



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

LESSONS FROM THE IMPLEMENTATION OF CASH AND COUNSELING IN ARKANSAS, FLORIDA, AND NEW JERSEY

June 2003

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This report was prepared under contract #HHS-100-95-0046 between the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging and Long-Term Care Policy and the University of Maryland. For additional information about this subject, you can visit the DALTCP home page at <http://aspe.hhs.gov/daltcp/home.shtml> or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: Pamela.Doty@hhs.gov.

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June 2003

Prepared for
Office of Disability, Aging, and Long-Term Care Policy
Office of the Assistant Secretary for Planning and Evaluation
U.S. Department of Health and Human Services
Contract #HHS-100-95-0046

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ACKNOWLEDGMENTS

Many people have contributed to this report. Special thanks are due to the members of the Cash and Counseling program staff in Arkansas, Florida, and New Jersey who cheerfully answered our seemingly endless questions. Among them, Deborah Ellis of Arkansas, Lou Comer of Florida, and Carolyn Selick of New Jersey particularly deserve mention.

We are also indebted to the others we interviewed during our visits to Arkansas, Florida, and New Jersey, including senior officials of each of these states, staff of the counseling and fiscal agencies, and representatives of agencies providing traditional personal care.

We would also like to thank Patricia Ciaccio and Walt Brower, who carefully edited the report, and Marjorie Mitchell, who skillfully produced it.

Finally, we are deeply grateful to the people of Arkansas, Florida, and New Jersey who participated in the Cash and Counseling Demonstration, in either the treatment or control group. Without their willingness to join in this endeavor, none of this would have been possible. We have learned much from them.

EXECUTIVE SUMMARY

About 1.2 million people receive disability-related supportive services at home through state Medicaid plans or home- and community-based waiver programs. Under state plans, services traditionally have been restricted to human assistance with personal care and homemaking provided by licensed agencies. Waiver programs have offered additional services, but coverage often has been limited, with a case manager deciding whether services were needed.

In contrast to these traditional service models, states are increasingly offering Medicaid beneficiaries and their families the opportunity to obtain supportive services from individual providers. This alternative is called “consumer-directed” care.

Cash and Counseling is an expanded model of consumer-directed supportive services. It provides a flexible monthly allowance (based on the consumer’s care plan or on claims history) that consumers can use to hire their choice of workers, including family members, and to purchase other goods and services. Cash and Counseling requires that consumers develop spending plans showing how they would use the allowance to meet their needs for supportive services. It also provides counseling and fiscal assistance to help consumers manage their allowance and their responsibilities as employers. Consumers who are unable or unwilling to manage their allowance and responsibilities themselves can 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 Cash and Counseling Demonstration was implemented in three states-- Arkansas, Florida, and New Jersey. Based on their experiences, this paper draws lessons on designing and implementing a Cash and Counseling program, to provide information useful to states thinking of adopting such a program.

Outreach and Enrollment. Cash and Counseling programs need the cooperation of agencies that provide traditional supportive services (for example, in obtaining information on care plans). However, outreach and enrollment through agencies that provide traditional home care services creates problems, since such agencies often are not supportive of a cash program.

Direct outreach, which targets eligible beneficiaries, works better than community education in generating enrollment. Family members of beneficiaries are often involved in the decision to participate, so outreach to them can also be useful. Easy-to-understand materials that address the language diversity of the Medicaid population are critical.

Home visits are a necessary part of the enrollment process, but advance preparation can reduce the need for repeat visits. Because family members and friends may serve as workers or representatives involved in the care of the beneficiary, they should be present at the home visit.

Allowing all interested, eligible beneficiaries to enroll is workable but might be costly. Considerable staff time could be required to obtain care plan information and calculate what the value of the allowance would be were the beneficiary to enroll. Enrollment cost per cash recipient will be high if all interested beneficiaries are allowed to enroll, but many of them drop out before receiving the allowance.

The Cash and Counseling model is attractive to substantial minorities of both elderly and nonelderly adults with physical disabilities, particularly the latter. It also appears attractive for children and adults with developmental disabilities.

Representatives. Many consumers need or want assistance with managing the allowance and name representatives, usually relatives already providing care, to help them. The role of the representative varies depending on the consumer's abilities, but consumers and representatives typically share decision making and management of services. Reportedly, nearly all representatives in the three Cash and Counseling programs served consumers' interests. Special forms of monitoring can limit conflict of interest when the same person serves as both a representative and a worker.

Spending Plans and Counseling. Consumer need for help in developing the spending plan does not indicate inappropriateness for a Cash and Counseling program.

Helping consumers develop spending plans can be time-consuming for counselors, and plans must be revised as consumer needs change. Advance preparation minimizes the number of counselor visits required for developing the initial spending plan; flexible plans reduce the need for revision; and software expedites paperwork, partly by minimizing errors in arithmetic.

Initially, counselors could be concerned that they will be held responsible for poor outcomes arising from consumer decisions (as case managers may be). States that initiate Cash and Counseling programs might want to emphasize that this is not the case.

Use of Allowance and Workers. Nearly all consumers use the allowance to hire workers, usually relatives or acquaintances. A Cash and Counseling program can improve access to care by tapping this labor supply.

Consumers who lack a relative or friend to hire often have difficulty recruiting a worker. States may wish to emphasize training counselors to assist such consumers with

recruiting or to develop referral mechanisms (such as registries or informal lists of potential workers).

Consumers will terminate the employment of relatives and friends whose work is unsatisfactory. However, they may need support from counselors, especially when firing a worker who lives in the same household.

The flexibility of the Cash and Counseling allowance permits consumers to meet their needs better through the purchase of goods and services not available in the traditional system. Two examples are companion services for consumers with Alzheimer's disease and security systems for consumers with autism.

Fiscal Services. If fiscal services are provided at little direct expense to consumers, nearly all will rely on the fiscal agent for check writing and payroll functions (such as preparing and submitting tax returns). States may wish to encourage or mandate use of the fiscal agent as a means of preventing abuse of the allowance. However, organizations that provide fiscal services might need assistance with cash flow until they reach a "break-even" caseload.

Fiscal agents could have difficulty responding to the consumer's needs--including the need for clear, timely financial statements--especially early in the cash program, when caseloads are small. To help prevent such difficulties, states must, when selecting a fiscal agent, define the responsibilities of the agent and assess the ability of that agent to meet them.

Because the monthly allowance is paid prospectively, consumers will sometimes receive payment for which they have become ineligible. Procedures can be established to minimize overpayments and facilitate recouping of overpayments. Through administrative error, consumers will occasionally overspend their allowance; they can be allowed to reimburse the program over time from future allowance payments.

Prevention of Exploitation and Abuse. Consumer exploitation was very rare in Cash and Counseling. Most cases of potential exploitation were identified at the time of the initial counselor home visit and referred to adult protective services or to the traditional program before an allowance was paid. Periodic telephone calls and visits are adequate to ensure that recipients of the allowance are not exploited as their situations change.

Abuse of the allowance was nearly nonexistent in the three Cash and Counseling programs. Two reviews are critical to its prevention: (1) review of spending plans to ensure they contain only permissible goods and services, and (2) checking time sheets and check requests against plans. The requirement that consumers retain receipts is not needed to prevent abuse of funds managed by the fiscal agent. Though review of receipts could help prevent abuse of cash held by the consumer (including cash for incidental

expenses), when the amounts involved are small (as is generally the case), such review may not be an effective use of counselor time.

Structure and Procedures for Counseling and Fiscal Services. Having multiple organizations that offer counseling and/or fiscal services could provide an alternative if one organization withdraws or performs unsatisfactorily. However, consumers do not necessarily value having a choice of counselors within a given area. If they are to do so, consumers must have information on which to base their choice.

Provision of counseling by agencies that provide traditional services is problematic, as such agencies may not be supportive of the program. However, case managers are more likely to support a cash program if they see that it benefits their clients, and may respond to demand from their clients that they provide counseling. States interested in implementing Cash and Counseling programs through traditional networks may need to devote considerable effort to securing the cooperation of these networks.

Full-time counselors appear to be more efficient than part-time ones, but the latter can function satisfactorily. When counselors are full-time, they master the complexities of an allowance program more quickly and are likely to develop their own techniques to assist consumers. However, a counselor can function satisfactorily only so long as his or her caseload is large enough to occupy a substantial portion of his or her time. Similarly, a counseling organization can function satisfactorily only so long as its caseload can keep one or two counselors busy part-time. However, such a situation is not ideal: counseling organizations in this situation struggle to supervise and support their counselors.

The time from enrollment to receipt of the allowance varies considerably; it can be reduced by developing mechanisms to help consumers identify workers (such as worker registries) and by efficient program structure and procedures.

One efficient structure combines counseling and fiscal services in one organization and makes counselors responsible for some fiscal tasks, thereby reducing the need for communication and coordination with respect to these tasks. An efficient approach to the review of spending plans entails (1) giving counselors full authority to approve plans that request only goods and services on a preapproved list, (2) requiring that counselors seek program office approval for items not on the list, and (3) conducting audits to ensure adherence to these procedures.

Program Costs. The costs of a Cash and Counseling program might be constrained in a number of ways. To limit the cost per recipient of the allowance, it might be necessary to “cash out” a care plan at a discount. (Discounting accounts for the fact that some of the services included in traditional care plans typically are not delivered, for example, because a client is hospitalized or an aide turns out to be a “no-show.”) To prevent increases in care

plan hours for cash recipients, reassessments may be assigned to independent parties rather than counselors, who might act as consumer advocates.

To avoid excessive counseling costs when the completion of the spending plan is delayed (possibly in addition to the cost of traditional services), the payment to counselors to assist with the plan can be limited, for example, by stipulating a fixed payment for that assistance. Costs for ongoing counseling can also be limited, for example, by capping counselor hours.

While improvement in access to care might be an important program goal under Cash and Counseling, overall costs could increase if access to care is improved, even if cost per month per recipient is constrained. Overall public costs could also increase if the availability of an allowance increases demand relative to that for traditional services.

Crosscutting Lessons. States can benefit from technical assistance in implementing a Cash and Counseling program. Assistance with fiscal issues could be the most important.

Cash and Counseling programs can be implemented successfully to serve populations with various disabilities and in various age groups. Moreover, other evidence shows that the great majority of consumers in each of the three Cash and Counseling programs were very well satisfied. While impact results are currently available only for Arkansas, disability-related health outcomes for treatment group members there were at least as good as those for control group members, and treatment group members were less likely to report unmet need and more likely to report satisfaction with their supportive services (Foster et al. 2003).

