Contract No.:QI46901MPR Reference No.:8349-093

MATHEMATICA Policy Research, Inc.

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

Interim Memo

October 2002

Leslie Foster Randall Brown Barbara Carlson Barbara Phillips Jennifer Schore

Submitted to:

Center on Aging University of Maryland 1240 HHP Building Valley Drive College Park, MD

Project Officer: Kevin J. Mahoney Submitted by:

Mathematica Policy Research, Inc. P.O. Box 2393 Princeton, NJ 08543-2393 Telephone: (609) 799-3535 Facsimile: (609) 799-0005

Project Director: Randall Brown This memorandum describes the experiences of 240 early clients in New Jersey's Cash and Counseling Demonstration, the Personal Preference 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 monthly cash grants. Mathematica Policy Research, Inc. (MPR), the demonstration evaluator, administered the survey.

After briefly describing the New Jersey 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. Among the findings discussed in this memorandum, the following are particularly interesting:

- Of the clients in this cohort, 76 percent were still enrolled in Personal Preference at the time of the nine-month interview, 17 percent had disenrolled, and 7 percent had died.
- Of the clients who were still enrolled after nine months, only 65 percent had begun receiving their monthly cash grants, and 46 percent used their grants to hire caregivers. Overall, only about half of clients (including disenrollees) received cash grants by the nine-month point.
- Of the clients who used their grants to hire caregivers, most (63 percent) hired family members, but many hired friends, neighbors, or church members (20 percent), or former agency workers (16 percent).
- Nearly all clients (99 percent) who used their cash grants to hire caregivers were satisfied with their relationships with those caregivers. Among satisfied clients, 88 percent were "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.

- More than 7 out of 10 cash recipients stated that the monthly cash grants had improved their lives. Most stated that being able to choose their own caregivers was the most important improvement.
- Ninety-seven percent of clients who used their cash grants to hire caregivers would recommend the Personal Preference program to others seeking more control over their personal care.

A. CASH AND COUNSELING IN NEW JERSEY

New Jersey's Personal Preference program gives beneficiaries who are eligible for Medicaid personal assistance services (PAS) a chance to receive monthly cash grants in lieu of traditional services. As part of the demonstration's evaluation, eligible beneficiaries interested in receiving the cash grants are randomly assigned by the evaluator to the treatment group (whose members receive the grants) or to the control group (whose members continue to receive traditional Medicaid PAS). As noted, this memorandum describes the experiences of beneficiaries assigned to receive the grants. Throughout the memorandum, we refer to these beneficiaries as "clients" of the program.²

Personal Preference clients may use their monthly grants to hire caregivers or to purchase services or goods related to their need for personal assistance that would enhance their ability to live independently. Clients who are unable to manage their cash grants (for example, to make decisions about whom to hire and how much to pay) may have a representative do it for them. This representative may be a family member, friend, guardian, or other individual.

In addition to the monthly cash grants, the demonstration provides counseling and fiscal services. For example, many clients receive help from a consultant in developing their

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 proxies sometimes responded on clients' behalf and even though some clients disenrolled from or never actively participated in the program.

cash-management plans, which are prerequisite to receiving monthly cash grants. Other counseling services (such as help recruiting and training caregivers hired with the cash grants) are available at the client's request. Clients who opt to use the program's fiscal services (such as paying and withholding taxes for caregivers hired with the cash grants) pay a modest fee per transaction. New Jersey contracts with several counseling agencies throughout the state and one fiscal intermediary service organization (FISO). If more than one counseling agency operates in their area, clients may choose the one from which they receive 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 monthly cash grants. As noted, MPR administered the interviews about nine months after random assignment. The interviews included in this analysis were conducted between August 2000 and early May 2001. (Thus, interviewees were randomly assigned to the treatment group between November 1999 and July 2000.) To obtain a complete picture of clients' experiences, we conducted the nine-month interviews even with disenrolled clients and the proxies of deceased clients.

Questions in the nine-month interview refer to a variety of reference periods, including the day of the interview, the most recent two weeks 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 one that had been conducted earlier, 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 a recent two-week reference period for questions about daily activities because the interview day may have been atypical and use of the two-week reference period should not create serious problems resulting from 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 to clients' cash-management plans and other employer responsibilities refer to the period between the six- and nine-month interviews.

The tables in this memorandum present percentage distributions, frequencies, and crosstabulations 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 PAS at the time of random assignment (referred to elsewhere in this memorandum as "preenrollment PAS use").³ The age subgroups consist of adults aged 65 or older, and adults younger than age 65. Similarly, clients who had used PAS for three months or longer prior to random assignment are distinguished from newer users—those who used PAS for fewer than three months by that time. Given the small sample available for this analysis, we note only subgroup differences that are 15 percentage points or larger. Smaller differences may well be due to chance.

As noted, 240 clients completed nine-month interviews by the cut-off date for this analysis, yielding a response rate of 93 percent for this sample and its subgroups (see Table 1).⁴ Slightly more than half the clients in the cohort were aged 65 or older, and 69 percent had been using PAS for three months or longer before enrolling in Personal Preference. About half the

³The Personal Preference program provided data on age and preenrollment PAS use.

