Cash & Counseling

This national program introduced or expanded participant-directed personal assistance services in Medicaid

SUMMARY

The Cash & Counseling program introduced or expanded participant-directed personal assistance services for frail older Medicaid recipients with disabilities and other Medicaid recipients with disabilities in 15 states. The program ran from 1996 to 2009 and was a joint venture between the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Service (DHHS). Three states participated in the demonstration phase, and 12 others participated in the replication phase. As the main users of personal assistance services, older adults were a key focus. RWJF funded the program with $22.6 million. In April 2009, RWJF and the Atlantic Philanthropies established the National Resource Center for Participant-Directed Services at Boston College School of Social Work.

CONTEXT

Frail older adults with disabilities and other people with disabilities who receive Medicaid have historically faced many challenges in getting the personal assistance services they needed when they needed them—services such as help at home with bathing, dressing, grooming, preparing meals, and housekeeping.

Before the mid-1990s, states traditionally contracted with home care agencies to provide these services. But Medicaid beneficiaries had little say about who provided the services, or when or how they were provided. Most home care agencies offered services only during regular working hours on weekdays.
“It seemed like I got a different worker every week,” says Calvin Dodson, a 50\textsuperscript{1}-year-old man living in Trenton, N.J., who is blind, has impaired physical coordination from being struck by a car, and needs dialysis for kidney disease. “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.”

Services were rarely tailored to the person, due to worker shortages and high staff turnover at home care agencies, and these agencies were not allowed to drive people around or give them their medications.

Harold Hamilton, 70,\textsuperscript{2} of Eden Valley, Minn., lost his sight to diabetes and was getting personal care services from an agency every day while his wife Violet worked. But his diabetes kept spiraling out of control because neither he nor his agency-employed aides recognized when he was in danger of going into diabetic shock. Violet was the only person who spotted the signs and symptoms quickly enough to prevent this.

The idea of letting consumers have choices about and control over their personal assistance services—consumer direction (now often called participant direction)—began in the 1970s, with the independent living and disability rights movements. By the early 1990s, many groups representing disabled people were focusing on consumer direction.

A health care reform task force established by President Clinton in 1992 proposed a national home and community-based services program to be managed by the states that would enhance consumer direction. Although Clinton’s health reform package was not enacted, it helped set the stage for more work in consumer direction, as did increased spending for long-term care between 1985 and 1995, a trend that was expected to continue as the baby boom population aged.

These factors led policy-makers to look to consumer direction as a more cost-effective way to provide personal assistance services, respond to people’s preferences, and improve their quality of life.

**The Cash and Counseling Approach**

One new way to pay for long-term care for people who are disabled was called cash and counseling. Under this approach, the government gives people cash budgets to pay for the

\textsuperscript{1} Dodson was 50 in 2002 when he was enrolled in New Jersey’s cash and counseling program.

\textsuperscript{2} Hamilton was 70 in 2002 when he was enrolled in Minnesota’s cash and counseling program.
personal assistance services that would best meet their personal care needs and it pays for counseling to help them manage their services. This flexibility enables people to hire family members or friends as their service providers if they wish, and to choose when and how these providers deliver the personal assistance.

Participants in cash and counseling programs can also use their allowance to modify their homes or vehicles or buy things that help them live independently (e.g., a microwave or a hands-free phone). The counseling helps them make decisions about how to spend their allowance and manage their services. Those who do not want to make decisions on their own can appoint someone to make decisions with or for them.

Cash and counseling is not intended to replace traditional services and providers but to give an alternative to people who want one. It can also increase access to personal assistance services, when, for example, people live in rural areas that are hard to get to or when agencies do not have enough service providers to go around. For some adults with developmental disabilities, cash and counseling is seen as potentially a life-transforming program because in lieu of routinely attending an adult day treatment center, they have the resources to get out into the community to explore volunteer and paid job opportunities and, ultimately, to transition to competitive employment and more independent living.

**Generating Evidence for Cash and Counseling**

James R. Knickman, PhD, then vice president for Research and Evaluation\(^3\) at the Robert Wood Johnson Foundation (RWJF) and a former faculty member at New York University, had done a lot of research on ways to deliver long-term-care. That, coupled with his personal experience in caring for an older aunt in Brooklyn, N.Y., led him to believe that there had to be a better way to provide personal assistance services. “It was a crazy model,” he said, citing the high costs and inadequate care. “I would see care workers not doing what people wanted done and there would be neighbors down the hall or relatives who would be great caregivers.”

In 1994, RWJF commissioned James P. Firman, PhD, and his colleagues at the United Seniors Health Cooperative to study cash and counseling across the world.\(^4\) Firman and his team found that cash and counseling programs were popular and saved money when compared with traditional agency personal assistance services. They concluded that cash and counseling was worthy of greater experimentation in the United States. See Program Results Report for more details.

---

\(^3\) Knickman is now president and chief executive officer of the New York State Health Foundation.

\(^4\) Grant ID 23584.
**RWJF’s Interest in This Area**

Improving the care and support of people with chronic illnesses and disabilities became a goal of RWJF in 1991. The Foundation supported work to better organize and deliver services to people with chronic illnesses and disabilities. Its strategies include making the funding and service delivery systems more flexible and creating demonstrations of ways to increase independent living and lower the cost of long-term care. See the RWJF Retrospective on Chronic Care for more information on its strategy and programs.

**Strengthening the Role of Older Adults and People With Disabilities in Overseeing Their Care**

In 1995 and 1996, the Foundation launched three national programs to test ways to give people who were older or disabled more choices about the services they use and the people who provide these services:

- *Self-Determination for Persons with Developmental Disabilities*
- *Independent Choices: Enhancing Consumer Direction for People With Disabilities*
- *Cash & Counseling*

Each program focused on a different group.

*Self-Determination for Persons With Developmental Disabilities* helped 18 states implement more cost-effective care while giving families and people with disabilities (primarily younger people with developmental disabilities) more choice about the services they received. The program ran from November 1995 to September 2001. See Program Results Report.

RWJF also wanted to understand whether consumer direction would work for frail older adults with disabilities, whom advocates believed were less interested in and less capable of directing their own services than younger people with disabilities. The other two programs included frail older adults with disabilities.

*Independent Choices: Enhancing Consumer Direction for People With Disabilities*, was intentionally broader than *Cash & Counseling*, supporting different approaches, apart from cash, to foster choice and control in long-term care for disabled people of all ages. This program supported 13 smaller projects: nine demonstration projects and four research projects. It ran from 1995 to 1999. See Program Results Report.

*Cash & Counseling*, the subject of this report, was designed as a large-scale demonstration and a rigorous evaluation of the cash and counseling approach in the United States. The U.S. Department of Health and Human Services’ (DHHS) Office of the Assistant Secretary for Planning and Evaluation (ASPE) partnered with RWJF on this
program. *Cash & Counseling* ran from 1996 to 2009, and is described under *The Program and Its Results*.

For more information on RWJF’s strategy related to consumer choice and these three programs, also see *Consumer Choice in Long-Term Care* (RWJF anthology chapter).

**DHHS’s Interest in This Area**

Robyn I. Stone, DrPH, a long-time colleague of Knickman’s and deputy assistant secretary in the Office of Disability, Aging and Long-Term Care Policy at the Office of the Assistant Secretary for Planning and Evaluation, was also interested in the cash and counseling approach. Knickman and Stone began discussing ways to work together on a consumer-direction demonstration program, which became *Cash & Counseling*.

The Office of Disability, Aging and Long-Term Care Policy was created in 1993 to support policy development and research on long-term care. Leaders there viewed participant direction as a potentially important strategy for achieving more efficient and effective home and community-based care.

**THE PROGRAM AND ITS RESULTS**

The *Cash & Counseling* program introduced or expanded participant-directed personal assistance services for frail older Medicaid recipients with disabilities and other Medicaid recipients with disabilities in 15 states. The program ran from October 1996 to March 2009, first with a demonstration and then a replication phase. Three states participated in the demonstration phase, and 12 additional states participated in the replication phase. As the main users of personal assistance services, older adults were a key focus. However, roughly half of the participants were younger adults with disabilities, and Florida included children in its program.

*Cash & Counseling* was not the first program to allow consumers to hire caregivers, but it was the first to allow them to use flexible budgets to hire workers or purchase goods and services. It was also the first to be subjected to a rigorous, randomized evaluation.

The program was a joint venture between RWJF and the Office of the Assistant Secretary for Planning and Evaluation (ASPE). RWJF and ASPE collaborated in all phases of the program, including deciding where to house it, providing funding, selecting demonstration and later replication states, and designing the evaluation and selecting the evaluator. During the second of two phases, the Administration on Aging, now called the

---

³ She is now the executive director of the LeadingAge Center for Applied Research and senior vice president of research.
Administration for Community Living, also contributed some funding, but ASPE remained the primary government sponsor.

RWJF provided a little more than $18 million to support the Cash & Counseling program, with an initial authorization by the Board of Trustees in 1995 and a renewal authorization in 2003. The federal government contributed nearly $7.5 million—close to $6.9 million from ASPE and $600,000 from the Administration for Community Living. RWJF funding supported the grants to the states and technical assistance. ASPE funded program evaluations and technical assistance.

The partnership between RWJF and ASPE was crucial in achieving the goals of the Cash & Counseling program. RWJF needed a partner in the federal government to navigate roadblocks and advocate for the program while ASPE needed external funding to mount a program of this size and scope. “RWJF brought money, flexibility, and reputation to the table. ASPE brought policy relevance,” said Knickman. “It was as if from the very beginning the federal government owned this idea. That was important in getting this implemented.”

“Our contribution increased the chances that people in the government would pay attention to the results and act on them,” said Pamela Doty, PhD, senior policy analyst in ASPE’s Office of Disability, Aging and Long-Term Care Policy and ASPE’s project manager for the Cash & Counseling program. ASPE also contributed crucial knowledge about the nuts and bolts of implementing a complex Medicaid demonstration program.

For more information on the partnership between RWJF and ASPE, see “The Public/Private Partnership behind the Cash and Counseling Demonstration and Evaluation: Its Origins, Challenges, and Unresolved Issues,” (Health Services Research, 2007).

The Cash & Counseling program was an important, complicated program about which much has been written. This report provides an overview of the program and its major results, insights, challenges, and lessons. Links to sources of more information are provided throughout the report.

**Program Management**

RWJF and ASPE selected Kevin Mahoney, PhD, MSW, to direct the Cash & Counseling national program office and housed it at the University of Maryland Center on Aging.

