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**Enabling Personal
Preference: The
Implementation of the
Cash and Counseling
Demonstration in
New Jersey**

Final Report

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EXECUTIVE SUMMARY

About 1.2 million people receive disability-related supportive services in their homes through state Medicaid plans or home- and community-based waiver services programs. Under state plans, services are restricted largely to human assistance with personal care and homemaking and must be provided by licensed agencies. Additional services (such as adult day care and home modifications) and goods (such as assistive devices) may be offered under waiver programs. However, coverage of these additional services is often limited, and a case manager decides whether they are needed.

In contrast to these traditional service models, states are increasingly offering Medicaid beneficiaries and their families the opportunity to obtain personal care from individual providers—an alternative known as “consumer-directed” care.

Cash and Counseling is an expanded model of consumer-directed supportive services that provides a flexible monthly allowance for consumers to use to hire their choice of workers, including family members, and to purchase other services and goods. Cash and Counseling requires consumers to develop plans that show how they would use the allowance to meet their personal care needs and provides counseling and fiscal assistance to help them plan and manage their responsibilities. Consumers who are unable or unwilling to manage their care themselves may designate a representative, such as a family member, to help them or do it for them. These features make Cash and Counseling adaptable to consumers of all ages and with all types of impairments.

The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services are sponsoring a demonstration and evaluation of Cash and Counseling. A National Program Office operates from the University of Maryland, Center on Aging. The Centers for Medicare & Medicaid Services (CMS) is helping with the demonstration, primarily with technical assistance and obtaining waivers of federal Medicaid regulations. Mathematica Policy Research, Inc. (MPR) is evaluating the demonstration, which has been implemented in three states: Arkansas, Florida, and New Jersey. The evaluation uses a randomized design—half the enrollees are assigned to a treatment group to receive the cash allowance, half to a control group to continue in traditional supportive services.

This report describes the design and implementation of Personal Preference, New Jersey’s model of Cash and Counseling. It also draws lessons from the state’s experience. The report is based primarily on in-person interviews conducted in April 2001, about 18 months after the program began enrolling beneficiaries (November 1999). Interviews were conducted with New Jersey state officials, Personal Preference program staff members, officials of organizations representing the personal care industry in New Jersey, and staff members of organizations providing outreach, enrollment, consulting, and fiscal services under Personal Preference. (New Jersey used the term “consulting” rather than “counseling” in its demonstration.)

THE PERSONAL PREFERENCE PROGRAM

Program “Cashed Out” and Eligibility. New Jersey chose to “cash out” Personal Care Assistance (PCA) under its state Medicaid plan. It did *not* cash out any of its seven Medicaid home- and community-based waiver programs, which provide a variety of services to special populations, such as medically fragile children and frail elderly people with incomes above the usual Medicaid threshold. Only PCA clients were to be eligible for Personal Preference (including current recipients of PCA and those accessed by traditional personal care agencies and found eligible for PCA).

PCA clients who wished to participate in Personal Preference but were unable to manage their own services were eligible to enroll. They could name a family member or friend as a representative to act on their behalf if they were selected for the cash allowance.

Outreach and Enrollment. To identify eligible beneficiaries, New Jersey required that a personal care agency send the Personal Preference program a form with contact information for each beneficiary assessed or reassessed for PCA. The form also included information on care plan hours, which was used in determining the amount of the cash allowance for demonstration participants assigned to the treatment group.

The state did not work through personal care agencies to conduct outreach for Personal Preference; instead, it contracted with other organizations and hired state employees. Some agency staff members were concerned that the quality of care would suffer under Personal Preference, others that it would affect agency revenue and their employment. Therefore, New Jersey avoided working through agencies, out of concern that some agency staff might discourage PCA clients from participating in Personal Preference.

Although some agency staff members reportedly did discourage participation in the demonstration, personal care agencies were cooperative overall. The industry believed that the program was appropriate for some people with disabilities, and it had a long history with and professional respect for the director of Personal Preference. Moreover, Personal Preference responded to an important industry concern by discouraging consumers from hiring their agency aides.

During the demonstration, New Jersey both contracted with other organizations and hired state employees to conduct outreach and enrollment for Personal Preference. Concerned about possible delay in hiring state employees, New Jersey initially amended the contract of an organization that was helping the state market Medicaid managed care, adding responsibility for outreach and enrollment under Personal Preference. State Personal Preference staff mailed materials on the program to PCA recipients. Staff of the enrollment contractor telephoned and visited those who received materials to explain the program and enroll them if they wished to participate. Despite revisions to outreach and enrollment procedures, however, the pace of enrollment consistently fell below the contract target, and costs were higher than anticipated. Therefore, Personal Preference decided to hire state employees to conduct outreach and enrollment and was able to do so after substantial delay. (Because of attrition of state-employed enrollment staff later—after spring 2001—New Jersey again obtained a contractor for outreach

and enrollment. It did so this time by amending the contract of the organization providing fiscal services under Personal Preference.)

The day-to-day outreach and enrollment activities of the enrollment contractor and the Personal Preference program were coordinated using a common database. This database was initiated with the contact and care plan information that personal care agencies provided and combined with information from New Jersey's Medicaid program. It was updated weekly as outreach and enrollment continued.

Ultimately, about 1,750 people participated in the Personal Preference Demonstration in New Jersey (in the treatment and control groups combined). They enrolled between December 1999 and June 2002.

Determining the Amount of Allowance. New Jersey based the amount of the cash allowance on the current PCA care plan. Hours planned were cashed out at the hourly rates the state paid for weekday and weekend PCA services (in New Jersey, care plans differentiate between weekday and weekend hours). At about the time of our visit, the amount of the allowance ranged from about \$300 to about \$2,800 a month. The average was about \$1,300.

No discounting was applied in determining the amount of the allowance under Personal Preference. (Discounting is intended to ensure the budget neutrality of the cash program when the cost of services received is less, on average, than the cost of services planned—a result, for example, of hospital admission of consumers or an insufficient supply of aides). While planning the demonstration, New Jersey had determined that the historical cost of PCA services received was approximately equal to the cost of services planned—an indication that discounting was unnecessary.

Reassessment. PCA recipients are reassessed in New Jersey at six-month intervals. Nurses employed by personal care agencies do the reassessments, using a structured form that the state developed. To mimic this process, Personal Preference arranged for nurses employed by the Medicaid program to conduct reassessments of cash recipients, using the same form as that used for agency service recipients. This procedure eliminated the possibility that consultants—acting as advocates for consumers—might increase care plan hours (and, thus, the amount of the allowance).

Cash Planning and Uses of Cash Allowance. Before receiving a cash allowance, Personal Preference required that consumers develop a plan for its use. A member of the state Personal Preference program staff had to approve all cash management plans and all revisions to those plans.

Nearly all consumers who received a cash allowance hired a worker—usually a family member or friend—with the funds. New Jersey exercised its option under demonstration waivers to allow consumers to hire legally liable relatives. Thus, consumers in Personal Preference could hire their spouses. (Under federal regulations, spouses are the only legally liable relatives of adults.) Some consumers also purchased assistive equipment and personal care supplies (not covered by Medicaid) with the allowance, and a few modified their homes (for example, by adding a ramp).

Consulting Agencies. Initially, New Jersey recruited a large number of human service agencies across the state to provide consulting under Personal Preference. It did this to best serve New Jersey's culturally diverse population and to provide consumers with a choice of consulting agencies. To help in recruiting these agencies, New Jersey made agency participation administratively straightforward by signing memoranda of agreement (rather than contracts) with agencies providing consulting. Ultimately, 34 agencies signed such agreements. Some were public (for example, county departments of social services); some were private, nonprofit (for example, an Independent Living Center); and some were private, for-profit (for example, an agency that provided case management services).

Over time, the number of consulting agencies dropped dramatically (there were 12 in spring 2001). Some agencies withdrew from the cash program (partly because of competing demands on staff time), and Personal Preference dropped agencies not performing satisfactorily. It was possible to have fewer consulting agencies, partly because consumers did not have experience or information to help them choose an agency and did not particularly value having a choice. Therefore, the program began assigning consumers to agencies.

Personal Preference paid the consulting agency a lump sum to complete the cash management plan (initially \$53, later increased to \$75) and thereafter an hourly fee for consulting (initially \$18, increased to \$26). Rates were increased in part because agencies reported that the initial rates covered the cost of salaries, but not the cost of fringe benefits and other overhead.

The approach that Personal Preference adopted for payment for consulting services limited the state's costs for consulting. In addition to the single, lump-sum payment for development of the initial cash management plan (no matter how much consultant time was required to complete it), the cost of hourly consulting services was capped by limiting payment to 19 hours (later, 20 hours) annually per consumer.

New Jersey did not require Personal Preference consultants to have professional credentials, but most were human services professionals. Given the number of consulting agencies and the overall Personal Preference caseload, the caseload of most agencies was not large. At the time of our visit, most agencies had small caseloads and only one or two consultants, who also had other agency responsibilities.

Consultants had many responsibilities under Personal Preference. They visited treatment group members to help them prepare their initial cash management plans and revisions to plans. They then submitted the plans to the state Personal Preference office for approval. Consultants also advised consumers about the nonfiscal responsibilities of an employer, including recruiting, hiring, training, supervising, and (if necessary) firing workers. In addition, consultants monitored the condition of the consumer, speaking to consumers by telephone at least monthly (for the first six months after enrollment) and visiting them quarterly. Consultants were not responsible for monitoring the uses of the cash allowance.

Fiscal Services. Personal Preference issued a solicitation for a single organization to provide fiscal services for consumers across the state. After a long process, including a legal

dispute contesting the organization chosen initially, the state signed a contract with a New Jersey organization that provided a variety of human services. (Later, this organization provided consulting, outreach, and enrollment services in addition to fiscal services.)

The major fiscal services provided to Personal Preference consumers were assistance with preparation and submission of payroll tax returns and other documents (including those pertaining to federal and state payroll taxes and state unemployment insurance) and check-writing services. The fiscal agent implemented strict procedures for comparing timesheets and check requests with the cash management plan before checks were cut.

Personal Preference allowed consumers to receive the allowance in cash and accept full responsibility for its management (including payroll taxes), but they had to pass a skills examination before doing so. At the time of our visit, no consumers were managing the allowance themselves. Rather, the fiscal agent was holding the allowance on behalf of each consumer and disbursing funds in accordance with his or her cash management plan.

The fiscal agent earned fees from consumers for fiscal services that they used, and it earned fees from the state for the other services it provided to consumers. A schedule of charges was developed. Consumers were charged for such tasks as cutting a check (75 cents per check) stopping payment on a check (\$28 per stop-payment order), and arranging for a criminal background check (\$15 to \$60, depending on the extent of the search). The fiscal agent charged the state for other tasks, such as processing W-4 forms and other forms in worker employment packets (\$90 per packet).

New Jersey also provided the fiscal agent with start-up funds. Before there was a substantial caseload of cash recipients, the fiscal agent had a serious cash flow problem and obtained an internal loan from its host organization. New Jersey had intended that the up-front payment of start-up funds would limit cash flow problems; however, the fiscal agent used these funds mainly to purchase office equipment for its Personal Preference operation.

LESSONS FROM PERSONAL PREFERENCE

New Jersey's experience provides many lessons about operating a consumer-directed cash allowance program under Medicaid. The state was willing to learn from its experience and to try a different approach if problems arose.

Outreach and Enrollment

- ***Self-screening of personal assistance recipients for appropriateness is workable.*** It would have been difficult (if not impossible) to develop a formal process to identify in advance consumers who would be unable to manage the cash benefit, either by themselves or with the help of representatives. Instead, Personal Preference relied on consumers and representatives to screen themselves, and this approach worked.
- ***Providing for language diversity is important and possible in a consumer-directed program.*** Non-English-speaking consumers may be able to benefit greatly from hiring workers who speak their languages and are familiar with their cultures. Personal Preference hired staff members who spoke the languages most common in

New Jersey. It also translated program materials into these languages, prepared a notice in 14 languages asking consumers to have materials translated, asked family members and friends to translate, and used the AT&T language line.

- ***Information should be available in multiple media to accommodate those with vision and hearing impairments and those who are not competent readers in any language.***
- ***To keep program costs down, efficiency in arranging home visits to describe the program and enroll beneficiaries is important.*** Travel time can be reduced by scheduling visits on the same day to several beneficiaries in the same area. Repeat visits can be avoided by having family members present during the initial enrollment visit, even if that visit has to be scheduled outside of business hours.
- ***To conduct outreach and enrollment, external contracting is not necessarily better than the hiring of state employees (or vice versa).*** Neither the Personal Preference enrollment contractor nor state employees were able to sustain an enrollment pace that met the sample-size target for the evaluation.
- ***While both elderly adults and younger adults with physical disabilities found Personal Preference attractive, younger adults appear to have been more likely to enroll.*** More than half (53 percent) of those enrolled in the demonstration were elderly beneficiaries. However, younger adult participants in the Personal Preference demonstration represented more than 20 percent of the number of non-elderly adult PCA recipients in New Jersey in the year before the demonstration, while the elderly participants represented just over 10 percent of the number of elderly PCA recipients that year. Thus, the cash program in New Jersey attracted a substantial minority, but not a majority, of adult Medicaid personal care recipients.

Consulting Agencies

- ***Cash allowance programs may find it difficult to recruit enough agencies to provide consumers across the state with a choice of agencies providing satisfactory consulting services.*** New Jersey had difficulty recruiting multiple agencies in some parts of the state and dropped some agencies out of dissatisfaction with the consulting services provided.
- ***Consumers do not necessarily value having a choice of consulting agencies.*** Most Personal Preference consumers did not have knowledge about or experience with the agencies offering consulting and did not seem to value having a choice.
- ***Agencies of a variety of auspices can satisfactorily provide consulting.*** Satisfactory consulting services were provided to Personal Preference consumers by public; private, nonprofit; and for-profit agencies.
- ***A minimum agency caseload is necessary for efficient provision of consulting. This caseload needs to be large enough to support a single consultant, working for an appreciable portion of time on the Cash and Counseling program.*** Consultants with

small caseloads have difficulty staying up-to-date on program procedures and policies. Having a single consultant per agency can work, although that consultant needs peer support, supervision, and backup.

- ***Having 10 to 15 consulting agencies statewide can work.*** Having a large number of consulting agencies consumes program staff time to recruit (and replace) agencies and to ensure the quality of consulting services. By spring 2001, 12 agencies (down from 34) were providing Personal Preference consulting, and the state program staff was satisfied with their performance.

Cash Planning and Consulting Services

- ***Careful planning of the initial consulting home visit reduces the need for multiple visits and thus cuts delays in receipt of the cash allowance and program costs.*** Before the initial consulting visit, Personal Preference consumers were asked to begin to think about how to spend the allowance, whom to hire, and whether to name a representative. Family members and friends who were potential workers and representatives were asked to be present.
- ***Revisions to the cash management plan are frequently necessary.*** Because expenditures are checked against the cash management plan, the plan must be revised to reflect changes in consumer need, and such changes occur frequently.
- ***The need for revisions to cash management plans can be reduced by writing flexible plans, and the cost of revision can be reduced by automation.*** Personal Preference reduced the number of situations in which a revision was required by writing flexible cash plans that did not name workers or vendors. The program entered the cash plan into an electronic spreadsheet, thereby speeding recalculation of plan totals.
- ***Consumers need varying amounts of consultant assistance, with some needing a substantial amount.*** Some Personal Preference consumers needed substantially more consulting assistance than others did, and some needed substantially more than expected. The 19 hours of consulting a year for which Personal Preference would pay (after the cash plan was in place) was sometimes exhausted.

Representatives

- ***Many consumers participating in the Cash and Counseling model will name a representative to help them manage the cash allowance.*** Personal Preference consultants reported that up to two-thirds of elderly beneficiaries named representatives. Sometimes, the family (rather than the consumer) wanted a representative named.
- ***Representatives are usually family members or friends who are already helping the consumer***

- ***The need for a representative depends on the availability of training from consultants, familiarity with the cash program, and availability of supportive equipment—as well as consumer disability.*** As consumers learn about the cash program from consultants, the consumer may take over management of the allowance from a representative. Rarely, supportive equipment (such as a talking computer for a blind consumer) can eliminate the need for a representative.
- ***The role of the representative can vary considerably.*** While the representative was the sole decision maker for those Personal Preference consumers who were completely unable to communicate their preferences, both the consumer and representative typically contributed to the management of the cash allowance under Personal Preference. In some cases, representatives solicited consumer preferences; in other cases, consumers and representatives functioned as a team. Sometimes, the consumer was the primary decision maker and the representative functioned as a liaison to the outside world.
- ***Representatives successfully manage the cash allowance on behalf of consumers.*** Consultants judged that representatives were obtaining input from the consumers when possible and were faithful to the best interests of the consumers.

Amount of Allowance

- ***The appropriate discount rate may change over time.*** New Jersey personal care industry sources reported a substantial reduction during the demonstration in average hours of personal assistance received, as a result of a state utilization review. Hours received also may have been reduced by changes in the supply of aides as the unemployment rate fell. These changes may have resulted in a change in the ratio of the cost of hours of care planned to hours of care received, and possibly a need to introduce a discount rate for Personal Preference.

Uses of Cash

- ***Restrictions on the use of the cash allowance need not trouble consumers.*** Most consumers did not find the Personal Preference program's restrictions on the uses of the cash allowance troublesome. While insisting that purchases be related to the need for personal assistance, the program fostered creative use of the allowance and interpreted it broadly.
- ***The Cash and Counseling model appears to tap a new source of personal assistance workers—family members and friends.*** Program staff reported that most workers hired by consumers were willing to assist a loved one but were not interested in agency employment. Family members and friends can help people whom agencies were not able to serve fully.

Time to Receipt of Cash Payment

- ***Streamlined procedures can reduce time to receipt of the first cash payment.*** Under Personal Preference, the time required for each of the steps leading up to receipt of the cash payment could appreciably delay its receipt. Elimination of consumer choice of consulting agencies reduced delay to receipt of the first cash payment, and Personal Preference decreased notice time to personal care agencies regarding consumers about to receive their first cash payments.
- ***Communication problems can be serious enough to increase the time to receipt of the first cash payment.*** With four major actors (consumer/representative, consultant, state program staff, and fiscal staff), there were 12 one-way communication pathways under Personal Preference. From this perspective, it is not surprising that communication was sometimes serious enough to delay receipt of the first cash payment.
- ***Efficient procedures can reduce communication problems.*** Personal Preference improved communication by training consumers about whom to call for what issue, adding an explanation of errors in exception reports from the fiscal agent, and using multiple-party telephone calls to reduce the need for several one-on-one calls.

Consumers as Employers

- ***Almost all consumers (including those with representatives) prefer to have a fiscal agent handle payroll functions and disburse funds from the allowance.*** Although Personal Preference consumers paid modest fees for the services of the fiscal agent, they overwhelmingly chose to delegate responsibility for payroll functions and check writing to the fiscal agent.
- ***Recruiting is critical for those consumers who do not have family or friends available to hire as workers.*** Personal Preference program staff reported that the receipt of the cash allowance was delayed for consumers who had difficulty recruiting a worker and that those who could not recruit a worker tended to drop out of the program. (Since our visit, New Jersey has moved to develop a worker registry to assist consumers in recruiting workers.)
- ***Almost all consumers (who are able to recruit workers) learn to fulfill the non-fiscal responsibilities of employers.*** Personal Preference consumers (and representatives) varied with respect to the amount of consultant training they needed on hiring, training, supervising and firing workers. However, even those who needed a substantial amount of consultant assistance, learned in time to fulfill successfully the non-fiscal responsibilities of an employer.

Avoiding Abuse and Exploitation

- ***Abuse of a cash allowance—even an allowance of a substantial amount—can be prevented by careful development of a management cash plan, followed by strict***

enforcement of procedures to ensure payment for only those goods and services allowed under the plan. Personal Preference cash allowances averaged about \$1,300 a month at the time of our visit. Every cash management plan (including every revised plan) was reviewed to be sure that only allowable goods and services were included, and the fiscal agent rigorously checked every disbursement against the cash plan. Review of receipts was not required in Personal Preference and thus was unimportant in preventing abuse of the cash allowance in New Jersey.

- *Neglect and exploitation of consumers can be eliminated before cash payment is made if members of the program staff are mindful of the possibility and attentive to cases in which something seems amiss.* Under Personal Preference, the few cases of potential neglect or exploitation were identified before or during the first home visit by consultants. These cases were resolved before the consumers received their first cash payment.

Value of Counseling and Fiscal Services to Consumers

The tenet of the Cash and Counseling model that most distinguishes it from other benefit and voucher programs is the provision of counseling and fiscal services to help consumers manage the cash allowance. Clearly, consumers valued having fiscal services available. Although consumers were charged fees for fiscal services, almost all chose to use the fiscal agent.

The value of consulting services is more difficult to assess. Consumers varied greatly in the amount of advice and assistance they needed from consultants. Many needed oral explanations of the program and its procedures, in addition to written materials. Some needed a great deal of assistance as they developed a cash management plan, recruited workers, and fulfilled the other responsibilities of an employer. Overall, consulting seems to have been very valuable—perhaps essential—to the success of the cash program in New Jersey. Future analysis of surveys that asked consumers about their satisfaction with consultants will shed more light on this issue.

Future Cash Program?

New Jersey views a consumer-directed cash program as a valuable part of a package of programs within its Medicaid state plan designed to meet the needs of its citizens. The state is working to offer an ongoing waiver program similar to Personal Preference and is interested in expanding the personal assistance benefit to include equipment so that it can offer a consumer-directed program similar to Personal Preference without waiver authority.

I. INTRODUCTION

A. BACKGROUND

1. A New Model of Medicaid Personal Assistance

About 1.2 million people receive disability-related supportive services in their homes through state Medicaid plans or home- and community-based waiver services programs (LeBlanc et al. 2001; and Kitchener and Harrington 2001). Under state plans, services must be provided by licensed home care agencies and are largely restricted to human help with personal assistance and homemaking. The agencies recruit, train, schedule, and supervise the aides or attendants who assist beneficiaries. Under waiver programs, adult day care, assistive devices, and home modifications can be offered in addition to in-home aide services. However, coverage of these additional services is often limited, and a case manager, not the beneficiary, decides whether they are needed.

In contrast to these traditional service models, states are increasingly offering Medicaid beneficiaries and their families the opportunity to obtain personal assistance from individual providers (Velgouse and Dize 2000). This alternative is called “consumer-directed” care, as Medicaid beneficiaries who use individual providers assume the employer’s role of hiring, managing, and (possibly) terminating their workers (Eustis 2000). An expanded model of consumer direction would allow beneficiaries to manage not only their human assistance but other covered supportive services as well.

Cash and Counseling is an expanded model of consumer-directed supportive services. It provides a flexible monthly allowance that consumers can use to hire their choice of workers, including family members, and to purchase other services and goods (as states permit). Cash and Counseling requires that consumers develop plans showing how they would use the allowance to

meet their personal assistance needs and provides counseling and fiscal help to aid them in planning and managing their responsibilities. Consumers who are unable or unwilling to manage their care themselves may designate a representative, such as a family member, to help them or do it for them. These features make Cash and Counseling adaptable to consumers of all ages and with all types of impairments.

With funding from the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) of the U.S. Department of Health and Human Services, the Cash and Counseling Demonstration and Evaluation was implemented in three states—Arkansas, Florida, and New Jersey.¹ The Centers for Medicare & Medicaid Services (CMS) was responsible for the waivers of federal Medicaid regulations required for the demonstration.²

Because their Medicaid programs and political environments differed considerably from each other, the demonstration states were not required to implement a standardized intervention, but they did have to adhere to basic Cash and Counseling tenets, as summarized above. The states' resulting demonstration programs differed in their particulars, so each is being evaluated separately, by Mathematica Policy Research, Inc. (MPR).

¹For simplicity, we refer to a single Cash and Counseling *Demonstration*. Because each state was expected to design its own demonstration (within the constraints laid down by the funders and federal regulations, including waiver terms and conditions), the program was originally referred to as the Cash and Counseling *Demonstrations*. However, because a single National Program Office provided oversight and guidance to all the states and a single evaluation contractor was selected, references to a single “demonstration” eventually supplanted references to multiple “demonstrations.”

²At that time, CMS was called the Health Care Financing Administration (HCFA).

2. Possible Advantages and Disadvantages of Cash and Counseling

When planning for the Cash and Counseling Demonstration began, its designers saw the payment of a cash allowance as having the potential to give beneficiaries the power to purchase services that best fit their long-term care needs and individual values. Beneficiaries were expected to design individual service packages. As alternatives to disability-related supportive services, they could hire workers privately, make home modifications, purchase equipment and supplies, or purchase commercial services (Cameron 1995; and Kane 1996). They were thus in a better position to arrange for services at times that best met their needs. They could also hire their friends and relatives if they believed that doing so was in their best interest. Depending on the level of the cash allowance, the cost of traditional services, and the cost of alternative services, beneficiaries might also be able to purchase more hours of services than they received from the traditional program. These changes were seen as having the potential to increase autonomy, address unmet needs better, and improve satisfaction—changes that might in turn result in improved functioning (Kane 1996).

In addition, at that time, reductions in public expenditures were viewed as possible because traditional case management services and administrative functions were being eliminated under Cash and Counseling, and beneficiaries took responsibility for managing their own services. If the cost of providing counseling was less than that of these traditional functions, savings would accrue. Savings might also accrue if the cost of paying the cash allowance was less than the cost of processing claims. Moreover, the consumer (not the state) was the employer of record under Cash and Counseling—a difference that could potentially reduce state costs (see, for example, Jackson 1994; Cameron 1995; Doty et al.1996; and Flanagan 1994). Because the state was not the employer of record, it might avoid collective bargaining with attendant unions (and the costs

of that bargaining). In addition, the likelihood of successful liability actions against the state (and costly settlements) might be reduced because it was not the employer of record.

At the time the Cash and Counseling Demonstration was being designed, states had little experience with cash allowance programs. Therefore, public officials were concerned about possible abuse of the program. They feared that relatives or workers might neglect or exploit beneficiaries or that beneficiaries might not use their cash allowance for the intended purpose. Some public officials were also concerned that a cash allowance might create more demand for services (the so-called “woodwork” effect) and strain available resources.

There was concern that traditional providers of supportive services might object to Cash and Counseling because it might reduce their revenue and place them at a competitive disadvantage relative to privately hired workers. Traditional providers might also object that potential workers would not be adequately trained or supervised. Finally, organized labor might not support Cash and Counseling, because no collective bargaining entities existed to represent privately hired workers (Cameron and Lagoyda 1997).

B. SOLICITATION FOR THE CASH AND COUNSELING DEMONSTRATION

The central question RWJF and ASPE posed for the demonstration was: How does Cash and Counseling compare to traditional case-managed supportive services? States interested in participating in the demonstration were free to propose Medicaid personal assistance services (PAS) funded under the optional state plan benefit, Medicaid programs funded under home- and community-based waivers, or programs funded by state general revenues.³ These were the

³The Medicaid PAS benefit covers only personal assistance services; as a state plan service, it must be made available to all eligible Medicaid beneficiaries statewide who apply. In contrast, home- and community-based waivers may cover a variety of goods (for example, personal care supplies) and services (for example, chore services and behavioral therapy). Waiver services can

demonstration “feeder” programs. Existing consumer-directed programs were excluded from the demonstration.

RWJF and ASPE also stipulated an evaluation that employed a rigorous randomized design. Thus, people participating in the demonstration were to be assigned either to a treatment group (to receive the cash allowance) or to a control group (to continue under traditional PAS, home- and community-based waiver services, or a state-funded program). The effect of the requirement for a randomized design was to limit the demonstration to states with large PAS, waiver, or state-funded programs (or combinations of programs). Only in such states was it possible to obtain the sample sizes needed for the evaluation.

States were expected to include elderly people with disabilities, as well as younger adults with disabilities, in the Cash and Counseling Demonstration. Younger adults with disabilities have long advocated for consumer-directed care. Adoption of a disability model for personal assistance for elderly people was being debated at the time the solicitation for the demonstration was issued, and there was policy interest in extending such care to elderly people with disabilities (see, for example, Simon-Rusinowitz and Holland 1993; and Doty et al. 1996). The states could include children with disabilities if they wished.

The solicitation anticipated that states would seek waivers of the federal regulations restricting cash payments under the Medicaid program. To grant such waivers (as in demonstration waivers generally), CMS required that the cash program affect the federal budget no more than the PAS or home- and community-based waiver program being “cashed out.” That is, the cash program was required to be “budget neutral.” CMS’s traditional approach to

(continued)

be restricted to particular groups (for example, medically fragile children), and the number of slots in waiver programs can be capped.

calculating budget neutrality involves comparing the monthly cost per recipient of the demonstration program and the traditional program. Another of the terms and conditions for the demonstration waivers limited the potential impact of the demonstration on public costs by restricting the number of new entrants to the cash program. During the demonstration, the ratio of the number of new entrants to the number of current recipients entering the cash program was not to exceed the historical average for the traditional program.⁴

The demonstration solicitation required that the cash allowance cover a broad range of services (such as equipment and home modifications) in addition to personal assistance workers. Furthermore, the solicitation anticipated that legally liable relatives (that is, spouses and parents of minor children) might be hired as personal assistance workers and that states would have to seek a waiver of the federal restriction on such hiring.

Consistent with the Cash and Counseling model, the demonstration solicitation required that counseling and fiscal services be provided. These services were to help personal assistance recipients by giving them information and advice, teaching them skills, and providing support services, including help with payroll and bookkeeping activities. Demonstration states could decide what specific counseling services to offer.

