



Robert Wood Johnson Foundation

Choosing Independence

*An Overview of the Cash & Counseling Model
of Self-Directed Personal Assistance Services*



Cash & Counseling is a national grant program of the Robert Wood Johnson Foundation® as well as the Office of the Assistant Secretary for Planning and Evaluation and the Administration on Aging, U.S. Department of Health and Human Services.

The Cash & Counseling national program office is housed at the Center for the Study of Home and Community Life, Boston College Graduate School of Social Work, with research assistance provided by the University of Maryland Center on Aging.

The Centers for Medicare & Medicaid Services provide participating states with technical assistance and oversight with regard to the federal waivers required to implement a Cash & Counseling program.

The evaluation of the three-state Cash & Counseling Demonstration and Evaluation program was conducted by Mathematica Policy Research, Inc. A qualitative evaluation was conducted by the University of Maryland, Baltimore County.

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TABLE OF CONTENTS

1 INTRODUCTION

4 CONSUMER STORY

Mrs. Josie Dickey; Fort Smith, Ark.

6 PART 1

Cash & Counseling Model of Self-Directed Personal Assistance Services

8 Three-State Demonstration and Evaluation Program

14 CONSUMER STORY

Mr. Louis Corvese; Cranston, R.I.

16 PART 2

Cash & Counseling Evaluation Results

17 Quality Outcomes

26 Cost Outcomes

29 Worker Outcomes

31 Evaluation Conclusion

32 CONSUMER STORY

Ms. Karla Herrera; Miami, Fla.

34 PART 3

Cash & Counseling Going Forward

38 Cash & Counseling and the 2005 Deficit Reduction Act

40 CONSUMER STORY

Mr. Calvin Dodson; Trenton, N.J.

42 CONCLUSION

44 CONSUMER STORY

Mr. Harold Hamilton; Eden, Minn.

46 RESOURCES FOR ADDITIONAL INFORMATION ON CASH & COUNSELING

46 Web sites

47 Published Materials

INTRODUCTION

“We think Cash & Counseling is significant because it is as if we’re giving consumers the opportunity to drive the system, rather than having the system drive the consumer.”

—Arkansas Governor

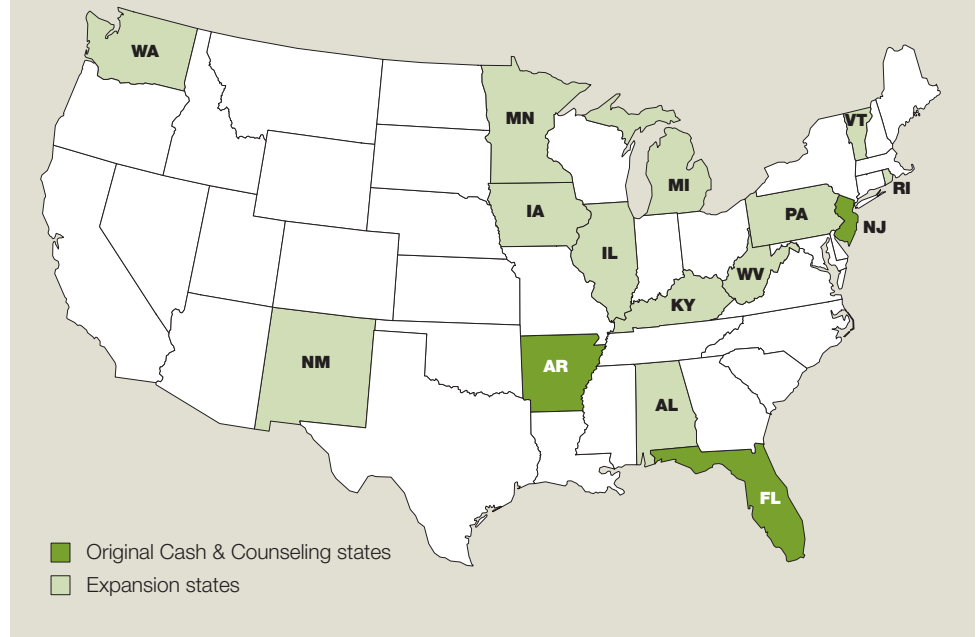
Mike Huckabee, June 2001

Cash & Counseling offers Medicaid consumers who have disabilities more choices about how to get help at home. Specifically, it gives frail elders and adults and children with disabilities the option to manage a flexible budget and decide for themselves what mix of goods and services will best meet their personal care needs. Cash & Counseling participants may use their budget to hire their own personal care aides as well as purchase items or make home modifications that help them live independently.

Funded jointly by the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services (DHHS), Cash & Counseling was first launched as a demonstration project in Arkansas, Florida, and New Jersey. According to the independent evaluation of that demonstration, consumers were overwhelmingly satisfied with Cash & Counseling. The large majority of those who participated in the three-state program said it significantly improved the quality of their lives. The evaluation also found that, compared to a control group, Cash & Counseling reduced participants’ unmet needs for care and helped them maintain their health. It also significantly improved the lives of their primary caregivers. And initial concerns about possible Medicaid fraud and abuse as well as adverse effects on participants’ health proved unfounded.

The three states found that Cash & Counseling can be implemented without costing substantially more than traditional services. Overall costs to Medicaid were somewhat higher for Cash & Counseling participants in each state, mainly because home care agencies failed to deliver approved care to consumers in the control group. But savings in other Medicaid long-term-care costs helped to offset the higher personal care costs. Further, all three states learned important lessons about controlling costs so that the Cash & Counseling option need not cost Medicaid more than traditional services.

Cash & Counseling States



SOURCE: Cash & Counseling national program office

Today, based on the encouraging results of the demonstration, Cash & Counseling programs are being implemented in 12 more states with support from the funders of the original three-state demonstration program. But the federal government soon will make it significantly easier for any state to introduce a Cash & Counseling option through new provisions in the 2005 Deficit Reduction Act. After January 2007, federally approved “waivers” will no longer be required for states to offer flexible budgets to eligible Medicaid consumers and their families so that they may purchase the disability services and supports of their choosing.

In light of this major change and assuming that other states may want to learn more about Cash & Counseling, this publication offers an in-depth description of the option, a discussion of key findings from the three-state demonstration, and preliminary information about the program’s expansion into 12 more states. At the end is a list of resources—both Web sites and published materials—for further information on Cash & Counseling. In addition, stories about consumers who have first-hand experience with Cash & Counseling appear throughout this publication. They are profiles of the people whose lives are being changed by the opportunity to direct their own personal assistance services.

“As I talk with seniors, what I hear most is that they want to stay in their homes as long as they can. However, too many seniors struggle to afford quality home- and community-based care and, as a result, are forced into institutional care they don’t want, adding to the strain on our Medicaid program.”

—U.S. Senator Hillary Rodham Clinton, in April 2006, introducing her “Community-Based Choices for Older Americans Act”, which was based on Cash & Counseling



cash & counseling consumer story

Mrs. Josie Dickey, Fort Smith, Ark.



When Josie Dickey suffered a massive stroke in August 2002, few people would have given her more than a year to live.

Today, not only is Josie alive, but she has a life—one that revolves around her family and around doing as much as she is able, especially when spurred on by her daughter Brenda Terry, with whom she lives and who gives her round-the-clock care. Some days might involve an excursion to Wal-Mart with Brenda, or an afternoon putting puzzles together or playing Nerf ball with her great-grandchildren, or simply watching her favorite cardinal at the birdfeeder.

“The more she does, the better she is,” Brenda says of her mother, who’s now 87 and suffers from diabetes, arthritis, heart ailments, and other health problems that leave her too frail to care for herself. “She’s participating in life—and that’s a great big deal.”

It wasn’t always this way. Following her stroke, Josie went to live in a nursing home. But she was neglected there and contracted pneumonia. After six weeks, Brenda brought her home to live with her. Then came a string of home health aides—about 30 in the space of three years. Meanwhile, Brenda was working full time at a high-stress job and recovering from breast cancer herself. “I was just trying to keep things going,” she recalls. “I was trying to keep my mom safe and at home.”

Josie’s care coordinator told Brenda about Arkansas’ Cash & Counseling program, called IndependentChoices. Brenda quit her \$13-an-hour job to work as her mother’s caregiver for less than half that pay. She has no regrets.

“Before this program, I used to worry about Mom all the time,” Brenda says. Now she knows that her mother is getting the care she deserves because Brenda provides the care herself. “I’d rather it be me than someone else who doesn’t care as much.”

Since Brenda has taken over her mother’s care, Josie has been healthier, more active, and more engaged in her life. Initially, it took three people to lift Josie out of bed.

Now, Brenda can manage that task on her own because Josie is stronger and uses her own muscles. During her stay in the nursing home, Josie’s mental functioning slid dramatically. Now, she is more focused, alert, and responsive. And, in the year that she’s been enrolled in IndependentChoices, she hasn’t been sick once.



PART 1

Cash & Counseling Model of Self-Directed Personal Assistance Services



The Florida [Cash & Counseling program] challenges the traditional mindset...that the individuals charged with overseeing and coordinating care for Medicaid recipients know what is best for their clients, and that Medicaid waiver service recipients are incapable of managing their own care effectively and responsibly.

—Secretary Terry White, Florida Department of Elder Affairs, in May 2003 testimony before the U.S. House Energy & Commerce Committee

Cash & Counseling was created to address the serious barriers that eligible Medicaid consumers sometimes meet when seeking personal assistance services—essentially help at home with daily activities like bathing, dressing, grooming and meal preparation—from state-contracted home care agencies. Although the traditional model of agency-provided personal assistance services works well for many consumers, others get little or none of the services they need and are authorized to receive.

Home care agencies frequently experience worker shortages and high staff turnover that make it difficult to meet consumers' needs. This is a particular problem for rural consumers who live too far away for agency workers to reach efficiently, and for urban consumers who live in high-crime areas that workers do not want to enter.