---

6 In April 2012, the Department of Health and Human Services created a new organization, the Administration for Community Living, which brings together the Administration on Aging, the Office on Disability, and the Administration on Developmental Disabilities with the goal of increasing access to community supports and full participation in life, while focusing on the needs of older Americans and people with disabilities.
When Mahoney joined the faculty of Boston College in 1999, the program office moved with him.

Mahoney and his team provided technical assistance and direction to the states, coordinated the evaluations of the program, and disseminated key materials related to cash and counseling. Technical assistance and direction included:

- Convening annual meetings and retreats for project directors
- Creating and maintaining the Cash & Counseling website
- Writing and/or disseminating publications, reports, and issue briefs
- Preparing tools and toolkits to help states implement cash and counseling programs
- Moderating technical assistance calls once or twice a month
- Providing individual assistance via:
  - Visiting sites
  - Making available services from designated state liaison mentors
  - Giving sites time with subject matter consultants

The Cash & Counseling program convened a group of policy-makers and researchers to provide initial guidance on the design of the evaluation during the demonstration phase, and another group of experts to provide guidance on the design of the replication phase and the selection of the states.

The national program office team gave high priority to keeping legislators, policy-makers, and staff of federal agencies, including Centers for Medicare & Medicaid Services (CMS) and the Administration for Community Living, informed about the program’s progress and evaluation findings. Through meetings, congressional briefings, presentations at conferences attended by federal government employees and policy-makers, brochures geared toward state policy-makers and legislators, and informal communication, the team increased knowledge of and interest in the participant-directed approach.

While the national program office was located at the University of Maryland, RWJF gave it several other grants to:

- Conduct focus groups and surveys to inform the development of the demonstration phase

---

7 It is now the website for the National Resource Center for Participant-Directed Services.
8 Mentors were part-time staff hired by the national program office who had retired from the state programs or the evaluation team from the demonstration phase and lived in different parts of the country.
• Partially support a national conference to highlight the progress by states and providers in designing services that meet the preferences and needs of beneficiaries better than traditional long-term care\textsuperscript{10}

• Supplement the funding for the national program office\textsuperscript{11}

**The Demonstration Phase**

Both RWJF and ASPE staff believed that the idea of giving people cash allowances would require strong evidence that participants or their families did not misuse the money and that their care needs would be met. They designed *Cash & Counseling* as a demonstration program with a rigorous evaluation design involving random assignment and careful analysis of process and outcomes.

“It had to be a controlled experiment that was run with the highest scientific standards to get people to pay attention,” said Mahoney.

*Cash & Counseling* had the gold standard, a randomized trial. That level of research is what helps people get behind it. Without that, it’s just another program that people think is a good idea,” said Nancy Fishman, MPH, the RWJF program officer for the *Cash & Counseling* program during its replication phase. Also, ASPE wanted to exemplify and champion high-quality policy research, according to ASPE’s Doty.

Involving CMS, which had veto power over the demonstration program, was crucial. Early in the process, staff from ASPE met with the CMS director to ensure that he was not unalterably opposed to testing the cash and counseling concept. Then ASPE staff began to meet with CMS staff to gain their buy-in to the *Cash & Counseling* program. CMS staff participated in the site visits to select the demonstration states and in the selection of the evaluator. Staff also participated in the ongoing *Cash & Counseling* program management calls between RWJF, ASPE, the national program office, and Mathematica Policy Research (the evaluation firm that was selected).

Three states—Arkansas, Florida, and New Jersey—developed and implemented demonstration programs comparing the cash and counseling model with the traditional agency-directed model for delivering personal-assistance services. Each state received several grants from RWJF between October 1996 and June 2003, totaling between $693,457 and $765,696 per state. A fourth state, New York, participated from 1996 to 1999 but was unable to meet the requirements of its grant within the time frame, and withdrew from the program.

\textsuperscript{9} Grant ID 30555 ($176,310; November 1, 1996 to July 31, 1998) and Grant ID 30861 ($291,393; January 1, 1997 to September 30, 1998).

\textsuperscript{10} Grant ID 42370 ($75,004; May 1, 2001 to January 31, 2002).

\textsuperscript{11} Grant ID 30862 ($1,100,000; from May 1998 to April 2002), Grant ID 38750 ($436,394; June 2000 to July 2005). Grant ID 42387 ($399,727; October 2001 to July 2005).
Getting Federal Waivers for Cash & Counseling

When states want to test new or existing ways to deliver and pay for health care services under their Medicaid programs they need to apply for a waiver from CMS.

The demonstration programs under the Cash & Counseling program demonstration phase required Section 1115\(^1\) research and demonstration waivers. These federal waivers give states flexibility to offer nontraditional Medicaid services in order to demonstrate and evaluate policy approaches such as:

- Expanding eligibility to people who are not otherwise eligible
- Providing services not typically covered by Medicaid
- Using innovative service delivery systems that improve care, increase efficiency, and reduce costs

The 1115 research and demonstration waivers require that programs cost no more than traditional personal assistance services (be “budget neutral”). The formula for determining that a proposed demonstration would be budget neutral had to be negotiated with and approved by the Office of Management and Budget, which was a very difficult process.

CMS helped the states develop their waiver applications and assisted with the negotiations and ASPE’s Doty worked with staff from the Office of Management and Budget. But Doty was only able to work with lower level staff there and she soon learned that senior staff did not believe the cash and counseling demonstrations could be budget neutral.

To resolve this, Doty asked the assistant secretary for health policy to intercede and arrange a meeting with a senior manager at the Office of Management and Budget, after which they came to an agreement about budget neutrality. In all, it took two years to get the waivers approved for Arkansas, Florida, and New Jersey.

A Rigorous Evaluation

Participants in each state were randomly assigned to the treatment group, whose members directed their services through cash and counseling programs, or the control group, whose members received traditional personal assistance services through an agency.

Researchers at Mathematica Policy Research\(^1\) in Princeton, N.J., conducted a rigorous, independent evaluation of the demonstration program. The evaluation explored outcomes

---

\(^1\) Section 1115 refers to Section 1115 of the Social Security Act.

\(^1\) Mathematica Policy Research, Inc. is a Princeton, N.J.-based organization that collects and analyzes information to assess the effectiveness of policies and programs to improve public well-being.
for both groups, including health status, caregiver satisfaction, patient satisfaction, services received, and cost. Randall S. Brown, PhD, vice president of the health research division, led the evaluation team.

For more about the evaluation and its findings, see Overall Program Activities and Results: The Demonstration Phase below.

**The States Implement Participant-Directed Programs**

The states began enrolling people into their participant-directed programs between December 1998 and June 2000, and stopped enrolling when they reached their enrollment targets or in July 2002, whichever came first.

All participants had to be enrolled in Medicaid and need personal assistance services. All three demonstration states offered their participant-directed programs to adults with physical and/or cognitive disabilities. Florida also offered its program to adults and children with developmental disabilities.

Cash and counseling participants got a monthly monetary allowance or budget based on a professional assessment of their needs and comparable to the value of the services they would receive through an agency. Participants prepared a written plan for spending the allowance in permissible ways and submitted bills for allowable goods and services.

Counselors (also called consultants) and fiscal agents (also called bookkeepers) were available to help participants. The states contracted with independent organizations for counseling and fiscal services.

The counselors, who are often social workers:

- Helped participants develop, review, and revise plans for spending the monthly allowance in permissible ways
- Offered advice about developing emergency backup plans and recruiting, hiring, training, and dismissing workers
- Offered advice about other services available in the community
- Monitored consumers’ well-being
- Monitored use of the allowance

Counselors also checked in with the participants every month and were always available by phone.

Since participants became employers when they hired workers, fiscal agents from financial management services agencies helped them with the paperwork required to pay an employee’s wages and withhold taxes. Doty calls the fiscal agents “the lynchpin” of
the cash and counseling approach. She notes that it would have been very difficult for participants to deal with the paperwork on their own, and that having fiscal agents reassured the state and federal governments and the Internal Revenue Service that there was not widespread fraud or misuse of the money.

Cash and counseling participants who could not or did not want to make decisions about how to spend their personal assistance allowances could choose someone, usually a relative or friend, to help.

For more information about the cash and counseling programs in Arkansas, Florida, and New Jersey, see Overall Program Activities and Results: The Demonstration Phase below. For details on the grants to these three states, see Appendix 1.

**CMS’s Continued Involvement in Participant Direction**

During the demonstration phase, CMS staff continued to participate in program management calls. ASPE's Doty noted that CMS saw participant-directed services as one way to implement the Supreme Court’s 1999 Olmstead decision, which requires states to eliminate unnecessary segregation of people with disabilities and to ensure that they receive services in the most integrated setting appropriate to their needs.

*Despite his physical challenges, Calvin Dodson wants to be independent for as long as he can. Through New Jersey’s cash and counseling program, he has been able to hire people he knows he can trust, including his sister. Calvin also used part of his monthly allowance to buy a voice-activated microwave so he could prepare his own food, and voice-recognition software for his computer so he could shop online for groceries, clothes, and other necessities.*

*“It’s me who is in control, instead of the agency,” he said. “I know that the money is paying for what it is supposed to pay for.”*

To help states implement participant-directed services programs more easily and more quickly, in 2002, CMS began incorporating participant-directed options—including giving participants authority to manage budgets—into the 1915(c) Home and Community-Based Services waiver application and developing a template for them to use in completing the application.14

---

14 A 1915(c) waiver allows states to provide long-term-care services in home and community settings rather than in institutional settings. This waiver can be used instead of an 1115 waiver. 1915(c) waivers do have to be less expensive than institutionalization.
Overall Program Activities and Results: The Demonstration Phase

- Between December 1998 and July 2002, Arkansas, Florida, and New Jersey enrolled 6,583 Medicaid beneficiaries with disabilities in the demonstration program (including both cash and counseling programs and traditional personal assistance services programs):
  - Arkansas: 2,008 adults
  - Florida: 2,820 people (1,818 adults and 1,002 children)
  - New Jersey 1,755 adults

The majority of participants in Arkansas (72.3%) and New Jersey (53.7%) were age 65 and older. In Florida, the majority of participants were children or younger adults with developmental disabilities, but almost one-third (32.1%) were older adults (defined in Florida as 60 and older).

The three states have continued their participant-directed programs.

- A modest proportion (6% to 10%) of eligible adults enrolled in the three states, but the program attracted 16 percent of Florida’s Medicaid children with developmental disabilities before the state reached the evaluation quota and enrollment ended.

Research into who chose to enroll and why suggests that cash and counseling is not for everyone. It is particularly attractive to Medicaid beneficiaries and families who are dissatisfied with their existing service plans or service providers.