Seventeen states submitted bids in response to the solicitation for the Cash and Counseling Demonstration. Four states were selected: Arkansas, Florida, New Jersey, and New York. New York dropped out of the demonstration before beginning operations, because its local social service districts had little interest in participating.

⁴Only those who were currently receiving PCA or who already had been assessed and approved for PCA were eligible for Personal Preference. Because the latter group was very small, this term and condition had little effect on the New Jersey program.

This report on New Jersey is one of a series of three. Each report tells the story of the implementation of the Cash and Counseling model in a particular state.

C. DESIGN OF THE EVALUATION

The MPR evaluation of the Cash and Counseling Demonstration has two goals.⁵ The first goal is to estimate the impacts of provision of a cash allowance in lieu of disability-related supportive services. The second goal is to document and analyze the implementation of the Cash and Counseling model as it unfolded. These two goals are interrelated, as impacts can be interpreted and generalized only in light of how the Cash and Counseling model was implemented.

1. Evaluation of Impacts

The evaluation will estimate impacts on consumers, caregivers, and costs to the public. It will also describe participation in the demonstration.

Cash and Counseling is expected to affect consumers' use of, unmet need for, and satisfaction with supportive services. As a result, it may also affect their health and functioning. Because consumers purchase supportive services on their own, rather than relying solely on agencies, they are likely to have more control over who provides their services and how and when these services are delivered. Consumers may use different amounts or mixes of services than they would have received under traditional Medicaid programs. They may also use their funds to buy equipment that increases their independence. This greater flexibility that the cash allowance provides should reduce consumers' unmet need and improve their satisfaction with

⁵In addition, the University of Maryland, Baltimore County, is conducting a qualitative study of triads consisting of consumers, their caregivers, and their consultants.

supportive services. In addition, if the quality of personal assistance improves, consumers' functional independence and disability-related health may also improve. Although the cash program is expected to improve consumer outcomes, the evaluation will also assess whether any outcomes worsen.

Cash and Counseling could affect caregivers in several ways. Family and friends providing unpaid care to consumers prior to the consumer's enrollment in the demonstration could face fewer demands on their time if consumers hire attendants or use the cash allowance to purchase assistive equipment. If consumers mismanage the allowance, however, unpaid caregivers may need to provide more care than they did before. The evaluation will also investigate the experience of caregivers who are hired and paid under the demonstration. The working conditions, job satisfaction, and physical and emotional strain that paid caregivers experience will be measured and compared to that of agency workers providing care to control group members.

The evaluation will estimate Cash and Counseling's effects on Medicaid costs for supportive services alone and for all costs paid by Medicaid and Medicare. Costs for personal assistance may increase or decrease, depending on the amount of the monthly cash allowance (on average) and the number of months in which people receive the cash allowance, relative to traditional supportive services. Costs for other health care may also increase or decrease. If consumers receiving the cash allowance are more likely to receive care when they need it, they may have fewer falls or pressure sores (for example) and thus have lower health care costs. On the other hand, if recipients of the cash allowance hire workers, who are less well trained than agency workers, their health may suffer, resulting in higher health care costs.

The major sources of evaluation data for the impact analyses are (1) telephone surveys with demonstration participants and their caregivers, and (2) Medicare and Medicaid eligibility and

claims data. People who agree to participate in the demonstration must complete a baseline telephone interview before they are randomly assigned to the treatment or control group. Six months later, MPR interviews treatment group members about their early experiences with the program. Nine months after enrollment, MPR interviews both treatment and control group members to collect information on their satisfaction, quality of care, quality of life, use of other formal and informal care, and health and functional status. Around the same time, unpaid caregivers identified at baseline are interviewed about the type and amount of care they provide, their relationship with the consumer, and their satisfaction with the paid care the consumer receives. Samples of paid workers identified in the nine-month survey are also interviewed about earnings and benefits, job satisfaction, and problems encountered on the job. Medicaid and Medicare claims and eligibility data will be used to study the cost of supportive services, the use and cost of medical services, and the participation rate in the program being cashed out.

2. Process Analysis

A second component of the evaluation examines program structure and implementation. This process analysis, of which this report is a part, has two objectives. First, it documents demonstration operations and the context in which the demonstration operated in each of the three states (Arkansas, Florida, and New Jersey) participating in the Cash and Counseling Demonstration. In doing so, it informs the quantitative analyses of impacts. Second, the process analysis develops lessons about designing and managing a Cash and Counseling program.

Specifically, this report seeks to address three major sets of questions:

1. How did New Jersey structure its Cash and Counseling program, and what led it to adopt this structure?
2. How did New Jersey implement its program? Did it implement it according to its plans? If not, how and why did it depart from its plans?

3. What lessons can we learn from the New Jersey experience about structuring and operating a Cash and Counseling program?

The process analysis is based mainly on three data sources, the primary one being in-person interviews conducted in April 2001 with:

- State officials of the New Jersey Department of Human Services, the department that sponsors the Personal Preference program, including cabinet- and subcabinet-level officers
- State Personal Preference staff, including the program director, the program manager, the coordinator of consulting services, and an enrollment specialist
- Staff of the enrollment contractor, including the program manager, the community relations manager, and an enrollment specialist⁶
- Staff of the fiscal agent, including the executive director of the host organization and the program manager for Personal Preference⁷
- Executive directors of three organizations representing the personal care industry in New Jersey
- Staff of six agencies providing consulting at the time of our visit, including the director and one or more consultants at each agency

With the help of state Personal Preference program staff, we identified six agencies, operating under different auspices (public, private nonprofit, and private for-profit) and located in different regions of the state, whose staff members were knowledgeable about Personal Preference. In addition, we interviewed members of the staff of one agency that had dropped out of Personal Preference after helping only a few consumers.⁸

⁶We refer to the initial enrollment contractor. After our visit, New Jersey contracted with the organization providing fiscal services to provide outreach and enrollment as well.

⁷At the time of our visit, the fiscal agent⁷ had recently begun to provide consulting services. We did not interview a consultant there; nor did we interview staff of the fiscal agent about the provision of consulting services there.

⁸Staff members at this agency were interviewed by telephone.

The second source of information for the process analysis is demonstration documents, such as demonstration state protocols prepared for CMS, state quarterly reports required by the National Program Office, and forms and materials for consumers and consultants.

The third data source is information the authors obtained by participating in project meetings and telephone conference calls, which included project status reports and discussion of issues facing the Cash and Counseling states. The authors attended project meetings, which were held twice a year. One of the authors regularly participated in telephone conference calls that were held with state program staff weekly (later biweekly) throughout the demonstration.

A major strength of this process analysis is that it uses the reports of those who were directly involved in Personal Preference. Many people were interviewed in person. The interviews were extensive and the interviewees extremely knowledgeable—at times, insightful. Their reports are certainly credible. Moreover, state Personal Preference staff reported on the cash program in numerous telephone conference calls and meetings.

However, this strength is also a limitation in that this report relies on the perceptions of those involved in Personal Preference. To minimize the possibility of error based on misconception, we have collected information on key topics from multiple perspectives (when possible).

Another project report will supplement this description of the implementation of Personal Preference. It will combine the perspectives of program staff, presented here, with those of consumers and consultants and with descriptive data (such as fiscal agent data categorizing the actual uses of cash). When the quantitative analyses are complete, we will have better evidence about the validity of many of these perceptions. One of the strengths of this evaluation is having multiple data sources based on different methods.

D. GUIDE TO THIS REPORT

This report has 10 chapters. Chapter II describes the goals of the state and other key stakeholders and the approach that New Jersey took to critical issues in designing Personal Preference. Chapter III explains how New Jersey selected organizations to provide outreach and enrollment, consulting, and fiscal services, as well as the organizations that the state chose. Chapter IV describes outreach to develop community interest in Personal Preference and the enrollment process for it. Chapter V discusses the development and approval of cash management plans and the uses of cash. Chapter VI details the selection and functioning of representatives named to manage the cash allowance on behalf of consumers. Chapter VII considers how consumers, with the help of consultants and the fiscal agent, fulfilled their role as employers. Chapter VIII discusses monitoring and the lack of both abuse of the cash allowance and consumer neglect and exploitation. Chapter IX considers whether the demonstration was implemented as planned, summarizes lessons about the components of the program discussed in Chapters IV through VIII, and describes the lessons of the New Jersey experience that cut across components of the program. Finally, Chapter X looks at New Jersey's plans for the future and for an ongoing Cash and Counseling program.

II. PERSONAL PREFERENCE: ISSUES AND DECISIONS

The solicitation for demonstration proposals provided the basic outline for the Cash and Counseling Demonstration projects. It stipulated that a cash allowance was to be provided instead of traditional Medicaid PAS or home- and community-based waiver services (HCBS) and was to cover goods and services that would promote independence. Furthermore, the demonstration would provide support services to help a consumer manage the cash allowance and act as an employer. New Jersey called its counselors “consultants,” so hereafter we refer to them as such and use the term “consulting” to refer to their work. New Jersey named its Cash and Counseling Demonstration program “Personal Preference.”

New Jersey had to make many design decisions to flesh out the program that the state proposed in response to the solicitation. The experience of consumer-directed programs in the United States and abroad influenced these decisions. In addition, New Jersey made many of the decisions in consultation with the other states participating in the Cash and Counseling demonstration and the staff of the demonstration’s National Program Office.

Most of New Jersey’s made most of its decisions were made during the design phase of the demonstration—that is, beginning in early 1997 (when the Robert Wood Johnson Foundation [RWJF] provided the funding for New Jersey to design its demonstration program) through spring 1998 (when the state began to implement Personal Preference). However, a legal dispute over the selection of the organization to provide fiscal services kept the program from enrolling beneficiaries until December 1999. This delay did create problems, as some data collection and training activities had started months before enrollment began. Table II.1 lists key dates for the design phase and the first months of operation.

In this chapter, we first describe the state’s goals for its Cash and Counseling program and the reaction of stakeholders in the state to the prospect that a cash allowance would be available instead of Medicaid personal assistance. The rest of the chapter describes the major issues that arose in designing the Cash and Counseling Demonstration and New Jersey’s approach to addressing them.

TABLE II.1

KEY DATES OF DESIGN AND EARLY OPERATIONS OF THE CASH AND COUNSELING DEMONSTRATION IN NEW JERSEY

Date ^a	Event
February 1996	New Jersey submitted a proposal to RWJF
November 1996	Submitted a revised demonstration budget to RWJF
January 1997	New Jersey funded to design its program
April 1998	Began training consultants
July 1998	Signed contract for enrollment services
August 1998	Issued solicitation for a fiscal agent
January 1999	Submission of data by personal care agencies begins
November 1999	Enrollment begins

^aWhen the document reviewed indicated only the quarter in which an event occurred, we have given the date as the middle month of that quarter.

A. NEW JERSEY’S PERSONAL ASSISTANCE PROGRAMS AND GOALS FOR THE DEMONSTRATION

New Jersey’s goals for the Cash and Counseling Demonstration are best understood within the context of the personal assistance and HCBS waiver programs it was already providing.

1. New Jersey’s Medicaid Personal Assistance Programs

Early in 1996, when it applied for the Cash and Counseling Demonstration, New Jersey offered personal assistance to eligible Medicaid beneficiaries under its state Medicaid plan

benefit, Personal Care Assistance (PCA). The state also offered seven Medicaid home- and community-based waivers. At that time, PCA served about 12,000 beneficiaries annually statewide. Each of the seven waiver programs was offered statewide; together, they served about 4,000 beneficiaries annually. The largest of the waiver programs, Community Care Program for the Elderly and Disabled (CCPED), served about 3,000 of these beneficiaries. The largest of the other six waivers was the AIDS Community Care Alternatives Program. The remaining five waivers served children and adults who were blind and disabled (three separate waivers), children who were medically fragile, and those who had experienced traumatic brain injury.

Most of the recipients of services under these seven waivers did *not* also receive PCA under the state Medicaid plan. The CCPED waiver (serving about three-fourths of all New Jersey recipients of waiver services) was for individuals with incomes above the usual Medicaid threshold who were not eligible for any other Medicaid services. Other HCBS waivers were intended to help people who needed medically involved care (for example, the waivers for people with AIDS), many of whom did not receive personal assistance as a waiver service.

In addition, at the time that New Jersey applied for the Cash and Counseling Demonstration, it offered one state-funded, consumer-directed personal assistance program, the Personal Assistance Services Program (PASP).¹ Operating through Independent Living Centers or a county coordinator (as designated by the county), PASP serves adults with physical disabilities who can direct their own care and who are either working, looking for work, or in school. PASP

¹During the demonstration, New Jersey began another consumer-directed program, Jersey Assistance for Community Caregiving (JACC). Funded entirely with state funds, JACC is designed for people with income and assets above the regular Medicaid thresholds. It allows people to hire their relatives (other than a spouse) as caregiver.

coordinators help clients develop their own service plans and train them to self-direct their care. While PASP clients are referred to a personal care agency, they can refuse the workers the agency assigns to them and instead recruit their own personal assistance workers. In either case, PASP clients are responsible for directing their workers in such tasks as housekeeping, personal assistance, and communication. The PASP population is similar to part of the Cash and Counseling population, and several of the worker-related features of PASP are similar to those of the Cash and Counseling model. However, PASP does not offer the flexibility to purchase equipment and supplies and home modifications. Moreover, PASP is limited in size, in part because it relies exclusively on state funding. When New Jersey applied for the Cash and Counseling Demonstration, PASP served about 500 beneficiaries statewide. Beneficiaries were typically on the PASP waiting list from 6 to 18 months before they were accepted, which suggested that some beneficiaries found this model of care attractive.

2. Goals for the Cash and Counseling Demonstration

In applying for the Cash and Counseling Demonstration, New Jersey sought to expand the options it offered Medicaid beneficiaries—especially elderly beneficiaries—to include programs offering greater opportunity for consumer direction. If feasible, the state wanted to recognize the competence of its citizens by expanding their choice and giving them greater control over their services.

The state wanted to participate in the demonstration primarily to test the feasibility of including a cash allowance model of consumer direction as a state-plan Medicaid service. It wanted to investigate the key issues involved in implementing such a program in preparation for adding a cash allowance option to its regular PCA program, should the cash allowance prove workable.

New Jersey was also interested in how consumers could use the Cash and Counseling allowance to purchase equipment that Medicaid did not cover. The state office responsible for the Cash and Counseling proposal was keenly aware of equipment needs, since one of its responsibilities was to advise citizens with disabilities about equipment that would best meet their needs.

When it entered the Cash and Counseling Demonstration, New Jersey had a shortage of personal care aides, especially in rural and affluent areas, and was considering alternate ways to provide services. In particular, senior state officials were interested in making aide work more attractive by “professionalizing” it—that is, by reforming the Nurse Practice Act so that aides could perform more professional tasks, rather than primarily housekeeping chores.

Initially, overcoming an aide shortage was not one of New Jersey’s primary objectives for participating in Cash and Counseling. During the demonstration, however, the worker shortage became more serious, and some program staff members began to stress the value of expanding the labor supply by allowing consumers to hire relatives and friends under the Cash and Counseling model.

New Jersey did *not* enter the Cash and Counseling Demonstration to generate savings of state funds. However, the state believed that the cash allowance might be more cost-effective than traditional personal care because it allowed consumers to use commercial services, for which competition helped to hold prices down. Moreover, the state believed that the consumer’s ability to hire multiple workers at different skill levels would foster cost-effectiveness because it would create a better match between the demands of the job and worker skills and compensation.

B. REACTION OF STAKEHOLDERS

Both governmental and private stakeholders had important roles as New Jersey was designing its Cash and Counseling program.

1. Governmental Stakeholders

Because it was the state host agency, the New Jersey Department of Human Services (DHS) was a major stakeholder in the Cash and Counseling Demonstration. DHS, Division of Medical Assistance and Health Services (DMAHS), submitted the Cash and Counseling Demonstration proposal and applied for and received the waivers needed for the demonstration. The director of DHS/DMAHS delegated authority for administration of the program to the New Jersey State Office on Disability Services (ODS) within DHS. The executive director of ODS became the project director for the Cash and Counseling Demonstration. As of July 1999, ODS became the Division of Disability Services (DDS); we refer to it as DDS hereafter.

New Jersey's governor was not directly involved in designing the Cash and Counseling Demonstration. However, the Commissioner of Human Services, the cabinet-level official leading DHS, strongly supported the demonstration. The DMAHS director, who felt that the cash model had wide applicability, also strongly supported the demonstration.

A few months after receiving demonstration funding, the state formed an interdepartmental work group to help implement the Cash and Counseling Demonstration. Among those in the work group were staff members of the PASP program, who shared their expertise on self-directed care. The work group also included a representative from the Office of Information Services (OIS) within DMAHS. Staff members of OIS developed and implemented project-specific software for New Jersey's Cash and Counseling Demonstration to track eligible beneficiaries, demonstration enrollees, and cash recipients, and they worked with a contractor to identify cash recipients on the state's Medicaid Management Information System.

The state legislature in New Jersey has supported community care in general, but it was not a major stakeholder in the Cash and Counseling Demonstration. As there was no need for

revision of state legislation to implement the demonstration, DHS did not involve the state legislature.

Nor were unions a major stakeholder in New Jersey during the design of the demonstration, so union concerns did not shape the procedures of the Personal Preference program. However, unionization of personal care began in New Jersey while the Cash and Counseling Demonstration was under way.

2. Private Stakeholders

DDS involved advocate organizations and providers of home- and community-based services in the design of the Cash and Counseling Demonstration to garner the support of private stakeholders for the demonstration. Such stakeholders were not involved in the decision to apply for the grant or the preparation of the initial proposal. However, New Jersey began to develop an advisory council before the state received funding from RWJF to design its Cash and Counseling Demonstration. After funding was assured, New Jersey quickly completed establishing the council. The state invited members of advocacy organizations for nonelderly adults with disabilities and the elderly, as well as representatives of traditional personal care agencies and other agencies providing home- and community-based services, to join the council. The council held its first meeting in spring 1997.

a. Advocates

Advocates for elderly people and nonelderly adults with disabilities had no major concerns about the Cash and Counseling model and strongly supported the demonstration. During the early planning for the demonstration, the Alzheimer's Association was concerned that beneficiaries with cognitive impairment might be discriminated against by being excluded from the cash program. This concern was resolved when Personal Preference decided to allow those

who could not manage the cash allowance (including those with Alzheimer’s disease and other cognitive impairments) to participate if they had a representative to plan and arrange care services on their behalf.

b. Personal Care Industry

When the demonstration began, the personal care industry in New Jersey consisted of about 250 personal care service agencies, of which more than 200 were for profit. These agencies are licensed by the state to provide personal care and private-duty nursing. There were also about 50 home health agencies that served Medicare beneficiaries. The demonstration had less effect on the home health agencies than on the personal care service agencies.

According to the organizations representing the personal care industry of New Jersey, its members had mixed feelings about the Cash and Counseling Demonstration. The industry saw some advantages to a cash allowance program. First, it believed that some clients—especially adults with disabilities who could work if they had help—needed a more flexible personal care program and could benefit from a cash program. Moreover, the industry recognized that clients who were difficult to serve in traditional programs might be referred to the cash allowance program. The Personal Preference staff marketed the program to the industry by suggesting that agencies refer their “hard” cases to Personal Preference. Finally, although personal care agencies were not allowed to bid on the provision of consulting services, the industry recognized that its member agencies could become suppliers of services (such as housecleaning and chore services) to cash recipients.

On the other hand, the personal care industry did not believe that the demonstration was appropriate for less capable beneficiaries, including most elderly ones. The industry was proud of the quality of personal care it provided in New Jersey and genuinely concerned about the well-

being of less capable beneficiaries. It recognized that the fiscal agent and consultants helped to safeguard the allowance and the well-being of cash recipients. Nevertheless, the industry was concerned about potential abuse of the cash allowance by consumers and possible exploitation of consumers by family members who were hired as workers but did not provide agreed-upon care. In addition, the industry was concerned about the potential for increased medication errors because nurses would not supervise workers who had been hired with the cash allowance.

The personal care industry also was concerned about the effect of a cash allowance program on its business. To some extent, the industry was concerned about losing clients to the Cash and Counseling Demonstration.² However, its major concern was that cash recipients might hire their agency aides, thereby reducing the agency labor force—at a time when agencies already faced a shortage of personal care workers—making it more difficult for agencies to serve their clientele as a whole. This concern was heightened because a consumer might offer an aide a higher hourly wage than the agency would pay.

The industry took the position that consumer hiring of agency aides was illegal. They argued that agencies in New Jersey must invest considerable time and resources in training and certifying aides and in completing hiring paperwork. Referring to the demonstration, one industry representative put the concern this way: “As I see it, we have to do the paperwork and

²Perhaps the impact of the Cash and Counseling Demonstration on their revenues was dwarfed by a general reduction in hours of personal assistance rendered. Industry representatives reported that average hours of personal care dropped from 22 to 16 hours per week during the demonstration. Industry representatives attributed the drop to state efforts to stem growth in the PCA program following cutbacks in Medicare home health care mandated by the federal Balanced Budget Act of 1997. Senior program staff reported that state policy on the provision of PCA services did not change during the demonstration, but noted that hours of personal care likely fell as a result of the state’s utilization review activities. As part of these activities, the state reviewed care plans for clients of agencies that were providing appreciably more hours of personal care per client than the typical agency (that is, “outliers”). As a result of these reviews, care plan hours (and, thus, hours of service) were reduced for some beneficiaries.

then they'll take the client and the client will take the aide with them.” Without concurring with the industry position that it was illegal for consumers to hire their aides, the state Personal Preference staff did respond to the industry’s concern by adopting a policy that discouraged consumers from hiring agency aides, including writing to cash recipients to discourage such hiring. Turnover of agency aides may have limited such hires, since consumers were unlikely to try to hire aides with whom they had not developed personal relationships. Another factor that limited such hires may have been that it was generally not in an aide’s interest to give up the greater income and security of agency employment to work for one individual. Moreover, if an aide worked exclusively for a consumer, he or she would not be in a position to maintain the certification required to work for an agency and might have a difficult time finding other work if and when the consumer no longer needed personal assistance.

The personal care industry also was concerned that agencies be given adequate notice that a personal care client was to become a cash recipient. In response, New Jersey agreed to provide notice 30 days before a consumer switched to cash.³

In addition, the industry was concerned about the costs to agencies of supplying information needed to administer the cash allowance program. Agencies were required to complete a consumer data form) that included information from the care plan of every client they assessed. The state used the information on care plan hours from the form to determine the amount of the cash allowance to which a consumer would be entitled. In addition, personal care agencies had to provide a copy of their most recent assessment for clients who were assigned to the treatment group. The industry perceived submission of this information as a condition of participation in the PCA program and unsuccessfully sought to have the state reimburse these costs. Moreover,

³The notice period was later reduced to 14 days.

as the enrollment period for the demonstration was extended again and again, the personal care industry became frustrated that its members had to submit consumer data forms and copies of assessments for far longer than originally planned.

Finally, the personal care industry resented the fact that the extensive regulations that the state had imposed on its agencies would not apply to workers hired directly by consumers. Industry representatives described New Jersey personal care as “very regulated,” with supervision, certification, and time-consuming criminal background checks involving the FBI, state police, and state nursing practice board. None of these regulations applied to workers hired with the cash allowance. Case Example II.1 presents the explanation one industry representative gave for the resentment of differences in regulations.

Case Example II.1: Resentment of Differences in Regulations

Under the Cash and Counseling program, the state says, “We’ll wipe that out for Cash and Counseling, but *you* still have to do it.” Moreover, the state does not pay us to comply with the regulations. We have had only one rate increase in 10 years, and that was 50 cents an hour. The state created the rules, now the state won’t have to follow them.

The industry did not substantially impede the implementation of the Cash and Counseling Demonstration, partly because the state Personal Preference project staff carefully considered the industry’s concerns and responded to some of them. Indeed, the industry supported the demonstration with timely submission of consumer data forms and copies of assessments and by referring clients. Organizations representing the personal care industry also agreed to notify member agencies about the evaluation’s worker survey and encourage them to cooperate with it.

Moreover, the industry greatly respected the project director of Personal Preference—they knew him well through his work as executive director of DDS. This respect made the industry more willing to cooperate with the Cash and Counseling Demonstration. Case Example II.2

presents the description one industry representative gave of this respect and its importance to the demonstration.

Case Example II.2: Trust and Respect for DDS Executive Director

The state has good people trying to make the program work fairly for everybody. The person chosen to head this up has made a positive difference. He has experience with disability, is open, fair, has a history in personal care and community-based services, and knows what clients need. He is the least bureaucratic of the state people. He sincerely cares. We knew we could trust him to be honest. If it were not for him, we would have hated the program more.

Some of the industry’s most serious concerns were not realized. There were no instances of serious abuse of the cash allowance or of exploitation of consumers. Agency labor supply was affected very little, because consumers hired few agency aides. In addition, some of those hired may have continued to work for agencies while working for cash recipients “on the side,” perhaps without the knowledge of their agency employers.

C. DESIGN ISSUES AND DECISIONS

Decisions of the funders (RWJF and DHHS/ASPE) and federal law and regulations (including the terms and conditions of the demonstration waivers) set parameters for the Cash and Counseling Demonstration. Within these parameters, New Jersey made many decisions that shaped the Personal Preference program. As noted earlier, these decisions were influenced by the experience of other consumer-directed programs and shaped by the work of the Cash and Counseling National Program Office. Many were made jointly with the other Cash and Counseling programs. These decisions involved all of the major components of the Cash and Counseling model: eligibility and appropriateness, outreach and enrollment, services to be

covered by the cash allowance, determination of the level of the cash allowance, and consulting and fiscal services.⁴

1. Eligibility and Appropriateness

The solicitation for the Cash and Counseling Demonstration permitted states to cash out either Medicaid state-plan PCA or Medicaid home- and community-based waiver services.

As mentioned earlier, New Jersey had both state-plan PCA and waiver services when it responded to the solicitation. It proposed to cash out only state-plan PCA. Later, under pressure to expand the pool of eligible beneficiaries to increase the likelihood of reaching the targets for enrollment needed for the Cash and Counseling Evaluation, New Jersey considered cashing out some of its home- and community-based waivers. However, only one waiver program—CCPED—served enough clients (about 3,000 annually) to materially expand the pool of eligible beneficiaries. The senior program staff was reluctant to cash out the CCPED waiver, for two main reasons. First, state-plan PCA participants are entitled to other Medicaid benefits, while CCPED clients are entitled only to the services the CCPED waiver covers. Second, authorization procedures for state-plan PCA and CCPED waiver services differed in that services authorized under CCPED (and most of the other waivers) were subject to cost caps. Because of these differences, CCPED participants were expected to use a different proportion of their care plan services than were PCA participants, making it more complex to cash out the care plan while ensuring that the cash program would cost no more (on average) than did services actually delivered. Moreover, those responsible for the CCPED program apparently had little interest in

⁴For a discussion of the decisions the Cash and Counseling states faced, see Mahoney et al. 2000.

participating in the Cash and Counseling Demonstration. Ultimately, New Jersey decided to cash out only state-plan PCA services under its Personal Preference program.

Both current recipients of PCA services and PCA applicants were eligible to enroll in Personal Preference, except that New Jersey excluded beneficiaries who were receiving both PCA and home- and community-based waiver services.⁵ New Jersey was concerned that including recipients of both PCA and waiver services would cause confusion, as these beneficiaries would have both Cash and Counseling consultants and waiver case managers. Moreover, New Jersey was concerned that, if beneficiaries receiving both PCA and waiver services were included in the demonstration, the difference in authorization procedures for PCA and waiver services would make it difficult to interpret the results of the evaluation.⁶ As the number of beneficiaries receiving both PCA and waiver services was small, their exclusion had little effect on the size of the eligible population.

Given the decision to cash out state-plan PCA, New Jersey needed to decide which, if any, beneficiaries of that program would be inappropriate for Personal Preference and how to identify them so that they could be excluded. From the beginning, New Jersey wished to exclude as few PCA beneficiaries as possible. So it could more readily meet the target sample sizes for the evaluation, the state wanted to retain the largest possible pool of eligible participants. Moreover, New Jersey pointed out that those not capable of managing the cash allowance for themselves could have representatives. New Jersey realized that developing a structured screening process

⁵PASP recipients were ineligible for Personal Preference.

⁶Later, New Jersey allowed beneficiaries who received both PCA and services under the waiver for developmentally disabled adults to participate in the demonstration. This waiver was the only one of the seven that did not impose cost caps on the care plan. Five such beneficiaries enrolled in Cash and Counseling.

would be problematic. For example, a history of alcohol abuse did not necessarily mean that a beneficiary was currently inappropriate for the cash allowance program.

The decision about a structured screening process offers a good example of the work of the National Program Office and the collaboration of the Cash and Counseling states during the design phase of the demonstration. All of the demonstration states shared New Jersey's concerns about a structured screening process. The National Program Office for Cash and Counseling formed a task force on screening. While deliberations on screening were under way, an attorney on Arkansas's advisory council said that a structured process that denied participation might not be legally defensible. If the process was not legally defensible and a consumer chose to contest exclusion from the program, a state might be held liable for such exclusion.

Ultimately, New Jersey decided to implement only a single criterion pertaining to appropriateness for Cash and Counseling. PCA recipients who were not expected to be living in a community setting for at least six months were excluded on the grounds that consumers typically require several months to develop a cash management plan and hire workers. Thus, those who were not expected to be living in a community setting for at least six months were not likely to benefit from the cash program. To implement this criterion, the consumer data form asked personal care agency nurses to indicate whether they expected PCA services to be required for at least six months.