In addition, some consumers are dissatisfied with the quality of services provided by home care agencies. Consumers report that agency workers are not always reliable or sometimes fail to complete their tasks. Some consumers have reported being neglected, mistreated, or abused by agency workers, while others have expressed discomfort with workers who, while competent and reliable, are essentially strangers sent to their homes to help with very personal and intimate needs.

Finally, problems may arise because home care agencies cannot tailor their services to consumers' individual needs. Serious misunderstandings and conflicts can result when the consumer and agency worker speak different languages or come from different cultures. And, frequently, consumers can't get the services they need at the time they most want them because of agency workers' schedules. Agency workers generally do not work evenings or weekends.

These workers are not allowed to provide two services needed by many people with disabilities—transportation and administering medications—due to liability concerns. In addition, agencies only provide workers; they can not provide assistive devices, such as microwaves for heating up meals when a worker is unavailable. And, agencies do not make home modifications—such as building wheelchair ramps or widening doorways—so that consumers with limited mobility can be more independent at home.

In contrast to the agency model, Cash & Counseling provides consumers with a flexible budget that enables them to hire (and fire) their own workers, who may be

friends or family members. Although Cash & Counseling is not the first program to allow consumers to hire their own personal care aides, it is unique. Two of the original Cash & Counseling states allowed program participants to hire spouses or parents to be their paid caregivers, which had not been previously permitted in other programs. Cash & Counseling also allows consumers to negotiate with their workers over wages, hours, and benefits, as long as they remain within their budget and do not violate minimum wage and other labor law requirements.

As an employer, the consumer determines her workers' schedules as well as the scope of services she needs. Cash & Counseling recognizes that consumers may have little experience acting as employers and provides them with counseling and fiscal support services to assist them in planning their budgets, locating workers and resources, keeping up with paperwork, and tracking expenditures.

Cash & Counseling also allows consumers to use their allowances to modify their homes or vehicles or to purchase items—such as microwaves, touch lamps, or lift chairs—that help them continue to live independently. And the program allows consumers who don't feel confident about making decisions on their own to appoint a representative—such as a family member or trusted friend—to make decisions with or for them.

Cash & Counseling is not for everyone, however, because not everyone is willing or able to manage all of the requirements. Nor does everyone have a trusted representative to do so for them. And Cash & Counseling is not intended to replace agency services. Instead, it provides an alternative to those who want one. Cash & Counseling may also serve as a way to increase access to personal assistance services in certain circumstances, such as when agencies are experiencing worker shortages or in rural areas where consumers are hard to reach.

Cash & Counseling is a voluntary option, designed for people who want to remain at home and accept the responsibility of managing a flexible budget and employing workers—or appoint a representative to do this for them.

Three-State Demonstration and Evaluation Program

With support from RWJF and DHHS, the Cash & Counseling model of self-directed personal assistance services was put to the test in Arkansas, Florida, and New Jersey. In 1996, all three states applied for and received grants to implement a Cash & Counseling program that was monitored by the Centers for Medicare & Medicaid Services (CMS). CMS granted the states Section 1115 research and demonstration waivers, and the program was evaluated by Mathematica Policy Research, Inc., and by the University of Maryland, Baltimore County.

The “Cash & Counseling Model” Vision Statement

The Cash & Counseling service model is a form of consumer-direction or self-direction intended to empower individuals to make choices and take control of the community support services that they receive. The goal of the model is to enhance their ability to live the life they wish to in the community. This vision evolved from a tested model which yielded very positive results. Cash & Counseling seeks to create a new model through the inclusion of principles that go beyond what is already possible. The following principles are essential to the Cash & Counseling model.

- Cash & Counseling reflects a belief that individuals, when given the opportunity to choose the services they will receive and to direct some (or all) of them, will exercise their choice in ways that maximize their quality of life.
- Cash & Counseling is one option among several service delivery models but it should be available for all participants that choose it.
- Because participation in Cash & Counseling is voluntary, there should be a seamless process for moving between this option and the traditional system.
- Consumer-direction is not used as a vehicle for reducing benefits to recipients.
- Cash & Counseling includes participant-centered planning to ensure that the participant is making personal choices for the spending of the budget based on his or her own goals.
- Cash & Counseling requires a flexible individualized budget that the participant may spend on services that assist the individual to meet his/her community support needs and enhance his/her ability to live in the community.
 - The participant may use the individualized budget to choose and directly hire workers to provide the services.

- The participant may use the individualized budget to purchase goods, supplies, or items to meet community support needs.
- A flexible budget means the participant has significant choice in the allocation of his/her funds between hiring workers and making other purchases.

- Cash & Counseling allows participants to select a representative to help them with making decisions and managing their services.
- Cash & Counseling provides a system of supports to assist the participant in developing and managing his/her spending plan; fulfill the responsibilities of an employer, including managing payroll for workers he/she hires directly; and obtain and pay for other services and goods.
- Cash & Counseling obtains feedback from participants, representatives, and family members (when appropriate) as well as data from support service providers to continuously improve the program.

Ideally, the fully flexible budget would allow the participant to hire legally responsible relatives, purchase goods and services from vendors without Medicaid provider agreements, and receive some part of the budget in cash.

The system of supports in a Cash & Counseling program is designed by the sponsoring governmental entity, with input from participants, families, and other stakeholders. Many functions may be included and these may be performed by a variety of staff types in any particular state design. The table on the following page sets out key elements of the Cash & Counseling model.

Key Elements for Cash & Counseling

STATE RESPONSIBILITIES AND ACCOUNTABILITIES

- Provide information and outreach to ensure that individuals have access to this option.
- Establish the individual budget amount using a transparent, equitable, and consistent methodology.
- Identify and address potential conflicts of interest in the design and operations of the program (for example, the representative hiring him/herself as a paid worker).
- Establish expectations and standards for the supports system and build sufficient capacity to sustain the system and serve participants in a timely manner.
- Ensure that participants/representatives are involved in the design and operation of the program.
- Establish effective communication paths among support entities, participants, their representatives, and the state program.
- Establish a process for review and approval of spending plans
- Establish a quality management system, including but not limited to:
 - Ensuring that the program reflects the principles of Cash & Counseling and obtains feedback from participants and representatives,
 - Monitoring the supports system performance, and
 - Conducting program reviews that assess program compliance and financial accountability.

SYSTEM OF SUPPORTS: SUPPORTS BROKER AND FISCAL MANAGEMENT SERVICES (SPECIFICALLY FISCAL/EMPLOYER AGENT) TYPE FUNCTIONS

- Provide the participant/representative with information about the concepts of self-direction and participant rights and responsibilities.
- Assist the participant in identifying his/her own goals and needs using a participant-centered-planning process.
- Assist the participant in developing his/her spending plan.
- Provide clarification and explanation about program allowable expenditures and documentation/record keeping.
- Assist the participant/representative in developing an individual back-up plan
- Provide training and assistance to participants/representatives on recruiting, hiring, training, managing, evaluating, and dismissing self-directed workers.
- Assist the participant/representative in monitoring expenditures under the spending plan.
- Assist the participant/representative in revising his/her spending plan.
- Assist the participant/representative in obtaining services included in spending plan.
- Instruct and assist participant/representative in problem solving, decision-making, and recognizing and reporting critical events.
- Coordinate activity among support entities, participants/representatives, and state program.
- Process hiring package for directly hired workers.
- Process payroll for directly hired workers in accordance with federal, state, and local tax, labor, and worker compensation laws for domestic service employees and government or vendor fiscal/employer agents operating under Section 3504 of the IRS code¹.
- Process and make all payments for goods and services in accordance with the participant's approved spending plan.
- Issue easily understood reports of budget balances to participants/representatives and support brokers periodically and upon request.
- Issue programmatic and financial reports to government program agency/Medicaid agency periodically and upon request.

¹ Oregon is the exception to this, for historical reasons.

Each state implemented a Cash & Counseling program that adhered to the basic tenets of the model but was also uniquely tailored to the needs and realities of enrollees in that state. The key features of each state’s program are described below and summarized in the table on page 13.

- **Target Population.** Arkansas’ program, called IndependentChoices, was open to frail elderly adults and younger adults with physical disabilities who were eligible to receive or already receiving Medicaid personal care services. New Jersey’s program, called Personal Preference, was open only to adults who had already applied and been assessed for Medicaid personal care services, including frail elderly and adults with physical disabilities. Florida’s program, called Consumer Directed Care, was open to consumers who were already enrolled in one of two home- and community-based waiver programs, either the Developmental Disabilities waiver or the Aged and Disabled Adults waiver.
- **Monthly Allowance.** Arkansas’ median allowance was \$313 per month, Florida’s median was \$829 for adults and \$831 for children, and New Jersey’s median was \$1,097. Arkansas and New Jersey based their allowances on consumers’ Medicaid personal care plans, while Florida based its allowances on the value of all the benefits in consumers’ home- and community-based waiver care plans.
- **Random Assignment.** Because Cash & Counseling originally was a research and demonstration program, each state recruited volunteers and randomly assigned them to either the treatment group, composed of Cash & Counseling enrollees, or the control group, composed of consumers who relied on home care agencies for their services. The treatment and control groups were of equal size in each state. Arkansas enrolled a total of 2,008 adults, New Jersey enrolled 1,755 adults, and Florida enrolled 1,818 adults and 1,002 children.
- **Decision-Making Support.** All three states offered Cash & Counseling participants help in making decisions about their personal assistance needs and managing their monthly allowances. Counselors (also called consultants) monitored participants’ well being, helped them develop their mandatory spending plans, monitored their expenditures, and gave advice about hiring and training workers. Help with fiscal tasks such as bookkeeping and check writing was also made available to consumers who needed it, with 93 percent of Cash & Counseling participants taking advantage of this assistance.