⁴We calculated the response rate as of May 2, 2001. The rate equals the number of respondents who completed interviews divided by the number of sample members who were approximately nine months past random assignment. The rate excludes 45 sample members for whom we were still pursuing a completed interview.

| | Clients for Inte | 0 | Respo | ndents | Response Rate |
|-------------------------|---------------------|---------|--------|---------|---------------|
| Subgroup | Number | Percent | Number | Percent | (Percent) |
| Age | | | | | |
| 65 years or older | 137 | 52.9 | 129 | 53.8 | 94.2 |
| 18 to 64 years | 122 | 47.1 | 111 | 46.3 | 91.0 |
| Preenrollment PAS Use | | | | | |
| Three months or longer | 182 | 70.3 | 166 | 69.2 | 91.2 |
| Fewer than three months | 77 | 29.7 | 74 | 30.8 | 96.1 |
| Total | 259 | 100.0 | 240 | 100.0 | 92.7 |

DISTRIBUTION OF CLIENTS ELIGIBLE FOR INTERVIEW AND RESPONDENTS, BY AGE AND PAS USE

Source: Personal Preference program and Mathematica Policy Research, Inc. CATI reports.

^aThese data refer to the pool of sample members who were eligible for a nine-month interview as of May 2, 2001, the cut-off date for responses from completed interviews to be included in this analysis. The 259 sample members in this pool include 6 refusers and 13 individuals who could not be located. Approximately 45 cases that were still being pursued as of May 2 are excluded from these figures.

PAS = personal assistance services; CATI = computer-assisted telephone interview.

interviews were completed by the clients themselves; the other half were completed by proxy respondents (not shown). One-quarter of the proxies were also paid to care for clients.

C. CLIENT CHARACTERISTICS AND UNPAID HELP

Most clients described themselves as having fair or poor health, and large percentages had chronic conditions or functional impairments. Forty-one percent rated their health as poor compared with the health of other people their age, and 86 percent had at least one chronic condition that required care (Table 2). Without help, bathing would have been very difficult or impossible for 62 percent of clients. Both getting in or out of bed or using the toilet would have been very difficult or impossible for more than one-third of the clients.

Substantial fractions of clients lived alone or did not receive unpaid help. Overall, more than one-third lived alone, and about one-quarter had no unpaid caregivers (Table 3). Most clients who did have unpaid help received it from two or more people. More than half the clients (59 percent) had at least one live-in unpaid caregiver. Eighty-five percent of clients with unpaid caregivers were helped by relatives (not shown).

D. PROGRAM PARTICIPATION

Three-quarters of the clients in the cohort reported that they were still participating in Personal Preference nine months after random assignment (Table 4). Of the remaining quarter (57 clients), 16 (7 percent of all clients) had died, and 41 (17 percent of all clients) had disenrolled. Of the 41 clients who disenrolled, 20 had already done so by the time of the six-month interview (not shown).

About 57 percent of all clients, including disenrollees, stated that they had received the monthly cash grants by the time of the nine-month interview (24 percent started getting cash

HEALTH AND FUNCTIONING, BY AGE AND PAS USE (Percentages)

| | | Age | e | Preenrollment PAS Use | nt PAS Use |
|---|----------------|---------------------|--------------------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Self-Rated Relative Health Status (A2) Excellent or good | 21.7 | 19.7 | 24.0 | 23.2 | 18.2 |
| Fair | 37.6 | 43.6 | 30.8 | 37.4 | 37.9 |
| Poor | 40.7 | 36.8 | 45.2 | 39.4 | 43.9 |
| Has Chronic Condition that Requires Care (A16) | 86.0 | 87.1 | 84.2 | 88.2 | 80.0 |
| Activity Would Be Very Difficult or Impossible Without Help | | | | | |
| Bathing (Å19) | 62.3 | 60.7 | 64.2 | 63.5 | 59.7 |
| Getting in or out of bed (A20) | 39.0 | 34.2 | 44.3 | 41.1 | 33.3 |
| Toileting (A21) | 34.6 | 30.1 | 39.6 | 37.1 | 28.6 |
| Number of Respondents ^a | 224 | 117 | 107 | 157 | 67 |
| Source: Mathematica Policy Research Inc.'s Nine-Month Cash and Counselino Evaluation Interview. Ouestion numbers are in parentheses | -Month Cash an | d Connseling Evalua | tion Interview. Ou | estion numbers are in | narentheses. |

ý à ^aIncludes respondents who were living at the time of the nine-month interview. Sample sizes vary slightly (from 217 to 223) from measure to measure because of item nonresponse and skip patterns.

| | | Age | a | Preenrollm | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Number of People in Client's Household, Including Client (B5 and B12) | | | | | |
| 1 | 35.0 | 35.6 | 34.3 | 37.2 | 29.9 |
| 2 | 26.9 | 28.0 | 25.7 | 26.3 | 28.4 |
| σ | 18.4 | 13.6 | 23.8 | 16.7 | 22.4 |
| 4 or more | 19.7 | 22.9 | 16.2 | 19.9 | 19.4 |
| Number of Unpaid Caregivers (C4) | | | | | |
| 0 | 26.0 | 28.8 | 22.9 | 26.9 | 23.9 |
| 1 | 26.0 | 22.0 | 30.5 | 28.2 | 20.9 |
| 2 | 18.8 | 19.5 | 18.1 | 17.3 | 22.4 |
| 3 or more | 29.2 | 29.7 | 28.6 | 27.6 | 32.8 |
| Among Clients with Unpaid Caregivers, Number of Live-In Unpaid Caregivers (C4, C24, and C26) | | | | | |
| 0 | 40.6 | 36.9 | 44.4 | 38.6 | 45.1 |
| 1 | 39.4 | 39.3 | 39.5 | 42.1 | 33.3 |
| 2 | 10.9 | 11.9 | 9.6 | 8.8 | 15.7 |
| 3 or more | 9.1 | 11.9 | 6.2 | 10.5 | 5.9 |
| Overall Respondents ^a | 223 | 118 | 105 | 156 | 67 |
| Clients with Unpaid Caregivers | 165 | 84 | 81 | 114 | 51 |

HOUSEHOLD SIZE AND NUMBER OF UNPAID CAREGIVERS, BY AGE AND PAS USE

TABLE 3

PAS = personal assistance services.