Except for this one structured criterion, New Jersey relied on a self-screening process for Personal Preference for both consumers and representatives. The materials provided to consumers described their responsibilities, as well as their rights, under Personal Preference and stated that only those who were willing to assume these responsibilities were to enroll in the cash program. Similarly, New Jersey developed materials describing the responsibilities of the representative and asked that potential representatives review these materials before making a

commitment to serve in that capacity. (Legal guardians and other court-appointed representatives were expected to serve as Personal Preference representatives if the person for whom they acted enrolled in the program.) Appendix A presents these materials, and Chapter VI discusses representatives in detail.

While New Jersey did not adopt a formal process to determine whether a given person was appropriate as a representative, it did specify that the same person could not serve as both a worker and a representative. Serving as both could create a conflict of interest, since the representative's responsibilities would typically include signing worker time sheets and supervising worker activities.

2. Outreach and Enrollment

Outreach to the community was necessary to create awareness of the Cash and Counseling Demonstration and to increase interest among beneficiaries in receiving a cash allowance, as well as interest from agencies in providing consulting services. The state Personal Preference staff was responsible for the marketing phase of outreach. Most marketing involved presentations to potential participants, as well as to advocacy, community, and professional groups.

New Jersey had to make two related design decisions about enrollment: (1) when it would take place, and (2) who would be responsible for it. These decisions in turn affected procedures for outreach to individuals. The basic options for *timing* of enrollment were to allow consumers to enroll at any time or to require them to enroll only at the time of their assessment for PCA—that is, as ongoing recipients were reassessed to determine the need for continuing care and as new applicants were assessed. The basic options for *responsibility* for enrollment were for state employees (or state contractors) to contact beneficiaries or to rely on organizations already serving PCA recipients.

Enrollment at assessment had two advantages. First, the care plan developed from an assessment was to be the information source needed to determine the amount of the cash allowance. If enrollment were timed to follow assessment, that care plan would remain in force for about six months (barring a material change in the beneficiary's condition or circumstances requiring a new assessment). If enrollment were divorced from assessment, a new care plan might be required before the consumer could complete the development of the cash plan. Second, enrollment at assessment would spread the volume of enrollment-related work out over time, making the workload for enrollment staff more manageable. If consumers could enroll at any time, the enrollment staff might find it impossible to meet demand at peak times—especially following a major outreach effort. On the other hand, restricting enrollment to the time of assessment could be problematic if outreach could not target those who were about to be assessed or had been assessed recently. If beneficiaries who expressed interest in Personal Preference had to wait several months before being allowed to enroll, they might lose interest in the cash program altogether.

As noted earlier, the state might vest responsibility for outreach in state employees or contractors (contractors might be independent assessors) or work with other organizations, including providers of traditional services. Providers of traditional services might readily couple enrollment with assessment, as the latter is often among their responsibilities. For example, those conducting assessments might explain the cash program and leave reading material about the program with the consumer. Consequently, relying on traditional providers to conduct outreach might be more efficient than hiring state employees or a state contractor—other things being equal.

However, objectivity, as well as efficiency, was an important consideration in selecting an approach to enrollment in Personal Preference. Staff members at traditional agencies who were

resistant to the cash program might influence consumers not to participate. In addition, independent assessors might perceive the cash program as a threat to their professional norms (for example, norms about the need for nurses to supervise the administration of medication).

Concerned about the possible resistance of traditional personal care agency staff to Personal Preference, New Jersey decided not to give responsibility for either outreach or enrollment to these providers. Instead, the state vested responsibility for outreach and enrollment in its own staff and an external contractor. Thus, it separated outreach and enrollment from the assessment process for which traditional personal care agencies were responsible.

Initially, New Jersey rejected hiring state employees for other aspects of outreach or for enrollment. Instead, it contracted with a for-profit firm for these tasks. There were three major arguments against hiring state employees for outreach and enrollment. First, New Jersey would be able to hire only a small state staff for Personal Preference. With a small staff, it would be nearly impossible to have staff members fluent in Spanish and Russian, foreign languages spoken by a substantial number of Medicaid beneficiaries in New Jersey. Second, it would be difficult for a small staff to visit the homes of consumers throughout the state. Third, New Jersey was concerned about the possibility of lengthy delays (of six months or more) in hiring state employees. It did not want to be forced to postpone the implementation of the demonstration due to delays in hiring state employees for enrollment. However, many months after implementing the demonstration, New Jersey hired state employees to take over the outreach and enrollment responsibilities from the for-profit firm. (Chapter IV provides a detailed description of Personal Preference outreach and enrollment.)

Although New Jersey separated responsibility for assessment and enrollment, it initially timed enrollment to follow assessment. State receipt of the consumer data form for a given beneficiary (submitted after assessment) triggered outreach to see if that person was interested in

enrolling in Personal Preference. New Jersey rejected the idea of having assessment nurses leave brochures about Personal Preference with the consumer at the time of the assessment home visit. The state did not want these nurses to respond to questions about the cash program because it feared they would not answer objectively, and the agencies pointed out that it did not make sense for their nurses to leave brochures if they were not allowed to respond to questions consumers might have about Personal Preference. Later, New Jersey mailed materials about Personal Preference to all consumers listed on a database developed from the consumer data forms who had not previously expressed interest in the cash program (see Chapter IV).

3. Permissible Uses of the Cash Allowance

The solicitation for the Cash and Counseling Demonstration did not envision that a state would provide unfettered cash, as in an income supplement program. However, it insisted that states permit the cash allowance to cover a range of goods and services that would help consumers function more independently.

Two key issues that arose were (1) the breadth of goods and services that could be purchased with the cash allowance, and (2) the method (if any) by which their purchase would be authorized. New Jersey could opt for a relatively narrow list of covered goods and services, or it might interpret coverage broadly. Furthermore, New Jersey could require state Personal Preference staff to review and approve cash plans or delegate authorization to do so to consultants.

In developing an approach to covered goods and services, New Jersey was torn between concern about the possibility of abuse of the cash allowance and pressure from the National Program Office, RWJF, and DHHS/ASPE to broaden the goods and services covered under the cash allowance. Facing skeptics and critics who initially equated cash with abuse, New Jersey was concerned about the potential harm to the cash program if abuse of the cash allowance led to

adverse publicity. The director of Personal Preference recalled that he dreaded the possibility of a newspaper comment that a consumer “went to Atlantic City on the money.”

New Jersey decided to use the opportunity afforded by the demonstration to develop lists of approved goods and services for the demonstration and of unapproved goods and services for use in a future program (if the cash allowance program were continued beyond the demonstration). To maintain control over the approval process during the demonstration, New Jersey decided that the state Personal Preference staff would be responsible for reviewing and approving cash management plans.

The Personal Preference program staff did not want to give consultants the power to approve cash plans because it was concerned that doing so would place consultants in an adversarial role and damage their relationships with consumers. New Jersey preferred that the state be the “bad guy” when it was necessary to disapprove a consumer request to include a good or service in the cash plan.

Another issue was who would be eligible to be hired as a worker. The waivers for the Cash and Counseling Demonstration permitted payment of legally responsible relatives—that is, spouses and parents of minor children. New Jersey decided to avail itself of this provision of the waivers—it would allow consumers to hire their spouses with the cash allowance. (No cash recipients in New Jersey were minors, as the PCA program did not serve minors.)

As a cash management plan is being developed, the availability of goods and services from other public sources must be taken into account. New Jersey (and the other Cash and Counseling states) recognized that it was not in the consumer’s interest to use the cash to purchase services already available at no cost (or reduced cost) to the consumer. The consumer would incur an unnecessary expense if he or she purchased such goods or services. In addition, another program might be better able to help the client choose the most appropriate good or service. For example,

a program specializing in assistive equipment could offer expert advice on what type of equipment was best under different circumstances. To address this issue, New Jersey had Personal Preference consultants advise consumers about the goods and services available under other public programs during the development (and any later revisions) of the cash management plan. In addition, staff members at DDS were knowledgeable about technology to help people with disabilities and made their expertise available to the Personal Preference consultants.

4. Determining the Level of the Cash Allowance

In cash programs, the level of allowance may vary, depending on the consumer's level of need (or a related concept such as disability) or on his or her history of benefits in the traditional program. One advantage of basing the level of the cash allowance on the historical benefit level is that doing so reduces the likelihood that demand for PAS will increase because beneficiaries not interested in agency services apply for the cash allowance because they find it attractive, thereby increasing public costs. Such induced demand is sometimes labeled the “woodwork effect.”⁷

On the other hand, basing the level of the cash allowance on the historical level of benefits is problematic, for two reasons. First, the condition of the beneficiary or his or her situation can change—perhaps dramatically; the historical level of benefits may be inadequate in such situations. Second, those not already enrolled in the traditional program will not have a track record of historical benefits on which to base the amount of the cash allowance. If beneficiaries are to participate in the cash program without first participating in the traditional program until

⁷To prevent an increase in public costs due to the woodwork effect, the special terms and conditions for the waiver for the Cash and Counseling Demonstration stipulated that the ratio of the number of new clients to the number of current clients was not to exceed a historical average.

they establish a claims history, the amount of their allowance must be based on need, and a mechanism must be developed outside of the traditional program for assessing that need.⁸

New Jersey based the level of the cash allowance on approved PCA care plan hours. Consumers were not required to have a history of PCA benefits, but they could not enter Personal Preference directly. To be eligible for Personal Preference, a Medicaid beneficiary had to be a current recipient of PCA or be assessed and approved for PCA by a traditional agency, which then developed a care plan. However, to reduce the potential for demand induced by the attractiveness of a cash allowance, New Jersey deliberately focused outreach for Personal Preference on *current* recipients of PCA services.

Channeling enrollment of those not already receiving PCA through traditional agencies had another advantage. By doing so, New Jersey facilitated arrangement of traditional services on an interim basis (if needed) while beneficiaries developed their cash management plans.

The formula for determining the level of the cash allowance in New Jersey involved calculating the cost to the state of the hours in the PCA care plan (separately for weekday and weekend hours as the hourly cost differed), then deducting 10 percent to cover the costs of Personal Preference consulting and part of the cost of fiscal services. (Consumers were also charged for certain services provided by the fiscal agent if they used these services, such as cutting checks and conducting criminal background checks). Information on hours in the PCA care plan was obtained from the consumer data form, which was completed by staff of traditional

⁸Level of need might be based on professional judgment or on an algorithm that takes into account the beneficiary's functional impairment and informal care.

agencies and instituted expressly for this purpose.⁹ The hours on the care plan the traditional agency prepared indicated the number of hours the agency planned to deliver. However, if the traditional agency planned to deliver more than 25 hours of care a week, it first had to obtain authorization from the state.

When using care plans to set cash allowance levels, a major issue is the potential for differences between the hours of traditional service planned and the hours actually delivered. The hours of service delivered generally do not exceed that the number planned, since the care plan typically represents the maximum authorized. Rather, the number of hours of care received is often less than the hours planned, for several reasons. Agencies sometimes may plan for somewhat more care than they expect to provide so that they can increase the amount without revising the care plan. That is, total hours planned may include a hedge against possible future increases in need. More frequently, events preclude providing all the hours of care planned. A client may be unexpectedly hospitalized and thus not available when an aide arrives. A personal care aide may not appear for work when expected. An agency may be unable to find enough workers to provide the planned care. If the worker shortage is prolonged, an agency may reduce care plan hours to lessen consumer expectations.

Because the number of hours of service received may be less than the hours planned, a “discount rate” may be required to ensure budget neutrality—that is, it may be necessary to discount the hours in the care plan before cashing them out to ensure that the cost of the cash program does not exceed the cost of the traditional program. Such budget neutrality was a condition of the Cash and Counseling Demonstration waivers.

⁹Prior to requiring the consumer data form, New Jersey did not have ready access to data on care plan hours, as it was necessary for the state to ask agencies for data on care plan hours on a case-by-case basis.

To assess the need for a discount rate, New Jersey collected information on care plan hours for a historical sample of PCA clients and compared those hours to hours of care received, as indicated by Medicaid claims. As there was little difference between hours planned and hours received for the sample, New Jersey decided against discounting care plan hours for the cash allowance.

5. Consulting and Fiscal Services

In designing Personal Preference, New Jersey faced several major issues concerning consulting and fiscal services. It had to decide what consulting and fiscal services would be offered, how these services would be organized, and how they would be paid for and monitored.

a. Organization of Consulting and Fiscal Services

New Jersey had several options in deciding how to organize assistance for consumers receiving the cash allowance. First, it could either combine consulting and fiscal functions in a single host organization or separate these functions, assigning them to different organizations. The major argument for separating consulting and fiscal functions is the difference in the types of expertise required, especially expertise for preparing and filing payroll taxes and related documents.

Second, New Jersey could choose to have one host organization serve the entire state (for consulting, fiscal services, or both) or to have multiple host organizations—(perhaps serving different regions or different populations). Having one host organization might take better advantage of economies of scale. If the consumer is to be able to choose among providers of assistance, however, more than one host organization must be available. Moreover, a single host organization might not be able to cover all regions of the state or serve all population groups

equally well. Finally, the state could opt for different numbers of host organizations for consulting and for fiscal services.

New Jersey chose to separate the fiscal and consulting functions. It contracted with a single organization to provide fiscal services for the entire state and established agreements (called “partnerships”) with 34 organizations to provide consulting services across the state. (Agencies providing traditional personal care services were not permitted to provide consulting services.) New Jersey has a diverse population, and the state wanted to have a variety of human services agencies providing consulting to different ethnic communities. It also wanted to give consumers a choice of agencies that provide consulting. Moreover, the consultants needed to be located throughout the state, since they were required to visit consumers’ homes periodically. Having a large number of organizations providing consulting also helped to ensure that the human services organizations in the state would support Personal Preference.

Given the large number of consulting agencies, it was expected that each would typically have a small volume of Personal Preference cases. Agency staff members were expected to continue to have other duties and to provide consulting part-time or even after hours.

New Jersey judged that it would be inefficient for agencies serving only a few consumers to provide fiscal services under Personal Preference. To keep costs as low as possible, a fiscal agent needs to process a volume of checks and payroll documents. It might also be inefficient if multiple organizations were required to become expert in acting as the agent of the consumer. Moreover, the fiscal agent does not need to be located close to the consumer, since its activities can be handled primarily by telephone and mail. Finally, New Jersey would have had to devote more resources to monitoring if it selected multiple host organizations to provide fiscal services.

To provide checks and balances, New Jersey also separated the consulting and fiscal functions. The Personal Preference program staff was concerned about increasing the potential

for abuse if staff of the same organization helped to develop the cash plan, then approved the checks under that plan. For example, such abuse might arise if a consumer hired a member of the consultant's family as a worker at the consultant's urging. Arguably, staff of a separate organization might be more likely than staff in the same organization to question the appropriateness of payment in a situation such as one in which the payee had the same last name as the person reviewing the cash plan.

b. What Consulting and Fiscal Services to Offer

In the Cash and Counseling model, many aspects of consulting and fiscal services are intended to help consumers and may be used at their discretion. Others are intended to prevent abuse of the cash allowance and exploitation of the consumer and are mandatory. New Jersey had to decide which aspects of consulting/fiscal services would be offered and which would be mandatory. In particular, consultant assistance with the development of the cash management plan might be discretionary, while consultant review of the uses of cash might be mandatory. Consultant assistance with recruiting, hiring, training, and supervising workers might be discretionary, but New Jersey might require that the fiscal agent prepare the appropriate tax and unemployment insurance forms (or ensure that the consumer did so). Furthermore, during the design of the Cash and Counseling program, New Jersey had to decide whether a consumer who wished to manage the cash allowance without help from the fiscal agent would be required to pass a skills examination on preparation of payroll documents to ensure that federal and state tax liabilities would be met. Finally, New Jersey had to decide how frequently consultant contact with consumers would be required to prevent abuse and exploitation.

In addition to these basic services, a consulting agency or fiscal agent might perform other services for consumers. These include maintaining a worker registry to help consumers identify

workers to hire, assisting in securing criminal background checks for potential workers, keeping staff to serve as back-up workers if a consumer's regular worker were unable to care for him or her, and hosting a peer support group. Consultants might also be responsible for enrollment in the cash program and for reassessment of the care needs of participants in the cash program.

The New Jersey design for Personal Preference made three aspects of consulting/fiscal services mandatory. First, the consultant had to review (but not approve) the initial cash management plan and all subsequent revisions to it. A revised plan was required when the amount of the cash allowance changed or if the consumer proposed changes in the use of cash that were inconsistent with the current cash plan. After consultant review of the cash management plan, the consultant was to forward the plan to the state Personal Preference program staff in Trenton for approval.

Second, consultants were required to visit consumers face-to-face at least quarterly and speak to them at least monthly for the first six months after their assignment to the treatment group. In this way, they could monitor consumers' circumstances and condition and their use of the cash allowance. New Jersey did not require consumers or representatives using the fiscal agent to retain receipts to document expenses for review by consultants. The state reasoned that such consumers had direct control of only small amounts of cash for incidental expenses, which were limited to no more than 10 percent of the allowance. Moreover, any use of the cash allowance for incidental expenses had to be included in the cash management plan.

The third mandatory feature New Jersey adopted was fiscal review for consumers who chose not to use the fiscal services for payroll taxes and related documents. (This decision was made in conjunction with the other Cash and Counseling programs and the National Program Office.) Consumers who chose not to use fiscal services were required to pass a skills examination on the

preparation of payroll documents and present their payroll records for review by the fiscal agent if requested to do so.

Optional consulting services for participants in New Jersey included:

- Training and support services related to the development of cash management plans
- Training and support services related to recruiting, hiring, training, and firing workers
- Contacting the fiscal agent or the state Personal Preference office on the consumer's behalf
- Providing referral information on services that might assist the consumer, including public services (such as transportation from the local Area Agency on Aging) and private services (such as an insurance agent who would write a rider for workmen's compensation to a renter's policy)
- Making initial contacts with service providers on the behalf of the consumer
- Identifying equipment, assistive technology, and other goods that could increase independence

The amount of optional consulting service available to a given consumer was limited by the system New Jersey adopted for payment of consultants (discussed further in Subsection c below). Specifically, hourly payments to consultants were capped at no more than 19 hours a year for a given consumer, with a separate lump-sum payment for the development of the initial cash management plan.¹⁰ New Jersey adopted this cap on consultant hours partly to contain the costs of consulting. In addition, it wanted to avoid having consultants assume the role of case managers and thereby help ensure that the philosophy of consumer direction was indeed implemented in Personal Preference.

The consulting agencies and fiscal agent provided some services beyond the basic consulting and fiscal services. New Jersey required that consulting agencies facilitate peer

¹⁰The cap was later increased to 20 hours a year for a given consumer.

support among participants in the Personal Preference program. Some of the consulting agencies did sponsor peer support programs for other groups or refer their clients to peer support programs sponsored by other organizations. However, no consulting agency that we visited reported special programs to foster peer support among the Personal Preference consumers to whom it provided consulting services. Specialized peer support programs probably were not a priority for organizations providing consulting agencies to only a small number of consumers. The Personal Preference program did develop a list of consumers who were willing to speak to interested beneficiaries about enrolling in the cash program. In effect, these consumers were engaged in a peer support activity. The fiscal agent provided criminal background checks as an optional service (consumers were charged an additional fee for this). However, neither the consulting agencies nor the fiscal agent provided worker registries or back-up workers as optional services.¹¹

Consultants were not responsible for enrollment or reassessment in New Jersey. As described earlier, the state initially contracted with a private firm to enroll beneficiaries in Personal Preference and later hired state employees as enrollment staff. New Jersey arranged for Medicaid nurses to reassess cash recipients.

c. Payment for Consulting and Fiscal Services

Another issue that New Jersey faced in designing Personal Preference was how to pay for consulting and fiscal services. First, it had to decide whether consumers would be charged for nonmandatory services. For example, were they to be charged a monthly fee for bookkeeping or

¹¹After our visit to New Jersey, the state received a “Systems Change” grant for Community Living from the Health Care Financing Administration (now the Centers for Medicare & Medicaid Services). New Jersey planned to devote some of the grant funds to the development of a worker registry.

a service charge for each check issued? The major argument in favor of such consumer charges is that they work to ensure that those who use the services bear the cost. The major argument against such charges is that consumers might be discouraged from using a service from which they would benefit.

New Jersey opted to have consumers charged service fees for the tasks that they requested the fiscal agent to perform. A schedule of charges was developed, covering such tasks as cutting a check, stopping payment on a check, and arranging for a criminal background check.

Second, New Jersey had to decide how to structure the state's payment for consulting and fiscal services. The basic options were a fee-for-service or capitated approach. A fee-for-service approach might pay by the hour or establish payment for a particular task, while a capitated approach might pay the consulting or fiscal agent a monthly fee for every consumer on its caseload. One issue in designing a capitated approach was whether the level of services a given consumer required was likely to decrease over time as he or she (or a representative) mastered the responsibilities of an employer. Under either a fee-for-service or a capitated approach, it might be feasible to pay for some specific services under another authority. For example, reassessment might be rendered outside the cash program and paid for as a separate Medicaid service.

New Jersey decided in favor of a fee-for-service approach for consultants, with a lump-sum payment for the development of the initial cash plan (originally \$52), followed by payment of \$16 an hour (up to a maximum of 19 hours annually).¹² Consumers were not charged directly for consulting services. Rather, all consulting costs were paid from the funds generated by taking

¹²The lump-sum payment was later increased to \$75 and the hourly payment for consulting services was later increased to \$26 an hour (up to a cap of 20 hours per consumer per year).

the top 10 percent off all “cashed out” care plans before arriving at the consumer’s allowance level.

New Jersey adopted a fee-for-service approach to paying the fiscal agent. In addition to the fees paid by consumers, the state paid the fiscal agent for some services rendered to consumers. For example, the state paid the fiscal agency for processing the papers in a worker employment packet. A fee schedule was also developed for these services. The top 10 percent of all “cashed out” care plans was also the source for these payments from the state to the fiscal agent.

d. Monitoring Consulting and Fiscal Services

New Jersey planned to monitor consulting services in several ways. First, state program staff members were to review documents submitted by consultants pertaining to individual consumers (primarily cash management plans and reports on quarterly visits to consumers). Second, consultants were required to submit detailed invoices naming the consumers they had assisted. Third, consultants were required to document their contacts with consumers and to maintain a minimum data set about each consumer. Fourth, New Jersey planned to conduct on-site quality assurance audits of consulting services. As a part of those audits, state program staff members were to review the consultant’s documentation. In addition, New Jersey planned to survey consumers about their satisfaction with Personal Preference, and consumers were to receive a toll-free number that they might use to report difficulties with the program. (Monitoring to ensure the quality of consulting services is considered in Chapter III.)

New Jersey planned to monitor the work of the fiscal agent in several ways. First, the fiscal agent was required to submit reports of its activities. Second, New Jersey set standards for the performance of fiscal services and mandated the notification of state program staff if these

standards were not met. Third, New Jersey planned audits of the fiscal agent. (Monitoring of the fiscal agent is also discussed further in Chapter III.)

D. POISED FOR IMPLEMENTATION

Working with the National Program Office, RWJF, DHHS/ASPE, and the other Cash and Counseling states, New Jersey completed the design of its Personal Preference program by mid-1998, about a year and a half after it received funding to do so and was poised to begin implementation. By early 1998, New Jersey had developed agreements with agencies throughout the state to provide consulting and had developed a training curriculum for consultants. In April 1998, Personal Preference began to train consultants. A few months later, New Jersey contracted with an organization to provide outreach and enrollment and began the procurement process for an organization to serve as fiscal agent. Because New Jersey expected to implement the cash program early in 1999, the state required that personal care agencies begin to submit consumer data forms in January of that year. However, a legal dispute arose over the selection of the fiscal agent. This dispute was protracted and delayed full implementation of Personal Preference until November 1999. The delay caused problems. Personal care agencies were submitting information about PCA recipients that was of limited value, as the Personal Preference program could not begin to enroll participants. Some of the consultants who had been trained resigned before enrollment began, and the others needed refresher training. Nevertheless, when the legal dispute was finally resolved, New Jersey's Personal Preference program was up and running quickly. In the next several chapters, we describe its operation.

III. ORGANIZATIONS PROVIDING OUTREACH AND ENROLLMENT, CONSULTING, AND FISCAL SERVICES

A variety of organizations—private and public—are partners with the state of New Jersey in the Personal Preference program. These organizations provide outreach and enrollment, consulting, and fiscal services. Their selection marks the transition from the design of Personal Preference to its operation.

This chapter discusses organizations that provide outreach and enrollment, consulting, and fiscal services. We describe how New Jersey selected these organizations, the organizations themselves, and the procedures the state used to ensure the quality of their services.

A. OUTREACH AND ENROLLMENT CONTRACTOR

As Chapter II indicated, New Jersey initially used an external contractor for outreach and enrollment services. However, Personal Preference was displeased with the services of the contractor and did not renew that contract. The program staff then brought outreach and enrollment activities in-house, 15 months after enrollment began. Here, we describe the initial contractor and how it was selected. In Chapter VI, we discuss the shortcomings of external contracting that led New Jersey to discontinue that service.

1. Criteria

New Jersey used four major criteria in selecting a contractor for outreach and enrollment. First, it sought a contractor with a good record in human or health services programs. Outreach and enrollment staff members needed to be sensitive to the needs and concerns of elderly and disabled Personal Care Assistance (PCA) recipients and their families. Second, the state sought a contractor that already had a multilingual staff. New Jersey is an ethnically diverse state, and PCA recipients represent a variety of ethnic groups. Because many PCA recipients speak a

language other than English, the state sought a contractor with staff members able to talk with them in at least Spanish or Russian (and ideally in other languages as well) to explain the demonstration and seek their participation. Third, New Jersey sought a contractor with staff located throughout the state. Personal Preference was to be implemented statewide, and outreach and enrollment staff members would need to visit the homes of potential demonstration participants in all parts of the state. New Jersey also sought to minimize travel costs by seeking an organization that had staff throughout the state. Finally, New Jersey sought a contractor with a toll-free telephone number, as potential participants would have to telephone the outreach and enrollment contractor. To ensure that participants would be able to call without cost to themselves, New Jersey sought a contractor that had a toll-free telephone number in place (or at least that was willing to install one and maintain a staff to answer it).

2. Outreach and Enrollment Contractor

As its outreach and enrollment contractor, New Jersey selected a for-profit firm already under contract with the state to enroll Medicaid beneficiaries in managed care. Headquartered in the Trenton area (in the center of the state), the firm met the state's selection criteria. It had successfully enrolled a Medicaid population in a health services program, and the state had been pleased with the pace of enrollment. The firm had a multilingual staff located throughout the state and also had a toll-free telephone number. An added benefit was that the current contract could simply be amended to cover outreach and enrollment for Personal Preference. The state thus avoided the full procurement process, which can take a long time.

Unbeknownst to the state at the time, the contractor had conducted all its previous marketing by telephone. It had no experience conducting home visits, which may have exacerbated its later problems with conducting enrollment.

3. Assuring the Quality of Outreach and Enrollment Services

To help assure the quality of outreach and enrollment services, New Jersey established standards, several of which pertained to the timeliness and extent of outreach and enrollment activities. The most important of these standards required that the outreach and enrollment contractor do the following:

- Contact a Medicaid PCA beneficiary within 10 days of receiving his or her name from the Personal Preference program
- Make three attempts (on different days of the week and at different times of the day) to reach a beneficiary by telephone
- Arrange a home visit within 10 days of a beneficiary agreement for a visit (unless unusual circumstances prevailed)
- Make two attempts to conduct a home visit
- Forward all signed consent forms to the Personal Preference program office within one week of their receipt

New Jersey also set a standard for the number of enrollments to be generated: 30 a week. In addition, the outreach and enrollment contractor was required to file a weekly report on the status of its activities.

B. CONSULTING AGENCIES

New Jersey cast a broad net for consulting services. As Chapter II indicated, the state sought human services agencies—most of which would have a small caseload of Personal Preference participants—from across the state to provide consulting services. (However, agencies that provide traditional PCA were excluded.) The state specified minimal educational requirements for consultants and left agencies free to determine how best to staff and supervise consulting for Personal Preference. Finally, to minimize reporting burden, New Jersey

streamlined standards for documentation and the reporting requirements imposed on consultants and consulting agencies.

1. Recruiting Consulting Agencies

To recruit consulting agencies, New Jersey relied heavily on presentations to human services executives. Shortly after the state received funding to design its Cash and Counseling program, Personal Preference staff began giving presentations at regional meetings of human services executives, with the goal of fostering interest in providing consulting services. Early in 1998, New Jersey intensified these efforts, launching a major campaign to recruit agencies to provide consulting. The director of Personal Preference wrote a letter to every health and human services organization in the state (public, private nonprofit, and private for-profit agencies), inviting the organizational leadership to regional meetings. At these meetings, Personal Preference program staff provided information about expectations and reimbursement for consulting services, as well as about the Personal Preference program in general.

New Jersey set minimal criteria for participation as a consulting agency. The agency had to demonstrate interest in Personal Preference by sending its staff to training at no expense to the state, and had to sign an agreement (in the form of a simple letter) with the state. This approach to procurement minimized the administrative effort required to participate as a consulting agency. An executive of one consulting agency reported that she was pleased that the state had made that aspect of participation so straightforward.

A total of 34 agencies from across the state signed the letter of agreement. These agencies included county boards of social services, Independent Living Centers, adult day care centers, private case management agencies, and Area Agencies on Aging (AAAs). Personal Preference program staff especially welcomed the participation of several boards of social services, because these boards have contact with many PCA recipients and are knowledgeable about the resources

available in their communities. While the number of AAAs participating as consulting agencies was smaller than the state had hoped, other agencies that serve elderly people participated.