Parents of developmentally disabled children in Florida were experiencing particularly high levels of dissatisfaction with the services their children were receiving (or should have been receiving but were not), which enabled the enrollment quota for Florida children to be met more quickly than the quotas for the other subgroups in all three states.

Thirteen-year-old Jewel Stephen of Tampa, Fla., was born without a properly formed brain stem and cannot walk or talk. Jewel needs constant supervision. Her mom Trish manages her care, providing most of it herself. Trish loves the flexibility of Florida’s cash and counseling program, and uses the allowance for things that Medicaid does not pay for, such as massage therapy to help loosen and soothe her daughter’s tight muscles, dietary supplements to help Jewel’s digestion, and modifications to make the bathroom easier for Jewel to use. Trish loves the empowerment with support the program gives her.

---

15 Stephen was 13 in 2002 when she was enrolled in Florida’s cash and counseling program.
Among adults who enrolled compared to those who were eligible but did not enroll, individuals with more severe disabilities were more likely to enroll. A desire to employ family caregivers as paid aides was an important motivating factor among those who enrolled as was, for some, the opportunity to reduce reliance on paid aide services in favor of purchasing other goods and services, including ones not normally covered by Medicaid.

**Evaluation of the Demonstration Phase**

The evaluation by Mathematica Policy Research covered:

- The program’s effects on:
  - Participating beneficiaries
  - The beneficiaries’ paid and unpaid caregivers
  - Costs to Medicaid and Medicare
- How the *Cash & Counseling* program operated

The evaluation drew on multiple data sources, including:

- Interviews and telephone surveys with Medicaid beneficiaries in the cash and counseling treatment and control groups at baseline and again nine months later
- Interviews and surveys with unpaid and paid caregivers (paid caregivers were both workers whom participants hired and agency workers) at about 10 months after the participant enrolled
- Medicaid and Medicare claims data on service use and expenditures
- State Medicaid assessment data and care plan data for all program participants
- Discussions with program leads in each state and various types of staff involved with the program

The evaluators evaluated program effects separately for older participants (aged 65 or older in Arkansas and New Jersey, aged 60 or older in Florida), for other adult participants in each state, and for children. They used the age groups defined by each state.\(^{16}\)

The evaluators estimated program effects by comparing the experiences, on average, of people assigned to cash and counseling treatment group (regardless of whether they actually ever received an allowance) to the experiences of the control group. They then used statistical models to make these comparisons, in order to improve the precision of

---

\(^{16}\) Arkansas: 18 to 64 and Age 65+; Florida: Age 3 to 17, Age 18 to 59, and Age 60+; and New Jersey: Age 18 to 64 and Age 65+
the estimates and ensure than any chance pre-existing differences between cash and counseling participants and the control group were accounted for. All differences between the cash and counseling group and the control groups were tested to ensure that they were unlikely to be due to chance. Only those differences that met this rigorous statistical significance requirement were considered to be true program effects.

Key implementation questions related to: the people the program targeted, operational aspects, and performance measures. Evaluators used in-person discussions with staff, mail surveys of counselors, telephone surveys of program participants, and data collected from state agency staff to answer these questions.

For details on the methods, see Appendix 2.

Demonstration Evaluation Findings

RWJF incorporated findings from the evaluation into a 2007 report Choosing Independence: A Summary of the Cash & Counseling Model of Self-Directed Personal Assistance Services.17 All of the information in this section is excerpted from the report except comments that are attributed to Brown and Fishman and the stories about Cash & Counseling participants.

Evaluators reported that in general, the cash and counseling approach “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 this, the evaluators noted that careful attention must be paid to the design and implementation of a cash and counseling program to ensure that it is efficient and avoids unnecessary cost increases.

The report highlighted six of the most significant findings of the evaluation:

- **Cash and counseling “significantly reduced the unmet needs of Medicaid consumers who require personal assistance services.”** Ten percent to 40 percent fewer cash and counseling participants in each state reported unmet needs compared with the control group. The program also significantly increased the percentage of people receiving services in Arkansas and New Jersey.
  - In Arkansas, at nine months after enrollment, 95 percent of cash and counseling participants reported getting paid personal assistance services in the previous two weeks, compared to less than 75 percent of the control group, despite the fact that all were approved for such services. Even control group members who got services got only 68 percent of the care hours they were approved to receive.

17 The results and detailed descriptions of the methodology are also included in a special issue of the journal Health Services Research, 42(1.2): February 2007. Available online.
— In New Jersey, at nine months after enrollment, more than 90 percent of the cash and counseling participants got services in the previous two weeks, compared to about 80 percent of the control group.

Tammy Svihla of High Bridge, N.J., is a 36-year-old\textsuperscript{18} single mother of three who has multiple sclerosis and gets around in a wheelchair. She needs help with activities like dressing, showering, getting up and down the stairs, cooking, cleaning, and shopping and had been unhappy with the high rate of staff turnover at the agencies that provided her care. Tammy jumped at the chance to direct her own care through New Jersey’s cash and counseling program.

“\textit{I saw it as an opportunity to take control; to decide for myself who walks through my front door},” she says. Through the program, Tammy has hired two reliable helpers: a friendly neighbor and an aide she found by posting flyers around her neighborhood. She also uses her monthly allowance to buy things that help her live independently, including an air conditioner and touch lamps.

- **Cash and counseling participants “experienced positive health outcomes.”**
  Participants in all age groups in all three states were no more likely to suffer care-related health problems than those receiving traditional agency services. In some cases, cash and counseling participants had significantly less risk of health problems (e.g., urinary tract infections) and adverse events (e.g., falls) than the control group.

  For 11 health-related measures,\textsuperscript{19} cash and counseling participants were significantly less likely to experience health problems than those receiving traditional services in almost one-third of the comparisons made for the separate age groups in each state. For example:

  — In New Jersey, older and younger adult cash and counseling participants were less likely than comparable control group members to have fallen.

  — In Arkansas and New Jersey, older cash and counseling participants were less likely to have had contractures (a permanent shortening of a muscle or joint) develop or worsen than older members of the control group.

  — Younger adult cash and counseling participants in Florida were less likely than their control group counterparts to have urinary tract infections.

---

\textsuperscript{18} Svihla was 36 in 2002 when she was a participant in New Jersey’s cash and counseling program.

\textsuperscript{19} The measures were: had a fall; contractures developed or worsened; bedsores developed or worsened; had a urinary tract infection; saw a physician due to a fall; saw a doctor because of a cut, burn, or scald; was injured while receiving paid help; shortness of breath developed or worsened; had a respiratory infection; current health was poor; and was hospitalized or in a nursing home during the past two months.
— Among younger adults in both Arkansas and New Jersey, participants were less likely than control group members to develop bedsores or have them worsen.

“One of the big fears was that people were going to get inferior care, and that they would fall or be injured, because they weren’t being seen by professionals anymore; they were getting care from family members, a neighbor, or somebody from church. That didn’t happen,” said Mathematica’s Brown. “We couldn't find a single quality measure where the treatment groups did worse.”

According to ASPE’s Stone, showing that the cash and counseling approach worked for older adults was key in dispelling the perception that it was suitable only for younger people with disabilities.

*Janice Maddox of Pine Bluff, Ark., has diabetes and glaucoma, and has had several major operations and possibly several strokes. The 75-year-old uses a wheelchair and needs help getting in and out of bed, dressing, bathing, preparing food, taking her medications, and doing housework.*

*By enrolling in Arkansas’ cash and counseling program, Janice has been able to hire family members to care for her, including an adult granddaughter who spends at least two hours a day helping her.*

“There’s just something about having family look after her,” says Janice’s daughter, Johnetta Thurman. “She doesn’t get nearly as many allergic reactions or bedsores now, and I think that’s because when it’s your own you’re looking after, you pay more attention.”

- **The cash and counseling approach “greatly improved quality of life for participants and their caregivers.”**

Cash and counseling participants across the three states were:

— Up to 90 percent more likely than those in the control group to say they were very satisfied with how they led their lives

— Half as likely to say they were dissatisfied with their lives

Of the cash and counseling participants, up to two-thirds reported that the program had greatly improved their lives, and at least 85 percent of participants in any age group or state said they would recommend it to others.

Cash and counseling participants’ primary unpaid caregivers across all three states were significantly less likely to be dissatisfied with participants’ paid care when compared with primary unpaid caregivers of control group members

---

20 Maddox was 75 in 2002 when she was enrolled in Arkansas’ cash and counseling program.
After Josie Dickey of Fort Smith, Ark., had a massive stroke, she went to live in a nursing home, where she was neglected and got pneumonia. Her daughter Brenda Terry brought her home, where a string of home health aides—about 30 in three years—provided personal assistance services.

Josie, who is 87, enrolled in Arkansas’ cash and counseling program and Terry became her paid caregiver. Since then, Josie has been healthier, more active, and more engaged in her life. For example, it used to take three people to lift Josie out of bed but now that Josie is stronger, Terry can do this alone. “The more she does, the better she is,” says Terry. “She’s participating in life—and that’s a great big deal.”

● The cash and counseling approach 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 the program started.”

In each state, informal caregivers for program participants reported:

— Less physical, financial, and emotional stress than caregivers for the control group, and reported fewer injuries due to caregiving

— Less disruption in their work lives and home lives due to caregiving than did caregivers for the control group

— Much greater overall satisfaction with life

They attributed these benefits to the far greater flexibility that cash and counseling allowed them in meeting the needs of their loved ones.

● “Medicaid personal care costs were somewhat higher” under the cash and counseling approach, “mainly because enrollees received more of the care they were authorized to receive.”

— In Arkansas and New Jersey, under the cash and counseling programs many more consumers received the paid hours of service they were authorized to receive, resulting in higher Medicaid costs than the control group incurred. Control group members in these states who did get some paid care received only a fraction of their authorized care, and some received no services.

— Costs were higher in Florida under the cash and counseling program due to short-term statewide increases in personal care funding for people with disabilities. The

---

21 Dickey was 87 in 2002 when she was enrolled in Arkansas’ cash and counseling program.
timing of these increases made more funding available to participants than to control group members.

The fact that costs were higher because more people were now getting services they were supposed to be getting is important, says RWJF’s Fishman. “I think states understood this,” she said. “Everybody’s worried about the bottom line, but at the same time, states don’t want to be seen as not providing what they said they’d provide.”

