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**Consumer and Consultant
Experiences in the New
Jersey Personal
Preference Program**

Final Report

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EXECUTIVE SUMMARY

Introduction

Consumer Direction of Medicaid Supportive Services. Roughly 1.4 million people with disabilities receive Medicaid-funded, noninstitutional supportive services each year. Home care agencies provide many of these services: under professional supervision, agency workers help beneficiaries with bathing, meal preparation, light housework, and other basic activities. “Consumer-directed care,” in which Medicaid beneficiaries hire, train, supervise, and pay workers of their choice, is an alternative to the professional service model. Consumer direction increases beneficiaries’ autonomy and control, but it also increases their responsibilities.

Cash and Counseling is a model of consumer-directed care that offers eligible Medicaid beneficiaries the opportunity to receive a monthly allowance to hire workers, including family members, and purchase other disability-related services and goods. Adult consumers can designate a representative, such as a family member or friend, to help them manage their care. Cash and Counseling also offers counseling and fiscal services to consumers and representatives. New Jersey, along with Arkansas and Florida, has tested the Cash and Counseling model as part of a three-state demonstration. Mathematica Policy Research, Inc. (MPR) is the demonstration evaluator.

In New Jersey, the demonstration was open to adult Medicaid beneficiaries who were (1) using state plan personal care assistance (PCA) or had been assessed as eligible for it, (2) not also participating in home- and community-based waiver programs or a state-funded consumer-directed program, and (3) expected to require PCA for at least six months. The evaluation randomly assigned demonstration enrollees to participate in New Jersey’s Personal Preference program (the treatment group) or to use PCA as usual (the control group).

Goals of This Report. This report describes the implementation of Personal Preference by synthesizing information from in-person discussions with program staff, a mail survey of program consultants, telephone interviews with consumers in the treatment group, and program records. It discusses the program’s goals and features, the ways consumers managed their program responsibilities and took advantage of increased flexibility, and the degree to which consumers were satisfied with the program. (Other reports from the evaluation estimate the program’s impacts on consumers, their caregivers, and public costs; describe the types of beneficiaries and workers that chose to participate in the demonstrations; and explain demonstration implementation and program operations in greater detail.)

The Personal Preference Intervention. The Personal Preference allowance was based on the value of beneficiaries’ Medicaid PCA plans. At enrollment, consumers were eligible for monthly allowances of \$1,062, on average. To receive the allowance, consumers or their representatives had to develop a written cash management plan that met the approval of the Personal Preference program. Consultants helped consumers develop their plans and monitored consumers’ well-being. They were also available to advise consumers about recruiting workers and accessing community services. The fiscal agent was available to write checks for goods and

services purchased with the allowance and to process payroll taxes and employment forms for consumers who hired workers. The program did not charge consumers directly for consulting services, but consumers did pay for some of the fiscal services they used. (The program paid for others.)

Major Findings

Industry Support. Personal Preference garnered the cooperation of personal care agencies, which it relied upon to identify prospective demonstration enrollees and the hours of care planned for them. The industry viewed consumer direction as inevitable and even beneficial for some people with disabilities. Moreover, the program director responded to industry concerns by, for example, discouraging consumers from hiring workers away from agencies.

Outreach and Enrollment. New Jersey initially planned to recruit 2,000 beneficiaries into its demonstration in 12 months, but it actually recruited 1,755 beneficiaries in 32 months (November 1999 to July 2002). To boost enrollment midway through the demonstration, Personal Preference made two major changes to its approach to outreach and enrollment. It originally delegated outreach and enrollment activities to a private, for-profit firm with which the state had an existing Medicaid contract. The enrollment contractor was to invite eligible beneficiaries to join the demonstration when they were assessed or semiannually reassessed for PCA. When enrollment rates consistently fell short of expectations and costs consistently exceeded them, the program hired state employees to conduct outreach and enrollment activities. It also separated the timing of enrollment from that of assessment.

Enrollment did not increase much after these changes, but the changes demonstrate the pros and cons of alternative approaches. The key advantage of having an existing contractor conduct outreach and enrollment was expediency—it took less start-up time than beginning contract procurement anew or recruiting and hiring new state employees. The advantage of linking outreach with PCA assessments was that the care plans developed from beneficiaries' assessments provided an up-to-date basis for calculating the allowances consumers would receive under Personal Preference. Conversely, the key advantage of hiring state employees was that program staff had more control over outreach procedures and could experiment with them. As long as enrollment rates lagged, the key advantage of separating outreach from assessment was that it enlarged the pool of potential enrollees that outreach workers could pursue at any time.

Consumer Characteristics. Despite its difficulties, New Jersey eventually recruited a fairly diverse population for its demonstration. The evaluation randomly assigned 871 beneficiaries to the treatment group—404 nonelderly adults and 467 elderly ones. Slightly more than half of these consumers were white, and slightly more than one-third were Hispanic. About 4 in 10 consumers had graduated from high school.

Planning for, and Using, the Allowance. Six months after being assigned to Personal Preference, slightly more than half of all consumers had received the program allowance, and nearly one-quarter were still enrolled but had not received it. (Three percent of consumers were deceased at this time, and the other fifth had disenrolled from the program.) Getting started on

the allowance was subject to many procedural delays. The program eventually reduced three sources of delay by (1) assigning consumers to consulting agencies instead of offering them a choice of agencies; (2) consolidating caseloads across a smaller number of agencies; and (3) cutting, from 30 to 14 days, the notice it gave to personal care agencies to discontinue services to beneficiaries assigned to Personal Preference. Still, because of the number of people involved in the development, review, and approval of cash management plans, getting started on the allowance took a long time. Consumers and representatives, consultants, program staff, and fiscal agent staff all played roles.

Consumers who received the Personal Preference allowance took advantage of the opportunity to use it flexibly. Among those who were receiving the allowance at the time of the nine-month follow-up interview, 80 percent said they used the allowance to hire one or more workers. Nearly 75 percent of these consumers hired family members, and about 40 percent hired friends or neighbors. Most workers helped consumers with household and community tasks, personal care, and routine health care, and many provided assistance with transportation.

According to program records, consumers used about 80 percent of their monthly allowance to pay workers. Roughly 5 in 10 consumers received up to 10 percent of the allowance as cash for incidental purchases, of types specified in their cash management plans. Slightly fewer than 1 in 10 consumers used the allowance to buy assistive equipment during the month observed for this analysis.

Recruiting Workers. Recruiting workers was difficult for some consumers. One-quarter of all consumers said they tried to hire but could not. Nearly 30 percent of those who did hire said it was difficult, often because of a lack of interested or qualified candidates. Some consultants said they were uncertain about how much recruiting assistance the program expected them to provide to consumers, especially those who did not have a family member they wished to hire.

Consulting and Fiscal Services. Consultants reported that their most time-consuming Personal Preference duties were helping consumers develop cash management plans, performing administrative tasks, and advising consumers about payroll-related activities. Consultants believed their services were of value to consumers, and most consumers confirmed that consultants provided useful help.

All allowance recipients used the program's fiscal services—availability of these services seemed to be an important part of consumers' successful management of their fiscal responsibilities. Moreover, the program relied on the fiscal agent to prevent misuse of the allowance by double-checking the accuracy of consumers' cash management plans and verifying that check requests matched those plans.

Consumer Satisfaction. Nine months after being assigned to the Personal Preference program, 91 percent of consumers said they would "recommend the program to others who wanted more control over their personal care services." Among consumers who received the allowance, 82 percent said it had improved their life greatly or somewhat. Consumers who used their allowance to pay workers were uniformly satisfied with how workers performed their tasks

and with their relationships with workers. Elderly and nonelderly consumers were equally satisfied with most aspects of paid workers' reliability, promptness, and disposition.

Disenrollment. Despite high levels of satisfaction, 22 percent of consumers chose to leave the Personal Preference program within a year of enrolling. Although there was no single overriding reason for voluntary disenrollment, consumers most commonly said they disenrolled because they believed it was or would be difficult to assume the responsibilities of an employer (34 percent) or changed their minds and were satisfied with their usual PCA services (30 percent). In addition, some consultants reported that some consumers enrolled in the program without fully understanding consumer direction, then disenrolled after they learned more about it. Nearly three-quarters of consumers who disenrolled or died did so without having received the program allowance.

Experiences of Different Types of Consumers. Multivariate models used to assess the experiences of different types of treatment group consumers suggested that, all else being equal, consumers who considered it very important, at baseline, to be able to pay family or friends for caregiving were more likely than other consumers to receive the monthly allowance and stay in the program. Treatment group consumers who lived alone were less likely than others to receive the monthly allowance and stay in the program. Hispanic treatment group consumers were less likely than non-Hispanic ones to receive the allowance and stay in the program, and black consumers were less likely than white consumers to receive the allowance. Among consumers who hired or tried to hire workers, those who were elderly were less likely than those who were not to say hiring was difficult. Age was not otherwise associated with program experiences.

Policy Implications

Some policymakers have concerns about consumer direction of public funds. These include (1) whether consumer direction should be available to all users of supportive services, (2) whether to allow family members to be paid for caregiving, (3) how to ensure consumer safety, (4) how to prevent the exploitation of workers, and (5) how to prevent the misuse of public funds. Personal Preference procedures addressed each of these concerns to some extent.

Assessing Suitability for Consumer Direction. New Jersey's policy was to *not* screen prospective enrollees on their suitability for consumer direction. Rather, the policy was to inform them of their responsibilities and rights under the program and let them decide whether to enroll and whether to select a representative. Consumers received PCA services as usual until they began receiving their program allowance, and they could disenroll from Personal Preference at any time and revert to usual services. Thus, Medicaid beneficiaries could try consumer direction without incurring great risk. A multivariate analysis suggested that New Jersey's decision to open the demonstration to all groups—including elderly adults, consumers with cognitive impairment, and those in need of large amounts of PCA—was sound.

Paying Family Members. While policymakers debate using public funds to pay family members, New Jersey allowed Personal Preference consumers to hire family members, including legally responsible spouses. The option to hire relatives probably was critical to the functioning of the program. Nearly three-quarters of consumers who hired workers hired family members

(although only two percent hired a spouse). Although some consumers (27 percent) hired workers who were not family members, the proportion that did so successfully was considerably smaller than the proportion that tried.

Ensuring Consumer Safety. There was no evidence from consumers, consultants, or program staff that participation in Personal Preference led to any adverse effects on consumers' health and safety. Personal Preference monitored consumer safety and care quality primarily through consultants' contacts with consumers and representatives, which occurred by telephone and in consumers' homes. Moreover, while there was very little evidence or suspicion of consumer neglect or exploitation in Personal Preference, procedures existed for consultants and program staff to follow up if anything seemed amiss.

Preventing the Exploitation of Workers. Although Personal Preference workers had no formal mechanism to report grievances, worker abuse did not emerge as a serious problem in the program. More than half the consumers who used the allowance to pay workers, including family members, signed work agreements with them. Few Personal Preference consumers provided fringe benefits to their workers. Nearly all the workers were part-time, however, and part-time work rarely includes fringe benefits.

Preventing the Misuse of Public Funds. Misuse of the allowance was not a serious problem under Personal Preference, probably because the program took the potential for such a problem seriously. Appropriate use of the allowance was ensured primarily through program approval of the cash management plan and fiscal agent review to verify that expenditures were included in the plan.

Conclusion

The Cash and Counseling model proved administratively feasible and politically tenable in New Jersey during the evaluation period. Data from discussions with program staff, consultant questionnaires, and consumer surveys show that many consumers, who participated in Personal Preference voluntarily, ably managed their supportive services and found it rewarding to do so. In terms of retention and satisfaction, the program seemed equally attractive to elderly and nonelderly adults. New Jersey plans to continue offering Personal Preference as an option to eligible Medicaid beneficiaries.

INTRODUCTION

Consumer Direction of Medicaid Supportive Services

Each year in the United States, about 1.4 million people with disabilities receive Medicaid supportive services benefits that help them live at home or in other community settings, instead of in institutions (Harrington and Kitchener 2003). Whether states offer such benefits as state plan personal care services (PCS) or home- and community-based services (HCBS), they cover them in limited amounts and select the providers or vendors who can supply them. Often, case managers decide which benefits beneficiaries need, and nurses supervise home care workers. This system of service delivery has been criticized for over-medicalizing supportive services and for being too inflexible to effectively meet individual needs. Moreover, home care workers are in perennially short supply. Supply shortages worsen when the economy is strong, and they will likely deepen as the U.S. population ages and demands more supportive services.

As an alternative to traditional models of service delivery, states are increasingly offering Medicaid beneficiaries and their families opportunities to obtain supportive services directly from individual providers (O'Brien and Elias 2004; Velgouse and Dize 2000). This alternative has become known as "consumer-directed care," because beneficiaries who use individual providers assume the employer's role of hiring, managing, and (possibly) terminating their paid caregivers (Eustis 2000). Consumer-directed care is based on the premise that, because supportive services are "low tech" and nonmedical, they do not require the intervention of medical professionals. Rather, beneficiaries should be empowered to direct their own benefits as service consumers (Benjamin 2001; Stone 2001; Eustis 2000; Doty et al. 1996). In 1999, an estimated 139 publicly funded consumer-directed programs served adults or children with physical or developmental disabilities in the United States (Flanagan 2001).

From the perspective of many people affected by disabilities, consumer direction has the potential to meet individual needs better than traditional PCS or HCBS and to promote autonomy and independence. These two basic American values have been affirmed in recent years through policies such as President George W. Bush's New Freedom Initiative. Consumer direction also could help address the shortage of home care workers by allowing people to pay family and friends for caregiving, thereby expanding the pool of potential workers. Finally, consumer direction could lower public costs by eliminating home care agency involvement in hiring, training, and supervising workers (Stone 2000; Eustis 2000).

Publicly funded consumer-directed programs also raise concerns. These include (1) whether consumer direction should be available to all users of supportive services, (2) whether to allow family members to be paid for caregiving, (3) how to ensure consumer safety, (4) how to prevent the exploitation of workers, and (5) how to prevent the misuse of public funds (Benjamin 2001; Feinberg and Whitlach 2001; Kane and Kane 2001; Kapp 2000; Simon-Rusinowitz et al. forthcoming; Simon-Rusinowitz et al. 2000; Tilly et al. 2000; Doty et al. 1996).

The Cash and Counseling Model

Cash and Counseling, which is a fairly expansive model of consumer-directed care, provides a flexible monthly allowance that consumers may use to hire workers, as well as to purchase other services and goods they may need (within state guidelines). Adult consumers can designate a representative, such as a relative or friend, to manage, or help them manage, their care. Parents manage the care of consumers younger than 18. In addition, Cash and Counseling offers counseling and fiscal services to help consumers and representatives handle their program responsibilities. These tenets of Cash and Counseling—a flexible allowance, use of representatives, and availability of counseling and fiscal services—are meant to make consumer direction adaptable to consumers of all ages and abilities.

Arkansas, Florida, and New Jersey have each tested the Cash and Counseling model in their Medicaid systems as part of a three-state demonstration. The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services funded the demonstration. The Centers for Medicare & Medicaid Services (CMS) approved the demonstration under Section 1115 authority of the Social Security Act. The National Program Office for the evaluation, at Boston College and the University of Maryland, provided technical assistance to the states and oversaw the evaluation. Mathematica Policy Research, Inc. (MPR) is the demonstration evaluator.

The Cash and Counseling Evaluation

The evaluation addresses four broad questions: (1) Who participated in the Cash and Counseling demonstration? (2) How were the demonstration programs implemented? (3) How did the programs affect consumers and their caregivers? and (4) How did the programs affect public costs? To estimate the programs' effects on consumers, caregivers, and costs, the evaluation randomly assigned demonstration enrollees either to participate in Cash and Counseling (the treatment group) or to rely on PCS or HCBS as usual (the control group). With data from telephone interviews and Medicaid and Medicare claims, the evaluation compares the groups' outcomes at designated follow-up intervals. The evaluation also is describing eligible beneficiaries' reasons for agreeing or declining to participate in Cash and Counseling, and it is examining trends in the use of PCS and HCBS for indirect evidence that the demonstration affected the number of beneficiaries that used such services.

Guide to This Report

Research Questions. This report addresses the second broad evaluation question by describing the implementation of New Jersey's Cash and Counseling demonstration program,

Personal Preference. Unlike a companion report that describes demonstration design and program operations in greater detail (Phillips and Schneider 2003), this report focuses on program implementation as experienced by consumers and the program consultants who worked with them. The report considers:

- The major goals and features of Personal Preference
- The characteristics of treatment group consumers
- How consumers handled their responsibilities under the program
- How consumers used the program's flexibility
- Whether consumers were satisfied with the program and whether the program worked better for some types of consumers than for others
- The lessons that Personal Preference offers policymakers and program developers

Sources and Methods. This report draws on information and data from several sources:

- ***New Jersey Site Visit.*** Researchers held in-person discussions with New Jersey state officials, Personal Preference staff members, officials of organizations representing the personal care industry in New Jersey, and staff members of organizations providing enrollment, consulting, and fiscal services under Personal Preference. (New Jersey used the term “consulting,” instead of “counseling,” in its demonstration.) The discussions were conducted in April 2001, about 18 months after the demonstration began random assignment.
- ***Consultant Survey.*** Also about 18 months into the demonstration, MPR administered a mail survey to Personal Preference consultants. The survey questionnaire contained sections on consultants' background, program caseload, uses and perceived misuses (if any) of the program allowance by consumers or representatives, and consultant activities. It also contained sections on whether the consultant had seen evidence of abuse of consumers by workers or representatives, recommended changes to consulting activities, and consultants' overall assessment of the program. Most survey questions offered multiple-choice responses and asked consultants to circle all applicable responses or write in other responses. Questions eliciting consultants' recommendations and overall program assessment were open-ended. Questionnaires were sent to all 50 consultants who had active Personal Preference caseloads when the survey was administered, and 37 consultants returned them.
- ***Consumer Surveys.*** MPR conducted telephone interviews with consumers or knowledgeable proxy respondents immediately before consumers were randomly assigned to participate in Personal Preference, and six and nine months later. Each

survey instrument covered a range of topics (listed in Table 1). Interviews were completed by 871 treatment group respondents at baseline, 783 at six months, and 747 at nine months.¹ To obtain a complete picture of consumers' Personal Preference experiences, we conducted follow-up interviews even if consumers had disenrolled from the program, were not receiving the monthly allowance, or had died (in which case we interviewed a proxy respondent).

Even among living consumers the use of proxy respondents was fairly widespread. For example, proxies completed 40 percent of baseline interviews (28 percent of interviews for nonelderly adults and 50 percent for elderly adults). Proxy respondents were asked to assess the opinions of consumers. Thus, during follow-up interviews, questions eliciting opinions were not asked if consumers were unable to form opinions (for example, because of a cognitive impairment) or if proxies did not feel comfortable assessing the consumer's opinion. Questions about the consumer's satisfaction and unmet needs were not asked if the proxy respondent was also a paid caregiver, because the proxy may have been unable to answer objectively.

- **Program Records.** Personal Preference program records were available for the 871 consumers who were randomly assigned to participate in the program. The records included data on reasons for disenrollment and on receipt and use of the monthly allowance.

Survey and program data were analyzed primarily through an examination of frequency distributions, means, and cross-tabulations of constructed variables. Researchers also reviewed and coded open-ended responses to the consultant and consumer surveys. Logistic regression analysis was used to assess whether certain types of consumers fared better in the program (for example, by starting on the allowance and remaining in the program for at least a year). The regression models included a set of explanatory variables drawn from baseline interview and program records data.

¹This report focuses on the experiences of New Jersey treatment group members. Companion reports present estimates of program impacts based on comparisons of the treatment and control groups. (See the List of Companion Reports following the References.)

Table 1: Topics Covered in MPR Consumer Surveys

| Baseline Survey | Six-Month Follow-Up Survey | Nine-Month Follow-Up Survey |
|--|---|---|
| Household composition and living arrangements | Program participation and allowance receipt | Program participation and allowance receipt |
| Unpaid assistance | Allowance spending plan | Health and functioning |
| Paid assistance, unmet needs, and satisfaction | Use of the allowance | Living arrangements |
| Use of HCBS | Employer responsibilities | Unpaid assistance |
| Health and functioning | Reasons for disenrollment | Paid assistance |
| Attitudes about consumer direction | | Satisfaction with care and unmet needs |
| | | Equipment, supplies, and modifications |
| | | Use of allowance for equipment, supplies, and modifications |
| | | Receipt of community services and use of allowance |
| | | Use of allowance to hire workers |
| | | Allowance spending plan and employer responsibilities |
| | | Reasons for disenrollment |

HCBS = Home- and Community-Based Services

Presentation and a Limitation. The body of this report consists of a narrative text and tables of selected descriptive statistics. The report’s appendix also contains many statistical tables. Some of these statistics are discussed in the report. For example, to enlighten the debate about the suitability of elderly adults for consumer direction, many of the appendix tables present statistics by consumer age group (18 to 64, and 65 or older). In addition, measures of satisfaction and unmet needs are presented by whether consumers responded to evaluation surveys themselves or through proxy respondents.

The report covers a period beginning in early 1996, when New Jersey submitted its demonstration proposal, and ending in July 2003, a year after the last demonstration enrollees had been randomly assigned for the evaluation. Nonetheless, the report is limited in that we conducted site visit discussions at only one point (April 2001), although Personal Preference of course continued to evolve, learn from experience, and make improvements. The report notes

some programmatic changes that occurred after the site visit, but it was not possible to document them all.

KEY FEATURES OF CASH AND COUNSELING IN NEW JERSEY

Goals

In implementing a Cash and Counseling demonstration, New Jersey wished to test the feasibility of including a cash allowance model of consumer direction as an option for its state plan Medicaid Personal Care Assistance (PCA) program. From the outset, the state was particularly interested in learning whether consumers would use the allowance to purchase assistive equipment that the PCA program did not cover. As the demonstration unfolded, and a statewide shortage of personal care workers worsened, program staff also became interested in the potential of consumer direction to enlarge the supply of such workers. Although the state did not view savings as a goal of its demonstration, it did believe that Personal Preference might be more cost-effective than traditional PCA because it allowed consumers to purchase services in the free market. The federal government required that the demonstration be budget neutral.²

Target Population

Adult Medicaid beneficiaries were eligible to enroll in the demonstration if they (1) were using PCA or had been assessed as eligible for it, (2) were not also participating in HCBS waiver programs or a state-funded consumer-directed program, and (3) were expected to require PCA for at least six months. Recipients of both PCA and HCBS were excluded because authorization procedures differed for those services and consumers would have received assistance from Personal Preference consultants *and* HCBS case managers, which the program feared would

²In a budget-neutral demonstration, the average monthly costs of serving recipients of Personal Preference services would not exceed those of serving recipients of traditional PCA services. That is, costs per recipient per month would be equal for the two groups over the life of the five-year demonstration.

cause confusion. It decided to include only beneficiaries who were expected to require PCA for at least six months because consumers would need several months to develop and implement a plan for spending the Personal Preference allowance.³ Except for this criterion, New Jersey relied on potential enrollees to decide whether they wanted to take on the responsibilities of consumer direction. It continued consumers' usual PCA benefits until they developed and implemented their cash management plans, and it let them disenroll from Personal Preference at any time. Thus, the state ensured that Medicaid beneficiaries could try consumer direction without great risk.⁴

Stakeholders

Key government and private-sector stakeholders supported, or were actively involved in, the New Jersey demonstration. Within the state Department of Human Services (DHS), the Division of Medical Assistance and Health Services (DMAHS) prepared the demonstration proposal and applied for the required federal waivers. The Division of Disability Services (DDS) administered the Personal Preference program, and the executive director of DDS became the project director of Personal Preference. Although the New Jersey governor's office was not directly involved in the demonstration, both the cabinet-level commissioner of DHS and the DMAHS director strongly supported it. The state board responsible for New Jersey's Nurse Practice Act also viewed Personal Preference favorably. (The act limits the medical tasks personal care aides can perform, but the board did not believe the activities of workers hired by Personal Preference consumers should be similarly limited. Mindful of the shortage of personal

³Personal Preference relied on personal care agency nurses to assess whether PCA services would be required for at least six months.

