

History of and Lessons from
the Cash and Counseling Demonstration and Evaluation

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Introduction

Currently, in many states, if you are either an elderly individual or a younger person with disability, and if you need assistance through Medicaid to perform activities of daily living like bathing, dressing, toileting, transferring, or eating you will rarely have much control over who provides services or the scheduling of those services, never mind what services are provided. For years, persons with disabilities have been saying, “If I had more control over my services, my quality of life would improve and I could meet my needs for the same amount of money or less.” The Cash and Counseling Demonstration and Evaluation (CCDE), which is described in this chapter, is at its heart, a policy-driven evaluation of this basic belief. CCDE, funded by the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE) at the U.S. Department of Health and Human Services, is a test of one of the most unfettered forms of consumer direction -- offering consumers a cash allowance to be used toward personal assistance services in lieu of the traditional agency-delivered (controlled) services. Through the CCDE project consumers are able to choose, hire, and manage their service provider; choose their mix of services; and choose the scheduling of their services. CCDE operates under a research and demonstration waiver granted by the Centers for Medicare and Medicaid Services (CMS).

Program Implementation Phases, and Current Status

The Cash and Counseling Demonstration and Evaluation has gone through four distinct stages. In this paper we concentrate on only the first 3 stages, but near the end we describe the fourth stage.

Stage 1: January, 1996 to January, 1997: Choosing States and the Evaluator

In January of 1996, the University of Maryland Center on Aging (which is coordinating this demonstration on behalf of the Robert Wood Johnson Foundation and ASPE) sent out a call for proposals to all states. The volume and quality of the responses were unexpected: 42 states called for additional information; 17 applied and, by the end of 1996, 4 states were chosen –Arkansas, New York, Florida, and New Jersey. Besides having determined which states would participate in the demonstration the other major accomplishment of the first year was the selection of Mathematica Policy Research, Inc. (MPR) as program evaluator after a national open competition for this critical role. MPR’s role was to conduct a quantitative analysis of the impact of the demonstration on the program’s major stakeholders, the financial implications and an evaluation of its implementation strategies.

Stage 2: February, 1997 to November, 1998: Preparation

Once the players were selected, the planning began in earnest. The “preparation stage” can be seen as being comprised of five major parts: Waiver negotiations; preference study; policy expert interviews; state infrastructure construction; and protocol development and readiness reviews.

Waiver Negotiations

In order for the demonstration to proceed, the states needed approval from the Centers for Medicare and Medicaid Services (CMS) for Section 1115 Research and Demonstration Waivers.

These waivers freed the states from two Medicaid requirements. The first requirement ‘waived’ through agreement with CMS is that every provider needs to sign an agreement with Medicaid. The second allowed the states to disregard the amount of Medicaid funds a consumer received for personal assistance when determining Medicaid income and resource eligibility. In addition, the individual states had to negotiate approval from SSI and the Food Stamp program to allow members of the treatment group to carry Medicaid personal assistance service (PAS) resources forward from month to month without jeopardizing the consumers’ eligibility status for these other vital income supplements.

Preference Study

At the start of the demonstration, the participating states had little notion of how many consumers would be interested in the cash allowance option, which ones, and why. To make an informed decision, they needed to know what type(s) of information consumers and their representatives needed about the program and its options. The states also needed to know what types of supportive services consumers desired. To meet these information needs, the Robert Wood Johnson Foundation funded a series of focus groups and surveys, which were conducted by the University of Maryland Center on Aging, in each of the four states. The Preference Studies showed that at least half the adults with disabilities, and a third of the elderly respondents were interested in learning more about the new option (Simon-Rusinowitz, Mahoney, Desmond, Shoop, Squillace, & Fay, 1998).

Policy Expert Interviews

Faced with the prospect of implementing consumer-directed programs, experts in aging and disability policy helped identify the key issues for consumers, providers, policy-makers, and funders. They also explored potential barriers to implementing consumer-directed programs.