The Personal Preference staff members were satisfied with the overall level of interest in providing consulting under Personal Preference. One agency executive speculated that more agencies—especially smaller ones—might have participated if the state had offered a higher payment rate for consulting services. (Later, New Jersey increased the payment for consulting.) Agency executives reported that while the initial consulting payments did cover the direct cost of staff time to provide consulting services, they did not cover the cost of staff benefits. Thus, if agency staff were to receive benefits for the portion of their time devoted to Personal Preference, the agency had to draw on other resources to cover the cost of those benefits. Small agencies may have had fewer resources than larger ones from which to cover these costs and thus may have found participation in Personal Preference less attractive.

The executives of agencies that chose not to participate in Personal Preference also may have been concerned about competing demands on the time of their staff. While we did not speak to the executives of any agencies that declined to participate, we did interview the staff of one agency that dropped out after working with only a few consumers. This agency was instituting two other new programs at the same time as Personal Preference, and an executive there cited competing demands on staff time as the main reason for dropping out.

While agencies considered a variety of factors when deciding whether to participate in Personal Preference, a common theme was a desire to transcend the limitations of the traditional personal care system. Agency executives saw the Cash and Counseling model as a possible solution for some of their clients, especially younger adults with disabilities who wanted to have more control over their own services. In these agencies, the leadership supported the philosophy of consumer direction. Case Example III.1 presents the comments of three agency executives on

why their agencies chose to provide consulting under Personal Preference. They represent public, private nonprofit, and private for-profit agencies.

At the time of our visit, 12 agencies were providing consulting services under Personal Preference, just over a third of the 34 that sent staff to consultant training. Recognizing the diversity of its population, the Personal Preference staff had hoped to attract enough consulting agencies to give consumers a choice. However, the program found that consumers generally had little or no information or experience to draw on in selecting a consulting agency and did not seem to value having a choice, at least not in these circumstances. Over time, Personal Preference whittled the list to 12 agencies that were providing effective consulting services.

Case Example III.1: Becoming a Consulting Agency

Public Agency. Our agency has provided case management since 1993. The case manager plays a pivotal role. We wanted to know if people were capable of taking on this role themselves. Also, we thought that we might be better able to meet the needs of younger adults with disabilities through a cash program. The younger disabled are really independent minded, so a consumer program is really perfect for them.

Private Nonprofit Agency. We have had a good, long-standing relationship with the Personal Preference project director. His enthusiasm was a big factor in our decision to participate. We also liked the fact that the program empowered beneficiaries—making them consumers rather than clients. Our agency likes to be involved in programs that make people as independent as possible. The philosophy in our case management program has long been to give people the information they need but not to make their decisions for them. Also, our experience is that people pay more attention to the quality of their services if they are paying for them.

Private For-Profit Agency. This agency has been doing case management for 13 or 14 years. It wanted to establish a working relationship with the state. Also, agency leadership felt that the cash program was right for some clients. It is common for the personality of the client and the worker to clash. The cash program offered a way to solve that. Also, agency leadership knew that some clients would be interested in the program. Some younger disabled clients have asked why they couldn't just get the money the state was spending and purchase their own services.

2. Recruiting Consultants

New Jersey set only minimal educational criteria for consultants. However, most of those who became consultants were experienced human services professionals.

a. Criteria to Become a Consultant

New Jersey required that, to become a Personal Preference consultant, a person merely have a high school diploma and complete a training course. (Section B.3 describes training.) The state did not require that consultants be human services professionals, in part because it was concerned that the norms of many professionals would conflict with the philosophy of consumer direction. Many professionals were accustomed to taking charge themselves and solving problems, instead of empowering consumers to take responsibility for their own care.

Executives of consulting agencies identified several attributes necessary for success as a consultant: (1) listening skills, (2) the ability to help consumers realize their goals, (3) the patience to allow consumers to proceed at their own pace, (4) the ability to handle budgets, and (5) “people” skills in general.

Case Example III.2: What Makes a Successful Consultant?

A consultant has to be practical—definitely has to be able to deal with budgetary concepts. Has to have good listening skills. “What is the consumer really saying?” Needs to be able to control the urge to “fix it” for the person. For the pilot project, a consultant has to be flexible, as there will inevitably be changes.

Most agency executives thought that a consultant should have a college degree. One commented that a college degree indicated general proficiency in reading and in mathematics. Another suggested that a college degree in a human services field should be required, as those who pursue such a degree are “self-selected” as people who enjoy working with others.

b. Who Are the Consultants?

With few exceptions, consultants for Personal Preference were members of the existing agency staff, rather than newly recruited staff. Two factors led consulting agencies to assign members of their existing staff to provide consulting. First, as indicated, the volume of Personal Preference cases at many agencies was low. Low volume made it possible for existing staff to assume responsibility for Personal Preference along with their other duties. In addition, given low volume, agencies may have wanted to avoid recruitment costs. Second, agencies may have been reluctant to have consulting provided by someone they did not know. One agency executive noted that a consultant holds a position of trust because he or she helps consumers with their financial affairs (at least to the extent of assisting with the cash management plan). The activities of a consultant who abused this trust could damage the consulting agency's reputation.

Despite the state's willingness to accept consultants without college degrees, most had them. Only one agency of the six we visited had a consultant without college training.

Most of the consultants were human services professionals. That is not surprising, as most had been full-time employees of human services organizations, with responsibilities other than consulting for Personal Preference. An example of a consultant who was not a human services professional is a young woman who was trained in accounting and was working for the agency as an assistant to the chief financial officer. She is featured in Case Example III.3, along with a senior consultant at the same agency.

3. Training Consultants

New Jersey set minimal criteria for consultant educational credentials. However, a great deal of effort was devoted to developing consultant training.

a. Initial Training of Consultants

New Jersey contracted with Rutgers University School of Social Work to develop a curriculum for training consultants. After a pilot test of this curriculum, New Jersey substantially revised both the curriculum and the design of Personal Preference. Before the pilot test, New Jersey had planned to make consultants responsible for outreach and enrollment, as well as for helping consumers after they had enrolled in the demonstration. However, the human services staff participating as trainees in the pilot training did not want to take on the outreach and enrollment functions, because they did not see themselves as social marketers. Because of their reaction, New Jersey decided to separate the outreach and enrollment functions from the other consultant functions and to contract for the former.

Initially, Rutgers University staff ran the training sessions, with state Personal Preference staff giving presentations on selected topics. However, because of the extension of the enrollment period for the demonstration and consultant turnover, more training sessions were required than had been anticipated, so the budget for Rutgers training was exhausted. Personal Preference staff felt that they themselves could conduct training more efficiently than the Rutgers University staff members, who were not involved in the Personal Preference program day to day. Thereafter, Personal Preference staff members conducted all aspects of the training.

Initially, the training lasted five days and was divided into several sessions so that agency staff would not have to be out of their offices for an entire week. The five-day curriculum covered the philosophy of consumer direction and the procedures for the Personal Preference program. It also devoted substantial time to role-playing to reorient trainees who had a case manager background and to provide experience to consultants who did not have a human services background.

Some early trainee consultants felt that the role-playing unnecessarily lengthened the training session. The state agreed, and the session was reduced to three days. Extensive role-playing seems to have been superfluous, for two major reasons. First, most trainees were experienced human services professionals. Second, most did not need extensive orientation to convince them of the value of the consumer direction philosophy. A few trainees reacted negatively to it, but most accepted consumer direction as a good choice for some beneficiaries, even if they sometimes had to struggle with a desire to fix problems themselves. Most human services professionals with a strong negative reaction to consumer direction probably avoided the Personal Preference program altogether.

All the consultants we visited reported that the training had been good or excellent. Some described it as “very effective”; another noted, “I enjoyed it.”

Nonetheless, they did have ideas for improvement. Some consultants suggested more training on how to help the consumer develop the cash management plan. One specific idea was to prepare the consumer in advance of the home visit so the visit could be as productive as possible. They also suggested teaching consultants about the type of official correspondence that consumers should expect. For example, consultants should know to warn consumers that they are likely to receive a letter from the Internal Revenue Service about the amount of payroll taxes due for their employees and that the letter should be forwarded to the fiscal agent for payment (assuming the consumer was using the fiscal agent). In addition, the fiscal agent suggested that a member of its staff participate in training sessions to teach consultants about the information that must be collected to complete the cash management plan and employment documents.¹

¹The state Personal Preference staff indicated that, because the state would have incurred additional charges for their time, they had not asked fiscal agent staff to participate in consultant training sessions.

b. Ongoing Training

Personal Preference offered refresher training because the initial consultant training sessions (in mid-1998) took place more than a year before operations began. The program staff had expected to enroll the first demonstration participants shortly after the initial sessions, but a legal dispute over the selection of the fiscal agent forced the state to postpone enrollment for many months.

Even with the refresher training, the initial group of consultants reported that they had to teach themselves by going through the manual and that they had to learn some things by trial and error. One noted, “Once I made a mistake, I learned from it and never made that mistake again.”

Over time, many consultants received on-the-job training from the Personal Preference consultant coordinator. She spent a substantial proportion of her time “coaching” consultants, continuing to do so throughout the demonstration.

At the time of our site visit in the spring of that year, New Jersey was planning meetings of practicing consultants to be held shortly thereafter. This was to be the first formal training session since the refresher training. One goal of this meeting was to provide an opportunity for consultants to learn from each other.

4. Supervision of Consultants

The local supervision available to Personal Preference consultants varied considerably, as it depended largely on the size of the Personal Preference caseload at a given agency. When the caseload was small, an agency often had only one staff member trained in consulting. New Jersey did not require that consultant supervisors complete the Personal Preference training, and agencies did not voluntarily send supervisors to training. The lack of trained supervision did not seem to be a serious problem, as consultants were able to function somewhat independently from day to day. In addition, the senior executive of the agency usually had a basic understanding of

the Personal Preference program from regional briefings and state-supplied materials and could draw on that understanding to advise the consultant if questions arose.

The most serious problem caused by having only one trained consultant at an agency involved responding to questions that arose when the consultant was not available. An executive at an agency that had only one trained consultant reported having to scramble to respond expeditiously to consumer requests that came in when the consultant was out of the office.

As Personal Preference caseloads grew and agencies had enough volume for two or more trained consultants (each of whom was part-time), one of the consultants might be named as the local Personal Preference supervisor. However, the typical relationship between consultants at the same agency seemed to be a collaborative one, rather than that of supervisor and subordinate. Case Example III.3 describes one such relationship. Collaboration did not typically extend to visiting consumers as a team, although a joint home visit might be made when something about the case generated suspicion or when a newly trained consultant was making a first visit.

Case Example III.3: Local Supervision of Consulting at One Agency

Consultant A is the supervisor. She has the Personal Preference files in her office. She is a case manager, but she runs an emergency services unit—so she is used to dealing with the problem at hand and not trying to solve all the problems in the case. Consultant B is an assistant to the financial officer. She is “a whiz” on the budget side. However, she wants to “make it right.” One cannot do that in Personal Preference, as the consumer has to make the decision. These consultants make a very good team, as they bring different strengths to the process. They also have senior agency executives at their disposal—the executive director of the agency for social work matters and the financial officer for business matters.

5. Assuring the Quality of Consulting

To limit the burden on organizations providing consulting, as well as on the consultants themselves, New Jersey imposed minimal reporting requirements, which focused on interaction with individual consumers. Before submitting the cash management plan to the state program

office, consultants were required to sign it to indicate that they had reviewed it. They also had to submit a report to Personal Preference about each consumer's condition and situation following the quarterly visit to that consumer. In addition, when they submitted an invoice, consultants had to include the names of the consumers assisted and itemize the services provided to each. Personal Preference staff checked that the required reports (cash management plans and quarterly reports) had been received before approving invoices for payment.

These reporting requirements were important in enabling members of the state Personal Preference staff, particularly the consultant coordinator, to become quite knowledgeable about the strengths and weaknesses of consultants. Program staff first got to know consultants in Personal Preference training. Then the coordinator reviewed every cash management plan after consultants had reviewed it. The coordinator also reviewed quarterly reports. In addition, state program staff members and consultants sometimes interacted while troubleshooting problems on behalf of consumers. During the demonstration, Personal Preference staff drew on their knowledge of the consultants to channel new enrollees in Personal Preference to agencies that offered strong consulting services.

Initially, New Jersey imposed only a single formal standard on consultants. They were required to maintain case notes on their contacts with consumers and to include a specified minimum data set in these notes. The documentation was to be made available for review during planned on-site audits of consultants.

Several months into demonstration operations, the state added a standard on the timeliness of initial contact with the consumer. Some consultants were apparently not prompt enough in contacting consumers who had been referred for consulting, so New Jersey stipulated that consultants were to contact a consumer to begin to arrange for a home visit within 48 hours after

receiving a referral. Consultants were expected to telephone on weekends as necessary to meet the 48-hour requirement.

When demonstration operations began, the Personal Preference program did have a standard about the timeliness of the development of the initial cash management plan, and this standard had implications for consultants. Initially, the program expected consumers to have completed a cash management plan and be receiving cash within 90 days after their assignment to the treatment group (with 15-day extensions provided with the approval of staff). This requirement imposed an implicit standard on the work of the consultant in helping the consumer develop the cash management plan. For reasons explained in Chapter V, development of the plan often took much longer than 90 days, and the Personal Preference program did not enforce the 90-day standard. Senior program staff feared that doing so might lead consultants to develop the cash plans themselves instead of assisting the consumer in doing it.

C. FISCAL AGENT

As mentioned in Chapter II, New Jersey contracted for a single fiscal agent to serve Personal Preference cash recipients across the state.

1. Procurement Process

The procurement process to secure a fiscal agent was protracted, extending over more than a year. In August 1998, New Jersey issued a formal request for proposal (RFP) to solicit an organization to provide fiscal services for the Cash and Counseling Demonstration under a three-year contract. Although the state expected to have the fiscal agent contract in place by early 1999, this did not happen until November 1999.

New Jersey prepared the RFP for the fiscal agent carefully, even hiring an expert in fiscal services to help prepare the statement of work and holding a bidder's conference. The state

sought an organization with a minimum three-year history as a financially viable business and with a philosophy compatible with consumer direction. The state also laid out a number of programmatic criteria in the RFP, including:

- Ability to produce payroll checks (including doing so in certain emergency situations), pay nonlabor-related invoices, and disburse cash grants quickly and accurately
- Ability to automate key payroll, accounting, and data collection functions to achieve economies of scale
- Knowledge of federal and state tax, labor, unemployment, disability, and workmen's compensation rules and regulations pertaining to the employment of household/domestic service employees and independent contractors
- Ability to communicate effectively with consumers (including accessing translation services) regardless of disability, and to respond to all participant requests and inquiries
- Ability to develop training and skills-examination tools pertaining to payroll for domestic service/household employees
- Ability to train and assess consumers using these tools
- Ability to develop a code structure for all types of labor and nonlabor expenditures and to create expenditure reports that contain the needed data elements, are accurate and clearly laid out, and are produced in a timely manner
- Ability to hire and train professional and nonprofessional staff to respond to a staggered schedule as the caseload builds
- Ability to broker a life/health insurance option package

Using these criteria, the state evaluated the bids received in response to the RFP and rejected them all as unsatisfactory. Citing technical errors in the RFP, the state withdrew its initial solicitation and revised and reissued it.

An award was made to one of the bidders on the reissued RFP, but only after a time-consuming legal and administrative process. Two companies submitted satisfactory bids to the revised RFP, and New Jersey awarded the contract to one of them. However, the other appealed

the decision, and a final award was delayed for months by the ensuing legal proceedings. Ultimately, in November 1999, the state awarded the contract to the bidder that had appealed.

2. Host Organization for Fiscal Services

The host organization for fiscal services under Personal Preference is a community human services organization in a large city in the northern part of New Jersey.

Staff of the organization believes that the philosophy of consumer direction is consistent with the philosophy of its organization—helping people to help themselves—and see consumer direction as the “wave of the future.” Although the organization already had a program in which consumers could hire their own workers, Personal Preference offered even more flexibility, which intrigued the staff. An executive indicated that the organization also realized the need to increase the supply of personal attendants and saw the Cash and Counseling model as tapping a different labor supply. This labor supply could help ease a critical shortage of personal care attendants in New Jersey, one that extended beyond personal care to community institutions, such as group homes.²

a. Variety of Services

The host organization for fiscal services provides a wide variety of other services, many of them for people with disabilities. These services include:

- ***Residential Services.*** Supportive living, supervised apartment, foster home, group home, home sharing, and supervised transitional living for at-risk youth
- ***Counseling and Job Placement.*** Crisis intervention, family counseling, case management, and employment placement

²This executive reported that 20 group homes that had planned to open in 2000 were unable to do so, because of their inability to hire attendants to staff them.

- ***Education and Information.*** Recreation and education, enrichment programs for parents of children who are developmentally delayed, conferences and training for people with disabilities (including training to help them manage their own personal care attendants), and information and referral
- ***Personal Care.*** Respite services for caregivers of people with disabilities, and a stipend program for people with disabilities to allow them to hire their own workers
- ***Other.*** Retired senior and volunteer program

b. Consulting Services Under Personal Preference

At the time of our visit, the host organization for fiscal services was also providing consulting services. However, this had not been the case when demonstration operations began. The organization had responded to the original letter from the director of Personal Preference soliciting human services agencies to provide consulting, and it had been approved. However, once the fiscal agent contract was awarded, the state withdrew its approval for the host organization. As Chapter II indicated, the state program staff was concerned about the absence of checks and balances if one organization provided both consulting and fiscal services.

When the demonstration had been operating for more than a year, the state agreed to allow the host organization that was providing fiscal services to provide consulting as well, as long as it maintained a “firewall” between the two services. At the time of our visit, the organization had two consultants on staff and planned to hire two more. Fiscal staff at that organization confirmed that they did not interact with the Personal Preference consultants. After our visit, the host organization providing fiscal services also became responsible for outreach and enrollment.

3. Staffing for Fiscal Services

At the time of our visit to New Jersey in spring 2001, about 250 consumers were receiving cash, and the fiscal agent had two full-time staff devoted to Personal Preference fiscal services.

The host agency's finance director supervised them.³ One of the full-time staff members for Personal Preference was a consumer liaison, taking consumers' telephone calls and responding to their questions. The other was responsible for (1) reviewing cash plans, employment forms (such as for federal income tax withholding), and other materials as they were received from consumers to make sure that they were completed correctly; and (2) reconciling check requests against cash management plans. Administrative staff members, who worked on a number of programs, were responsible for cutting and mailing Personal Preference checks and for preparing payroll reports for the federal and state governments.

4. Assuring the Quality of Fiscal Services

New Jersey monitored the quality of fiscal services through monthly and annual reports and semiannual audits. The reports showed the total number of packets of employment forms processed and the number of checks cut. A contractor hired by the National Program Office for the Cash and Counseling Demonstration visited all three state demonstration fiscal agents every six months to audit their operations. The New Jersey fiscal agent viewed these contractor visits as very helpful.

New Jersey also required that the Personal Preference program be notified immediately if payroll or disbursements were not made in a timely way.

In addition to this formal reporting, frequent interaction between the staff of the fiscal agent and of the state staff helped ensure the quality of fiscal services.

³At the time of our visit, the finance director had just resigned, and the Personal Preference staff was temporarily reporting to the host organization's executive director.

D. CONCLUSION

New Jersey was able to attract organizations to provide enrollment, fiscal services, and consulting under Personal Preference. A for-profit organization already under state contract to market a Medicaid managed care program was willing to expand the scope of that contract to include enrollment for Personal Preference. Two nonprofit organizations in the state were keenly interested in providing fiscal services—so much so that they were willing to engage in a protracted legal dispute to determine the successful bidder. Even though payment was reportedly not adequate initially to cover the full cost of providing consulting services, many agencies from across New Jersey came forward to do so.

How can we account for New Jersey’s success in attracting organizations to Personal Preference? It is in part due to the respect its director commanded. More fundamentally, interest in Personal Preference stemmed from the human services community’s recognition of the flaws of the traditional system of providing personal care—specifically, characteristics that engendered dependence among clients, lack of responsiveness to client need, and inability to secure an adequate labor supply. Organizations were attracted to Personal Preference because it offered a potential solution to these problems. As such, Personal Preference was perceived as the “wave of the future.”

IV. OUTREACH AND ENROLLMENT

New Jersey initially decided to make state Personal Preference staff responsible for outreach and an external contractor responsible for enrollment. The state did this because there was a possibility that the staff of agencies providing traditional personal care might not explain Personal Preference objectively. Later, because the pace of enrollment was lagging far behind that necessary to meet the evaluation sample-size target, the state hired employees to be enrollment specialists, and the Personal Preference staff assumed responsibility for all aspects of outreach and enrollment.¹ In this chapter, we describe how Personal Preference implemented outreach and enrollment, including how it provided information to the community and how it reached out to potential participants and enrolled them.

A. COMMUNITY INFORMATION

The state Personal Preference program staff informed the community about the program. A major goal of its marketing campaign was to provide information about the cash program to human services agencies statewide in the interest of recruiting them to serve as consulting agencies. (We described this aspect of the campaign in Chapter III.)

Another goal was to inform the provider community about the Personal Preference program. To do this, the director and assistant director of Personal Preference gave presentations at meetings and conferences, such as those held by the state nursing board and organizations representing the personal care industry.

¹In fall 2001, several months after our visit, one state enrollment specialist resigned, and Personal Preference again moved to have outreach and enrollment services provided under contract.

At the time of our visit to New Jersey in spring 2001, the Personal Preference program was working with the demonstration's National Program Office to develop a color brochure on Personal Preference. They planned to distribute copies to interested parties (such as beneficiaries and their families and those working in the personal care industry) to emphasize the successes of Personal Preference.

New Jersey did not conduct a mass community information campaign to recruit demonstration participants. Only current recipients of Medicaid Personal Care Assistance (PCA) were eligible for Personal Preference, and the state did not want to generate demand among people who were not eligible. Therefore, the state did not seek publicity for Personal Preference through mass media (such as newspaper articles or television public service announcements). New Jersey had learned from the experience of Arkansas, which drew many inquiries from Medicare and Medicaid beneficiaries who were not eligible for Medicaid PAS and thus not eligible for the cash program. Arkansas had difficulty meeting a surge in demand for enrollment in its cash program immediately following a direct mass mailing. Moreover, as described in Chapter II, Personal Preference was designed to identify potential participants at the time of assessment (or reassessment) for Medicaid personal care. Initially, the state program staff did not want to generate demand among PCA recipients who had not recently been assessed and who would have to wait several months to be enrolled. Later, Personal Preference relaxed the plan to enroll recipients shortly after assessment.

When enrollment began, the contractor was contacting many individuals for whom agencies had submitted consumer data forms many months before. (As Chapter II indicated, agencies began to submit consumer data forms in January 1999, but the legal dispute about procurement of a contractor for fiscal services delayed implementation until November 1999.) When the enrollment contractor tried to contact individuals for whom consumer data forms had been

submitted, some could no longer be reached at the telephone number given on the forms, some were no longer community residents, and some were no longer eligible for Medicaid.

When it became apparent that enrollment was not proceeding at the pace required in the enrollment contract (30 signed consent forms a week), the staff of the enrollment contractor made presentations to small groups of people who might be interested and eligible (without regard for their assessment dates or current receipt of PCA). For example, enrollment staff sometimes asked social workers in public housing projects to invite a group who might be receiving Medicaid personal assistance to hear a description of the program. According to the enrollment contractor, these presentations usually were unsuccessful. Most such groups included only a few people who were eligible for Medicaid. Those who were eligible often did not acknowledge their Medicaid eligibility—seemingly because they were reluctant to do so in a public meeting.

In addition, we speculate that Medicaid beneficiaries attending such meetings who were *not* current PCA recipients may have been discouraged because they would have had to enroll in PCA before becoming eligible for the demonstration. In addition, Personal Preference did not offer them help in applying for PCA.

With enrollment lagging, Personal Preference also encouraged providers of traditional PCA services to refer some of their clients to Personal Preference—another departure from the plan to enroll participants only after assessment. The director of the Personal Preference program wrote to the directors of all Medicaid PCA providers urging them to refer PCA clients they found difficult to serve. This letter was intended to decrease the resistance of providers of traditional personal care to the Personal Preference program, as well as to generate referrals. In response, providers did refer many clients. PCA providers felt that clients who did not like the structure or rules involved in working with an agency might be better suited to self-directed care and often

referred such clients to the Personal Preference program. Agencies also referred clients who lived in areas (including rural ones) in which it was difficult for agencies to recruit employees. New Jersey did not ask advocacy groups to help recruit demonstration participants.

B. OUTREACH AND ENROLLMENT

State Personal Preference program and external contractor staff were responsible for initial outreach to individual consumers. State program staff prepared a database of Medicaid PCA recipients eligible for Personal Preference and mailed them flyers about the cash program. The enrollment contractor staff was responsible for the remaining steps in outreach and enrollment. In this section, we describe the roles of the state Personal Preference staff and of the enrollment contractor.

1. Determining Eligibility and Initial Flyer

Potential participants in Personal Preference were first identified at the point of assessment (or reassessment) for Medicaid PCA. After completing an assessment, the nurse for the provider of traditional services completed a consumer data form, which was sent to the state Personal Preference program. This form contained the following information:

- ***Beneficiary Identifying and Contact Information.*** Name, social security number, Medicaid number, telephone number, and address
- ***Relative Identifying and Contact Information.*** Name and telephone number
- ***Care Plan Data.*** Number of personal care hours authorized for weekdays and for weekends for the upcoming six-month care plan
- ***Other.*** Primary language spoken, diagnosis, whether the person was expected to be in the community in six months, and names of the agency, agency nurse, and client physician

The completed consumer data forms were sent to the Personal Preference state office, where staff members verified eligibility against Medicaid records. They identified anyone who was not

a Medicaid PCA recipient or who had lost eligibility for Medicaid since the assessment was completed.

After eligibility was confirmed, the state Personal Preference program staff mailed an introductory letter and flyer to the PCA recipient. These briefly explained the Personal Preference program and said that someone would telephone the recipient to schedule a home visit to provide more information about it.

Later, because enrollment continued to lag, Personal Preference added a Spanish translation of the description, as well as a toll-free telephone number, to the flyer. The flyer invited people to call if they were interested in learning more about the cash program, and state program staff answered the toll-free number. (Appendix A shows the revised flyer.)

New Jersey also experimented with printing the flyer on colored paper. State staff reported that pink paper seemed to be the most effective in generating interest in the cash program, although the reason for its apparent success was not clear.

2. Databases

Drawing on the consumer data forms, the Personal Preference staff created a database to support the outreach and enrollment process. Information from the consumer data forms was entered and sent to the Medicaid Information Services (MIS) office, where it was combined with information from the state's Medicaid Management Information System to create a master, cumulative database of PCA recipients on whom consumer data forms had been received. This master database was used to check eligibility and served as the basis for the tracking systems that the enrollment and evaluation contractors used.

An extract from the master cumulative database was distributed weekly to the enrollment contractor, and an enrollment database was created from it. Each week, the enrollment contractor identified the names of PCA recipients who had been newly added to the database.

Enrollment contractor staff added the new names to a separate database that was used to track the status of all contact attempts and contacts. Cases were tracked on this database until the number of contact attempts required in the contract with the state had been completed or until an individual had decided whether to participate in the demonstration (and had signed a consent form if he or she had decided to participate). The master database was also updated with information on the outcome of the enrollment process.² A code for the outcome was entered on the current extract of the master database, and a copy was returned to the MIS office, where the master database was updated.

In addition, the evaluation contractor received an extract from the master database weekly. This extract identified the names of people who had just signed consent forms to participate in the demonstration. The evaluation contractor then telephoned these people to conduct baseline interviews. After a baseline interview was completed, the evaluation contractor randomly assigned the individual to the treatment or control group. Random-assignment status was communicated daily to the Personal Preference program, which notified the individual of the assignment in writing. The evaluation contractor staff also added random-assignment status to its extract of the current master database and returned a copy of it weekly to the New Jersey MIS office, where the master database was updated.

The Personal Preference office also received a copy of the weekly extract of the database, which it used to troubleshoot problem cases. For example, if a consumer called about his or her

²Participants in the demonstration signed consent forms, usually during the home visit from the enrollment contractor staff. However, the evaluation adopted the date of random assignment as the demonstration enrollment date. Those who signed a consent form but withdrew before random assignment were not considered enrolled.

random assignment, Personal Preference staff could determine whether the case had been randomly assigned and, if so, whether the assignment was to the treatment or control group.

In addition, at the request of the Personal Preference program, the MIS office compared the master Personal Preference database to Medicaid claims to assess whether consumer data forms were being received for all PCA recipients. The program staff asked for the comparison because it was concerned that providers might be “prescreening” clients they judged inappropriate for the Personal Preference program. They could do this simply by not submitting a consumer data form. However, the comparison of the master database and claims showed that consumer data forms were routinely being completed for all PCA recipients.

To prevent delays in transmission, the database file was typically distributed each week as an attachment to an e-mail message. If e-mail systems were down, a disk containing the file was hand delivered (the offices of the Personal Preference program, enrollment contractor, and evaluation contractor were only a few minutes driving time from the MIS office).

3. Procedures of the Enrollment Contractor

Enrollment contractor staff members contacted PCA recipients by telephone and in person. Although the number of staff members varied over the course of the contract, the enrollment contractor reported typically having three telephone staff members and seven or eight field staff members dedicated to the project.³ According to the director of Personal Preference, enrollment staff turnover was high.

³The Personal Preference program staff reported that the enrollment contractor had up to 12 individuals staffing enrollment for Personal Preference but described them as part-time.

a. Telephone Outreach and Enrollment

As the enrollment contractor received names of recipients, they were separated by primary language spoken (as indicated on the consumer data form). Those whose primary languages were English, Spanish, or Russian were assigned to telephone staff members who spoke their language. Others were assigned to English-speaking telephone staff members. If necessary, the enrollment staff identified English-speaking family members or friends to translate for the PCA recipients.