⁴Going back to traditional PCA may not have been entirely seamless for consumers who disenrolled after receiving the monthly allowance, however. For example, if their former personal care aide had been assigned other cases in the interim, they might have to resume services with a different aide.

care aides in the state, the board supported the demonstration *because* it tapped a different labor supply than that available to agencies.)

The state formed an interdepartmental work group to handle certain implementation issues. For example, staff from DMAHS's Office of Information Services developed special software to track eligible beneficiaries, demonstration enrollees, and allowance recipients, and they worked with a contractor to identify allowance recipients on the state's Medicaid Management Information System. The staff of a state-funded consumer-directed personal care program shared their experiences with Personal Preference staff.

DDS also involved advocacy organizations and providers of HCBS in the design of Personal Preference. Abiding by the wishes of the Alzheimer's Association, the state allowed people with cognitive impairments to participate in the demonstration if family members, friends, or other representatives could help them. Otherwise, advocates for elderly people and nonelderly adults with disabilities had no major concerns about the Cash and Counseling model and supported the demonstration. The state's personal care agencies, on the other hand, saw both pros and cons to the experiment in consumer direction.⁵ In general, the personal care industry believed some beneficiaries, especially adults who could work if they had help, needed a more flexible personal care program and would benefit from the Cash and Counseling model. The industry also welcomed the prospect of referring to Personal Preference those beneficiaries who were perpetually dissatisfied with agency services. On the other hand, the industry was concerned that consumers could abuse the allowance, family members hired as workers would exploit their situation by not providing agreed-upon care, and workers would not be adequately trained. The

⁵When the demonstration began, about 250 state-licensed personal care agencies operated in New Jersey, providing personal care and private-duty nursing to Medicaid beneficiaries. Roughly 50 home health agencies served Medicare beneficiaries in the state, but the demonstration affected them very little.

industry's major concern, however, was that consumers might hire its agency aides and reduce the agency labor force. To allay this concern, Personal Preference adopted a policy of discouraging consumers from hiring agency aides, and it informed allowance recipients of this policy in writing. Finally, industry representatives who took part in site visit discussions said that, because they knew and respected the director of Personal Preference, they were more willing to cooperate with the demonstration than they might have been otherwise.

Outreach and Enrollment

To meet the needs of the demonstration evaluation, New Jersey set out to enroll 2,000 beneficiaries (half of whom would be randomly assigned to Personal Preference) into the demonstration in a year's time. In the previous year, the state had provided PCA to an estimated 12,000 beneficiaries, so the enrollment target represented about 17 percent of eligible beneficiaries. When it became clear that New Jersey could not meet this target, the target was lowered to 1,755, and the enrollment period was extended to 32 months (November 1999 to July 2002).

From the outset of the demonstration, the program conducted community- and beneficiary-level outreach activities. The director and assistant director of Personal Preference were responsible for community-level outreach. They made presentations to (1) advocacy organizations, because their constituents were potential demonstration enrollees; (2) PCA providers, because the state would rely on them to identify potential demonstration enrollees; and (3) human services agencies, because the state planned to recruit them to provide consulting services to Personal Preference consumers. Community outreach was largely successful—the program garnered support and cooperation from advocacy organizations, PCA providers, and human services agencies. At the beneficiary level, however, outreach and enrollment proved challenging enough that the program employed two distinct approaches to these tasks.

Initially, the program contracted with a private, for-profit firm to handle outreach and enrollment, believing that using a contractor would be administratively practical and good for consumers. The selected firm had conducted Medicaid enrollment activities in New Jersey under an existing contract, which was easily amended to encompass Personal Preference. Amending an existing contract was faster than procuring a new contract or recruiting and hiring new state employees. More important, the contractor employed a large, multilingual staff. Compared with the small number of new state employees the program would have been able to hire to conduct enrollment, the contractor seemed to have greater capacity to reach and communicate with the demonstration's geographically and ethnically diverse target population.

Initially, eligible beneficiaries were invited to enroll in the demonstration when they were assessed or reassessed for PCA. Timing the invitation in this way also seemed to have important advantages. First, the care plan developed from an assessment was needed to determine the amount of the Personal Preference allowance. If enrollment were timed to coincide with assessment, that care plan would remain in effect for about six months (barring a material change in the beneficiary's condition or circumstances). Second, enrollment at assessment would spread the volume of enrollment-related work over a longer time, making the workload manageable for enrollment staff.

Outreach and enrollment activities initially included the following steps. Whenever personal care agencies conducted assessments of new beneficiaries or reassessments of continuing ones, they completed consumer data forms and sent them to Personal Preference.⁶ To identify and contact prospective demonstration enrollees, Personal Preference program staff

⁶These forms included contact information for the beneficiary and a close relative, the number of personal care hours authorized on weekdays and weekends for the next six months, and the beneficiary's primary language, diagnoses, prognosis for requiring PCA for at least six months, agency nurse, and primary care physician.

verified beneficiaries' eligibility against Medicaid records, entered their data into an electronic database, and mailed eligible beneficiaries an introductory letter and flyer. These materials briefly described Personal Preference and said that someone would telephone the beneficiary to schedule a home visit. Program staff then forwarded the prospective enrollee's contact information to the enrollment contractor, who carried out the remaining activities.

At the enrollment contractor, staff members telephoned each new referral. Using a prepared script, the staff members asked if the beneficiary had received the introductory material, explained the demonstration, and tried to schedule a home visit. Staff scheduled visits when members of the beneficiary's family would be present, because beneficiaries often sought family members' advice about whether to participate in the demonstration and because family members might become representatives or paid workers under Personal Preference. During the home visit, enrollment field staff explained the program in detail and told beneficiaries what their monthly allowance would be if they were randomly assigned to the treatment group. Field staff also followed a prepared script, and some showed beneficiaries informational videotapes that had been made for the New Jersey demonstration. Depending on the beneficiary's participation decision or inclination, field staff either helped them complete enrollment consent forms or tried to schedule a follow-up visit.

Although the enrollment contractor followed agreed-upon procedures, it consistently failed to meet its target of 30 enrollees a week and consistently overspent its budget. Personal Preference took four steps to address these problems. It (1) asked the contractor to spend less time pursuing reluctant or hard-to-reach beneficiaries; (2) referred new prospects directly to the enrollment contractor, without first mailing introductory materials; (3) began to allow beneficiaries to enroll in the demonstration without a home visit if they did not want one and were already knowledgeable about the demonstration; and (4) separated enrollment from

assessment. In particular, it implemented the fourth step by encouraging personal care agencies to refer dissatisfied clients to Personal Preference at any time and by allowing the enrollment contractor to make presentations to groups of Medicaid beneficiaries without already knowing whether they were eligible for PCA.

These changes seemed to boost enrollment slightly, but temporarily. Midway through the demonstration, the director of Personal Preference took the major step of hiring state employees to assume outreach and enrollment responsibilities. In so doing, the program hoped to increase its control over outreach and enrollment, making it easier to try different approaches and to quickly discard those that failed.

Three state employees began work as full-time enrollment specialists in February 2001, after being trained by Personal Preference staff, the enrollment contractor, and a social marketing firm working under contract to the Cash and Counseling National Program Office.⁷ The enrollment specialists telephoned potential demonstration participants from the Personal Preference office one or two days a week. They spent the rest of the week making home visits and kept in touch with their supervisors by email. Six months after the state employees began work, however, they also had been unable to meet enrollment goals. They enrolled fewer than 50 beneficiaries a month, on average, far below the 70 needed to reach the revised evaluation target. (Appendix Table A.1 shows that half of all Personal Preference consumers enrolled during the first 14 months of the demonstration period; the other half enrolled during the last 18 months.)

Although demonstration enrollment was lower than expected, this may have been because expectations were too high, not because outreach fell short. Personal Preference enrolled about the same percentage of eligible PCA users as did the Arkansas demonstration program. Overall,

⁷The salaries of the enrollment specialists, whom Personal Preference would not expect to employ as part of an ongoing program, were paid with a grant from RWJF.

about eight percent of New Jersey's eligible Medicaid beneficiaries enrolled in the demonstration, representing six percent of eligible elderly beneficiaries and nine percent of eligible nonelderly beneficiaries (Foster et al. 2005). Although the program might have tried to boost enrollment in other ways (for example, in Arkansas, a letter from the governor seemed to attract beneficiaries), it is impossible to know how many more people might have enrolled if it had done so.

Organization of Consulting and Fiscal Services

As noted earlier, New Jersey recruited human services agencies to provide consulting services under Personal Preference. The program was mindful of needing to serve a culturally diverse population and wished to give consumers a choice of agencies from which to receive consulting services. Therefore, the program initially signed memoranda of agreement with 34 agencies throughout the state. These included county boards of social services, Independent Living Centers, adult day care centers, private case management agencies, and Area Agencies on Aging.

Within a few months, however, it became clear that most consumers did not want to choose an agency, and few had enough experience or information on which to base a choice. Thereafter, the program began assigning consumers to agencies based on geographic area and the capacity of agencies to serve consumers effectively. Eventually, the program was assigning consumers to one of 12 agencies (down from 34). Most of these agencies had one or two staff members serving as consultants in addition to performing other agency responsibilities. Personal Preference paid agencies a lump sum per consumer to complete a cash management plan (initially \$53, later \$75) and an hourly fee thereafter for consulting (initially \$18, later \$26). It limited these payments to 19 hours (later 20 hours) per consumer per year.

New Jersey selected one organization, a for-profit human services firm, to provide fiscal services to all Personal Preference consumers. The fiscal agent earned fees from consumers and the state. Specifically, consumers were charged for such tasks as cutting checks (75 cents per check), stopping payment on checks (\$28 per stoppage), and conducting criminal background checks (\$15 to \$60 per investigation). The state paid for other tasks, such as processing W-4 and other employment-related forms (\$90 per set of forms).

The Personal Preference Allowance

Personal Preference based consumers' allowances on their PCA care plans. These plans, prepared by Medicaid personal care agencies, indicated the number of weekday and weekend care hours the agency planned to deliver. (Special state authorization was required for more than 25 hours a week.) To determine Personal Preference allowances, the state calculated the amount it would have paid for agency services, then deducted 10 percent to cover the costs of consulting and part of the costs of fiscal services.⁸

Consumers could use the allowance only for the goods and services specified in their cash management plans. They could receive up to 10 percent of the monthly allowance as cash for incidental purchases if they specified the type of purchase in their plan (for example, care supplies or taxi fare). Likewise, consumers could save a portion of the allowance for one-time purchases identified in their plan (for example, bathroom modifications). Consumers could not use the allowance for food, entertainment equipment or supplies, or vacation- or entertainment-

⁸Although the other demonstration states discounted consumers' allowances to help ensure budget neutrality, New Jersey did not. While planning for the demonstration, the state determined that the historical costs of PCA services received were approximately equal to the costs of service planned—an indication that discounting was unnecessary.

related travel. The average monthly allowance at the time of consumers' enrollment was \$1,069 for nonelderly consumers and \$1,056 for elderly ones.

FINDINGS

Consumer Characteristics

The New Jersey Medicaid beneficiaries who enrolled in the demonstration—half of whom were randomly assigned to the treatment group to participate in Personal Preference—were a diverse group. Forty-six percent of treatment group consumers (404) were 18 to 64 years old, and 54 percent (467) were 65 or older. Slightly more than half these consumers described themselves as white, 38 percent as black, 9 percent as some other race, and slightly more than one-third as Hispanic (regardless of race) (Table 2). Three consumers in four were female, and 41 percent had graduated from high school.

Approximately one-third of the consumers lived alone, but more than 8 in 10 received assistance from informal (unpaid) caregivers (Table 2). A substantial proportion of consumers said they lived in nonrural areas characterized by high crime or poor public transportation, where obtaining agency services or hiring individual providers might be difficult. Two-thirds of consumers needed help transferring and using the toilet, and 86 percent needed help bathing.

Nearly 60 percent of consumers said their functioning was worse at baseline than it had been during the previous year. About three-fourths of consumers said they needed more help with personal care than they were receiving at baseline. At that time, slightly less than half of all consumers (45 percent) had been receiving Medicaid PCA for at least six months.

Consumers in the two age groups differed notably in some respects. Elderly consumers were more likely than nonelderly ones to be female, be Hispanic, and have less than a high school education (Appendix Table A.2). Although consumers in both age groups were equally likely to need help transferring, bathing, and using the toilet at baseline, elderly consumers were

Table 2: Consumer Characteristics at Random Assignment

| | Percentage |
|--|------------|
| Age | |
| 18 to 39 | 15.3 |
| 40 to 64 | 31.1 |
| 65 to 79 | 32.3 |
| 80 or older | 21.4 |
| Self-Identified As: | |
| White | 52.9 |
| Black | 38.0 |
| Other race | 9.1 |
| Hispanic (Regardless of Race) | 35.5 |
| Female | 74.2 |
| Graduated High School | 41.2 |
| Lives Alone | 35.3 |
| Has at Least One Informal Caregiver | 84.3 |
| Lives in an Area That Is: | |
| Rural | 10.5 |
| Nonrural but with high crime or poor public transportation | 44.6 |
| Not Independent In: | |
| Transferring | 66.8 |
| Using toilet | 67.0 |
| Bathing | 86.3 |
| Functioning Worse Now than Last Year | 58.7 |
| Needs More Help with Personal Care ^a | 74.3 |
| Proxy Respondent Completed at Least Half of Baseline Interview | 40.0 |
| Used Medicaid PCA for 6 Months or Longer | 45.2 |

Source: Personal Preference program records and MPR consumer interviews conducted by telephone immediately before consumers' random assignment. The table summarizes the characteristics of the 871 consumers randomly assigned to participate in Personal Preference.

^aPersonal care includes bathing, transferring, eating, and using the toilet during the week before the interview.

PCA = Personal Care Assistance.

more likely than nonelderly ones to say their functioning had worsened. Among elderly consumers, primary informal caregivers were most commonly their adult children (60 percent). In contrast, nonelderly consumers reported a greater variety of primary informal caregivers, including parents (25 percent), sons and daughters (19 percent), other relatives (17 percent), and nonrelatives (16 percent). Regardless of age group, few consumers reported that a spouse was their primary informal caregiver.

At the time of the baseline interview, more than 9 in 10 consumers said having a choice about the types of help they received was very important (Appendix Table A.3). More than 8 in 10 said having a choice about when caregivers came was very important. Three-fourths of consumers said the ability to pay family members was very important, and 7 in 10 said the same about paying friends.

Consumer–Consultant Interactions

Consumers could begin using Personal Preference consulting services as soon as they were assigned to the program. Of the 37 consultants who completed the MPR questionnaire, 20 had been working for the Personal Preference program for more than a year when surveyed, the rest for less time (Appendix Table A.4). Each had an average caseload of six consumers when surveyed but reported having worked with an average of nine consumers altogether.

Consultants potentially had many responsibilities. During initial home visits, they helped consumers (or representatives) develop written plans for using the monthly allowance. Consultants reviewed the completed cash management plans and sent them to the Personal Preference program for formal approval. The program required consultants to speak with consumers by telephone at least monthly for the first six months after random assignment and to meet them in person quarterly, to monitor their well-being. Most consultants told consumers who had completed their cash management plans to call them if any questions arose while they

were implementing their plan. For example, consumers could ask consultants for advice about recruiting and hiring workers and about making back-up arrangements. If consultants did not hear from newly enrolled consumers, they would call the consumers to fulfill the monthly requirement. If consumers needed to revise their cash management plans at any time, consultants helped them make revisions, reviewed the new plan, and forwarded it to the state program office for approval.

According to data from the consultant questionnaire, consultants devoted most of their time to a few tasks. At the time the questionnaire was administered, consultants spent only four hours a week, on average, on Personal Preference duties (Appendix Table A.5). However, it is likely that consultants later spent more time on program duties as demonstration enrollment continued, the number of consulting agencies decreased, and consultants' caseloads grew.

Consultants reported that their most time-consuming tasks were (1) helping consumers develop cash management plans; (2) performing administrative activities such as record keeping, updating case notes, and contacting other program staff; (3) advising consumers about payroll-related activities, such as setting wages and estimating payroll taxes; and (4) listening to or encouraging consumers. Most consultants believed that these services were of value to consumers. Of 37 consultants, 13 reported that at least one of their consumers required extensive monitoring (Appendix Table A.6). Consultants said the most common reasons for this were that consumers had difficulty completing paperwork (reported by 10 consultants), had no experience as an employer (reported by 7 consultants), or experienced frequent worker turnover (reported by 7 consultants).

Starting on the Allowance

Many consumers were enrolled in Personal Preference for a long time before they began receiving their monthly allowance (Table 3). Others disenrolled without ever having received it. Three months after being assigned to the program, about 30 percent of all consumers had begun receiving the allowance, 61 percent were still enrolled but had not received the allowance, 7 percent had disenrolled, and 2 percent had died (Appendix Tables A.7 and A.7a). Six months after assignment to Personal Preference, slightly more than half of all consumers had received the allowance, and nearly one-quarter were still enrolled but had not received it. Between the three- and six-month points, the proportion of disenrolled consumers tripled (from 7 to 21 percent).

Initially, the program expected consumers to have completed a cash management plan and be receiving the allowance within 90 days of random assignment to the treatment group. (Consultants, not consumers, would have been held to this standard.) For reasons explained below, however, developing the plan often took much longer than 90 days, and the program did not enforce the 90-day standard. Senior program staff feared that doing so might lead consultants to develop the plan instead of helping the consumer do it. In effect, the program gave consumers as much time as they needed to make the transition to consumer direction. Of the 198 consumers who were still enrolled but had not received the allowance at six months, 22 percent (44 consumers) did receive the allowance before the end of the follow-up year (not shown). Their eventual success may affirm the program's view that it was never too late for consumers to become active program participants. Some of these consumers may have been delayed by illness or by trying to recruit workers other than family members. Others may have needed more time to fully understand the program. For most consumers, however, not receiving the allowance within six months was tantamount to never receiving it, at least during the follow-

Table 3: Time from Random Assignment to Start of Monthly Allowance, by Age Group

| | Percentages | | |
|--|-------------|----------|-------------|
| | Overall | 18 to 64 | 65 or Older |
| Started Monthly Allowance by End of Month: | | | |
| 3 | 31.5 | 31.7 | 31.3 |
| 6 | 56.7 | 58.7 | 55.0 |
| 9 | 64.8 | 67.1 | 62.7 |
| 12 | 66.6 | 69.6 | 64.0 |

Source: Personal Preference program records for the year following consumers' random assignment. This table represents the 871 consumers randomly assigned to participate in Personal Preference.

up year. Of the 198 consumers mentioned above, 93 formally disenrolled, and 47 simply did not receive the allowance during the year. (The remaining 14 consumers died.)

Allowance-planning procedures, which affected the amount of time it took for the consumer to receive the allowance, were as follows. Consumers worked with their consultant to develop the cash management plan, which was to identify workers and other vendors, itemize desired goods and services in the amounts required, multiply these by unit or hourly costs, and account for applicable taxes. The consultant sent completed plans to the Personal Preference program office, where staff approved or denied the requested goods and services. The program office returned unacceptable plans to the consumer and forwarded approved plans to the fiscal agent. The fiscal agent double-checked all plans for accuracy and reviewed the forms in the proposed worker's employment package for consistency with the plan. If the fiscal agent found problems with the plan or the employment forms, it returned the paperwork to the consumer. After all paperwork was approved and processed, the program office notified the consumer's usual Medicaid personal care agency that it was to stop serving the consumer in 30 days' time. Regardless of when the planning process was completed, however, the allowance would commence only on the first day of the following month, because of how New Jersey's Medicaid Management Information System operated.

The program office took two steps that helped reduce the length of time it took to start the allowance. It reduced the notice it gave to personal care agencies from 30 to 14 days, and it began assigning consumers to consulting agencies, instead of asking them to choose an agency, as they entered the program. Still, completing a cash plan could be onerous. When the fiscal agent returned paperwork to consumers, those consumers who did not understand the problem or how to resolve it would have to contact their consultant. Some consultants complained that the fiscal agent returned paperwork without indicating the error. Even consultants sometimes could not identify the error and had to call the fiscal agent for an explanation. Both Personal Preference program staff and consultants reported frequent communication problems between consumers (or representatives) and consultants, state program staff, and fiscal agent staff. The number of people involved made it difficult for consumers to know whom to call about a particular type of problem. When problems arose, some consultants saved time by holding three-way calls among the consumer, the fiscal agent, and the consultant.

Consumer Management of Program Responsibilities

Use of Representatives. As noted earlier, Personal Preference consumers could designate an (unpaid) representative to manage, or help them manage, their program responsibilities. Representatives could help consumers decide how to spend the allowance (for example, whether to hire a worker, whom to hire, and how much to pay), supervise workers and monitor care, sign worker time sheets, and handle other program paperwork. No one could serve both as a consumer's representative and as a paid worker.

During site visit interviews, Personal Preference consultants reported that up to two-thirds of elderly consumers named a representative, while the proportion was considerably smaller among

nonelderly adults.⁹ Most consultants who completed questionnaires (30 of 37) said they worked with at least one consumer who used a representative (Appendix Table A.8). Representatives almost always were consumers' family members or close friends. New Jersey's ethnic and language diversity was a major reason for the widespread use of representatives. The program sometimes had to send consumers materials written in English only, and consumers may have depended on representatives to translate them. (Such mailings included brief notices that the materials were important and should be translated. The notices themselves were printed in 14 languages.) In addition, consumers with cognitive impairments or who already were receiving assistance with their affairs, such as help maintaining a checking account, were likely to use representatives. Program staff believed that about half the consumers who named representatives could have managed independently but felt too insecure to try.

Representatives' decision-making roles varied considerably. Except when consumers were completely unable to communicate their preferences, consumers and representatives typically shared decisions. In some cases, they made decisions as a team. In others, the representative asked the consumer's preference but then made the final decision. In still other cases, the consumer was the primary decision maker, but the representative served as a liaison to the program. Four consultants who completed questionnaires indicated that they "questioned the suitability" of a consumer's representative, and one indicated observing "a serious divergence of wishes or interest" between a consumer and a representative. (Quotes indicate the wording of closed-ended questions, not responses. Respondents were not asked to elaborate.)