The policy experts believed that the key issues for consumers were: consumers need training to manage their care; consumers’ preferences for services may differ by age, type of disability, and age of onset; family must be considered in consumer direction; and the risk of abuse and/or neglect by personal care workers may be heightened in the program, without agency monitoring as a safeguard.

Regarding providers, the policy experts identified other issues of concern: agencies fear increased business competition; provider agencies may not accept consumer autonomy; providers are concerned about client competency and agency liability; and independent providers are concerned about employment conditions.

Finally, payers and policy makers had concerns about safety, liability, and accountability surrounding the use of cash in the demonstration. (Simon-Rusinowitz, Bochniak, Mahoney, Marks, & Hecht, 2000).

State Infrastructure Construction

Individually, the states had the massive task of designing and operationalizing the outreach, counseling, fiscal intermediary (e.g., bookkeeping, check writing, etc.), and quality management components for the demonstration. In addition to the design choices, states had to both procure new providers and contract with them as well as to make many basic decisions including how to cash out the traditional agency-delivered benefits.

States relied on a range of technical assistance activities available from the project's national program office including expertise in program design, development of the counseling and fiscal intermediary functions, communications, quality management, and information systems design. States also shared information with each other through ongoing meetings and structured technical assistance calls.

Protocol Development and Readiness Reviews

In granting the 1115 Research and Demonstration Waivers, CMS specified twenty-three terms and conditions relating to monitoring activities, financial reporting, data, and budget neutrality requirements. Each state had to prepare an "Operational Protocol" covering virtually every facet of the demonstration. Once this Protocol was approved, CMS conducted a final "Readiness Review."

Stage 3: December, 1998 to June 2003: Implementation/Data Gathering

Within one month of having received waiver approval Arkansas was poised to get underway. New Jersey and Florida, took a year, and a year and one-half, respectively, to get up and running. In October of 1999, New York was dropped from the demonstration as that state had difficulty recruiting support from Local Social Service Districts and had fallen far behind the evaluation schedule. TABLE 1, Cash and Counseling At a Glance, summarizes the state of the three remaining states at end of June, 2002.

TABLE 1

Cash & Counseling at a Glance, June 30, 2002

| | Arkansas <i>IndependentChoices</i> | New Jersey <i>Personal Preference</i> | Florida <i>Consumer-Directed Care</i> |
|--|---|--|---|
| Implementation Date | December 1998 | November 1999 | May 2000 |
| Populations Served | Elderly & Adult Disabled Medicaid Personal Care Recipients | Elderly & Adult Disabled Medicaid Personal Care Recipients | Elderly, Adult Disabled & Children w/ Developmental Disabilities Medicaid 1915c Home & Community-Based Service Waiver Clients |
| Departments Involved | <u>Primary:</u> Division of Aging & Adult Services, Department of Human Services <u>In Coordination With:</u> ⇒ Division of Medical Services, Department of Human Services | <u>Primary:</u> Division of Disability Services, Department of Human Services <u>In Coordination With:</u> ⇒ Division of Medical Assistance & Health Services, Department of Human Services | <u>Primary:</u> Department of Elder Affairs <u>In Coordination With:</u> ⇒ Department of Children and Families (Developmental and Adult Services Programs) ⇒ Department of Health (Brain and Spinal Cord Injury Program) ⇒ Agency for Health Care Administration |
| Territory Covered | Statewide | Statewide | <ul style="list-style-type: none"> • Central & South Florida-Elderly & Adult Physically Disabled • Statewide-Children & Adults w/Developmental Disabilities |
| Enrollment Targetsⁱ | 2000 | 2000 | 3000 |
| Final Caseload (For Evaluation) | 2008 <ul style="list-style-type: none"> • Adults - 556 • Elderly - 1452 | 1762 <ul style="list-style-type: none"> • Adults - 821 • Elderly - 941 | 2820 <ul style="list-style-type: none"> • Children - 1004 • Adults - 1002 • Elderly - 814 |
| Open-Enrollment End Date | April 30, 2001 | June 30, 2002 | Children: August 31, 2001 Adults: October 31, 2001 Elderly: June 30, 2002 |

ⁱ Enrollment Targets refers to the minimum number of consumers that the evaluator, Mathematica, must interview. Half of the consumers are randomly assigned to the experimental group to receive the cash allowance, whereas the other half are randomly assigned to the control group and remain with traditional services.