Cash & Counseling participants (or their representatives) developed and followed written plans for spending their allowances. Consumers could choose to receive 10 to 20 percent of their allowances as cash for incidental expenses, such as taxi fares.

They also could save portions of their allowances for large purchases, such as home modifications. While some consumers did make purchases that would contribute to their self-sufficiency and independence—examples include a microwave oven, a washer and dryer, a chair lift for the stairs, an air conditioner, and an orthopedic bed—the majority of consumers used their funds primarily to hire their own workers, including relatives, friends, and neighbors.

Policy-makers and state program administrators have expressed concern that because Cash & Counseling allows the payment of family caregivers, Medicaid might end up paying for care that relatives would otherwise provide free. But states only authorize personal assistance services that a person’s unpaid caregivers cannot provide. For example, a daughter who provides care in the evenings and on weekends may be unable to do so during weekdays because she is at work. Thus, once the state has assessed a person’s need and determined the level of Medicaid-financed home care that is appropriate and necessary, it does not matter whether the paid caregiver is from an agency, a stranger hired through a newspaper ad, or a friend or relative. At that point, Medicaid has determined that the consumer requires assistance beyond what can be reasonably expected from unpaid caregivers.

“Even before the Supreme Court’s Olmstead decision, we had been looking for new ways to get needed services to consumers at home, particularly hard-to-reach people in rural areas of the state. Cash & Counseling offered us a new way that seemed to make sense—give people an allowance so they could hire their relatives and neighbors to care for them at home. We were skeptical, but we really wanted it to work, and it did.”

—Suzanne Crisp, former assistant director, Arkansas Division of Aging and Adult Services

When the Cash & Counseling demonstration was launched in 1996, little empirical evidence existed that consumers could or would successfully direct their own personal assistance services. The idea made sense—advocates were passionate about it and policy-makers from both major political parties were intrigued by it—but it had not been rigorously tested. Cash & Counseling tested the idea and found encouraging results.

Key Features of Cash & Counseling Programs in Arkansas, Florida, and New Jersey

FEATURE	ARKANSAS IndependentChoices	FLORIDA Consumer Directed Care	NEW JERSEY Personal Preference Program
Demonstration enrollment period	December 1998 to April 2001	June 2000 to July 2002 (adults) and June 2000 to August 2001 (children)	November 1999 to July 2002
Eligible population	Elderly and nonelderly adults with physical disabilities (may also have cognitive disabilities) who were eligible for the state plan Medicaid personal care program.	Elderly and nonelderly adults with physical disabilities, and children and adults with developmental disabilities who were receiving services under the HCBS [*] waiver.	Elderly and nonelderly adults with physical disabilities who were already enrolled in the state plan Medicaid personal care program.
Services included in calculating the allowance amount	Personal care	HCBS waiver services, except case management/support coordination. ¹	Personal care
Hiring restrictions	Could not hire legally responsible relatives (such as spouses or parents) or representative.	None	Could not hire representative.
Median monthly prospective allowance of all demonstration enrollees	\$313	\$829 (adults) and \$831 (children)	\$1,097
Funding for fiscal agent and counseling services	Paid for through pool of money generated from difference between \$12.36 per hour paid to agencies and \$8.00 per hour rate at which allowance was cashed out. Originally, agencies were paid a per-client per-month rate for counseling and fiscal services, which was reduced at six-month intervals. Later in the demonstration, agencies were paid a fixed rate for developing a spending plan and then paid per client per month for counseling and fiscal services.	Counseling paid for through existing Medicaid funding stream for case management and support coordination in traditional program. Fiscal agent fees paid for by schedule of fees charged to consumers (for example, \$5 per check) up to a maximum of \$25 per month.	Set aside 10 percent of care plan value to cover counseling services and some fiscal agent costs. From this pool of money, the state paid human services agencies a lump sum per consumer to complete a cash management plan and an hourly fee thereafter for consulting. State also paid fiscal agent for some tasks, such as the processing of employment-related forms. Consumers paid some fiscal agent fees (such as for cutting and stopping checks).
Entity conducting reassessment	Agencies (for traditional program) and counselors (for allowance recipients).	Support coordinators or case managers (for traditional program) and counselors (for allowance recipients).	Agencies (for traditional program) and Medicaid nurses (for allowance recipients).
Participation in other consumer-directed or home care programs	Demonstration enrollees could also participate in the HCBS waiver programs ElderChoices or Alternatives. ²	For adults with developmental disabilities, the demonstration excluded some northern counties with a state-funded consumer-directed program.	Demonstration enrollees could not participate in HCBS waiver programs or a state-funded consumer-directed program.

SOURCE: Mathematica Policy Research, Inc.

* HCBS=home- and community-based services.

¹ HCBS services covered under Florida's waiver included a wide variety of services, including behavioral therapy and personal care supplies, as well as personal care.

² ElderChoices provides nurse-supervised homemaker, chore, and respite services to nursing home-qualified elderly adults. Alternatives provides attendant care and environmental modifications to nonelderly adults and lets them choose and supervise caregivers. Among demonstration enrollees, 62 percent of the elderly participated in ElderChoices, and 9 percent of the nonelderly participated in Alternatives.

cash & counseling consumer story

Mr. Louis Corvese III, Cranston, R.I.



Louis Corvese, who is 52, was paralyzed from the shoulders down in a 1976 car accident, but his paralysis has not defined him or his life.

He says it is important to him that people see him and not his wheelchair.

“I had trouble at first adjusting to being in a wheelchair,” says the former U.S. Marine, “but you got to get used to it. It’s just the way it is. Deal with it and move on.”

And move on he has. Since his accident, he has worked in a restaurant, volunteered at the local Boys and Girls Club, served on the board of a disability advocacy organization, and become a college student. Currently, he is close to obtaining his associate’s degree at the Community College of Rhode Island, but he hopes to transfer to a four-year college and pursue a degree in social work. He wants to work with kids and with people who need help adjusting to life with a disability.

Louis would have difficulty doing all of this from a nursing home. And he tried many years ago to work with a home care agency. “Agency workers have their own agenda,” he says. “They come in and do what they want to do, what they think you need help with, and that’s it. It doesn’t have a lot to do with you and what you want.”

Louis, who lives in a separate apartment in his parents’ house, began receiving personal assistance services at home in the 1990s through a waiver program that allowed “severely disabled” Medicaid beneficiaries to hire their own workers. He has had the same worker—a close family friend—for 12 years and relies on him for “everything”—getting in and out of bed, dressing and undressing, toileting and grooming, cooking and cleaning, and transportation.

In June 2006, Louis switched from the waiver program to Rhode Island’s new Cash & Counseling program, called PersonalChoice. He says that PersonalChoice allows him to pay his longtime worker more per hour than he could before. He also says he’s excited about the added flexibility in his budget. “Before I could only pay my worker, but now I can save up for things that make it easier for me to live on my own,” he says.



PART 2

Cash & Counseling Evaluation Results



In general, Cash & Counseling worked well for consumers of all ages—including the elderly—and their caregivers. It appears to be an excellent option for states seeking to increase access to personal care and improve the well-being of both consumers and caregivers. Despite the favorable outcomes, however, careful attention must be paid to the design and implementation of a Cash & Counseling program to ensure that the program runs efficiently and to avoid unnecessary cost increases.

Below is a discussion of the key findings of the independent evaluation of the Cash & Counseling three-state demonstration. Results are divided into three categories: Cash & Counseling’s impact on quality of care and the health and safety of participants (quality outcomes); its impact on Medicaid costs (cost outcomes); and its impact on both paid and unpaid caregivers (worker outcomes).

“...[P]atients make intelligent decisions—when we let them do it. For instance, disabled people in government-run ‘cash and counseling’ programs—monthly, need-based health allowances, spent at the discretion of the participants—consistently receive better care than those who lack discretion.”

—U.S. Representative Tom Coburn in *Wall St. Journal* op-ed on May 18, 2006

Quality Outcomes

Because personal assistance services are delivered at home to consumers who are considered especially vulnerable, quality is a key concern. In each of the original three states and across all age groups, Cash & Counseling participants reported that the program resulted in a major improvement to their care and overall well-being. Among the evaluation’s key quality findings, Cash & Counseling: (1) significantly reduced unmet personal care needs; (2) did not increase adverse health outcomes and, in some cases, reduced the risk of such outcomes; (3) received high marks for the quality of life experienced by participants and their primary caregivers; and (4) did not result in misuse of Medicaid funds or abuse of consumers.

1. **Cash & Counseling significantly reduced the unmet needs of Medicaid consumers who require personal assistance services.** Cash & Counseling participants were far less likely to report unmet needs for personal assistance services than those enrolled in the control group. Cash & Counseling reduced the percentage of people reporting unmet needs by 10 to 40 percent in each of the three states, and significantly increased the percentage of consumers receiving services in Arkansas and New Jersey.

- In Arkansas, nine months after enrolling, 95 percent of Cash & Counseling participants reported receiving paid personal assistance services in the previous two weeks, while less than 75 percent of the control group received any paid personal assistance services. Even control group members who did receive services got only 68 percent of the care hours they were approved to receive.
- In New Jersey, nine months after enrollment, more than 90 percent of the Cash & Counseling participants received services in the previous two weeks, while about 80 percent of control group members received services in the same time period.

Cash & Counseling participants were more likely to get paid help with house-keeping and with routine health care, including help with medications, blood pressure checks, and physical exercise. In addition, Cash & Counseling consumers received more hours of paid care on average than did the control group. And Cash & Counseling participants reported higher levels of satisfaction with the job done by their hired caregivers, who were more likely to arrive on time and complete their work. Cash & Counseling participants also were less likely than control group members to be neglected, treated disrespectfully, or have things stolen from them.