*Elsa Torres had been caring for her parents Gregorio and Felicita Cruz for many years. She serves as a 24/7 personal caregiver for her 86-year-old\(^\text{22}\) father, who lost both his legs to gangrene infection from diabetes, and has many other illnesses, including prostate cancer, coronary vein disease, and early-stage Alzheimer disease. He is bed-bound and requires round-the-clock supervision and care. Felicita Cruz, age 78,\(^\text{23}\) gets around pretty well, but has high blood pressure, diabetes, and arthritis. She tends to forget to take her medications. Elsa helps her mother manage her health and take care of the house.*

*Since the Cruzes enrolled in Florida’s cash and counseling program, Elsa has been able to do more for her parents and do it better. She is now paid to provide personal assistance services, and uses their budget to hire a neighbor to help when she goes out, buy her parents personal care supplies, and make necessary home improvements. She is also happier, less stressed, and more energetic. “I feel like I am getting myself back,” she says. But the best part, “is that I know my parents are getting really good care.”*

- **Increased Medicaid personal care costs under the cash and counseling programs 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 (mostly home health care), were lower under the cash and counseling programs 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.” Institutional or other long-term-care costs were 17 percent and 15 percent lower, respectively, for the cash and counseling groups than for the control groups.

\(^{22}\) Mr. Cruz was 86 in 2002 when he was enrolled in Florida’s cash and counseling program.

\(^{23}\) Mrs. Cruz was 78 in 2002 when she was enrolled in Florida’s cash and counseling program.
— For the other age groups in these two states and for all adults in New Jersey, nonpersonal care costs were 4 percent to 7 percent lower under the cash and counseling approach.

— In Arkansas, savings in long-term-care costs under the cash and counseling approach helped offset higher personal care costs. A longer-term follow-up study of the Arkansas cash and counseling program showed that savings in long-term care continued in the third year after enrollment. By then, the program had reduced nursing facility use 18 percent over the entire three-year study period.

For people who were receiving agency services before enrolling in cash and counseling, the savings in other Medicaid services fully offset the higher personal care costs over three years.

— In Florida and New Jersey, however, total Medicaid costs for cash and counseling participants during the second year were 8 percent to 12 percent higher than they would have been had those beneficiaries not enrolled in cash and counseling. Data from the third post-enrollment year are not available for Florida and New Jersey.

In a separate report (Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services, 2007), evaluators noted that their analyses of program effects on costs differ substantially from the budget neutrality calculations performed by the three states for CMS and that CMS determined that the states satisfied the budget neutrality requirements.

For more information about how budget neutrality was determined, see Appendix 3.

• The cash and counseling approach “need not cost more than traditional Medicaid personal care programs if states carefully design and monitor their programs.” States can design their cash and 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.”

Other strategies to control costs 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.”

— “…reducing allowances” for cash and counseling consumers if they exceed spending on agency services for consumers with comparable care plans. However, cash and counseling consumers should not be penalized if those receiving agency services do not get all of their authorized hours.”
Other key findings, not included in the Mathematica report to RWJF but noted by the national program office, include:

- **The cash and counseling approach did not result in misuse of Medicaid funds or abuse of participants.** Counselors reported very few cases of abuse or neglect of the participants, or fraudulent use of the allowance.

  “People thought this would be rampant with fraud and abuse and individuals would be exploited. What we found in Arkansas is that, instead of seeing widespread fraud and abuse, it’s really been able to empower families to pick a family member or a friend, someone they have a trusted relationship with … . And instead of promoting or encouraging fraud, I think in many ways it has perhaps curtailed it,” said Mike Huckabee, governor of Arkansas during the demonstration.

- **Directly hired workers under the cash and counseling programs and home care agency workers felt equally prepared to do the job expected of them.** Only 50 percent to 70 percent of directly hired workers received formal training on how to perform their jobs, compared with 95 percent or more of agency workers, but the groups were equally likely to feel prepared to handle their responsibilities.

  — More than two-thirds of directly hired workers were previously unpaid caregivers—mostly family members—and these workers continued to provide many hours of unpaid care.

  — Directly hired workers received wages roughly similar to agency workers, but the directly hired group was much more satisfied with the pay.

  — Directly hired workers and agency workers experienced similar levels of physical strain and job-related injuries but the directly hired workers had more emotional strain and feelings of being unappreciated by the care recipients’ families and friends, because they were related to their care recipients.

Read the complete findings in the 2007 Mathematica Policy Research report, *Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services.*

Read about challenges and lessons from the demonstration phase under **Challenges Faced and Lessons Learned.**

**Ethnographic Study**

Researchers at the University of Maryland Baltimore County also conducted an ethnographic study from June 2000 through August 2004 in which they interviewed 21 cash and counseling participants, their workers, and their primary caregivers in Arkansas, Florida, and New Jersey about their experiences in the program.\(^\text{24}\) They presented case

\(^\text{24}\) Funded through grant IDs 30862 and 38750 for the evaluation.
histories on six of these participants and their families and the following key finding in an article in *Health Services Research*.  

Among the situations examined by the case histories are the following:

- **Finding a caregiver with the flexibility to match the hours needed by the consumer and family.** A granddaughter was able to arrange a worker with a 10:00–4:00 schedule four days a week to care for her grandmother who lived with her. This allowed the granddaughter to resume her own business as an accountant, working one day a week from home. A niece lives in the house and in exchange for board and room also provides some care.

- **Cash option offers consumer flexibility to pay for nontraditional services including respite.** A family arranged for a variety of services, including horseback riding, for their 26-year-old son with cerebral palsy and a seizure disorder from encephalitis. They were also able to pay for maintenance for the van they use to take him to a daycare center for adults with developmental delays.

- **Consumer chooses cash and counseling for improved access to a reliable family worker.** A 55-year-old woman who had has 30 fractures in her spine and ribs and has been confined to bed for the last seven years, hired her son to be her caregiver. She needs care starting a 1 p.m. when she can get out of bed, not the morning when the agency wanted to send someone. Her son is also attending community college and works part-time at a hospital.

The three other case studies cover these situations:

- **Cash option offers an independent consumer the ability to create backup systems and obtain important services prohibited under the previous system.**

- **Cash option offers ethnic elders and their families the ability to obtain culturally appropriate care.**

- **Cash option offers services that allow families to expand involvement in the community.**

The main finding of the study was:

- **Cash and counseling benefited consumers and caregivers by allowing consumers increased continuity and reliability of care, increased ability to set hours of care, more satisfaction with how caregiving is offered, and more satisfaction with the quality of care.**

---

The researchers concluded that:

- **The cash option allowed consumers to create, schedule, and manage their own model of care.** Some consumers faced challenges in the program with paperwork, accounting, worries about receiving care, and some ineffective state consultants who could have been more helpful.

**The Replication Phase**

Based on the positive state experience, participant responses, and research findings about the participation of Arkansas, Florida, and New Jersey in the *Cash & Counseling* program, RWJF and ASPE decided to support an expansion of the program to other states.

The Administration for Community Living provided some funding for this phase, as a signal to the Aging Network\(^\text{26}\) to pay attention to participant direction. “There was a pretty pervasive paternalism about taking care of older people that didn’t jibe with the research that was coming out of the demonstration and research conducted by AARP,”\(^\text{27}\) said John Wren, MPA, deputy administrator for disability and aging policy at the Administration for Community Living.

To prepare for the replication, Mahoney and his team in the national program office conducted an environmental scan to learn:

- How many states might be interested in a cash and counseling-like approach
- The types of technical assistance they would need
- How much help they would need with start-up funds
- What barriers they might face in moving forward

About 45 states participated in national teleconferences, 21 states took part in regional meetings, and 21 states completed needs assessment interviews. Twenty states and the District of Columbia applied for the replication grants.

---

\(^{26}\) The Aging Network was established as part of the Older Americans Act of 1965. It is headed and supported by the Administration for Community Living and includes State Agencies on Aging, Area Agencies on Aging, American Indian aging programs, service providers, aging and disability resource centers, and volunteers. For more information about key organizations in the network, see Appendix 4.

\(^{27}\) Wren is referring to two AARP surveys: a 1997 survey, which found that 76 percent of people age 50 and older would prefer to manage their own home care services rather than receive services through an agency, and a 2002 survey of people with disabilities age 50 and older, which found that only 15 percent preferred agency-directed services.
In 2004, RWJF awarded grants to 11 states to replicate the cash and counseling model from the demonstration phase:

- Alabama
- Iowa
- Kentucky
- Michigan
- Minnesota
- New Mexico
- Pennsylvania
- Rhode Island
- Vermont
- Washington
- West Virginia.

These grants averaged about four years and ranged from $196,798 to $350,000 per state; most sites received grants of about $240,000. For grant details, see Appendix 1.

The following year, the Retirement Research Foundation\(^{28}\) funded Illinois to participate in the program, for a total of 12 states participating in the replication.

By this time, CMS was calling the cash and counseling approach a budget authority, which gives participants a flexible budget for use in buying goods and services to meet their needs. Many of the states already had programs that gave participants the employer authority, which allows them to hire, supervise, and dismiss workers (e.g., personal care attendants). All of the replication states agreed to give cash and counseling participants both types of authority.

As in the demonstration phase, participants received cash budgets and had access to counselors and fiscal agents. They could also choose a representative to help them make decisions.

\(^{28}\) The Chicago-based Retirement Research Foundation ([www.rrf.org](http://www.rrf.org)) is devoted to improving the quality of life of older adults, especially those who are vulnerable due to advanced age, economic disadvantage, or disparity due to race and ethnicity.
The Impact of Changes in Federal Medicaid Policy

Changes in federal policy during the replication phase firmly established participant-directed services as an option in Medicaid, but also resulted in important delays for the states participating in the Cash & Counseling program and major delays in most of their programs.

First, when the replication states received their Cash & Counseling program grants in 2004, they could offer their program with the budget authority under Medicaid through either a 1915(c) waiver or an 1115 waiver. By 2005, however, CMS had completed a revised 1915(c) waiver application and template, and most of the replication states used this provision to secure their waivers.

The new application and template made it much easier for states to add participant-direction options, including the budget authority, to existing waivers, but they required more information from states.

Second, the Deficit Reduction Act of 2005 amended the Medicaid statute by establishing 1915(j) authority, which allowed states to implement participant-directed programs by amending their state plans, thereby eliminating the need for waivers. As a result, the federal government would no longer approve applications to offer participant direction under 1115 waivers. Alabama, which had spent more than a year developing an 1115 waiver application, had to switch gears and develop an application under the 1915(j) authority. Alabama was the first state to use the 1915(j) authority.

Vermont was the only state that used a 1115 waiver to implement its participant-directed program during the Cash & Counseling replication, as this was part of a major reform of the state’s entire long-term care system that CMS had approved.