Source: <http://www.umd.edu/aging>; www.cashandcounseling.org

The basic design of the Cash and Counseling Demonstration is the same for each state. Consumers are offered a choice between receiving the traditional agency-delivered personal assistance (PAS) services or home care waiver services listed in their care plans, or in managing a cash allowance roughly equivalent to the dollar amount of that care plan. Those consumers who volunteer for the demonstration are referred to the evaluator for a baseline interview; they are then randomly assigned to the treatment group (the cash allowance benefit coupled with a menu of counseling services) or to the control (traditional agency-delivered services) group. More precisely, Medicaid beneficiaries who are eligible for PAS or waiver services enter the system as they have done in the past. After receiving a comprehensive assessment, an individualized care plan is developed by caseworkers to meet the client's unmet needs. At this juncture, consumers are given information that will help them to make an informed choice between the "traditional" and "consumer-directed" options. If he or she opts to be part of the demonstration, (s)he stands a 50-50 chance of being randomly selected to receive the cash allowance. All the people who receive the cash allowance have access to a wide range of counseling services, and these services include assistance with the fiscal tasks associated with being an employer.

The evaluation phase of the demonstration compares outcomes of the treatment and control groups on measures including client satisfaction and quality of care, costs, and differences in the types and amounts of PAS consumers' purchase. The evaluation also examines ways in which the program affects informal caregivers as well as the experiences of paid workers. It includes a study assessing consumers' and their representatives' preferences for traditional or consumer-directed services, a process evaluation, and a counselor feedback questionnaire. In addition, researchers from the University of Maryland, Baltimore County conducted an in-depth ethnographic study examining 25 triads of consumers/workers/counselors in each state in order to capture people's experiences with consumer direction.

Several features cross-cut each of the demonstration states:

- Consumers must spend their cash allowances only to meet personal assistance needs. Within that framework, is considerable flexibility. Each of the three states decided that every consumer would be required to develop a plan for the use of their cash allowance. This was a major decision, as each state understood the need for accountability when using public/Medicaid funds.
- Consumers are allowed to return to the traditional program at any time they wish. If consumers have trouble making consumer direction work but wish to remain in the program, counseling services can be augmented.
- Consumers are assured that they can receive the cash allowance for at least two years. (This became an important part of program since planners were concerned whether consumers would make such a major program/plan switch if the cash allowance were offered only for a brief period of time.)
- Consumers who want to be part of the demonstration, but who are not capable of total self-direction, are allowed to have "representatives." What this means in practical terms is that the consumer and his/her representatives share tasks, which include decision making and service management. Representatives are directed to elicit the views/preferences of the consumer and to speak on behalf of them (as opposed to expressing their own opinions). What this really means is that no one is automatically eliminated from the cash option because of concerns about his/her capacity. Every consumer, it is assumed, is capable of expressing opinions about their own care and services.

Even though these three states implemented the same core demonstration, there were important differences in the way they implemented the project. Existing delivery systems affected the way Cash and Counseling was operationalized.

Arkansas contracted with one agency in each region that provided both fiscal and counseling support. New Jersey had a more diversified structure, with outreach consultants, multiple counseling entities, and state program control over changes to the consumer purchasing plans. In Florida, one fiscal intermediary handled the monitoring and payment of the cash plans, but separate counseling approaches were used. For older consumers the program relied on case managers from the area agency network, whereas for consumers with developmental disabilities the local county developmental disability network was used.

TABLE 2 shows how each state divided up the various counseling tasks for the CCDE. It is useful to note how the states differed in the degree to which they integrated counseling and fiscal intermediary (FI) or bookkeeping functions. Arkansas had one agency in each region performing both counseling and FI functions. New Jersey and Florida, believing that there were economies of scale, and that the skills needed for a FI were quite different from the expertise needed to perform counseling duties, selected one FI for the whole state.