2. **Cash & Counseling participants experienced positive health outcomes.**

Cash & Counseling participants in all age groups in all three states were no more likely to suffer any care-related health problems than those receiving traditional agency services. In some cases, Cash & Counseling enrollees demonstrated a reduced risk of experiencing health problems, such as urinary tract infections, and adverse events, such as falls. In almost one-third of the comparisons made for the separate age groups in each state on 11 different health-related measures, Cash & Counseling participants were significantly less likely to experience health problems than those receiving traditional services. For example:

- In New Jersey, elderly and nonelderly adult Cash & Counseling enrollees were less likely than control group members to have fallen.

Percentage of Consumers Reporting an Unmet Personal Care Need at Nine Months

Nonelderly Adults

% Arkansas



Florida



New Jersey



Elderly Adults

Arkansas



Florida



New Jersey



Children

Florida



0

30%

60%

■ Treatment group (Cash & Counseling participants)

■ Control group

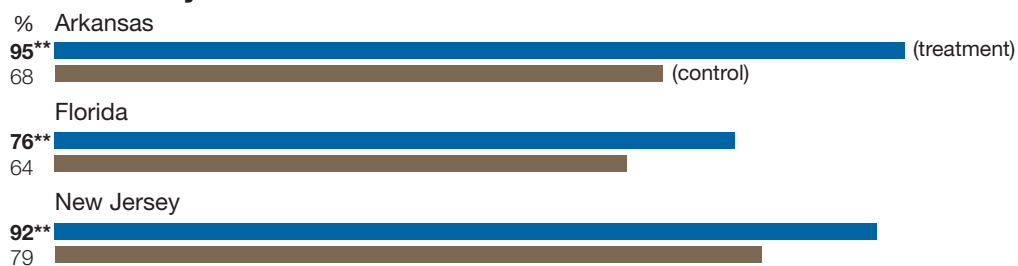
* ** Significantly different from control group at .05, .01 level, respectively

SOURCE: Mathematica Policy Research, Inc.

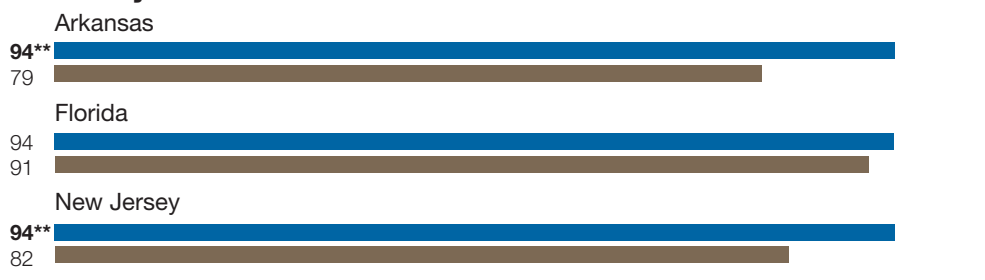
NOTE: Sample is restricted to consumers residing in the community at the time of the nine-month interview.

Percentage of Consumers Receiving Paid Personal Assistance at Nine Months

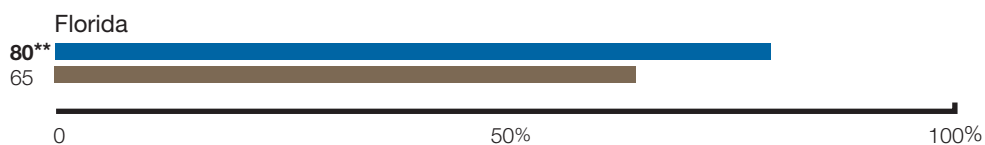
Nonelderly Adults



Elderly Adults



Children



0 50% 100%

■ Treatment group (Cash & Counseling participants)

■ Control group

*, ** Significantly different from control group at .05, .01 level, respectively

SOURCE: Mathematica Policy Research, Inc.

NOTE: Sample is restricted to consumers residing in the community at the time of the nine-month interview.

Percentage of Consumers Reporting Care-Related Health Problems

	Arkansas		Florida		New Jersey	
	TREATMENT GROUP	CONTROL GROUP	TREATMENT GROUP	CONTROL GROUP	TREATMENT GROUP	CONTROL GROUP
Nonelderly Adults						
Had a fall	28	29	15	18	19**	28
Contractures developed/worsened	26	25	9	14	25	28
Bedsore developed/worsened	6	13	4	6	9	13
Had a urinary tract infection	19	22	8	12	17	19
Elderly Adults						
Had a fall	19	19	18	20	13**	20
Contractures developed/worsened	16	20	20	22	18**	27
Bedsore developed/worsened	8	7	8	9	7	7
Had a urinary tract infection	18	21	20	22	16	16
Children						
Had a fall			27**	36		
Contractures developed/worsened			9*	13		
Bedsore developed/worsened			3*	6		
Had a urinary tract infection			3*	6		

■ % Treatment group (Cash & Counseling participants) ■ % Control group

*, ** Significantly different from control group at .05, .01 level, respectively

SOURCE: Mathematica Policy Research, Inc.

NOTE: Means were predicted using logit models. Sample sizes for some variables in this table were smaller because of differences in item nonresponse and skip patterns.

- In Arkansas and New Jersey, elderly Cash & Counseling participants were less likely to have had contractures develop or worsen than members of control group.
- Nonelderly adult Cash & Counseling participants in Florida were less likely than the control group to have urinary tract infections.
- Nonelderly adults in both Arkansas and New Jersey were less likely than their control group peers to have had bedsores develop or worsen.

Thus, initial concerns that Cash & Counseling might place participants at greater risk of illness or injury were unwarranted.

3. **Cash & Counseling improved quality of life for participants and their caregivers.** Across all three states, Cash & Counseling participants were up to 90 percent more likely than those in the control group to be very satisfied with how they led their lives. They also were half as likely to report that they were dissatisfied with their lives. Up to two-thirds of those enrolled in Cash & Counseling reported that the program had greatly improved their lives, and at least 85 percent of participants said they would recommend the Cash & Counseling program to others.

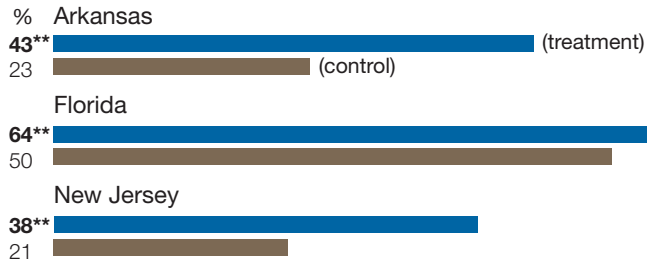
Cash & Counseling also greatly improved the quality of life for participants' primary unpaid caregivers—those who delivered the lion's share of unpaid personal assistance services to consumers before Cash & Counseling started. Examples of primary caregivers are the adult daughter of a frail elderly parent or the mother of a child with disabilities. Under Cash & Counseling, these primary caregivers were significantly less likely to report being dissatisfied with the consumers' paid care when compared to the primary caregivers of control group members.

In addition:

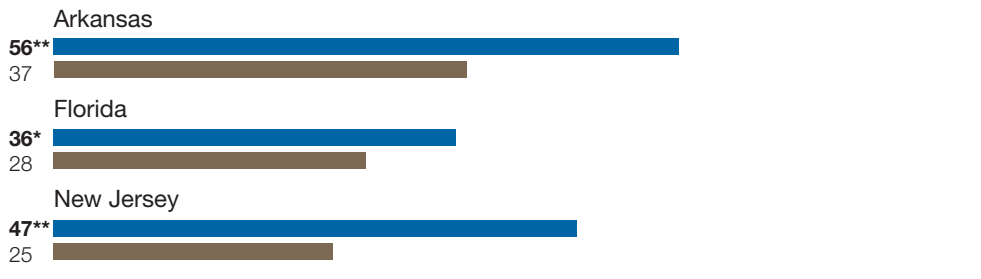
- Primary caregivers of Cash & Counseling participants were much less likely than primary caregivers of control group members to report emotional and financial stress, and were significantly more satisfied with their lives in general.
- Cash & Counseling participants' primary caregivers were less likely to report that their care-giving duties limited their privacy or got in the way of their social lives.
- Cash & Counseling participants' caregivers were more satisfied, in general, with the overall care that the person they were caring for received.

Percentage of Consumers Reporting They are Very Satisfied with Life

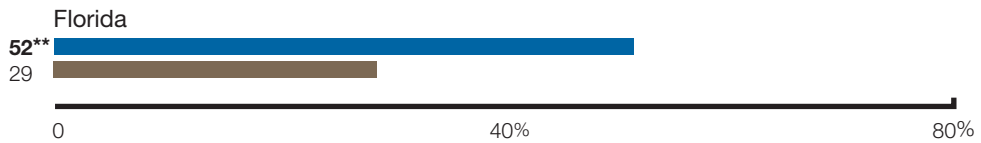
Nonelderly Adults



Elderly Adults



Children



■ Treatment group (Cash & Counseling participants)
■ Control group

*, ** Significantly different from control group at .05, .01 level, respectively

SOURCE: Mathematica Policy Research, Inc.

Percentage of Consumers Reporting that Cash & Counseling Improved Their Lives a Great Deal

% Nonelderly Adults



Elderly Adults



Children



0 40% 80%



SOURCE: Mathematica Policy Research, Inc.