The rest of the states used 1915(c) waivers (existing, new, or amended) to implement their programs.

The Scope of the Replication Programs

The states implemented their cash and counseling programs between November 2004 and July 2009, with most implementing in 2006 and 2007. All states made the program available to older and younger adults with physical disabilities. Four states (Iowa, Kentucky, New Mexico, and Pennsylvania) also included other groups, such as children and/or adults with mental impairment or other developmental disabilities. Some states piloted their programs in a limited geographic area before implementing it statewide.

For more information about challenges during the replication phase, see Implementing Self-Direction Programs With Flexible Individual Budgets: Lessons Learned From the Cash and Counseling Replication States (2009).
Overall Program Activities and Results: The Replication Phase

In Minnesota, Irma and Ray Brunz were able to live together at home, with their daughter Donna Nelson as their caregiver, through the cash and counseling program. Irma had Alzheimer disease and had been living in a nursing home for five years. Ray needed care for a heart condition. “Once we brought her home, her health changed. Her happiness was entirely different. And the same thing with my dad. He could be at home with her and kiss her goodnight and this was very important for both of them,” said Donna.

To make the house more accessible for her parents, Donna used the allowance to modify the bathroom and build a ramp. She also pays other workers to provide services when she wants to run errands, attend church, or socialize, and needs respite care. “The most rewarding part of my job was to see my mom and dad together happy,” said Donna. “They celebrated their 70th wedding anniversary.”

- The 12 states enrolled 10,235 Medicaid beneficiaries in their cash and counseling programs (as of September 30, 2009) and all of the states made their programs permanent. Four of the replication states (Iowa, Kentucky, Michigan, and New Mexico) had enrollments exceeding 1,000, and seven states (Alabama, Kentucky, Michigan, New Mexico, Rhode Island, Vermont, and West Virginia) had close to 10 percent or more of their target population selecting cash and counseling during the program.

- Through Mi Via, New Mexico is meeting the needs of the state’s growing number of people with disabilities and older people on Medicaid and helping them have a better quality of life.

New Mexico's cash and counseling program, Mi Via (“my path,” “my way,” or “my road”), is helping Jessica Guttman of Santa Fe, N.M., recover from a brain injury. “Mi Via is phenomenal. It’s for people like me, who are proactive in getting the help they deserve,” says Jessica, who uses Mi Via to pay her provider “a living wage,” work out at a gym where staff are patient and responsive to her disability, and to get acupuncture to relieve her pain. She also got a computer, which she uses to play computer games as part of her rehab. “It’s a really big deal to be able to live on my own safely,” she says.

Read a story on New Mexico’s program.
Kentucky, a rural state that did not have enough agency home care workers, gave more people with disabilities access to personal assistance services through its participant direction program.

Read a story on Kentucky’s program.

Minnesota focused on enrolling more older adults with disabilities and on building the infrastructure to expand participant direction to more older and younger people with disabilities statewide.

Read a story about Minnesota’s program.

One replication state—Pennsylvania—faced especially significant challenges in implementing Services My Way, its participant-directed program. Despite the challenges, the state is committed to the program and is taking steps to help it serve more people.

Read a story about Pennsylvania’s program.

The Cash & Counseling program created champions in the federal government for participant-directed services and contributed to the spread of these services through changes in policy, law, and regulation. The close working relationship of RWJF, ASPE, and the national program office with CMS, the positive results from the randomized controlled demonstration phase, the spread of the program through the replication phase, and continuous communication with policy-makers about the program all contributed to the spread of participant-directed services.

“The replication provided the necessary momentum to begin to spread and replicate the model. It provided greater visibility for the model, which helped feed into the statutory changes in the Medicaid program that made it easier for states to adopt the model,” said Wren at the Administration for Community Living.

CMS made it easier for states to implement participant-directed services by:

- Revising the 1915(c) home and community-based services waiver regulations to allow states to add cash and counseling services to existing waivers

- Working through the details so that everyone eligible for a state’s 1915(c) home and community-based services waiver had the option of participant-directed services. CMS also simplified the rules for purchasing goods and services. Before this, people using cash and counseling had to have written agreements with any store where they bought covered goods.

- Allowing participants or their representatives to choose to employ certain categories of relatives (spouses and parents/guardians for minor children) who had previously not been permitted to become paid caregivers.

Federal legislation made it easier for states to implement participant-directed services by:
● Including a provision in the Deficit Reduction Act of 2005 allowing states to offer participant-directed programs within their regular state plans as of 2007, without waivers [provisions 1915(j) and 1915(i)]. 1915(i) allowed people who did not need an institutional level of care to qualify for home- and community-based services and did not limit spending on such services relative to the cost of institutional care.

● Including a provision in the 2006 reauthorization of the Older Americans Act making it possible to include a participant-directed option in the provision of services funded under this act.

— The Veterans Administration launched the Veteran-Directed Home and Community-Based Services Program in 2009. This program lets veterans manage their own budgets for personal care services, and choose the goods and services that best meet their needs; hire and supervise their workers, including family and friends; and buy things or services that help them live more independently.

Read more about this in Afterward.

“The replication showed that you could bring participant-directed services to scale, that it wasn’t just something you could do in the incubator,” said Mahoney.

● The national program office’s research and development efforts informed the implementation of participant-directed services and assisted in its spread and maintenance, according to Mahoney. Examples include:

— Developing & Implementing Participant Direction Programs & Policies: A Handbook, is a guide for state staff who are interested in and/or responsible for designing and implementing participant-directed programs, as well as for policy-makers who want to better understand these programs.

— Toolkits to help program developers deal with common problems, such as resistance from traditional home care providers, are available throughout the National Resource Center for Participant-Directed Services’ website.

— Training modules and other resources to help care managers make the paradigm shift from a medical to an empowerment model are available online.

— Cash & Counseling program demonstration and evaluation data are available to policy-makers, program administrators, and researchers online for review and analysis. An interactive data tool enables users to easily find answers to specific questions.

29 Originally passed in 1965, the Older Americans Act authorizes an array of community social services for older Americans through a national network of state agencies on aging, area agencies on aging, service providers, tribal organizations, and native Hawaiian organizations.
• **Participant-directed services are now available in all 50 states.** Most states offer these programs with both budget and employer authority, following the true cash and counseling model.

  Jan Dressman, 49, had a congenital condition (cervical spina bifida) that severely affected her mobility. Despite this, she worked as an education assistant with kindergarten and first-grade students at an elementary school in Ames, Iowa. But she felt very isolated, mostly because she was always afraid of falling. Jan enrolled in Iowa’s participant-directed program so that she could take charge of her physical therapy.

  Jan uses her budget for a personal trainer, a specialized physical chiropractor, regular water exercises, and to buy special shoes. Now, she can often walk without using a walker, and she has made so much progress that specialists asked to study her case to see what they could learn to help others.

“One thing we did, and folks at RWJ were really supportive, when the replication was designed, it was intentionally designed to encourage state units on aging to get involved, so it wasn’t a Medicaid only replication. That was a result of our involvement,” said Wren.

**The Replication Evaluation**

Janet O’Keeffe, DrPH, RN, an independent evaluator in Macon, N.C., conducted a process evaluation focused on lessons learned from the 12 states’ experience in developing and implementing their programs. The evaluation was intended to inform other states interested in participant-directed programs, and not to track individual participant outcomes.

O’Keeffe gathered information about the states’ cash and counseling programs over a two-year period from written summaries of the grants prepared by project directors, the states’ presentations at meetings, and discussions during technical assistance calls. Most of the data came from summaries written by the project directors, using a template developed for this study. O’Keeffe reviewed these summaries and conducted in-depth phone calls with the project directors and other staff to discuss the summaries and get more information.

**Lessons From the Evaluation of the Replication**

O’Keeffe reported the following lessons in *Implementing Self-Direction Programs With Flexible Individual Budgets: Lessons Learned From the Cash and Counseling Replication States* (2009). The information in this section is excerpted from this report.
“Involving participants and a broad range of stakeholders in the planning, design, and implementation of a new program is essential.” Allowing participants to direct their services and manage the budget for those services is a major paradigm shift in the long-term-care service delivery system. Some stakeholders may not support—or may actively oppose—a new self-direction program. States need to conduct a stakeholder analysis to identify the new program’s likely supporters and opponents and to develop a plan to address concerns.

Involving participants and their families and advocates will help to ensure that the new program will meet their needs, and can defuse opposition. For example, while case managers may feel free to tell state officials that they do not think participants are capable of directing their services, they are much less likely to express this view if potential participants are at the table stating they want to do so.

“Delineate roles and establish an effective and efficient communication system.” If multiple agencies are involved in program development and implementation, it is essential to clearly delineate each agency’s role and to establish an efficient and effective communication system. If not, agencies tend to disagree about who has the authority to make policy, which delays decision-making.

While states generally recognize the importance of involving stakeholders and the need to coordinate activities among multiple agencies, they often underestimate how much commitment, staff time, and resources are required.

“Develop a formal communication strategy.” A communication strategy serves many purposes:

— Explaining the new program to potential participants
— Educating everyone who will work with the program about their roles and responsibilities
— Addressing stakeholder concerns
— Countering misinformation—both intentional and unintentional
— Dealing with outright resistance

Many of the states faced opposition to the new program among traditional case managers due to lack of understanding and negative views about the ability of participants—particularly older people—to direct their services. In such instances, a communication strategy needs to be targeted to address specific concerns using many approaches: education, training, and working with influential opinion leaders whose support for the new program will be more effective in changing attitudes than the exhortations of state officials and program staff.

For more detailed findings and lessons from the replication, see Appendix 5.
Conclusion From the Evaluation

O’Keeffe drew the following conclusion in Implementing Self-Direction Programs With Flexible Individual Budgets: Lessons Learned From the Cash and Counseling Replication States (2009).

The experience of the participating states shows that “it can take a long time for a state’s long-term-care system to make a paradigm shift to a system that allows participants to have maximum control over the services they receive. Because state staff has little to no control over many factors that can significantly delay a new program, states that want to offer an entirely new self-direction program or a new option in an existing program should allocate at least two years for planning and development.

“Despite the considerable time, effort, and resources needed to implement a new budget authority program, program staff in the replication states believe it is well worth doing because the ability to direct services and supports makes a positive difference in the lives of many individuals with disabilities and their families.”