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

Questions used in this table refer to a recent two-week period.

Note:

| | | Age | je | Preenrollment PAS Use | nt PAS Use |
|---|----------------|-------------|----------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Enrollment Status at Nine Months (A1a) | | | | | |
| Enrolled | 76.3 | 76.7 | 75.7 | 78.9 | 70.3 |
| Disenrolled | 17.1 | 14.0 | 20.7 | 15.7 | 20.3 |
| Deceased | 6.7 | 9.3 | 3.6 | 5.4 | 9.5 |
| Cash Grants (A1b) ^a | | | | | |
| Started before six-month interview | 32.4 | 33.6 | 30.9 | 31.7 | 33.8 |
| Started between six- and nine-month Interviews | 24.4 | 21.9 | 27.3 | 26.2 | 20.3 |
| Not started by nine-month interview | 43.3 | 44.5 | 41.8 | 42.1 | 46.0 |
| Number of Respondents | 240 | 129 | 111 | 166 | 74 |

ENROLLMENT STATUS AND RECEIPT OF MONTHLY CASH GRANTS AT NINE MONTHS, BY AGE AND PAS USE (Percentages)

TABLE 4

PAS = personal assistance services.

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

between their six- and nine-month interviews; Table 4).⁵ Of the clients who were still enrolled after nine months, 65 percent had received cash grants (Table 5). Only 15 percent of disenrollees had received grants.

Several factors, two of which we summarize here, explain why only a small percentage of early clients had begun receiving their monthly grants by the time of their nine-month interview.⁶ First, a demonstration state cannot begin distributing cash grants until it (1) selects a FISO to transmit cash grants from the program to the clients, (2) obtains federal approval for the selected FISO, and (3) develops and implements operational procedures for transmitting grants and other fiscal activities. New Jersey experienced delays in each of these steps and, as a result, could not begin distributing any cash grants until May 2000, even though the first clients were randomly assigned in November 1999. Second, the state had begun marketing the demonstration to prospective enrollees months before random assignment began. When random assignment did begin, everyone assigned to the treatment group needed the assistance of a Personal Preference consultant to develop, or obtain approval for, their cash-management plans. Because program staff could not meet this high level of demand for counseling services, some cash-management plans-and ensuing grants-were delayed. In addition, if a client's cash-management plan indicated that the client intended to use the monthly grants to hire a caregiver, then cash would not be transmitted until someone had been hired. As noted later in this memorandum, many

⁵Program data on whether clients received their cash grants within nine months of random assignment are roughly similar to these self-reported data.

⁶The evaluation's forthcoming site visit report will describe the implementation of the Personal Preference program in detail and will provide additional insights as to why this percentage is lower than might be expected. Such a discussion is beyond the scope of this memorandum.

ENROLLMENT STATUS, BY RECEIPT OF MONTHLY CASH GRANTS AT NINE MONTHS

| Enrollment Status (A1a) | Number of Respondents | Percentage Receiving Grants (A1b) |
|------------------------------|--------------------------|--------------------------------------|
| Enrolled | 181 | 64.6 |
| Disenrolled | 41 | 14.6 |
| Deceased | 16 | 75.0 |
| All Respondents ^a | 238 | 56.7 |

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

^aIncludes respondents who answered a question about receipt of cash grants.

clients tried but were unable to hire caregivers and may not have started receiving their grants by the time of the nine-month interview for this reason.

E. USE OF SERVICES, GOODS, AND CASH

1. Personal Assistance Services

Most clients in the sample had recently received personal assistance from a paid caregiver. Overall, 90 percent of clients who lived at home for at least two weeks during the two months before the interview were helped during that period by a paid caregiver (Table 6). However, less than half (43 percent) had used Personal Preference grants to hire their caregivers; the remainder received care from some other paid source, such as a home care agency. Sixty-four percent of the clients who received cash grants as of the nine-month interview used their grants to hire caregivers (not shown).

Of the 87 clients who hired caregivers with their cash grants and had paid assistance during a recent two-week period, 64 percent were helped by one paid caregiver, 25 percent by two, and 10 percent by three or more.⁷ Nearly three-quarters of these clients had visiting paid caregivers, and 37 percent had live-in caregivers. Clients younger than age 65 were notably more likely than older clients to have visiting paid caregivers. Conversely, they were less likely than older clients to have live-in paid caregivers. A majority of clients (63 percent) who hired with their cash grants received paid assistance from a relative. We see little difference in these characteristics between clients with at least three months' preenrollment PAS use and those who used PAS for a shorter period.