The states that have experienced Cash and Counseling firsthand have already decided that they want to make the program available permanently to all eligible Medicaid beneficiaries.

INTRODUCTION

About 1.2 million people receive disability-related supportive services in their homes through state Medicaid plans or home- and community-based waiver programs (LeBlanc et al. 2001; and Kitchener and Harrington 2001).¹ Under state plans, services traditionally have been restricted to human assistance with personal care and homemaking and must be provided by licensed agencies, which recruit, train, schedule, and supervise the aides or attendants. Under waiver programs, adult day care, assistive devices, home modifications, and other services can be offered in addition to in-home aide services. However, coverage of these additional services often has been limited, and a case manager decided whether services were needed.

In contrast to these traditional service models, states are increasingly offering Medicaid beneficiaries and their families the opportunity to obtain supportive services 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 both their human assistance and other covered supportive services.

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 goods and services (as states permit). Cash and Counseling requires that consumers develop spending plans showing how they would use the allowance to meet their needs for disability-related supportive services. It also provides counseling and fiscal assistance to help them manage their allowance and their responsibilities as employers. Consumers who are unable or unwilling to manage their allowance and responsibilities 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 Service, the Cash and Counseling Demonstration and Evaluation was

¹ Because some people receive services from more than one program, the total number of users may be overestimated.

implemented in three states--Arkansas, Florida, and New Jersey.² The Centers for Medicare & Medicaid Services (CMS) was responsible for the waivers of federal Medicaid regulations required for the demonstration.³ (The Cash and Counseling Demonstration operated under Section 1115 of the Medicaid regulations, which permit such waivers.)

Because their Medicaid programs and political environments differed considerably from each other, the demonstration states were not required to implement a standardized intervention. However, they had to adhere to basic Cash and Counseling tenets (summarized above). The states' resulting demonstration programs differed in their particulars, so each is being evaluated separately, by Mathematica Policy Research, Inc. (MPR). Nonetheless, the evaluation results for the three states will be compared to assess whether these state differences led to different program effects.

This paper is the first to consider the Cash and Counseling program in all three states. It draws lessons about the structure and policies of a Cash and Counseling program, to provide information useful to other states considering adopting such a program.

The paper draws on the experience of those responsible for the demonstration and evaluation at the Cash and Counseling National Program Office, ASPE, RWJF, CMS, the three participating states, and MPR.⁴ Evaluation staff visited each of the three Cash and Counseling programs about 18 months after each began to operate, and these visits provide an important source of data. Arkansas began enrolling beneficiaries in December 1998, New Jersey in November 1999, and Florida in June 2000.

² For 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), the program was originally referred to as the Cash and Counseling *Demonstrations*. However, 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 several "demonstrations."

³ At that time, CMS was called the Health Care Financing Administration (HCFA).

⁴ The staff of the National Program Office is at the University of Maryland and Boston College.

A. KEY FEATURES OF THE THREE DEMONSTRATION PROGRAMS

As they began their demonstrations, Arkansas, Florida, and New Jersey all wanted to test the Cash and Counseling model in their state environments. None expected to save public funds. Arkansas stressed increasing access to care more than the other states.

The demonstration programs of all three states shared key features, but their designs also differed in important ways. This section summarizes the main features of the three Cash and Counseling programs, focusing on features that affected their success and that are relevant to the lessons we draw about the implementation of the Cash and Counseling Demonstration.

1. Eligible Population, Enrollment, and Allowance

All three Cash and Counseling programs offered an allowance instead of Medicaid disability-related supportive services. Arkansas and New Jersey “cashed out” Medicaid state-plan personal care to elderly adults and nonelderly adults with physical disabilities.⁵ Florida cashed out Medicaid home- and community-based waiver services for elderly adults, nonelderly adults with physical disabilities, and children and adults with developmental disabilities.⁶ Outside of the waiver programs, Florida offered little personal care under Medicaid.⁷

Eligibility for each program was linked to Medicaid personal care or waiver services: Arkansas beneficiaries had only to be eligible for personal care, New Jersey beneficiaries had to have been assessed for personal care, and Florida beneficiaries had to be

⁵ Some adults in Arkansas and New Jersey had developmental disabilities, but these people cannot be differentiated from those with other disabilities.

⁶ In Florida, fewer than 50 nonelderly adults with physical disabilities enrolled. This small number appears to be primarily a result of idiosyncrasies in the organization of services. The unit responsible for nonelderly adults with physical disabilities was housed in the Department of Children and Families (which also housed the unit responsible for services to those with developmental disabilities), but it was to follow the procedures for the allowance program adopted by the Department of Elderly Affairs. The apparent result was that, during implementation of the allowance program, the unit responsible for nonelderly adults with physical disabilities was sometimes overlooked.

⁷ Florida offered personal care services as part of its Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program for children. Under federal regulations for EPSDT, states must provide regular, periodic examinations for eligible children and any necessary services prescribed pursuant to these examinations.

receiving waiver program services.⁸ Arkansas allowed those eligible for (but not receiving) Medicaid personal care to enroll, due in part to concern about access to care. None of the three programs screened eligible consumers for appropriateness; rather, consumers were allowed to enroll if they (and their representatives) felt that the Cash and Counseling program was appropriate.

The three programs differed in their initial approach to staffing outreach and enrollment. Arkansas hired nurses as state employees. The state chose nurses partly because it planned to have enrollment staff assess enrollees who were not already receiving Medicaid personal care and state regulations stipulated that only nurses could conduct such assessments. To staff outreach and enrollment, Florida initially used its existing networks of case managers (for elderly adults and nonelderly adults with physical disabilities) and of support coordinators (for adults and children with developmental disabilities). Later, Florida hired two teams of temporary state employees: one for elderly adults, one for children and adults with developmental disabilities. Large teams were required to cover the state: at the height of the enrollment effort, the team for elderly adults consisted of nine enrollment specialists and a team leader. New Jersey was concerned about the possibility of delay in hiring state employees, so it initially amended the contract of a firm already providing outreach and enrollment for another state program. Later, New Jersey hired state employees to staff outreach and enrollment, but when faced with turnover of those employees, the state again turned to an existing contractor.

The costs of hiring enrollment staff are substantial. Florida estimated that its cost of hiring temporary enrollment staff was about \$350,000. However, the Cash and Counseling programs did receive grant funds to help with the cost of hiring enrollment staff. All three Cash and Counseling programs allowed consumers to name representatives to help them manage the allowance (such as by completing paperwork and supervising workers) or to manage the allowance on their behalf. Minor children (in Florida) were, of course, required to have representatives--all of whom were a parent or guardian.

In Arkansas and New Jersey, the amount of the allowance was based on cashing out a consumer's care plan. In Florida, it was based either on a consumer's care plan or the consumer's Medicaid claims history.⁹ As enrollment ended, the amount of the average monthly allowance was about \$350 in Arkansas, \$975 for elderly adults and adults with physical disabilities in Florida, \$1,400 in New Jersey, and \$1,825 for children and adults with developmental disabilities in Florida. Several waivers of federal regulations were required to facilitate the payment of an allowance instead of delivery of services. Some

⁸ In New Jersey, a beneficiary had to be assessed for traditional personal assistance services to be eligible for the allowance program but was not required to have received any aide services.

⁹ The claims history was to be used if it was stable and consistent with the current care plan. In practice, the claims history was not used for those with developmental disabilities. Their care plans were being revised as the demonstration began in Florida following a substantial increase in state funding for the traditional program.

allowed various public programs (for example, supplemental security income and food stamps) to disregard the amount of the allowance when determining consumer income and assets. The Medicaid regulation requiring payment *after* services had been rendered was waived to permit prospective payment of the allowance--that is, payment for a given month in advance of receipt of services for that month.

The terms and conditions under which CMS approved the demonstration required that each program attain budget neutrality--that is, that the cost per recipient per month was no greater in the Cash and Counseling program than in the traditional program--by the end of the five-year demonstration. To help ensure budget neutrality, Arkansas and Florida discounted hours in care plans before valuing them at the rates paid to providers of traditional services. Florida also discounted goods (such as diapers) included in its care plans. Discounting adjusts for the fact that clients of traditional services receive fewer hours of care (or fewer goods and services) than planned for due, for example, to client hospitalization or to aide "no-shows." In Arkansas and Florida, comparison of samples of care plans and claims had shown that the cost of goods and services received was less than the cost of goods and services planned, on average. (In New Jersey, cost of care received differed little from cost of care planned, on average.)

The demonstration terms and conditions also required the programs to make sure that the offer of an allowance instead of agency services did not induce demand for Medicaid supportive services. Demonstration enrollment of those who were not yet recipients of Medicaid supportive services (new recipients) was to be suspended if the ratio of the number of new to continuing recipients in the allowance program exceeded the historical average ratio for the traditional program. In Arkansas, the demonstration ratio never exceeded the historical average ratio for traditional Medicaid personal care. The ratio requirement was easily met in New Jersey and Florida, where only those enrolled in personal care and waiver services programs were eligible for the Cash and Counseling programs. It is possible, however, that some beneficiaries in New Jersey enrolled in personal care services with the goal of moving to the allowance program as soon as they had been assessed for traditional services and a care plan developed. The number of such beneficiaries is probably small, since New Jersey limited direct outreach to those who had already been assessed for Medicaid personal care services. In addition, we cannot rule out the possibility that some Floridians enrolled in waiver services with the goal of moving to the allowance program.

Consumers in all three programs were required to develop a spending plan specifying the goods and services to be purchased with the allowance. Only goods and services related to the consumer's disability were permissible. Plans could include relatively small amounts--10 to 20 percent of the allowance, depending on the state--to be paid to the consumer in cash for incidental expenses (such as taxi fare) that were related to the consumer's disability but not readily purchased through an invoicing process. If they wanted to, consumers were allowed to hire relatives to care for them. A waiver of federal

regulations permitted consumers to hire legally liable relatives--that is, spouses of adults and parents of minor children. Florida and New Jersey exercised this waiver, but Arkansas did not, partly out of concern that it would be politically controversial there. Consumers who hired workers became their employer of record and were thus responsible for filing payroll taxes and other official documents.

To avoid possible conflict of interest, Arkansas and New Jersey did not allow the same individual to serve as both representative and worker. Florida did allow the same person to serve as both, partly because the state was mindful that parents typically both represent *and* care for their children.