Use of, and Satisfaction with, Consulting and Fiscal Services. Like representatives, program consultants and fiscal agent staff helped consumers manage their program

⁹The program could not give the exact number of consumers with representatives.

responsibilities. In spite of allowance delays, many consumers were pleased with the consulting and fiscal services they received. During six-month follow-up interviews, 72 percent of all consumers said a Personal Preference consultant helped them or their representative develop a cash management plan (Table 4 and Appendix Tables A.9 to A.9b).¹⁰ More than 9 in 10 consumers who received help from consultants found it useful. They most commonly said consultants' explanations of program rules were useful (reported by 76 percent of consumers), as was help clarifying goals, options, and priorities (reported by 40 percent of consumers) (Appendix Table A.10). By the time of their six-month interviews, 58 percent of consumers had received materials about recruiting workers, and 84 percent of them found the materials useful (Appendix Table A.9). Although a smaller percentage of consumers (42 percent) said their consultant advised them about recruitment (as opposed to simply giving them materials), the proportion that found the advice useful was high (92 percent)(Appendix Table A.9). As we describe later, some consultants who took part in site visit discussions said they were not sure how much recruitment assistance the program expected them to provide.

The major fiscal services offered to consumers were (1) check writing, and (2) preparing and filing tax returns for workers hired with the monthly allowance. Personal Preference allowed consumers to receive the allowance in cash and handle fiscal responsibilities themselves if they first passed a skills examination. This option garnered little interest, however; according to program staff, all consumers chose to use the services of the fiscal agent during the evaluation follow-up year. Of consumers who started receiving the cash allowance within nine months of random assignment, 97 percent said they used the program's fiscal services, and 92 percent of

¹⁰Although consultants were required to help consumers develop their cash management plans, some consumers disenrolled from Personal Preference before reaching that stage of program participation.

Table 4: Use of, and Satisfaction with, Personal Preference Services

| | Percentage Reporting | Of Users, Percentage Finding It Useful |
|--|----------------------|--|
| Had Help with Cash Management Plan During First 6 Months | 71.7 | 93.7 |
| Received Advice About Recruiting During First 6 Months | 42.0 | 91.5 |
| Received Advice About Training Workers During First 6 Months | 33.9 | 86.5 |
| Used Fiscal Services During First 9 Months (if Received Allowance) | 97.0 | 92.4 |

Source: MPR consumer interviews, conducted by telephone 6 and 9 months after consumers' random assignment. The table summarizes responses of 783 consumers who completed 6-month interviews and of 747 consumers who completed 9-month interviews.

them said the services were useful (Appendix Table A.9).¹¹ These proportions varied little by age group.

Recruiting and Hiring Workers. Fifty-seven percent of all consumers reported that they had hired at least one worker with the allowance by the time of the nine-month follow-up interview, 25 percent had tried to hire but did not, and 18 percent had not tried (Table 5 and Appendix Table A.11). Most consumers who tried to hire family members were able to do so, but consumers had less success hiring other people they knew, such as friends, neighbors, church members, and agency workers.¹² Consumers who tried to hire workers they did not already know (for example, by asking others for recommendations or posting ads) also were less successful than those who hired family.

Although similar proportions of elderly and nonelderly consumers hired successfully, a larger proportion of nonelderly consumers than elderly ones tried to hire but did not (30 versus

¹¹In a slight contrast with survey data, program staff said *all* allowance recipients used fiscal services—that is, none chose to handle fiscal responsibilities themselves.

¹²Although the personal care industry initially was concerned that Personal Preference consumers would hire away their staff, the concerns dissipated when a smaller-than-expected proportion of beneficiaries enrolled in the demonstration. Thus, even though some consumers did hire agency workers, this did not cause a problem for the industry.

Table 5: Recruiting and Hiring Workers

| | Percentage |
|--|------------|
| Hiring Workers with Allowance During First 9 Months | |
| Hired a worker | 57.2 |
| Tried to hire a worker, but did not | 24.7 |
| Did not try to hire a worker | 18.1 |
| Attempted Recruiting Methods, if Hired or Tried to Hire Workers | |
| Tried to hire: | |
| Family member | 73.8 |
| Friend, neighbor, or church member | 40.0 |
| Home care agency worker | 28.9 |
| Asked family or friends to recommend worker | 32.1 |
| Posted or consulted advertisements | 7.5 |
| Contacted employment agency | 5.5 |
| Successful Recruiting Methods, if Hired Workers | |
| Hired: | |
| Family member | 72.5 |
| Friend, neighbor, or church member | 23.6 |
| Home care agency worker | 13.3 |
| Through a recommendation | 11.4 |
| Through an advertisement | 5.3 |
| Through an employment agency | 0.9 |
| Through other means | 1.4 |

Source: MPR consumer interviews, conducted by telephone 6 and 9 months after consumers' random assignment. The table summarizes responses of 815 consumers who responded to either or both interviews.

20 percent; Appendix Table A.11). The difference seems related to whom nonelderly and elderly consumers tried to hire. Nonelderly consumers were less like than elderly ones to try to hire family (68 versus 79 percent), and they were more likely to try to hire friends and neighbors (48 versus 32 percent; top panel of Appendix Table A.12).

Of consumers who hired workers, 29 percent said they had difficulty doing so, and one-third of them said the difficulty was finding interested or qualified candidates (Appendix Table A.11). Consultants confirmed that it was difficult for some consumers to hire or keep workers. Eighteen consultants who completed a questionnaire said they worked with at least one consumer who had serious problems because their workers quit or were fired (Appendix Table A.13). Still, some consumers did have success with creative recruiting strategies. One

consultant described a Chinese consumer who advertised in a Chinese-language newspaper and successfully recruited a worker who spoke the consumer's language and prepared the consumer's preferred foods. Another consumer hired a live-in aide through a non-Medicaid agency, after years of being dissatisfied with visiting aides from Medicaid PCA agencies.

In addition to recruiting and hiring workers, consumers had to decide whether and how to train them, how much to pay, whether to offer fringe benefits, and whether to describe such arrangements in a contract or written agreement. A sizable proportion of consumers or representatives who hired workers by the time of their nine-month interviews trained them in some way. Overall, 44 percent showed the worker how to perform tasks, and another 4 percent arranged for training outside the home (Appendix Table A.11). Only 11 percent of these consumers said that training workers was difficult. Consumers paid workers \$9.84 an hour, on average. Fifteen percent of consumers said they provided fringe benefits, such as paid sick time, to their workers.¹³ Fifty-three percent of consumers who used their allowance to pay workers, including family members, signed contracts or work agreements with them. (Data on wages, fringe benefits, and contracts are not shown in tables.)

Neglect, Exploitation, and Abuse. The possibility that consumers could be exploited by workers or representatives, or vice versa, and the possibility that the Personal Preference allowance would be misused or squandered were major concerns for all involved in the program, as they were for the demonstration programs in Arkansas and Florida. At the same time,

¹³We also asked about fringe benefits during separate interviews with samples of workers who (1) were hired directly by treatment group consumers, or (2) were agency workers for control group members. In contrast to the proportion of consumers who said they provided fringe benefits (15 percent), only 5 percent of directly hired workers said they received them. The discrepancy may have resulted from a difference in question wording. Consumers were prompted to include paid insurance, sick days, vacations, and free room and board as fringe benefits. However, the directly hired and agency workers were prompted to include insurance, sick leave, and paid holidays, but not room and board, as fringe benefits. Twenty-four percent of agency workers said they received such benefits.

everyone directly involved in the demonstration realized that extensive control and oversight of consumers and their families were incompatible with the philosophy of consumer direction. Consumers had to be free to make their own choices, even if others disagreed with them. Personal Preference relied on consultants to be alert for evidence that consumers were being financially exploited or physically or verbally abused. It also established procedures for consultants to follow if they suspected anything was amiss. At the time of the New Jersey site visit and the consultant survey, neither neglect or exploitation, nor abuse of the allowance, seemed to be serious problems. On the questionnaire, one consultant out of 37 indicated seeing evidence of financial exploitation of one consumer by a worker, but did not provide any information about the case (Appendix Table A.14). No consultants who completed a questionnaire reported verbal or physical abuse of consumers by representatives or workers, but one reported seeing evidence of consumer self-neglect.

During site visit discussions, a consultant described one case in which a consumer seemed to have been subject to neglect. The problem was identified during the consultant's initial home visit with the consumer—when the consultant found the consumer lying on a couch apparently comatose—before program participation had even begun. Following established procedure, the consultant immediately notified the state program office that the case needed investigation. For this case and others that caused concern, program staff then referred the case to a nurse employed by the state Medicaid program. The nurse visited the home to make an assessment, and program staff reviewed the nurse's report. If the staff concluded that neglect or exploitation was likely, the case was referred to Adult Protective Services.

Personal Preference used two methods to prevent misuse of the monthly allowance: (1) program approval of cash management plans; and (2) verification, by the program's fiscal agent, that expenditures were authorized under the plan. No one who participated in site visit

discussions—program staff, fiscal agent staff, program consultants, or stakeholders in the personal care industry—reported seeing evidence of material abuse of the allowance under Personal Preference. When a few consumers planned to use the allowance in ways not related to their personal care or independence, the program simply denied the requests.¹⁴ In addition, the fiscal agent was also required to provide consumers with monthly statements of their account credits, debits, and payments pending. The main purpose of the statements was to ensure that consumers knew their account balances; however, many consumers seemed not to understand that invoices pending were not reflected in the statement’s bottom line. Thus, the statements probably were not very useful in preventing misuse of the allowance (although they did allow consumers to identify any errors the fiscal agent made).

How Consumers Took Advantage of Increased Flexibility

Consumers who used their allowance to hire workers determined how many to hire, what tasks they would perform, and when they would help. Among consumers who used the Personal Preference allowance to pay workers, about three-fourths hired one worker, another fifth hired two workers, and the remaining five percent hired three or more workers (Table 6 and Appendix Table A.16). Forty-four percent of consumers who hired had a paid worker who lived with them at the time of the nine-month interview. The number and type of workers (live-in or visiting) hired with the allowance varied little by age group.

Although consumers in both age groups paid their workers to provide the same *types* of care, they differed in the *amount* of care they purchased. During the two-week period asked about in follow-up interviews, more than 9 in 10 consumers in both age groups said their paid workers

¹⁴On the questionnaire, two consultants indicated that they had seen evidence of allowance misuse, but neither specified its nature (Appendix Table A.15).

Table 6: Assistance from Paid Workers Among Consumers Who Hired with the Allowance, by Age Group

| | Overall | 18 to 64 | 65 or Older |
|--|---------|----------|-------------|
| In 2-Week Period Shortly Before Interview: | | | |
| Had 1 Worker | 75.0 | 71.4 | 78.3 |
| Had 2 or More Workers | 25.0 | 28.7 | 21.7 |
| Had Visiting Worker(s) | 64.8 | 67.0 | 62.8 |
| Had Live-In Worker(s) | 43.6 | 41.6 | 45.4 |
| Worker Helped With: | | | |
| Housework or community chores ^a | 99.5 | 99.5 | 99.5 |
| Personal care ^b | 97.7 | 97.3 | 98.1 |
| Routine health care ^c | 91.8 | 90.3 | 93.2 |
| Transportation ^d | 66.8 | 70.8 | 63.3 |
| Hours of Paid Care | | | |
| 14 or fewer | 5.1 | 5.2 | 5.0 |
| 15 to 42 | 48.0 | 48.6 | 47.5 |
| 43 to 70 | 31.1 | 36.4 | 26.5 |
| 71 or more | 15.8 | 9.8 | 21.0 |

Source: MPR consumer interviews, conducted by telephone 9 months after consumers' random assignment. The table summarizes the responses of 392 consumers who hired with the allowance by the time of their interview and received paid assistance during a 2-week period shortly before the interview. Of these consumers, 11 had disenrolled from Personal Preference and were probably reporting on help from agency workers.

^aHousework or community chores include light housework, yard work, meal preparation, and shopping.

^bPersonal care includes bathing, transferring, eating, and using the toilet.

^cRoutine health care includes taking medications, checking vital signs, and doing exercises.

^dTransportation includes trips for medical and nonmedical reasons.

helped them with housework or community chores, personal care, and routine health care (Table 6 and Appendix Table A.16). Two-thirds of consumers reported that their workers helped them with transportation (this percentage was somewhat higher for nonelderly consumers). During the same period, about half the consumers in both age groups paid their workers for 15 to 42 hours of the care they provided. Elderly consumers were more likely than their nonelderly counterparts to pay workers for substantially more hours. One-fifth of elderly consumers paid for 71 or more hours of care in two weeks, compared with one-tenth of nonelderly consumers.

According to fiscal agent records from month 8 of consumers' program participation, more than 8 in 10 consumers used part of their allowance to pay workers, roughly 5 in 10 received some of the allowance as cash for incidental purchases, and fewer than 1 in 10 used the allowance to buy equipment (Appendix Table A.17).¹⁵ Both elderly and nonelderly consumers spent about 80 percent of the allowance paying workers (Appendix Tables A.17a and A.17b). They received about eight percent of the allowance as cash for incidental purchases that month. This amounted, in the month studied, to \$29 received as cash by elderly consumers and \$42 received as cash by nonelderly consumers.

Consultants' reports about the contents of consumers' cash management plans were consistent with the data from the fiscal agent. At least 10 of the consultants who completed questionnaires reported the following plans for spending the allowance (other than paying workers): taxi fare or other transportation services, chore or homemaker services, laundry services, and ramps (Appendix Table A.18). When responding to the questionnaire, few consultants mentioned creative uses of the allowance (Appendix Table A.19). During site visit discussions however, some did mention creative equipment purchases. These included (1) a portable support for a voice synthesizer so that the consumer could wear the synthesizer outside his home; (2) a scanner and talking computer that allowed a consumer to read mail and check worker time sheets; and (3) a fax machine so that a consumer with quadriplegia could send papers to doctors, insurance companies, and Personal Preference. While the Personal Preference program staff was ultimately responsible for approving or denying the items in consumers' cash plans, eight consultants mentioned that they denied consumers' attempts to include cigarettes, food, or alcohol in their plans. For their part, 30 percent of consumers said program rules kept

¹⁵For this analysis, allowance use data from the program's fiscal agent were available only for month 8 of consumers' program participation.

them from using their allowance to buy things that would have increased their independence. (They were not asked to provide examples.) However, only five consumers who voluntarily disenrolled cited program rules as the reason they did so.

Consumer Satisfaction

Satisfaction with Personal Preference. Consumers were quite satisfied with the Personal Preference program. Of all respondents to the nine-month evaluation interview, 91 percent said they would recommend the program to others who wanted “more control over their personal care services” (Table 7). Among allowance recipients, 82 percent said the allowance had improved their quality of life “a great deal” or “somewhat.” Across age groups, elderly consumers were slightly more likely than nonelderly ones to report a great deal of improvement. When asked about the most important way the allowance improved their lives, consumers in both age groups most commonly cited the ability to choose their own caregivers (reported by 42 percent of elderly consumers and 33 percent of nonelderly ones), followed by the ability to obtain a higher quality of care than had been available previously (reported by 13 and 19 percent of elderly and nonelderly consumers, respectively) (Appendix Tables A.20a and A.20b). About 12 percent of consumers in both age groups said the allowance helped them feel more independent, in control, or emotionally healthy.

Satisfaction with PCA. Nine months after random assignment, most consumers reported they were somewhat or very satisfied with their overall care arrangements and with specific aspects of their paid care (such as whether it was usually completed). Nonetheless, sizable proportions of consumers needed help, or more help, with some activities. Across age groups, consumers were largely, but not altogether, similar in their reports of satisfaction. Where differences appeared, elderly consumers were more sanguine than their nonelderly counterparts. For example, when asked to rate their satisfaction with their overall care arrangements, elderly

Table 7: Satisfaction with Personal Preference, by Age Group

| | Percentages | | |
|--|-------------|----------|-------------|
| | Overall | 18 to 64 | 65 or Older |
| Would Recommend Personal Preference to Others Wanting More Control Over Their Personal Care Services | 91.1 | 90.9 | 91.2 |
| Effect of Monthly Allowance on Quality of Life, Among Recipients | | | |
| Improved a great deal | 57.2 | 54.2 | 60.0 |
| Improved somewhat | 24.7 | 26.7 | 22.9 |
| Stayed the same | 17.5 | 17.8 | 17.1 |
| Reduced somewhat | 0.4 | 0.9 | 0.0 |
| Reduced a great deal | 0.2 | 0.4 | 0.0 |

Source: MPR consumer interviews, administered by telephone 9 months after consumers’ random assignment. The table summarizes the responses of 747 consumers.

consumers were more likely than nonelderly ones to be “very satisfied” and less likely to be “dissatisfied” (Appendix Table A.21a). Elderly consumers were also more likely to report that it would *not* be difficult to change their paid caregivers’ schedules if they needed to, and they were more likely to say paid caregivers *never* neglected them.

Among consumers who hired with the allowance, the proportions reporting unmet needs for help with activities around the house or community, personal care, routine health care, and transportation ranged from about one-third to one-half (Appendix Table A.21a). In each instance, elderly adults were less likely than nonelderly ones to report unmet needs. The largest differences were in unmet needs for help with housework or community chores (reported by 40 percent of elderly adults and 54 percent of nonelderly ones) and for help with transportation (reported by 31 percent of elderly adults and 46 percent of nonelderly ones). Like the other demonstration states, however, New Jersey did not expect that consumer direction would eliminate all unmet needs, which may be impossible at any cost.

Because proxy respondents commonly completed evaluation interviews on consumers’ behalf, we compared their reports of consumers’ satisfaction with those of self-respondents

(Appendix Tables A.20b and A.21b). The two groups' assessments were largely consistent with each other; however, proxy respondents were more likely than self-respondents to give very favorable ratings on broad measures of consumer satisfaction, such as overall satisfaction, the ability to get help with transportation, and the effects of the monthly allowance on quality of life. Proxy respondents were more likely than self-respondents to report that consumers had unmet needs for PCA at followup. This could be because proxies saw unmet needs where consumers did not or because consumers who needed proxies began with greater needs and still had them despite the program.¹⁶

Disenrollment. As in the other demonstration states, a substantial proportion of New Jersey consumers—33 percent—disenrolled from Personal Preference within a year of enrollment (Appendix Table A.22). Most did so voluntarily, according to program records, but others were disenrolled because they lost Medicaid or PCA eligibility, or because the program could not locate them. In addition, six percent of all consumers died. Disenrollment was not more common in one age group than the other, but more elderly than nonelderly consumers died during the follow-up year (seven versus four percent). Sixty-three percent of consumers who disenrolled from the program did so within six months of enrolling.

During six- or nine-month interviews, consumers who disenrolled voluntarily were asked why they had done so. The most commonly cited reasons pertained to employer responsibilities (reported by 34 percent of voluntary disenrollees) (Appendix Table A.22). Given that most

¹⁶We also examined key measures of satisfaction and unmet needs of consumers who used the allowance to hire workers while controlling for whether any of those workers were related to them. Some differences were sizable (but not statistically significant because of the rather small sample sizes available) (not shown). Among consumers who hired, those who did not hire any family members were more likely than other consumers to report unmet needs for help doing things around the house and community (53 versus 41 percent) and unmet needs for help with routine health care (34 versus 24 percent). Compared with consumers who hired family, those who did not were less likely to be very satisfied with their overall care arrangements (59 versus 66 percent) and more likely to say they felt neglected by paid workers at least sometimes (20 versus 13 percent).

consumers (73 percent) disenrolled without ever having received the program allowance, we infer that many of these disenrollees decided they did not wish to *assume* the responsibilities of an employer or could not find anyone to hire. Others who disenrolled said they changed their mind or were satisfied with their usual PCA services (30 percent), that they had problems with fiscal responsibilities (11 percent), or that the allowance was not enough (9 percent). Consumers' reasons for choosing to disenroll differed somewhat by age group, even though their overall rates of disenrollment did not. Nonelderly consumers were most likely to disenroll because they believed it was or would be difficult to assume the responsibilities of an employer, which may reflect their difficulty in hiring nonrelatives. In contrast, elderly consumers were most likely to disenroll because they changed their minds or were satisfied with their usual PCA services.

Experiences of Different Types of Consumers

Because demonstration enrollment was voluntary, Personal Preference presumably attracted Medicaid beneficiaries who wished to direct their own personal care. Nonetheless, participating in the program—developing a cash management plan, hiring workers, and purchasing other services and goods—may have required more effort than some consumers and representatives were willing to expend. Satisfaction with the program was high, but not universal. After being randomly assigned to the treatment group, what types of consumers found Personal Preference worthwhile and satisfying? One could speculate that consumers who felt ill served by New Jersey's usual PCA program would be more willing than others to undertake the responsibilities of Personal Preference. This group might include consumers who found agency workers unreliable or too unlike them ethnically or culturally. Consumers with a strong desire to pay family or friends for caregiving might also be more motivated than others to fully participate in the program once enrolled. Conversely, one could speculate that consumer direction might be

difficult for consumers with poor health or functioning, for those without hiring or supervisory experience, or for those without someone in mind to hire. Understanding the relationship between the characteristics, circumstances, and motivation of consumers and their probability of success at consumer direction could help program administrators hone their outreach efforts, identify possible shortcomings in program services, and dispel any prejudices about beneficiaries' suitability for consumer direction.¹⁷

In this analysis, key indicators of consumers' experiences with Personal Preference were regressed against a fairly comprehensive, but selected, set of characteristics measured during consumers' baseline interviews. The outcomes were whether treatment group consumers:

- Started receiving the allowance within nine months of enrollment
- Voluntarily left the program within nine months or one year of enrolling
- Found it difficult to hire a worker or tried to hire but failed
- Said the program's spending rules kept them from doing things that would have increased their independence
- Said the allowance had greatly improved their life (if they received the allowance)
- Were very satisfied with overall care arrangements at the nine-month interview
- Had an unmet need for personal care at the nine-month interview

The following discussion considers characteristics that were associated with outcomes at the .05 significance level. Estimated coefficients and p-values are found throughout Appendix Tables A.23 to A.27, as noted.

¹⁷Mahoney et al. (2004) found that interest in Cash and Counseling varied among subgroups of Medicaid beneficiaries in Arkansas, Florida, New Jersey, and New York during preference studies conducted to aid demonstration design. (New York later withdrew from the demonstration.) In particular, interest was positively associated with having hiring and supervisory experience, more severe levels of disability, having a live-in caregiver, and minority status.

Several characteristics were associated with whether treatment group consumers received the program allowance within nine months of random assignment and remained in the program for nine months or one year. Consumers who considered it very important, at baseline, to be able to pay family or friends for caregiving were more likely than other consumers to receive the monthly allowance and stay in the program (Appendix Tables A.23 and A.27). These consumers had a particular motivation for joining the demonstration, and they already had workers in mind to hire. Consumers who needed help getting in or out of bed and consumers who had unmet personal care needs were more likely than other consumers to stay in the program. These consumers, if they objected to the timing of agency services or to having agency workers help them with intimate tasks, may have found a better way to meet their needs under Personal Preference. Consumers whose primary informal caregivers were employed at baseline also were more likely than others to stay in the program. Employed caregivers may have found the inflexibility of agency services frustrating, and consumer direction may have provided the opportunity to hire workers who could be more accommodating.

In contrast, some treatment group consumers who did not receive the allowance or remain in the program may have been satisfied with their usual PCA services. In particular, consumers who had two or more paid caregivers in the week before baseline were less likely than consumers with no paid caregivers to receive the allowance or stay in the program (Appendix Tables A.23 and A.27). If these consumers felt that their Medicaid PCA agency served them well, they may simply have decided not to switch to consumer direction.

