregiver ^a						
Helps with medication and routine health care (E26)	100.0	100.0	100.0	100.0	100.0	100.0
Helps with personal care duties (E22)	97.9	100.0	93.1	100.0	96.7	100.0
Helps with household or community duties (E24)	97.8	100.0	92.9	100.0	96.6	100.0
Satisfied with Times of Day They Receive Help (E20)	99.0	100.0	96.9	100.0	98.4	100.0
Changing Caregiver's Schedule Would Be Difficult (E20b)	58.8	50.0	50.0	64.4	57.1	61.8
Paid Caregiver(s) Complete(s) Tasks (E31)						
Always or almost always	87.4	85.7	75.8	93.7	85.3	91.4
Usually or sometimes	10.7	0.0	21.2	6.3	13.2	5.7
Rarely	1.9	14.3	3.0	0.0	1.5	2.9
Number of Clients Overall^b	170	23	60	87	111	59
Clients Who Hired with the Monthly Budget^c	103	7	33	63	68	35

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Except for questions E14 and E16, which refer to the time at which the interview was conducted, questions used in this table refer to a two-week period within the two months before the interview. Responses about satisfaction may apply to assistance paid for with the monthly budget as well as assistance paid for with other sources.

^aThese tabulations exclude clients who did not need the service in question during the two-week period.

^bIncludes clients who answered questions about satisfaction, but excludes proxies who were also paid caregivers because such respondents have a vested interest in the client's satisfaction.

^cIncludes clients who had paid assistance during a recent two-week period and hired with the monthly budget, but excludes proxies for the reason given in footnote b. Sample sizes vary (from 68 to 103) from measure to measure because questions were asked only of clients who met certain criteria.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 17
 QUALITY OF LIFE AND UNMET NEEDS AMONG CLIENTS WHO RECEIVED THE MONTHLY BUDGET,
 BY AGE AND HCBS USE
 (Percentages)

Characteristic	Age			Preenrollment HCBS Use		
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Satisfied with Life (E13)	89.6	80.0	86.4	93.0	86.1	95.7
Not Getting Enough:						
Help with personal care (E37)	30.1	33.3	32.0	28.2	30.6	29.2
Help with meals and housework (E40)	34.1	16.7	42.0	31.4	36.9	29.2
Help with transportation (E41)	28.6	33.3	30.0	26.8	25.0	30.6
Help with medication or routine health care (E42)	21.1	33.3	26.0	15.5	20.8	21.2
Personal care supplies (E44)	20.3	33.3	20.0	18.3	20.0	20.8
Health Problems or Lack of Assistance Limited:						
Recreational, cultural, social, or religious activities (E46) ^a	57.1	75.0	52.0	57.8	57.7	56.3
Ability to do paid work (E49) ^{a,b}	84.3	100.0	83.3	NA	87.5	72.7
Educational pursuits (E48) ^{a,b}	61.5	66.7	61.2	NA	67.5	41.7
Number of Clients^c	133	12	50	71	85	48

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

NOTE: Questions used in this table refer to the time at which the interview was conducted.

^aThis tabulation excludes clients who were not interested in pursuing the activity.

^bThis question was asked only of a subset of 52 clients who were 18 to 74 years old. It was not asked of proxy respondents who were also paid caregivers or who could not assess client limitations.

^cIncludes clients who received their monthly budget, but excludes proxies who were also paid caregivers or who could not assess client satisfaction. Sample sizes vary (from 125 to 133) from measure to measure because some questions were only asked of clients who met certain criteria.

HCBS = Home- and Community-Based Waiver Program Services; NA = not applicable.

H. SATISFACTION WITH THE CONSUMER-DIRECTED CARE PROGRAM

In addition to being satisfied with their paid care, the great majority of CDC clients were happy with the program itself. Ninety percent of all clients, including disenrollees, would recommend the program to others wanting more control over their personal care (Table 18). This percentage was considerably higher for the parents of clients younger than age 18 (95 percent) than it was for elders (80 percent). Moreover, 97 percent of clients who used the monthly budget to hire caregivers would recommend the program (compared with 85 percent of those who tried to hire but failed, and with 72 percent of those who did not try; not shown).

Eighty-eight percent of clients who received the monthly budget said it improved the quality of their lives, with 73 percent of that group reporting a great deal of improvement (Table 18). Ten percent of clients said the monthly budget did not affect their quality of life, and 2 percent said the quality of their lives had been diminished. We asked the 148 clients whose lives the budget had improved to name the most important way it did so (many clients identified more than one way; Table 19). The ability to choose their caregivers and to obtain the right kinds of personal assistance or other services were the most common improvements (cited by 45 and 32 clients, respectively). Other fairly common improvements were the ability to obtain enough care or care at the right time, to obtain a higher quality of care, or to obtain personal care supplies. Clients also said that greater independence and the flexibility to care for themselves through a combination of goods and services were important improvements. Finally, several parents of clients younger than age 18 said the monthly budget provided respite or enabled them to spend more time engaging their children in activities other than caregiving.