Percentage of Caregivers Reporting Emotional, Physical, and Financial Strain

Caregivers experienced “great deal” of *emotional strain*

% **Adults**

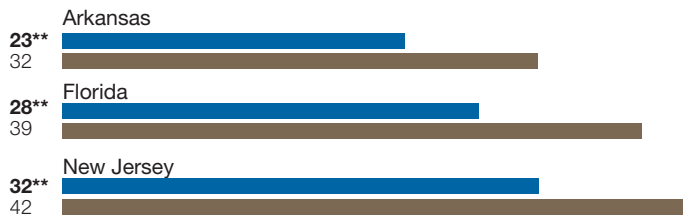


Children



Caregivers experienced “great deal” of *physical strain*

Adults

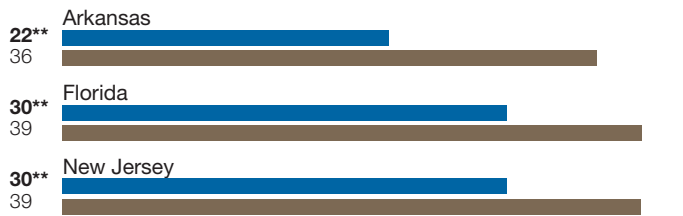


Children



Caregivers experienced “great deal” of *financial strain*

Adults



Children



0 30% 60

■ Treatment group (Cash & Counseling participants)
 ■ Control group

*, ** Significantly different from control group at .05, .01 level, respectively

SOURCE: Mathematica Policy Research, Inc.

- Caregivers of Cash & Counseling participants were less likely to report high levels of physical strain or to have experienced physical health problems. They also were less likely than control group caregivers to rate their health as “poor” or “fair”.

4. **Cash & Counseling did not result in misuse of Medicaid funds or abuse of consumers.** Cash & Counseling gives consumers control over how state Medicaid funds are spent to address their personal care needs. Early concerns included the possibility that consumers might misuse their allowances or that consumers might be exploited or abused by family members or other hired workers. Contrary to these predictions, however, while most Cash & Counseling participants hired family members as their workers, there was virtually no fraud or abuse under Cash & Counseling.

To receive an allowance, consumers were required to prepare a spending plan that laid out how they would use that allowance, and those plans had to be approved by state-provided counselors, who were available to give consumers advice and guidance. Support staff hired by the Cash & Counseling programs in each state also monitored check requests and employee time sheets. Interviews with counselors revealed that instances of fraud and abuse were exceedingly rare. For example, only one of 37 counselors interviewed in New Jersey reported any incidents of financial exploitation of consumers, and that incident was related to a single enrollee and was quickly resolved.

Cost Outcomes

Cash & Counseling was designed to give consumers control and flexibility over their care without costing Medicaid any more than if those consumers received personal assistance services the traditional way, through a Medicaid-contracted home care agency.

Regarding costs, the Cash & Counseling evaluation found that: (1) Medicaid personal care costs were higher under Cash & Counseling than under the traditional agency model, mostly because enrollees received more of the care they were authorized to receive; (2) Increased Medicaid personal care costs under Cash & Counseling were partially offset by savings in institutional and other long-term-care costs; and (3) Cash & Counseling need not cost more than traditional services if states carefully design and monitor their programs.

1. **Medicaid personal care costs were somewhat higher under Cash & Counseling, mainly because enrollees received more of the care they were authorized to receive.** In Arkansas and New Jersey, higher costs under Cash & Counseling resulted from so many more consumers receiving the paid hours of service they were authorized to receive. Recipients of agency care in these two states received only a fraction of their authorized care plan hours, and some received no services at all. In Florida, the higher costs under Cash & Counseling were the result of short-term statewide increases in funding for personal care for people with disabilities, the timing of which made increased funds more available to Cash & Counseling enrollees than to consumers in the control group.
2. **Increased Medicaid personal care costs under Cash & Counseling were partially offset by savings in institutional and other long-term-care costs.** Costs for other Medicaid services, primarily nursing home and other types of long-term care, were lower under Cash & Counseling in each state and each age group. The most significant differences in the first year after enrollment were for younger adults in Arkansas and for children in Florida. For those two groups, nonpersonal care costs were 17 percent and 15 percent lower, respectively, under Cash & Counseling compared to the control groups. For each of the other age groups in these two states and for both younger and older adults in New Jersey, nonpersonal care costs were 4 to 7 percent lower under Cash & Counseling.

Cash & Counseling’s Effects on Long-Term Care and Total Medicaid Costs in Arkansas over Three-Year Grant Period

	TREATMENT GROUP	CONTROL GROUP	DIFFERENCE
Incurred Any Medicaid Nursing Home Expenditures by End of Third Year (%)			
New applicants for Personal Care Services (PCS)	10.7	15.0	-4.3*
Continuing PCS users	17.3	20.3	-3.0*
Cumulative Medicaid Long-Term-Care Costs, Per Consumer (Other than PCS) for Three Years (\$)			
New applicants	8,100	9,725	-1,625
Continuing PCS users	11,362	13,443	-2,081*
Cumulative Medicaid Costs Per Consumer Over Three Years, All Services (\$)			
New applicants	34,655	25,567	9,088*
Continuing PCS users	34,244	33,799	445

*Statistically significant at the .05 significance level

SOURCE: Mathematica Policy Research, Inc.

Points:

- Cash & Counseling reduced nursing home use and total long-term-care costs (other than personal care) by about 15 to 17 percent for both new applicants for PCS and those who already were receiving the services at time of enrollment.

- For continuing beneficiaries, savings in nursing home use and other Medicaid services essentially offset the higher personal care costs. The treatment group’s total Medicaid cost per person over the three years was only 1.3 percent above the control group’s. For new applicants for PCS, the savings in other long-term-care costs did not offset the much higher PCS costs, which arose from most control group members not getting any services.

In Arkansas, in particular, savings in long-term-care costs under Cash & Counseling helped offset higher personal care costs. A special, longer-term follow-up study of the Arkansas Cash & Counseling program, made possible by the fact that it started almost a year earlier than the other two states, showed that savings in long-term care persisted in the third post-enrollment year. By then, Cash & Counseling had reduced nursing facility use 18 percent over the entire three-year study period. The results are especially striking for consumers who were receiving agency services before enrolling in Cash & Counseling. For this group, the savings in other Medicaid services fully offset the higher personal care costs over the three-year grant period. In Florida and New Jersey, total Medicaid costs for Cash & Counseling participants during the second year were 8 to 12 percent higher than they would have been had those beneficiaries not enrolled in Cash & Counseling. Data from the third post-enrollment year are not available for Florida and New Jersey.

3. **Cash & Counseling need not cost more than traditional programs if states carefully design and monitor their programs.** Cash & Counseling does not need to cost states more than its traditional Medicaid personal care programs. How? States can design their Cash & Counseling programs so that the cost per month is budgeted to match the cost per month of its traditional system, assuming that home care agencies will fully meet their care obligations. If the traditional system delivers the services beneficiaries are authorized to receive, there should be no difference in planned costs.

Additional cost-controlling strategies to consider include:

- Paying less for financial management and counseling services than home care agencies would be paid for administrative overhead, which is feasible and appropriate because consumers take over some responsibilities.
- Recovering allowance amounts that are not used. Cash & Counseling allows enrollees to carry over unused allowance funds from month to month, but states should require that any unbudgeted funds remaining at the end of the year be returned to the state.
- Regularly monitoring the costs of both Cash & Counseling and home care agency programs, and reducing allowances for Cash & Counseling consumers if they exceed spending on agency services for consumers with comparable care plans. However, Cash & Counseling consumers should not be penalized if those receiving agency services do not get all of their authorized hours.

Worker Outcomes

Cash & Counseling recognizes the intimacy of the care-giving relationship by allowing consumers to directly hire and pay workers whom they trust, including family members and friends. Concerns about Cash & Counseling among home care industry professionals and union representatives, however, range from questions about the health, safety, or exploitation of directly hired personal care workers to worries about Cash & Counseling's potential to hurt the home health industry.

To respond to some of these concerns, the Cash & Counseling evaluation compared the experiences of paid workers hired by Cash & Counseling participants and paid agency workers assisting those in the control group. The evaluation found that: (1) Directly hired workers under Cash & Counseling and home care agency workers felt equally prepared to do the job expected of them; (2) Directly hired workers and agency workers reported very similar rates of physical strain and injuries due to caregiving; (3) Directly hired workers were twice as likely as agency workers to report satisfaction with their compensation; and (4) Higher levels of emotional stress among directly hired workers were limited to those workers who were related to the employing consumer.

Further, the previously reported quality data on the control group's unmet needs for care suggest that (5) Cash & Counseling had a minimal effect on the revenues of home care agencies.

1. **Directly hired workers under Cash & Counseling and home care agency workers felt equally prepared to do the job expected of them.** Fifty to 70 percent of Cash & Counseling workers reported that they had had formal training in caregiving compared to 95 percent of agency workers, but both groups reported that they felt prepared to handle their duties. Between one-quarter and one-half of caregivers hired by Cash & Counseling consumers had previously worked for those consumers as unpaid primary caregivers, and only 20 percent of caregivers hired under Cash & Counseling did not have a prior relationship with their employer. Up to 40 percent of Cash & Counseling caregivers lived with their employer. Most caregivers for children were their mothers, while caregivers for young adults were usually parents. Daughters tended to be the caregivers of older adults.
2. **Directly hired workers and agency workers reported very similar rates of physical strain and injuries due to caregiving.** Despite the fact that Cash & Counseling workers were less likely to have received formal training, the evaluation found no evidence that they suffered unusual levels of physical strain and injury for the tasks they were performing and the hours of care provided. In fact, their injury

Working Conditions

	DIRECTLY HIRED WORKERS (Cash & Counseling)	AGENCY WORKERS
Hourly Wage		
Arkansas	\$6.00	\$6.30
Florida and New Jersey	\$10.00	\$9.00
Receives Fringe Benefits	2 to 5%	17 to 24%
Very Satisfied with Wages and Benefits	41 to 50%	19 to 23%
Very Satisfied Overall	79 to 85%	69 to 83%

SOURCE: Mathematica Policy Research, Inc.

rates were generally similar to rates reported by agency workers. And directly hired workers in New Jersey were significantly less likely than agency workers in that state to report high levels of physical strain. The same was found for workers directly hired to care for children in Florida.