⁷We cannot assume from the survey responses that clients hired *all* their paid caregivers with their cash grants, but it seems unlikely that many clients would have had an additional source of paid care.

| | | Age | e | Preenrollment PAS Use | nt PAS Use |
|---|----------------|--------------|--------------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Had Paid Caregiver(s) in Recent Two Weeks | 100 | 200 | У Г0 | L 10 | 9 Y O |
| Paid with cash grants | 43.3 | 47.8 47.8 | 87.0 39.4 | 91.7 43.4 | ou.u 43.1 |
| Did not pay with cash grants | 56.7 | 52.2 | 60.6 | 56.6 | 56.9 |
| Among Those Who Had Paid Caregivers(s) and Paid with Cash Grants | | | | | |
| Number of Paid Caregivers (D1) 1 | 64.4 | 67 4 | 614 | 1 19 | 56 () |
| | 25.3 | 27.9 | 22.7 | 19.4 | 40.0 |
| 3 or more | 10.4 | 4.7 | 15.9 | 12.9 | 4.0 |
| Had Visiting Paid Caregiver(s) (B5, D1, and D30) | 73.6 | 65.1 | 81.8 | 71.0 | 80.0 |
| Had Live-in Paid Caregivers(s) (D28) | 36.8 | 44.2 | 29.5 | 37.1 | 36.0 |
| Had Related Paid Caregiver(s) (D3) | 63.2 | 65.1 | 61.4 | 64.5 | 60.0 |
| Overall Respondents ^a | 223 | 118 | 105 | 156 | 67 |
| Clients Who Hired with the Cash Grant ^b | 87 | 43 | 44 | 62 | 25 |

USE OF PAID CAREGIVERS, BY AGE AND PAS USE (Percentages)

TABLE 6

Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses. Questions used in this table refer to a two-week period within the two months preceding the interview. Source: Note:

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

^bIncludes respondents who hired with the cash grants and had paid assistance during a recent two-week period.

About half the 61 clients who used their cash grants to hire *visiting* caregivers paid for 15 to 42 hours of care during the two-week period we asked about (roughly 1 to 3 hours of care per day; Table 7). Another third purchased more than 42 hours of care (at least 3 hours of care per day). More than half the 31 clients who used their cash grants to hire *live-in* caregivers paid for more than 42 hours of care. Relatively few clients paid for 14 or fewer hours of care during the two weeks from either visiting or live-in caregivers.

Clients who used their monthly cash grants to hire caregivers received help with many aspects of their care, including household activities and personal care. All or most of them paid someone who helped them with light housework (100 percent), meal preparation (95 percent), or shopping (89 percent) (Table 8). In addition, many had help with bathing (92 percent), getting in or out of bed (83 percent), taking medicine (79 percent), or performing other routine health care tasks, such as checking blood pressure or exercising (70 percent).

2. Goods and Community Services

Since random assignment, about 45 percent of the 135 cash recipients obtained or repaired equipment for household chores, personal activities, communication, or safety, with 12 percent using their cash grants to do so (Table 9). Seventeen percent of cash recipients modified their homes during the same period; 7 percent used their cash grants for that purpose. Slightly less than 25 percent of elderly clients made modifications to their homes, compared with about 10 percent of nonelderly adults (Table 10). Very few clients (less than 1 percent) made vehicular modifications, and none used their cash grants to do so.

Cash recipients used a variety of community services while participating in Personal Preference (although they may not have paid for the services with their cash grants). Overall, 40 percent used transportation services, for example to see a physician or run errands (Table 11). New PAS users were more likely than continuing users to have done so. Smaller percentages of

HOURS OF CARE PAID FOR WITH CASH GRANTS (Numbers)

| Hours of Care Paid for Over Two Weeks (D65, D41, and D46) | From Visiting Paid Caregivers | From Live-In Paid Caregivers |
|---|----------------------------------|---------------------------------|
| 14 or Fewer | 9 | 1 |
| 15 to 42 | 32 | 12 |
| 43 to 70 | 12 | 9 |
| 71 or More | 8 | 9 |
| Number of Respondents ^a | 61 | 31 |

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 total hours of paid care received during a two-week period within the two months preceding the interview.

^aIncludes respondents who hired with their cash grants, used paid assistance during a recent twoweek period, and answered questions about the hours of care they received from visiting and live-in paid caregivers. Of the 87 respondents who hired with their cash grants and used paid assistance during the reference period, 9 had both visiting and live-in caregivers, but 4 did not answer questions about the hours of care they received from each type of caregiver.

TYPES OF CARE FROM CAREGIVERS HIRED WITH CASH GRANTS, BY AGE AND PAS USE Ē,

| Ľ. | \mathbf{S} |
|----|--------------|
| | e |
| | 60 |
| | 3 |
| | ŭ |
| | |
| | 5 |
| | ercentages |
| | 2 |
| | 5 |
| | <u> </u> |
| | |

| | | V | Age | Freemonn | Freenrollment FAS Use |
|--|----------------|--------------|--------------|---------------------------|----------------------------|
| Type of Paid Caregiver Help Received | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Health Care | | | | | |
| Taking Medicine (D8) Other Routine Health Care (D9) | 79.3 70.1 | 83.7 72.1 | 75.0 68.2 | 83.9 71.0 | 68.0 68.0 |
| Personal Care | | | | | |
| Bathing/Showering (D17) | 92.0 | 90.7 | 93.2 | 93.6 | 88.0 |
| Getting in or out of Bed (D15) Eating (D14) | 82.8 75.9 | 79.1 83.7 | 86.4 68.2 | 85.5 77.4 | 76.0 72.0 |
| Toileting (D16) | 70.1 | 72.1 | 68.2 | 72.6 | 64.0 |
| Other (D18) | 89.7 | 88.4 | 90.9 | 91.9 | 84.0 |
| Household/Community Chores | | | | | |
| Light Housework (D21) | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| Meals (D20) | 95.4 | 95.3 | 95.5 | 95.2 | 96.0 |
| Shopping (D22) | 88.5 | 86.0 | 90.9 | 88.7 | 88.0 |
| Transportation (D23) | 51.7 | 53.5 | 50.0 | 54.8 | 44.0 |
| Other (D24) | 78.2 | 74.4 | 81.8 | 77.4 | 80.0 |
| Number of Respondents ^a | 87 | 43 | 44 | 62 | 25 |