2. Counseling and Fiscal Services

In all three Cash and Counseling programs, consumers were offered the assistance of counselors (called “consultants” in New Jersey and Florida) and of a fiscal agent (called a “bookkeeper” in Arkansas). Counselors interacted with consumers to (1) review initial and revised spending plans to ensure that they included only permissible goods and services, (2) help with employer functions, and (3) monitor consumer condition and the uses of the allowance. Florida and New Jersey required that state- or district-level staff review *all* spending plans. Arkansas required such review only if a plan contained an item that was not on a preapproved list of clearly permissible goods and services. Counselors in all three programs advised consumers about recruiting, hiring, training, supervising, and (if necessary) firing workers.

Counselors were required to telephone and visit consumers periodically to monitor their condition and their use of the allowance. While the frequency of required calls and visits varied across the three programs, counselors provided additional monitoring and problem-solving calls and visits as needed. In addition, Medicaid nurses in New Jersey monitored consumer condition when they visited them every six months to perform the reassessment that the state requires for all recipients of personal care services.

Consumers in all three programs were offered assistance with fiscal tasks, including the payroll functions of an employer (such as preparing and submitting payroll tax returns) and check writing. A consumer who demonstrated the ability to assume responsibility for these fiscal tasks was allowed to do so. Florida and New Jersey required that consumers pass a fiscal skills examination, while Arkansas program staff individually assessed the ability of each consumer who applied for responsibility for fiscal tasks. In both Arkansas and Florida, a small number of consumers assumed responsibility for all fiscal tasks. Despite an offer of free training, no consumer in New Jersey chose to take the skills examination; therefore, none assumed responsibility for all fiscal tasks.

To prevent abuse of the allowance, worker time sheets and check requests in all three programs were verified against spending plans before funds were disbursed. In Florida and New Jersey, the fiscal staff was responsible for this verification; in Arkansas, it was a counselor responsibility (with back-up review by the bookkeeper).

As part of monitoring the uses of the allowance, counselors in Arkansas and Florida checked receipts for expenditures under the allowance. (New Jersey did not require any receipts.) Arkansas required receipts for all purchases except for those for incidental expenses. Florida required receipts for incidental expenses and for all purchases made by the few consumers who assumed responsibility for fiscal tasks themselves. The fiscal agent conducted a “desk review” of the receipts and expenditures of the latter group of consumers. Florida counselors reviewed receipts for incidental expenditures of other consumers (however, some counselors reported that they did not do so routinely).

Counseling and fiscal services were structured and funded differently in the three programs. Following a competitive bidding process, Arkansas contracted with two human services organizations (one for-profit and one nonprofit) in different areas of the state.¹⁰ Each organization was to provide both counseling and fiscal services in the area it served. Agencies providing traditional personal care were allowed to bid for these contracts, provided they established a separate business unit to offer counseling services. In Arkansas, most counselors devoted full time to the Cash and Counseling program. Arkansas set aside one-third of the cashed-out value of each care plan to fund counseling and fiscal services.

New Jersey signed memoranda of agreement with a number of public, for-profit, and nonprofit human services organizations across the state to provide counseling. (Agencies providing traditional personal care were excluded.) Each organization served its local area, with some areas served by more than one organizations. Typically, one or two staff members devoted some time to counseling and some to other programs. Following a competitive bidding process, New Jersey contracted with a single human services organization to provide fiscal services statewide. New Jersey set aside 10 percent of the cashed-out value of each care plan to cover the cost of counseling and fiscal services.

Florida arranged for counseling to be provided by the existing networks of case managers (for elderly consumers) and agencies and independent contractors providing support coordination (for consumers with developmental disabilities). A single case management agency served elderly consumers who lived in a given region of the state. However, in many areas of Florida, consumers with developmental disabilities could choose among several support coordination agencies (typically, proprietary firms) and independent contractors offering support coordination. Counseling was funded through the existing Medicaid funding streams for case management and support coordination.

¹⁰ Arkansas contracted with three organizations, but one dropped out shortly thereafter.

(These services were not among the waiver services that had been cashed out.) Typically, the Cash and Counseling consumers at a given agency were assigned to one or two counselors, who also continued to provide case management or support coordination to other clients. Similarly, independent contractors provided both counseling and support coordination. Following a competitive bidding process, Florida contracted with another human services organization (which was located out of the state) to provide fiscal services statewide. Florida did not set aside funds for fiscal services before paying the allowance; the only source of funding for the Florida fiscal agent was a system of fees charged to consumers (see discussion below).

Finally, the payment methodology for counseling and fiscal services differed markedly across programs. Arkansas initially paid a monthly rate per enrollee for both counseling and fiscal services, with the rate falling every six months for two years. Later, Arkansas moved to a lump-sum payment for the development of the spending plan, followed by a fixed monthly rate per consumer. New Jersey paid counselors a lump-sum payment for the development of the spending plan, followed by hourly rates for counseling services rendered (with a cap on the total hours per consumer per year). New Jersey set up a schedule of fees for the fiscal agent, some of which the consumer paid (for example, 75 cents per check cut), and some of which the state paid (for example, \$90 to process the documents involved in hiring a worker). For consumers with developmental disabilities, Florida paid consultants the same monthly rate per enrollee that it paid to support coordinators. For elderly consumers, Florida paid counselors a separate, fixed payment for visits to develop the spending plan (with the number of such visits capped for each consumer), followed by hourly rates for counseling services rendered (with quarterly payments capped for each consumer). For fiscal services, Florida developed a schedule of consumer fees (for example, \$5 per check cut), with the total capped at \$25 per consumer per month.

B. LESSONS

Any demonstration affords an opportunity to learn from experience, including mistakes. In addition, the Cash and Counseling Demonstration allowed Arkansas, Florida, and New Jersey to learn and work together, with the assistance and guidance of the Cash and Counseling National Program Office. Many lessons were learned from implementing the Cash and Counseling Demonstration, often from the joint effort of the three states and the National Program Office. These lessons will influence the design of the future allowance programs of Arkansas, Florida, and New Jersey. The rest of this paper presents these lessons.

1. Lessons on Outreach and Enrollment

- a. A Cash and Counseling program needs the cooperation of agencies that provide traditional services. However, assigning them responsibility for outreach and enrollment can create many problems. To build a caseload quickly, hiring dedicated employees may be the best approach to staffing, although state hiring procedures may be a source of delay.**

The cooperation of traditional agencies is needed to implement a Cash and Counseling program. Agencies have their clients' trust, and without agency support, workers might discourage consumers from enrolling. In addition, information from agency care plans often is the basis for determining the amount of the allowance.

Outreach and enrollment were marked by troubled interaction between the three Cash and Counseling programs and agencies providing traditional services. Arkansas and New Jersey, concerned that agencies would not cooperate because of differing professional norms and fear of loss of revenue, designed their programs to limit the role of these agencies. Their concern proved valid, especially in Arkansas, where the industry lobbied the state legislature to withdraw the state from the demonstration. In New Jersey, industry representatives were generally cooperative. In both Arkansas and New Jersey, however, some aides tried to persuade Medicaid beneficiaries not to participate in the demonstration. Florida's initial approach of working through its existing networks for case management (for elderly beneficiaries) and support coordination (for children and adults with developmental disabilities) was unsuccessful. Case managers and support coordinators were pressed by other responsibilities and sometimes opposed to consumer direction, and few gave priority to the time-consuming tasks of outreach and enrollment.

To produce enrollment to meet the evaluation sample-size targets (as well as to build caseloads sufficient for viable programs), all three programs eventually relied on workers

whose time was dedicated to outreach and enrollment. Arkansas's dedicated state staff successfully conducted outreach and enrollment until the evaluation sample-size target was reached, after which the state shifted responsibility for outreach and enrollment to counselors and phased out the positions for state employees. After months of trying to work through traditional case management and support coordination agencies, Florida hired temporary state employees as dedicated enrollment staff; one group of employees enrolled elderly beneficiaries, another group those with developmental disabilities. As discussed in Lesson 1d, enrollment surged with their employment and direct mailings to Medicaid supportive services recipients. After the initial New Jersey contractor consistently failed to meet its monthly enrollment target, the state hired employees as dedicated outreach and enrollment staff, but only after a long delay. (Arkansas and Florida did not experience such long delays in hiring state employees.) Still later, faced with turnover of perhaps the most productive member of its state enrollment staff, New Jersey again turned to a contractor--this time, the organization that provided fiscal services under Cash and Counseling.

- b. Self-screening--allowing all interested to enroll--proved workable in Cash and Counseling. However, self-screening can be costly, particularly if a substantial proportion of enrollees drop out before receiving the allowance. States may want to design self-screening materials that stress the importance of recruiting a worker in an allowance program or develop program features to support recruiting.**

The Cash and Counseling programs wrestled with the question of how to identify consumers (and representatives) with the ability to assume the responsibilities of consumer-directed care. None adopted a formal screening process, as such a process is inconsistent with the philosophy of consumer direction. In addition, it may not be legally defensible, as no validated screening criteria are available. Rather, all three programs relied on self-screening--they explained the rights and responsibilities of consumers and representatives under Cash and Counseling, then allowed them to determine whether to enroll.

This self-screening process proved workable, but it can be costly. First, estimating the amount of the allowance for prospective participants requires staff time to obtain care plans from traditional agencies and then to compute the value of the program allowance, especially if many services are involved. Second, self-screening may be costly *per cash recipient* if many beneficiaries enroll only to discover that the program is not right for them and then disenroll after receiving some counselor assistance but before receiving an allowance.

States developing Cash and Counseling programs may want to design self-screening materials that emphasize the consumer's ability to identify a worker readily from

among family or friends--a factor critical to consumer success. A state with many beneficiaries who moved there after retirement may want to pay special attention to this issue. Florida believes that the large number of "snowbirds" among its elderly beneficiaries contributed to disenrollment from its allowance program. States also may want to build in program features, such as worker registries, that help in recruiting (see Lesson 4d).

Asking traditional agencies to identify candidates for Cash and Counseling is a poor alternative to self-screening. While agencies were willing to refer their "difficult" cases to all three programs, agency staff tended to believe that only a tiny fraction of consumers could direct their own care--a far smaller fraction than actually did so successfully in the demonstration.

c. Easy-to-understand materials are critical to successful outreach. A variety of media should be used, with materials in the languages of the eligible population.

It can be difficult for a consumer to understand the procedures of a Cash and Counseling program. The role and responsibilities of a participant in an allowance program differ substantially from those in a traditional program. Moreover, some Medicaid beneficiaries will have limited education. Consequently, Cash and Counseling programs need to explain their features through materials that are easy to understand, available in different languages, and produced in different media for those who are visually impaired or who have limited comprehension of written materials. Allowance programs also need to provide beneficiaries with an opportunity to have their questions answered.