Living alone seemed to be an obstacle to full program participation. Treatment group consumers who lived alone were less likely than consumers who lived with others to receive the monthly allowance and more likely to say hiring was difficult (Appendix Tables A.23 and A.24). Live-in family members often serve as representatives or paid workers, and consumers without

such nearby resources may have had difficulty participating in Personal Preference by themselves. In fact, consumers with two informal caregivers at baseline were more likely than consumers with none to receive the allowance and stay in the program for at least nine months (although the associations were significant only at the .10 level) (Appendix Tables A.23 and A.27).

Hispanic treatment group consumers were less likely than non-Hispanic ones to receive the Personal Preference allowance and stay in the program, and black consumers were less likely than white consumers to receive the allowance (Appendix Tables A.23 and A.27). Nonwhite consumers were more likely than white consumers to say program rules were too restrictive (Appendix Table A.25). New Jersey's population of PCA users is ethnically and racially diverse. The state tried to address this diversity in its marketing and informational materials, but it may have had difficulty providing consulting services to this population. For example, during baseline surveys, 36 percent of consumers described themselves as Hispanic, compared to 16 percent of consultants (or 6 of 37). Although some consumers may have liked the idea of hiring workers of their own ethnicity, communicating with others involved in the program may have been problematic if the consumer did not speak or read English.

All else being equal, treatment group consumers who joined the New Jersey demonstration relatively early in the enrollment period were less likely than later enrollees to have received their allowance promptly (Appendix Table A.23). Early enrollees were also more likely to find hiring difficult and less likely to be very satisfied with their overall care (Appendix Tables A.24 and A.26). The better outcomes for later enrollees suggest that the program's efforts to shorten or remove some allowance delays may have succeeded. In addition, the specially hired state employees may have enrolled a more select group of beneficiaries—ones who understood the

program well or were more motivated to participate—than the group enrolled by the contractor initially retained for outreach and enrollment.

Among treatment group consumers who hired or tried to hire workers, a few characteristics (in addition to those already mentioned) were predictive of whether hiring was difficult (Appendix Table A.24). Consumers who lived in nonrural areas with crime or transportation problems were more likely than consumers who lived in nonrural areas without those problems to have difficulty hiring. In addition, consumers who had unmet needs for help with housework or community chores at baseline were more likely than others to say hiring was difficult. These consumers may have had difficulty finding workers who were willing or able to perform the tasks they needed assistance with. Elderly consumers were *less* likely than their nonelderly counterparts to have difficulty hiring. This may be because elderly consumers were more likely than nonelderly ones to hire family members or because elderly consumers were less demanding of potential recruits.

Finally, treatment group consumers who had unmet needs for transportation assistance at baseline were more likely than other consumers to say program rules prevented them from buying things that would increase their independence (Appendix Table A.25). These consumers might have wished to receive a larger portion of the allowance as cash for taxi fare (the maximum was 10 percent) or to use the allowance for entertainment- or vacation-related travel, which the program did not allow.

Few other significant relationships emerged. However, consumer characteristics that were *not* associated with program outcomes bear mentioning. Age was not associated with outcomes other than whether hiring was difficult. There was no evidence to suggest that consumers' education, work experience, or self-reported health status were associated with their experiences in Personal Preference. The amounts of consumers' program allowances were generally not

associated with the outcomes examined. All else being equal, whether treatment group consumers used a proxy respondent for the baseline interview was not associated with whether they received the allowance, which may suggest that cognitive impairment (or being physically unable to use a telephone) did not inhibit consumer direction.

In summary, this analysis suggests that no discernible segment of New Jersey’s eligible population had consistently negative experiences in the Personal Preference program; however, some groups might need additional help to become participants. Consumers in ethnic or racial minorities (non-English speakers in particular) might have more success in the program if consultants with backgrounds similar to their own assisted them. Consumers who live alone might need additional assistance identifying and recruiting workers—the development of regional worker registries could help with this task.¹⁸ Meanwhile, the results of this analysis also indicate that New Jersey’s decision to offer consumer direction to all groups—including the elderly, consumers with cognitive impairment, and those in need of large amounts of PCA—was a sound one.

Consultant Assessment of Personal Preference

Consultants also were asked to assess the experiences of different types of consumers. Many (26 of 37) said they worked with at least one consumer or representative who needed extensive assistance from them (Appendix Table A.28). Consumers most likely to require extensive help were those with little experience recruiting, hiring, or training workers, or preparing budgets and solving problems. In addition, consultants said Personal Preference worked best for consumers who had a relative or friend in mind to hire as a worker (reported by

¹⁸After our site visit, New Jersey applied for, and received, a federal Systems Change grant to develop worker registries such as might be used in consumer-directed programs, including Personal Preference.

12 consultants) or who were dissatisfied with their usual PCA services (reported by 8 consultants) (Appendix Table A.29). Thirteen consultants said the program did not work well for consumers who could not manage their own care and did not know anyone who could serve as a representative. One consultant described the program as a success for one non-English speaker, who hired workers who spoke his Indian dialect, but as a hardship for another non-English speaker, who did not have a representative and could not communicate with the consultant or read program materials.

Concerning their own responsibilities and training, 10 of 37 consultants indicated they would change their Personal Preference responsibilities in some way (Appendix Table A.30). Few recommended specific changes, however. Three consultants thought they and their colleagues should spend more time with consumers who needed extra help. Three others, however, thought they should do less for consumers, by behaving more like advisers and not explaining the program to them in great detail. Most consultants (30) thought they were adequately trained for their Personal Preference responsibilities. Of those who made suggestions about program training, 13 consultants would change its content. Some wanted less emphasis on training philosophy and more on the practicalities of helping consumers develop cash management plans and doing paperwork. Three consultants said their training manuals were difficult to use because they did not include a table of contents, an index, or numbered pages (not shown). During site visit interviews, consultants suggested they would have liked to meet each other periodically to share tricks of the trade.

Consultants also were asked to assess the program more generally and recommend changes on the MPR questionnaire. Five consultants reported that the program had not been thoroughly explained to consumers before they enrolled, leaving the consultants to explain it in detail. One consultant said some of these consumers disenrolled from the program after they understood it

better, and another said some consumers disenrolled because they never understood the program. (This may have reflected difficulties the program had with its initial enrollment contractor.) During site visit discussions and on the questionnaire, consultants reported that the quality of the program's fiscal services sometimes was poor. Consultants reported that workers' paychecks arrived late and that the fiscal agent was unresponsive to them or to consumers who called the fiscal agent directly.¹⁹ Perhaps with experiences like these in mind, a few consultants remarked that Personal Preference, at least at the time the questionnaire reached them, worked better in theory than in practice.

SUMMARY, LESSONS, AND POLICY IMPLICATIONS

Summary

New Jersey's Personal Preference program was one of three Cash and Counseling demonstrations to test a model of consumer-directed Medicaid supportive services. Like the other demonstrations, Personal Preference provided consumers with a monthly allowance and counseling and fiscal services and let them designate a representative decision maker if they wished to do so. New Jersey allowed consumers to hire spouses as paid workers; however, no one could serve both as a consumer's representative and as a paid worker.²⁰ The state took a decentralized approach to consulting services. Approximately 18 months into the demonstration, about 50 consultants from human services agencies throughout the state were working with consumers. In contrast, the state used a single contractor to provide fiscal services.

¹⁹State program staff indicated that they, too, noticed that telephone calls to the fiscal agent were not returned promptly when one of the two full-time staff members was out of the office. As for the timeliness of workers' paychecks, however, during site visit interviews, the fiscal agent indicated that some consumers failed to submit time sheets promptly, which led to payment delays.

²⁰In comparison, Arkansas did not let consumers hire spouses or representatives. Florida did not restrict hiring during the evaluation period, although it later revised its operational protocol so that no one could serve as both the consumer's representative and a paid worker.

The Personal Preference program enrolled an ethnically and linguistically diverse population of elderly and nonelderly adults, most of whom participated actively for at least a year after enrolling, by developing cash management plans and using the program allowance to meet PCA needs. On average, consumers were satisfied with the program. Those who developed cash management plans said they received helpful guidance from program consultants. Those who received the allowance hired workers of their choice, and they were highly satisfied with these workers. In both age groups, consumers most commonly hired family members, but some consumers, especially nonelderly ones, hired nonrelatives. Many consumers chose to receive a small portion of the allowance as cash for incidental purchases each month, and some used it (or saved it) for assistive equipment.

New Jersey's Cash and Counseling demonstration proved that including a consumer-directed option as a state plan Medicaid service is politically and administratively feasible. The state's experiences offer several valuable lessons about program implementation.

Implementation Lessons from Personal Preference

Industry Support. The demonstration program garnered the cooperation of personal care agencies, which it relied upon to identify eligible PCA users and the hours of care planned for them. Several factors contributed to the good relations between agencies and the Personal Preference program. First, the industry viewed consumer-directed personal care as inevitable and, indeed, beneficial for some people with disabilities. Second, Personal Preference responded to industry concerns by discouraging consumers from hiring agency employees as workers. Third, because a smaller percentage of PCA users participated in Personal Preference than was initially anticipated, agencies did not lose many clients to the demonstration. Fourth, the personal care industry respected the Personal Preference director and his staff.

Outreach and Enrollment. Personal Preference was systematic and focused in its outreach and enrollment activities, but it had to modify some procedures to raise enrollment and contain costs. For example, the program’s introductory mailings initially were timed to coincide with beneficiaries’ semiannual assessments for Medicaid PCA. Later, to enlarge the pool of potential enrollees, the program decided to separate outreach from assessment. In addition, the program at first attempted to conduct home visits with all prospective enrollees. As costs mounted, however, the program reduced the number of home visits by (1) scheduling home visits only when key members of the beneficiary’s family would also be present, (2) not pursuing reluctant beneficiaries with multiple visits, and (3) allowing beneficiaries to enroll by telephone if they demonstrated a thorough understanding of the demonstration and were willing to forgo a home visit.

The two approaches Personal Preference used for outreach and enrollment—external contracting and hiring state employees—each had advantages and disadvantages. A key advantage of external contracting was expediency—the program was able to quickly launch outreach and enrollment activities by amending an existing contract with a human services provider. In contrast, when the program brought the activities in house, it took several months to hire new employees. The key advantage of hiring state employees was that program staff had more control over procedures and could experiment with them. However, neither the external contractor nor the state employees met the enrollment targets set by the evaluation contractor and agreed to by the state. It seems neither approach was to blame. Although New Jersey might have tried other means to boost enrollment, such as a letter from the governor, it is not certain that such attempts would have materially affected enrollment. In the end, during the demonstration intake period, New Jersey enrolled roughly eight percent of the Medicaid beneficiaries who used PCA services. The other demonstration states achieved similar rates.

Consumer Understanding of the Program. According to consultants, some consumers enrolled in the demonstration without completely understanding the consumer-directed program. Some enrollment workers, in trying to meet enrollment targets and deadlines, may not have explained the program thoroughly. Moreover, the program did have some complex procedures. Ultimately, consultants spent more time than they expected explaining the program and its procedures. Some consumers chose to disenroll from the demonstration after they learned more about it, and others may have encountered linguistic barriers to participation. Because consumers continued on PCA as usual until their allowance started, and because disenrollment was permitted at any time, consumers who enrolled in the program without fully understanding it were not at undue risk.

Consultants, Fiscal Agents, and Representatives. Consultants, fiscal agents, and consumer-designated representatives all contributed to consumers' participation in Personal Preference. The program initially recruited more than 30 human services agencies to provide consulting services, and it asked consumers to choose the agency they wished to use. Both aspects of this approach, although well intentioned, had some drawbacks. Because consumers did not have much information or experience on which to base a choice of agency, they did not value the opportunity to choose one. Moreover, choosing an agency delayed development of the cash management plan and receipt of the program allowance. The program began assigning consumers to the most effective agencies, until only 12 were actively serving consumers. The concentration of consumers across fewer agencies had important benefits. It helped ensure that the agency staff who worked as consultants had caseloads of more than only one or two consumers, and it increased the likelihood that more than one staff member per agency worked as a consultant. Thus, consultants gained experience more quickly, were more motivated to keep abreast of program procedures, and benefited from having peer support and backup. Moreover,

without the step of consumers choosing a consulting agency, consultants could promptly start working with them on the cash management plan.

In general, consumers were satisfied with the consultant services they received, and many consultants reported positively about consumers' experiences in the program. Most consultants felt they had been adequately trained for their responsibilities.

New Jersey's demonstration experience offers two important lessons about the role of a fiscal agent in consumer direction. First, New Jersey consumers overwhelmingly preferred to use—and pay for—services from the program fiscal agent, rather than to receive their allowance as cash and assume all fiscal responsibilities. Second, a program fiscal agent can play an instrumental role in preventing misuse of the allowance. In New Jersey, the fiscal agent double-checked the accuracy of consumers' cash management plans and verified that all check requests matched those plans.

By allowing consumers to designate representatives, New Jersey made consumer direction a reality for interested Medicaid beneficiaries with a broad range of abilities. Without representatives, participation may have been beyond the reach of consumers with cognitive impairments or limited English skills. Other consumers, such as those who were already receiving help maintaining a checking account, probably felt more at ease in the program with a representative than they would have on their own. Moreover, consultants judged that representatives were obtaining input from consumers when possible and were faithful to their best interests.

Starting Consumers on the Monthly Allowance. Getting consumers started on the allowance quickly may not have been the top priority of the New Jersey demonstration program. Staff realized that even the appearance of misuse of public funds could jeopardize the entire program, so they implemented a complex allowance-planning process. In addition, staff wished

to accommodate the abilities of consumers, so they let them take the time they needed to make the transition to consumer direction. Whether or not the program was satisfied with having started only 57 percent of consumers on the allowance within six months of random assignment, the result had important downsides. The number of allowance recipients increased so slowly that it created cash flow problems for the fiscal agent and hampered its ability to serve consumers efficiently. Moreover, some consumers must have found the number of steps and people involved in allowance planning frustrating.

New Jersey did take some steps to reduce allowance delays. It assigned consumers to consulting agencies (instead of asking them to choose), consolidated caseloads across a smaller number of consulting agencies, and gave personal care agencies less notice to discontinue services. In addition, some consultants streamlined allowance planning by using three-way calls, instead of several one-way calls, to solve problems. The program might have reduced delays further by (1) telling consumers whom to call (the program, consultant, or fiscal agent) about particular issues; and (2) instructing the fiscal agent to clearly indicate the nature of any errors in consumers' cash management plans.²¹ Moreover, the program might have made consultants more responsible for helping consumers get past the allowance-planning hurdle, as did Arkansas, another demonstration state. Under the Arkansas demonstration program, the fiscal agent/counseling agency was contractually obligated to start consumers on the allowance within 45 days (originally 60 days). A program database generated periodic reminders to counselors about consumers not yet on the allowance. The strategy seemed effective; 80 percent of

²¹As of early 2003, New Jersey was planning two program design changes as part of a proposal to continue Personal Preference as a Section 1115 waiver program. First, it would authorize consultants to approve cash management plans if they included only items on a list specified by the program. Second, it would offer consulting and fiscal services through a single organization. These changes, if approved by CMS as part of the program's operation protocol, would be expected to reduce the time to allowance receipt.

Arkansas consumers received the program allowance within three months of random assignment, compared to 32 percent of New Jersey consumers.

Recruiting and Hiring Workers. For some consumers, getting started on the allowance was difficult because recruiting a worker was difficult. Although having the opportunity to pay family members for caregiving was important to many consumers when they enrolled in the demonstration, the ability to exercise choice and control more generally is the Cash and Counseling model's reason for being. If consumers seek choice and control but do not have family members they wish to hire, programs could help such consumers recruit other workers without actually doing it for them. Such assistance would be valuable in a full-employment economy, when personal care workers tend to be scarce.

Personal Preference consultants who participated in site visit discussions expressed uncertainty about how much assistance they were expected to give consumers when they were trying to recruit workers. As a result, their approaches varied. Some consultants gave suggestions on recruiting techniques to those who did not have a family member or friend they wanted to hire. They shared personal hiring experiences with consumers and gave them copies of materials on recruiting. For example, some copied materials on advertising, interviewing, and other aspects of recruiting from the Personal Preference consultant manual and gave them to consumers. One consultant also gave consumers copies of materials developed by another program because she thought they were helpful. Another consultant recommended that consumers seek workers through their churches. Others named places to post free ads, such as bulletin boards in colleges and Laundromats. The consumers these particular consultants served may have benefited from their assistance. However, consultants and consumers probably would have benefited from more training for consultants on their responsibilities in helping consumers recruit. Recruiting nonrelatives was difficult for consumers in the other two demonstration states

as well as in New Jersey. Therefore, in addition to any worker registries that states might develop, it might also be helpful for the Cash and Counseling National Program Office to develop consumer-friendly materials on recruiting or to maintain a cross-state list of creative, successful recruiting strategies for consultants' reference.

Addressing Diversity. Of the three demonstration states, New Jersey enrolled the most demographically diverse population. Consumers in ethnic or linguistic minorities might find consumer-directed programs especially attractive because they can hire workers with similar backgrounds. However, marketing new programs to a diverse target population is challenging, as is providing consulting services to a diverse group of enrollees.

Personal Preference dealt with diversity in several ways. It stipulated that those involved in enrollment (first the contractor, then the state employees) speak English and Spanish, the two most common languages in the state. Many program materials were printed in these languages and Russian, which also is commonly spoken in the New Jersey Medicaid population. The program sometimes had to send materials in a language not everyone could read. The program included a notice in those mailings informing the addressee in 14 languages that the material was important and asking the addressee to have someone translate it immediately. In addition, when speaking with consumers by telephone, Personal Preference staff used the AT&T language line, which provides translator services in many languages, frequently (about 10 times a day). Any state seeking to offer consumer-directed programs to diverse populations must consider the costs of translating written material and the spoken word.

Despite the program's efforts to address diversity, our analysis found some evidence that consumers in minority groups had difficulty in the program. In particular, Hispanic treatment group consumers were less likely than non-Hispanic ones to receive the Personal Preference allowance and remain in the program. As noted, according to self-reports, the proportion of

Hispanic consumers was more than twice that of Hispanic consultants. Consumers might be able to hire workers with backgrounds similar to their own, but states may find it difficult to accommodate diversity in providing consulting services.

How Personal Preference Addressed Policy Concerns

As noted earlier, policymakers have several concerns about consumer direction in a publicly funded program like Medicaid. We conclude by discussing how the structure and procedures of New Jersey's Personal Preference program addressed these concerns.

Assessing Suitability for Consumer Direction. With one minor exception, New Jersey's policy was to *not* screen prospective enrollees for their suitability for consumer direction. As noted earlier, it excluded beneficiaries who were expected to require PCA for less than six months, because it would take consumers several months to develop acceptable cash management plans and hire workers. In all other cases, the state informed prospects of the rights and responsibilities of Personal Preference consumers and let them decide whether to enroll. Giving consumers the right to return to traditional PCA services at any time and to receive PCA services until the Personal Preference allowance started made it unnecessary to ascertain suitability in advance (which would probably have been impossible).

An important lesson from Personal Preference is that consumer direction is an attractive, viable option for some elderly Medicaid beneficiaries. Younger adults were more likely than elderly ones to enroll in Personal Preference. Once enrolled, however, elderly and nonelderly consumers had remarkably similar program experiences, a finding that may be contrary to expectations. Moreover, among consumers who hired or tried to hire workers, those who were elderly were *less* likely than others to say hiring was difficult, all else being equal.

Paying Family Members. There is a long-standing debate about the appropriateness of using public funds to pay family members (Simon-Rusinowitz et al. forthcoming; Doty 2004;

Benjamin 2001; Benjamin et al. 2000; Tilly and Weiner 2001; Doty et al. 1999; Simon-Rusinowitz et al. 1998). Proponents of paying family members contend that the practice may help postpone burnout or compensate for the constraints that caregiving may place on employment opportunities. Some opponents argue that payment may erode traditional values about familial responsibility, while others worry that consumers may feel obligated to hire family members and thus not exercise full autonomy. Other opponents worry about the effects of payment on public costs. Would consumer direction lead government to pay for services that family caregivers have long provided free? Would it induce caregivers to demand payment?

This analysis has shown that the ability to hire family members was an important aspect of consumers' success in the New Jersey program. Before random assignment, nearly 8 in 10 consumers said hiring family was important to them; among consumers who hired workers, more than 7 in 10 hired family; and among allowance recipients, 4 in 10 said the ability to choose caregivers or compensate informal caregivers was the greatest benefit of program participation. Consultants did not mention observing frayed family relationships as a result of consumers' paying relatives. However, they did advise consumers who wanted to hire relatives that it might not work out. For example, they emphasized that consumers might find it difficult to discipline a worker who was a relative. During site visit discussions, one consultant reported that she advised consumers not to hire family members who were already burning out from providing unpaid care.

Finally, current federal law allows relatives to be paid as caregivers only if they are not legally responsible for the care recipient. (Parents are legally responsible for minor children, as are spouses for adults.) In contrast, the federal waivers for the Cash and Counseling demonstrations did allow legally responsible relatives to be paid caregivers. In New Jersey's Personal Preference program, however, only four percent of nonelderly consumers and less than

one percent of elderly ones had a spouse as a paid caregiver. (The number of consumers who hired spouses was too few to support analysis of any differences between their program experiences and those of other consumers.)

Ensuring Consumer Safety. Ensuring the health and safety of vulnerable consumers without oversight from home care agencies and hands-on involvement of case managers is a major concern for consumer direction. For many years, regulations for agency-delivered home care have been in place to ensure care quality through requirements about agency structure and worker training and supervision (Kapp 2000; Doty et al. 1996). However, researchers and policymakers disagree about the fundamental definition of care quality in consumer-directed models and how to assess it. Should the uniform professional standards of agency-based care apply? Or are consumers the more appropriate arbiters of quality? In 1999, most U.S. consumer-directed personal assistance programs (74 percent) required workers to have specific qualifications; nearly half (45 percent) required some type of worker training; and most (88 percent) conducted quality-monitoring activities such as case management, consumer satisfaction reviews, and program evaluations (Flanagan 2001).

Consumers, consultants, and program staff provided no evidence that participation in Personal Preference led to adverse effects on consumers' health and safety. Personal Preference monitored consumer safety and care quality primarily through consultants' contacts with consumers and representatives, which occurred by telephone and in consumers' homes, and through semiannual reassessment visits by independent Medicaid nurses. Consultants were required to telephone consumers once a month during their first six months of program participation. Some consultants endorsed the calls, while others considered them unnecessarily frequent for some consumers. The consultants who took part in site visit discussions did not question the value of quarterly home visits. Although neither the calls nor the visits were used

exclusively to assess consumer safety, Personal Preference did have follow-up procedures in place if consultants suspected that anything was amiss.