Three clients said the monthly budget had reduced their quality of life. Two said the budget would not purchase the same amount of services as they received under the HCBS waiver program. According to the other, the budget would not cover the costs of having a senior

TABLE 18

SATISFACTION WITH CONSUMER-DIRECTED CARE, BY AGE AND HCBS USE
(Percentages)

Question	Age				Preenrollment HCBS Use	
	All Clients	65 or Older	18 to 64	3 to 17	Three Months or Longer	Fewer than Three Months
Would Recommend Program (J34)	90.0	80.0	87.2	95.3	89.1	91.7
Among Those Who Received the Monthly Budget						
Effect of the Monthly Budget on Quality of Life (J35)						
Improved	88.1	89.5	86.2	89.0	88.0	88.3
Stayed the same	10.1	5.3	12.1	9.9	10.2	10.0
Reduced	1.8	5.3	1.7	1.1	1.9	1.7
How Much Quality of Life Was Improved (J36)						
A great deal	73.0	70.6	68.0	76.5	74.7	69.8
Somewhat	27.0	29.4	32.0	23.5	25.3	30.1
Number of Clients Overall^a	219	35	78	106	147	72
Clients Who Received the Monthly Budget^b	168	19	58	91	108	60

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses.

^aIncludes clients who answered a question about whether they would recommend the program.

^bIncludes clients who received the monthly budget and answered a question about the effect of the budget on their quality of life.

HCBS = Home- and Community-Based Waiver Program Services.

TABLE 19
MOST IMPORTANT WAYS MONTHLY BUDGET IMPROVED LIFE

Improvement (J37)	Number Citing Improvement
Improvements Pertaining to Care and Caregivers	
Monthly Budget Enables Client to:	
Choose caregivers	45
Obtain the right types of personal assistance or other services	32
Obtain enough care or care at the right time	17
Obtain higher quality care than had before	15
Compensate caregivers or enable them to leave other jobs	9
Improvements Pertaining to Supplies and Modifications	
Budget Enables Clients to Buy:	
Unspecified items related to personal assistance needs	11
Food or nutritional supplements	3
Diapers	1
Budget Enables Client to Modify Home	1
Attitudinal and Health-Related Improvements	
Client Feels More Independent or in Control of Care	17
Client Worries Less, Is Happier, or Has More Self-Esteem	7
Client Is Healthier Since Receiving the Monthly Budget	3
Other Improvements	
Program's Flexibility Enables Client to Choose the Best Combination of Goods and Services	17
For Clients Younger than Age 18, Budget Provides Respite for Parents or Increases the "Quality Time" that Parent and Child Spend Together	7
Client Is More Financially Secure	1
Number of Clients^a	148

SOURCE: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. The question number is in parentheses.

NOTE: This table is based on open-ended responses that were coded after the interview. Although they were asked to provide the most important reason, some clients gave more than one; all are represented here.

^aIncludes clients who said the monthly budget had improved the quality of their lives.

companion. (It was not clear whether the client believed a senior companion was an unallowable expense or whether the client could not afford one, given the monthly budget).

I. CONCLUSION

This analysis of the perspectives of 231 early CDC clients with nine months of program experience suggests that the program generally works well for most clients, as measured by continued enrollment, receipt of the monthly budget, and client satisfaction. The program may work especially well for young and nonelderly clients and for clients who can readily hire caregivers. For example, compared with elderly adults, much larger percentages of children and nonelderly adults were still enrolled in the program after nine months. The parents of child clients were considerably more likely than elderly adults to say they would recommend the program to others. In addition, clients who used their monthly budget to hire caregivers were more likely to recommend the program than those who did not hire.

Generally speaking, both the freedom and responsibility associated with consumer-directed care were evident in clients' responses to the nine-month survey. For instance, clients exercised their options about use of the monthly budget. Although most used the budget to hire caregivers, many paid for personal care supplies, equipment, or home modifications, and some purchased a combination of services and goods. At the same time, clients' responsibilities were not negligible, nor were all their problems solved. Nearly half the clients who hired or tried to hire described that process as difficult, and nearly half said they decided to change caregivers' hours, wages, or duties while they were recruiting or after they hired. Furthermore, some clients said they needed more help with basic activities or needed more personal care supplies. On balance, however, most consumers were highly satisfied with the care they purchased and with the CDC program itself.