All three programs used written, oral, and videotaped descriptions of program features. Written materials were often tailored to the reading level of the average Medicaid beneficiary. Some had question-and-answer formats, which Medicaid beneficiaries found easy to understand.

Dealing with language diversity was an issue in Florida and New Jersey. Both programs secured enrollment specialists who were fluent in Spanish, translated materials into common languages, and relied on consumers' relatives and friends to translate. New Jersey also developed a cover sheet in 14 languages spoken among its Medicaid population, asking the recipient to have someone translate the enclosed materials. If no other translator was available, New Jersey used a language-line service. This service was costly, but New Jersey found that it was often needed.

d. To generate enrollment, direct outreach through personal letters to Medicaid beneficiaries receiving supportive services works better than community education. However, community education can help to build support among providers.

All three Cash and Counseling programs found that direct, targeted outreach through mailings to Medicaid personal care or waiver recipients was more effective than community education in generating enrollment. In Arkansas and Florida, enrollment surged after recipients received a letter from the governor informing them of the new program.

Community education programs were most useful in generating enrollment when they could target the eligible population. Florida had some success with generating enrollment through presentations by program staff at meetings of parents of children with disabilities. In contrast, public service announcements in Arkansas early in the demonstration sparked interest among people who were not eligible, and responding to their inquiries burdened program staff. Community education programs also can help generate support for a Cash and Counseling program among providers. In New Jersey, community meetings were effectively used to recruit human services organizations to provide counseling.

- e. Home visits are usually necessary to explain the Cash and Counseling program. Involving family and friends, who are active in the beneficiary's care, minimizes the number of home visits required before enrollment and thus reduces cost. However, the presence of aides from traditional agencies should be avoided, as they may discourage participation.**

It is easier to explain the Cash and Counseling program, and to involve all interested parties, in a visit than by telephone. In a visit, everyone has an opportunity to ask questions. Of the three programs, only New Jersey tried enrollment by telephone, and it did this only for selected beneficiaries who were already very familiar with the allowance program and who preferred to proceed without a home enrollment visit.

Sending outreach staff to a beneficiary's home is costly. To minimize the number of visits (and hence the cost of enrollment), family members and friends who are active in caring for the beneficiary should be present for the home visit, even if the visit must be scheduled outside business hours. These family members and friends are likely to become representatives and workers. In addition, if multiple people are present during the visit, one of them can later explain issues that another did not understand.

Enrollment visits should be scheduled to avoid the presence of staff members from traditional agencies. They sometimes discouraged participation in all three Cash and Counseling programs. Their opposition resulted partly from misunderstanding of program features, commonly from ignorance of the program waiver providing that consumers did not incur tax liability for the allowance. (Consumers were liable for the employer's portion of payroll taxes for their workers.) States considering Cash and Counseling programs may want to explain key program features to agency staff and let them know that it is inappropriate for them to intervene in the participation decision.

- f. Family members often are involved in the decision to participate in an allowance program. States implementing a Cash and Counseling program may want to devote some outreach efforts to the families of eligible beneficiaries.**

Family members often are involved in the decision to participate in an allowance program. Sometimes, they make the decision on behalf of a beneficiary who is unable to do so him- or herself (for example, a young child or an adult with severe cognitive disabilities). Family members may also persuade a reluctant beneficiary to participate. They may have an important stake in the participation decision; for example, family members may have had to take time off from work to care for a relative when agency services were not provided as scheduled. States implementing a Cash and Counseling program may want to devote some outreach efforts to the families of eligible beneficiaries.

- g. The Cash and Counseling model is attractive to substantial minorities of elderly and nonelderly adult recipients of Medicaid supportive services, but it appears to be more attractive today to nonelderly adults than to elderly ones. The model appears attractive for both children and adults with developmental disabilities.**

As enrollment for the evaluation ended, *elderly* participants in each of the three Cash and Counseling states represented roughly 8 to 10 percent of the number of elderly Medicaid personal care or waiver service recipients in the year before the demonstration.¹¹ This is a substantial minority--larger than many would have predicted, but substantially less than the one-third or more of elderly recipients who expressed interest in consumer-directed care in state-specific surveys conducted before the demonstration (Mahoney et al. forthcoming).

The possibility of being randomly assigned to the evaluation's control group may have dampened participation in the demonstration relative to an ongoing program. CMS does not require random assignment for future allowance programs.

The number of *nonelderly* adults participating in the three demonstration states as enrollment for the evaluation ended was roughly 15 to 20 percent of the number of people eligible in the year before the demonstration. In Arkansas and New Jersey, participating nonelderly adults with physical disabilities represented about 15 and 20 percent (respectively) of the number of nonelderly adults who received Medicaid personal care that year. Assuming all the nonelderly adult participants in Florida had developmental

¹¹ This cross-state comparison of participation rates across programs is preliminary. It is subject to two major sources of error. First, the enrollment periods differed for the three programs. Second, the eligible populations may have been changing at different rates. Analysis of claims data will permit more accurate cross-program comparison of the percentage of the eligible population that enrolled.

disabilities (which is largely correct), they represented about 15 percent of the number of such adults who received, or were on the waiting list for, waiver services in the year before the demonstration.

The higher rates for nonelderly than for elderly adults in this preliminary examination suggest that the Cash and Counseling model is somewhat more attractive to nonelderly adults than to elderly ones. Tomorrow's elderly adults may find the mix of control and responsibility of the Cash and Counseling model more attractive than do today's elderly adults.

Florida's was the only Cash and Counseling program open to children, and it was an attractive alternative for this population. The number of children with developmental disabilities participating when enrollment ended for the evaluation was roughly 25 percent of the number in the year before the demonstration who received Medicaid waiver services or who received state-funded services and were eligible to move to waiver services. (The number of slots in the state-funded programs was being reduced in the year before the demonstration.)

2. Lessons About Representatives

- a. Many consumers name representatives to help them manage the allowance. Most representatives are related to the consumer and have provided care to the consumer.**

In all three Cash and Counseling programs, at least a substantial minority of adult consumers voluntarily named a representative to help them manage the allowance. Program staff sometimes *suggested* that a consumer name a representative, but they seldom *mandated* that one be named. In Arkansas and New Jersey, the percentage naming representatives was greater among elderly adults than among nonelderly ones. In Arkansas, for example, about a quarter of nonelderly adults with physical disabilities and slightly less than half of elderly adults named representatives. In Florida, nearly all adults with developmental disabilities named a representative. (Representatives were required for minor children.)

Nearly all representatives were already helping the consumer with activities such as personal care or banking. Most were relatives, usually close relatives, of the consumer.

- b. The role of the representative varies depending on the consumer’s abilities, but representatives and consumers typically share responsibility for decision making and management of services. Nearly all representatives serve the consumer’s interests.**

In all three Cash and Counseling programs, the role of the representative varied, depending on the consumers’ abilities. When consumers were not able to make decisions, representatives generally sought to learn and honor consumers’ preferences. Often, the consumer and representative shared decision making and management of care. After gaining experience with the Cash and Counseling program, consumers occasionally took over management of the allowance from their representatives. Counselors reported that nearly all representatives served well the interests of the consumers they were assisting.

- c. Special forms of monitoring can be used when a representative is also a worker, as this situation presents an inherent conflict of interest.**

Because representatives are responsible for supervising workers, allowing the same person to play both roles creates a conflict of interest. Of the three Cash and Counseling programs, only Florida allowed the same person to be both representative and worker, primarily to avoid precluding a parent from serving in both roles for their child. To monitor cases in which the same person was both, the state asked someone the consumer identified to check on the consumer’s well-being, and the counselor telephoned that person as well as the representative.

Florida also allowed one parent to be a worker and the other to be the representative. Although this situation could present an inherent conflict of interest, since the child’s parents would usually be husband and wife, Florida did not ask a third party to check on the consumer’s well-being in such cases. No instances of exploitation or abuse attributable to this situation were identified.

3. Lessons on Counseling and the Spending Plan

- a. States may want to emphasize to counselors that they will not be held responsible for poor outcomes arising from consumer decisions.**

The experience of the Cash and Counseling programs is that organizations providing counseling and counselors often need assurance that they will not be held responsible for poor consumer outcomes (as case managers may be). For example, counselors attending training sessions in New Jersey visibly relaxed when told they were not liable for the outcomes of consumer decisions, only for following established program procedures.

b. Working with a consumer on the initial spending plan can be time-consuming for counselors. However, a consumer's need for help in developing the initial spending plan does not indicate inappropriateness for Cash and Counseling.

Consumers and representatives generally do not have difficulty deciding what goods and services they would like to include in spending plans, but some need substantial help from counselors in developing initial plans. Some consumers need assistance to understand the program rules and documents that must be completed (including employment documents such as W-4 forms). For other consumers, the arithmetic necessary to compute the cost of the plan is a stumbling block.

Difficulty developing the spending plan does not in itself indicate that a consumer is not appropriate for Cash and Counseling. Even those who struggle in developing the plan can usually manage their own care day to day after the plan has been implemented.

c. Advance preparation can minimize the number of home visits required to help with the development of the spending plan.

The experience of the three Cash and Counseling programs is that advance preparation can reduce the counselor time needed to help with development of the initial spending plan, especially by reducing the need for multiple home visits. Ideas for advance preparation include (1) asking the consumer to consider whom to name as a representative or hire as a worker, (2) arranging for those people to be present during the initial visit, (3) having employment documents available during the initial visit so that the worker can begin to complete them, and (4) sending a program manual to the consumer before the initial visit. Although some consumers will mislay a program manual sent in advance, many consumers will begin to familiarize themselves with program rules. A manual also becomes an important consumer reference book.

d. Spending plans must be revised as consumer needs and plans change, and program staff must spend a great deal of time on these revisions. However, flexible plans can reduce the need for revision, and paperwork can be expedited.

Because the spending plan is critical to ensuring that the allowance is not abused, it must be revised to accommodate changes in consumer needs. As consumers and representatives gain experience with the program, they need less counselor help in revising spending plans. However, counselors, and perhaps other program staff, must review the revised plans, and fiscal staff may need to revise electronic files to conform to revised plans.