Preventing Exploitation of Workers. Some policymakers and program planners worry that exploitation of workers is a potential problem in consumer-directed programs. Although Personal Preference workers had no formal mechanism to report grievances, exploitation does not seem to have been a serious problem. During our site visit, consultants mentioned one case in which a consumer inappropriately withheld a worker's paycheck. Program staff intervened, and the worker was paid thereafter. On the questionnaire, one consultant reported seeing evidence of worker abuse by a consumer's representative but did not elaborate further. During site visit interviews, program staff said they mandated that a consumer who was making unreasonable demands on her paid workers have a representative. While that mistreatment may have been intentional, in other cases, it seemed to stem from consumers' inexperience as employers. For example, after a consumer fired a satisfactory worker without notice, she was surprised to learn that the worker was upset. As she explained to her consultant, "No one ever told me I was supposed to give a worker notice before firing them." Similarly, other consumers had to learn the importance of submitting workers' time sheets on schedule so that they would be paid on time.

Preventing Misuse of Public Funds. Misuse of the allowance was not a serious problem under Personal Preference, probably because the program took the *potential* for such a problem seriously. The primary method Personal Preference used to ensure appropriate use of the cash allowance was program approval of the cash management plan, coupled with fiscal agent review to verify that expenditures were included in the plan. In addition, the fiscal agent provided consumers with financial statements to ensure that consumers knew, and thus did not inadvertently overspend, their account balances. (However, some consumers apparently did not

understand that the statements were “snapshots” of their accounts and that some charges may have been pending when the statement was prepared.) When the program suspected intentional misuses of the allowance, it investigated further. In one case, the program disenrolled a consumer for misusing the allowance; in two other cases, investigations of suspected misuse revealed nothing improper.

Conclusion

By providing a flexible monthly allowance and consulting and fiscal services to interested Medicaid beneficiaries, New Jersey’s Personal Preference program helped a diverse group of people control the who, what, how, and when of their disability-related supportive services. At the same time, the state addressed many important concerns about publicly funded consumer-directed care. It developed policies that adhered to the tenets of the rather expansive Cash and Counseling model of service delivery, and it made procedural adjustments as needed during the demonstration. Because it has evidence that a substantial minority of PCA users find satisfaction in directing their own supportive services, New Jersey plans to continue offering Personal Preference as an option to eligible Medicaid beneficiaries.

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COMPANION REPORTS

Impacts on Quality of Care and Use of Personal Care

These reports compare treatment and control group members, using data from telephone interviews describing, among other outcomes measured nine months after random assignment: satisfaction, unmet need, disability-related health, and hours and types of personal care received.

Carlson, Barbara Lepidus, Stacy Dale, Leslie Foster, Randall Brown, Barbara Phillips, and Jennifer Schore. “Effect of Consumer Direction on Personal Care and Well-Being in Arkansas, New Jersey, and Florida.” Princeton, NJ: Mathematica Policy Research, Inc., May 2005.

Foster, Leslie, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. “Does Consumer Direction Affect the Quality of Medicaid Personal Assistance in Arkansas?” Princeton, NJ: Mathematica Policy Research, Inc., March 2003.

Also see published version of this report: Foster et al. “Improving the Quality of Medicaid Personal Care Through Consumer Direction.” *Health Affairs* Web exclusive W3, March 26, 2003, pp. 162–175.

Dale, Stacy, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. “The Effect of Consumer Direction on Personal Assistance Received in Arkansas.” Princeton, NJ: Mathematica Policy Research, Inc., April 2003.

Also see published version of this report: Dale et al. “The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas.” *Health Affairs* Web exclusive W3, November 19, 2003, pp. 566–575.

Foster, Leslie, Stacy Dale, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. “Do Consumer-Directed Supportive Services Work for Children with Developmental Disabilities?” Princeton, NJ: Mathematica Policy Research, Inc., September 2004.

Impacts on the Cost of Medicaid and Medicare Services

These reports compare treatment and control group members, using Medicaid and Medicare data describing the cost of personal care and other covered services measured during the year after random assignment, as well as presenting information about Cash and Counseling program costs. Reports on costs in the Arkansas program and on costs for children in the Florida program are listed below. A report on adults in all three programs is forthcoming.

Dale, Stacy, Randall Brown, and Barbara Phillips. “Does Arkansas’ Cash and Counseling Program Affect Service Use and Public Costs?” Princeton, NJ: Mathematica Policy Research, Inc., July 2004.

Dale, Stacy, Randall Brown, and Barbara Phillips. “Medicaid Costs Under Consumer Direction for Florida Children with Developmental Disabilities.” Princeton, NJ: Mathematica Policy Research, Inc., December 2004.

Impacts on Informal Caregiving

These reports compare the experiences of primary informal caregivers of treatment and control group members (identified at the time of random assignment), using data from telephone interviews describing caregiver burden and well-being nine months after random assignment. The Arkansas report and one on caregivers for children participating in the Florida program are listed below. A report on caregivers for adults from all three programs is forthcoming.

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. “Easing the Burden of Caregiving: The Impact of Consumer Direction on Primary Informal Caregivers in Arkansas” Princeton, NJ: Mathematica Policy Research, Inc., August 2003.

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. “The Effects of Cash and Counseling on the Primary Informal Caregivers of Children with Developmental Disabilities.” Princeton, NJ: Mathematica Policy Research, Inc., April 2005.

Experiences of Paid Workers

These reports compare the experiences of primary paid workers of treatment and control group members (identified nine months after random assignment), using data from telephone interviews describing working conditions, burden, and well-being 10 months after random assignment. The Arkansas report is listed below; a report on workers for the Florida and New Jersey programs is forthcoming.

Dale, Stacy, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. “The Experiences of Workers Hired Under Consumer Direction in Arkansas.” Princeton, NJ: Mathematica Policy Research, Inc., June 2003.

Program Implementation

These reports describe program goals, features, and procedures in detail based on in-person interviews with program staff. There is one report for each state program and a fourth report presenting implementation lessons drawn across the three programs.

Phillips, Barbara, and Barbara Schneider. “Moving to Independent Choices: The Implementation of the Cash and Counseling Demonstration in Arkansas.” Princeton, NJ: Mathematica Policy Research, Inc., May 2002.

Phillips, Barbara, and Barbara Schneider. "Enabling Personal Preference: The Implementation of the Cash and Counseling Demonstration in New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., March 2003.

Phillips, Barbara, and Barbara Schneider. "Changing to Consumer-Directed Care: The Implementation of the Cash and Counseling Demonstration in Florida." Princeton, NJ: Mathematica Policy Research, Inc., July 2004.

Phillips, Barbara, Kevin Mahoney, Lori Simon-Rusinowitz, Jennifer Schore, Sandra Barrett, William Ditto, Tom Reimers, and Pamela Doty. "Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., June 2003.

The current report is the third of a set of three. These reports provide an overview of program implementation by distilling information from the site visit reports noted above and synthesizing this information with data from a mail survey of counselors and telephone interviews with consumers in the program treatment groups.

Schore, Jennifer, and Barbara Phillips. "Consumer and Counselor Experiences in the Arkansas Independent Choices Program." Princeton, NJ: Mathematica Policy Research, Inc., January 2004.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the Florida Consumer Directed Care Program." Princeton, NJ: Mathematica Policy Research, Inc., June 2005.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the New Jersey Personal Preference Program." Princeton, NJ: Mathematica Policy Research, Inc., July 2005.

Program Demand and Participation

This report will describe changes in enrollment in demonstration feeder programs before and after demonstration implementation, as well as compare program participants with eligible nonparticipants. The report will include all three state programs.

APPENDIX A
ADDITIONAL TABLES

TABLE A.1
ENROLLMENT FLOW, BY AGE GROUP

| | Percentage of Consumers Enrolled | | |
|-------------------------------------|----------------------------------|---------------|-----------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Enrollment Month | | | |
| November 1999 to June 2000 | 30.2 | 30.0 | 30.4 |
| July 2000 to December 2000 | 20.8 | 21.5 | 20.1 |
| January 2001 to June 2001 | 19.6 | 19.3 | 19.9 |
| July 2001 to December 2001 | 13.1 | 11.9 | 14.1 |
| January 2002 to July 2002 | 16.3 | 17.3 | 15.4 |
| Number of Consumers Enrolled | 871 | 404 | 467 |

Source: Personal Preference program records.

TABLE A.2

CONSUMER CHARACTERISTICS AT THE TIME OF RANDOM ASSIGNMENT, BY AGE GROUP
(Percentages)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|---|---------|---------------|-----------------|
| Demographic Characteristics | | | |
| Age | | | |
| 18 to 39 | 15.3 | 32.9 | 0.0 |
| 40 to 64 | 31.1 | 67.1 | 0.0 |
| 65 to 79 | 32.3 | 0.0 | 60.2 |
| 80 or older | 21.4 | 0.0 | 39.8 |
| Sex | | | |
| Female | 74.2 | 67.3 | 80.1 |
| Race | | | |
| Self-identified as: | | | |
| White only | 52.9 | 50.4 | 55.2 |
| Black only or black and some other race | 38.0 | 42.7 | 33.8 |
| Some other race | 9.1 | 6.9 | 11.1 |
| Hispanic | 35.5 | 30.3 | 39.9 |
| Years of Education | | | |
| 8 or fewer | 40.0 | 23.3 | 54.6 |
| 9 to 12, nongraduate | 18.9 | 22.8 | 15.4 |
| 12 (high school graduate) | 19.6 | 26.7 | 13.3 |
| More than 12 (some college) | 21.6 | 27.2 | 16.7 |
| Living Arrangement/Marital Status | | | |
| Lives alone | 35.3 | 35.9 | 34.7 |
| Lives with spouse only | 9.5 | 7.7 | 11.1 |
| Lives with others/not married or married and living with two or more other people | 55.2 | 56.4 | 54.2 |
| Health and Functioning | | | |
| Health Status | | | |
| Excellent or good | 20.0 | 22.3 | 18.0 |
| Fair | 35.2 | 30.8 | 39.0 |
| Poor | 44.8 | 46.9 | 43.1 |
| Health Compared with Last Year | | | |
| Better or about the same | 50.8 | 60.8 | 43.1 |
| Worse | 49.1 | 39.0 | 42.1 |
| Expected Health Next Year | | | |
| Better | 31.6 | 36.7 | 27.2 |
| Worse | 24.6 | 17.9 | 30.4 |
| Same | 24.7 | 27.8 | 22.0 |
| Could not say | 18.9 | 17.3 | 20.3 |

TABLE A.2 (continued)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|--|---------|---------------|-----------------|
| Last week, Not Independent In: ^a | | | |
| Transferring | 66.8 | 65.9 | 67.5 |
| Bathing | 86.3 | 86.1 | 86.5 |
| Using toilet | 67.0 | 67.8 | 66.2 |
| Functioning Compared with Last Year | | | |
| Better or about the same | 41.2 | 50.9 | 32.8 |
| Worse | 58.7 | 48.9 | 67.2 |
| Unpaid and Paid PCA | | | |
| Had Unpaid or Paid Help at Home Last Week With: | | | |
| Personal care ^b | 86.8 | 87.4 | 86.3 |
| Transportation ^c | 61.5 | 65.8 | 57.7 |
| Routine health care ^d | 77.3 | 74.0 | 80.2 |
| Housework or community chores ^e | 95.1 | 94.8 | 95.3 |
| Number of Unpaid Caregivers Last Week | | | |
| None | 15.7 | 15.4 | 16.1 |
| One | 25.5 | 25.0 | 25.9 |
| Two | 23.4 | 24.8 | 22.3 |
| Three or more | 35.4 | 34.9 | 35.8 |
| Primary Unpaid Caregiver Relationship to Consumer | | | |
| Spouse | 6.5 | 7.7 | 5.6 |
| Parent | 11.8 | 25.0 | 0.4 |
| Child | 40.9 | 19.1 | 59.7 |
| Other relative | 14.2 | 16.6 | 12.2 |
| Nonrelative | 9.6 | 15.6 | 4.5 |
| Had no primary informal caregiver | 16.9 | 16.1 | 17.6 |
| Primary Informal Caregiver Employed | 39.7 | 35.5 | 43.4 |
| Number of Paid Caregivers Last Week | | | |
| None | 17.0 | 17.6 | 16.5 |
| One | 57.9 | 53.5 | 61.7 |
| Two | 15.4 | 17.1 | 13.9 |
| Three or more | 9.8 | 11.9 | 7.9 |
| Had Paid Live-in Caregiver Last Week | 1.6 | 1.5 | 1.7 |
| Received Help at Home from Privately Paid Source Last Week | 14.0 | 13.1 | 14.8 |

TABLE A.2 (continued)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|---|---------|---------------|-----------------|
| Goods and Services Purchased Last Year | | | |
| Social/Recreational Programs | 15.0 | 17.6 | 12.9 |
| Adult Day Care | 13.7 | 15.8 | 12.0 |
| Transportation | 54.1 | 62.2 | 47.1 |
| Home or Van Modification | 21.9 | 25.5 | 18.8 |
| Equipment Purchase | 29.8 | 28.5 | 30.9 |
| Unmet Need for, and Access to, PCA | | | |
| Last Week, Needed Help (or More Help) With: | | | |
| Personal care ^b | 74.3 | 76.0 | 72.8 |
| Transportation ^c | 69.0 | 71.7 | 66.7 |
| Housework or community chores ^e | 79.5 | 81.6 | 77.7 |
| Potential Difficulty Hiring Due to Location | | | |
| Lives in a rural area | 10.5 | 8.5 | 12.2 |
| Lives in a nonrural area, but transportation difficult or high crime | 44.6 | 49.6 | 40.1 |
| Lives in a nonrural area, but transportation not difficult and not high crime | 44.9 | 41.9 | 47.6 |
| Satisfaction with Paid PCA | | | |
| Satisfaction with How Paid Help Provided ^f | | | |
| Very satisfied | 32.5 | 32.3 | 32.7 |
| Satisfied | 27.6 | 24.1 | 30.7 |
| Dissatisfied | 20.8 | 24.3 | 17.8 |
| No paid help with personal care, routine health care, housework | 19.1 | 19.3 | 18.8 |
| Satisfied with When Paid Help Provided Among Those Receiving Personal Care ^f | | | |
| Very satisfied | 25.8 | 25.3 | 26.2 |
| Satisfied | 27.3 | 26.1 | 28.4 |
| Dissatisfied | 25.4 | 26.1 | 24.9 |
| No paid help with personal care | 21.5 | 22.6 | 20.6 |
| Satisfied with Paid Services and Goods Overall | | | |
| Very satisfied | 29.3 | 27.8 | 30.6 |
| Satisfied | 35.8 | 32.9 | 38.3 |
| Dissatisfied | 30.2 | 36.2 | 25.0 |
| No paid services or goods ^g | 4.7 | 3.1 | 6.1 |

TABLE A.2 (continued)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|---|------------|---------------|-----------------|
| Quality of Life | | | |
| How Satisfied with Life Overall | | | |
| Very satisfied | 11.6 | 10.6 | 12.5 |
| Satisfied | 19.2 | 20.4 | 18.1 |
| Dissatisfied | 28.2 | 39.7 | 18.1 |
| Proxy respondent not asked | 41.0 | 29.4 | 51.1 |
| Employment Experience | | | |
| Currently Employed | 2.5 | 3.6 | 0.6 |
| Ever Employed | 78.8 | 76.9 | 80.4 |
| Ever Supervised Someone | 32.2 | 34.7 | 30.0 |
| Ever Hired Someone Privately | 29.4 | 30.7 | 28.2 |
| Type of Respondent | | | |
| Majority of Baseline Questions Answered by Proxy Respondent | 40.0 | 28.7 | 49.7 |
| PCA Tenure and Program Allowance | | | |
| Length of Time with Medicaid PCA | | | |
| Less than six months | 54.8 | 56.4 | 53.3 |
| Six months or longer | 45.2 | 43.6 | 46.7 |
| Mean Monthly Allowance (Dollars) | \$1,062 | \$1,069 | \$1,056 |
| Number of Respondents to the Baseline Interview | 871 | 404 | 467 |

Source: Age and sex come from Personal Preference program records. All other data come from MPR baseline interviews conducted in New Jersey between November 1999 and July 2002.

Note: "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

^dRoutine health care includes taking medications, checking vital signs, and doing exercises.

^eHousework and community chores include light housework, yard work, meal preparation, and shopping.

TABLE A.2 (continued)

^fFor 35 cases, proxy respondent is providing own level of satisfaction because sample member reportedly is not capable of forming opinion.

^gSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = Personal Care Assistance.

TABLE A.3

PROGRAM FEATURES IMPORTANT TO CONSUMERS AT THE TIME OF RANDOM ASSIGNMENT,
 BY AGE GROUP
 (Percentages)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|--|------------|---------------|-----------------|
| Having a Choice About the Types of Help Received | | | |
| Very important | 91.4 | 94.1 | 89.1 |
| Important or somewhat important | 6.5 | 5.0 | 7.9 |
| Not important | 2.1 | 1.0 | 3.0 |
| Having a Choice About When Helpers Come | | | |
| Very important | 87.8 | 91.1 | 85.0 |
| Important or somewhat important | 9.3 | 6.9 | 11.4 |
| Not important | 2.9 | 2.0 | 3.6 |
| Paying Family Members to Help | | | |
| Very important | 77.6 | 78.9 | 76.5 |
| Important or somewhat important | 13.8 | 14.1 | 13.5 |
| Not important | 8.6 | 7.0 | 10.1 |
| Paying Friends to Help | | | |
| Very important | 69.1 | 71.0 | 67.5 |
| Important or somewhat important | 16.8 | 18.9 | 15.0 |
| Not important | 14.1 | 10.2 | 17.6 |
| Primary Informal Caregiver Expressed Interest in Being Paid | | | |
| | 29.7 | 32.1 | 27.6 |
| Number of Respondents to the Baseline Interview | 871 | 404 | 467 |

Source: MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002).

TABLE A.4

CONSULTANT CHARACTERISTICS AND EXPERIENCE WITH PERSONAL PREFERENCE

| Characteristic | Number |
|---|-----------|
| Professional Background | |
| Social work | 29 |
| Education | 1 |
| Accounting | 1 |
| Not specified | 5 |
| Highest Educational Degree | |
| Less than high school | 0 |
| High school graduate or GED | 8 |
| Associate | 2 |
| Baccalaureate | 17 |
| Master's or doctorate | 8 |
| Missing data | 2 |
| Sex | |
| Female | 33 |
| Hispanic or Latino | 6 |
| Race | |
| White | 23 |
| African American/black | 7 |
| Other | 3 |
| Missing data | 4 |
| Country of Birth | |
| United States | 30 |
| Time Working for Personal Preference | |
| 12 months or less | 14 |
| More than 12 months | 20 |
| Missing data | 3 |
| Number of Consumers with Whom Consultant Has Worked Since Started with Personal Preference, if Any ^a | |
| Mean | 8.7 |
| Median | 5.5 |
| Minimum | 1.0 |
| Maximum | 60.0 |
| Number of Consumers with Whom Consultant Working at Present | |
| Mean | 5.8 |
| Median | 4.0 |
| Minimum | 0.0 |
| Maximum | 26.0 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

^aOne consultant reported not having yet worked with a consumer.

TABLE A.5

ACTIVITIES CONDUCTED BY CONSULTANTS

| | |
|---|-----------|
| Mean Number of Hours Consultants Worked per Week for Personal Preference | 4.0 |
| Number of Consultants Spending at Least 20 Percent of Consulting Time on the Following Activities with Consumers: | |
| Assisting with spending plan or advising about purchases | 15 |
| Administrative activities ^a | 15 |
| Advising about payroll activities for workers ^b | 11 |
| Listening or providing encouragement or support | 9 |
| Reinforcing decision to participate | 1 |
| Linking to peer counseling or other local services | 1 |
| Reassessing Medicaid plans or investigating Medicaid problems | 1 |
| Advising about worker training | 1 |
| Assisting in disputes with workers or advising about firing | 0 |
| Assisting with emergency back-up arrangements | 0 |
| Monitoring or investigating misuse of allowance or abuse/neglect/exploitation | 0 |
| Number of Consultants Reporting the Following as Valuable to Consumers: | |
| Assisting with spending plan or advising about purchases | 29 |
| Assisting with paperwork | 28 |
| Listening or providing encouragement or support | 27 |
| Advising about payroll activities for workers | 23 |
| Linking to peer counseling or other local services | 6 |
| Assisting with emergency back-up arrangements | 6 |
| Advising about worker training | 2 |
| Assisting in disputes with workers or advising about firing | 2 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

^a“Administrative activities” include record keeping, updating case notes, and contacting other program staff.

^b“Payroll activities” refer to such activities as setting wages and estimating payroll taxes.

TABLE A.6
CONSUMER MONITORING

| | |
|--|-----------|
| Number of Consultants Reporting That at Least One Consumer Needed Extensive Monitoring | 13 |
| Average Number of Consumers on Caseload Who Needed Extensive Monitoring | 0.5 |
| Number of Consultants Reporting the Following Reasons for Monitoring: | |
| Consumer or representative had difficulty completing paperwork | 10 |
| Consumer or representative had no experience as employer | 7 |
| Workers changed frequently | 7 |
| Consumer or representative appeared to be abused, neglected, or financially exploited | 2 |
| Consumer's living environment was unsafe | 1 |
| Representative changed | 2 |
| Consumer or representative was ill | 6 |
| Consumer or representative appeared to be abusing or financially exploiting worker | 0 |
| Consumer or representative was having difficulty staying on budget | 0 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

Note: Consultants were asked about consumers or representatives who required extensive monitoring due to concerns about their ability to manage the cash benefit or about their safety.

TABLE A.7

TIME BETWEEN RANDOM ASSIGNMENT AND MONTHLY ALLOWANCE START,
DISENROLLMENT, OR DEATH: ALL CONSUMERS

| | Percentage of Consumers |
|---|-------------------------|
| Started Monthly Allowance by End Of:^a | |
| 1 month | 0.2 |
| 2 months | 9.3 |
| 3 months | 31.5 |
| 4 months | 43.3 |
| 5 months | 51.7 |
| 6 months | 56.7 |
| 7 months | 60.3 |
| 8 months | 63.0 |
| 9 months | 64.8 |
| 10 months | 65.4 |
| 11 months | 66.0 |
| 12 months | 66.6 |
| Snapshot at End of 3 Months^b | |
| Enrolled and started allowance | 30.2 |
| Enrolled and allowance not started | 61.3 |
| Disenrolled | 6.9 |
| Deceased | 1.6 |
| Snapshot at End of 6 Months^b | |
| Enrolled and started allowance | 53.0 |
| Enrolled and allowance not started | 23.0 |
| Disenrolled | 21.3 |
| Deceased | 2.8 |
| Snapshot at End of 9 Months^b | |
| Enrolled and started allowance | 58.1 |
| Enrolled and allowance not started | 8.8 |
| Disenrolled | 28.7 |
| Deceased | 4.4 |
| Snapshot at End of 12 Months^b | |
| Enrolled and started allowance | 56.8 |
| Enrolled and allowance not started | 5.5 |
| Disenrolled | 32.1 |
| Deceased | 5.7 |
| Number of Consumers Enrolled | 871 |

Source: Personal Preference program records for the year following consumers' random assignment.

^aPercentages in this panel are cumulative and include consumers who started on cash before the referenced month but subsequently disenrolled or died.

^bExcludes 10 consumers without valid disenrollment data.