TABLE 2
Cash & Counseling: Delivery System Components

| | Outreach/ Enrollment | Consumer Training | Cash Plan Development/ Counseling | Cash Plan Approval/ Changes | Fiscal Intermediary | Monitoring | Reassessment |
|-----------|---|-------------------------------|--|--|--|--|-------------------------------|
| AR | State | | Counseling Entity* | Counseling Entity* | Counseling Entity* (1 per region) | Counseling Entity* | Counseling Entity* |
| FL | Counseling Entity* | Counseling Entity* | Counseling Entity* | Counseling Entity* | (1) Fiscal Intermediary (F.I.) | Counseling Entity* | Counseling Entity* |
| NJ | For Profit Firm specializing in outreach | | Counseling Entity* | State | (1) Fiscal Intermediary (F.I.) | Counseling Entity*/ Fiscal Intermediary | Medicare RNs |

*Counseling Entities are organizations that employ professionals who provide cash and counseling supportive services. In some states, the cash and counseling consultants / support brokers were employed by traditional case management agencies; in other cases, organizations specializing in cash and counseling fiscal and support services employed the counselors / consultants.

In New Jersey and Arkansas, where traditional personal care provider agencies were their own gatekeepers, the CCDE Program felt it was necessary to set up a separate outreach capability to assure that information about CCDE was being delivered in an unbiased manner. In fact, Arkansas and New Jersey chose to establish completely new, parallel delivery systems for Cash and Counseling, while Florida attempted to rely on the existing system to the extent possible.

Implementation Lessons

Coordination of Activities

As a general rule, the greater the number of actors (See Table 2), the greater the need for coordination and the longer it took for consumers to start getting the cash allowance. For this reason, the Cash and Counseling states have gradually become convinced that there are real advantages in linking the counseling and FI functions and in using dedicated workers for the consumer-directed option.