The need for revised plans can be reduced--while still guarding against abuses of the allowance--by writing spending plans that are more flexible. Techniques for doing this

include (1) listing the wage and hours for a position, rather than naming a specific person; (2) listing the maximum expenditure for a service, rather than naming a specific vendor; (3) requiring an addendum (instead of a formal revision) to change the item for which a consumer was saving (when the monthly amount saved was unchanged); and (4) earmarking a larger proportion of the allowance for incidental expenses to increase flexibility for small purchases. While Arkansas and New Jersey allowed a maximum of 10 percent of the plan paid to consumer in cash for incidental expenses, Florida routinely allowed 20 percent, and more if the circumstances justified it.

The revision of the spending plan can be expedited by allowing counselors to authorize minor revisions by telephone, with the revised plan formally completed by mail or during the next consultant visit. If counselors have access to computers, spreadsheet software expedites revisions. Even if computers are available only to state program and fiscal agent staff, the use of spreadsheet software can greatly reduce the time needed to check for arithmetic errors in spending plans.

4. Use of the Allowance and Workers

- a. Nearly all consumers receiving the allowance use it to hire workers. Nearly all workers are relatives or acquaintances of the consumer. Access to care can be improved by tapping this “labor supply” of family and friends.**

In each of the three Cash and Counseling programs, nearly all recipients of the allowance used it to hire workers. Nearly all consumers hired workers who were relatives or acquaintances. Few consumers hired agency aides. Some aides may have wanted to work more hours than one consumer could afford. Turnover of agency aides and dissatisfaction with agency services also may have been factors, as consumers are likely to offer employment only to aides with whom they have developed a satisfactory relationship. Only a small minority of consumers hired someone not previously known to them.

Especially in a full-employment economy, traditional agencies may struggle to hire enough aides to meet demand. Hiring family and friends taps a source of assistance usually unavailable to traditional agencies. These caregivers are motivated primarily by their relationship with the consumers, not by a desire for employment as aides. Analysis of interview data for Arkansas indicates that treatment group members were much more likely than control group members to receive paid care (Dale et al. 2002). This finding is consistent with tapping the “labor supply” of family and friends. Similar analyses are not complete for the other two programs, but program staff in Florida and New Jersey reported improvement in access to care.

b. Consumers who do not have a relative or friend to hire often have difficulty recruiting a worker. States may wish to emphasize training counselors to help such consumers with recruiting or to develop referral mechanisms to assist in recruiting.

In all three Cash and Counseling programs, consumers had difficulty hiring a worker if they did not have a relative or friend to hire. Counselors differed in the amount of advice about recruiting that they provided such consumers. Some left the task largely to the consumer, while others offered advice about recruiting techniques, such as canvassing neighbors and fellow church members in an ever-widening “circle of friends.” States considering Cash and Counseling programs may want to emphasize counselor training on recruiting.

Consumers who could not identify a worker almost always left the Cash and Counseling program, often without ever receiving the allowance. Two referral mechanisms may be helpful. The first is the development of lists of potential workers by counseling agencies. Arkansas counselors maintained a list of (1) workers employed by one consumer who were also willing to work for another consumer, and (2) workers who were willing to work for another consumer after the death of the relative or friend who had employed them. Similar lists were not developed in Florida and New Jersey, perhaps in part because counseling agencies in those two states had relatively small caseloads of Cash and Counseling consumers.

The second referral mechanism is a formal worker registry. None of the three programs operated a formal registry in conjunction with the Cash and Counseling program. Some consumers might not find a registry attractive anyway, since a worker hired through one would be unknown to them and to their family and friends. Nevertheless, New Jersey has received a separate grant that will seek to develop a registry for consumer-directed programs.

c. Consumers will terminate the employment of family members and friends whose work is unsatisfactory. Some need the support of counselors to do so, especially when firing members of the same household.

The ability of consumers to terminate the work of family members and friends whose work was unsatisfactory was a concern to the designers of the Cash and Counseling demonstrations. The experience of the three demonstration programs indicates that this concern was not warranted. Most consumers and representatives terminated the employment of family members or friends who were not satisfactory workers. The situation was often handled gently by taking the position that “This is not working out” or “You are a wonderful relative, but not the best personal care worker.”

Consumers and representatives sometimes needed counselor support in firing workers who were family members, especially when the worker lived in the same household. Generally, counselors offered advice to consumers on how to handle the situation. Occasionally, counselors trained consumers (for example, through role-playing exercises), but rarely were counselors present to support the consumer when a family member was fired. Because firing a family member can create a tense situation, states implementing a Cash and Counseling program may want to warn consumers about it when they first enroll in an allowance program.

d. The flexibility of the Cash and Counseling allowance can allow consumers to better meet their needs.

The flexibility of the allowance permitted consumers to purchase goods and services that met their needs better than traditional services did (see also Lesson 9b on reductions in unmet need). Consider two examples. First, a consumer in New Jersey with Alzheimer's disease who needed companion services (which are not covered in New Jersey) had a care plan that included only a small number of hours of personal care each week. The allowance based on cashing out that care plan was used to purchase companion services—the service that was really needed. Moreover, the number of hours of companion services purchased was larger than the number of hours of personal care in the care plan. Second, the parents of an autistic child in Florida were taking turns staying up at night to ensure that the child did not wander off. The allowance was used to purchase a security system (not traditionally covered), which made it possible for the parents to get a good night's sleep. The entire family benefited because the adults were no longer routinely deprived of sleep.

5. Lessons on Fiscal Services

a. If fiscal services are provided at little direct expense to consumers, nearly all consumers will choose to use the fiscal agent for payroll functions and check writing. States may wish to encourage or mandate use of the fiscal agent as a way to prevent abuse of the allowance.

Nearly all Cash and Counseling consumers and representatives chose to rely on the fiscal agent to pay bills and to process payroll tax returns and other payroll documents. Only a few chose to study the required tasks and demonstrate that they had mastered them, as was required if the consumer was to receive the full allowance in cash and manage it him- or herself.

It is possible that fewer consumers would use the fiscal agent if their direct costs of fiscal services were higher than in the three Cash and Counseling programs. Consumers in Arkansas were not charged direct fees for the fiscal services they used. Those in Florida were charged fees, but these were capped at \$25 a month. Fees in New Jersey were

modest (for example, 75 cents per check cut), especially relative to the amount of the average allowance (averaging \$1,400 per month as demonstration enrollment ended).

As described in Lesson 6b, reviewing invoices against spending plans was critical to the prevention of abuse of the allowance in the three Cash and Counseling programs. Since few consumers chose to receive the full allowance in cash, each of the three Cash and Counseling states plans to mandate that consumers use fiscal services in future allowance programs.¹² Other states interested in allowance programs may wish to encourage or mandate use of the fiscal agent.

- b. Since the monthly allowance is paid prospectively, consumers will sometimes receive payment for which they have become ineligible. Procedures can be established to minimize overpayments and facilitate recouping of overpayments. Because of administrative error, consumers will occasionally overspend their allowance; they can be allowed to reimburse the program over time from future allowance payments.**

In each of the three Cash and Counseling programs, some consumers received allowance payments that exceeded the amount they were entitled to. This happened when consumer circumstances changed during a month and the consumer was no longer eligible for the full amount of the monthly allowance that he or she had received earlier that month. Consumers lost eligibility, for example, because of out-of-state moves, loss of Medicaid eligibility, and nursing home placement. Some consumers died while enrolled. Overpayment of the allowance sometimes continued in ensuing months because the state program office was not informed promptly of a change in consumer circumstances or because disenrollment forms were not processed right away. In addition, consumers in Arkansas were not eligible for the allowance from the sixth day of a hospital stay until they returned to the community. Similarly, those in Florida were not eligible after the 30th day of a hospital stay. Such stays were identified after the fact from Medicaid claims files. Occasionally, delays in forms processing following reductions in care plan hours at reassessment led to overpayment. Finally, because of administrative error, a few consumers received the monthly allowance before final approval of their spending plans.

While the cumulative amount of overpayment could be substantial (for example, more than \$500,000 in New Jersey), recouping overpayments was straightforward when funds had not yet been drawn down by consumers. This was typically the situation when the consumer had died or was no longer eligible for the program. All three of the Cash and Counseling programs recouped funds held by the fiscal agent to which the consumer was not entitled. They required the fiscal agent to return the funds to the Medicaid program and processed adjustments to correct Medicaid claims files.

¹² There is interest, however, in allowing the small number of consumers who have been managing their allowances themselves to continue to do so.

Recouping funds that already had been drawn down by consumers was more complex. If an overpayment was due to the fiscal agent's error, the agent was sometimes required to reimburse the program. For example, Arkansas required a counseling/fiscal agent to make good on overpayments due to its failure to reduce the amount of the allowance promptly following reductions in care plan hours.

Consistent with the philosophy of consumer direction, however, consumers were generally held responsible for paying expenses associated with their employees, even if these expenses had not been properly anticipated in the spending plan and they had overspent their allowance. In these situations, consumers were allowed to reimburse the programs over time from future payments of the monthly allowance. For example, early in the demonstration, some Arkansas workers who did not meet the Internal Revenue Service criteria for independent contractors were nevertheless treated as such, and taxes were not withheld from their wages. When this error was identified and the taxes paid, the accounts of some consumers were overdrawn. These overdrafts were treated as if they were non-interest-bearing loans, which the consumers repaid over time from the monthly allowance. In some early Florida cases, the fiscal agent paid for more hours than provided for in spending plans, citing state law as requiring payment for all hours on approved worker time sheets. The consumers involved were required to repay the resulting overdrafts from future allowance payments, and the fiscal agent was required thereafter to contact the state program before making any payments that exceeded spending plans.

States implementing Cash and Counseling programs may want to establish procedures to minimize overpayment and overdrawn accounts. To minimize overpayment, states can encourage timely reporting of changes in consumer circumstances and timely processing of disenrollment forms and of revised care plans. States may also want to implement procedures for periodic recoupment of overpayments and to specify ownership of any interest on overpayments the fiscal agent holds. To minimize accounts overdrawn as a result of misunderstanding about regulations on worker status and payroll taxes, states could emphasize these regulations in training sessions for counselors and consumer handbooks. States may also wish to review state law on payment of approved time sheets and to stress to fiscal agents that they must never make payments that exceed spending plans without explicit program approval.

- c. Fiscal agents may have difficulty in producing understandable, timely financial statements for consumers. Before selecting a fiscal agent, states might want to assist in the production of financial statements or assess the ability to produce such statements.**

A number of months passed before the fiscal agents in Florida and New Jersey were able to supply consumers with monthly financial statements that were timely and easily understandable. Without such statements, consumers cannot readily monitor the payments made by the fiscal agent from their accounts and track their balances.

Experience suggests that consumers value a statement that clearly lists the amount and payee of each check cleared during a specified period, as well as beginning and ending balances.