TABLE A.7a

TIME BETWEEN RANDOM ASSIGNMENT AND ALLOWANCE START, DISENROLLMENT, OR DEATH,
BY AGE GROUP AND PCA TENURE

| | Percentage of Consumers | | | |
|---|-------------------------|-------------|----------------------------------|--------------------|
| | Age | | Length of Time with Medicaid PCA | |
| | 18 to 64 | 65 or Older | Less than 6 Months | 6 Months or Longer |
| Started Monthly Allowance by End Of:^a | | | | |
| 1 month | 0.3 | 0.2 | 0.0 | 0.5 |
| 2 months | 7.9 | 10.5 | 11.7 | 6.4 |
| 3 months | 31.7 | 31.3 | 35.4 | 26.7 |
| 4 months | 45.1 | 41.8 | 47.8 | 37.8 |
| 5 months | 52.5 | 51.0 | 56.0 | 46.5 |
| 6 months | 58.7 | 55.0 | 60.2 | 52.5 |
| 7 months | 61.9 | 58.9 | 63.5 | 56.4 |
| 8 months | 65.4 | 61.0 | 66.5 | 58.9 |
| 9 months | 67.1 | 62.7 | 67.3 | 61.7 |
| 10 months | 68.1 | 63.2 | 67.9 | 62.4 |
| 11 months | 68.6 | 63.8 | 68.3 | 63.2 |
| 12 months | 69.6 | 64.0 | 68.6 | 64.2 |
| Snapshot at End of 3 Months^b | | | | |
| Enrolled and started allowance | 30.3 | 30.1 | 34.2 | 25.4 |
| Enrolled and allowance not started | 61.7 | 61.0 | 55.0 | 69.0 |
| Disenrolled | 7.3 | 6.5 | 8.9 | 4.4 |
| Deceased | 0.8 | 2.4 | 1.9 | 1.3 |
| Snapshot at End of 6 Months^b | | | | |
| Enrolled and started allowance | 54.9 | 51.3 | 59.6 | 49.7 |
| Enrolled and allowance not started | 23.1 | 22.9 | 18.1 | 29.0 |
| Disenrolled | 20.8 | 21.7 | 23.1 | 19.0 |
| Deceased | 1.3 | 4.1 | 3.2 | 2.3 |
| Snapshot at End of 9 Months^b | | | | |
| Enrolled and started allowance | 60.2 | 56.3 | 59.9 | 55.9 |
| Enrolled and allowance not started | 8.8 | 8.9 | 6.2 | 12.1 |
| Disenrolled | 28.3 | 29.0 | 29.3 | 28.0 |
| Deceased | 2.8 | 5.8 | 4.7 | 4.1 |
| Snapshot at End of 12 Months^b | | | | |
| Enrolled and started allowance | 59.4 | 54.6 | 57.5 | 55.9 |
| Enrolled and allowance not started | 5.0 | 5.8 | 3.6 | 7.7 |
| Disenrolled | 31.8 | 32.3 | 32.3 | 31.8 |
| Deceased | 3.8 | 7.4 | 6.7 | 4.6 |
| Number of Consumers Enrolled | 404 | 467 | 477 | 394 |

Source: Personal Preference program records for the year following consumers' random assignment.

^aPercentages in this panel are cumulative and include consumers who started on cash before the referenced month but subsequently disenrolled or died.

^bExcludes 10 consumers without valid disenrollment data.

PCA = Personal Care Assistance.

TABLE A.8
USE OF REPRESENTATIVES

| | |
|--|-----------|
| Number of Consultants Working with Consumers Who Used Representatives | 30 |
| Of Those Consultants, Number Reporting That: | |
| Representatives acted according to the wishes and best interest of consumers | 30 |
| Representative's suitability was questionable in at least one case | 4 |
| Consumer disenrolled because representative was unsuitable | 1 |
| Representative had a serious divergence of wishes or interests from consumer | 1 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

TABLE A.9
USE OF, AND SATISFACTION WITH, PROGRAM SERVICES

| | Percentage of Consumers Reporting | Percentage of Users Reporting Service Useful/Satisfied with Service |
|--|-----------------------------------|---|
| Help Developing Cash Management Plan Between Baseline and 6-Month Interviews | 71.7 | 93.7 |
| Help Revising Cash Management Plan Between 6-Month and 9-Month Interviews | 27.8 | n.a. |
| Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews | 38.9 | n.a. |
| Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire) | 57.6 | 83.5 |
| Advice About How to Recruit Workers Between Baseline And 6-Month Interviews (Among Those Who Tried to Hire) | 42.0 | 91.5 |
| Advice or Materials About How to Recruit Workers Between 6-Month and 9-Month Interviews (Among Those Who Tried to Hire) | 31.3 | n.a. |
| Use of Program Fiscal Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance) | 97.0 | 92.4 |
| Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired) | 33.9 | 86.5 |
| Advice About How to Train Workers Between 6-Month and 9-Month Interviews (Among Those Who Hired) | 23.9 | n.a. |
| Use of Peer Counseling Services Between Baseline and 6-Month Interviews (Among Those Receiving Allowance) | 4.4 | 93.8 |
| Use of Peer Counseling Services Between 6-Month and 9-Month Interviews (Among Those Receiving Allowance) | 2.0 | n.a. |
| Number of Respondents to the 6-Month Interview | 783 | |
| Number of Respondents to the 9-Month Interview | 715 | |

Source: MPR consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

n.a. = not asked.

TABLE A.9a

USE OF, AND SATISFACTION WITH, PROGRAM SERVICES: NONELDERLY ADULTS

| | Percentage of Consumers Reporting | Percentage of Users Reporting Service Useful/Satisfied with Service |
|---|-----------------------------------|---|
| Help Developing Cash Management Plan Between Baseline and 6-Month Interviews | 72.9 | 92.8 |
| Help Revising Cash Management Plan Between 6-Month and 9-Month Interviews | 26.1 | n.a. |
| Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews | 34.4 | n.a. |
| Materials About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire) | 57.8 | 84.1 |
| Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire) | 39.4 | 91.3 |
| Advice or Materials About How to Recruit Workers Between 6-Month and 9-Month Interviews (Among Those Who Tried to Hire) | 29.2 | n.a. |
| Use of Program Fiscal Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance) | 95.7 | 90.5 |
| Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired) | 32.2 | 77.2 |
| Advice About How to Train Workers Between 6-Month and 9-Month Interviews (Among Those Who Hired) | 27.0 | n.a. |
| Use of Peer Counseling Services Between Baseline and 6-Month Interviews (Among Those Receiving Allowance) | 5.3 | 88.9 |
| Use of Peer Counseling Services Between 6-Month and 9-Month Interviews (Among Those Receiving Allowance) | 2.1 | n.a. |
| Number of Respondents to the 6-Month Interview | 367 | |
| Number of Respondents to the 9-Month Interview | 345 | |

Source: MPR consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

n.a. = not asked.

TABLE A.9b

USE OF, AND SATISFACTION WITH, PROGRAM SERVICES: ELDERLY ADULTS

| | Percentage of Consumers Reporting | Percentage of Users Reporting Service Useful/Satisfied with Service |
|--|-----------------------------------|---|
| Help Developing Cash Management Plan Between Baseline and 6-Month Interviews | 70.7 | 94.5 |
| Help Revising Cash Management Plan Between 6-Month and 9-Month Interviews | 29.3 | n.a. |
| Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews | 43.0 | n.a. |
| Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire) | 57.4 | 83.0 |
| Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire) | 44.6 | 91.7 |
| Advice or Materials About How to Recruit Workers Between 6-Month and 9-Month Interviews (Among Those Who Tried to Hire) | 33.9 | n.a. |
| Use of Program Fiscal Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance) | 98.1 | 94.0 |
| Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired) | 35.4 | 93.4 |
| Advice About How to Train Workers Between 6-Month and 9-Month Interviews (Among Those Who Hired) | 20.0 | n.a. |
| Use of Peer Counseling Services Between Baseline and 6-Month Interviews (Among Those Receiving Allowance) | 3.6 | 100.0 |
| Use of Peer Counseling Services Between 6-Month and 9-Month Interviews (Among Those Receiving Allowance) | 1.9 | n.a. |
| Number of Respondents to the 6-Month Interview | 416 | |
| Number of Respondents to the 9-Month Interview | 402 | |

Source: MPR consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

n.a. = not asked.

TABLE A.10

ASPECTS OF PROGRAM SERVICES FOUND USEFUL, BY AGE GROUP

| | Percentage | | |
|--|------------|---------------|-----------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Among Those Receiving Help with Cash Management Plan, What Aspect of Help Found Useful: | | | |
| Explaining program rules | 75.6 | 75.1 | 76.1 |
| Clarifying goals, options, and priorities | 40.3 | 38.2 | 42.2 |
| Handling paperwork | 27.1 | 26.1 | 28.0 |
| Determining service costs | 10.0 | 10.0 | 10.1 |
| Getting approval for special uses of allowance | 8.6 | 7.5 | 9.7 |
| Among Those Receiving Advice About How to Recruit Workers, What Aspects of Advice Found Useful: | | | |
| Locating potential workers | 23.1 | 24.0 | 22.2 |
| Setting wage or benefit levels | 24.0 | 23.0 | 25.0 |
| Screening or interviewing potential workers | 28.4 | 27.0 | 29.6 |
| Arranging for background check | 3.4 | 3.0 | 3.7 |
| Providing training or advice of unspecified nature | 48.6 | 48.0 | 49.1 |
| Number of Respondents to the 6-Month Interview | 783 | 367 | 416 |

Source: MPR consumer interviews conducted 6 months after consumers' random assignment.

TABLE A.11

DIFFICULTIES ASSUMING THE ROLE OF EMPLOYER, BY AGE GROUP

| | Percentage | | |
|--|--------------------------|---------------------|-----------------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Hiring Workers | | | |
| Hiring Workers with Allowance Between Baseline and 9-Month Interviews | | | |
| Hired a worker | 57.2 | 56.7 | 57.7 |
| Tried to hire a worker, but did not | 24.7 | 30.3 | 19.8 |
| Did not try to hire a worker | 18.1 | 13.1 | 22.5 |
| Among Those Who Hired with Allowance Between Baseline and 9-Month Interviews, Found Hiring Hard | | | |
| | 28.8 | 30.9 | 27.0 |
| Among Those Who Found Hiring Hard Between Baseline and 6-Month Interviews, Aspect That Was Hardest | | | |
| Could not find interested/qualified workers | 33.0 | 35.3 | 30.8 |
| Wages offered were too low | 8.7 | 7.8 | 9.6 |
| Applicants disliked hours or tasks | 18.5 | 19.6 | 17.3 |
| Getting references/judging qualifications | 10.7 | 13.7 | 7.7 |
| Did not trust applicants | 4.9 | 3.9 | 5.8 |
| Training Workers | | | |
| Among Those Who Hired with Allowance, Provided Training for Workers Hired with Allowance Between Baseline and 9-Month Interviews | | | |
| Shown worker how to carry out tasks | 44.1 | 38.7 | 48.9 |
| Arranged for training outside the home | 4.0 | 2.5 | 5.3 |
| Among Those Who Trained Workers Between Baseline and 9-Month Interviews, Found Training Hard | | | |
| | 11.0 | 11.1 | 10.8 |
| Among Those Who Found Training Hard Between Baseline and 6-Month Interviews, Aspect That Was Hardest | | | |
| | Numbers (overall n = 13) | | |
| Worker did not seem to understand/difficult to communicate what was wanted | 0 | 0 | 0 |
| Worker wanted to do task some other way | 2 | 0 | 2 |
| Consumer or family unable to demonstrate task/answer questions about task | 2 | 0 | 2 |
| Difficult to find training programs | 2 | 0 | 2 |
| Worker had no experience | 4 | 2 | 2 |
| Difficult to train and also get work done | 0 | 0 | 0 |
| Difficult for consumer and worker to get used to each other | 0 | 0 | 0 |
| Number of Respondents to the 6- or 9-Month Interview | 815 | 380 | 435 |

Source: MPR consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

TABLE A.12
RECRUITING METHODS, BY AGE GROUP

| | Percentage | | |
|--|------------|---------------|-----------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Recruiting Methods Attempted, Among Those Who Hired or Tried to Hire Worker | | | |
| Tried to Hire | | | |
| Family member | 73.8 | 68.3 | 79.4 |
| Friend, neighbor, or church member | 40.0 | 48.4 | 31.8 |
| Home care agency worker | 28.9 | 32.4 | 25.4 |
| Asked Family or Friend to Recommend Worker | 32.1 | 35.3 | 29.0 |
| Posted or Consulted Advertisements | 7.5 | 7.7 | 7.4 |
| Contacted Employment Agency | 5.5 | 5.5 | 5.4 |
| Recruiting Methods Resulting in Hires, Among Those Who Hired | | | |
| Hired Family Member | 72.5 | 65.7 | 78.5 |
| Hired Friend, Neighbor, or Church Member | 23.6 | 31.4 | 16.7 |
| Hired Former Agency Worker | 13.3 | 12.8 | 13.7 |
| Hired Worker Recommended by Family or Friend | 11.4 | 13.2 | 9.9 |
| Posted or Consulted Advertisement | 5.3 | 4.4 | 6.0 |
| Contacted Employment Agency | 0.9 | 0.0 | 1.7 |
| Hired Through Other Means | 1.4 | 2.0 | 0.9 |
| Number of Respondents to the 6- or 9-Month Interview | 815 | 380 | 435 |

Source: MPR consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

TABLE A.13

SATISFACTION WITH WORKERS, AS REPORTED BY CONSULTANTS

| Consultants Reporting That He or She Worked with at Least One Consumer Who: | Number |
|---|-----------|
| Included a Paid Worker in Cash Management Plan | 35 |
| Had Serious Problem Due to Workers Resigning or Being Fired | 18 |
| Hired a Relative | 32 |
| Was very satisfied with worker | 31 |
| Was very dissatisfied with worker | 5 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

TABLE A.14

CONSULTANT REPORTS OF ABUSE OF CONSUMERS AND WORKERS

| | |
|---|--------------|
| Financial Exploitation of Consumers | |
| Number of Consultants Reporting Evidence of Financial Exploitation ^a | 1 |
| Number of Consumers per Consultant for Whom There Was Evidence of Financial Exploitation | 1 |
| Number of Consultants Reporting Financial Exploitation of Consumers By: | |
| Representatives | 0 |
| Workers | 1 |
| Physical or Verbal Abuse or Neglect of Consumers | |
| Number of Consultants Reporting Evidence of Abuse or Neglect | 1 |
| Number of Consultants Reporting Abuse or Neglect, by Type | |
| Self-neglect | 1 |
| Physical or sexual abuse | 0 |
| Neglect of physical needs or abandonment | 0 |
| Verbal, emotional, or psychological abuse | 0 |
| Average Number of Consumers for Whom There Was Evidence of Abuse or Neglect | No responses |
| Number of Consultants Reporting Abuse or Neglect of Consumers By: | |
| Representatives | No responses |
| Workers | No responses |
| Physical or Verbal Abuse of Workers | |
| Number of Consultants Reporting Evidence of Abuse of Workers by Consumers, Their Representatives, or Families | 1 |
| Number of Consultants Reporting Worker Abuse or Neglect, by Type | |
| Physical or sexual abuse | 0 |
| Verbal, emotional, or psychological abuse | 1 |
| Number of Consumers per Consultant for Whom There Was Evidence of Abuse of Workers | 1 |
| Number of Consultants Reporting Abuse of Workers By: | |
| Representatives | No responses |
| Consumers | 1 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

^aFinancial exploitation includes stealing money or possessions from consumers, intentional overbilling, and coercing to sign over assets.

TABLE A.15

CONSULTANT REPORTS OF MISUSE OF THE MONTHLY ALLOWANCE

| | |
|---|-----------|
| Number of Consultants Reporting Evidence of Misuse of the Allowance | 2 |
| Number of Consultants Reporting Misuse, by Type | |
| Purchased nonpermissible goods or services | 0 |
| Had worker purchase nonpermissible goods or services | 0 |
| Overspent allowance | 0 |
| Did not report worker hours in timely way | 0 |
| Did not pay worker on time or correct amount | 0 |
| Not specified | 2 |
| Number of Consultants Reporting Misuse More Likely Among Consumers Without Representative | 0 |
| Number of Consultants Reporting Misuse Less Likely Among Consumers Without Representative | 1 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

TABLE A.16
PAID ASSISTANCE, BY AGE GROUP

| | Percentage | | |
|--|------------|------------------|--------------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Hired a Worker with Monthly Allowance Between Baseline and 9-Month Interview | 55.6 | 56.8 | 54.5 |
| Had Paid Worker in 2 Weeks Before 9-Month Interview | 86.5 | 87.2 | 85.8 |
| Hired Worker with Monthly Allowance Between Baseline and 9-Month Interview and Had Paid Worker in 2 Weeks Before Interview | 52.5 | 53.6 | 51.5 |
| Among Those Who Hired Worker with Monthly Allowance and Had Worker in 2 Weeks Before 9-Month Interview ^a | | | |
| Had 1 worker | 75.0 | 71.4 | 78.3 |
| Had 2 workers | 19.4 | 19.5 | 19.3 |
| Had 3 or more workers | 5.6 | 9.2 | 2.4 |
| Had visiting worker(s) | 64.8 | 67.0 | 62.8 |
| Had live-in worker(s) | 43.6 | 41.6 | 45.4 |
| At least one worker was consumer's | | | |
| Spouse | 2.3 | 4.3 | 0.5 |
| Parent | 10.7 | 22.2 | 0.5 |
| Child | 42.9 | 24.3 | 59.4 |
| Other relative | 23.0 | 24.3 | 21.7 |
| Nonrelative | 27.3 | 33.0 | 22.2 |
| Worker helped with | | | |
| Routine health care ^b | 91.8 | 90.3 | 93.2 |
| Personal care ^c | 97.7 | 97.3 | 98.1 |
| Housework or community chores ^d | 99.5 | 99.5 | 99.5 |
| Transportation ^e | 66.8 | 70.8 | 63.3 |
| Hours of paid care | | | |
| 14 or fewer | 5.1 | 5.2 | 5.0 |
| 15 to 42 | 48.0 | 48.6 | 47.5 |
| 43 to 70 | 31.1 | 36.4 | 26.5 |
| 71 or more | 15.8 | 9.8 | 21.0 |
| Worker helped | | | |
| Before 8 A.M. on weekdays | 48.3 | 50.8 | 46.1 |
| After 8 P.M. on weekdays | 68.4 | 69.7 | 67.2 |
| On weekends | 86.0 | 86.5 | 85.5 |
| Number of Respondents to the 9-Month Interview | 747 | 345 | 402 |
| Number of Consumers Who Hired with the Monthly Allowance and Reported on Care Received During a 2-Week Period | 392 | 185 | 207 |

TABLE A.16 (continued)

Source: MPR consumer interviews conducted by telephone 9 months after consumers' random assignment.

^aDescription is of all paid workers for treatment group members who hired with the allowance, including workers for 11 consumers who had disenrolled from Personal Preference and were probably reporting on help received from agency workers.

^bRoutine health care includes taking medications, checking vital signs, and doing exercises.

^cPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^dHousework or community chores include light housework, yard work, meal preparation, and shopping.

^eTransportation includes trips for medical and nonmedical reasons.

TABLE A.17

USES OF THE MONTHLY ALLOWANCE: ALL CONSUMERS

| During Month 8 After Random Assignment | Percent Using Allowance | Mean Expenditure (Dollars) | Percent of Allowance Spent (Mean) |
|---|-------------------------|----------------------------|-----------------------------------|
| Paid a Worker | 86.1 | 925 | 80.3 |
| Purchased Home Care Agency Services | 1.6 | 12 | 0.8 |
| Purchased Home Modifications | 1.0 | 1 | 0.1 |
| Purchased Vehicle Modifications | 0.0 | 0 | 0.0 |
| Purchased Equipment ^a | 7.5 | 7 | 1.1 |
| Purchased Personal Care Supplies ^b | 1.2 | 1 | 0.2 |
| Purchased Community Services ^c | 2.6 | 2 | 0.6 |
| Received Cash ^d | 51.2 | 35 | 7.9 |
| Other Expenses | 0.8 | 1 | 0.2 |
| Total Expenses Paid During Month 8 | 94.7 | 984 | n.a. |
| Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8 | | 506 | |

Source: Personal Preference program bookkeeper records.

Note: Of the 871 treatment group members, 118 had disenrolled or died before month 8, and 247 were still enrolled but had no record with the bookkeeper for month 8. In addition, 27 were still enrolled and had a record for month 8, but the record showed no spending for goods or services during that month; these cases are included in the means as zeros.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, and housekeeping.

^bPersonal care supplies include diapers or pads to protect bedding, ostomy supplies, and feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.

^dConsumers could receive up to 10 percent of the monthly allowance as cash for incidental purchases.

n.a. = not applicable.

TABLE A.17a

USES OF THE MONTHLY ALLOWANCE: NONELDERLY ADULTS

| During Month 8 After Random Assignment | Percent Using Allowance | Mean Expenditure (Dollars) | Percent of Allowance Spent (Mean) |
|---|-------------------------|----------------------------|-----------------------------------|
| Paid a Worker | 86.7 | 882 | 79.1 |
| Purchased Home Care Agency Services | 2.1 | 17 | 1.1 |
| Purchased Home Modifications | 0.8 | 2 | 1.1 |
| Purchased Vehicle Modifications | 0.0 | 0 | 0.0 |
| Purchased Equipment ^a | 10.9 | 13 | 1.6 |
| Purchased Personal Care Supplies ^b | 2.5 | 2 | 0.3 |
| Purchased Community Services ^c | 2.9 | 2 | 0.7 |
| Received Cash ^d | 55.6 | 42 | 8.2 |
| Other Expenses | 1.7 | 2 | 0.5 |
| Total Expenses Paid During Month 8 | 95.8 | 962 | n.a. |
| Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8 | | 239 | |

Source: Personal Preference program bookkeeper records.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, and housekeeping.

^bPersonal care supplies include diapers or pads to protect bedding, ostomy supplies, and feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.

^dConsumers could receive up to 10 percent of the monthly allowance as cash for incidental purchases.

n.a. = not applicable.

TABLE A.17b

USES OF THE MONTHLY ALLOWANCE: ELDERLY ADULTS

| During Month 8 After Random Assignment | Percent Using Allowance | Mean Expenditure (Dollars) | Percent of Allowance Spent (Mean) |
|---|-------------------------|----------------------------|-----------------------------------|
| Paid a Worker | 85.8 | 963 | 81.4 |
| Purchased Home Care Agency Services | 1.1 | 8 | 0.6 |
| Purchased Home Modifications | 1.1 | 1 | 0.1 |
| Purchased Vehicle Modifications | 0.0 | 0 | 0.0 |
| Purchased Equipment ^a | 4.5 | 2 | 0.7 |
| Purchased Personal Care Supplies ^b | 0.0 | 0 | 0.0 |
| Purchased Community Services ^c | 2.2 | 2 | 4.4 |
| Received Cash ^d | 47.2 | 29 | 7.7 |
| Other Expenses | 0.0 | 0 | 0.0 |
| Total Expenses Paid During Month 8 | 93.6 | 1,005 | n.a. |
| Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8 | | 267 | |

Source: Personal Preference program bookkeeper records.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, and housekeeping.

^bPersonal care supplies include diapers or pads to protect bedding, ostomy supplies, and feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.

^dConsumers could receive up to 10 percent of the monthly allowance as cash for incidental purchases.

n.a. = not applicable.