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

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

^aIncludes respondents who hired with their cash grants and had paid assistance during a recent two-week period.

TABLE 9 EQUIPMENT AND MODIFICATIONS BY CASH RECIPIENTS (Percentages)

| Activity | Performed Activity | Used Cash Grant to Perform Activity |
|--|--------------------|--|
| Obtained/Repaired Equipment ^a (F7, F8, F9, G23, and G29) | 44.7 | 11.9 |
| Modified Home (F4 and G11) | 17.0 | 6.7 |
| Modified Vehicle (F5 and G17) | 0.7 | 0.0 |
| Number of Respondents ^b | 135 | 135 |

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

^bIncludes respondents who said they received cash grants. Sample sizes vary slightly from measure to measure because of item nonresponse.

| | | A, | Age | Preenrollme | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Activity | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Obtained/Repaired Equipment (F7, F8, F9) | 44.7 | 43.7 | 45.3 | 47.4 | 37.5 |
| Modified Home (F4) | 17.0 | 23.9 | 9.4 | 17.9 | 15.0 |
| Modified Vehicle (F5) | 0.7 | 1.6 | 0.0 | 1.1 | 0.0 |
| Number of Respondents ^a | 135 | 71 | 64 | 95 | 40 |

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

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

^aIncludes respondents who said they received cash grants. Sample sizes vary slightly from measure to measure because of item nonresponse.

PAS = personal assistance services.

TABLE 10

EQUIPMENT AND MODIFICATIONS BY CASH RECIPIENTS,

BY AGE AND PAS USE (Percentages)

18

| | | Age | ge | Preenrollme | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Received Special Transportation Services (H7) | 39.3 | 35.2 | 43.8 | 34.7 | 50.0 |
| Attended Social or Recreational Programs (H5) | 12.6 | 12.7 | 12.5 | 13.7 | 10.0 |
| Attended Adult Day Care (H4) | 9.6 | 11.3 | 7.8 | 11.6 | 5.0 |
| Received Home-Delivered Meals (H6) | 8.2 | 8.5 | 7.8 | 8.4 | 7.5 |
| Number of Respondents ^a | 135 | 71 | 64 | 95 | 40 |

USE OF COMMUNITY SERVICES BY CASH RECIPIENTS, BY AGE AND PAS USE (Percentages)

TABLE 11

PAS = personal assistance services.

^aIncludes respondents who said they received cash grants.

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

parentheses.

Note:

cash recipients attended social or recreational programs (13 percent), attended adult day care (10 percent), or received home-delivered meals (8 percent).

F. HIRING CAREGIVERS AND PERFORMING OTHER RESPONSIBILITIES

1. Hiring Caregivers

In addition to asking clients about the types of help they received from paid caregivers (described in the preceding section), we asked about recruiting, hiring, and training the caregivers they hired, or tried to hire, with their cash grants. We found that, as of the nine-month interview, 40 percent of all clients (including disenrollees) had hired caregivers, a full 32 percent tried to hire caregivers but failed, and the remaining 29 percent had not tried to hire anyone (Table 12). Of the 93 clients who hired, 65 percent had done so by the time of their six-month interview (not shown).⁸ Among those still enrolled at the time of the nine-month interview, 46 percent hired, 32 percent tried but failed, and 21 percent had not tried (Table 12).

Of 165 clients who tried to hire caregivers by the time of the nine-month interview and answered questions about that experience, 70 percent tried to hire a family member; 42 percent tried to hire a friend, neighbor, or church member; 36 percent asked friends or family to recommend a caregiver; and 32 percent tried to hire an agency worker (Table 13).⁹ Elderly clients were more likely to try to hire family members, whereas younger clients were more likely to try to hire family members.

⁸Ninety-three clients had ever hired caregivers with their cash grants. Our previous references to 87 clients who hired with their grants pertain to a subset of clients who hired with their grants *and* received paid care during a recent two-week period.

⁹The percentages sum to more than 100 percent because we asked clients to identify all the recruiting methods they attempted.

| | To | Total | Enrolled (+ | Enrolled (A2 and A1a) | Disenrolle | Disenrolled/Deceased |
|---|--------|---------|-------------|-----------------------|------------|----------------------|
| Hiring Status | Number | Percent | Number | Percent | Number | Percent |
| Hired Caregiver (C2 and J3) | 93 | 39.6 | 85 | 46.4 | × | 15.4 |
| Did Not Hire Caregiver (D2 and J4) Tried to hire | 75 | 31.9 | 59 | 32.2 | 16 | 30.8 |
| Did not try | 67 | 28.5 | 39 | 21.3 | 28 | 53.8 |
| Number of Respondents ^a | 235 | 100.0 | 183 | 100.0 | 52 | 100.0 |

^aIncludes respondents who answered questions about hiring and attempting to hire.