Resource Center Supports and Spreads Participant-Directed Services

The National Resource Center for Participant-Directed Services builds on lessons learned during the Cash & Counseling program to help states, agencies, and organizations that offer participant-directed services to people with disabilities. Established in April 2009 with funding from the Atlantic Philanthropies and RWJF, the center is based at the Boston College School of Social Work and directed by Richard Petty, MBA, who took over in November 2014 from Kevin Mahoney, who directed Cash & Counseling. Most of the center’s work is done through contracts, including with the Administration for Community Living and ASPE.

“Participant direction is important in order to lead the most healthy, most productive life. We still need to change policies and infrastructure to implement that care and that’s what the resource center is working on.”—Wendy L. Yallowitz, MSW, RWJF program officer for the resource center.

The center:

- Delivers technical assistance to Medicaid and non-Medicaid funded programs
- Offers trainings, toolkits, and educational opportunities on building quality participant-directed options in states

---

30 Grant ID 63987 ($4,751,055; September 2008 to August 2014).
• Coordinates research and policy efforts to spark the expansion of quality participant-directed programs

• Supports participants and caregivers through the National Participant Network.

• Conducted the National Inventory of Participant Direction Programs in 2011 and 2013. It provides key outcome measures related to publicly funded participant-directed services to determine whether the center’s work is having an impact on the field. It also tracks growth in the number of programs and participants and participant characteristics, and offers a national data set that can inform participants, researchers, and policymakers.

To develop the national inventory, researchers surveyed state administrators of participant direction programs and reviewed other data, such as:

— The Medicaid waiver database

— Participant-directed programs’ websites and their financial management services providers

AARP used the results of the 2013 inventory in the Participant Direction Domain of its Long-Term Services and Supports Scorecard.

2013 Inventory Key Findings

There are 277 participant-directed programs available nationwide, including in every state and the District of Columbia; they involve 835,000 participants. The majority of states have 1,000 to 5,000 participants enrolled these programs. Since 2010:

• Fifty-three new participant-directed programs started.

• There has been moderate growth in the use of participant-directed programs (an increase of approximately 90,000 participants nationwide).

• Some 18 states use managed care to deliver participant-direction services, a significant increase since the 2011 national inventory.

• Despite the increases, less than 6 percent of people nationwide who are eligible for Medicaid are enrolled in participant-directed programs.

Information about the inventory methodology and findings are available online in Facts and Figures: 2013 National Inventory Survey of Participant Direction.

The Partnership Between RWJF and ASPE: Challenges and Successes

Although the Cash & Counseling national program would not have been possible without the partnership between RWJF and ASPE, the partners did have to overcome challenges related to the different cultures and constraints of the private and public sectors. Challenges included different rules and procedures for external funding and internal
reviews, different management styles, and how to do joint decision-making and program management.

RWJF and ASPE work very differently, starting with different rules and procedures for external funding. For example, RWJF awards grants, while ASPE uses contracts for external work. Different requirements for internal review and approval affected the timing of funding for various components of the program.

ASPE has a much more hands-on, directive approach to managing the contracts it awards, while RWJF delegates much of management for a national program to a national program office, which it establishes for that purpose.

“When you embark on these partnerships, it takes time to understand the other organization’s culture and motivations. You have to go into it with the best of intentions and try to work on the relationship,” said ASPE’s Doty. “There are going to be differences. You have to make sure those don’t cause fissures and conflicts that are problematic.”

During the demonstration phase, weekly conference calls between ASPE, RWJF, the national program office at the University of Maryland and later Boston College, and Mathematica Policy Research, enabled the partners to deal with their different cultures and constraints, build their relationships, ensure that everybody knew what everybody else was doing, and reach consensus.

“If you didn’t resolve something, you knew you would come back and revisit it,” said Fishman, who extolled the benefits of “partnering early and often.”

The national program office facilitated communication between the partners between the conference calls. Knickman noted that Mahoney’s previous work on the RWJF Program to Promote Long-Term Care Insurance for the Elderly enabled him to understand how both RWJF and the federal government worked. “Kevin was a great bridge between the two cultures,” he said.

An administration change within the executive branch of the federal government and a change of leadership at RWJF could have threatened the Cash & Counseling program during the demonstration phase. But, due in large part to the longevity of the program officers at RWJF and the project officers at ASPE—and the national program office’s direction—the program not only survived but continued into a replication phase.

Developing a working relationship with the states was a challenge, due to the tension that is often inherent between the federal and state governments. But the partnership between

---

31 Mahoney was the project director for planning grants in Connecticut (Grant ID 12555 [$352,274; August 1987 to March 1990]) and California (Grant ID 12999 [$381,594; August 1988 to May 1992]) to design a public/private long-term care insurance program. See Program Results Report.
staff at ASPE, RWJF, and the national program office helped facilitate the negotiation between CMS and state officials. While the details involved in implementing the participant-direction demonstration programs in Arkansas, Florida, and New Jersey were sometimes daunting, the public/private partnership helped the participants work through the process.

The partnership between RWJF and ASPE was effective for many reasons, including:

- Knickman at RWJF and Stone at ASPE knew each other well and were very interested and invested in participant-direction and the Cash & Counseling program.
- Both RWJF and ASPE have a tradition of working on large-scale, analytical projects and value objective, rigorous evidence.
- The Cash & Counseling program for most of its life was under the radar screen. It was not one of RWJF’s large investments, and it was just one of many initiatives underway at ASPE. Thus, the demonstration took place relatively quietly.

“It was a wonderful public/private partnership and an example of how foundation money could be leveraged to help test and spread and potentially replicate a model that had a high probability of changing policy,” said ASPE’s Stone. “It was a great partnership with a federal agency,” added Fishman.

Read more about the partnership between RWJF and ASPE in “The Public/Private Partnership behind the Cash and Counseling Demonstration and Evaluation: Its Origins, Challenges, and Unresolved Issues.”

**Another View of the Radar Screen**

Doty notes that the program was and was not under the radar screen at ASPE. When Stone left ASPE in 1997, the year after Cash & Counseling began, Doty took over program management. She was a civil servant, however, and did not have the clout of a high-level political appointee such as Stone. Without Stone there to advocate for Cash & Counseling, there was a lack of interest in the program within the Department of Health and Human Services and the program, thus, operated under the radar screen.

Later, Cash & Counseling was “very much on the radar screen,” says Doty, when the Bush administration tried to claim credit for the program and use it for political purposes.

**Communications and Communication Results**

To “catalyze systemic change,” says Program Director Mahoney, the Cash & Counseling program used a strategic approach to communicating activities and findings that targeted

---

different audiences—policymakers, the research community, and state staff working on participant-directed programs.

To reach policymakers, the national program office and other members of the management team did congressional briefings, made presentations at conferences attended by federal government employees and policymakers, and developed brochures and reports for state policymakers and legislators summarizing findings, participants’ experiences, and state policymakers’ testimonials.

A special issue of *Health Services Research* in 2007, “Putting Consumers First in Long-Term Care: Findings from the Cash & Counseling Demonstration and Evaluation,” captured the results for the research community.

*Developing and Implementing Participant Direction Programs and Policies: A Handbook* is a guide for state staff who is interested in and/or responsible for designing and implementing participant-directed programs. O’Keeffe worked on this with Burness Communications and the national program office.

The national program office disseminated copies of reports and brochures to the different target audiences and also worked with national membership and advocacy organizations such as AARP, the Alzheimer’s Association, the National Council on Independent Living, and the National Conference of State Legislators to disseminate program findings through those networks.

National program office staff also published many journal articles, including in *Care Management Journals, Health Services Research*, and *Journal of Aging & Social Policy*, and made presentations at national meetings, including the Home and Community-Based Care Services Conference, and meetings of the National Association of Area Agencies on Aging, International Conference on Self-Direction, AcademyHealth, and the Gerontological Society of America.

See the National Program Office Bibliography for details about the publications.

**SIGNIFICANCE OF THE PROGRAM**

By empowering people with choices about their care, the *Cash & Counseling* program created a cost-effective model for improving the health of frail older adults with disabilities and other people with disabilities. It contributed to participant-directed services becoming a national policy that has been or is being implemented in most states’ home and community-based services.

---

33 *Health Services Research*, 42(1), 2007
Tommy G. Thompson, HHS secretary during the Cash & Counseling program demonstration phase, said that the projects proved that participants made good choices about their health and safety, improving their quality of life. He said:

_This approach gives people with disabilities more freedom and responsibility in the same way that all of us want to be in charge of our lives and our choices. It lets the individuals themselves decide how to best use the Medicaid dollars they are already entitled to._

“It is a myth to think that the case managers or agencies know best,” said Mike Huckabee, governor of Arkansas during the demonstration phase. “How can anyone know better what the needs of the client are than the people who perhaps live or socialize with that individual?”

AcademyHealth gave Mathematica Policy Research the 2009 Health Services Research Impact Award for the evaluation of the Cash & Counseling program, stating that the evaluation,

... altered policy-makers’ thinking about consumer-directed care, leading the federal government to pass legislation encouraging it, and states to incorporate it into their Medicaid programs.

The award recognizes outstanding research that has had a significant impact on health and health care, and has been successfully translated into health policy, management, or clinical practice.

“It’s a fundamental shift in the approach to delivering services to consumers who need them, from the traditional provider or case managed approach,” added Wren.

Participant direction has spread to the Veterans Administration and some private insurance plans. “Participant direction is a movement that has transformed supportive services in many states across the country and many different payment systems,” says former RWJF Vice President Knickman.

“The controlled experiment nailed forever the issue that this option really made life better. Participant-directed services dramatically improved access to services. People had a lot less unmet needs, were a lot more satisfied, and did a whole lot better on a range of health outcomes,” said Mahoney. “The replication showed that you could bring it to scale, that it wasn’t just something you could do in the incubator.”

The Cash & Counseling program “has had long-lasting implications,” said ASPE’s Stone, in giving frail older adults and other people with disabilities on Medicaid more options and choice for personal assistance services.
“The bottom line is, it worked for all groups and all ages so it spread,” said ASPE’s Doty, who noted that participant-direction is not for everyone; it is only appropriate for people who are willing to take on more responsibility. “I think we’ve now come to an understanding that there are a variety of different ways of financing and delivering long-term care services and supports, and there have to be a lot of different options available. It’s not one size fits all.”

**CHALLENGES FACED AND LESSONS LEARNED**

Challenges and Lessons Learned From the Demonstration Phase

*Potential Challenges Related to Costs and Overall Funding*

Challenges Noted by the Evaluators

Brown and colleagues at Mathematica Policy Research identified potential challenges to cash and counseling programs, and lessons learned by the states about controlling costs. The information below is excerpted from their 2007 report *Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services.*

Total costs to Medicaid were consistently higher with cash and counseling than without it, a worrisome concern in times of tightening Medicaid budgets, even if the higher costs were due mostly to correction of failings of the traditional system.