Members of the telephone enrollment staff called each new referral, using scripts that the enrollment contractor had developed and the state Personal Preference staff had approved. The telephone staff asked if the PCA recipient had received the materials mailed from the state Personal Preference program, briefly explained the program, and tried to schedule a home visit so a member of the field enrollment staff could give a presentation about the program.

The visits were typically scheduled between 10:30 A.M. and 6:00 P.M., at a time when family members could attend but the personal care aide would not be present. The time for the visit was tailored to fit a schedule that many recipients followed. As an enrollment staff member noted, “Seniors get up late and eat an early dinner.” However, visits would be scheduled later in the evening if that were more convenient for family members.

Enrollment staff scheduled visits when family members could be present because consumers often sought advice from their family about whether they should participate. In addition, family members might become representatives or employees under Personal Preference. Enrollment staff also felt that family members usually would support participation. One noted, “For seniors, you need a son or daughter there. If the person is close to the aide, they won’t change unless the son or daughter is there to argue the benefits.”

Enrollment staff tried to schedule visits when the personal care aide would not be present. As discussed in the next section, aides sometimes joined the discussion and discouraged participation in the cash program. One member of the enrollment staff noted, “I’ll ask ‘from what time to what time will your aide be there?’ and then I try to avoid that time.” Some consumers have close relationships with their aides and may feel that it is appropriate for the aide to join in the discussion.

b. Home Visits

After the home visit was scheduled, the case was transferred to an enrollment field staff member, who made the visit. Usually, the staff member telephoned the PCA recipient two days before the appointment to confirm the date and time.

PCA recipients often broke their appointments. Despite having confirmed their appointments, field staff members reported often “going to the home, only to find no one there.” Some other recipients would make appointments, then call to say that they had changed their minds and were no longer interested.

The enrollment staff believed that many recipients who did not keep their appointments had been dissuaded from participating by their personal care aides. One reported that aides had participated in discussions about demonstration participation “on at least a dozen occasions.” Another reported that aides discouraged participation in her presence. These aides had spoken in Spanish, unaware that she understood that language.

Like the telephone enrollment presentation, the home visit presentation was based on a script that the enrollment contractor had developed and the state Personal Preference staff had approved. Often, the PCA recipient and family members viewed a videotape about Cash and Counseling in New Jersey during the home visit. One member of the enrollment field staff

estimated showing the videotape in 30 to 40 percent of cases, sometimes leaving a copy for others to view later.

The discussion following the home visit presentation focused on issues that those in attendance raised. As one enrollment staff member said, “They want to know, ‘How will this program benefit me?’” During the discussion, the enrollment staff indicated what the dollar amount of the cash benefit would be if a recipient were randomly assigned to the treatment group. (The amount was based on the number of hours of care listed on the consumer data form.)

If the PCA recipient and his or her family decided to participate in the demonstration, the field staff visitor read and explained the consent form, section by section, before requesting a signature. If the recipient was unsure about participating or wanted time to discuss the decision with someone else, the enrollment staff tried to schedule another home visit or called back later to arrange one.

4. Changes in Enrollment Contractor Procedures over Time

The pace of enrollment consistently failed to meet the contractual obligation of the enrollment contractor to produce 30 signed consent forms a week (the pace that was necessary to meet the evaluation sample size targets). In response, the state Personal Preference staff and the enrollment contractor began reviewing enrollment procedures and developing new approaches. They held many meetings for several months to do this.

They identified two major issues. First, the enrollment contractor often had difficulty reaching PCA recipients by telephone due to incorrect telephone numbers and disconnected telephone lines. Second, enrollment staff members were making more than the required three attempts to schedule a home visit, sometimes trying five or six times. The director of the Personal Preference program judged that the enrollment contractor was pursuing reluctant people

for too long and should give up and move on. In addition, the enrollment contractor was sometimes making multiple home visits to try to get signed consent forms. These additional contacts increased the costs incurred by the enrollment contractor with little payoff.

In January 2000, Personal Preference program staff and the enrollment contractor agreed upon revised procedures. The revisions included relaxing the standard for the first telephone contact from 5 to 10 business days following identification of a PCA recipient, as well as instituting a procedure for writing to those who were not readily contacted by telephone. If the recipient did not have a working telephone number or the enrollment contractor was unable to reach the recipient after the third telephone attempt, the contractor mailed a letter explaining the demonstration and asking the recipient or a family member to call the enrollment contractor within 10 days if they were interested in learning more about Personal Preference. If the recipient or family did not call, these cases were not pursued further. In addition, to reduce travel costs, recipients were grouped by zip code before assignment to field enrollment staff for home visits.

Perhaps the most fundamental revision of the enrollment procedures involved shifting, in selected cases, from in-person to telephone presentations of the Personal Preference program. The telephone enrollment staff began explaining the cash program. Consumers (usually those already familiar with Personal Preference) were occasionally enrolled over the telephone, without a home visit. If the consumer or family member understood the features of the cash program, declined a home visit, and found telephone enrollment acceptable, the enrollment contractor would mail a consent form, as well as written material explaining Personal Preference, and ask the recipient to sign the consent form and return it by mail. If the recipient did not return the consent form, the enrollment contractor would follow up by telephone. If the recipient and

his or her family wanted a home visit or were undecided following the telephone presentation, a home visit was scheduled.

These revisions were somewhat successful. The time required for a case to reach a final enrollment outcome was decreased. The pace of enrollment also increased; however, this improvement proved short-lived.

When the pace of enrollment slowed once more, the Personal Preference program and the enrollment contractor again revised their procedures. Instead of the program sending out a letter and flyer to be followed up by the enrollment contractor, information from the consumer data form was made available to the contractor without delay, and telephone enrollment staff began making cold calls to the PCA recipients who had recently been assessed. This revision to procedure also generated a spurt in enrollments. However, this improvement also was short-lived.

Finally, the enrollment contractor established a team responsible for the Personal Preference program. The team member who made the initial telephone enrollment call also made the home visit (unless the consumer declined the visit). The assumption underlying this procedure was that recipients would be more comfortable during the home visit (and thus more likely to participate) if they were discussing the cash program with someone with whom they had already talked.

The enrollment contractor reported that all these methods of outreach and enrollment worked for some people and recommended that any enrollment effort use several approaches. The enrollment contractor staff also suggested that New Jersey should market the Personal Preference program more broadly, arguing that word-of-mouth can be powerful: “Everybody should hear about it; then consumers would be hearing about it from their friends and neighbors.”

The costs the enrollment contractor incurred were higher than it had projected. New Jersey initially responded by adding funds to the enrollment contract. However, the director of the Personal Preference program, frustrated by the slow pace of enrollment month after month and the high cost per enrollee, decided to hire state employees as enrollment specialists and to have Personal Preference staff members supervise them. The Personal Preference staff hoped the pace of enrollment would improve if it could supervise the enrollment process more closely than had been possible with a contractor. We discuss the work of the state enrollment specialists in the next section.

5. Hiring and Training State Employees as Specialists

Midway through the demonstration, the director of Personal Preference began the process of hiring three full-time state employees (in temporary positions) as enrollment specialists. Getting permission to create state jobs, even temporary ones, took several months. Permission was finally granted when it became apparent that one or two similar positions were open in other parts of state government. The potential workers were identified months before the positions were approved; fortunately, the three were still available when approval came. The state enrollment specialists began work in February 2001, shortly before our visit.

All three of the state enrollment specialists were bilingual in Spanish and English, and their backgrounds were in social work and marketing/communications. One lived in northern New Jersey, the others in central New Jersey. The three specialists shared two state automobiles, which they used to make home visits.

The state enrollment specialists were trained by staff from the Personal Preference program, the enrollment contractor, and a social marketing firm working under contract to the Cash and Counseling National Program Office. Senior Personal Preference staff members explained the cash program and their responsibilities to the state specialists. The specialists then met with

enrollment contractor staff members, who gave them advice on marketing and on health and safety issues involved in making home visits. Finally, staff members of the social marketing firm trained the state specialists in communication skills. The social marketing training was extremely well received; the state enrollment specialists left the training enthusiastic about the cash program.

When we visited, the state specialists had been in their positions for only about two months. Senior Personal Preference staff members were pleased with their progress and reported that they were “becoming a good team.” The specialists were also engaged in a healthy competition among themselves to enroll large numbers of PCA recipients in Personal Preference.⁴

6. Enrollment Procedures Under State Specialists

As responsibility for all outreach and enrollment activities moved from the enrollment contractor to the Personal Preference program, some procedures were revised. We describe these revisions next.

a. Database

The database in the state Personal Preference office was revised to provide more detail for tracking the status of enrollment contacts. Obviously, the enrollment contractor no longer needed to receive information from the master database. Having one less recipient for this information eliminated an occasional source of delays in the weekly transmissions of copies of the database.

⁴A few months after our visit, one of the state enrollment specialists resigned. Mindful of the delays in hiring state employees, the state Personal Preference staff decided to amend the contract of the fiscal agent to provide outreach and enrollment services in northern New Jersey. The remaining two state employees were to continue to provide outreach and enrollment in central and southern New Jersey.

At the time of our visit in spring 2001, the Personal Preference staff anticipated that it would soon assume all responsibility from MIS staff for the maintenance of the database. In New Jersey, as programs move from demonstration to permanent status, programs typically become responsible for their own databases. In this case, however, the shift in responsibility came before the program achieved permanent status because the MIS staff member who had been maintaining the Personal Preference database was promoted and no longer able to maintain the database.

b. Outreach and Enrollment Procedures

At the time of our visit, the state enrollment specialists were focusing on New Jersey counties where the most PCA recipients had recently been added to the database. They did this to increase enrollment quickly (to meet evaluation sample-size targets) and minimize travel time. Because of this strategy, however, referrals to consulting agencies in counties with fewer recipients were lagging. One consulting agency we visited was particularly eager for new referrals.

The state enrollment specialists followed the procedure adopted by the enrollment contractor of having the same staff member responsible for both the enrollment telephone call and the home visit. The specialists telephoned potential participants from the Personal Preference office one or two days a week. Over the telephone, they explained the cash program and tried to schedule home visits. They also entered the results of their contacts into the database. The state enrollment specialists spent the rest of the week making home visits. They worked from home, sending an e-mail to their supervisor indicating where they would be on a given day and calling in twice a day. If a home visit fell through, the specialists called to get a referral of another PCA recipient they might be able to visit in the area. (To make this process easier, the names of recipients newly added to the database were sorted by county of residence.)

The state enrollment specialists developed some enrollment techniques of their own. One specialist stopped using the telephone script that the enrollment contractor had developed. Instead, he tried to establish rapport with the PCA recipients so they would feel more comfortable during his visit to their home. This approach worked well—recipients enjoyed visiting with him and sometimes called the office and asked him to come back for another visit.

The state enrollment specialists also relied less on written materials than did the enrollment contractor, which was useful since some PCA recipients did not understand written material and felt overwhelmed by it. One specialist gave recipients a basic understanding of the cash program when he telephoned. He believes the telephone is particularly important because many people do not, or cannot, read letters. “They’ll say they are waiting for their grandson to read it,” he said. Another way to avoid written material is to send the video before the home visit. However, this often does not work for elderly PCA recipients, as few of them have a video player. Yet another technique is the use of a PowerPoint presentation instead of written material. Case Example IV.1 describes the PowerPoint presentation that one of the state enrollment specialists developed.

At the time of our visit, another change to outreach and enrollment procedures was about to be implemented. After unsuccessful attempts to reach a PCA recipient by telephone, specialists were to begin mailing another copy of the flyer describing the Personal Preference program and enclosing the specialist’s business card, which listed the program’s toll-free telephone number. The state Personal Preference staff had suggested this approach to the enrollment contractor, but the contractor did not implement it.

Case Example IV.1: PowerPoint Presentation

One specialist developed a PowerPoint presentation that is very simple; it just lists “talking points” about Personal Preference. He said, “I like to keep it simple. Families are rushing; there is not enough time.” He takes his laptop with a big screen to the home and uses the presentation to go through the features of Personal Preference, point by point. “It walks me through the details. That way, I don’t go off track.” He answers questions at the end. Some of the typical questions are answered in the PowerPoint presentation. The presentation is in English, but the specialist translates it into Spanish, as necessary. He also uses the video but reports that people seem to like to see the Power Point presentation first.

C. ATTRACTIVE AND UNATTRACTIVE FEATURES OF PERSONAL PREFERENCE

The enrollment staff—both those employed by the enrollment contractor and the state—were in a good position to identify the features of Personal Preference that potential demonstration participants found attractive or unattractive. (The evaluation will report on participant satisfaction with various aspects of the cash program based on interviews with consumers, but we do not draw on those data here.)

1. Attractive Features

Both the enrollment contractor and state enrollment specialists listed several features of Personal Preference as attractive to consumers. First, enrollment staff reported that consumers liked being able to hire someone they knew, like a relative, friend, or neighbor. This was especially true if the consumer had identified someone they wished to hire. Although most consumers did not want to hire a stranger, enrollment staff reported that some did not want to hire a family member. Such consumers sometimes expressed satisfaction that they could help their communities by providing employment and liked the idea that they were helping their community at the same time that people in the community were helping them.

Enrollment staff reported that having control over the funds was a second attractive feature of Personal Preference. Some consumers were dissatisfied with the amount of traditional

personal care they received and thought they could get more hours of care than they had been receiving if they controlled the funds. Some thought that they could get more care by stretching the funds farther than traditional providers did. Others were surprised to learn the number of hours of personal care included in their care plans—they had been receiving far fewer hours. A few had not seen their aides in months.

A third attractive major feature was the flexibility of the cash benefit. Consumers liked being able to schedule care when it was needed. They also liked being able to purchase goods and services. These goods and services included equipment (such as a small appliance or medical equipment that Medicaid did not cover) and home modifications (such as a ramp) that consumers needed to become more self-sufficient. They particularly valued the ability to purchase transportation services.

Finally, enrollment staff reported that the availability of bookkeeping services from the fiscal agent was another attractive feature.

2. Unattractive Features

The enrollment contractor and state enrollment specialists identified three unattractive features. Two of these are artifacts of the demonstration and evaluation and would not be present in a regular program. First, enrollment staff agreed that consumers found the 50/50 chance of being randomly assigned to the control group unattractive. They reported that almost all consumers reacted negatively to this feature of the demonstration and evaluation. Some consumers questioned the rationale for random assignment, asking, “How come if the state is willing to give the money, we have to do the 50/50?”

Deferring description of random assignment may have contributed to its unattractiveness. The written materials about Personal Preference clearly indicate that half the participants will be

assigned to continue to receive traditional services. However, enrollment specialists reported sometimes deferring oral descriptions of random assignment until the later part of their presentations—perhaps after the consumer had already made an informal decision about participation. One state enrollment specialist reported waiting until toward the end of a contact with a consumer to mention the 50/50. This specialist also reported that disillusionment with random assignment gave rise to a negative image of the cash program, noting, “So word of mouth spreads that you shouldn’t talk to these people.”

The length of the demonstration was a second unattractive feature. Some consumers were apparently dissatisfied that they were assured of receiving cash for only two years.

The third unattractive feature (which would be part of a regular program) was the effort required to manage the cash benefit, especially the paperwork. One enrollment staff member put it this way: “Cash is easy, but the paperwork of the cash management plan is off-putting.” Some consumers apparently were overwhelmed by the prospect of managing the cash benefit, in spite of being able to get help from the fiscal agent.

The enrollment specialists agreed that those who refused to participate in the demonstration generally did so because they were satisfied with their services under the traditional system. Some consumers had been with one agency and aide for a long time. The aide was their friend or like part of the family, and they did not want to lose that relationship.

D. LESSONS ABOUT OUTREACH AND ENROLLMENT

In this section, we present lessons gleaned from the experience of the Personal Preference program staff in outreach and enrollment.

1. Should Personal Preference Adopt a Formal Screening Process?

Like the other Cash and Counseling states, Personal Preference did not adopt a formal screening process to exclude those inappropriate for a cash program (except that those not expected to remain in the community for six months were excluded).

One lesson of Personal Preference is that a policy of “taking all comers” can work. Moreover, program staff indicated that it would be very difficult (if not impossible) to identify in advance consumers who are unable to manage the cash benefit, either by themselves or with help from a representative and the fiscal agent. The staff of the enrollment contractor enthusiastically endorsed the idea that everyone should be given all the facts about the cash program and then allowed to decide whether they wanted to participate. State Personal Preference staff members were more ambivalent about this issue. While they believed everyone should have a chance to try to manage a cash benefit, they also knew from working with the consultants that some consumers had great difficulty doing so. They cited two examples: a person with a psychiatric diagnosis who was not following her medication regimen and a person who lived in deplorable circumstances and was receiving Adult Protective Services. Nonetheless, state Personal Preference staff members were at a loss to define a basis by which applicants could be screened out.

2. Providing for Language Diversity

Diversity—ethnic, cultural, and language—characterizes New Jersey’s population of PCA recipients. While the state Personal Preference staff was aware of New Jersey’s diversity from the beginning of the program, the extent of the diversity was unexpected. For example, so many PCA recipients were assigned to the “other” language category on the consumer database that the state added additional categories for specific languages.

Providing for language diversity is particularly important because non-English-speaking consumers should be good candidates for a cash program, since aides who spoke their language and were familiar with their cultures were often not available from traditional providers. With the cash benefit, a person who did not speak English could hire someone who spoke their language and shared their ethnic or cultural background. As a result, a consumer might be more satisfied with their care.

Mounting a successful outreach and enrollment effort in a diverse community is a challenge, and Personal Preference used several techniques to try to meet it. First, New Jersey insisted that the enrollment specialists (both the contractor and state employees) include those who spoke the languages most common in New Jersey (English and Spanish). Many program materials were translated into these languages and into Russian, the third most common language in the state.

Since it was not possible to translate all the materials into a number of languages, Personal Preference relied on translators, who often were family members of the PCA recipient. If no family members were available, someone from the community might be called upon to help translate during a telephone call or home visit. Because Personal Preference sometimes had to send people written material in a language they could not read, the program included a notice in those mailings that informed the addressee in 14 languages (including English) that the material in the mailing was important and requested him or her to ask someone to translate it immediately. (Appendix A shows this notice.)

In addition, Personal Preference used the translation services on the AT&T language line. To use this service, a program staff member would put a telephone call on hold and dial an access number, after which a translator fluent in the requested language would join the call. While expensive, this service was frequently needed. On average, the Personal Preference program staff used the language line for 10 calls a day.

New Jersey enrollment specialists emphasized that information should also be available in several media. Accommodations were needed for people with vision and hearing impairments, as well as for the many people who are not competent readers in any language.

3. Importance of Family Participation

Enrollment specialists emphasized the importance of including family members in home visits and of being flexible in scheduling these visits so family members could attend. PCA recipients seemed to feel more comfortable having someone they trusted in their homes when the enrollment staff member visited. They also seemed to want a family member involved in making the decision about participation. Often, a family member would be serving as a worker or representative if the recipient chose to participate.

Flexibility in scheduling was necessary to meet with relatives, who often worked. One enrollment specialist noted, “If you only work nine to five, they think you don’t care. I am successful in asking people to meet early in the morning before work or during the early part of the workday.”

4. Difficulty in Meeting Enrollment Goals

In an ongoing Medicaid program, New Jersey might allow caseload to build gradually (at least once caseload was large enough to support the efficient provision of consulting and fiscal services.) However, to secure a relatively large sample for the evaluation, the Personal Preference program was asked to enroll a large number of people in a relatively short time. Consistent with this requirement, New Jersey set an initial goal of 30 new enrollees a week, or more than 120 a month. While the pace of enrollment varied over time, it consistently fell far short of the goal. In response, the target for the evaluation was reduced and the enrollment period extended from a year to 30 months. With these changes, enrollment of 70 a month would

have been enough to meet the evaluation sample-size target. However, Personal Preference often did not enroll 70 participants in a month.

Can we account for the difficulty that Personal Preference experienced in meeting its enrollment goals? Next, we assess whether the basic organization of outreach and enrollment, staffing levels, marketing techniques, and consumer interest might account for New Jersey's difficulty in meeting the enrollment goals for Personal Preference.

a. Organizational Structure of Enrollment

New Jersey's two approaches to organizing outreach and enrollment—external contracting and internal state employees—provide an opportunity to assess the relative advantages and disadvantages of these approaches, as well as their relative success in meeting enrollment goals.

Contracting for enrollment in Personal Preference proved very expensive per case enrolled. To review, New Jersey was able to obtain the services of an external contractor quickly by amending a current state contract, and the enrollment contractor met the selection criteria the state had developed. However, the enrollment contractor was unable to meet the weekly target of 30 enrollees called for in its contract. Moreover, it experienced costs beyond those budgeted. (Perhaps its initial budgets were unrealistic due in part to its lack of experience with home visits.) New Jersey increased the funding for the enrollment contractor, but the pace of enrollment was still below the contractual target. As a result, cost per case enrolled was high.⁵ State Personal Preference staff attributed the high cost per case to poor contact information and the continued pursuit of reluctant PCA recipients. They concluded that contracting for outreach and enrollment had not been successful.

Hiring state employees as enrollment specialists also proved problematic. To review, New Jersey initially avoided using state employees due to concerns about delays in hiring. This concern was well founded—state enrollment specialists were not on the job until many months after the Personal Preference program first sought approval to hire them. Moreover, one resigned to take another job after only nine months. On the other hand, after state employees were on the job, delays caused by having the enrollment contractor involved were reduced. Moreover, although Personal Preference program staff found it difficult to supervise staff members who did not come into the office, they had closer control of the enrollment procedures with state employees. Closer control increased the state’s ability to experiment with different approaches and quickly discard those that did not prove successful. Such flexibility is especially valuable in a new program that is attempting to “shake out the bugs.” However, state employees also were unable to meet the goal for the pace of enrollment. Six months after they began work, the monthly enrollment had fallen to less than 50 consumers, compared to 70 a month needed to reach the revised evaluation target.

We conclude that the basic organizational structure of outreach and enrollment in New Jersey does not seem to explain the failure to meet the targeted enrollment pace. Neither contractor staff nor state employees were able to do so.

b. Was State Enrollment Staffing Adequate?

Personal Preference sought to use the state enrollment specialists’ time efficiently. The director gave state enrollment specialists equipment that would let them keep in touch and allow

(continued)

⁵New Jersey’s policy of visiting *all* PCA recipients to explain Personal Preference also increased enrollment costs relative to those of the Arkansas program, where only those who expressed an interest in Cash and Counseling were visited before enrollment.

them to use their time productively. They had laptops and beepers, and they could call the program's toll-free line from a consumer's home. (At the time of our visit, the state enrollment specialists did not have mobile telephones, but the director felt that they needed them.) The specialists also had state vehicles.

To minimize travel time, the state enrollment specialists initially focused on areas of the state with the largest concentrations of newly assessed PCA recipients. The numbers of cases enrolled in a month likely would have increased had outreach covered the entire state. It seems likely, however, that three full-time staff members were not enough to enroll recipients across the state. In contrast, the enrollment contractor had employed three telephone staff members and seven to eight field staff members to cover the state. Even if the contractor field staff members worked on Personal Preference part-time, they lived in different parts of the state, so their travel time might actually have been less than that of the state-employed enrollment specialists.⁶

c. Outreach Techniques

A change in outreach techniques might have increased the pace of enrollment in the Personal Preference program.

Letters and Testimonials. One outreach technique used successfully in Arkansas (and later in Florida) was a letter from the state governor. At the time of our visit in spring 2001, the Personal Preference program was aware of the Arkansas experience but had not used a letter from the governor. The Personal Preference staff was considering a letter from either the governor or a member of his cabinet, the commissioner of Human Services. However, the

⁶At the time of our visit in spring 2001, state enrollment specialists had been on the job for only two months. It is possible that with time they would have developed ways to cover enrollment in the entire state. However, by fall 2001, one of the enrollment specialists had resigned, and Personal Preference was again considering contracting for enrollment services.

director of Personal Preference had several concerns. He thought that getting the state bureaucracy to approve a letter could be time-consuming and result in a delay. He also felt that, given the diversity of languages spoken in New Jersey, the purpose of the letter might not be readily understood and might even create anxiety among some Medicaid recipients. Finally, the director felt that a letter from New Jersey's governor would not be as successful as one from Arkansas's governor. The Arkansas governor was well known and popular with his constituents, while the New Jersey governor had assumed that position only a few months before our visit (when the former governor accepted a cabinet position in the federal government).

At the time of our visit, Personal Preference had also made relatively little use of testimonials from satisfied cash recipients as an outreach technique. Arkansas had made extensive use of testimonials from consumers who had enrolled in its cash program—for example, by enclosing copies in direct mailings to PCA recipients. Greater use of testimonials would be consistent with the suggestion of the enrollment contractor that New Jersey rely more on word of mouth to generate interest in Personal Preference. When we visited New Jersey in spring 2001, the Personal Preference program had made a list of participating consumers willing to speak to potential participants but was not mailing testimonials to PCA recipients. In addition, at that time, a social marketing firm, with funding from the National Program Office, was preparing a multicolor brochure on the Personal Preference program. This brochure was to feature consumers participating in Personal Preference.

c. Consumer Interest

Finally, it is possible that Personal Preference recruited most of the PCA recipients in New Jersey who were interested in participating in the cash program during the sample intake period. From the inception of the demonstration, New Jersey's ability to reach the sample-size target for

the evaluation had been a concern, given that its Medicaid PCA program served only about 12,000 beneficiaries annually—the smallest number of any Cash and Counseling state. This concern was somewhat assuaged by the results of a telephone survey of a randomly selected sample of Medicaid PCA recipients, conducted while Personal Preference was being planned. These results indicated that more than 40 percent of New Jersey PCA recipients were interested in a cash program (Simon-Rusinowitz et al. 1998). Nonetheless, despite concerted efforts by the Personal Preference program, enrollment fell far short of the level that the results of the telephone survey predicted. Personal Preference enrolled about 1,750 participants in the demonstration by the time enrollment for the demonstration closed at the end of June 2002.⁷ These 1,750 enrollees represent about 14 percent of the number of PCA recipients in the year prior to the demonstration—a percentage that is roughly the same as the comparable percentage in Arkansas (between 10 and 15 percent). Enrollment percentages in New Jersey and Arkansas are also roughly comparable if one separates enrollment among elderly adults and among nonelderly adults with physical disabilities. During the year before the demonstration, a larger percentage of Medicaid personal care recipients were under age 65 in New Jersey than in Arkansas (about 30 percent, versus about 20 percent). In each state, however, the number of elderly enrollees is roughly 8 to 10 percent of the number of elderly PCA recipients in the year before the demonstration. Similarly, in each state, the number of nonelderly enrollees is roughly

⁷The exact number in the evaluation research sample is 1,714. Approximately another 50 people participated in Personal Preference but not in the evaluation research sample. They were members of a household with another person in the research sample.

15 to 20 percent of the number of nonelderly PCA recipients in the year before the demonstration.⁸

e. In Conclusion

Would Personal Preference have been able to recruit more demonstration participants if it had adopted different outreach and enrollment procedures? It is not possible to answer this question definitively, but it seems unlikely that different procedures would have produced a materially larger number of enrollees. A letter from the governor or testimonials might have been useful, but perhaps only marginally so. Coverage of the entire state by state-employed outreach specialists probably would have increased the number of enrollees in Personal Preference. This strategy, too, might have been only marginally helpful since the state-employed specialists focused on the most promising areas of the state—those with concentrations of newly assessed PCA recipients.

The fact that Arkansas was able to recruit roughly the same percentage of annual recipients of Medicaid personal assistance as New Jersey leads us to the tentative conclusion that it was unrealistic to expect a much larger number of participants in New Jersey and thus that outreach and enrollment under Personal Preference was generally successful. Arkansas used a letter from the governor and testimonials to good effect, and Arkansas's outreach and enrollment staff were able to cover the entire state for the entire sample intake period (see Phillips and Schneider 2002). Even so, that state enrolled no larger a percentage of the eligible population (as of the year before the demonstration), albeit during a slightly shorter intake period (29 months for

⁸This cross-state comparison of enrollment rates is preliminary. Error would arise because enrollment occurred in different periods in the two states and because the populations of personal care recipients may have been changing at different rates in the two states. Planned analyses of claims data will support a more accurate comparison.

Arkansas, versus 32 for New Jersey). It is possible that no more than about one in five of the eligible population finds a cash program attractive enough to enroll—at least in the context of a randomized experiment of a new social program. Thus, the simple fact that Arkansas had a larger population of personal assistance recipients may explain why that state was able to meet the sample-size targets for the evaluation while New Jersey was not.

On the other hand, the New Jersey and Arkansas situations differ in other ways that presumably should have made the New Jersey cash program more attractive than that of Arkansas. In particular, the amount of the average cash benefit was much higher in New Jersey than in Arkansas. Thus, our conclusion that the number of New Jersey enrollees could probably not have been increased materially must remain tentative.

Although the pace of enrollment in Personal Preference did not match original expectations, the cash program attracted large numbers of beneficiaries relative to the size of a typical pilot program. As a result of the demonstration, New Jersey confirmed that the cash program was attractive to a sizable minority of PCA recipients. Moreover, the demonstration proved that a cash program is attractive to elderly consumers in that state. As of the time of our visit, just over half (53 percent) of those enrolled in the demonstration were elderly beneficiaries.

V. CASH PLANNING AND MANAGEMENT

After a demonstration participant was randomly assigned to the treatment group to receive cash, the state Personal Preference staff notified the consumer and referred the case to a consulting agency. This chapter describes the referral process. It then discusses the process for developing and revising the plan to manage the cash allowance.