Some of the difficulty that fiscal agents experienced in producing such statements arose because the names of workers were not on the database containing information on consumer account balances. States implementing Cash and Counseling programs may want to consider mandating a specific format for statements (consumer input may be useful in developing a format), providing technical assistance on developing financial statements, or reviewing prototype statements before awarding a contract to the fiscal agent.

States may also want to train consumers on the use of the financial statements. Some New Jersey consumers did not understand the need to adjust the ending balance to account for invoices that they had submitted to the fiscal agent but that had not cleared as of the closing date and therefore did not appear on the statement. New Jersey encouraged consumers to call the fiscal agent if in doubt about their current account balance. States implementing Cash and Counseling programs may want to consider automating responses to consumer queries about their balances.

d. Organizations that offer fiscal services may have difficulty responding to the needs of consumers, especially when caseloads are small. To help prevent such difficulties, states should clearly delineate the responsibilities of the fiscal agent before selecting one.

The three Cash and Counseling programs experienced few problems with inaccurate fiscal services (such as issuing checks for erroneous amounts). However, achieving good consumer service initially proved difficult in New Jersey and Florida. Although both states had deliberately selected human services organizations with the goal of ensuring that the fiscal agent was sensitive to consumer needs, consumers in both reported non-responsiveness and rudeness. Eventually, consumer service improved in those states following clarification of the responsibilities of the fiscal agent and changes in senior personnel within the fiscal agent.¹³

In contrast, the quality of consumer service was never a serious issue in Arkansas. The difference may be attributable partly to the fact that Arkansas combined counseling and fiscal services, while the other two programs did not. Counselors in Arkansas knew consumers well, which may have enabled them to address fiscal issues with particular sensitivity. In addition, the initial consumer service problems in New Jersey and Florida may have been exacerbated by the inability to realize economies of scale when caseloads

¹³ These states are now satisfied with the services provided by their fiscal agents.

were small. Economies of scale were critical in Florida, where the payment per consumer was capped at \$25 a month.¹⁴ Combining counseling and fiscal services may have given Arkansas program managers more flexibility, which allowed them to operate efficiently with a small caseload.

e. Organizations that provide fiscal services may need assistance with cash flow until they reach a “break-even” caseload.

Organizations that provide fiscal services are generally unable to cover their operating costs when caseloads are low. States need to consider how to assist with agency cash flow in the early months of operation of a Cash and Counseling program. Both New Jersey and Florida provided their fiscal agents with some start-up funds. States may also want to consider devoting more resources to outreach and enrollment until break-even caseload is reached.

In each of the three Cash and Counseling programs, the organization responsible for fiscal services did not cover its costs in early months. For these organizations, break-even caseload varied from roughly 200 to 1,000 consumers receiving the allowance (with the number dependent on the amount and method of payment). The experience of the Cash and Counseling programs is that building a caseload of 200 cash recipients would take six months or more, depending on the success of outreach and enrollment and the speed with which consumers are able to complete their spending plans and move to the allowance.

6. Lessons on Preventing Exploitation of Consumers and Abuse of the Allowance

a. Consumer exploitation was *extremely* rare in Cash and Counseling. Of the very small number of cases of *potential* exploitation, some were identified at the time of the initial counselor home visit and resolved before an allowance was paid. Periodic telephone calls and visits are adequate to ensure that recipients of the allowance are not exploited as their situations change.

In all three Cash and Counseling programs, counselors were alert to the possibility that people occasionally might attempt to enroll their relatives in Cash and Counseling to obtain the allowance for their own use. A few questionable situations were identified through the initial home visit. Counselors referred such cases of potential exploitation to state program staff for investigation. Before the first allowance was paid, some of these cases were referred to adult protective services (or a similar program) or to the traditional

¹⁴ As the Cash and Counseling Demonstration ended, the “going rate” for fiscal services was reportedly \$60 or more per consumer per month.

program. To ensure prompt action in such situations, Florida developed formal referral arrangements with adult protective services.

Instances of exploitation of consumers who were already receiving the allowance were rare in the three Cash and Counseling programs. Those that did occur were resolved, for example, by mandating a change in representative or requiring that the consumer return to traditional services.

All three Cash and Counseling programs required that counselors periodically telephone and visit consumers. Arkansas initially required monthly telephone calls and quarterly visits. With experience, the state adopted a more individualized approach; thereafter, some consumers were visited more often than quarterly, but most were telephoned monthly and visited semiannually (for many consumers, semiannual visits were required for reassessment). New Jersey required monthly telephone calls for the first six months following a consumer's enrollment and quarterly visits. Florida required monthly telephone contact and a visit two months after enrollment and annually thereafter, but some Florida staff reported that visits were needed more frequently.

Information or impressions gleaned in a telephone contact can signal the need for a discretionary visit by a counselor to investigate an unsatisfactory situation. Arkansas counselors, who routinely contacted both the representative and consumer, reported that telephone monitoring was more useful for identifying unsatisfactory situations when both were contacted.

b. Abuse of the allowance was almost nonexistent in the three Cash and Counseling programs. Checks of spending plans and review of timesheets and check requests were critical to the prevention of such abuse.

Abuse of the allowance was almost nonexistent in the three Cash and Counseling programs. Two procedures were critical. First, review of the spending plan ensured that only permissible goods and services were included. Second, to ensure that time sheets and check requests were consistent with the spending plan, the counselors (Arkansas) or the fiscal agent (Florida and New Jersey) examined them before approving them.

c. With checks of spending plans and review of time sheets and check requests, review of receipts is not critical to preventing abuse of funds managed by the fiscal agent. Review of receipts may help to prevent abuse of cash held by the consumer, including cash for incidental expenses. However, when the amounts of cash involved are small, review of receipts may not be an effective use of counselor time.

The three Cash and Counseling programs differed with respect to review of consumer receipts.¹⁵ As described in Section A.2, Arkansas required that consumers maintain receipts for expenditures other than those for incidental expenses, and counselors reviewed these receipts, typically during visits with consumers. New Jersey required no receipts. Florida required review of receipts for funds held by the consumer--usually funds for incidental expenses. However, some counselors reported that they did not routinely review receipts for incidental expenses. The fact that abuse of the allowance was almost nonexistent in each of these three programs--despite the differences in review of receipts--indicates that such review is not critical to preventing abuse of funds managed by the fiscal agent.

The requirement that consumers document incidental expenses with receipts may help to prevent the expenditure of small amounts of cash for the purchase of impermissible goods and services. In Florida (where receipts were not always reviewed), a few instances of such purchases were reported. However, states may want to consider whether reviewing receipts for cash for incidental expenses is an effective use of counselor time when the amounts involved are generally small. It was for this reason that New Jersey decided not to review receipts for incidental expenses.

7. Lessons on Structure and Procedures for Counseling and Fiscal Services

a. Having multiple organizations offering counseling and/or fiscal services may provide an alternative if one withdraws or performs unsatisfactorily.

Arkansas originally contracted with three organizations to provide both counseling and fiscal services. Each organization served a different area of the state. When one organization dropped out, Arkansas was able to transition its consumers to one of the other agencies with relative ease. In addition, New Jersey discontinued referrals to counseling agencies that were not performing satisfactorily.

b. Using agencies that provide traditional services also to provide counseling services can create problems. However, support among traditional case managers could improve if they observe the value of an allowance program to some beneficiaries. Moreover, a traditional system that offers a choice of counselors can be responsive to consumer demand.

¹⁵ Since very few consumers managed the allowance without the assistance of the fiscal agent, the Cash and Counseling Demonstration offers little experience on the importance of the review of receipts in such cases.

Florida is the only one of the three Cash and Counseling states with substantial experience with providing counseling services through agencies that also provided traditional supportive services. As described above, Florida arranged (1) for agencies that provide case management and waiver services also to provide counseling to elderly adults, and (2) for agencies and independent contractors that provide support coordination also to provide counseling to children and adults with developmental disabilities.

Traditional case management was provided by “lead agencies” under contract to the local Area Agencies on Aging. The lead agencies typically operated under public auspices (such as a county department of social services) and were responsible for all case management in the area they served. They also were responsible for subcontracting for, or directly providing, Medicaid waiver services for the elderly population. Many lead agencies and case managers were not supportive of Cash and Counseling, and elderly case management clients did not tend to come forward requesting enrollment in the allowance program. However, some Florida case managers were so impressed with the value of the allowance program for the elderly consumers who had enrolled that they became champions of the allowance program. One took a leave of absence from her case management position to supervise outreach to and enrollment of elderly beneficiaries across the state. States interested in implementing Cash and Counseling programs through existing traditional networks may need to devote considerable effort to securing the cooperation of these networks.

In Florida, proprietary firms and independent contractors provided traditional support coordination to children and adults with development disabilities. Many areas of the state were served by multiple support coordinators, who competed with one another to serve beneficiaries living in a given area. Beneficiaries were free to change support coordinators at any time. After a slow start, support coordinators appear to have become more supportive than case managers of Cash and Counseling. This support appears to have been attributable in part to responsiveness to beneficiary demand. In response to Florida’s targeted outreach efforts, parents began to enroll their children in Cash and Counseling and request counseling from their support coordinators, many of whom responded to the requests of their clientele.

c. To make an intelligent choice among counselors, consumers must have useful information.

As described in Lesson 7b, having a choice of support coordinators seems central to the responsiveness of the existing system in Florida to the demands of consumers. However, New Jersey’s experience was quite different. New Jersey initially offered consumers a choice of counselors, but discontinued that practice after finding that it sometimes delayed the start of the allowance and that consumers did not seem to value having this choice.

The difference in the experience of the two states suggests the importance of information to making an intelligent choice. Florida support coordinators mailed brochures explaining the services they offered to potential clients who were new to the system. Moreover, the information “grapevine” in Florida was quite active among parents of children with developmental disabilities. In contrast, New Jersey consumers had little information or experience on which to base an initial choice of counselors. With more experience, New Jersey consumers might value the ability to change counselors, especially those consumers whose initial experience with a counselor was not favorable.