The failure of traditional programs to provide the number of authorized hours because of agencies’ inability to find enough workers should not be compounded by scaling down allowances by a comparable percentage for those who self-direct.

Costs could increase if the program’s existence leads eligible Medicaid beneficiaries who would not have applied for services under the agency model to do so under cash and counseling. However, limiting enrollment to current recipients of services prevents people who have access problems under the traditional program from resolving these problems through cash and counseling.

The savings in other Medicaid costs for adults—most notably long-term-care costs—did not continue into the second year, except in Arkansas. This suggests that substantially increasing the number of eligible beneficiaries receiving services and filling major gaps between actual and authorized levels of services may be the only way to generate savings in other long-term care costs.
Challenges Related to Using a Discount Factor

Both Mathematica’s Brown and ASPE’s Doty noted challenges with using a discount factor to scale down participant-directed budgets by the share of services that beneficiaries actually receive. This would adjust for the fact that, on average, traditional service providers do not deliver—and therefore cannot bill Medicaid for—all the services previously authorized as necessary to meet participants’ needs.

Mathematica reported that a discount factor may be needed to keep costs down, but could leave some consumers with too little in their budget to meet their needs. Since none of the three states restricted budgets in this way, the demonstration provides no evidence on what would happen if the budget were discounted.

Doty noted that few program administrators feel comfortable applying a discount factor and saw this as “penny wise, pound foolish” insofar as discounting budgets risks further reinforcing existing patterns of underservice.

Even when the discount factor was small and the evaluation results indicated that the resulting budget reductions still left program participants with adequate purchasing power, many program administrators were troubled by its use. They considered it unfair to discount benefits based on the percentage of services traditional providers routinely fail to deliver because this rationale for reducing benefits violates the principle of allocating health program benefits based on beneficiaries’ assessed needs.

Program administrators who remained focused on achieving program goals preferred to identify ways other than a discount factor to minimize cash and counseling costs. These included:

- Not allowing program participants who manage budgets to save and carry over unbudgeted funds indefinitely
- Keeping the fees paid to financial management services providers and counselors well below the percentage of reimbursement for traditional services that covered traditional providers’ overhead expenses

Over time, creative program administrators have demonstrated an ability to hold down cash and counseling costs by using these and other methods that do not adversely affect beneficiaries’ access to the full amount of Medicaid funding authorized to meet their individual needs.

Challenges Noted by ASPE and the National Program Office

Upon review of this report, Doty and Program Director Mahoney also noted other challenges.
The amount of funding that policymakers, especially state policymakers, believe they can afford to allocate to Medicaid—and especially to optional services such as personal care and other home- and community-based services—is limited at any point in time. Thus, if innovations in service delivery are expected to improve quality and access to care but are seen as unlikely to save money, policymakers typically want to be reassured that these improvements will not increase costs.

Although total Medicaid expenditures were higher for program participants who were permitted to self-direct compared to those who were restricted to receiving traditional services in all three states and for most subgroups, the cost differences were not statistically significant—except during the first demonstration year for the elderly in Arkansas and younger adults with developmental disabilities in Florida. Higher costs associated with self-directing program participants’ increased access to personal care and home- and community-based services (HCBS) waiver services were partially offset by lower use of other expensive Medicaid-covered services such as nursing home care and skilled home health services.

After the requirement to assure strict budget neutrality went away (it applied only to the original experimental programs that operated under special research and demonstration waivers) state policymakers had more freedom of judgment and action. For example, they were free to weigh whether and to what extent the positive outcomes for beneficiaries, their informal caregivers, and paid workers justified tolerating some cost increases—especially if the research evidence suggested these would be small and short-term (largely confined to the program start-up phase and disappear over time).

**Lessons Related to These Challenges**

Doty and Brown, and colleagues at Mathematica Policy Research, noted the following lessons learned.

1. **Independent trained state staff, rather than counselors, should prepare the assessments and reassessments used to determine participants’ personal care services waiver benefits because counselors may act more as advocates for the consumer than as objective assessors of need.** (Mathematica 2007 report, *Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services.*)

2. **The assessments and reassessments should be done without regard to whether the consumers will be directing their own care or will receive services through the traditional model.**

   Over time, program administrators came to realize that assessment instruments and protocols along with benefit allocation formulas should be standardized in such a way that the needs assessment process would result in a needs-based budget allocation. Thus, one self-directing beneficiary would not get a larger budget than another with
similar disability needs simply because he or she had previously had a service plan that included greater use of expensive services or services from providers that were more reliable in delivering services than others.

This approach would be fair to both self-directing and non-self-directing program participants insofar as both professional care managers developing traditional service plans for their clients and self-directing program participants would have to stay within budget. (Mathematica 2007 report and Doty/ASPE)

3. **States should contract for counseling services in a cost-efficient way.** For example, Arkansas found that the length of time until consumers’ spending plans were completed, and the corresponding cost to the program, decreased substantially when the state shifted from paying counselors a fixed monthly fee per consumer even before program participants began receiving budgets, to a fee-payment schedule that encouraged counselors to facilitate participants’ timely transition from traditional service use to self-direction. (Mathematica 2007 report and Doty/ASPE)

4. **States should recover unused allowance amounts at regular scheduled intervals and inform participants about the schedule.** (Mathematica 2007 report)

5. **States should monitor costs for both cash and counseling and traditional personal care services against authorized care-plan amounts.** This will help ensure that Medicaid beneficiaries receiving agency care and those who self-direct both receive the care that has been authorized, and prevent cost disparities between the two systems, according to Mathematica (2007 report).

   Doty noted that it is important to ensure that participants with traditional service plans actually receive all or almost all of the services prescribed for them and that self-directing program participants are spending their budgets on services of their choosing. Not making purchases to meet one’s needs is a red flag indicating that the beneficiary may no longer be fully capable of self-direction and either requires a representative or may need a change of representative.

   In either case, program participants who are not accessing the benefits authorized for them based on their needs assessment may be experiencing unmet needs for assistance that increase their risk of adverse health events and of transitioning from community living to institutional care. (Mathematica 2007 report and Doty/ASPE)

For additional lessons from Mathematica Policy Research’s reports, see Appendix 6.

**Additional Lessons From the National Program Office**

Mahoney offered additional lessons from the *Cash & Counseling* program.

6. **States should monitor to make sure prescribed services are delivered.** This appears especially true with agency-delivered care.
7. **Provide individual technical assistance to states or organizations that are trying to make complex systems changes.** The states needed technical assistance to make the complex systems changes required to implement participant-directed programs. The lessons learned in one state were often difficult to translate in other states, due to different infrastructures, politics, and cultures.

8. **Peer learning is an important way to share experiences across states.** During the *Cash & Counseling* program, the states learned from each other through a retreat and regular conference calls.

9. **Expect the optimal timing and scope of implementing a participant-directed program to vary among states.** There was some disagreement among the states about how fast a participant-directed program should be implemented. The original three states (Arkansas, New Jersey, and Florida) aimed to reach thousands of participants in a few years, although Florida phased the program in by regions. Among the replication states, New Mexico and Kentucky implemented their programs statewide, but in retrospect state leaders wished they had gotten the kinks worked out first. On the other hand, states such as Alabama, Illinois, and Vermont intentionally started small, restricting the territory and/or the numbers of enrollees. Some argue that starting very small does not fully test the infrastructure that will be needed for a larger program. Michigan and Iowa seemed to achieve the happy medium with a planned phase-in for going statewide.

For more lessons from the national program office, see Appendix 6.

**THE WORK GOING FORWARD**

**Resource Center Continues to Support and Spread Participant-Directed Services**

The National Resource Center for Participant-Directed Services is now following a strategic plan developed in 2013 to achieve its mission and remain self-sustaining. RWJF funding runs through August 2015. The plan, and the center’s work, focuses on six initiatives:

**Participant Direction in Managed Care**

- Establishing the center as the expert in participant-directed services in managed care, promoting quality participant direction programs in managed care, and securing contracts with managed care organizations for technical assistance in establishing participant directed programs

- In 2012, ASPE funded the resource center to conduct a study of the issues involved in implementing consumer direction programs for people who receive their health care coverage through managed care organizations. This is part of a larger ASPE-funded study of managed long-term care.
In 2013, the center conducted two studies to assess the state of participant direction in Medicaid managed care settings and in programs that integrate services provided to people eligible for both Medicare and Medicaid.\textsuperscript{34} Findings of the studies include:

- A lack of standardized requirements
- Inconsistent service coordinator training
- A lack of quality indicators and data reporting.

Recommendations include

- Developing best practices to guide effective program design
- Establishing quality measures and reporting requirements

**Aging and Disability Network/Workforce Development**

- Providing training and technical assistance and obtaining financial support for work related to participant direction within the Aging and Disability Network

**National inventory of Participant-Directed services**

This findings from the 2013 inventory were described earlier in this report.

**Membership**

- Sharing information and resources and enhancing participant direction programs through program and financial management services memberships
  
  - Program membership provides resources and support for state agencies administering or seeking to administer participant-directed programs. This includes technical assistance and webinars.
  
  - Financial management services membership, for fiscal entities serving participant-directed programs, offers access to online education, issue briefs, and technical assistance.

**Helping Veterans Who Need Long-Term Care**

One key project of the resource center is its work providing training and technical assistance to staff at the VA Medical Centers for veterans enrolled in the Veteran-Directed Home and Community-Based Services Program. In this program, veterans manage budgets for personal care services and choose the goods and services that best meet their needs; hire and supervise their workers, including family and friends; and buy things or services that help them live more independently.

\textsuperscript{34} Selected Provisions from Integrated Care RFPs and Contracts: Participant Direction in Home and Community-Based Services and Participant-Directed Services in Managed Long-Term Services and Supports Programs: A Five State Comparison.
Wren and other staff from the Administration for Community Living linked the VA Medical Centers with the state aging and disability centers, which assess the long-term care needs and options of veterans under contracts from the VA Medical Centers. Staff from the National Resource Center for Participant-Directed Services (which grew out of the Cash & Counseling national program office) and the Administration for Community Living train and provide technical assistance on participant direction to the aging and disability centers and follow the program locally to ensure that the veterans are satisfied and the services are being delivered according to the cash and counseling model.

By late 2014, more than one-third of all Veterans Administration hospitals offered the Veteran-Directed Home and Community-Based Services Program. It was available in 49 hospitals in 29 states and Washington, D.C., and had served 1,400 veterans. Another 800 veterans were using the program as of October 2014. The goal is to offer the program throughout the United States.