A. REFERRAL TO CONSULTING AGENCY

As Chapter II indicated, New Jersey chose to have multiple consulting agencies. A member of the state Personal Preference staff referred consumers to one of these agencies.

1. Choice of Consulting Agency

Initially, a member of the state Personal Preference staff contacted consumers assigned to the treatment group and offered them a choice of consulting agencies in their area. If the chosen consulting agency declined a referral, the program staff contacted the consumer and asked that he or she choose another agency. These procedures delayed the start of consulting and lengthened the time it took for the consumer to receive the initial cash allowance. (Consumer choice was not an issue in referral for fiscal services, as a single organization served the entire state.)

After a few months, Personal Preference began to assign consumers to a consulting agency based on geographic area and on the agency's capacity. This reduced the delay in getting consulting under way. Few consumers had experience with these agencies or knowledge of their performance on which to base a choice. Consequently, few found it important to have a choice. Finally, not all consumers had a choice. New Jersey recruited 34 consulting agencies, but in some areas there was only one

The state Personal Preference staff contacted the consulting agency to complete the referral. In addition to the consumer's name and contact information, the referral included demographic information on the consumer and care plan hours, both from the consumer data form.

2. Selecting a Consultant

After the state Personal Preference office gave the referral information to a consulting agency, the agency assigned a consultant to the case. The method of selecting a consultant varied, depending in part on the volume of Personal Preference cases. In some agencies, there was no decision to be made, because only one staff member was trained in Personal Preference consulting. Other agencies reported rotating assignments of new referrals. In one such agency, consulting fees were passed on to the consultants, and the agency wanted to make sure that each consultant had equal access to this source of extra income.¹ Finally, an agency with a large caseload reported dividing its catchment area into zones and assigning a consultant based on the zone in which the consumer lived. This approach reduced travel time when consultants were making home visits. An exception to the zone approach was made for Spanish-speaking consumers, who were assigned to the only Spanish-speaking consultant.

B. DEVELOPING THE CASH PLAN

After receiving a referral, the consultant telephoned the consumer to schedule a home visit to train the consumer (and a representative, should the consumer name one) on how to develop the cash management plan.

¹Of those we visited, only this one agency reported passing the consulting fees on to consultants.

1. Arrangements for the Initial Home Consulting Visit

Consultants reported different approaches to preparing the consumer for the initial home consulting visit. They also reported revising their procedures as they learned how to use the home visit time as efficiently as possible.

At the time of our visit in spring 2001, consultants differed in their approach to mailing materials to consumers before the initial home visit. Some consultants believed that people often mislaid pre-mailed materials, so they brought materials with them when they came for the visit. Other consultants reported mailing materials in advance. One reported that she asked consumers to call her when they had reviewed the materials and were ready to discuss them. If she did not hear from them in a week, she called them. By using this approach, this consultant may have reduced the chance of the materials being mislaid.

Consultants also used the home visit scheduling call to prompt consumers to prepare for the visit. They asked consumers to think about how they would use the cash allowance. Some asked consumers to start to identify a potential worker and to think about what hourly wage rates they would pay. To ensure that consumers considered payroll taxes when they thought about hourly wage rates, one consultant (who mailed materials in advance) reported specifically mentioning the tables on payroll deductions included with the training materials. Other consultants asked consumers to think about what purchase they would like to save for if they had any funds left over after paying their workers.

Consultants suggested that, to make the home visit as productive as possible, others besides the consumer be present. Some consultants asked consumers to have potential workers and potential representatives present. Others asked that *all* family members involved with the care of the consumer attend, whether or not they had been identified as a potential worker or representative. Home visits were scheduled at times when family members could be present. As

Case Example V.1 indicates, having several family members present at the initial home visit could reduce the need for additional training if workers changed. Finally, a consultant reported asking consumers who did not speak English to have a translator present when she came for the home visit.

Case Example V.1: Value of Having Family Members Present

In most of my cases, everyone is waiting for me when I get there for the home visit. They have the worker there. They have the family members there. In one case, there were three daughters and four granddaughters at the home visit. Two of them became workers. Since that visit, one of the original workers has been replaced by one of the others also present at the home visit. That person already knew about the program, so switching workers was easy.

2. Initial Consulting Home Visit

Initial consulting home visits lasted two or three hours. During these visits, consultants reviewed any features of Personal Preference with which the consumers were not already familiar.

To begin to develop cash management plans, consultants sat down with consumers (and/or representatives) and carefully reviewed the financial aspects of the program.² Consultants reviewed the amount of the cash allowance that the consumer would receive. At the time of our visit, the values of Personal Preference cash plans ranged from \$262 to \$2,630 a month, with an average value of \$1,300 a month. Consultants also reviewed the allowable uses of the cash with consumers. One consultant reported that she stressed how the cash could be spent, because the letter consumers received notifying them of assignment to the treatment group was “a little vague” on that subject.

²For brevity, we do not distinguish between consumers and representatives in the rest of this discussion of development of the cash management plan.

Personal Preference designed a form to help consumers and consultants think about uses of the cash. Entitled “Decision Tree for the Development of the Cash Management Plan,” the form presents a list of activities in four categories (personal care, nutrition needs, mobility/transportation, and other). Consumers are asked to (1) check the activities with which they need assistance; (2) indicate whether they plan to use the cash allowance to meet each need they check; and (3) if so, whether they plan to hire workers, purchase agency services, purchase assistive devices or other equipment or supplies, and/or modify their homes. Program staff reported that the decision tree was useful in training consultants. However, they estimated that it was completed during the development of only about a quarter of initial cash management plans.

During these discussions, consultants reported introducing other programs that provide goods and services that consumers might be able to obtain at no cost (or reduced cost), which could reduce the demands on the cash allowance. Consultants who worked for agencies that offered a variety of human services seemed especially aware of the importance of considering other services that might be available to the consumer. However, none of the consulting agencies we visited had developed a handbook of available community resources. Sometimes, services available from the community were still included in the cash management plan to avoid long waiting lists. Using Area Agency on Aging services to build a ramp was cited as an example of a service with a long waiting list.

Consultants and consumers next discussed plans to hire workers. They began with the number of workers to be hired and the hourly wage rates and cost after taxes and other expenses (such as fringe benefits). Consultants reminded consumers that they needed to identify back-up workers. One consultant reported having recommended an agency as a source of back-up

workers; this consultant acted on the consumer's behalf to negotiate a rate with the agency. In her experience, agencies wanted to stay involved with these clients.³

Consultants and consumers next discussed purchases of equipment or home modifications to be included in the cash management plan. They asked consumers to identify the goods or services they wanted to save for, sometimes urging them to think creatively about how to use the cash.

In a few cases in which the consumer's requested purchase was not allowable but nevertheless had merit, the program staff suggested "trade-offs." The staff identified purchases made with personal funds that might instead be covered by the cash allowance, thus freeing personal funds for uncovered purchases. Trade-offs were rare and occurred only in cases of unallowable but meritorious requests. The possibility of a trade-off was not mentioned to most consumers.

Consultants also advised consumers on how to make purchases. For example, since the fiscal agent required a purchase order to issue a check to a vendor, consultants advised consumers to pool several small items into a single order (frequently, a catalog order). One consultant reported reminding a consumer who was bedbound that she did not need to be able to leave her home to shop—she could use the telephone to do so.

If time permitted during the initial home visit, the consultant might next discuss the forms in the employment package. This package included the forms that the fiscal agent needed to initiate employment, such as W-4 forms for federal tax withholding. The consumer, as an employer,

³However, agencies that were having difficulty hiring enough staff members to serve their regular clientele would not be a good source of back-up workers.

was responsible for making sure that these forms were completed and submitted to the fiscal agent.

Often, after the initial home visit, telephone calls would be required to complete the planning process. Sometimes, additional home visits were needed. This was often true for consumers who were recruiting workers other than family members and friends.

Consultants varied in how much they helped consumers during recruitment. Some kept in close touch with consumers by telephone. Others waited for consumers to contact them when they were ready to hire. One consultant said: “Consumers are accustomed to professionals taking care of all the details and paperwork. They have to learn to be responsible for it themselves.” Some consultants reported uncertainty about how much they should be helping with hiring, which probably contributed to the variation in how much help they gave consumers.

At the end of the planning process, the formal cash management plan form was completed. Consultants reported that the cash plan form (which appears in Appendix A) was not “user-friendly.” Consumers and consultants found it difficult to follow. Some consultants also reported being uncomfortable with performing the calculations required to complete the form, although they did become more facile over time with doing the arithmetic. The consumer and consultant each kept a copy of the completed cash management plan, and the consultant sent a copy of the completed form to the state Personal Preference office for its review.

3. Program Review of the Cash Plan

Consultants reviewed cash management plans before submitting them to the Personal Preference office, but they did not formally approve the cash plans. State-level program staff members reviewed all cash plans to determine whether the goods and services requested were allowable. (See discussion in Chapter II.)

Personal Preference adopted a broad interpretation of allowable goods and services, permitting a purchase if it was demonstrated that the purchase would contribute to personal independence (if that were not self-evident). For example, the program allowed the purchase of a new mattress because an old mattress was so broken down that it hampered the consumer's ability to get out of bed without help. In contrast, a request to cover the cost of demolishing a wall in a consumer's house was denied because the modification was not linked to her independence. Other examples of disallowed goods and services included a suite of furniture, cosmetics, and pantyhose.

Consultants sometimes advocated a purchase on behalf of a consumer. One consultant said, "I call the state program office and make the case and have not been denied."

C. USES OF CASH

Consultants reported that nearly all consumers used the cash allowance to hire a worker (or workers). The next most commonly reported use of cash in New Jersey was to purchase equipment. Consumers often purchased medical equipment (such as lift chairs) or appliances (such as microwave ovens). As the examples in Case Example V.2 show, some consumers were creative in selecting equipment for purchase. One consultant reported that she was trying to arrange for a consumer to purchase a specially trained monkey as a service animal. She noted, "That monkey could do everything he needs."

Consultants reported that some consumers used the cash allowance to modify their homes, primarily by building ramps. The number of home modifications was likely limited because many Personal Preference participants were renters, and owner permission is usually required to modify rental property. Moreover, consumers might be reluctant spend their cash allowances to modify rental property since they would be unlikely to benefit from any increase in the value of

the property. In addition, major home modifications are expensive—consumers probably would not have been able to save enough funds from the cash allowance for major modifications.

On rare occasions, consumers obtained loans instead of waiting to accumulate enough savings to make a purchase. Consultants reported that none of the consumers had applied to obtain a bank loan to be repaid from the cash allowance. However, two had borrowed money from family members and were repaying the loans in installments. One had borrowed money to have a ramp built, the other to purchase an adjustable bed.

Case Example V.2: Creative Equipment Purchases

A young man purchased a walker-like support for his voice synthesizer so that he could speak to people he met on the street without stopping and taking the synthesizer out of his backpack.

A blind woman bought a scanner and talking computer to allow her to read mail and check worker time sheets. She saved a portion of her cash allowance for a year to purchase this equipment.

A person with quadriplegia purchased a fax machine to use for sending medical papers to doctors and insurance companies, as well as for Personal Preference correspondence.

Under Personal Preference, consumers could use the cash allowance to cover the costs involved in managing their own services. For example, workmen's compensation was available as a rider to homeowner's or renter's insurance, and consumers who did not already have a policy were allowed to include the full cost of such insurance, not simply the cost of the rider. In addition, consumers were allowed to purchase personal post office boxes to reduce the chance of a worker's check mailed to their home being stolen.

D. TIME TO RECEIPT OF CASH

Many Personal Preference participants were enrolled in the program for several months before they received their first monthly cash allowance. Data from evaluation interviews with an

early cohort of more than 200 Personal Preference participants randomly assigned to the treatment group indicated that only about a third received their first cash payment during the first six months following enrollment. Another quarter received their first cash payment between six and nine months after their enrollment.⁴ The rest of this early cohort had not received a cash payment by the ninth month following enrollment. (Future reports based on interview data will provide similar information for the entire treatment group.) Here, in this process analysis, we describe factors that contributed to delays in receiving the cash allowance.

Some factors were structural. First, allowing consumers a choice of consulting agencies added another step to a complex process, delaying the average time it took to receive the cash allowance. Second, in response to concerns from the personal care industry, Personal Preference initially gave Personal Care Assistance (PCA) providers 30 days notice to discontinue services for a client who was to become cash recipient. Partly in response to the urging of the National Program Office to reduce delay in receipt of the first cash allowance, New Jersey later reduced the agency notice period to 14 days.⁵ Third, consumers had to wait until the beginning of a month to receive their first cash payment, because a variable was set on the New Jersey Medicaid Management Information System (MMIS) to indicate that a beneficiary was a cash recipient (and thus not eligible to receive traditional PCA services), and the MMIS was updated only monthly. New Jersey did not develop a procedure to provide a cash payment for a partial month before the MMIS had been updated.

⁴Memorandum from Leslie Foster dated November 29, 2001.

⁵The shorter notice period was apparently acceptable to personal care agencies. Senior Personal Preference staff reported that they did not receive any complaints from agencies (or, indeed, any comments at all) about the reduction in the notice period.

Consumers who did not have family members or friends to hire as workers typically had more difficulty than other consumers with completing a cash management plan fairly quickly, because they needed more time to identify and recruit a worker. In addition, they sometimes had difficulty meeting the obligations of an employer, which delayed receipt of the cash allowance. For example, one consultant cited the case of a consumer who had unrealistic expectations about the wages necessary to attract a worker. With no one available to serve as a representative, the consultant worked with this consumer to revise her expectations so that she could recruit a worker.

Finally, the development and review of every cash management plan required the participation of several people and groups. The consumer (perhaps a representative's help) and the consultant developed the cash management plan. The completed cash plan form was sent to the state Personal Preference program office for review and approval of the included goods and services. The Personal Preference office then sent approved cash plans to the fiscal agent, where the calculations were double-checked for accuracy before the consumer's cash account was established. The fiscal agent also reviewed the forms in the employment package for completeness and consistency.

If the state program or the fiscal agent identified problems with the cash management plan or the employment forms, the paperwork was returned to the consumer. A consumer who did not understand the problem and how to resolve it would have to contact the consultant. Some consultants with whom we visited complained that the fiscal agent returned paperwork without indicating what was in error. Consultants said that they themselves sometimes were unable to identify the error and had to call the fiscal agent for an explanation.

Both state Personal Preference staff and consultants reported frequent communication problems between consumers or their representatives (on the one hand) and consultants, state

program staff, and fiscal agent staff (on the other). The number of people involved made it difficult for consumers to keep track of which one to call about a particular type of problem. Consumers often would call the state Personal Preference staff when they should have called the fiscal agent. Some consumers placed a call to another person without giving the first a reasonable time to respond. Other consumers called the consultant, state program office, and fiscal agent, one after the other, perhaps thinking that this would get the problem resolved more quickly. In Section F, we describe some suggestions for improving communication in the Personal Preference program.

Consultants reported that fiscal agent staff members were slow to return telephone calls both to them and to consumers. State Personal Preference staff members indicated that they, too, had noticed that telephone calls to the fiscal agent were not returned promptly when one of the two full-time fiscal staff members was out of the office.

E. CHANGES TO THE CASH PLAN

To revise a cash plan, all those originally involved (consumer or representative, consultant, state Personal Preference staff, and fiscal agent), as well as all the steps taken for the original submission of the cash plan, were required. Revisions were often necessary, as the circumstances and conditions of consumers changed. Over time, some consultants, working with the fiscal agent, developed ways to reduce the number of times the cash plan had to be formally revised and to streamline the process when revision was necessary.

1. When Was a Cash Plan Revision Necessary?

The cash plan had to be revised if the total amount of the cash allowance changed or if the amount to be authorized for a given type of good or service (line item) changed. Changes arose as consumers' circumstances changed, as in the following examples. A worker left a consumer's

employ. A consumer had saved enough to purchase one piece of equipment and wanted to start saving for something else. A consumer wanted to change vendors. Consumers' care plan hours were increased at assessment due to a change in their condition or in the informal care available to them.

Changes were also sometimes required because state or federal policies or regulations changed. For example, changes were required in all Personal Preference cash plans when New Jersey increased the hourly rate paid for PCA services, thereby increasing the amount of the allowance for all cash recipients. A change in federal rules regarding withholding required the revision of most cash plans, since the costs of employees (and the associated line items in cash plans) changed under the revised rates.

2. Writing Flexible Cash Plans

Consultants and the fiscal agent learned how to write the original cash plan in a flexible way and reduce the number of circumstances in which a formal cash plan revision was required. Instead of naming a specific individual in the cash plan, the plan would list "Worker 1" at a specified rate for a specified number of hours a month. With a such cash plan, formal revision was not necessary if a worker changed, provided that the replacement was to be paid at the same rate and work the same number of hours a month. (A new employment package would of course be required for the replacement worker.)

Similarly, the cash plan could be made more flexible by listing a type of good or service, rather than naming a vendor. For example, the cash plan might list "laundry services" rather than specify "Tom's Spotless Laundry." With such a flexible cash plan, a formal revision was not required for the consumer to change vendors (perhaps to take advantage of a better price). The fiscal agent agreed to honor purchase orders for goods and services under flexible cash plans if the cost did not exceed what was listed for that line item in the cash plan.

Not all the consultants we spoke with in spring 2001 were writing flexible cash plans. Apparently, some did not understand that it was acceptable to write a cash plan that did not name specific workers or vendors.

3. More Efficient Revision of the Cash Plan

Consultants and the state Personal Preference office developed several techniques to make revision of the cash plan more efficient. One consultant created a tickler file to remind her when a consumer would have about enough money saved for a planned purchase. She would then call the consumer to ask him or her to begin to think about what good or service to purchase next and to schedule a home visit to develop the revised cash plan.

Another consultant asked consumers to give her signed, blank cash plan forms. The consultant then did not need to visit the consumer's home or to use the mail to get the revised plan signed. Instead, the consumer and consultant could discuss the necessary revisions to the cash plan over the telephone. A problem with this technique is that it is prone to error and possibly open to abuse. Consultants could inadvertently make the wrong changes to the cash plan, and the consumer would not be able to identify the error before the revised cash plan was submitted to the fiscal agent. In addition, consultants could conceivably make inappropriate changes in the cash plan without the consumer's knowledge. The consumer might not learn of an erroneous or inappropriate change until some time later when he or she received a financial statement from the fiscal agent—after funds had been expended.

At the time of our visit, a member of the state Personal Preference staff was introducing a spreadsheet version of the cash plan. She planned to distribute the spreadsheet to consultants—and some consumers—who had access to computers, as well as to use it at the state Personal Preference office. While entering the initial cash plan into the spreadsheet was time-consuming, its use was expected to expedite cash plan revisions because it would be unnecessary to copy

material that was unchanged and because the spreadsheet software would automatically do the math.⁶

F. KEEPING CONSULTANTS INFORMED

Consultants to whom we spoke indicated they needed a better way to be informed of revisions to program rules. (In a demonstration program, changes in program rules are especially likely.) One consultant suggested a monthly briefing for this purpose.

Consultants also suggested meetings to learn from Personal Preference staff and from one another. Such meetings seem particularly important when consultants work alone or in small groups and when they have a small volume of cases. With experience, consultants often would develop tricks to make the work go more smoothly and quickly. At meetings, they could share these with other consultants.

G. MAJOR LESSONS

Many lessons may be drawn from New Jersey's experience with Personal Preference.

1. Choice of Consulting Agencies

New Jersey tried to give consumers a choice of consulting agencies. However, doing so proved problematic. Some areas of the state were never served by more than one agency, and the number of agencies was greatly reduced over time. Consumers in New Jersey had little experience and knowledge on which to base their choice of a consulting agency and did not seem to place much importance on having a choice. Moreover, allowing for choice delayed the receipt

⁶We later learned that the spreadsheet version of the cash plan had been successful. Not only did it expedite cash plan revision, but it also reduced arithmetic errors in the initial cash plan and in revisions.

of the cash allowance. While appealing in theory, in practice, allowing consumers a choice of consulting agencies under Personal Preference created problems, with little or no gain.

2. Advance Planning for the Home Visit Is Essential

Advance planning is essential to make the initial consulting home visit as useful as possible and to minimize the need for additional home visits. Providing written materials before the visit is not critical. It may even be counterproductive, since materials may be mislaid. Moreover, PCA recipients may find the paperwork especially off-putting if no one is there to explain it. However, before the home visit, consumers need to think about how they would like to spend the cash allowance, whom they would like to hire as a worker, and whether a representative should help them manage the cash allowance. The potential representative should attend the initial home visit, and potential workers should attend if they have been identified. It is also advantageous if *all* family members involved with the care of the PCA recipient are present during the visit. With good planning, the need for multiple home visits can be minimized, thereby eliminating a source of delay in the receipt of the cash allowance.

3. Techniques to Minimize and Streamline Cash Plan Revision

Consultants, state Personal Preference staff, and fiscal agent staff learned a technique to reduce the number of circumstances that required a formal cash plan revision. This involved writing a flexible cash plan that did not name workers or vendors but instead indicated the type of good or service and key cost parameters—total cost for a given type of good or service and, for workers, hourly rates and hours.

Techniques were also developed to streamline revision of cash plans when necessary. These included (1) using spreadsheets to eliminate the need to copy material that had not changed and to do the math on the cash plan, (2) using tickler files to remind the consultant to begin to plan

for expected changes in the consumer's circumstances, and (3) allowing the consultant to retain blank cash plan forms that the consumer had already signed.

While the use of blank forms seems open to error and abuse, all these techniques appear to be useful in expediting revision of the cash plan. Putting the cash plan on a spreadsheet appears particularly promising. If consultants had access to laptop computers, the initial cash plan might be entered directly into the spreadsheet. To expedite review of draft cash plans, the spreadsheet might be sent electronically to the state Personal Preference office and the fiscal agent, with copies with original signatures to follow by mail when all errors had been resolved.

4. Time to Receipt of Cash Allowance

One lesson learned from Personal Preference is that the time required for each step in cash planning adds up and can appreciably delay the consumer's receipt of cash. Consumers can become discouraged if they are unable to participate in the cash program as they had expected. It is important, therefore, to prevent delays in cash receipt by eliminating unnecessary steps and by minimizing the time required for the remaining steps.

To reduce delay of the cash allowance, New Jersey (partly at the urging of the National Program Office) eliminated some steps and reduced the time required for others. It stopped giving consumers a choice of consulting agencies, as that proved to be of little value to them. Traditional providers must be notified to discontinue service to new cash recipients, but New Jersey reduced the notice time to 14 days, which seems to be adequate.

More may be possible. For example, while it may not be feasible to update an MMIS more often than monthly, Arkansas developed a procedure to allow consumers to receive a partial cash payment if they had completed the cash planning process by, say, the middle of a month. This procedure used a special revolving fund to cover the cost of a partial cash payment for one month.

5. Resolving Communication Problems

Personal Preference experienced serious communication problems. These problems contributed to delays in completing the cash management plan and getting the cash allowance. Resolution of such problems could reduce the time to receipt of cash.

Those we interviewed identified several ways to improve communication in Personal Preference. One suggestion was to train consumers about whom to call regarding what issues, including providing them with a “Who Does What” list. Another suggestion was that, when the state Personal Preference office or the fiscal agent returned documents for correction, exception reports be produced. These reports would indicate the error requiring resolution. Another consultant suggested using multiple-party telephone calls to reduce the need for several one-on-one calls. Case Example V.3 presents this consultant’s views on the value of these calls. The potential for communication problems is high in Personal Preference because so many people are involved in its day-to-day operations. We return to this issue in Chapter IX.

Case Example V.3: Multiple-Party Telephone Calls

When I have an issue with the fiscal agent, I do a three-way call. The consumer should call, but I want to see how to handle the issue. The consumer is involved and hears the transaction.

I say to the consumer, “Let’s call together. I’ll put you on hold and get the fiscal agent on the line.” When I reach the appropriate member of the fiscal agent staff, I say, “I have a consumer on the other line and we want to talk to you.” The call helps my credibility with both the consumer and the fiscal agent.

I do these calls with the state office, too. They are very effective.

The Arkansas experience suggests a second approach to resolving communication problems. This involves limiting the role of the state staff in reviewing cash management plans. Under the Arkansas cash program, a list of allowable goods and services was prepared. The Arkansas state

program staff reviews only those cash plans that call for unlisted goods or services. Through the Personal Preference demonstration, New Jersey has learned how to develop a list of allowable goods and services.⁷ Particularly if New Jersey adds a cash model to its permanent Medicaid program, there would seem to be little or nothing to gain from continued state-level review of all Personal Preference cash plans.

⁷After our visit, we learned that New Jersey plans to create a list of goods and services that would be clearly allowable in a future cash allowance program. Some would be allowable only in specified circumstances. For example, blenders and food processors would be allowable only for consumers who had difficulty with eating.

VI. REPRESENTATIVES

Many of those receiving the cash allowance under Personal Preference had representatives to help them manage it. Consultants reported that up to two-thirds of the elderly consumers had representatives, while the proportion was considerably smaller among nonelderly adults. Ethnic and language diversity likely contributed to the extensive use of representatives among elderly consumers in New Jersey. Those not fluent in written English probably were not comfortable handling the paperwork, such as the development of the cash management plan that Personal Preference required.

In this chapter, we describe the Personal Preference procedures pertaining to representatives. We also present lessons we have drawn from New Jersey's experience with the cash program.

A. SELECTION OF REPRESENTATIVES

In general, consumers could decide whether they wished to have a representative help them manage the Personal Preference cash allowance. Consumers who had legally appointed surrogates (such as legal guardians and social security payees) had to name their surrogates as representatives, but no one else who entered Personal Preference was required to have a representative. Rarely, New Jersey required that a representative be named if the consumer was to continue to participate. By the time of our visit in spring 2001, the state had mandated representatives in only three cases. For example, the state mandated a representative for a consumer who was making unreasonable demands on her employees.

The Personal Preference enrollment staff discussed the possibility of naming a representative when they contacted a Personal Care Assistance (PCA) recipient. However, representatives were not formally identified during an enrollment visit—the consultant did this after random assignment to receive the cash allowance. By delaying identification until after

assignment, New Jersey avoided naming representatives for those PCA recipients later assigned to the control group.

During the initial home visit, the consultant discussed and assessed the consumer's need and desire for a representative. The consultant looked at the types of assistance the consumer was currently receiving. Consumers who were already receiving assistance with their affairs, such as help maintaining a checking account, were viewed as likely to need a representative. Those who were accustomed to assistance with their affairs usually were happy to name a representative when a consultant recommended that they do so.

Usually, the choice of a person to serve as representative was obvious and grew out of the current relationships of the consumer. It was usually someone who already had been helping manage the consumer's financial affairs or services. Most had been giving informal help; few consumers had legal guardians or other surrogates who had been legally appointed.

Nearly all the representatives were family members—usually, close family members. Consultants reported that elderly consumers seemed more comfortable with the cash program if a family member was named as a representative.

Consultants helped prospective representatives decide whether they wished to undertake this role. They described the responsibilities that representatives were expected to assume and assessed whether prospective representatives had realistic expectations. They were asked to complete a self-screening questionnaire that the state Personal Preference staff had developed (see Appendix A). The items in this questionnaire raised pertinent issues, such as the frequency of contact between the consumer and the prospective representative and whether the latter was paid to care for the consumer. Another item asked prospective representatives to confirm their understanding that they could not pay themselves in that role. Many representatives were

pleased that their willingness to serve as a representative allowed their loved ones to participate in Personal Preference.

If a representative agreed to serve after completing the self-screening questionnaire, both the representative and the consumer signed a separate form designating the representative. This form could be completed during the consulting home visit if the representative was present.

Infrequently, representatives were named after the initial home visit. A consultant might recruit a representative for a consumer who was having difficulty developing the cash management plan or managing the cash allowance.

B. MAJOR LESSONS

New Jersey's Personal Preference program offers several lessons about representatives.

1. Selection of Representative Is Extension of Natural Process

The representative selection process was an extension of the relationships that consumers already had when they joined Personal Preference. Most representatives were relatives (usually close relatives) of the consumer. As indicated earlier, many consumers were already receiving help with their affairs, and the naming of a Personal Preference representative was a formal extension of that assistance. Some may have been receiving assistance because of their limited facility with English. In general, those who had been providing assistance simply assumed the role of representative.

The fact that representatives were generally close relatives probably made it easier for them to interact with providers and vendors. Many institutions (for example, banks and hospitals) are used to having close relatives act on behalf of their elderly or disabled loved ones. None of the

consultants or other program staff members we interviewed reported any problems that arose because of questions about the legal standing of representatives.¹

Representatives were usually happy to serve. Often, they wanted a loved one to participate in Personal Preference, and acting as a representative made that possible. In addition, the availability of fiscal services (at low cost to the consumer) may have made the selection of representatives easier by limiting the duties expected of them.

2. Need for Representative Depends on Several Factors

The need for a representative depends on the consumer's type and level of disability. For example, a consumer with a cognitive disability is likely to need help managing his or her affairs.

Other factors also affect the need for a representative. They include familiarity with the cash program, the availability of consultant training about how to manage cash, and the availability of equipment to support management activities. The familiarity of the consumer and of the consumer's family with the cash program affected the need for, and choice of, a representative. Many consumers originally named representatives for security, since the cash program was new and they were new to it. As they became more familiar with the program, they were able to assume more responsibility for managing the cash allowance. In some cases, a son or daughter might have pressed to be a representative early, out of concern about a parent's ability to manage the cash allowance without assistance. This same son or daughter might have felt more comfortable once the cash management plan was completed and might have allowed the consumer to assume more responsibility for his or her own care.

¹After our visit to New Jersey, the National Program Office arranged for an attorney to review legal issues pertaining to representatives. It did so at the request of some of the Cash and Counseling programs.