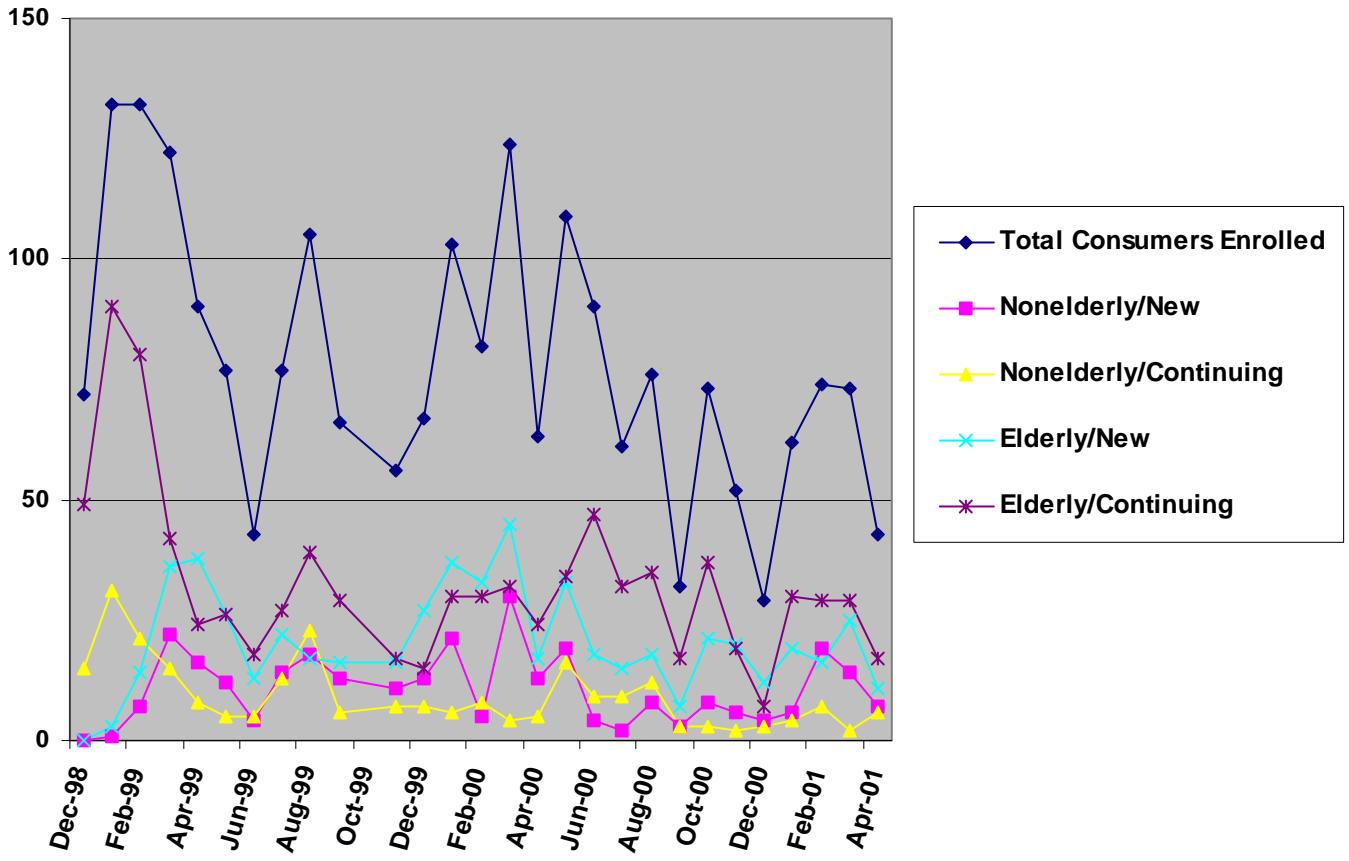
Outreach and Enrollment

The Cash and Counseling approach is not for everyone. Approximately 15 to 20% of the non-elderly personal care population in both Arkansas and New Jersey selected this option; in Florida this was closer to 15%. In all three states, approximately 8 to 10% of the eligible elderly individuals chose Cash and Counseling. (Phillips, Mahoney, Simon-Rusinowitz, Schore, Barrett, Ditto, Reimers, & Doty, 2003). Although interest in participation in the cash option was lower among the elderly than in the eligible non-elderly individuals, the demonstration has put the myth to rest that elderly people are not interested in consumer direction; 72% of Arkansas' clients are over 65.