- d. At a minimum, a counselor needs to have a sufficient caseload to occupy a substantial portion of his or her time. However, having full-time counselors appears to be more efficient. Having one or two counselors per organization is workable but not ideal.**

Comparison of the experiences of counselors in Florida and New Jersey to those of counselors in Arkansas suggests that several problems arise when counselors have very low caseloads. In New Jersey and Florida, counselors worked part-time with Cash and Counseling consumers and tended to have small counseling caseloads, while most counselors in Arkansas were full-time and had substantial caseloads. When caseloads were very small and counselors were part-time, new counselors were slow to learn program philosophy and rules, and they tended to forget what they had learned between new cases. In addition, when counselors have work responsibilities outside the program, Cash and Counseling consumers may get pushed to the “back burner,” especially since assisting consumers to develop a spending plan is often very time-consuming. Experience in Florida and New Jersey suggests that, at a minimum, counselors need to have a Cash and Counseling caseload large enough to occupy a substantial portion of their time (say, a third). Counselors are able to juggle the responsibilities under multiple programs, provided that the total demand on their time is reasonable.

Nevertheless, having dedicated full-time counselors working in organizations with larger counseling caseloads appears to be more efficient than having part-time counselors with smaller counseling caseloads and other work responsibilities. Largely to improve efficiency, New Jersey plans to gradually phase out part-time counseling in its future allowance program, opting instead to contract with a single organization to provide counseling across the state. Moreover, organizations with larger counseling caseloads may be in a better position to build in additional program features such as worker referral lists or registries (see Lesson 4b).

The experience of Florida and New Jersey indicates that it is workable (albeit not ideal) for an organization to have only one or two members of its staff working as counselors. A minimum of two counselors is preferable, as they can back up and support each other. Supervision is likely to be problematic with only one or two counselors per organization, because the supervisor may not be thoroughly familiar with the procedures of

the allowance program. Also, when counseling is provided by one or two of the staff of the organizations that also provide traditional services, some beneficiaries will not be able to retain the person who had been their case manager (or support coordinator) as their counselor. That was the case in Florida; however, few consumers refused to participate in the Cash and Counseling program on this account.

e. The time between enrollment and receipt of the allowance can be quite long. Some of the factors delaying receipt of the allowance can be addressed by developing mechanisms to identify workers and by streamlining program structure and procedures.

In all three Cash and Counseling programs, the time from enrollment to receipt of the first allowance ranged from less than a month to nine months or more. About 15 percent of treatment group members in Arkansas had not yet begun to receive the allowance nine months after enrollment (Schore and Phillips 2002). Preliminary data suggest that substantial percentages of treatment group members in the other two Cash and Counseling states also were not receiving an allowance nine months after enrollment.¹⁶ Consumers who experienced long delays in receipt of the allowance tended to disenroll. Common reasons for long delays in receipt of the first allowance included changes in life circumstances (such as illness), difficulty identifying a worker (see Lesson 4b), and problems with program procedures (considered here).

A list of the steps between enrollment in Cash and Counseling and receipt of the allowance is useful in understanding sources of delay due to program procedures:

1. Consumer (and often his or her relatives) reviews program rules and considers what goods and services to include in the plan, whether to name a representative (and if so whom), and whom to hire as a worker (if anyone).
2. Counselor visits the consumer (and, if possible, relatives and friends involved in the consumer's care) to answer questions or re-explain the program, as needed.
3. Consumer/representative and counselor prepare and sign a formal spending plan.
4. Assuming workers are to be hired, employment papers are completed and sent to the fiscal agent for review.
5. Counselor submits spending plan to state office (or other office, for example, a district office) for review and approval.

¹⁶ Data for early cohorts indicate that 25 percent of Florida treatment group members and 35 percent of New Jersey treatment group members were not receiving an allowance nine months after enrollment (see Foster et al. 2002; and Memorandum Describing Responses for an Early Cohort of Florida Treatment Group Members, April 17, 2002).

6. Any errors in the spending plan identified in state office review are resolved, requiring the interaction of the consumer/representative, counselor, and state office.
7. Approved plan is sent to fiscal agent, which initiates the consumer's account. Any remaining errors (for example, in arithmetic) are resolved, possibly requiring the interaction of the consumer/representative, counselor, fiscal agent, and state office.
8. Any errors in the employment papers identified in fiscal agent review are resolved, requiring the interaction of the consumer/representative, worker, fiscal agent, and possibly the counselor.
9. If the consumer is receiving traditional services, the agency is notified of the date on which it is to terminate service.
10. State Medicaid system is notified to initiate allowance and block further payment for traditional services.

Some program designs are more effective than others in reducing delay to receipt of the allowance. If counselors have reasonable Cash and Counseling caseloads, they are less likely to “back burner” the home visit to consumers (step 2), as sometimes happened in Florida. Eliminating the requirement (as in Arkansas) for multiple levels of review for all spending plans eliminates steps 5 and 6 for routine cases (see also Lesson 7f). Vesting responsibility for counseling and fiscal services in one organization and giving the counselor responsibility for some fiscal activities (as Arkansas did) reduces the number of actors whose actions must be coordinated and facilitates communication, thereby limiting the likelihood of delay in steps 6, 7, and 8 (see also Lesson 7g). In addition, procedures can be streamlined, for example, by “shaving” the notice time for traditional agencies (reduced in New Jersey from 30 to 14 days).

States implementing Cash and Counseling programs should monitor elapsed time from enrollment for those not yet receiving an allowance (as all three Cash and Counseling programs did). If lags prove long, programs can streamline their procedures (as described above) or offer assistance directly to consumers (as Florida did in letters to those not on the allowance by 90 days after enrollment).

- f. **Review of spending plans is critical to preventing abuse of the allowance, but it can be costly. An efficient approach is to give counselors full authority to approve goods and services on a preapproved list, refer requests for unlisted goods and services to the program office, and audit to ensure that these procedures are followed.**

In all three Cash and Counseling programs, some consumers asked to spend the allowance on goods and services that were not permissible. Thus, review and approval of spending plans is a critical step in preventing abuse of the allowance (see also Lesson 6b).

The review process differed in the three programs. In New Jersey and Florida, all spending plans were reviewed by a state- or district-level program office, which was costly and sometimes caused delays in plan approval. For example, some district offices in Florida reviewed spending plans promptly, and others did not. In contrast, Arkansas required state-level approval only for goods and services not on a preapproved list, and delay in plan approval was not a serious issue. However, an audit many months after the demonstration began uncovered instances of counselor failure to seek approval for unlisted items. As the failure was partly a result of staff turnover, Arkansas retrained counseling staff.

g. Counselors are responsible for tasks with important fiscal elements. An efficient program structure is to combine counseling and fiscal services in the same organization and make counselors responsible for some fiscal tasks.

Counselors are responsible for key tasks with important fiscal elements, including advising consumers on spending plans, reviewing those plans, and monitoring uses of the allowance. In carrying out these responsibilities, a counselor learns much about the fiscal affairs of a consumer. Armed with this knowledge, a counselor is more efficient at carrying out some fiscal tasks than someone who is responsible primarily for accounting tasks rather than interaction with consumers. For example, counselors may be more efficient at checking time sheets against spending plans and contacting consumers when there is a discrepancy to learn if a revised plan might be required. However, other fiscal tasks (such as those related to payroll tax documents) require specialized expertise and are better assigned to others.

Furthermore, if members of the counseling and fiscal staff are employed by different organizations, communication and coordination are likely to be more difficult than if they are employed by the same organization. Questions will sometimes be addressed to the “wrong” organization, and there may be a tendency to “pass the buck” between them. To minimize such problems, the roles of counselors and fiscal staff need to be clearly understood by all parties, including consumers.

A fundamental solution is to combine counseling and fiscal services in the same organization. Both programs that separated counseling and fiscal services (Florida and New Jersey) experienced serious problems with communication and coordination. In contrast, few such problems occurred in Arkansas, where counseling and fiscal services

were combined in the same organization and where counselors were responsible for some fiscal tasks.

The experience of the three Cash and Counseling programs suggests no critical offsetting advantages to separating counseling and fiscal services. Having a separate fiscal agent does not appear to provide a double-check that the goods and services in the spending plan are permissible. In both Florida and New Jersey, fiscal staff accepted the spending plan as given. New Jersey plans to drop the requirement of a “firewall” between counseling and fiscal tasks in its future allowance program.

Enhanced ability to attract an organization with fiscal expertise is often cited as the key advantage of having separate organizations for counseling and fiscal services. However, the experience of the three Cash and Counseling programs suggests that the organization responsible for fiscal services may need technical assistance with some fiscal tasks *regardless* of the organization of counseling and fiscal services. Perhaps the most serious fiscal error in any of the Cash and Counseling programs--a failure to return excessive withholding promptly--occurred in the Arkansas program (where counseling and fiscal services were combined). On the other hand, the production of timely financial statements for consumers proved difficult in Florida and New Jersey (where counseling and fiscal services were separated).

8. Lessons About Program Costs

- a. To constrain program costs, it may be necessary to cash out a care plan at a discount. However, a discount rate may embody a systematic undersupply of traditional services. Periodic review of a discount rate may also be necessary to maintain budget neutrality and to prevent inequity.**

Budget neutrality is one condition of the Section 1115 demonstration waiver under which the Cash and Counseling programs operated. In order to be budget neutral under Section 1115, Medicaid cost per month per recipient of the allowance cannot exceed Medicaid cost per month per recipient of traditional services. Future allowance programs may or may not seek Section 1115 demonstration waivers and thus may not be subject to this budget neutrality requirement.¹⁷ Nevertheless, states with allowance programs that do *not* require Section 1115 budget neutrality may wish to constrain program costs.

If the allowance is based on cashing out care plans, states may wish to consider discounting the hours (and other goods and services) in these plans. Discounting accounts for the fact that not all the goods and services included in traditional care plans are

¹⁷ Section 1915(c) budget neutrality involves comparison to Medicaid nursing home cost.

delivered, for example, because the client has been hospitalized or an aide has turned out to be a “no-show.” Discounting is accomplished by multiplying the estimated cost of the care plan being cashed out by a discount rate, which may be computed as the average ratio of the cost of goods and services delivered to the cost of goods and services planned for a sample of the population in the traditional program (usually expressed as a percentage).

A discount rate based on historical data does not distinguish between systematic undersupply due to a shortage of aides and occasional non-provision due to the temporary unavailability of a client or an aide. A state faced with a systematic undersupply of traditional services--but *not* required to develop a budget neutral allowance program under Section 1115--may wish to adopt a discount rate that is less deep than the historical average so that consumers receiving the allowance are not penalized for worker shortages.