21

TABLE 12

CAREGIVER HIRING STATUS, BY ENROLLMENT STATUS AS OF THE NINE-MONTH INTERVIEW, BY AGE AND PAS USE

| | | A | Age | Preenrollme | Preenrollment PAS Use |
|---|----------------|--------------|--------------|---------------------------|----------------------------|
| Recruiting Method | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Tried to Hire (D5 and J6) | | | | | |
| ramuy memoer Trijord anijekkon on skursk monskon | د.0/ ۱ | 7.01 | 00.2 2 01 | 00.7 | 7.61 |
| Friehd, heighdor, or church menuer Home care agency worker | 42.4 32.1 | 20.0 21.8 | 40.5 41.4 | 41.9 30.8 | 45.0 35.4 |
| Asked Family or Friend to Recommend Caregiver (D5A and J6A) | 35.8 | 28.2 | 42.5 | 37.6 | 31.3 |
| Posted/Consulted Advertisement (D5B and J6B) | 6.7 | 6.4 | 6.9 | 6.8 | 6.3 |
| Contacted an Employment Agency (D5C and J6C) | 5.5 | 6.4 | 4.6 | 5.1 | 6.3 |
| Number of Respondents ^a | 165 | 78 | 87 | 117 | 48 |

(D5, D5A, D5B, and D5C are from the six-month interview).

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

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

PAS = personal assistance services.

TABLE 13

Most clients who succeeded in hiring (63 percent) hired family members (Table 14). Substantial minorities hired friends, neighbors or church members (20 percent) and former agency workers (16 percent). Elderly clients were more likely than their younger counterparts to hire family members, whereas younger clients were more likely to hire caregivers recommended by others. Compared with new PAS users, continuing users were more likely to hire friends, neighbors, or church members. Relatively few clients hired or tried to hire people other than their own acquaintances, such as by contacting an employment agency or posting advertisements.

2. Performing Other Employer Responsibilities

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 cash-management 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 once they have had some experience recruiting and being cared for by the people they hired. In this early cohort, 30 percent of clients received a consultant's help in revising their original cash-management plans (Table 15). Of the 117 clients who hired or tried to hire with their grants since their six-month interview, or who hired before the six-month interview but not since, 35 percent changed the wages, hours, or types of work with which they wanted help. Of the clients who used the cash grants to hire (excluding those who died or disenrolled before the six-month interview), nine clients (11 percent) were providing their paid caregivers with fringe benefits, such as paid sick days, as of the nine-month interview (not shown). Three of the nine clients had added new benefits that they had not been providing at the time of the six-month interview. Only two clients said they received peer support between interviews (three clients had received such help by the time of the six-month interview) (not shown).

| | | Age | ē | Preenrollm | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Hired (D7 and J6E) | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Family Member | 63.4 | 71.7 | 55.3 | 62.7 | 65.4 |
| Friend, Neighbor, or Church Member | 20.4 | 15.2 | 25.5 | 25.4 | Τ.Τ |
| Former Home Care Agency Worker | 16.1 | 15.2 | 17.0 | 13.4 | 23.1 |
| Caregiver Recommended by Family or Friend | 11.8 | 4.4 | 19.2 | 13.4 | Τ.Τ |
| By Posting/Consulting Advertisement | 6.5 | 8.7 | 4.3 | 7.5 | 3.9 |
| By Contacting an Employment Agency | 1.1 | 2.2 | 0.0 | 0.0 | 3.9 |
| Number of Respondents ^a | 93 | 46 | 47 | 67 | 26 |

RECRUITING METHODS RESULTING IN HIRES AS OF THE NINE-MONTH INTERVIEW, BY AGE AND PAS USE

TABLE 14

Mathematica Policy Kesearcn, Inc. s (D7 is from the six-month interview).

Columns sum to more than 100 percent because some respondents hired more than one caregiver. Note: ^aIncludes respondents, including those who died or disenrolled, who ever used their cash grants to hire a caregiver.

| | | Age | G | Preenrollme | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Consultant Helped Client Revise Plan (J1) ^a | 29.1 | 27.3 | 31.2 | 28.5 | 30.5 |
| Changed Wages, Hours, or Type of Work (J16, J17, and J18) ^b | 35.0 | 32.8 | 37.3 | 35.9 | 33.3 |
| Overall Respondents ^a | 203 | 110 | 93 | 144 | 59 |
| Clients Who Hired or Tried to Hire ^b | 117 | 58 | 59 | 78 | 39 |

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

^aIncludes respondents who answered a question about revising their cash-management plan and who had not died or disenrolled before the sixmonth interview. ^bIncludes respondents who hired or tried to hire between the six- and nine-month interviews, or who hired before the six-month interview but not after, and who had not died or disenrolled before the six-month interview.

G. SATISFACTION WITH CARE AND UNMET NEEDS

Clients in this early cohort were largely satisfied with their lives and personal care. Eighty-five percent, including disenrollees, expressed overall satisfaction with their personal care (Table 16). Moreover, 64 percent of this group stated that they were very satisfied (as opposed to somewhat satisfied) with their care (not shown). Nearly all clients who used their cash grants to hire (99 percent) were satisfied with their relationship with their caregiver. All (or nearly all) clients who used their grants to pay for assistance with personal care, routine health care, or household activities were satisfied with the way their caregiver provided this assistance. Moreover, for each type of help, about 90 percent of satisfied clients were "very satisfied" with that aspect of their care (not shown). Three-quarters of clients who used their grants to hire reported that their paid caregivers always or almost always completed their tasks. Half of those who hired said it would be difficult to change their caregiver's schedule if needed, but 94 percent were satisfied with the times of day they received help.