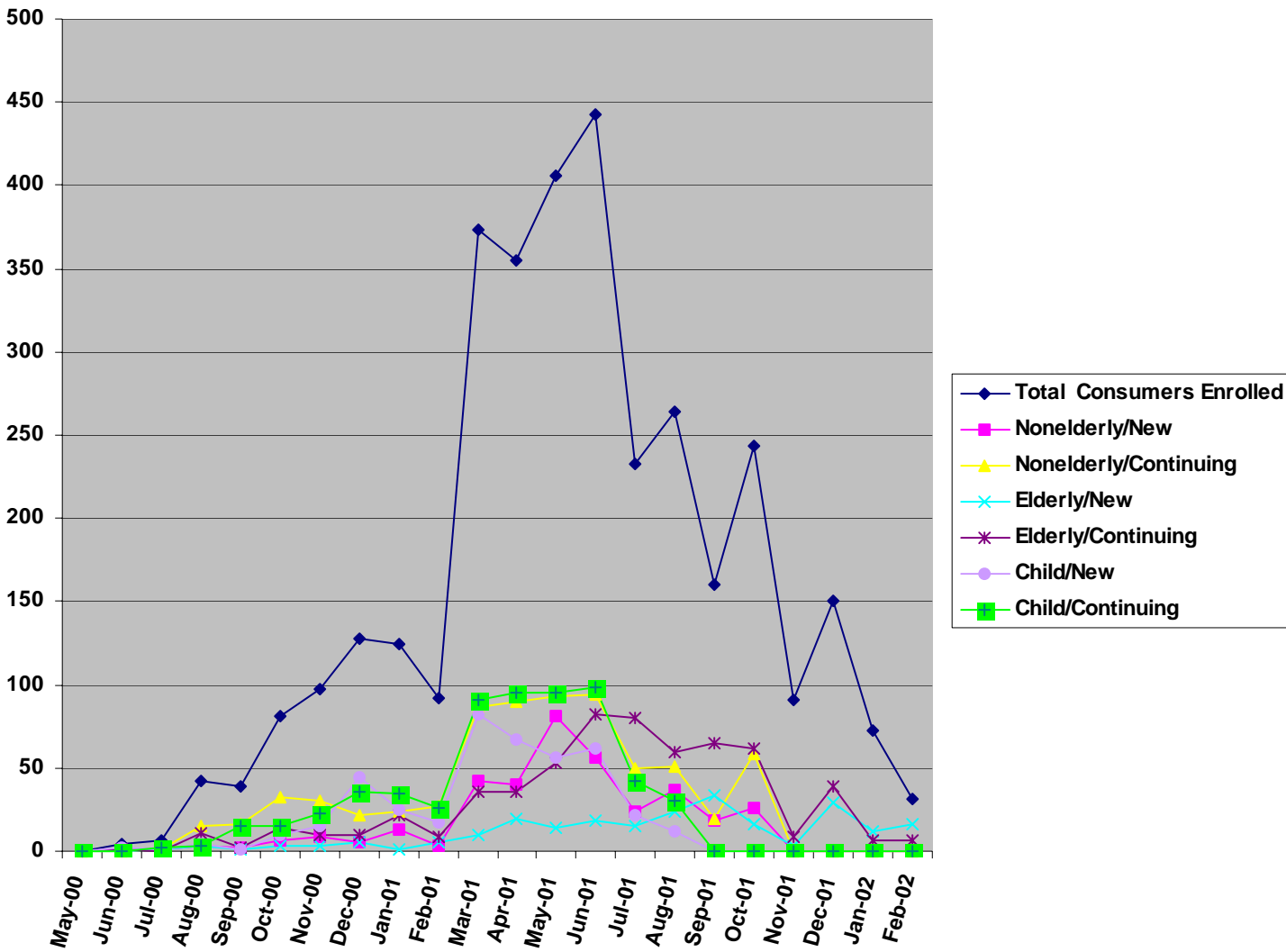
In Arkansas, we learned the value of a multi-faceted communications plan to stimulate demand. Enrollment can be impacted by outreach (see Table 3 below). An examination of monthly enrollment figures from Arkansas shows that every time the state made a new outreach effort (e.g., letters to consumers and holiday notes, newsletters, and focus groups with trusted professionals) enrollment numbers sprang up.

In Florida we learned the advantages of using dedicated outreach workers. Table 4 shows what happened in March of 2001 when that state switched to dedicated outreach workers.

**Arkansas, Consumer Enrollment in Cash & Counseling:
All Groups, April 2001**



**Florida, Consumer Enrollment in Cash & Counseling:
All Groups, February 2002**



Fiscal Intermediaries

Many of the CCDE's most important early contributions were in procedures for establishing and monitoring FIs. The CCDE has helped develop contracting guides, readiness review criteria, and a template that states can use for monitoring the performance of FIs.

During the first few years of operations, only a handful of consumers have wanted to handle their cash allowances directly. The vast majority of consumers of all ages wanted to use the FI as their "employer agent." In this model, the consumer develops a "cash plan" or individualized budget and instructs the FI on how to spend the cash allowance. With the FI handling the bookkeeping, tax paying, and record keeping tasks, concerns by policy makers over fraud and abuse have been allayed.

Outcomes

MPR (Phillips et al., 2003) released findings from the first 200 to 250 treatment group members completing the 9-month follow-up survey. Already we can see (Table 5) that the vast majority of clients in each state would recommend this program to others. Clients (73% to 79%) felt of the clients felt their quality of life was improved a great deal by the Cash and Counseling program, and no one felt they were worse off.