- 3. Directly hired workers were twice as likely as home care agency workers to report satisfaction with their compensation.** In Florida and New Jersey, Cash & Counseling caregivers were paid on average 10 to 15 percent (about \$1) more per hour than home care agency workers, while in Arkansas, Cash & Counseling caregivers were paid approximately 4 percent less per hour. Most Cash & Counseling workers worked part-time and very few received fringe benefits. More, but still less than one-quarter, of agency workers received such benefits.
- 4. Higher levels of emotional stress experienced among directly hired workers were limited to those workers related to the employing consumer.** Across states, 40 to 60 percent of the directly hired workers reported “some” or a “great deal” of emotional strain. Hired workers who were related to the consumers they were caring for reported higher rates of emotional strain than did agency workers. Conversely, directly hired workers who were not related to the people they were caring for reported rates of emotional strain that were almost identical to those of agency workers. Unrelated, directly hired workers also received higher wages, were more likely to receive training, and provided far fewer unpaid hours of care than did related workers.

5. **Cash & Counseling had a minimal effect on the revenues of home care agencies.** Some of the evaluation findings suggest that home care agencies frequently are unable to supply all of their clients' already authorized services. Thus, agencies probably lose relatively little revenue to Cash & Counseling because they would have difficulty meeting the needs of additional consumers. Furthermore, Cash & Counseling is not for everyone. Between 5 and 15 percent of eligible Medicaid beneficiaries enrolled in Cash & Counseling in the three demonstration states. Finally, some agencies have indicated that consumers who wish to manage their own care are often the ones who are most difficult for agencies to serve adequately. Allowing these consumers to direct their own care frees up agency resources to focus on the clients they are best suited to help.

Evaluation Conclusion

The Cash & Counseling Demonstration and Evaluation program successfully helped states meet their objectives to better serve the long-term care Medicaid population. The three-state demonstration program provided consumers, including the elderly, better access to care, more satisfactory care, and more flexibility in care plan design. In addition, the program substantially improved the lives of family caregivers, imposed no undue hardship on workers who were directly hired by Cash & Counseling participants, and had minimal financial impact on home care agencies. Overall, these results add up to fewer unmet needs and a higher quality of life for consumers and caregivers who participate in Cash & Counseling. Further, cost should not be a barrier to implementing a Cash & Counseling program.

INTERACTIVE CASH & COUNSELING DATA AVAILABLE ONLINE

For more details on the findings of the Cash & Counseling evaluation, including a user-friendly interactive data tool, please visit the Cash & Counseling Web site at www.cashandcounseling.org. The data tool allows users to review data, create charts, and explore statistics from the original Cash & Counseling demonstration. The data on this site are intended to serve several audiences. Policy-makers and program administrators may want quick information on variables of interest, while researchers may want to explore simple questions prior to conducting more complex analyses with the full public use data files.

cash & counseling consumer story

Ms. Karla Herrera, Miami, Fla.



Karla Herrera, 22, was born with microcephaly, cerebral palsy, and spastic quadriplegia. Her disabilities are severe and she requires constant help and supervision.

But her mother, Yolanda Herrera, has big plans for her: an education, a trade, and even her own baking business. “By next year,” Yolanda says, “she will be living a typical life, with assistance.”

None of this would be possible, Yolanda says, without the empowerment she found in Florida’s Cash & Counseling program, now called Consumer Directed Care Plus (CDC+). With the resources and flexibility afforded by CDC+, Karla has made quantum leaps developmentally. Before CDC+, Karla received personal assistance services, mostly for basic hygiene, from a home health agency. Since enrolling Karla in CDC+ five years ago, Yolanda has used her daughter’s monthly budget to purchase an array of professional services and products aimed at expanding Karla’s everyday living skills and building her independence.

“Some day, I’m not going to be around,” she says. “Karla needs to learn to be the most independent person she can be.”

Before CDC+, Yolanda says she felt she was failing her daughter. “With the help of CDC+, we were able to establish a learning environment for Karla,” Yolanda says. “We purchased professional help that gave us the opportunity to provide Karla with what she needs to function in society.”



Today, with assistance, Karla performs many of the day-to-day activities previously done for her by a home health aide. She reads on a first-grade level. She walks. With Karla’s CDC+ budget, Yolanda hired an expert to teach Karla and her family how to use a portable picture-based computer system to communicate. Karla recently graduated from high school, where she learned how to function in virtually any classroom setting.

Soon, Karla will participate in a culinary program at a vocational school, where she will learn to read recipes and bake. Yolanda plans to use part of Karla’s CDC+ budget to hire a student graduate from the

same vocational school to work with Karla at her new home-based office. The goal is for Karla to make and sell her own line of cookies and dog treats—dubbed “Karla’s Kookies”—so that she can begin generating her own income.

“Karla’s disabilities are so severe that she will always need someone to guide her,” says Yolanda, “but she has done a lot in a very short time. And we’re not done yet.”

PART 3

Cash & Counseling Going Forward



“This [expansion of Cash & Counseling] is wonderful news for elderly and younger people with disabilities. This successful model program will allow caregivers and beneficiaries to live independently and with the freedom they desire.”

—Tommy G. Thompson, former Secretary, U.S. Department of Health and Human Services

Today, the three original Cash & Counseling states are continuing and, in some cases, expanding their Cash & Counseling programs. And, based on the promising outcomes of the demonstration program, both the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services funded, in October 2004, an expansion of the program to 11 additional states.

- Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia were awarded three-year grants of up to \$250,000 to implement the Cash & Counseling model.
- Two of these states, Minnesota and New Mexico, were awarded an additional \$100,000 to implement innovative practices that go beyond the basic Cash & Counseling model.

Additionally, Illinois was funded separately by the Retirement Research Foundation to create a Cash & Counseling option, bringing the total number of states implementing Cash & Counseling to 15. As with the original three-state program, the Cash & Counseling national program office (NPO) located at the Boston College Graduate School of Social Work coordinates and directs the replication project and provides ongoing technical assistance to the states.

The expansion states were chosen by the funding partners and a national advisory committee. The states selected were those whose proposed programs were designed to serve both aging and disability communities; had adequate enrollment potential; demonstrated a clear understanding of the Cash & Counseling model; had experience with Medicaid waivers; and had a strong record of interagency communication, a realistic implementation plan, and commitment from significant leadership.

As of the fall 2006, the Cash & Counseling expansion states were in various stages of program implementation with all states expected to be fully functioning and enrolling consumers in 2007. The states are working with the Centers for Medicare & Medicaid Services (CMS) to obtain the currently necessary federal waivers that will allow them to implement their programs. Most states are working under 1915(c) waivers, with only two states opting for 1115 waivers. In January 2007, such waivers will no longer be required to implement a Cash & Counseling program.

“We’ve seen a decline in Vermont over the years in the number of people using agency services. We have 65 percent of our consumers self-directing now, and it’s a growing trend. Cash & Counseling is just the next logical step in where the provision of supports and services needs to go.”

—Theresa Wood, Deputy Commissioner, Vermont Department of Disabilities, Aging, and Independent Living

The 12 expansion states, from their various perspectives partway through their grants, can offer a broad spectrum of advice to states considering a Cash & Counseling program. Many have commented on the “hurry up and wait” process of applying for a federal waiver—a requirement that will soon be eliminated. Others comment that turnover in state government can cause unplanned implementation delays, and building and maintaining relationships with key stakeholders both within state government and the community at large require significant time and effort. States also advise building in adequate amounts of time to train program workers, including enrollment outreach workers, case managers and counselors, and fiscal agents, and to develop a comprehensive, consumer-tested marketing plan. A publication focused on technical assistance around implementation issues is forthcoming for states interested in creating a Cash & Counseling option.

While directing the expansion of the model to 12 more states, the Cash & Counseling national program office and its technical assistance staff and research affiliates also are addressing, through various efforts and projects, a number of implementation challenges that arose during the original three-state program. These efforts include:

- Development of a Web-based, consumer-direction module that will allow faster communication between consumers and their support team and generate reports on consumer expenditures.
- Exploration of worker registries to help link consumers with potential workers. Clearly, Cash & Counseling worked best for those who had family, friends, and neighbors ready to fill the paid worker role. Consumers who did not have workers on hand had trouble locating appropriate people, and some people did not participate in Cash & Counseling for this reason.
- Development of a training curriculum for consumer support staff. States implementing Cash & Counseling must retrain existing case managers or hire and train new counselors to assist consumers in managing the responsibilities of self-direction. Faculty at Boston College Graduate School of Social Work, with funding from CMS, are developing and testing a support broker training curriculum. The first modules of this curriculum can be found on the Cash & Counseling Web site: www.cashandcounseling.org.
- Development of a quality management system and a continuous quality improvement approach for self-directed personal assistance services. With help from the Scripps Gerontology Center at Miami University in Ohio, the Cash & Counseling NPO has created *A Guide to Quality in Consumer-Directed Services*, which can be found on the Cash & Counseling Web site.