A sense of insecurity probably explains why some consumers named representatives when they could have managed without them, at least in the view of the program staff. The state Personal Preference staff estimated that about half of all consumers who named a representative would have been able to manage the cash allowance independently had they chosen to do so.

The need for a representative could also depend on the availability of consumer training from the consultant. For example, one consultant asked a son to be a representative. When the son did not complete the forms, the consultant taught the consumer how to treat a worker so that she could manage the cash allowance herself.

Rarely, the need for a representative can depend on the consumer's environment. The blind woman mentioned in Case Example V.2 offers an example of how the environment affects the need for a representative. She purchased an electronic scanner and talking computer with the cash allowance so that she could personally read worker timesheets, as well as correspondence regarding the Personal Preference program. Her consultant had suggested naming a representative to review documents, but she resisted because she wanted to be independent. The equipment made that independence possible.

3. Role of the Representative Varies

Consultants encouraged representatives to involve consumers in decision making as much as possible. Typically, both the consumer and the representative contributed to the management of the cash allowance, although the nature and extent of their contributions varied.

Representatives generally asked consumers about their preferences. The representative was the sole decision maker only in the rare cases in which the consumer was unable to communicate his or her preferences or unable to act in his or her own best interests. For example, a representative for a New Jersey consumer who was nonverbal and had profound mental retardation was reportedly the sole decision maker. However, representatives sometimes

involved consumers with severe disabilities in decision making. One consultant reported an example of a parent who was the representative of a young man with cerebral palsy. Although others could not understand his speech, his parent could and kept bringing him into discussions about his care, turning to him and asking, “What do you think?” For example, he was consulted about whether he would like to use some of the cash allowance to buy a cordless phone.

Despite disability, a consumer may be the primary decision maker, while the representative serves as the consumer’s liaison with the outside world. In these cases, the designation of a representative may not be strictly necessary, but it may be more efficient. The representative can reduce the time required from the consultant and reduce the burden on the consumer.

Case Example VI.1: Representatives When the Consumer Is Primary Decision Maker

A man whose speech was severely impaired after a stroke (but whose other mental abilities were unaffected) selected his wife as his representative. She is the only one who can understand his speech and has even gone into the operating room with him to translate for his physicians.

A young man who is attending college selected his mother as a representative, not because his disabilities prevented him from undertaking the task, but because he was busy going to class and studying during the day. The mother was at home, with more time to interact with the consultant and the fiscal agent.

4. Representatives Are Functioning Well

All the consultants with whom we spoke reported that representatives were obtaining input from the consumers when possible and were faithful to consumers’ best interests. All these representatives were relatives of consumers. No incidents were reported in which consumers had changed representatives. Consultants described some of the representatives as “very close” to the consumers.

VII. CONSUMERS AS EMPLOYERS

For consumers who hired workers under Personal Preference, the success of consumer direction depended on the consumer's ability to be a good employer—to make decisions about recruiting, hiring, supervising, and (if necessary) firing workers.¹ Although consumers could not delegate these tasks (as they could fiscal tasks), they did have help carrying out their role as employers. Consultants provided much of this assistance, and the fiscal agent helped with particular tasks. In this chapter, we discuss consumers' performance of their employer responsibilities.

A. ASSISTANCE WITH EMPLOYER RESPONSIBILITIES

Consultants trained consumers on how to recruit, hire, train, supervise, and fire workers. However, consultants did not perform these tasks for consumers.

1. Initial Assistance

Consultants began to train consumers on employer responsibilities during the initial consulting home visit. As consultants helped consumers develop the cash management plan, they told them the prevailing wage rates in their community. For example, a consultant in the northern part of the state said that she told consumers that traditional agencies were raising hourly wage rates for their aides to \$9 to \$10 an hour and offering them a benefit package. Occasionally, a consumer had unrealistic views about wage rates. For example, one consumer wanted to hire a live-in worker for \$700 a month and charge that worker \$500 a month for rent.

¹For brevity, we do not distinguish between consumers and their representatives with respect to fulfilling the responsibilities of an employer.

During the initial home visit, consultants stressed how much payroll deductions would add to a given hourly wage. Consultants reported that the “tax tables” the state Personal Preference staff had developed were helpful. These tables presented the cost to the consumer to pay a given hourly wage, with all payroll deductions taken into account (for example, an hourly wage of \$11.50 would cost the consumer \$12.35 an hour).

Personal Preference workers were considered domestic workers. State law in New Jersey requires that employers (including employers of domestic workers) carry workmen’s compensation insurance, and insurance companies must offer this under low-cost riders to homeowner and renter insurance policies. Early in the demonstration, it was difficult to find an agent who would write the riders for renter insurance policies, which no longer were common in the industry. Because the cost for the rider was low, an agent received little compensation for writing it. However, consultants helped consumers obtain the riders. One consultant reported that she finally convinced an insurance agent to write workmen’s compensation riders to renter policies by arguing that he would receive a substantial volume of business from consumers whom she and other consultants referred to his agency. Eventually, consultants identified a handful of agents in the state who were willing to write the riders.

2. Recruiting Workers

Consultants used different approaches to helping consumers during recruitment. Some kept in close touch with consumers by telephone. Others depended largely on the initiative of the consumers, expecting that they would contact the consultant when ready to hire. As noted in Chapter V, some consultants reported uncertainty about how much help with recruiting they should provide, which probably contributed to the variation in the amount of assistance they did provide with this activity.

As mentioned in Chapter V, most consumers hired family member or friends as workers. Consultants advised consumers who wanted to hire a family member that doing so might not always work out. Consumers needed to understand that it could be difficult to discipline a worker who is a family member. One consultant reported that she also advised consumers to be careful not to hire a family caregiver who already was “burning out” from providing unpaid care.

Some consultants gave suggestions on recruiting techniques to those who did not have a family member or friend they wanted to hire. They shared their personal experiences with consumers and gave them copies of materials on recruiting. They copied materials on advertising, interviewing, and other aspects of recruiting from the Personal Preference consultant training manual and gave them to consumers. One consultant also gave consumers copies of materials developed by another program because she thought they were helpful. Because a newspaper ad could cost as much as \$100, she found the manual’s suggestions about places to post free ads (for example, churches, colleges, Laundromats) especially useful. Another consultant reported frequently recommending that consumers seek workers through their churches.

As Case Example VII.1 suggests, recruiting a worker could be difficult, and this difficulty sometimes led to delay in receipt of the cash allowance.

Case Example VII.1: Difficulty Recruiting a Worker Leads to Delay in Cash Allowance

One young man living in a supportive housing facility had no family members or friends whom he wished to hire as a worker. All his neighbors also had disabilities. The lack of bus or other public transportation made it difficult for potential workers to travel to the supportive housing facility to care for him. He tried to hire the janitor in the facility as his worker, but the housing management refused to allow that. He then tried to hire the janitor’s wife, but the management disapproved of that as well, leaving him without a worker at the time of our visit.

Personal Preference consultants pointed out to consumers that they could use agency services if they were unable to identify a worker. One consumer hired an agency that charged \$15 an hour—much less than traditional agencies usually charge. Another consultant reported that she had negotiated special rates with a traditional agency to provide back-up care for a consumer.

3. Hiring Workers

Consumers had to ensure that the workers they recruited completed employment packets. Consultants left one or more packets with the consumer at the initial home visit for the worker(s) to complete. The fiscal agent provided consumers with instructions on how to complete forms in the package. Although state and federal regulations require that these forms be completed in English, the fiscal agent prepared the instructions in both English and Spanish.

The fiscal agent also reviewed the completed employment packages. As with the cash management plans, consultants reported that they occasionally had to intervene with the fiscal agent about employment paperwork returned to the consumer for corrections. In these cases, the fiscal agent had not specified the nature of the error, and it was not obvious to the consultant.

4. Time Sheets

Consultants trained consumers and workers on the importance of submitting time sheets on schedule. Consultants advised workers that they were responsible for making sure the time sheet was mailed on time. Many consumers were homebound and had difficulty getting to a mailbox or post office. Consultants taught consumers and workers to leave enough time for the mail to travel to the fiscal agent's office in the northern part of the state.

Fiscal agent staff reinforced the training about time sheets on an ad hoc basis. When consumers called the fiscal agent to complain that worker paychecks had not been received as

expected, the fiscal agent investigated. Often, the time sheets had not been submitted on schedule. This situation afforded an opportunity to retrain the consumer about the importance of prompt submission of time sheets. After the consumer and the worker learned what was necessary, they usually submitted time sheets on schedule.

A small minority of consumers and workers repeatedly failed to submit time sheets on schedule. However, a fiscal agent executive reported that the kinds of problems she had seen with time sheets in Personal Preference were no different from those in the agency's other human services programs.

5. Firing Workers

The consultants with whom we spoke did not report helping any consumer to fire an unsatisfactory employee. One consultant reported counseling a consumer about giving appropriate notice when terminating an employee. Case Example VII.2 describes this.

Case Example VII.2: Firing Workers Without Notice

A consumer had fired a worker (who had been performing well) without notice so that she could hire her daughter-in-law. The worker complained to the consultant, but there was nothing the consultant could do. When the consumer's arrangement with the daughter-in-law fell through soon thereafter, the consumer wanted to rehire the worker and called the consultant to discuss doing so. The consultant told the consumer that the worker was upset about being fired without notice, to which the consumer replied, "No one ever told me I was supposed to give a worker notice before firing them."

B. CONSUMER MANAGEMENT OF PAYROLL FUNCTIONS

As indicated in Chapter II, New Jersey permitted consumers to take personal responsibility for managing their cash allowance—provided that they passed a skills examination covering preparation of payroll tax returns and related payroll documents. The skills examination was prepared by the fiscal agent and revised based on comments from a contractor the National

Program Office had hired. The examination was “open book”—consumers were allowed to consult relevant materials, such as the instructions for completing payroll tax returns, while taking it.

A few consumers asked to review the skills examination. Five had done so at the time of our visit. However, after reviewing the examination, all five decided not to take it. One consultant reported that a consumer with whom she worked was part of a family that ran a small business. This consumer had planned to take the examination; however, it was still being developed at that time. The consumer decided not to take the examination after it became available, as the family was happy with the services they had been receiving in the interim from the fiscal agent. One fiscal agent executive reported that the “taxes scare everyone.” Apparently, consumers preferred paying the charges for fiscal services to taking personal responsibility for preparing payroll tax returns and other payroll documents.

C. MAJOR LESSONS

We draw three major lessons from the experience of consumers as employers under Personal Preference.

1. Consumers Fulfilled Nonfiscal Responsibilities of an Employer

Most consumers satisfactorily fulfilled the nonfiscal responsibilities of employers—recruiting (which proved the most difficult), hiring, training, supervising, and firing. Consultant training of consumers played a major role in this success.

The amount of help that consumers need from consultants varies. Some consumers have substantial life experience as employers (for example, they might have helped run a family business). Others have little relevant life experience and may need a substantial amount of consultant assistance. When they enroll in a consumer-directed program, they may not

understand the basic responsibilities of an employer. They may not understand simple issues, like the consequences of failing to submit a time sheet on schedule, or sensitive ones, like the importance of giving adequate notice of termination. Although such consumers need much more consultant assistance in fulfilling the responsibilities of an employer, they can learn.

2. Recruiting Is a Critical Issue

Under Personal Preference, recruiting was perhaps the most critical issue for consumers who did not have family members or friends they wished to hire as workers. When asked what consulting functions were most critical in enabling consumers to effectively manage their cash allowance, one consultant replied, “Knowing where to go if they have problems, so they can move on. The biggest problem is where to look for workers.” The receipt of cash will be delayed for consumers who cannot recruit a worker called for in their cash plan. Program staff reported that consumers who could not recruit a worker tended to become frustrated by this and eventually dropped out of the cash program.

Personal Preference developed written materials to train consultants about recruiting, and the consultants shared these and other materials with consumers. However, consumers received varying amounts of help from consultants with recruiting. Although consultants realized that they were not to serve as case managers, they still had to determine what their new role would be. Both consultants and consumers might have benefited from more training for consultants on their responsibilities in helping consumers with recruiting.

What else might be done to help consumers recruit workers? The National Program Office helped New Jersey and the other Cash and Counseling states identify approaches to link consumers with workers. One possibility is the development of worker registries. Neither the state Personal Preference office nor the consulting agencies developed worker registries. However, we learned after our visit that the state of New Jersey had applied for, and received a

federal grant for, a program to develop worker registries. Part of the impetus for applying for this grant was the state's experience with Personal Preference.

Another possibility is to develop informal lists of Personal Preference workers willing to assist other consumers. The Personal Preference consultants with whom we spoke did not report having such lists. The volume of consulting cases for many Personal Preference consultants may simply be too small to give rise to the development of worker lists.

In addition, consumers who have difficulty recruiting workers could make greater use of agency services, at least until a worker can be identified. Less expensive alternatives to traditional Personal Care Assistance services do exist in New Jersey, and traditional agencies may be willing to negotiate special rates.

Finally, part of the difficulty of recruiting workers under Personal Preference probably was due to a full-employment economy. During our visit, we learned of shortages of personal attendants for other home- and community-based services. During a downturn in the economic cycle, consumers may find it somewhat easier to recruit workers.

3. Consumers Prefer to Share Fiscal Responsibilities of an Employer

Consumers value having the services of a fiscal agent to provide bookkeeping and prepare payroll tax returns and related documents. Under Personal Preference, consumers could assume all fiscal responsibility for the cash allowance if they passed an open-book skills examination. However, no consumers chose to take the test. Rather, all chose to split the fiscal responsibilities of an employer between themselves and the fiscal agent—they retained responsibility for approving and submitting time sheets, and the fiscal agent assumed responsibility for filing state and federal tax returns and related documents. With training from consultants, almost all consumers successfully completed the fiscal responsibilities they chose for themselves.

Is there cause for concern because consumers in Personal Preference unanimously elected to use the services of the fiscal agent? Does their use of this service suggest a lost opportunity for further training to foster independence? We think not. The state of New Jersey was happy to have consumers use the fiscal services and encouraged them to do so by subsidizing the cost of these services. Moreover, the general public often chooses to pay experts rather than to prepare their own tax forms. Surely we should not expect more of participants in a cash program.

VIII. MONITORING TO PREVENT ABUSE AND EXPLOITATION

The possibility that consumers could be exploited or that the cash allowance could be abused was a major concern of all involved in the Cash and Counseling Demonstration. Policymakers wanted to ensure that vulnerable consumers were not harmed and that public funds were not squandered. Even so, everyone involved realized that extensive control and oversight are inconsistent with consumer direction. Consumers must have freedom to make choices and manage on their own, even if others view some decisions as misguided.

In this chapter, we describe the methods Personal Preference used to prevent abuse of the allowance and neglect or exploitation of consumers. As of the time of our visit in spring 2001, there had been no abuse of the cash allowance or exploitation of cash recipients under Personal Preference.

A. PREVENTING ABUSE OF THE CASH ALLOWANCE

The primary method Personal Preference used to ensure appropriate uses of the cash allowance was state approval of the cash management plan, coupled with fiscal agent review to verify that expenditures were authorized under the cash plan. Personal Preference also provided for consumer review of monthly financial statements from the fiscal agent.

1. Fiscal Agent Checks That Expenditures Were Authorized

Perhaps the most important method for preventing abuse of the cash allowance was rigorous fiscal agent review of purchase orders against cash management plans. After the fiscal agent received an approved cash plan and checked it for accuracy, the information in the plan was data entered (using the Peachtree accounting software package) to create a consumer-specific budget. Thereafter, purchase orders were compared to the Peachtree budget as they were received (in this

context, a time sheet constitutes a purchase order). Only those purchase orders consistent with the budget (and thus the cash plan) were approved, and an approved purchase order was required before any check was cut. One fiscal agent executive put it this way: “If the purchase order does not mirror the cash management plan, the check is not cut.” Before a check was sent to the consumer, the accounting supervisor and the fiscal agent project manager both rechecked the amount against the Peachtree budget.

Others concurred that the fiscal agent’s procedures were rigorous. State Personal Preference staff members were pleased with the stringent approach, arguing that New Jersey could afford to be more flexible in approving uses of the cash because it could be confident that actual expenditures would reflect those allowed under the cash management plan. One consultant commented that the fiscal procedures were “so tight . . . I can’t think how [the procedures] could be abused unless the worker and the consumer were in cahoots.”¹

2. Monthly Financial Statements

New Jersey’s contract with the fiscal agent called for the agent to prepare a monthly financial statement for each consumer receiving the cash allowance (with a copy to the state). The main purpose of these statements was to ensure that consumers knew their account balances. However, they also provided a way for consumers to identify error by the fiscal agent. Consumers might also identify error or even abuse by consultants who retained blank, signed copies of cash management plans in order to expedite revisions to cash plans.

¹During our visit, we learned of one case in which a consumer had reported that another consumer and a “worker” were in cahoots to falsify a time sheet and split the earnings between them. Later, we learned that Personal Preference program staff had investigated this case and had judged that nothing untoward had happened. At that time, we also learned of another case in which one consumer reported that a second consumer had been falsifying a worker’s time sheet. Again, nothing appeared out of order upon investigation by program staff, who later learned that the two consumers in the second case had a long-standing feud.

At the time of our visit, the requirement that the fiscal agent prepare monthly financial statements for consumers had not been met satisfactorily. The initial financial statements that the fiscal agent had prepared were difficult to understand—even the director of Personal Preference said he did not understand them. In spring 2001, distribution of monthly financial statements to consumers had been suspended until the format of the statement could be revised to make it more user friendly. However, a revised format could not resolve one source of confusion. It was not feasible to list the names of workers who had been paid on the financial statement; the accounting system the fiscal agent was using would support listing them only as “Worker 1,” “Worker 2,” and so on. (Nonlabor invoices generally could be described in enough detail to avoid confusion.)

Because the financial statements were difficult to understand and irregularly produced, they had limited usefulness in preventing inappropriate use of the cash allowance.² Consultants reported that consumers could not use the financial statements to monitor the performance of the fiscal agent, because they did not know the status of their accounts.

However, even user-friendly financial statements would not have been an entirely satisfactory way to provide many consumers with information about the status of their accounts. Many consumers simply assumed that all invoices that had been submitted to the fiscal agent had been processed and treated the “bottom line” on the financial statement as accurately reflecting their *current* balance. They did not examine the statement to identify any invoices that were still pending at the time the financial statement was prepared. To avoid this problem, Personal

²After our visit, Personal Preference program staff reported that financial statements were being prepared in a timely way.

Preference staff recommended to consumers that they telephone the fiscal agent when they needed information on their current account balance.

B. MONITORING TO PREVENT EXPLOITATION

Under Personal Preference, two methods were used to monitor for neglect or exploitation of the consumer: (1) contact between consultants and consumers, and (2) reassessment visits by independent Medicaid nurses.³ Personal Preference did not have any explicit mechanisms to prevent exploitation of workers.

1. Contact Between Consultants and Consumers

Consultants and consumers were in contact by telephone and in person. Some contact was routine, while some focused on resolving problems. All contacts provided an opportunity to monitor the condition of the consumer and identify or prevent neglect and exploitation.

Personal Preference required that consultants speak to consumers at least monthly by telephone for the first six months after demonstration enrollment and see them in person quarterly. Consultants worked with consumers to develop the cash management plan. After this was done, consultants told consumers to call them when they had a question. Some consumers, especially those new to the program, called their consultants frequently—more frequently than necessary, according to one consultant. Another said, “I hear from one [particular] consumer every week.” Other consumers seldom called. If a consultant had not heard from a newly enrolled consumer in a month, the consultant would call the consumer to fulfill the requirement for monthly telephone contact.

³In the traditional program, nurses from the home care agency make reassessment visits.

Consultants' monthly calls to consumers were not structured—there was no required interview or checklist (although consultants were required to collect a minimum set of information on consumers). Consultants usually asked how the consumer was getting along and listened for hesitation or other subtle clues that suggested the consumer might be in trouble and that the consultant should investigate further. During the monthly calls, the consultants also reminded consumers about the process for revising the cash plan, including the need to start to think about revising the plan when that was pertinent. Consultants also responded to consumers' questions during the monthly telephone calls, which gave the consultants an opportunity to teach consumers about handling specific problems.

Consultants held different views on whether monthly calls were necessary for the first six months. Some endorsed the calls, while others considered them unnecessarily frequent for some consumers. Case Example VIII.1 presents different views on the value of monthly telephone contact between consumers and consultants.

Case Example VIII.1: Value of Monthly Telephone Contact

Consultant A: It is good to be in touch once a month. Sometimes, the consumer will say something like, "Oh yeah, I was thinking of calling you." Your call may remind them of something that was on their mind.

Consultant B: I call them if I do not hear from them for a month. They get tired of my calling. I always ask the same questions. It becomes kind of a joke with some of them. But they understand that I am supposed to call.

Consultants reported seeing consumers in person at least quarterly, as the Personal Preference program required. These visits might be in conjunction with obtaining a signature on a revised cash management plan, although one consultant (who had a small caseload) reported that she made quarterly visits whether or not she had to visit for a special reason. The consultants we talked with did not question the value of quarterly visits.

2. Reassessment Visits

Under contract to the state Personal Preference program, nurses employed by the Medicaid program visited recipients of the cash allowance semiannually to reassess their condition and to develop their care plans for the ensuing six months.⁴ During these visits, the Medicaid nurse consultants also had an opportunity to monitor the condition of the consumer and to identify or prevent neglect and exploitation. Through the reassessment visits, the Medicaid nurses had identified instances in which consumers needed more assistance, and care plan hours were increased accordingly.⁵ They also identified cases in which the consumers were receiving more hours of personal assistance than were justified, and care plan hours were reduced.⁶ However, no instances in which consumers were being neglected or exploited had been identified during reassessment at the time of our visit in spring 2001.

3. Exploitation of Workers?

The consumer, as employer, was responsible for employee working conditions. Consultants were trained to respect the consumer's role as employer, and they did not routinely contact workers. However, workers occasionally called consultants or the state Personal Preference office to complain about ill treatment by consumers. It is possible that lack of explicit reporting mechanisms caused some exploitation of workers to be unreported. One possible mechanism

⁴Medicaid beneficiaries receiving traditional Personal Care Assistance (PCA) services (including treatment group members who dropped out of Personal Preference) were reassessed by nurses employed by the PCA agency.

⁵The nurses also identified instances in which they judged that care plan hours were excessive; the consumer's hours and cash allowance were reduced accordingly.

⁶Unlike some of the nurses employed by personal care agencies, the Medicaid nurses had no personal financial interest in the number of hours in care plans. Some consumers appealed the reduction in their care plan hours, thereby initiating the state's fair hearing process.

might be to give workers the state's toll-free telephone number and invite them to call if serious problems arise in their work environments.

C. LITTLE OR NO EXPLOITATION OR ABUSE

In this section, we first consider the limited evidence of neglect or exploitation of consumers and workers and then the lack of evidence of abuse of the cash allowance. Personal Preference experienced no adverse publicity from what little exploitation occurred.

1. Very Little Exploitation of Consumers and Workers

State Personal Preference staff reported that only a few cases were identified in which a consumer may have been subject to neglect or exploitation. These cases were quickly investigated—before the cash allowance was received—and handled appropriately. Case Example VIII.2 describes the only case of potential neglect or exploitation that the consultants we visited mentioned; it illustrates how a consultant might identify a case of potential neglect or exploitation.⁷

When a consultant reported that something might be amiss, the state Personal Preference office referred the case to a Medicaid nurse, who visited the home to make an assessment. If during the home visit the nurse obtained information that suggested that the consumer had been abused, the state Personal Preference office checked with Adult Protective Services to see whether that office had a record on the case. The Personal Preference staff reviewed the report of the Medicaid nurse and any other evidence in cases of potential neglect or exploitation. If it concluded that neglect or exploitation was likely, the case was referred to Adult Protective

⁷It is possible that cases of potential neglect or exploitation could be identified prior to enrollment in Personal Preference. However, no instances in which enrollment staff identified a case of potential neglect or exploitation were reported to us.

Services, and the consumer was disenrolled from Personal Preference and returned to traditional PCA if appropriate.

Case Example VIII.2: Handling Cases of Potential Neglect or Exploitation

A consultant indicated that she had felt that something was amiss when she scheduled the initial home visit and that she had, therefore, asked another consultant to accompany her. When they arrived, they found the consumer lying on a couch, comatose. Both consultants felt that this situation was inappropriate, and that Adult Protective Services should be notified. They referred the case to the state Personal Preference office for investigation.

Consumers occasionally treated workers unfairly, but the consultants we visited mentioned only one case in which a consumer seems to have been exploiting a worker. In this instance, a family dispute arose when the son and daughter-in-law, who had been hired as a worker, moved out of the consumer's home, and the consumer withheld the daughter-in-law's paychecks. The worker complained to the consultant, who notified the state Personal Preference office. After a member of the state Personal Preference staff reminded the consumer that, as an employer, she was responsible for paying people who worked for her, she paid the daughter-in-law, thereby resolving the problem.

2. No Abuse of the Cash Allowance

No one we spoke with—representatives of the personal care industry, consultants, fiscal agent staff, or state Personal Preference staff—reported having seen evidence of material abuse of the cash allowance under Personal Preference. A few consumers asked to use the cash allowance for purchases not related to their independence, but such requests were denied.

D. MAJOR LESSONS

We draw three major lessons about preventing abuse and exploitation from the experience of Personal Preference.

1. Cases of Possible Exploitation of Consumers Can Be Eliminated Before Cash Payment

Unfortunately, elderly and disabled Americans are sometimes neglected and exploited. Therefore, it is not surprising that consultants suspected that a few PCA recipients entering Personal Preference were being so treated. The state Personal Preference office thoroughly investigated such cases before making a cash payment, and no cases of exploitation were reported after payments began. We conclude that consumers can be protected from the potential neglect and exploitation associated with a cash allowance program if staff are mindful of that possibility and attentive to cases where something seems amiss as they make their initial visits.

2. More Attention to Preventing Exploitation of Workers May Be Warranted

At the time of our visit, no cases of cash recipients being exploited by their workers, friends, or family had been identified, but one case in which a consumer exploited a worker had been. Personal Preference had no formal mechanism for workers to voice grievances about their employment situations. The one case reported suggests that such a mechanism might be useful, especially since consultants were trained not to interfere with the consumer-worker relationship.

3. Ensuring That Expenditures Are Authorized by a Cash Plan Prevents Abuse

From the Personal Preference experience, we draw the lesson that abuse of a cash allowance—even of a substantial amount—is preventable. At the time of our visit, Personal Preference had been operating for more than two years, and there had not been a single incident of cash allowance abuse. This was accomplished by developing a cash plan, taking care that it did not allow inappropriate goods and services, then following rigorous procedures to ensure payment for only those goods and services covered in the cash plan.

Review of receipts was not required and thus was not important in preventing abuse of the cash allowance in New Jersey. It might have been important if consumers had been managing the cash allowance themselves, but at the time of our visit all were using the fiscal agent.

IX. LESSONS FROM NEW JERSEY

New Jersey's experience with the Cash and Counseling model provides many valuable lessons. In this chapter, we first consider lessons related to the political and administrative feasibility of the Cash and Counseling model in New Jersey and examine whether Personal Preference was implemented as planned. Second, we present lessons about procedures, summarizing those drawn in previous chapters about particular components of Personal Preference, and we draw lessons that cut across components about the basic structure of the Cash and Counseling model as it was developed in New Jersey. Finally, we address the value of the Cash and Counseling model relative to a model of consumer-directed care offering only a cash allowance.

A. LESSONS ABOUT FEASIBILITY

New Jersey's primary goal in implementing the Cash and Counseling Demonstration was to test the feasibility of including a cash allowance model of consumer direction as a state plan Medicaid service and to investigate the main issues involved in implementing such a program.

New Jersey achieved this goal. Unopposed by the state's Nursing Practice Board and overcoming initial opposition of traditional agencies, the state implemented Personal Preference. It implemented the design largely as planned, discovered some problems with key parameters, and—learning from its experience—changed its procedures. New Jersey demonstrated that a cash program can work both administratively and politically in that state.

1. Nurse Practice Act Was Not a Barrier

New Jersey's Nurse Practice Act limits the medical tasks that a personal care aide can legally perform and requires that a nurse supervise aides. The state board responsible for nursing

practice did not feel that the activities of workers hired by consumers should be similarly limited or that consumers did not meet the requirements for supervision because they were not nurses. The director of Personal Preference presented the case for the Cash and Counseling model to officials of the board. Reportedly, because of the shortage of personal care aides in New Jersey, they viewed Personal Preference as a valuable addition that tapped a different labor supply.

2. Overcoming Opposition of Traditional Agencies

To implement Personal Preference, New Jersey overcame initial opposition from personal care agencies. Their cooperation was important, because without it New Jersey could not identify personal care recipients and the hours of care planned for them. Moreover, agency staff members could actively discourage Personal Care Assistance (PCA) recipients from participating in the demonstration. Although some personal care agency staff members did do this, agencies supplied care plan data as requested, and the industry was generally cooperative.

Several factors explain why New Jersey was able to overcome the initial opposition of personal care providers. First, as Case Example IX.1 indicates, the personal care industry respected the director of Personal Preference and the state program staff. Second, the industry saw the adoption of consumer-directed care as inevitable and, indeed, beneficial for some people with disabilities. Third, Personal Preference responded to industry concerns, especially by discouraging consumers from hiring agency employees as workers. The industry lost few staff members to Personal Preference consumers. Fourth, because a smaller percentage of PCA recipients participated in Personal Preference than initially anticipated, agencies did not lose a substantial amount of business.

Case Example IX.1: Industry Respect for Cash Program Director and Staff

The state has good people trying to make the program work fairly for everybody. The person chosen to head this up made a positive difference. He has experience with disability, is open, fair, has a history in personal care and community-based services, and knows what clients need. We knew we could trust him to be honest. He is the least bureaucratic of state people. He sincerely cares. If not for him, we would have hated the program more.