TABLE A.18

SPECIFIC TYPES OF CONSUMER PURCHASES REPORTED BY CONSULTANTS

Number of Consultants Reporting Consumer Purchases Of:

| | |
|--|----|
| Assistive or Safety Devices | |
| Device to aid with mobility | 9 |
| Home security or personal emergency response system | 1 |
| Device to aid with vision or hearing | 0 |
| Other assistive device or device related to safety | 0 |
| Talking computer | 2 |
| Other communications device | 3 |
| Personal Care Products and Appliances | |
| Incontinence supplies | 7 |
| Dietary supplements or products | 2 |
| Personal hygiene products | 3 |
| Supplies for urinary catheter or ostomy | 2 |
| Enteral/parenteral feeding supplies | 0 |
| Supplies related to use of home oxygen or ventilator | 2 |
| Electric toothbrush or shaver | 1 |
| Other personal care products or appliances | 3 |
| Home or Vehicle Modification | |
| Install shower stall or other bathroom remodeling | 4 |
| Install interior or exterior ramp | 10 |
| Modify van or automobile | 0 |
| Widen doorway | 3 |
| Change door handles or light switches | 0 |
| Lower counters or do other kitchen remodeling | 0 |
| Other home or vehicle modifications | 0 |
| Home or Yard Appliances | |
| Lawn mower or snow removal device | 1 |
| Clothes washer or dryer | 0 |
| Other kitchen appliances | 9 |
| Microwave oven | 0 |
| Other home or yard appliance | 1 |
| Commercial Services | |
| Transportation from a taxi or other car or van service | 19 |
| Chore or homemaker services | 10 |
| Delivery of prepared food from a restaurant or groceries from a retail store | 5 |
| Errand or shopping services | 8 |
| Laundry service | 10 |
| Other commercial services | 0 |
| Training or Educational Services | |
| Training or education for consumer | 1 |
| Training or education for worker | 1 |
| Other training or education | 0 |

TABLE A.18 (continued)

Number of Consultants Reporting Consumer Purchases Of:

| | |
|---|-----------|
| Other or Atypical Purchases | |
| Over-the-counter medications | 2 |
| Equipment repair or back-up equipment rental or purchase to use during repair | 2 |
| Exercise equipment or other devices to aid in rehabilitation | 3 |
| Day care | 0 |
| Prescription medications in excess of Medicaid limits | 0 |
| Service animal | 0 |
| Other Medicaid services in excess of coverage limits | 0 |
| Other purchases not listed elsewhere | 0 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

Note: Table contains responses to questions about specific types of consumer purchases (or approved plans to purchase) with the monthly allowance.

TABLE A.19

FLEXIBILITY AND CONSTRAINTS OF THE MONTHLY ALLOWANCE

| | Number of Consultants |
|---|-----------------------|
| Examples of Creative Purchases, as Reported by Consultants | |
| Hired family member or friend | 1 |
| Purchased combination of worker services and equipment | 1 |
| Hired live-in worker with desired qualifications | 2 |
| Purchased equipment to increase independence | 3 |
| Purchased housecleaning service | 1 |
| Examples of Denied Purchases, as Reported by Consultants | |
| Cosmetics, food, cigarettes, alcohol | 8 |
| Home modification not related to disability or health | 1 |
| Furniture, appliances, and equipment not related to disability | 1 |
| Savings | 1 |
| Recreational goods and services | 1 |
| Travel not related to disability | 1 |
| Percentage of Consumers Reporting Program's Spending Rules Kept Them from Getting Things That Would Have Enhanced Independence ^a | 29.9 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |
| Number of Respondents to the 6-Month Interview | 871 |

Source: MPR consultant survey administered by mail in April 2001 and consumer interviews conducted by telephone 6 months after consumers' random assignment.

^aBy age group, the percentage reporting restrictive program rules were: 32.2 percent, ages 18 to 64; 28.4 percent, age 65 and older.

TABLE A.20a

SATISFACTION WITH PERSONAL PREFERENCE, BY AGE GROUP

| | Percentage | | |
|---|------------|------------------|--------------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Would Recommend the Program to Others | 91.1 | 90.9 | 91.2 |
| Effect of Monthly Allowance on Quality of Life, Among Those Ever Receiving Allowance | | | |
| Improved a great deal | 57.2 | 54.2 | 60.0 |
| Improved somewhat | 24.7 | 26.7 | 22.9 |
| Stayed the same | 17.5 | 17.8 | 17.1 |
| Reduced somewhat | 0.4 | 0.9 | 0.0 |
| Reduced a great deal | 0.2 | 0.4 | 0.0 |
| Most Important Ways Monthly Allowance Improved Life, Among Those Who Reported Improvement | | | |
| Consumer feels more independent, in control, or emotionally healthy | 11.8 | 12.1 | 11.4 |
| Benefit enables consumer to: | | | |
| Choose caregivers | 37.6 | 33.0 | 41.8 |
| Get care of higher quality | 15.7 | 18.7 | 12.9 |
| Get enough care or care at the right time | 7.8 | 7.7 | 8.0 |
| Get the right types of care | 7.6 | 11.0 | 4.5 |
| Compensate informal caregivers or lessen their burden | 3.4 | 2.8 | 4.0 |
| Purchase other items related to personal care or health, food or nutritional supplements, or care-related supplies | 3.4 | 1.7 | 5.0 |
| Number of Respondents to the 9-Month Interview | 747 | 345 | 402 |

Source: MPR consumer interviews conducted by telephone 9 months after consumers' random assignment.

TABLE A.20b

SATISFACTION WITH PERSONAL PREFERENCE, BY TYPE OF RESPONDENT

| | Percentage | | |
|--|------------|----------------------|-------------------|
| | Overall | Consumer Respondents | Proxy Respondents |
| Would Recommend the Program to Others | 91.1 | 89.3 | 93.5 |
| Effect of Monthly Allowance on Quality of Life, Among Those Ever Receiving Allowance | | | |
| Improved a great deal | 57.2 | 54.7 | 60.7 |
| Improved somewhat | 24.7 | 24.5 | 24.9 |
| Stayed the same | 17.5 | 19.7 | 14.4 |
| Reduced somewhat | 0.4 | 0.7 | 0.0 |
| Reduced a great deal | 0.2 | 0.4 | 0.0 |
| Most Important Ways Monthly Allowance Improved Life, Among Those Who Reported Improvement | | | |
| Consumer feels more independent, in control, or emotionally healthy | 11.8 | 12.3 | 11.1 |
| Benefit enables consumer to: | | | |
| Choose caregivers | 37.6 | 37.4 | 37.8 |
| Get care of higher quality | 15.7 | 19.0 | 11.6 |
| Get enough care or care at the right time | 7.8 | 5.2 | 11.1 |
| Get the right types of care | 7.6 | 11.4 | 2.9 |
| Compensate informal caregivers or lessen their burden | 3.4 | 0.5 | 2.9 |
| Purchase other items related to personal care or health, food or nutritional supplements, or care-related supplies | 3.4 | 1.9 | 5.2 |
| Number of Respondents to the 9-Month Interview | 747 | 447 | 300 |

Source: MPR consumer interviews conducted by telephone 9 months after consumers' random assignment.

TABLE A.21a

SATISFACTION WITH, AND UNMET NEED FOR, PCA, BY AGE GROUP

| | Percentage | | |
|---|------------|---------------|-----------------|
| | Overall | Ages 18 to 64 | Age 65 or Older |
| Current Satisfaction With: | | | |
| Overall care arrangements ^a | | | |
| Very satisfied | 52.9 | 50.5 | 55.3 |
| Satisfied | 35.1 | 35.1 | 35.1 |
| Dissatisfied | 12.0 | 14.4 | 9.6 |
| Ability to get transportation when needed ^b | | | |
| Very satisfied | 53.6 | 52.7 | 54.6 |
| Satisfied | 28.2 | 26.2 | 30.3 |
| Dissatisfied | 18.2 | 21.2 | 15.1 |
| Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Satisfied With: ^{c, d} | | | |
| Relationship with paid caregiver | 99.3 | 98.7 | 100.0 |
| How paid caregiver helps with personal care ^e | 99.6 | 100.0 | 99.2 |
| How paid caregiver helps with routine health care ^f | 100.0 | 100.0 | 100.0 |
| How paid caregiver helps with housework or community chores ^g | 99.6 | 99.3 | 100.0 |
| Times of day help provided | 95.3 | 96.1 | 94.4 |
| Would Not Have Been Difficult to Change the Times of Day Help Provided ^{c, d} | 45.9 | 43.2 | 49.2 |
| Among Those Who Hired with Allowance, Paid Caregiver: ^{d, h} | | | |
| Always or almost always completed all tasks | 78.5 | 78.3 | 78.6 |
| Never neglected consumer | 83.6 | 80.8 | 87.0 |
| Never left early or arrived late, among those with regular schedule | 59.1 | 60.3 | 57.7 |
| Never was rude or disrespectful | 84.4 | 84.8 | 83.9 |
| Never helped when help was not wanted | 65.5 | 66.2 | 64.5 |
| Never took belongings without asking | 93.0 | 92.5 | 93.6 |
| Needs Help or More Help With: ⁱ | | | |
| Housework or community chores | 47.5 | 54.3 | 39.7 |
| Personal care | 42.1 | 43.9 | 40.0 |
| Routine health care | 31.1 | 34.8 | 26.8 |
| Transportation | 38.7 | 45.7 | 30.5 |
| Number of Respondents to the 9-Month Interview | 747 | 345 | 402 |

Source: MPR consumer interviews conducted by telephone 9 months after consumers' random assignment.

^aSatisfaction with overall care not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion.

TABLE A.21a (continued)

^bSatisfaction with ability to get transportation not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion, or if no transportation sought. Transportation includes trips for medical and nonmedical reasons.

^cSatisfaction with paid caregiver relationship and performance, and ability to change paid caregiver schedule, not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion, if consumer did not hire a caregiver with allowance, or if consumer had no paid help during the two weeks before the interview.

^dDescription is of all paid caregivers for consumers who hired with the allowance (with the exceptions noted) and includes paid caregivers for 11 consumers who had disenrolled from Personal Preference and were probably reporting about satisfaction with agency workers.

^ePersonal care includes bathing, transferring from bed, eating, and using the toilet. Not asked if consumer had no paid help with personal care.

^fRoutine health care includes taking medications, checking vital signs, and doing exercises. Not asked if consumer had no paid help with routine health care.

^gHousework or community chores include light housework, yard work, meal preparation, and shopping. Not asked if consumer had no paid help with housework or community chores.

^hSatisfaction with paid caregiver attitude and respectfulness not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion, or if consumer did not hire a caregiver with allowance.

ⁱUnmet need not asked if proxy respondent is also paid caregiver.

PCA = Personal Care Assistance.

TABLE A.21b

SATISFACTION WITH, AND UNMET NEED FOR, PCA, BY TYPE OF RESPONDENT

| | Percentage | | |
|---|------------|---------------------|------------------|
| | Overall | Consumer Respondent | Proxy Respondent |
| Current Satisfaction With: | | | |
| Overall care arrangements ^a | | | |
| Very satisfied | 52.9 | 49.5 | 60.9 |
| Satisfied | 35.1 | 38.0 | 28.2 |
| Dissatisfied | 12.0 | 12.5 | 10.9 |
| Ability to get transportation when needed ^b | | | |
| Very satisfied | 53.6 | 50.1 | 62.3 |
| Satisfied | 28.2 | 29.1 | 25.8 |
| Dissatisfied | 18.2 | 20.8 | 12.0 |
| Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Satisfied With: ^{c, d} | | | |
| Relationship with paid caregiver | 99.3 | 99.0 | 100.0 |
| How paid caregiver helps with personal care ^e | 99.6 | 99.5 | 100.0 |
| How paid caregiver helps with routine health care ^f | 100.0 | 100.0 | 100.0 |
| How paid caregiver helps with housework or community chores ^g | 99.6 | 99.5 | 100.0 |
| Times of day help provided | 95.3 | 95.6 | 94.7 |
| Would Not Have Been Difficult to Change the Times of Day Help Provided ^{c, d} | 45.9 | 43.3 | 52.7 |
| Among Those Who Hired with Allowance, Paid Caregiver: ^{d, h} | | | |
| Always or almost always completed all tasks | 78.5 | 79.1 | 76.9 |
| Never neglected consumer | 83.6 | 82.8 | 85.9 |
| Never left early or arrived late, among those with regular schedule | 59.1 | 58.8 | 60.0 |
| Never was rude or disrespectful | 84.4 | 84.9 | 82.9 |
| Never helped when help was not wanted | 65.5 | 67.7 | 59.2 |
| Never took belongings without asking | 93.0 | 90.8 | 98.9 |
| Needs Help or More Help With: ⁱ | | | |
| Housework or community chores | 47.5 | 47.4 | 47.8 |
| Personal care | 42.1 | 38.4 | 51.1 |
| Routine health care | 31.1 | 30.6 | 32.2 |
| Transportation | 38.7 | 42.3 | 30.0 |
| Number of Respondents to the 9-Month Interview | 747 | 447 | 300 |

Source: MPR consumer interviews conducted by telephone 9 months after consumers' random assignment.

^aSatisfaction with overall care not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion.

TABLE A.21b (continued)

^bSatisfaction with ability to get transportation not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion, or if no transportation sought. Transportation includes trips for medical and nonmedical reasons.

^cSatisfaction with paid caregiver relationship and performance, and ability to change paid caregiver schedule, not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer opinion, if consumer did not hire a caregiver with allowance, or if consumer had no paid help during the two weeks before interview.

^dDescription is of all paid caregivers for consumers who hired with the allowance (with the exceptions noted) and includes paid caregivers for 11 consumers who had disenrolled from Personal Preference and were likely reporting about satisfaction with agency workers.

^ePersonal care includes bathing, transferring from bed, eating, and using the toilet. Not asked if consumer had no paid help with personal care.

^fRoutine health care includes taking medications, checking vital signs, and doing exercises. Not asked if consumer had no paid help with routine health care.

^gHousework or community chores include light housework, yard work, meal preparation, and shopping. Not asked if consumer had no paid help with housework or community chores.

^hSatisfaction with paid caregiver attitude and respectfulness not asked if proxy respondent is used and proxy is also paid caregiver or cannot give consumer's opinion, or if consumer did not hire a caregiver with allowance.

ⁱUnmet need not asked if proxy respondent is also paid caregiver.

PCA = Personal Care Assistance.

TABLE A.22

DISENROLLMENT DURING FOLLOW-UP YEAR AND REASONS FOR DISENROLLMENT,
BY AGE GROUP
(Percentages)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|--|---------|------------------|--------------------|
| Disenrollment and Death During Follow-Up Year, According to Program Records (n = 861)^a | | | |
| Disenrolled for Any Reason Other than Death | 32.6 | 32.6 | 32.7 |
| Disenrolled Voluntarily | 22.4 | 21.1 | 23.6 |
| Died | 5.7 | 3.8 | 7.4 |
| Reasons for Disenrollment | | | |
| According to Program Records (n = 329) ^b | | | |
| Death | 14.9 | 10.3 | 18.5 |
| No longer eligible for Medicaid | 5.2 | 6.9 | 3.8 |
| No longer eligible for PCA | 7.3 | 7.6 | 7.1 |
| Abuse or mismanagement of allowance | 0.3 | 0.0 | 0.5 |
| Program initiated disenrollment for some other reason ^c | 13.6 | 17.3 | 10.9 |
| Consumer initiated disenrollment | 58.7 | 57.9 | 59.2 |
| According to Consumer or Proxy Reports (n = 192) ^d | | | |
| Death | 16.7 | 12.2 | 20.0 |
| Left the state | 0.0 | 0.0 | 0.0 |
| Entered hospital or nursing home | 1.6 | 0.0 | 2.7 |
| Lost or needed representative | 8.9 | 3.7 | 12.7 |
| No longer eligible for PCA | 20.3 | 29.3 | 13.6 |
| Program initiated disenrollment | 5.2 | 6.1 | 4.6 |
| Consumer initiated disenrollment | 47.4 | 48.8 | 46.4 |
| Reasons for Consumer-Initiated Disenrollment, According to Consumer or Proxy Reports (n = 91) | | | |
| Problem with employer responsibilities | 33.7 | 37.8 | 30.6 |
| Changed mind/satisfied with traditional services | 30.2 | 18.9 | 38.8 |
| Problem with fiscal responsibilities | 10.5 | 10.8 | 10.2 |
| Allowance not enough | 9.3 | 16.2 | 4.1 |
| Other problems with allowance | 3.5 | 5.4 | 2.0 |
| Consumer/worker/helper health worsened | 7.0 | 8.1 | 6.1 |
| Conflict with program staff/too many rules about use of allowance | 5.8 | 0.0 | 10.2 |
| Program never contacted consumer | 1.2 | 0.0 | 2.0 |
| Other reasons | 5.8 | 8.1 | 4.1 |
| Timing of Disenrollment | | | |
| Among Those Who Disenrolled or Died According to Records, Did So During Months (n = 330) ^a | | | |
| 1 to 3 | 22.7 | 22.8 | 22.7 |
| 4 to 6 | 40.6 | 37.9 | 42.7 |
| 7 to 9 | 23.6 | 25.5 | 22.2 |
| 10 to 12 | 13.0 | 13.8 | 12.4 |

TABLE A.22 (continued)

| | Overall | Ages 18 to 64 | Age 65 or Older |
|---|------------|------------------|--------------------|
| Among Those Who Disenrolled or Died According to Records (n = 325) ^e | | | |
| Disenrolled or died before started receiving allowance | 73.2 | 69.7 | 76.0 |
| Disenrolled after started receiving allowance | 18.5 | 22.5 | 15.3 |
| Died after started receiving allowance | 8.3 | 7.7 | 8.7 |
| Among Those Who Disenrolled or Died According to Consumer or Proxy Reports (n = 204), Did So | | | |
| Between baseline and 6-month interview | 68.6 | 70.5 | 67.2 |
| Between the 6- and 9-month interviews | 31.4 | 29.6 | 32.8 |
| Number of Consumers with Program Records | 871 | 404 | 467 |
| Number of Respondents to 6- or 9-Month Interview | 815 | 380 | 435 |

Source: Personal Preference program records and MPR consumer interviews conducted 6 and 9 months after consumers' random assignment.

^aExcludes 10 consumers without a valid disenrollment date.

^bExcludes 10 consumers without a valid disenrollment date and 1 without a recorded reason for disenrollment.

^cIncludes 10 unlocatable consumers, 8 consumers "no longer appropriate" for consumer direction, and 47 consumers for whom the reason for disenrollment was not specified.

^dExcludes 12 consumers who did not report a reason for disenrolling.

^eExcludes 5 consumers who reenrolled and then received the allowance.

PCA = Personal Care Assistance.

TABLE A.23

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER STARTED ON ALLOWANCE
WITHIN 9 MONTHS OF RANDOM ASSIGNMENT
(Omitted Categories in Parentheses)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|--------------------------|---------------------------|
| Demographic Characteristics | | |
| Age | | |
| (18 to 64) | | |
| 65 or older | -0.08 | .663 |
| Female | -0.23 | .253 |
| Hispanic | -0.61** | .012 |
| Self-Identified Race | | |
| (White only) | | |
| Black only or black and some other race | -0.45** | .029 |
| Some other race | -0.06 | .855 |
| Education | | |
| High school graduate | | |
| (Did not graduate high school) | -0.16 | .412 |
| Living Arrangement | | |
| Lives alone | | |
| (Lives with others) | -0.38** | .045 |
| Health and Functioning | | |
| Health Status at Enrollment | | |
| (Excellent or good) | | |
| Fair | -0.14 | .553 |
| Poor | 0.19 | .421 |
| Last Week, Not Independent In: ^a | | |
| Transferring | -0.09 | .681 |
| Bathing | 0.54** | .050 |
| Using toilet | 0.34 | .152 |
| Use of Unpaid and Paid Assistance | | |
| Number of Unpaid Caregivers Last Week | | |
| (None) | | |
| One | 0.26 | .362 |
| Two | 0.54* | .075 |
| Three or more | 0.31 | .298 |
| Primary Unpaid Caregiver Employed | 0.23 | .210 |

TABLE A.23 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Number of Paid Caregivers Last Week | | |
| (None) | | |
| One | 0.04 | .884 |
| Two or more | -0.60** | .041 |
| Unmet Need for, and Access to, Personal Assistance | | |
| Last Week, Needed Help (or More Help) With: | | |
| Personal care ^b | 0.22 | .304 |
| Transportation ^c | 0.05 | .792 |
| Housework and community chores ^d | -0.17 | .484 |
| Potential Difficulty Hiring Due to Location | | |
| Lives in a rural area | -0.39 | .199 |
| Lives in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime) | -0.32* | .077 |
| Satisfaction with Paid Personal Assistance | | |
| Satisfied with Paid Services and Goods Overall | | |
| Very satisfied | -0.37 | .114 |
| Satisfied (Dissatisfied) | -0.08 | .699 |
| No paid services or goods ^e | 0.17 | .718 |
| Employment Experience | | |
| Ever Employed | 0.00 | .989 |
| Ever Supervised Someone | 0.21 | .307 |
| Ever Hired Someone Privately | 0.34* | .092 |
| Type of Respondent | | |
| Majority of Baseline Questions Answered by Proxy Respondent | 0.11 | .606 |
| Demonstration Enrollment | | |
| Length of Time with PCA Upon Enrollment | | |
| Less than 6 months (6 months or longer) | 0.10 | .563 |

TABLE A.23 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Mean Weekly Allowance | | |
| (Less than \$150) | | |
| \$150 to \$299 | 0.03 | .902 |
| \$300 to \$499 | -0.16 | .503 |
| \$500 or more | -0.06 | .826 |
| Being Allowed to Pay Family or Friends Very Important | 0.52** | .032 |
| Having a Choice About Worker Schedule Very Important | 0.27 | .299 |
| Having a Choice About Types of Help Received Very Important | 0.23 | .471 |
| Primary Unpaid Caregiver Expressed Interest in Being Paid | 0.06 | .752 |
| Enrolled Between November 1999 and December 2000 | -0.66*** | .000 |
| Number of Consumers | | 802 |

Source: For independent variables, data on age and sex come from Personal Preference program records; other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002). For the dependent variable, data come from Personal Preference program records.

Notes: The relationship between consumer characteristics and the dependent variable was estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = personal care assistance.

*Significantly different from zero at the .10 level, two-tailed test.