Twelve States Implementing a New Cash & Counseling Option

STATE	PROGRAM NAME	GOALS	TARGET POPULATION	NUMBER OF ANTICIPATED PARTICIPANTS	AREA SERVED	WAIVER USED	LEAD AGENCY	GRANT AMOUNT
Alabama	Personal Choices	To expand consumer direction as an option in all traditional waivers.	Seniors and adults with physical disabilities currently receiving personal care or personal assistance in certain waivers.	90 in first year of enrollment	Seven counties: Bibb, Fayette, Greene, Hale, Lamar, Pickens, and Tuscaloosa	1115	Alabama Department of Senior Services	\$250,000
Illinois	Cash & Counseling	To expand consumer direction opportunities for Illinois' frail elderly.	Frail elderly age 60 and over.	200 in state fiscal year 2007	Four regions containing Kankakee, Tazewell, Marshall, Stark, Woodford, Macon, Bond, Clinton, Washington, Monroe, Randolph, and Madison counties	None at this time	Illinois Public Health Association and Illinois Department on Aging	\$378,000 from Retirement Research Foundation
Iowa	Consumer Choices Option	To use public funds as investments in people's lives rather than as mere mechanisms to purchase human services.	Older Iowans and people with disabilities who are eligible for HCBS waivers.	400 in first year of enrollment	Statewide by March 2007	1915(c)	Iowa Department of Human Services	\$250,000
Kentucky	Consumer Directed Option	To give consumers the option to control their non-medical 1915(c) waiver services,	People who are elderly or have disabilities; people with mental retardation or developmental disabilities, people with acquired brain injuries, and those enrolled in one of Kentucky's three 1915(c) waivers.	250 in first year of enrollment	Statewide	1915(c)	Cabinet for Health and Family, Department for Medicaid Services	\$250,000
Michigan	Self-Determination in Long-Term Care	To empower MI Choice participants through person-centered planning and control over service provision and resource utilization.	Elders and younger persons with physical disabilities.	600+ by the end of the three-year grant period	Four pilot sites: Detroit; Upper Peninsula, Lansing area, and Southwest Michigan	1915 (c)	Office of Consumer-Directed Home- & Community-Based Services, Michigan Department of Community Health	\$250,000
Minnesota	Consumer Directed Community Supports	To create permanent, multi-point, statewide access to a consumer-directed option for older adults, adults with physical disabilities, and their family caregivers.	Older adults and adults with physical disabilities.	750 by September 30, 2007	Statewide	1915 (c)	Minnesota Department of Human Services	\$350,000
New Mexico	Mi Via (My Way)	To facilitate greater participant choice and control over the types of services and supports that are purchased within an agreed-upon budgetary amount; to increase awareness and knowledge about Mi Via as a valuable waiver choice; to serve the most people possible within available resources.	Current participants in Medicaid waiver programs: Disabled and Elderly, Developmentally Disabled, HIV/AIDS, and Medically Fragile. Persons with brain injuries will also be eligible.	400 by October 2007	Statewide	1915 (c)	New Mexico Aging and Long-Term Services Department	\$349,153
Pennsylvania	Cash & Counseling	To permit people with disabilities or limitations to have the right to live in the least restrictive and most integrated setting appropriate to their needs and to receive consumer-centered services.	Pilot program for frail elderly.	400 by end of three-year grant period	Initially available in pilot sites, with the goal of phasing it in statewide for more populations.	1915 (c)	Governor's Office of Health Care Reform	\$250,000

Twelve States Implementing a New Cash & Counseling Option (continued)

STATE	PROGRAM NAME	GOALS	TARGET POPULATION	NUMBER OF ANTICIPATED PARTICIPANTS	AREA SERVED	WAIVER USED	LEAD AGENCY	GRANT AMOUNT
Rhode Island	Personal-Choice	To enable Medicaid recipients to direct their own services and supports by allowing the maximum flexibility of fund distribution to meet individual needs and preferences, while preserving necessary accountability to the state and federal governments.	Adults with disabilities and elders who are eligible for certain waivers.	400	Statewide	1915 (c)	Rhode Island Department of Human Services, Center for Adult Health	\$250,000
Vermont	Flexible Choices	To further shift the balance to home- and community-based services, and advance current trends in consumer direction.	Elders and adults with disabilities.	50 in first year, 250 by end of grant period	Statewide	1115	Department of Disabilities, Aging and Independent Living	\$249,416
Washington	New Freedom	To implement a service system that will expand consumer-directed care to a state-of-the-art level.	Adults with disabilities and older individuals who require nursing facility level of care.	100 in first year	King County	1915(c)	The Department of Social and Health Sciences	\$250,000
West Virginia	Personal Options	To have a home- and community-based system that is driven by the needs of consumers.	INITIALLY: Seniors over age 60 and adults with physical disabilities. FUTURE: Children and adults with mental retardation and developmental disabilities.	400	Statewide	1915 (c)	Bureau of Senior Services	\$250,000

Cash & Counseling and the 2005 Deficit Reduction Act

Cash & Counseling's success to date has created champions for the model within the federal government. The most notable evidence: the 2005 Deficit Reduction Act (DRA), which, when it takes effect on January 1, 2007, will remove the requirement that states must apply for and be granted a Section 1115 or 1915(c) waiver before adding a Cash & Counseling option to their Medicaid programs.

Specifically, the DRA makes available to states several new options for implementing a Cash & Counseling program. These options include: Section 1915(i), which creates a state plan option for home- and community-based waiver services; Section 1915(j), which creates a state option for Cash & Counseling; and the Money Follows the Person Rebalancing Demonstration.

Section 6086 of the DRA created a new Section 1915(i) of the Social Security Act, which allows states to amend their Medicaid state plans to offer home- and community-based waiver services as an optional benefit to consumers whose incomes are below 150 percent of the federal poverty level. Section 1915(i) removes the previous requirement that community-based services could be made available only to consumers with disabilities who would otherwise need to move into institutional care. The new 1915(i) option will make it possible to offer community-based services to consumers based on their functional need for services and not on their need for institutional care.

Section 6087 of the Deficit Reduction Act created a new Section 1915(j) of the Social Security Act. The new Section 1915(j) allows states to offer, without first obtaining a waiver, a “cash & counseling” option within their regular Medicaid state plans. Section 1915(j) authorizes states to offer program participants a flexible budget as opposed to a limited number of aide visits or hours of service. States also will be able to define more broadly the range of personal care services covered under their Medicaid plans and participants in self-directing programs will be permitted to purchase goods and services (such as chairlifts and touch lamps) and make environmental modifications (such as adding wheelchair ramps to their homes) that decrease their dependence on helpers and enable them to live more independently. In addition, federal law and regulations already permit consumers to hire, fire, supervise, and manage workers instead of requiring agency-delivered aide services, but under the DRA, with appropriate safeguards, states may elect to allow spouses and parents of minor children to become paid workers as well. Previously, this was possible for consumers receiving state plan personal care services only under hard-to-get 1115 waivers.

The Money Follows the Person Rebalancing Demonstration will make \$1.75 billion in competitive grants available to states that create “choice-based” financing for long-term-care services, such as implementing a Cash & Counseling option. Essentially, this federal grant program will help financially support states as they strengthen their systems of community-based supports and move more eligible Medicaid consumers with disabilities from institutional settings back to their homes and communities.

“The D(eficit) R(eduction) A(ct) is a long-awaited commitment to independence, choice, and dignity for countless Americans who want to have control of their lives, and gives states many of the tools they need to rebalance their long-term support programs.”

—Dennis Smith, director, CMS Center for Medicaid and State Operations, in July 2006 Congressional testimony

Although the full impact of these changes is still to be determined, the DRA does significantly change the bureaucratic requirements for states that want to implement a Cash & Counseling program and gives states several options beyond the long and cumbersome waiver application and renewal processes. Presumably, existing Cash & Counseling programs will no longer be required—but may still choose—to renew their current 1915(c) or 1115 waivers when they expire. These federal-level changes will make it possible for Cash & Counseling to become an option in more states—giving thousands more elderly adults and people with disabilities choice and control over their personal assistance services.

cash & counseling consumer story

Mr. Calvin Dodson, Trenton, N.J.



Calvin Dodson, who is blind, has impaired physical coordination from being struck by a car several years ago, and requires dialysis for kidney disease three times a week, remembers well the challenges of working with a home care agency.

“I used to change agencies every three months because I was so frustrated,” he says. “It seemed like I got a different worker every week. I have no idea how many different workers I had, there were so many. I was always having to explain everything from the beginning, every time. And those that came, usually came late or left early, and never wanted to do the jobs I needed them to do.”

Despite his physical challenges, Calvin, who is 50, wants to continue living alone in his own efficiency apartment for as long as he can. “I was in rehabilitation in a nursing home for six months after I was hit by a car,” he says. “I never want to go back. It’s not like living there; they just do what’s on their list for you, nothing more, nothing less.”

Through New Jersey’s Cash & Counseling program, called Personal Preference, Calvin has been able to hire people he knows he can rely on to help take care of him. “I’ve only had three different workers since I joined Personal Preference six or seven years ago,” he says. Currently, his sister works for him in the mornings before she goes to her regular job and in the evenings on her way home.

Calvin also used part of his monthly Personal Preference allowance to purchase a voice-activated microwave so he could prepare his own food, as well as voice-recognition software for his computer so he could do his own online shopping for groceries, clothes, and other necessities.

When he’s not receiving dialysis three times a week for four hours, he spends time in his apartment or visits neighbors in his building. “I tell other folks in the building about Personal Preference,” he says. “I tell them it really helps. It’s me who is in control, instead of the agency being in control. I know that the money is paying for what it is supposed to pay for. And the money I’m able to pay my sister helps her out too.”



CONCLUSION

“We see this [Cash & Counseling] as a model for other states. It doesn’t serve the needs of every client and we understand that and think that’s the beauty of it. It’s not meant to supplant but only to supplement other options that are out there for the client.”

—Arkansas Governor
Mike Huckabee, June 2001

When Cash & Counseling was launched in 1996, its designers did not know if frail elderly Medicaid consumers and those with disabilities could and would successfully manage their own personal assistance services at home. In 2006, we know that they can and will—and that they are likely to benefit as a result.