Periodic review of a discount rate may also be necessary to maintain Section 1115 budget neutrality and to prevent inequity. The discount rate necessary for such budget neutrality may change as economic conditions change. For example, a decrease in the supply of aides could result in a reduction in the proportion of planned care that is delivered and affect the discount rate. If the supply of aides later improved, the continuing use of the original discount rate arguably could result in inequitable treatment of cash recipients (relative to recipients of traditional services), because the average cost of the allowance after discounting could be less than the average cost of providing traditional services (and vice versa if labor supply was adequate when data for a discount rate were collected but an undersupply developed later). States implementing a program that cashes out care plans at a discount may want to consider periodic review of the discount rate.

b. While improvement in access to care may be an important program goal under Cash and Counseling, overall costs may increase if access to care is improved, even if cost per month per recipient is constrained. Overall public costs could also increase if the availability of an allowance increases demand relative to that for traditional services.

Overall cost for a Cash and Counseling program may exceed overall costs for traditional supportive services even if the former is budget neutral under Section 1115. This situation can arise if the allowance program improves access to care for beneficiaries for whom traditional services have been authorized but not provided. As indicated in Lesson 4a, Cash and Counseling may improve access to care by permitting people to hire relatives and friends when traditional agencies have insufficient labor to meet demand. Thus, while improvement in access to care may be an important program goal, this improvement may come at a cost.

The addition of Cash and Counseling program can also increase overall Medicaid costs above costs expected for a traditional program alone if the allowance program attracts beneficiaries who are not interested in receiving traditional services. Overall Medicaid costs would increase as the total number of beneficiaries receiving supportive services increased, other things equal.

- c. States may want to consider assigning responsibility for assessment and care planning of Cash and Counseling consumers to an external party who has no vested interest in the matter and is not likely to act as an advocate for the consumer.**

Acting as advocates for consumers, and less constrained by limits on the supply of workers, counselors may increase the hours in care plans for which they are responsible, relative to the hours that would have been included in traditional care plans. New Jersey assigned responsibility for reassessment to Medicaid nurses (rather than to counselors) to eliminate this possibility. The Medicaid nurses were not involved in any other way in the Cash and Counseling program and had no vested interest in the number of hours in the care plan. In some cases, they authorized fewer hours of care than had been authorized under the traditional system by nurses employed by personal care agencies. After reassessment by Medicaid nurses, some consumers contested reductions in their care plan hours and requested administrative hearings. In most cases, these hearings resulted in reductions in care plan hours, although the reductions were not necessarily as large as those called for by the Medicaid nurses.

In contrast, Arkansas assigned responsibility for reassessment following demonstration enrollment to counselors. Arkansas counselors appear to have requested approval for high-hour care plans (those authorizing over 64 hours a month) for a larger proportion of Cash and Counseling consumers than did traditional agencies for their clients. Florida also assigned responsibility for reassessment to counselors, who were also responsible for reassessment as case managers and support coordinators under the traditional system. There is no evidence that Florida reassessments for those in Cash and Counseling were systematically different from reassessments for those in the traditional program.

To eliminate the possibility that counselors will increase care plan hours, states may want to avoid assigning responsibility for assessment and reassessment to them. States may want to assign responsibility for all assessments (in both the traditional and allowance program) to external parties who have no vested interest in the care-planning process. Alternatively, states might consider using a standardized instrument to increase the objectivity of the assessment and care-planning process.

- d. To avoid excessive costs if the development of the spending plan is delayed, states should consider limiting the payment for counselors to assist with**

development of the spending plan (for example, by use of a one-time payment).

Some consumers will never complete a spending plan, and others will do so only after a number of months (during which they may be receiving supportive services from an agency). To avoid excessive costs for counseling services if the completion of the plan is delayed, states can adopt a payment methodology that limits payment for assisting with the development of the spending plan. New Jersey initially adopted a one-time, preset payment for completion of the spending plan, and Arkansas moved to this approach when its monthly payment per enrollee proved too costly. For its elderly population, Florida limited the cost of developing the spending plan by paying fixed amounts for visits to develop the spending plan and capping the number of such visits for which it would pay.

9. Crosscutting Lessons

a. States can benefit from technical assistance in implementing Cash and Counseling programs. Technical assistance with fiscal issues may be the most important.

The three Cash and Counseling states benefited from technical assistance provided by staff of the National Program Office and by consultants the office made available to them. This help covered a wide variety of topics. Initially, it covered issues relating to the design of the programs, such as the role of representatives, and then preparation for implementing an allowance program, such as securing organizations to provide counseling and fiscal services. After operations began, assistance focused on operating and refining an allowance program. Among the many issues on which assistance was provided were development of brochures and other print and video media for outreach and enrollment, improving interaction with traditional agencies, training of outreach and enrollment staff, implementing quality assurance programs for counseling, and making calculations to ensure budget neutrality.

The three states particularly valued technical assistance pertaining to fiscal agents, including development of payment methodologies, reporting standards, auditing procedures, and clarification of federal regulations. As the Cash and Counseling Demonstration began, federal regulations did not clearly specify which payroll tax forms the fiscal agent should be filing on behalf of consumers as employers of record. To resolve this issue, the ASPE project officer and a consultant for the National Program Office worked with the Internal Revenue Service. This resolution paves the way for future programs offering an allowance.

b. A Cash and Counseling program can successfully serve populations with various impairments and in various age groups. Other evidence shows that

consumers in all three allowance programs were very well satisfied with the allowance program. Further, in Arkansas, satisfaction with care was much increased and unmet need much reduced for those assigned to the allowance program.

The experience of the three programs shows that Cash and Counseling can be successfully implemented with elderly adults, nonelderly adults with physical disabilities, and children and adults with developmental disabilities. With help from representatives, counselors, and fiscal agents, almost all consumers who were interested in receiving the allowance and able to hire workers learned to manage their own supportive services. Abuse of the allowance was almost nonexistent. While a very few cases of possible exploitation of the consumer were identified, these were resolved without incident, often before the consumer received the first allowance.

Nearly all consumers appear to have been well satisfied with the Cash and Counseling program. At this writing, more than three-quarters of those who received the allowance in Arkansas (the only state for which complete data are available on consumer satisfaction) said that it had improved the quality of their lives (Schore and Phillips 2002). The percentage was roughly the same or higher for early cohorts of consumers in Florida and New Jersey.¹⁸

Moreover, in Arkansas, disability-related health outcomes (such as the incidence of decubiti) for treatment group members were at least as good as those for control group members, and treatment group members were less likely to report unmet need and more likely to report satisfaction with their supportive services (Foster et al. 2003). (Similar analyses have not yet been completed for Florida and New Jersey.)

Much analysis remains to be done to assess the effects of the Cash and Counseling program. For Florida and New Jersey, this includes analysis for the *full* samples of treatment and control group members on whether effects on consumer welfare are as favorable as those in Arkansas. The remaining analysis also includes assessment of effects on Medicaid and Medicare costs and on the welfare of paid workers and unpaid caregivers.¹⁹ The results of these analyses will help other states decide whether the Cash and Counseling program might work for them.

The states that have experienced Cash and Counseling firsthand have already decided that they want to make the program permanently available to all eligible Medicaid beneficiaries.

¹⁸ Foster et al., October 2002; and Memorandum Describing Responses for an Early Cohort of Florida Treatment Group Members, April 17, 2002.

¹⁹ At this writing, reports on the experiences of paid workers and of informal caregivers in the Arkansas Cash and Counseling program are under review.

REFERENCES

- Benjamin, A.E. "Consumer-Directed Services at Home: A New Model for Persons with Disabilities." *Health Affairs*, vol. 20, no. 6, 2001, pp. 80-95.
- Benjamin, A.E., Ruth Matthias, and Todd M. Franke. "Comparing Consumer-Directed and Agency Models for Providing Supportive Service at Home." *Health Services Research*, April 2000, vol. 35, no. 1, pp. 351-366.
- Dale, Stacy, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Carlson. "Improving Access to Medicaid Personal Assistance in Arkansas Through Consumer Direction." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., July 2002.
- Doty, Pamela, Judith Kasper, and Simi Litvak. "Consumer-Directed Models of Personal Care: Lessons from Medicaid." *Milbank Quarterly*, vol. 74, no. 3, 1996, pp. 337-409.
- Eustis, Nancy. "Consumer-Directed Long-Term Care Services: Evolving Perspectives and Alliances." *Generations*, vol. 20, no. 3, fall 2000, pp. 10-15.
- Flanagan, Susan. "An Inventory of Consumer-Directed Support Service Programs: Overview of Key Program Characteristics." Presentation at the Cash and Counseling annual meeting, Arlington, VA, 2001.
- Foster, Leslie, Randall Brown, Barbara Carlson, Barbara Phillips, and Jennifer Schore. "Cash and Counseling: Consumers' Early Experiences in New Jersey, Part II: Uses of Cash and Satisfaction at Nine Months." Interim memo. Princeton, NJ: Mathematica Policy Research, Inc., October 2002.
- Foster, Leslie, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Improving the Quality of Medicaid Personal Assistance Through Consumer Direction." *Health Affairs*, Web publication. [www.healthaffairs.org/WebExclusives/2203Foster.pdf], March 26, 2003.
- Kitchener, Martin, and Charlene Harrington. "Medicaid 1915(c) Home and Community Based Waivers: Program Data: 1992-1999." San Francisco: University of California, San Francisco, August 2001.
- LeBlanc, Allen, Christine Tonner, and Charlene Harrington. "State Medicaid Programs Offering Personal Care Services." *Health Care Financing Review*, vol. 22, no. 4, summer 2001, pp.155-173.

Mahoney, Kevin J., Kristen Simone, and Lori Simon-Rusinowitz. "Early Lessons from the Cash and Counseling Demonstration and Evaluation." *Generations*, vol. 20, no. 3, fall 2000, pp. 41-46.

Mahoney, K.J., L. Simon-Rusinowitz, D.M. Loughlin, S.M. Desmond, and M.R. Squillace. "Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Disabilities. Submitted to *Health Services Research*, 2003.

Memorandum Describing Responses for an Early Cohort of Florida Treatment Group Members. Princeton, New Jersey: Mathematica Policy Research, April 17, 2002.

Schore, Jennifer, and Barbara Phillips. "Putting Consumer Direction into Practice: Implementing the Arkansas Independent Choices Program." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., December 2002.

Stone, Robyn. "Providing Long-Term Care Benefits in Cash: Moving to a Disability Model." *Health Affairs*, vol. 20, no. 6, 2001, pp. 96-108.

Stone, Robyn. "Consumer Direction in Long-Term Care." *Generations*, vol. 20, no. 3, fall 2000, pp. 5-9.

Velgouse, Linda, and Virginia Dize. "A Review of State Initiatives in Consumer-Directed Long-Term Care." *Generations*, vol. 24, no. 3, fall 2000, pp. 28-33.