Although 76 percent of clients who hired caregivers with their cash grants said they were satisfied with their lives, substantial proportions said they were not receiving as much help as they needed when asked about specific activities (Table 17). Between 35 and 40 percent of these clients had unmet needs in transportation, medication and routine health care, personal care, or household activities. These percentages were notably higher for new PAS users than they were for those who had used PAS longer. Large proportions of clients who hired caregivers with their cash grants reported that health problems or lack of assistance limited their pursuit of paid work (93 percent), education (89 percent), or recreational, social, or religious activities (80 percent).

H. SATISFACTION WITH THE PERSONAL PREFERENCE PROGRAM

Clients found much to commend about the Personal Preference program. Eighty-six percent of clients (including disenrollees) said they would recommend the program to someone wanting

| | | Age | e | Preenrollment PAS Use | at PAS Use |
|---|------------------|----------------------|-----------------------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months Or Longer | Fewer than Three Months |
| Satisfied with Overall Care Arrangements (E14) Help with Transportation (E16) ^a | 84.6 82.5 | 88.6 83.3 | 80.2 81.7 | 87.8 81.4 | 77.4 85.0 |
| Among Those Who Hired with the Cash Grant Relationship with Caregiver Is Satisfying (E28) Satisfied with How Caregiver ^a | 98.5 | 100.0 | 97.4 | 97.9 | 100.0 |
| Helps with personal care duties (E22) Helps with medication and routine health care (F26) | 100.0 | 100.0 | 100.0 | 100.0 | 100.0 |
| Helps with household or community duties (E24) Paid Careoiver(s) Complete(s) Tasks (F31) | 98.5 | 100.0 | 97.4 | 97.9 | 100.0 |
| Always or almost always | 76.1 | 74.2 | 77.5 | 78.0 | 71.4 |
| Usually or sometimes | 15.5 | 16.1 | 15.0 | 14.0 | 19.1 |
| Rarely | 8.5 | 9.7 | 7.5 | 8.0 | 9.5 |
| Satisfied with Times of Day They Receive Help (E20) Changing Caregiver's Schedule Would Be Difficult (E20b) | 94.1 48.5 | 93.3 44.5 | 94.7 51.4 | 91.7 40.4 | 100.0 68.4 |
| Overall Respondents ^b | 201 | 105 | 96 | 139 | 62 |
| Clients Who Hired with the Cash Grant ^c | 71 | 31 | 40 | 50 | 21 |
| Source: Mathematica Policy Research, Inc.'s Nine-Month Cash and Counseling Evaluation Interview. Question numbers are in parentheses. | and Counseling] | Evaluation Interview | . Question number | s are in parentheses. | |
| Note: Questions used in the lower panel of this table refer to a two-week period within the two months before the interview. | two-week period | d within the two mor | aths before the inter | view. | |
| ^a Excludes clients who did not need the service in question during the two-week period | he two-week peri | iod. | | | |

SATISFACTION WITH CARE, BY AGE AND PAS USE (Percentages)

TABLE 16

PAS = personal assistance services.

^cIncludes respondents who hired with their cash grants and had paid assistance during a recent two-week period. We did not ask proxy respondents who also were paid caregivers to asses the client's satisfaction with their personal care because these respondents have a vested interest in the outcomes. Sample sizes

vary (from 58 to 71) from measure to measure because questions were asked only of clients who met certain criteria.

^bIncludes respondents who answered questions about satisfaction but excludes proxy respondents who also were paid caregivers.

| | | A | Age | Preenrollme | Preenrollment PAS Use |
|--|----------------|-------------|----------|---------------------------|----------------------------|
| Characteristic | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Satisfied with Life (E13) | 76.1 | 80.0 | 73.0 | 76.6 | 75.0 |
| Needs Help but Not Getting It or Needs More Help with | | | | | |
| Meals and housework (E40) | 40.5 | 36.4 | 43.9 | 36.5 | 50.0 |
| Personal care (E37) | 37.0 | 31.3 | 41.5 | 31.4 | 50.0 |
| Medication and routine health care (E42) | 36.5 | 39.4 | 34.1 | 32.7 | 45.5 |
| Transportation (E41) | 35.1 | 30.3 | 39.0 | 34.6 | 36.4 |
| Health Problems or Lack of Assistance Limit | | | | | |
| Ability to do paid work (E49) ^{a, b} | 92.5 | 100.0 | 90.2 | 91.7 | 94.1 |
| Educational pursuits (E48) ^{a, b} | 88.7 | 91.7 | 87.8 | 88.9 | 88.2 |
| Recreational, cultural, social, or religious | | | | | |
| activities (E46) ^a | 79.7 | 82.4 | 77.5 | 83.0 | 71.4 |
| Number of Respondents ^c | 93 | 46 | 47 | 67 | 26 |

QUALITY OF LIFE AND UNMET NEEDS AMONG CLIENTS WHO HIRED CAREGIVERS WITH THEIR CASH GRANTS, BY AGE AND PAS USE

TABLE 17

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

^aExcludes respondents who were not interested in pursuing the activity.