Satisfaction with Cash and Counseling: Preliminary Results from Interviews with the First 200 Consumers from Each State

| | Percent of Respondents | | |
|---------------------------------------|------------------------|------------|---------|
| | Arkansas | New Jersey | Florida |
| Overall Satisfaction | | | |
| Would Recommend Program | 93.3 | 86.1 | 90.0 |
| How Much Quality of Life Was Improved | | | |
| A great deal | 78.7 | 70.1 | 73.0 |
| Somewhat | 21.3 | 29.9 | 27.0 |
| Number of Respondents | 194 | 216 | 219 |

Source: Foster, L., Brown, R., Carlson, B., Phillips, B., Schore, J. (2000, 2002a, 2002b) Mathematica Policy Research Inc.'s Nine-Month Cash and Counseling Evaluation Interview.

The vast majority of consumers use at least part of their cash allowances to secure personal care attendants and many of these people hire family members and friends (See Table 6).

Cash and Counseling Demonstration:
Recruiting Methods Resulting in Hires

| | Percent of Respondents | | |
|-------------------------------------|------------------------|------------|---------|
| | Arkansas | New Jersey | Florida |
| Family Member | 78.0 | 63.4 | 55.3 |
| Friend, Neighbor, or Church Member | 15.4 | 20.4 | 29.1 |
| Former Home Care Agency Worker | 1.6 | 16.1 | 21.3 |
| By Posting/Consulting Advertisement | 0.8 | 6.5 | 12.8 |
| Recommended by Family/Friend | 2.4 | 11.8 | 19.2 |
| Through an Employment Agency | 0.8 | 1.1 | N/A |
| Other | 0.8 | N/A | 13.5 |
| Number of Respondents | 123 | 93 | 141 |

*Percentages total more than 100% as a result of consumers using multiple recruiting methods.

Source: Foster, L., Brown, R., Carlson, B., Phillips, B., Schore, J. (2000, 2002a, 2002b) Mathematica Policy Research Inc.'s Nine-Month Cash and Counseling Evaluation Interview.

Medicaid Costs

Data collected and analyzed by Arkansas (the first state to implement) tell the story. In a comparison of Medicaid beneficiaries who were randomized to receive either the cash option or traditional Medicaid services, state investigators found:

- Personal care assistance expenditures were higher for the Cash and Counseling beneficiaries. This may partially be accounted for because the Medicaid beneficiaries in the traditional services group did not receive personal assistance services in 40 % of the months during which they were eligible for them, compared to 9 % for those in the cash option group.
- Other Medicaid long-term care expenditures were lower among the Cash and Counseling beneficiaries. These other expenditures included those associated with home health services, home and community-based waiver programs, and nursing facilities. Institutional costs were 18 % higher for the traditional services group.
- Overall Medicaid costs per recipient per month were virtually identical for the traditional services and the cash option groups.*

* Through the first two years of operation, the cost per recipient per month for Independent Choices plus the cost per recipient per month for all other Medicaid services was 0.15% less.

What is next?

Stage 4

The demonstration was so successful that the RWJF and the Department of Health and Human Services, Assistant Secretary for Planning and Evaluation wanted to continue and expand upon the program. In August 2004, the demonstration expanded to 12 additional states. These additional states are: Alabama, Illinois, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia.

Given the early successes, the Cash and Counseling states are already looking at ways to make this option permanent. We now have sufficient data to measure budget neutrality using trend data based on the experiences of the initial study. The second step might involve broadening Medicaid's definition of "personal care" (so it is no longer limited to human assistance), and amending Medicaid policies governing 1915c waivers to specify how states might incorporate individual budgets into their home and community-based waivers. In the long run, states may find it beneficial to consider operating Cash and Counseling programs through prepaid health plans so they would have the flexibility to advance funds, pay out small amounts of cash, and offer cash allowance alternatives to a wider range of services.

Based on the experiences of Arkansas, Florida, and New Jersey in consumer direction, other states are expanding consumer-directed initiatives and are using individualized budgets to address consumer needs. We hope that these efforts can build on knowledge obtained through Cash and Counseling and make further advances in critical areas such as linking consumers (especially consumers without readily available family members) with workers, developing training for representatives acting on behalf of consumers, and testing quality management approaches (such as the one being developed for the Cash and Counseling states) appropriate for consumer-directed programs.

Acknowledgment

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