As evidenced by the independent evaluation, the Cash & Counseling model of self-directed personal assistance services significantly improves the lives of people of all ages who need such services, as well as the lives of their unpaid primary caregivers. It also increases access to personal assistance services, helps consumers maintain their health status, and it does not increase fraud and abuse. Furthermore, it does not cost more than traditional agency services, if states design and monitor their programs carefully.

The evaluation results show that Cash & Counseling is a viable option for policy-makers interested in shifting the balance of long-term-care services from institutional to community settings. By providing participants the help they need to remain at



“A Cash & Counseling program makes state resources more flexible—which is the key word—for people with disabilities. It helps our citizens with disabilities to live more independent and happier lives and, importantly, it is optional.”

—U.S. Senator Amanda Ragan,
co-chair, Iowa Senate Human
Resources Committee



home and reducing the burden on primary caregivers, Cash & Counseling may delay or reduce nursing home use. Recently enacted federal provisions are expected to streamline or eliminate bureaucratic requirements that made it difficult for states to introduce a flexible budget option. Soon it will be much easier for states to implement Cash & Counseling so that thousands more consumers will have greater choice and control over the care they receive.

The Cash & Counseling national program office, which is directing the expansion of the program in 12 more states and working on efforts to address some specific implementation challenges faced by states, has made valuable technical assistance resources on Cash & Counseling available via its interactive Web site at www.cashand-counseling.org. The NPO and its funders—the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services—invite researchers, policy-makers, and others interested in self-directed personal assistance services to use the data, resources, and materials available on the Web site to help determine the feasibility of implementing a Cash & Counseling program in their own states.

cash & counseling consumer story

Mr. Harold Hamilton, Eden Valley, Minn.



Last year, following a heart attack, Harold Hamilton's doctor gave him two months to live.

Today, Harold, who is also diabetic and blind, is still very much alive at age 70, but he requires round-the-clock help with daily personal care activities and his health care needs. He considers himself fortunate that the person taking care of him 24/7 is also the person who knows him best: his wife, Violet. She has been his paid caregiver since Harold's enrollment in Minnesota's Consumer Directed Community Supports (CDCS) program.

"He's much more comfortable with me," Violet says. "I can take him places, to his doctors' appointments, that the [home care agency] workers couldn't, and I know much more about his symptoms."

For years, Violet worked full-time at a Frigidaire plant an hour from home to support herself and Harold, while doing the best she could to ensure that his health care needs were being met and keeping a house on her own.

Following an episode of insulin shock that put Harold in the hospital, Violet learned how to get medical assistance for her husband so that he could have home health assistance for six-and-a-half hours a day while she was at work. That helped, but the situation was far from perfect. Harold cannot recognize when he's in danger of insulin shock, and neither could his home health aides. As a result, both Violet and Harold suffered a great deal of stress and anxiety.

Following Harold's heart attack, Violet learned about CDCS from a county nurse who's also a close friend. "I knew there was a program where people were taking care of other people, but I didn't think a relative could do that," she says. "I thought I'd try it."

Harold's CDCS budget pays Violet enough so that she doesn't have to work outside their home. Now, she is able to devote all her time to caring for Harold: monitoring his blood-sugar levels, preparing his meals, and making sure he takes his medications. And, having known Harold for more than 50 years, Violet also knows the warning signs of insulin shock. "He kind of slows down, and if he talks, his voice sounds different," she explains.

Since his enrollment in CDCS a little over a year ago, Harold has not been hospitalized once and Violet says the program has significantly relieved the strain in her life.



RESOURCES

for Additional Information on Cash & Counseling

WEB SITES

Cash & Counseling National Program Office

www.cashandcounseling.org

The Cash & Counseling Web site contains extensive resources on the program and on self-directed personal assistance services in general. Among the items found here are a searchable bibliography of research papers and published journal articles (see below for a list of selected titles) as well as sample materials from individual Cash & Counseling state programs, including assessment tools, enrollment forms, sample contracts with fiscal management agencies, and outreach and marketing materials. Also available are a user-friendly interactive data tool that allows users to review data, create charts, and explore statistics from the original Cash & Counseling demonstration and qualitative interviews conducted by the University of Maryland, Baltimore County with 75 Cash & Counseling participants and their families about their experiences. The site also contains helpful links to other Web sites, including individual Cash & Counseling programs by state.

The Robert Wood Johnson Foundation

www.rwjf.org

The RWJF Web site contains both general and specific information on this national health care philanthropy and its grant programs. Cash & Counseling falls within the Foundation's Vulnerable Populations interest area.

Office of the Assistant Secretary for Planning and Evaluation (ASPE)

http://aspe.hhs.gov

Information on ASPE and on consumer direction in general and on Cash & Counseling in particular. Click on "consumer direction" or search on "Cash & Counseling" for a list of research papers available from ASPE.

Administration on Aging (AOA)

www.aoa.gov

Information on AOA and on a variety of topics related to aging, including resources for elderly consumers and their caregivers. Also includes some general information about Cash & Counseling.

Centers for Medicare & Medicaid Services (CMS)

www.cms.gov

Extensive resources available on Medicaid waiver programs, consumer direction, and the 2005 Deficit Reduction Act.

PUBLISHED MATERIALS

The following is a sampling of the titles of the research papers and journal articles available through the Cash & Counseling Web site.

Many additional titles are available, including articles and reports on specific findings from individual Cash & Counseling state programs as well as on a broad range of topics related to self-directed personal assistance services more generally.

Addressing Liability Issues in Consumer-Directed Personal Assistance Services (CDPAS): The National Cash & Counseling Demonstration

The purpose of this article is twofold: first, focusing primarily on the Cash & Counseling model to identify the circumstances in which such conduct could result in liability and what persons or entities are likely to be liable, and second, to identify steps that can be taken to reduce exposure to such liability.

SOURCE: *STETSON LAW REVIEW*

Assessing the Appeal of the Cash & Counseling Demonstration in Arkansas, New Jersey and Florida

This report assesses the appeal of the Cash & Counseling demonstration by: (1) estimating the proportions of eligible beneficiaries that participated and comparing the characteristics of participants and nonparticipants; (2) describing beneficiaries' most common reasons for agreeing or declining to participate; and (3) examining whether the demonstration affected the number of beneficiaries accessing services over time.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and Community-Based Waiver Services

This report summarizes the findings from five years of research by Mathematica Policy Research, Inc. on how each of the three demonstration states implemented its program, and on how the programs have affected the participating consumers, the consumers' caregivers, and costs to Medicaid.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

Effect of Cash & Counseling on Medicaid and Medicare Costs: Findings for Adults in Three States

This study of the three participating states examines how a new service delivery model of consumer direction affected Medicaid and Medicare service use and costs. When designed, the program was expected to cost no more per recipient per month of service than the traditional program.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

Effect of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey and Florida

This study of the Cash & Counseling demonstration program for adults in the three participating states examines how a new model of consumer-directed care changes the way that consumers with disabilities meet their personal care needs and how that affects their well-being.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

Experiences of Workers Hired Under Cash & Counseling: Findings from Arkansas, Florida, and New Jersey

This study includes measures describing: (1) the worker's characteristics and relationship with the consumer; (2) the type, timing, and amount of paid and unpaid care provided during the past two weeks, along with perceptions of working conditions; (3) whether the worker received training; and (4) worker well-being, including wages, fringe benefits, stress, and satisfaction. The report is focused on describing the experiences of the directly hired workers for the treatment group, using agency workers' experiences as a benchmark.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

A Guide to Quality in Consumer-Directed Services

A practical handbook on ensuring and improving the quality of services. This guide is based on a philosophy that the views of the major program stakeholders—consumers, families, program staff, regulators, funders—are the necessary starting point for the design of a quality system.

SOURCE: SCRIPPS GERONTOLOGY CENTER

Hiring Relatives as Caregivers in Two States: Developing an Education and Research Agenda for Policy-makers

This two-state case study reports findings about views from policy experts regarding a policy option to hire relatives as caregivers in home- and community-based long-term care programs. Policy-makers also discussed information needed by other

states considering this option and effective approaches to disseminate findings about this option from the Cash & Counseling Demonstration and Evaluation.

SOURCE: *JOURNAL OF HEALTH & SOCIAL POLICY* (forthcoming)

How Cash & Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey

This report estimates the effects of Cash & Counseling on the caregivers who were providing the most unpaid assistance to adult beneficiaries when those beneficiaries volunteered to participate in the demonstration and completed a baseline interview. The caregivers in this analysis—identified by beneficiaries as their primary informal caregiver at baseline—were interviewed about 10 months later.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

Journal of Health Services Research: Compendium on Cash & Counseling

The most comprehensive resource to be published on Cash & Counseling (publication expected February 2007).

Lessons from the Implementation of Cash & Counseling in Arkansas, Florida, and New Jersey

This report documents the issues raised and opportunities uncovered during the design and implementation of Cash & Counseling programs in the original three demonstration states. The report discusses aspects of the program including counseling and spending plans, outreach and enrollment,

the role of representatives, uses for the cash allowance, preventing exploitation and abuse, and fiscal services.

SOURCE: MATHEMATICA POLICY RESEARCH, INC.

**Paying Family Caregivers:
An Effective Policy Option in the
Arkansas Cash and Counseling
Demonstration and Evaluation.**

To address policy-maker questions about an option to hire relatives as caregivers, this article compares Arkansas Independent-Choices consumers who hired family vs. non family workers. Consumers who hired relatives received more services and had equal or superior satisfaction and health outcomes, as compared to those who hired non relatives. The article draws on findings from paid worker surveys and focus groups as well as program experience.

SOURCE: *MARRIAGE AND FAMILY REVIEW*

**Reducing Nursing Home Use
Through Consumer-Directed
Personal Care Services**

This report demonstrates that nursing home use among Cash & Counseling participants in Arkansas was 18 percent lower for the treatment group than for the control group during the three-year follow-up period.

SOURCE: *MEDICAL CARE*



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