3. Implemented as Planned and Learning from Experience

Initially, Personal Preference was implemented as planned. As New Jersey learned from its experiences, it shifted the responsibility for certain tasks and revised detailed procedures. However, few of these changes involved the program's fundamental design.

Outreach and Enrollment. The design for Personal Preference called for New Jersey to enroll only PCA clients, and the state implemented and maintained this approach. Although Medicaid beneficiaries who were eligible for PCA could enter that service with the goal of subsequently enrolling in Personal Preference, New Jersey did not solicit their participation even when enrollment in Personal Preference was lagging. Nor did New Jersey solicit Personal Preference participation from beneficiaries participating in one or more of the state's home- and community-based waivers.

New Jersey did revise procedures for outreach to PCA clients. Initially, the state planned to focus on those who had recently been assessed (or reassessed). Mailings were to go out as consumer data forms were received following assessment. New Jersey departed from this design in that the timing of mailings was divorced from assessment. The state began sending mailings to all PCA clients who had not previously expressed any interest in Personal Preference. At the time of our visit, the state was considering sending them a letter from the governor, with the hope of giving enrollment a boost.

As the program learned from experience, the state also revised enrollment procedures. Attempting to increase the pace of enrollment, but with costs mounting, New Jersey and its first enrollment contractor repeatedly revised the detailed procedures for contacting those who had expressed interest in the cash program. Major changes included shifting from in-person to telephone presentations in selected cases and reorganizing work so that a given staff member handled a case through the entire enrollment process.

Despite these changes, New Jersey was dissatisfied with the work of its independent enrollment contractor and eventually hired state staff members as enrollment specialists. Because the number of in-house enrollment specialists was smaller than the number of contractor enrollment specialists, Personal Preference focused enrollment on the more populous areas of the state. However, the state continued to use many enrollment procedures that it and the enrollment contractor had developed at the start of the cash program.

Cash Allowance, Consulting, and Fiscal Services. The design for Personal Preference called for many consulting agencies, each serving a different area of the state. New Jersey kept this basic structure, but the number of consulting agencies was reduced dramatically (from 34 to 12 at the time of our visit) as some dropped out of the cash program and as New Jersey stopped referring consumers to agencies not performing satisfactorily. Moreover, New Jersey had planned to give consumers a choice of consulting agencies, but as consumers did not seem to value this choice, the state began assigning them to agencies. Moving from choice to assignment of consulting agencies was a fundamental change in the design of Personal Preference.

A legal dispute prolonged the contracting process for fiscal services. However, New Jersey selected a single fiscal agent to serve cash recipients throughout the state, as planned.

New Jersey did not change the fundamental payment structure for consulting and fiscal services. As planned, 10 percent of the cashed-out value of care plans was reserved to cover the

costs of consulting and the bulk of the costs of fiscal services. Schedules of fees were developed for fiscal services. The state paid for some fiscal services, and consumers were charged modest fees for fiscal services they used. The only material change in payment was increases in the rates at which consultants were paid. These increases were partly in response to agency concerns that the payment did not cover the costs agencies incurred in providing consulting services.

New Jersey followed the procedures it had designed for the development and revision of cash management plans. Consultants worked with consumers to develop cash management plans basically as planned. Minor revisions in detailed procedures were adopted over time, as the program learned from experience. Techniques were developed to reduce the need for formal revisions of care plans (for example, by writing more flexible plans) and to make formal revisions more efficient (for example, by putting cash plans onto electronic spreadsheets). As planned, the state Personal Preference staff reviewed all cash management plans.

The design for Personal Preference called for expenditures only in accordance with approved cash management plans. The fiscal agent successfully implemented this aspect of the design as planned, and this principle was never violated.

4. Avoiding Abuse and Exploitation

Critics of Personal Preference were concerned that vulnerable populations would be neglected or exploited or that the cash allowance would be abused. Proponents feared that even a single, widely publicized instance of abuse of the cash allowance or of neglect or exploitation of the consumer could make it politically impossible to adopt an ongoing cash program. As of the time of our visit, however, there had been no abuse of the allowance in New Jersey. State review of all cash management plans ensured that all included goods and services were allowable, and the fiscal agent employed rigorous checks to ensure that it only paid invoices that conformed to the cash plan. During their initial visits, consultants identified a few cases of

possible exploitation of consumers, which were referred to the state Personal Preference office for investigation and resolution. No neglect or exploitation of *cash recipients* was detected. Finally, one incident was reported in which a consumer appears to have exploited a worker (by withholding pay to a relative following a family dispute). None of the small number of incidents that occurred resulted in adverse publicity.

5. Achieving Budget Neutrality

Generating savings was *not* one of New Jersey's goals in implementing Personal Preference. However, a cash program that is appreciably more costly than traditional PCA would not be politically viable in that state. Moreover, the terms and conditions of the demonstration waivers required that Personal Preference be budget neutral (that is, cost no more per person per month than the traditional program). A definitive answer as to whether Personal Preference was no more costly to operate than the traditional program must await the impact analyses based on Medicaid claims. Here, we provide some information relevant to those analyses.

a. Cost of Personal Preference

As explained in Chapter II, New Jersey set aside 10 percent of the cashed-out value of every care plan (which averaged about \$1,300 a month at the time of our visit) to cover the cost of consulting and the bulk of the cost of fiscal services. Were these funds (together with those generated by modest user fees charged consumers) adequate to cover the costs incurred for consulting and fiscal services? In spring 2001, it seemed that fees that the fiscal agent earned from consumers and the state were adequate to cover the cost of fiscal services and that the 10 percent set-aside was adequate to fund consulting and fiscal services.

Early in the demonstration, the fiscal agent had serious cash flow problems. Although New Jersey had provided the fiscal agent with start-up funds, it used them for start-up capital costs,

primarily the purchase of equipment. The fiscal agent had projected that it could not cover its operational costs until the caseload reached 250. Caseload buildup was slow, and it reached 250 only about a year after the first cash allowance was paid. Moreover, some of the assumptions underlying the projection of 250 as an adequate caseload were overly optimistic. The average monthly cash allowance was slightly lower than assumed (the assumption was \$1,500 monthly), and the average number of workers hired per consumer was also slightly lower than assumed (1.3 instead of 1.5). To cover the initial cash flow problems, the host organization for the fiscal agent provided an internal loan.

Three important factors contributed to holding down the cost of Personal Preference in the demonstration. First, for assessing budget neutrality, two types of costs that would not be a part of an ongoing cash program were excluded. As New Jersey does not plan to have a separate enrollment effort in an ongoing program, the cost of enrollment in the demonstration was covered separately. (A grant from RWJF covered the salaries of the state enrollment staff.) Moreover, in an ongoing cash program, as in the demonstration, New Jersey plans to separate assessment from consulting. Assigning assessment to consultants could create a conflict of interest, because consultants might act as advocates for consumers and increase their care plan hours to raise the amount of their cash allowances. Under Personal Preference, New Jersey's Medicaid case management allowance covered the costs of reassessment visits for cash recipients. PCA agency nurses conducted reassessments for PCA recipients (including control group members), and those costs were included in the hourly rate the state paid for traditional PCA services.

The second factor holding down the cost was that New Jersey's payment structure limited the cost of consulting under Personal Preference. It paid a lump-sum fee to consultants to develop a cash management plan (initially \$53, raised to \$65 at the time of our visit) followed by

an hourly rate for consulting (initially \$18, raised to \$20). Even after this increase, the director of Personal Preference viewed these rates, especially the lump-sum fee for the cash management plan, as a bit low, and he was considering an additional increase when we visited.¹ New Jersey also held down the cost of consulting by setting a maximum number of hours (19) for which a consultant could be paid for a given consumer. At the time of our visit, New Jersey had no plans to increase the maximum number of hours.²

b. Need for a Discount Rate?

Since the amount of the cash allowance under Personal Preference is based on cashing out care plan hours, the cost of the cash allowance *relative* to the cost of traditional PCA care depends on the extent to which PCA recipients actually receive the care called for in their care plans. As indicated in Chapter II, while planning the demonstration, New Jersey found no appreciable difference between cost of hours of care planned and received for a sample of PCA recipients—that is, the ratio of the two costs was approximately one. Consequently, the state decided not to discount care plan hours before cashing them out.

From the site visit information, we cannot determine whether the *ratio* of cost of hours of care received to hours of care planned changed during the demonstration in such a way that discounting was needed to ensure budget neutrality. However, it is clear that, during the demonstration, hours of care planned and hours of care received were changing for the PCA population. Personal care industry representatives reported that the state had begun (1) to scrutinize beneficiary appropriateness for personal care more intensively, which resulted in denial of services to some long-time recipients; and (2) to reduce hours of care planned. These

¹Later, the lump-sum payment was raised to \$75 and the hourly rate to \$26.

²The maximum number of hours was later increased to 20.

industry representatives reported that hours of care received had fallen by almost 30 percent in the months before our visit, from 22 to 16 hours a week, on average. In addition, during the demonstration, changes in the labor supply may have affected hours of care received if agencies found it more difficult than before to staff all the hours of care that had been planned for their clients. With care planned and care received in flux, it is possible that the ratio of care planned and care received also changed so as to make a discount rate necessary.

B. LESSONS ABOUT PROCEDURES AND STRUCTURE

Some of the lessons learned from Personal Preference pertain to procedures for particular components of the program. Other lessons cut across components and pertain to its basic structure.

1. Component-Specific Lessons

a. Outreach and Enrollment

One lesson of Personal Preference is that “taking all comers” is workable. New Jersey’s experience suggests that consumers and representatives can screen themselves for appropriateness for a cash program, but it would be difficult (if not impossible) to develop a formal screening process to identify in advance consumers who are unable to manage the cash allowance, either by themselves or with the help of representatives.

Providing for language diversity is important in a cash program, because non-English-speaking consumers may be able to benefit greatly from hiring workers who know their language and are familiar with their culture. Yet mounting a successful outreach and enrollment effort in a diverse, multilingual state like New Jersey is clearly a challenge.

Personal Preference offers some lessons about techniques to meet that challenge. Enrollment specialists for Personal Preference spoke the languages most common in the state.

Many program materials were translated into the common languages, and a notice in 14 languages asked consumers to have a family member or friend translate materials in the accompanying package. Family members or friends also translated when enrollment specialists visited or telephoned. When no other translator was available, the specialists used the AT&T language line for telephone calls. Finally, information should also be available in multiple media, as well as in multiple languages, for those with vision and hearing impairments and those who are not competent readers in any language.

Another lesson of Personal Preference is the importance of including family members in enrollment home visits and of maintaining flexibility in scheduling these visits so that they can attend. In general, PCA recipients are more comfortable if family members are present and participate in the decision. Often, family members will be directly involved as workers or representatives. To accommodate the schedules of family members, home enrollment visits should be scheduled outside business hours upon request.

New Jersey's use of two approaches to organizing outreach and enrollment—external contracting and the hiring of internal state staff members—provides an opportunity to assess their advantages and disadvantages in a constant environment. A key advantage of external contracting was that services could be put in place quickly by amending a current state contract. In contrast, state employees were not on the job until many months after approval to hire them was sought (as the director of Personal Preference had expected). The key advantage of having state employees conduct outreach and enrollment was that the state Personal Preference staff had more control of enrollment procedures. Neither the external contractor nor state employees, however, could sustain a pace that met the evaluation target for enrollment. The basic organizational structure of outreach and enrollment in New Jersey does not seem to explain the failure to meet sample-size targets for the evaluation.

Revisions to procedures might have increased enrollment in Personal Preference (although we cannot be sure either of this or of the magnitude of any increase). New Jersey did not mail letters from the governor or other high-ranking officials to PCA recipients as part of its marketing campaign—a technique that Cash and Counseling programs in Arkansas (and later Florida) used with considerable success. In addition, for part of the demonstration intake period, outreach and enrollment was not provided across the entire state of New Jersey. However, the areas with the greatest concentrations of newly assessed PCA recipients were always covered, and the number of enrollees forgone was probably small.

New Jersey's experience in Personal Preference confirmed that the cash program was attractive to a sizable minority of PCA recipients. About 1,750 people had enrolled in the demonstration by the time enrollment was closed in New Jersey in June 2002. They represented about 14 percent of the number of PCA recipients in the year before the demonstration began (about 12,000). Just over half the 1,750 enrollees (53 percent) were elderly, which proves that a cash program is attractive to elderly consumers in New Jersey. However, relative to the size of the populations of elderly and nonelderly PCA recipients, elderly beneficiaries were less likely than nonelderly ones to enroll. The elderly enrollees represented just over 10 percent of the estimated number of elderly PCA recipients the year the demonstration began, while the nonelderly enrollees represented over 20 percent of the estimated number of nonelderly PCA recipients that year.

b. Consulting and Cash Management Planning

Planning is essential to making the initial consulting home visit as useful as possible. Consumers must begin to think about how they would like to spend the cash allowance, whom they would like to hire, and whether they want to name a representative to help them. It is important that potential representatives attend the initial consulting home visit and that potential

workers attend if they have been identified. Moreover, it is helpful for all family members involved in the care of the consumer to be present. With good planning, the need for multiple home visits can be minimized, thereby reducing costs and eliminating a source of delay in the receipt of the first cash payment.

Revisions to a cash management plan are often necessary, and they consume substantial staff resources. To reduce the number of circumstances in which a formal cash plan revision was required, Personal Preference wrote flexible cash plans that did not name workers or vendors. The program also developed useful techniques to streamline the revision of cash plans. One was entry of the original cash plan into an electronic spreadsheet. Another was using tickler files to remind the consultant to begin to plan for expected changes, such as a revision of the cash management plan when most of the funds needed for a planned purchase had been saved.

An important lesson learned from Personal Preference is that the time required for each step in cash planning adds up and can appreciably delay the receipt of the cash allowance. Personal Preference eliminated one step and reduced the time required for another, thereby reducing delay. It eliminated consumer choice of consulting agencies and reduced notice time to personal care agencies serving consumers who were about to begin to receive the cash allowance.

Communication problems can also extend the time to receipt of cash. (In Section 2.b below, we discuss the factors leading to communication problems in Personal Preference.) Lessons from Personal Preference about ways to improve communication include training of consumers about whom to call regarding what issues, exception reports from the fiscal agent indicating the nature of the error requiring resolution, and multiple-party telephone calls (for example, between the consultant, fiscal agent, and consumer) to reduce the need for several one-on-one calls.

c. Representatives

The representative selection process is an extension of the relationships that consumers already have in place and the assistance that they already receive. Thus, almost all representatives are family members or friends. Consumers who are already receiving assistance with their affairs generally were pleased to continue to have assistance. Representatives often were pleased to serve in that capacity to make it possible for the consumer to participate in the cash program.

The need for a representative depends on the familiarity of the consumer (and of the consumer's family) with the cash program, the availability of consumer training from consultants, and (rarely) the consumer's environment (for example, the availability of a talking computer and a scanner for a blind consumer)—as well as the consumer's level of disability.

The role of the representative varies. For those people who are completely unable to communicate their preferences, the representative obviously must be the sole decision maker. Typically, however, the consumer and representative both contribute to the management of the cash allowance, with the nature and extent of their contributions varying. Representatives may solicit consumer preferences, or consumers and representatives may function as a team. The consumer may even be the primary decision maker for the team, while the representative serves as the consumer's liaison with the outside world.

Perhaps the major lesson of Personal Preference with respect to representatives is that consultants judged that representatives were obtaining input from the consumers when possible and were faithful to the best interests of the consumers.

d. Consumers as Employers

A key lesson of Personal Preference is that consumers unanimously chose to use the fiscal agent. In doing so, they split the fiscal responsibilities of an employer between themselves and the fiscal agent. The consumer was responsible for timesheets, and the fiscal agent was responsible for the employer's other major fiscal tasks (including filing state and federal payroll tax returns and cutting paychecks).

Personal Preference teaches that consumers can satisfactorily fulfill the nonfiscal responsibilities of employers—recruiting (which proved the most difficult), hiring, training, supervising, and firing. Another lesson is that consultant training played a major role in this success.

The amount of consultant assistance that consumers needed varied considerably. The experience of Personal Preference is that even consumers who need a substantial amount of consultant assistance can learn in time to fulfill successfully the responsibilities of an employer, provided they can identify a worker to hire.

Recruiting was critical for those consumers who did not have family or friends whom they wished to hire as workers. The receipt of cash was inevitably delayed for consumers who had difficulty recruiting a worker. Program staff reported that consumers who could not recruit a worker tended to drop out of the cash program.

Personal Preference developed written materials to train consultants about recruiting, and the consultants shared materials with consumers. However, some consumers, particularly those without family or friends available to be workers, required more help with recruiting. Moreover, consultants were uncertain about how much assistance they were to provide consumers with recruiting, which suggests that both consultants and consumers would benefit from more consultant training on recruiting. In addition, New Jersey is developing a worker registry

(outside Personal Preference) to help such consumers. Finally, experience in New Jersey indicates that consumers who have difficulty recruiting workers might use agency services, at least until a worker can be identified, and that less costly agency services may be available. For example, one agency was willing to negotiate a special rate for a Personal Preference consumer.

Nearly all consumers submitted timesheets on schedule. Consultants trained consumers on how to fill out timesheets, and the fiscal agent reminded consumers to submit them on time.

e. Preventing Abuse of the Cash Allowance and Exploitation of Consumers

From the experience of Personal Preference, we draw the lesson that abuse of a cash allowance—even an allowance of a substantial amount—can be prevented. This can be done by careful development of a cash plan, followed by rigorous procedures to ensure payment for only those goods and services allowed under the plan. Review of receipts was not required under Personal Preference.

Another lesson is that cases of neglect or exploitation of consumers can be eliminated before cash payment is made. This can be done if program staff members keep the possibility of such cases in mind and look into any in which something seems amiss. No cases of possible neglect or exploitation were identified *after* consumers began to receive the cash payments.

More attention to preventing exploitation of workers may be warranted. One such case was reported to a consultant. Consultants were trained not to become involved in employer-worker relationships, and Personal Preference had no mechanism for workers to voice grievances about their employment situations.

2. How Should a Cash Program Be Structured?

The New Jersey experience provides two important lessons about structuring a Cash and Counseling program. These lessons pertain to (1) the number of consulting agencies, and (2) the effect of program structure on communication and on delay of receipt of the cash allowance.

a. Number of Consulting Agencies

New Jersey, mindful of the cultural diversity of its Medicaid PAS caseload, initially recruited 34 consulting agencies, to give consumers a choice. However, having a program with many agencies proved to be a problem. In some areas of the state, multiple agencies were never recruited. Other consulting agencies performed poorly, and Personal Preference dropped them from its roster. The program did not attempt to replace them, in part because it had learned that consumers in New Jersey did not consider having a choice of consulting agency important. Moreover, consumer choice of agency contributed to delays in the receipt of the first cash payment. By the time of our visit, 12 agencies were providing Personal Preference consulting, and the state was pleased with their performance in general.

We draw the lesson that having a large number of consultant agencies and allowing consumers their choice entails costs and may yield little or no gain.

As the number of consulting agencies increases, the average caseload size per agency falls (for a given statewide caseload). Some agencies will likely have caseloads that are too small to support efficient provision of consulting services. With small caseloads, consultants will learn from experience slowly, as they will seldom be assigned new cases. Moreover, they will grow “rusty,” since they will not constantly be performing consultant duties. When consultants leave agencies, their replacements will start at the bottom of the learning curve. Furthermore, the caseloads at some agencies will support only one consultant, and backup is necessary when the

consultant is not in the office. Moreover, providing peer support and supervision is more difficult with a lone consultant.

Having a large number of consulting agencies also consumes state staff resources. State program staff must recruit the consulting agencies and perhaps replace dropout agencies. As the number of agencies increases and the average agency caseload falls, the likelihood of an agency dropping out increases because it is more likely to view the cash program as a sideline. If a large number of consulting agencies is to be maintained, state staff must devote effort to recruiting replacement agencies. In addition, state staff resources are required to ensure the quality of consulting services. The more agencies, the more state effort required for quality assurance.

b. Effect of Program Structure on Communication and Delay in Receipt of Cash Allowance

Both state Personal Preference staff and consultants reported frequent communication problems among consumers (or representatives), consultants, state program staff, and fiscal agent staff. A consumer, consultant, member of the state program staff, or member of the fiscal agent staff might have a question or comment and direct it to any of the other parties. That is, there were 12 one-way communication pathways in the New Jersey cash program: (1) consumer to consultant, (2) consumer to state program staff, (3) consumer to fiscal staff, (4) consultant to state program staff, (5) consultant to fiscal staff, (6) state program staff to fiscal staff, (7) fiscal staff to state program staff, (8) fiscal staff to consultant, (9) fiscal staff to consumer, (10) state program staff to consultant, (11) state program staff to consumer, and (12) consultant to consumer. When the consumer had a representative, the number of one-way communication pathways increased to 20. With this number of communication pathways, it is not surprising that communication problems arose in Personal Preference and that these problems were sometimes serious enough to delay the receipt of the cash allowance.

An example is the completion of the cash management plan. Several people participated in the development and review of every cash management plan, including every revision. The consumer (perhaps with the help of a representative) and the consultant developed the plan. When the plan had been completed, it was sent to a member of the state Personal Preference staff to review the included goods and services. If the cash plan was approved, the Personal Preference office sent it to the fiscal agent, where the calculations were double-checked for accuracy before the consumer's cash account was established (or revised). If problems were identified in either state program office or fiscal agent review, the paperwork was returned to the consumer. If the consumer did not understand the problem and how to resolve it, he or she would have to contact the consultant or fiscal agent.

The best way to resolve communication problems and speed the receipt of the cash allowance may be to reduce the number of people involved day to day. Arkansas's experience suggests two approaches to reducing the number of people (see Phillips and Schneider 2002). The first is to combine consulting and many fiscal services in the same person.³ Under the Arkansas cash program, the same organization (in a geographic area) provides consulting and fiscal services, and the same *individuals* provide consulting and perform key fiscal tasks. The second approach is to limit the role of state staff in reviewing cash management plans. Arkansas state staff reviewed only those cash plans that called for items not on a list of allowable goods and services. Under the demonstration, New Jersey gained experience on which to base a list of allowable goods and services.

³Arkansas uses the term "counselor" instead of "consultant." For clarity, we retain the New Jersey terminology here.

C. VALUE OF COUNSELING AND FISCAL SERVICES

The Cash and Counseling model has a fundamental tenet that distinguishes it from other models of consumer direction: the provision of services to help consumers manage their cash allowances. Some critics of the Cash and Counseling model argue that an unfettered cash allowance would be preferable, because such an allowance is more consistent with the philosophy of consumer direction than a program that imposes restrictions on, and monitors, the uses of the cash allowance. States, however, must balance this argument with the concern that Medicaid funds might be misused, which could jeopardize political support for the program.

What can we learn from the New Jersey experience about the burden imposed by restrictions on the uses of cash and about the value of counseling and fiscal services to consumers?

Burden of Restrictions on Uses of Cash. The New Jersey experience suggests that most consumers who participated did not find the restrictions on the use of cash troublesome in their everyday lives. Personal Preference insisted that the allowance be used for purchases related to the consumer's need for personal assistance, and most consumers wanted to purchase "standard items." Nonetheless, New Jersey tried to foster creative uses of the allowance and interpreted the allowance broadly.

Value of Fiscal and Consulting Services. Clearly, consumers in Personal Preference valued the services of the fiscal agent. Although charged modest fees from the cash allowance for the use of fiscal services, all consumers chose to use the fiscal agent.

The value of consulting services is more difficult to assess than the value of fiscal services. Consumers varied greatly in the amount of advice and assistance they needed from consultants. A few consumers needed little or none. Many needed oral explanations of the program and its procedures, in addition to written materials. Still others needed a great deal of assistance as they developed a cash management plan and recruited workers—sometimes more than the 19 hours

annually for which consultants could be paid under Personal Preference. For nearly all consumers, consultant advice seems to have been a valuable service. Overall, consulting seems to have been valuable—perhaps essential—to the success of the cash program in New Jersey.

X. TOWARD AN ONGOING CASH PROGRAM IN NEW JERSEY

Based on its experience in the Cash and Counseling Demonstration, New Jersey was working at the time of our visit in spring 2001 to make many of the features of Personal Preference available under its Medicaid state plan. The state had already expanded the consumer-directed programs offered to Medicaid beneficiaries and was reviewing how cash allowance programs might respond to the need to provide care in the least restrictive setting possible. Later, New Jersey decided to seek another demonstration waiver under Section 1115.

A BROADER PERSONAL CARE ALLOWANCE

In spring 2001, New Jersey was seeking to expand its Medicaid state plan to add a consumer-directed form of Personal Care Assistance (PCA) as a permanent program. Under a broader personal assistance benefit, consumers could choose their own workers, but the program could not have all the features implemented under the demonstration waiver. Given its experience in the demonstration, New Jersey has no difficulty in giving up two features not currently possible without waivers: (1) having legally liable relatives hired as workers, and (2) direct payment of the cash to the consumer. Under federal Medicaid regulations, spouses of adults are legally liable for providing personal assistance and cannot be paid to provide that assistance (unless that regulation is waived). New Jersey is willing to forgo hiring spouses, because most of the consumers participating in the demonstration were not married. According to federal regulations, cash accumulated by consumers must be included in means tests for Medicaid eligibility and for other public programs (unless the relevant provisions are waived). New Jersey is willing to forgo direct payments in an ongoing program, because all consumers participating in the demonstration elected to use the fiscal agent. However, the state believes it is

important to allow consumers to have a small proportion of the allowance available for incidental expenses (such as taxi fare) and is interested in ways to accommodate that need.

The current Medicaid PCA regulations refer to “human assistance.”¹ New Jersey would like to see the definition of assistance expanded to include goods and services, authorized in a plan of care that would meet a consumer’s needs for personal assistance services. The state is particularly interested in being able to offer equipment, and to a lesser extent, home modifications, in a consumer-directed form of PCA under the state plan.

After our visit, CMS responded to New Jersey’s request for consideration of an expansion of the personal care benefit, indicating a need for study of the cost of covering equipment and, possibly, modifications. CMS was not prepared to expand the personal care benefit pending the results of such a study.

B. CONTINUATION OF PERSONAL PREFERENCE

In 2002, CMS made available the IndependencePlus templates for waiver applications from states interested in consumer-directed care. Using the IndependencePlus templates, New Jersey began to prepare to submit an application for a waiver under Section 1115 for an ongoing Personal Preference program.

As of early 2003, New Jersey was planning two major changes in the design of Personal Preference as part of its proposal for a new waiver program. First, the consultants would be allowed to approve cash management plans that contained only items on a prespecified list developed by the state based on its experience in the demonstration. Some of the items on the list would be conditional on the consumer’s disability. For example, blenders and food

¹Shortly after our visit to New Jersey, CMS indicated that a change in federal statutes probably was not required to broaden the definition for personal assistance. Rather, changes in regulations, including changes in the Medicaid Manual, would be sufficient.

processors would be listed only for consumers who had difficulty with eating. Thus, state-level approval of cash management plans would be required only for unusual requests. The second major change that New Jersey is planning is to combine all consulting and fiscal services in a single organization, gradually phasing out the work of the agencies that offer consulting alone. One of the state's principal reasons for combining consulting and fiscal services is to reduce the need for coordination and communication, thereby reducing time to the receipt of cash. Another is to increase consultant caseloads and thereby increase consultant efficiency.

C. EXTENDING CONSUMER DIRECTION TO OTHER POPULATIONS

New Jersey has long valued public programs that foster personal responsibility. Consumer-directed programs are consistent with that value. Before the Cash and Counseling Demonstration, New Jersey offered the Personal Assistance Services Program (PASP). As discussed in Chapter II, PASP is a state-funded program for adults with physical disabilities who are able to direct their own care and who are working, looking for work, or in school. PASP participants recruit, hire, supervise, and fire their own personal assistance workers.

The director of the Division of Medical Assistance and Health Services—the division of the New Jersey Department of Human Services that housed Personal Preference—felt that a cash allowance had wide applicability. Throughout the Cash and Counseling Demonstration, she promoted the cash model and advocated its adoption within other divisions of the department. For example, she asked the director of Personal Preference to make presentations to executives heading other divisions of the Department of Human Services.

The successful implementation of Personal Preference—particularly the high levels of consumer satisfaction with the program and the absence of abuse or exploitation—reinforced the validity of consumer-directed programs and contributed to the adoption of other cash allowance

programs in New Jersey. In spring 2001, two other divisions had already implemented cash programs. The Department of Health and Senior Services had initiated a consumer-directed waiver program for elderly beneficiaries—called Enhanced Community and Homecare Options (ECHO)—and the Division of Developmental Disabilities had initiated a self-determination project for beneficiaries it serves.

The director of Personal Preference had been working with the executives heading these other programs to identify state statutory and regulatory impediments to expansion of cash programs in New Jersey. For example, they determined that state legislation was required to permit New Jersey to adopt federal fair labor standards, including exemptions for live-in and companion services—thereby giving New Jersey consumers greater flexibility in setting hours and wages for employees hired under cash programs.

Finally, New Jersey’s interest in cash programs has been heightened as the state seeks to meet the mandate of the U.S. Supreme Court decision in *Olmstead v. L.C.*, which requires that states provide care for Medicaid beneficiaries in the least-restrictive setting reasonable. The state’s Olmstead Working Group examined how the cash model might be used in providing long-term care in the less-restrictive settings. After our visit, New Jersey applied for and received a “Systems Change” grant from CMS. A key aspect of this grant is to develop worker registries to assist consumers in recruiting workers.

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