**Significantly different from zero at the .05 level, two-tailed test.

***Significantly different from zero at the .01 level, two-tailed test.

TABLE A.24

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER FOUND HIRING DIFFICULT
(Omitted Categories in Parentheses)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Demographic Characteristics | | |
| Age | | |
| (18 to 64) | | |
| 65 or older | -0.41** | .038 |
| Female | 0.24 | .268 |
| Hispanic | 0.12 | .662 |
| Self-Identified Race | | |
| (White only) | | |
| Black only or black and some other race | -0.21 | .359 |
| Some other race | 0.45 | .192 |
| Education | | |
| High school graduate | 0.14 | .510 |
| (Did not graduate high school) | | |
| Living Arrangement | | |
| Lives alone | 0.51** | .024 |
| (Lives with others) | | |
| Health and Functioning | | |
| Health Status at Enrollment | | |
| (Excellent or good) | | |
| Fair | -0.11 | .666 |
| Poor | -0.10 | .695 |
| Last Week, Not Independent In: ^a | | |
| Transferring | 0.07 | .806 |
| Bathing | 0.06 | .858 |
| Using toilet | -0.02 | .942 |
| Use of Unpaid and Paid Assistance | | |
| Number of Unpaid Caregivers Last Week | | |
| (None) | | |
| One | -0.18 | .606 |
| Two | -0.21 | .554 |
| Three or more | -0.10 | .776 |
| Primary Unpaid Caregiver Employed | -0.31 | .115 |

TABLE A.24 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Number of Paid Caregivers Last Week | | |
| (None) | | |
| One | -0.24 | .384 |
| Two or more | 0.18 | .578 |
| Unmet Need for, and Access to, Personal Assistance | | |
| Last Week, Needed Help (or More Help) With: | | |
| Personal care ^b | -0.12 | .615 |
| Transportation ^c | -0.18 | .411 |
| Housework and community chores ^d | 0.61** | .024 |
| Potential Difficulty Hiring Due to Location | | |
| Lives in a rural area | 0.50 | .116 |
| Lives in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime) | 0.43** | .036 |
| Satisfaction with Paid Personal Assistance | | |
| Satisfied with Paid Services and Goods Overall | | |
| Very satisfied | -0.19 | .462 |
| Satisfied (Dissatisfied) | -0.27 | .236 |
| No paid services or goods ^e | -0.63 | .235 |
| Employment Experience | | |
| Ever Employed | 0.40 | .111 |
| Ever Supervised Someone | 0.07 | .768 |
| Ever Hired Someone Privately | -0.38* | .085 |
| Type of Respondent | | |
| Majority of Baseline Questions Answered by Proxy Respondent | 0.33 | .167 |
| Demonstration Enrollment | | |
| Length of Time with PCA Upon Enrollment | | |
| Less than 6 months (6 months or longer) | -0.11 | .556 |

TABLE A.24 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Mean Weekly Allowance (Less than \$150) | | |
| \$150 to \$299 | -0.04 | .873 |
| \$300 to \$499 | -0.22 | .404 |
| \$500 or more | -0.21 | .471 |
| Being Allowed to Pay Family or Friends Very Important | -0.67** | .027 |
| Having a Choice About Worker Schedule Very Important | 0.15 | .645 |
| Having a Choice About Types of Help Received Very Important | -0.38 | .316 |
| Primary Unpaid Caregiver Expressed Interest in Being Paid | 0.00 | .984 |
| Enrolled Between November 1999 and December 2000 | 0.72*** | .000 |
| Number of Consumers | 583 | |

Source: For independent variables, data on age and sex come from Personal Preference program records; other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002). For the dependent variable, data come from consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

Notes: The relationship between consumer characteristics and the dependent variable was estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = personal care assistance.

*Significantly different from zero at the .10 level, two-tailed test.

**Significantly different from zero at the .05 level, two-tailed test.

***Significantly different from zero at the .01 level, two-tailed test.

TABLE A.25

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER CONSUMER FOUND
PROGRAM SPENDING RULES RESTRICTIVE
(Omitted Categories in Parentheses)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|--------------------------|---------------------------|
| Demographic Characteristics | | |
| Age | | |
| (18 to 64) | | |
| 65 or older | 0.02 | .937 |
| Female | -0.49** | .030 |
| Hispanic | 0.18 | .530 |
| Self-Identified Race | | |
| (White only) | | |
| Black only or black and some other race | 0.40* | .098 |
| Some other race | 1.09*** | .002 |
| Education | | |
| High school graduate | 0.21 | .387 |
| (Did not graduate high school) | | |
| Living Arrangement | | |
| Lives alone | 0.38 | .112 |
| (Lives with others) | | |
| Health and Functioning | | |
| Health Status at Enrollment | | |
| (Excellent or good) | | |
| Fair | 0.31 | .284 |
| Poor | 0.11 | .699 |
| Last Week, Not Independent In: ^a | | |
| Transferring | 0.30 | .283 |
| Bathing | 0.48 | .173 |
| Using toilet | -0.36 | .211 |
| Use of Unpaid and Paid Assistance | | |
| Number of Unpaid Caregivers Last Week | | |
| (None) | | |
| One | 0.49 | .188 |
| Two | 0.60 | .117 |
| Three or more | 0.14 | .701 |
| Primary Unpaid Caregiver Employed | -0.02 | .935 |

TABLE A.25 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Number of Paid Caregivers Last Week | | |
| (None) | | |
| One | -0.35 | .246 |
| Two or more | -0.31 | .371 |
| Unmet Need for, and Access to, Personal Assistance | | |
| Last Week, Needed Help (or More Help) With: | | |
| Personal care ^b | 0.17 | .517 |
| Transportation ^c | 0.70*** | .006 |
| Housework and community chores ^d | 0.41 | .183 |
| Potential Difficulty Hiring Due to Location | | |
| Lives in a rural area | -0.34 | .346 |
| Lives in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime) | -0.07 | .745 |
| Satisfaction with Paid Personal Assistance | | |
| Satisfied with Paid Services and Goods Overall | | |
| Very satisfied | -0.63** | .024 |
| Satisfied (Dissatisfied) | -0.40* | .094 |
| No paid services or goods ^e | -0.37 | .543 |
| Employment Experience | | |
| Ever Employed | -0.12 | .651 |
| Ever Supervised Someone | 0.08 | .735 |
| Ever Hired Someone Privately | 0.08 | .739 |
| Type of Respondent | | |
| Majority of Baseline Questions Answered by Proxy Respondent | -0.17 | .509 |
| Demonstration Enrollment | | |
| Length of Time with PCA Upon Enrollment | | |
| Less than 6 months (6 months or longer) | 0.05 | .820 |

TABLE A.25 (continued)

| Baseline Characteristic | Estimated Coefficient | p-Value of Coefficient |
|---|-----------------------|------------------------|
| Mean Weekly Allowance (Less than \$150) | | |
| \$150 to \$299 | 0.38 | .196 |
| \$300 to \$499 | 0.37 | .199 |
| \$500 or more | 0.42 | .178 |
| Being Allowed to Pay Family or Friends Very Important | 0.22 | .487 |
| Having a Choice About Worker Schedule Very Important | -0.57* | .076 |
| Having a Choice About Types of Help Received Very Important | -0.41 | .284 |
| Primary Unpaid Caregiver Expressed Interest in Being Paid | -0.11 | .644 |
| Enrolled Between November 1999 and December 2000 | 0.13 | .547 |
| Number of Consumers | 594 | |

Source: For independent variables, data on age and sex come from Personal Preference program records; other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002). For the dependent variable, data come from consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

Notes: The relationship between consumer characteristics and the dependent variable was estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = personal care assistance.

*Significantly different from zero at the .10 level, two-tailed test.

**Significantly different from zero at the .05 level, two-tailed test.

***Significantly different from zero at the .01 level, two-tailed test.

TABLE A.26

EFFECT OF CONSUMER CHARACTERISTICS ON SATISFACTION AND UNMET NEED
(Omitted Categories in Parentheses)

| Baseline Characteristic | Allowance Improved Life a Great Deal | | Very Satisfied with Overall Care | | Has Unmet Need for Personal Care | |
|--|---|---------|-------------------------------------|---------|-------------------------------------|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Demographic Characteristics | | | | | | |
| Age (18 to 64) | | | | | | |
| 65 or older | 0.17 | .468 | 0.11 | .612 | -0.05 | .799 |
| Female | 0.10 | .711 | -0.10 | .671 | -0.11 | .613 |
| Hispanic | -0.26 | .423 | -0.02 | .959 | 0.18 | .518 |
| Self-Identified Race (White only) | | | | | | |
| Black only or black and some other race | -0.31 | .265 | -0.09 | .708 | 0.16 | .513 |
| Some other race | 0.03 | .937 | -0.22 | .564 | 0.36 | .331 |
| Education | | | | | | |
| High school graduate (Did not graduate high school) | 0.28 | .283 | 0.34 | .156 | 0.18 | .441 |
| Living Arrangement | | | | | | |
| Lives alone (Lives with others) | -0.46* | .076 | -0.39* | .083 | 0.37 | .101 |
| Health and Functioning | | | | | | |
| Health Status at Enrollment (Excellent or good) | | | | | | |
| Fair | 0.03 | .912 | -0.10 | .737 | 0.47 | .104 |
| Poor | 0.14 | .634 | 0.20 | .475 | 0.20 | .474 |
| Last Week, Not Independent In: ^a | | | | | | |
| Transferring | -0.15 | .619 | 0.35 | .181 | 0.29 | .268 |
| Bathing | -0.44 | .280 | -0.18 | .569 | 0.55 | .120 |
| Using toilet | 0.49 | .132 | 0.41 | .127 | 0.34 | .201 |
| Use of Unpaid and Paid Assistance | | | | | | |
| Number of Unpaid Caregivers Last Week | | | | | | |
| (None) | | | | | | |
| One | -0.49 | .267 | -0.11 | .731 | 0.58* | .095 |
| Two | -0.71 | .108 | -0.08 | .815 | 0.44 | .221 |
| Three or more | -0.64 | .145 | 0.03 | .935 | 0.49 | .176 |

TABLE A.26 (continued)

| Baseline Characteristic | Allowance Improved Life a Great Deal | | Very Satisfied with Overall Care | | Has Unmet Need for Personal Care | |
|---|---|---------|-------------------------------------|---------|-------------------------------------|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Primary Unpaid Caregiver Employed | 0.33 | .158 | 0.06 | .787 | 0.03 | .896 |
| Number of Paid Caregivers Last Week (None) | | | | | | |
| One | 0.52 | .114 | 0.71** | .024 | -0.24 | .432 |
| Two or more | 0.28 | .464 | 0.28 | .439 | 0.40 | .252 |
| Unmet Need for, and Access to, Personal Assistance | | | | | | |
| Last Week, Needed Help (or More Help) With: | | | | | | |
| Personal care ^b | -0.42 | .152 | 0.05 | .851 | 0.62** | .015 |
| Transportation ^c | 0.17 | .494 | -0.04 | .865 | 0.28 | .209 |
| Housework and community chores ^d | -0.14 | .642 | -0.30 | .289 | 0.47* | .094 |
| Potential Difficulty Hiring Due to Location | | | | | | |
| Lives in a rural area | 0.04 | .913 | -0.39 | .255 | 0.20 | .534 |
| Lives in a nonrural area but transportation difficult or high crime | -0.03 | .895 | -0.02 | .911 | 0.05 | .809 |
| (Lives in a nonrural area, but transportation not difficult and not high crime) | | | | | | |
| Satisfaction with Paid Personal Assistance | | | | | | |
| Satisfied with Paid Services and Goods Overall | | | | | | |
| Very satisfied | -0.58* | .066 | 0.95*** | .000 | -0.47* | .081 |
| Satisfied (Dissatisfied) | 0.01 | .985 | 0.72*** | .003 | -0.19 | .421 |
| No paid services or goods ^e | 0.54 | .404 | 0.53 | .372 | 0.01 | .993 |
| Employment Experience | | | | | | |
| Ever Employed | 0.01 | .982 | -0.23 | .432 | -0.22 | .438 |
| Ever Supervised Someone | 0.15 | .563 | -0.27 | .223 | -0.30 | .179 |
| Ever Hired Someone Privately | 0.41 | .117 | -0.13 | .536 | -0.06 | .801 |

TABLE A.26 (continued)

| Baseline Characteristic | Allowance Improved Life a Great Deal | | Very Satisfied with Overall Care | | Has Unmet Need for Personal Care | |
|--|---|---------|-------------------------------------|---------|-------------------------------------|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Type of Respondent | | | | | | |
| Majority of Baseline Questions Answered by Proxy Respondent | 0.47* | .095 | 0.00 | .995 | 0.39 | .136 |
| Demonstration Enrollment | | | | | | |
| Length of Time with PCA Upon Enrollment | | | | | | |
| Less than 6 months (6 months or longer) | 0.12 | .596 | -0.11 | .579 | 0.23 | .262 |
| Mean Weekly Allowance (Less than \$150) | | | | | | |
| \$150 to \$299 | -0.14 | .667 | 0.30 | .271 | -0.55** | .048 |
| \$300 to \$499 | 0.21 | .508 | 0.01 | .964 | -0.24 | .401 |
| \$500 or more | -0.01 | .979 | -0.04 | .907 | -0.29 | .329 |
| Being Allowed to Pay Family or Friends Very Important | 0.52 | .160 | 0.40 | .167 | -0.48* | .098 |
| Having a Choice About Worker Schedule Very Important | 0.95** | .015 | 0.44 | .182 | 0.05 | .894 |
| Having a Choice About Types of Help Received Very Important | -0.07 | .886 | -0.14 | .739 | 0.34 | .422 |
| Primary Unpaid Caregiver Expressed Interest in Being Paid | -0.40 | .114 | 0.27 | .244 | 0.30 | .193 |
| Enrolled Between November 1999 and December 2000 | -0.17 | .456 | -0.51** | .013 | -0.22 | .274 |
| Number of Consumers | 435 | | 536 | | 565 | |

Source: For independent variables, data on age and sex come from Personal Preference program records; other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002). For the dependent variables, data come from Personal Preference program records and consumer interviews conducted by telephone 9 months after consumers' random assignment.

Notes: The relationship between consumer characteristics and the dependent variable was estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

TABLE A.26 (continued)

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = personal care assistance.

*Significantly different from zero at the .10 level, two-tailed test.

**Significantly different from zero at the .05 level, two-tailed test.

***Significantly different from zero at the .01 level, two-tailed test.

TABLE A.27

EFFECT OF CONSUMER CHARACTERISTICS ON VOLUNTARY DISENROLLMENT
(Omitted Categories in Parentheses)

| Baseline Characteristic | Whether Disenrolled, According to Program Records, Within 1 Year of Enrollment | | Whether Disenrolled, According to Self- Reports, Within 9 Months of Enrollment | |
|---|---|---------|---|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Demographic Characteristics | | | | |
| Age | | | | |
| (18 to 64) | | | | |
| 65 or older | 0.03 | .864 | 0.11 | .706 |
| Female | 0.09 | .701 | -0.04 | .895 |
| Hispanic | 0.58** | .031 | 0.44 | .237 |
| Self-Identified Race | | | | |
| (White only) | | | | |
| Black only or black and some other race | -0.12 | .621 | -0.12 | .697 |
| Some other race | -0.14 | .733 | -0.64 | .325 |
| Education | | | | |
| High school graduate | | | | |
| (Did not graduate high school) | -0.29 | .196 | -0.08 | .809 |
| Living Arrangement | | | | |
| Lives alone | | | | |
| (Lives with others) | 0.09 | .690 | -0.04 | .906 |
| Health and Functioning | | | | |
| Health Status at Enrollment | | | | |
| (Excellent or good) | | | | |
| Fair | -0.17 | .537 | 0.29 | .433 |
| Poor | -0.10 | .718 | 0.07 | .851 |
| Last Week, Not Independent In: ^a | | | | |
| Transferring | 0.03 | .892 | 0.27 | .460 |
| Bathing | -0.59** | .049 | 0.58 | .219 |
| Using toilet | -0.29 | .300 | -0.43 | .246 |
| Use of Unpaid and Paid Assistance | | | | |
| Number of Unpaid Caregivers Last Week | | | | |
| (None) | | | | |
| One | -0.15 | .629 | -0.22 | .594 |
| Two | -0.47 | .161 | -0.78* | .098 |
| Three or more | -0.22 | .505 | -0.72 | .104 |

TABLE A.27 (continued)

| Baseline Characteristic | Whether Disenrolled, According to Program Records, Within 1 Year of Enrollment | | Whether Disenrolled, According to Self- Reports, Within 9 Months of Enrollment | |
|--|---|---------|---|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Primary Unpaid Caregiver Employed | -0.54** | .013 | -0.65** | .037 |
| Number of Paid Caregivers Last Week | | | | |
| (None) | | | | |
| One | 0.38 | .218 | 0.50 | .313 |
| Two or more | 0.69** | .047 | 1.05** | .048 |
| Unmet Need for, and Access to, Personal Assistance | | | | |
| Last Week, Needed Help (or More Help) With: | | | | |
| Personal care ^b | -0.20 | .401 | -0.79** | .013 |
| Transportation ^c | 0.26 | .244 | -0.13 | .658 |
| Housework and community chores ^d | -0.26 | .311 | 0.05 | .881 |
| Potential Difficulty Hiring Due to Location | | | | |
| Lives in a rural area | 0.07 | .833 | 0.09 | .845 |
| Lives in a nonrural area but transportation difficult or high crime | 0.13 | .518 | 0.06 | .826 |
| (Lives in a nonrural area, but transportation not difficult and not high crime) | | | | |
| Satisfaction with Paid Personal Assistance | | | | |
| Satisfied with Paid Services and Goods Overall | | | | |
| Very satisfied | 0.25 | .343 | -0.02 | .964 |
| Satisfied | 0.18 | .461 | 0.00 | .996 |
| (Dissatisfied) | | | | |
| No paid services or goods ^e | -0.51 | .429 | -1.33 | .272 |
| Employment Experience | | | | |
| Ever Employed | -0.20 | .453 | -0.59* | .096 |
| Ever Supervised Someone | 0.33 | .148 | 0.41 | .205 |
| Ever Hired Someone Privately | -0.07 | .742 | 0.00 | .999 |
| Type of Respondent | | | | |
| Majority of Baseline Questions Answered by Proxy Respondent | -0.19 | .461 | -0.05 | .892 |

TABLE A.27 (continued)

| Baseline Characteristic | Whether Disenrolled, According to Program Records, Within 1 Year of Enrollment | | Whether Disenrolled, According to Self- Reports, Within 9 Months of Enrollment | |
|--|---|---------|---|---------|
| | Estimated Coefficient | p-Value | Estimated Coefficient | p-Value |
| Demonstration Enrollment | | | | |
| Length of Time with PCA Upon Enrollment | | | | |
| Less than 6 months | -0.09 | .652 | 0.06 | .826 |
| (6 months or longer) | | | | |
| Mean Weekly Allowance | | | | |
| (Less than \$150) | | | | |
| \$150 to \$299 | -0.17 | .527 | -0.32 | .419 |
| \$300 to \$499 | 0.13 | .623 | 0.15 | .683 |
| \$500 or more | -0.23 | .434 | 0.07 | .871 |
| Being Allowed to Pay Family or Friends Very Important | -0.55** | .037 | -0.84** | .013 |
| Having a Choice About Worker Schedule Very Important | 0.02 | .943 | 0.20 | .623 |
| Having a Choice About Types of Help Received Very Important | -0.10 | .770 | -0.17 | .719 |
| Primary Unpaid Caregiver Expressed Interest in Being Paid | -0.16 | .493 | -0.12 | .725 |
| Enrolled Between November 1999 and December 2000 | 0.26 | .190 | 0.06 | .843 |
| Number of Consumers | 792 | | 714 | |

Source: For independent variables, data on age and sex come from Personal Preference program records; other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from November 1999 to July 2002). For the dependent variables, data come from Personal Preference program records and consumer interviews conducted by telephone 6 and 9 months after consumers' random assignment.

Notes: The relationship between consumer characteristics and the dependent variable was estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

^aReceived hands-on or standby help or did not perform activity at all.

^bPersonal care includes bathing, transferring from bed, eating, and using the toilet.

^cTransportation includes trips for medical and nonmedical reasons.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

TABLE A.27 (continued)

^eSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

PCA = personal care assistance.

*Significantly different from zero at the .10 level, two-tailed test.

**Significantly different from zero at the .05 level, two-tailed test.

***Significantly different from zero at the .01 level, two-tailed test.

TABLE A.28

CONSULTANT ASSESSMENT OF CONSUMER DIFFICULTIES
WITH PROGRAM RESPONSIBILITIES

| | |
|--|-----------|
| Number of Consultants Reporting That at Least One Consumer: | |
| Required extensive monitoring | 13 |
| Requested extensive amounts of assistance | 26 |
| Made unreasonable demands | 6 |
| Number of Consultants Reporting That Consumers Who Requested Extensive Assistance Had the Following Characteristics: | |
| Younger than 65 | 18 |
| 65 or older | 23 |
| Little experience budgeting | 16 |
| Little experience recruiting, hiring, training, or supervising workers | 18 |
| Poor problem-solving skills | 9 |
| Prior experience training or supervising workers | 4 |
| Ill health | 10 |
| No family members or friends to be paid workers | 15 |
| Not using fiscal services ^a | 2 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

^aAccording to program staff, all consumers did use fiscal services.

TABLE A.29

CONSULTANT ASSESSMENT OF CONSUMERS' OVERALL EXPERIENCES
WITH PERSONAL PREFERENCE

| | Number of Consultants Reporting |
|---|------------------------------------|
| Personal Preference Was Particularly Effective for Consumers Who | |
| Had a family member or friend in mind to hire as worker | 12 |
| Were dissatisfied with traditional home care/wanted more control over care | 8 |
| Wished to purchase care-related equipment or services not covered by Medicaid | 6 |
| Needed a lot of home care | 5 |
| Were well organized and decisive | 1 |
| Risked nursing home placement | 0 |
| Types of Consumers for Whom Personal Preference Did Not Work Well | |
| Unable to manage own care, no representative available | 13 |
| Did not understand program | 6 |
| Did not speak or read English | 5 |
| Unable to hire or retain suitable worker | 4 |
| Disliked program responsibilities | 3 |
| Needed more care than could be obtained with allowance | 1 |
| Needed very little care | 0 |
| Lived in a rural area | 0 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.

Note: Consultants were asked to describe consumers for whom the program was particularly effective and those for whom the program did not work well. Their open-ended responses were then categorized as indicated above.

TABLE A.30

CONSULTANT OPINIONS OF, AND RECOMMENDATIONS FOR, PERSONAL PREFERENCE

| | Number Reporting |
|---|------------------|
| Would Recommend Changes to Consulting Activities | 10 |
| Types of Changes Recommended to Consulting Activities | |
| Consultants should do more for consumers (for example, spend more than 19 hours per year with consumers if needed) | 3 |
| Consultants should do less for consumers (for example, play only an advisory role, not have to explain the program to the consumer) | 3 |
| Felt They Were Trained Adequately for Their Roles | 30 |
| Types of Changes Recommended for Consultant Training | |
| Change content of training (for example, put more emphasis on the cash spending plan and program paperwork, put less emphasis on program philosophy, update training as program rules or policies change) | 13 |
| Reduce time between training and first consumer assignment, or provide training refreshers | 1 |
| Making training more practical (for example, use role playing, make training manual more user-friendly, use peer counseling and shadowing) | 8 |
| Longer training | 1 |
| Shorter training | 2 |
| Types of Changes Recommended for Other Program Features | |
| Uses of cash: make less restrictive | 2 |
| Cash and cash management plan: simplify the paperwork | 2 |
| Outreach: improve description of program to consumers before enrollment, invite home care agencies to refer clients | 5 |
| Fiscal services: make services more responsive, professional, competent | 5 |
| Representatives: encourage wider use, pay them | 2 |
| Workers: increase pay, provide training | 0 |
| Other: provide services/written materials in languages other than English | 2 |
| Average Number of Consumers with Whom Consultants Have Worked | 8.7 |
| Number of Consultants Responding to Survey | 37 |

Source: MPR consultant survey administered by mail in April 2001.