^bThis question was not asked of clients aged 75 or older.

^cIncludes respondents who used their cash grants to hire a caregiver but excludes proxy respondents who also were paid caregivers. Sample sizes vary from measure to measure because some questions were only asked of clients who met certain criteria.

more control over their personal care (Table 18). More notably, 97 percent of clients who used their cash grants to hire would recommend the program (compared with 78 percent of those who did not hire; not shown). Overall, 76 percent of cash recipients reported that the monthly cash grant had improved their lives, and 70 percent of those reported a great deal of improvement. About one-fifth of cash recipients stated that the cash grants had no effect on the quality of their lives, and only 2 cash recipients in 126 said the quality of their lives diminished as a result of the grants.

Clients who reported that the cash grants improved their lives were asked to the state the most important way it did so. (Several clients cited more than one way.) More than half reported that the ability to choose one's own caregivers was the most important improvement (Table 19). About one-fifth of the clients cited the ability to obtain enough care or care at the right time, and about one-seventh cited the ability to obtain the right types of personal care or other services. Nine clients said being able to buy personal care supplies or food had been the most important improvement. In addition, 10 clients believed the cash grants were most important in giving them a feeling of control over their care or in enabling them to worry less about having unmet needs.

I. CONCLUSION

This analysis of the experiences of an early cohort of clients suggests that New Jersey's Personal Preference program works well for many clients, although some have less positive experiences. In particular, delays in clients' receipt of their monthly cash grants prevented many clients from actively participating in the program nine months after random assignment. Only 65 percent of the clients still enrolled at that time (76 percent of the cohort) had begun receiving their monthly cash grants. As Personal Preference matures, however, this percentage may increase.

29

| ∞ | |
|----------|--|
| | |
| Ц | |
| | |
| AB | |
| LA | |
| Г | |

SATISFACTION WITH PERSONAL PREFERENCE, BY AGE AND PAS USE (Percentages)

| | | Age | çe | Preenrollme | Preenrollment PAS Use |
|--|----------------|--------------|--------------|---------------------------|----------------------------|
| Question | All Clients | 65 or Older | 18 to 64 | Three Months or Longer | Fewer than Three Months |
| Would Recommend Program (J34) | 86.1 | 85.7 | 86.5 | 89.2 | 79.4 |
| Effect of the Cash Grants on Quality of Life (J35) | | | | | |
| Improved Staving the come | 76.2 22.2 | 78.1 21.0 | 74.2 27.6 | 74.4 2 / / | 80.6 16.7 |
| Reduced | 1.6 | 0.0 | 3.2 | 1.1 | 2.8 |
| How Much Quality of Life Was Improved (J36) | | | | | |
| A great deal | 70.1 | 76.0 | 63.8 | 70.2 | 70.0 |
| Somewhat | 29.9 | 24.0 | 36.2 | 29.9 | 30.0 |
| Overall Respondents ^a | 216 | 112 | 104 | 148 | 68 |
| Clients Who Received Cash ^b | 126 | 64 | 62 | 90 | 36 |

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

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

^bIncludes cash recipients who answered a question about the effect of the cash on their quality of life.

MOST IMPORTANT WAYS CASH GRANTS IMPROVED LIFE

| Improvement (J37) | Number Citing Improvement |
|---|------------------------------|
| Improvements Pertaining to Caregivers | |
| Benefit Enables Client to | |
| Choose caregivers | 50 |
| Obtain enough care or care at the right time | 21 |
| Obtain the right types of personal assistance or other services | 14 |
| Compensate caregivers or enable them to leave other jobs | 5 |
| Have tasks performed to their specifications | 3 |
| Nonspecific reasons pertaining to caregivers | 1 |
| Improvements Pertaining to Supplies | |
| Benefit Enables Clients to Buy | |
| Personal items related to personal care and health | 2 |
| Food or nutritional supplements | 2 |
| Unspecified items related to personal assistance needs | 5 |
| Attitudinal Improvements | |
| Client Feels More Independent or in Control of Care | 5 |
| Client Worries Less/Is Generally Happier | 5 |
| Financial Improvements | J |
| r muneau improvements | |
| Client Is More Financially Secure | 1 |
| Number of Respondents ^a | 96 |

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 was completed. Although asked to provide the most important reason, some respondents gave more than one; all are represented here.

^aIncludes respondents who reported that their cash grants had improved their quality of life.

In the meantime, most of the early clients who received cash were satisfied with the program and the help that the program enabled them to pay for. Seventy percent of cash recipients reported that the monthly cash grants had improved their lives. Cash recipients used their grants to purchase a range of personal care services (mostly from family members) and, to a lesser extent, to purchase equipment and modifications related to their need for personal care. Clients who used their cash grants to hire caregivers were highly satisfied with their personal care and with the Personal Preference program itself. Ninety-nine percent had satisfying relationships with their caregivers, and many were "very satisfied" with specific aspects of the care they received. Finally, 97 percent of clients who hired with their grants would recommend the Personal Preference program to other people seeking more control over their personal care.

As noted, our final analysis of data from the New Jersey nine-month interviews will be based on the responses of both clients who enrolled in Personal Preference later and this early cohort. In addition, it will compare the experiences of randomly assigned treatment and group control group members to examine how individuals receiving the monthly grants and other Personal Preference benefits fared relative to those receiving PAS through the traditional Medicaid program.