This program is especially important says Mahoney, because it will help develop the infrastructure (counseling and financial management services) necessary to implement participant-directed services on a large scale—an infrastructure that can then be used outside of the Veterans Administration.

**Working in Behavioral Health Care**

RWJF funded *An Environmental Scan of Self-Direction in Behavioral Health* that led to this work, which is being conducted with funding from RWJF and the federal Substance Abuse and Mental Health Services Administration, the National Resource Center for Participant-Directed Services and the Human Services Research Institute are conducting a large-scale demonstration and evaluation of self-direction in behavioral health. Based in Cambridge, Mass., and Tualatin, Ore., the institute consults and conducts research on intellectual and developmental disabilities, child and family services, mental health, substance use, and health data.

The National Resource Center for Participant-Directed Services is coordinating the demonstration and the Human Services Research Institute is conducting the evaluation. The evaluation involves a formative process evaluation focusing on implementation and a systems-level outcome evaluation focusing on cost. The project will include three to five states, yet to be chosen as of October 2014. The states will implement the cash and counseling model for people with mental illness and participate in the evaluation.

---

35 Also see the Program Results Report on this project.
36 Grant ID 71494 ($999,995; February 15, 2014 to February 14, 2017).
Making Resources Widely Available

Examples of recent resources available to the public include:

- Webinars and webinnettes, available on the center’s website: Webinars are live presentations that include slides, polls, and a chat box to communicate with presenters. They are recorded and posted on the website. Webinnettes are prerecorded presentations on a specific topic that include slides and a comprehensive resource guide.

- *Selected Provisions from Integrated Care RFPs and Contracts: Participant Direction in Home and Community-Based Services*, a review of 12 state contracts with managed care organizations and a toolkit with recommended contract language for states. It was published under a contract with Mathematica Policy Research through the federal Center for Medicare & Medicaid Services Integration Office, and is available online.

- *VD-HCBS: Sustainability Guidance*: A guide for local Veteran Administration Medical Centers in making a case for the sustainability of their Veteran-Directed Home and Community-Based Services Program programs. Available online.


- Issue briefs on topics of importance to financial management services members (e.g., the impact of the Affordable Care Act on participant direction). These are available only to members.

Sidebars

NEW MEXICO GIVES OLDER AND OTHER PEOPLE WITH DISABILITIES CONTROL AND CHOICE THROUGH PARTICIPANT-DIRECTED SERVICES

State officials in New Mexico saw that participant-directed services provided a way to meet the needs of the state’s growing number of older and disabled recipients of Medicaid. “We knew there was not enough money in the world to care for people in the traditional way: nursing homes. Self-direction and staying in the home became a real mantra for more people getting more services by living in their homes and having a healthier outcome,” said Marise McFadden, former director of the Elderly & Disability Services Division at the New Mexico Aging and Long-Term Services Department.
With support from a $347,260 grant in the *Cash & Counseling* program, New Mexico implemented a comprehensive participant-directed services program, called Mi Via (“my path,” “my way,” or “my road”).

**New Mexico’s Previous Experience With Participant Direction**

Before receiving the *Cash & Counseling* grant in 2004, New Mexico had limited experience with participant-directed programs. The state’s Medicaid plan included two programs in which participants could choose a family member (other than a spouse), friend, neighbor, or other person as their attendant. But only one of these let participants act as the employer and oversee the services. The state’s Self-Directed Family Support Program gave people with developmental disabilities authority to direct some of their services while they waited to become part of the home- and community-based services developmental disabilities waiver program.

The state moved a step closer to implementing participant-directed services more broadly when it passed the New Mexico Consumer Direction Act in 2003. The act required any department or agency of the state offering personal assistance services to people with disabilities to offer consumer direction as an option for these services.

**Establishing Mi Via**

Under the *Cash & Counseling* grant, the staff in three state agencies, the Aging and Long-Term Services Department, the Department of Health, and the Human Services Department worked together to establish Mi Via. The goal was to serve as many people as possible and to give them choice and control over their services and supports by giving them more say over how they allocated their care budgets.

The three agencies established Mi Via under two Medicaid 1915(c) Home- and Community-Based Services waivers. One waiver is for nursing-facility level of care, through which eligible people with disabilities and older people, and people with brain injuries enter the program; and the other is for the level of care in intermediate care facilities for the mentally impaired, through which people with developmental disabilities, medically fragile people, and people with AIDS can participate. (Waivers granted by CMS let states test new or existing ways to deliver and pay for health care services in Medicaid.)

Potential participants and their family members played a key part in the development of Mi Via and in designing outreach efforts. “It just made sense if we were going to do this

---

37 Grant ID 52106 ($347,260; October 1, 2004 to June 30, 2008).
program in a way to make a difference in their lives, to have them involved,” said McFadden.

Up to 100 potential participants and their family members attended monthly meetings to provide input on program design. Once Mi Via began, the three agencies formed the Self-Directed Waiver Subcommittee, composed of about 12 to 15 participants and family members from different parts of the state. Committee members helped identify information needs and reviewed outreach materials designed to help people decide whether Mi Via was right for them.

The easy-to-understand materials included a flyer, a participant guidebook, and frequently asked questions, available in English and Spanish; a video about Mi Via featuring participants, available in English, Spanish, Keres (the language of some of the Pueblo Indians), and Navajo; and a participant-friendly website linked to the websites of the three agencies. A Mi Via outreach liaison, usually accompanied by a Native American disability advocate and someone who spoke Spanish, made presentations, and did training about the program across the state at pueblos, reservations, senior centers, independent living centers, and advocacy group meetings.

**Launching the Program**

Mi Via launched statewide in November 2007, under the direction of the three state agencies. The Human Services Department runs the Medicaid program. The Aging and Long-Term Services Department operates the Mi Via nursing facility waiver and the Department of Health operates the Mi Via intermediate care facility for the mentally impaired waiver.

Mi Via covers traditional waiver services and other goods and services that participants select, including:

- Home appliances
- Computers and other assistive technology, devices, or services
- Durable medical equipment not covered by Medicaid
- Cost of social activities and community participation in social and recreational organizations
- Noncovered medical and dental expenses, nonmedical transportation, and alternative health services

A consultant (the counselor) and a financial management agent help participants with Mi Via, at no cost to them. New Mexico contracted with one consultant contractor agency and one financial management agency to work with Mi Via participants statewide, and a
third-party assessor to review and approve the participants’ service and support plan and budget.

The consultant is available up to 20 times a year to help the participant understand the program, develop and evaluate the service and support plan and budget, do the paperwork, and solve problems. Participants could also use someone they know as a consultant, as long as the person completes the necessary state-approved training.

The financial management agent works with the participant by phone and takes care of the payroll (timesheets, payroll, taxes, and other employer-related requirements) and sends checks to the participant’s employees and other vendors for goods and services. He or she also sends the participant a monthly budget, contacts the participant about requests that are not part of the approved plan and budget, and answers questions about payroll.

**Conquering Challenges**

While developing, launching, and implementing Mi Via was challenging, the three agencies, program contractors, and participants and their families were all committed to the program. Delivering the program consistently across the four groups of covered people and the three agencies required close collaboration and “hundreds of hours in meetings” on how the program should operate, and was “terribly complex,” said McFadden.

Complexities included the many steps in the eligibility and enrollment process and the coordination of the counseling, financial management, and assessor contractors. The focus on achieving consensus among stakeholders made everything take longer.

The three agencies also needed to figure out the roles and responsibilities of the consultants and the financial managers, and then to continually adjust the Mi Via process based on feedback from participants. This included making the service and support plan template and the budget worksheet more user friendly and revising the participant guidebook.

“I think we underestimated the amount of work a participant would have to do,” said McFadden. “It’s a lot of work to be an employer. I think we underestimated the complexity of that, even though there was a consultant agency and a financial management agency to help.” The first year of the program was very rough, she said.

**Improving Quality of Life for Mi Via Participants**

Despite the challenges, it was worth it. Participants say that they have a better quality of life because of Mi Via. Many report that the independence and freedom they get from directing their own care, hiring their own employees, and choosing their goods and services makes them healthier and happier, and able to live with more purpose.
“It’s a really big deal to be able to live on your own safely,” says Mi Via participant Jessica Guttman, who is recovering from a brain injury. She has used Mi Via to pay her provider “a living wage,” work out at a good gym where staff understand her situation, are patient and treat her well, and get acupuncture to help with her pain.

Tony Chavez also values his independence. “I’m the kind of person that likes responsibility,” says the Mi Via member. “I’m not a case that can be managed. I’m not a client.”

“Mi Via really does give participants so much more control and choice,” said McFadden, who noted the importance to participants of being able to choose people who care for them to provide services, and to be able to get these services when they want them. “The agency people might come put you to bed at 7:00 p.m., but you might want to stay up late. With Mi Via, you have the choice to live independently and do things the way you want to do them,” she said.

As of September 30, 2009, 1,691 people were enrolled in Mi Via. Of these, 1,084 had completed and implemented their plans and were using services. McFadden says that some people who enrolled were still deciding whether to participate, while people with brain injuries needed a lot of extra time to complete their paperwork.

Since the RWJF Cash & Counseling grant ended in June 2008, New Mexico developed a centralized Web-based computer system that makes Mi Via much easier for participants, who can now file paperwork online and review their spending report anytime. Participants and their families still provide input on the program through the Mi Via Advisory Committee, which replaced the Self-Directed Waiver Subcommittee. As of November 2012, Mi Via had 1,206 active participants and 1,550 people who had enrolled but had not completed their plans.

**A Final Thought About Costs and Benefits**

McFadden noted that the program is “extremely administratively expensive” adding “by the time you do a contract with a financial management agency or consultant, there are a lot of people involved. It's very costly for 1,100 or 1,200 people. In days of cost containment and state budgets, programs have to change so they are not nearly as costly to operate.”

Notwithstanding its costs “The program just keeps growing better and better very year,” said McFadden. “It's so much more sophisticated today.”
KENTUCKY LAUNCHES CONSUMER-DIRECTED OPTION FOR
PEOPLE WITH DISABILITIES

Disabled and Living in a Rural Area

People with disabilities living in rural areas of Kentucky often had little access to personal assistance services, such as help with bathing, preparing meals, and housekeeping. The home care agencies that provided these services rarely went into rural areas or did not have enough workers for everyone who needed help.

By 2004, Kentucky had three programs that allowed Medicaid beneficiaries who were disabled to direct their personal assistance services and hire workers to provide these services. The Personal Care Attendant Program helped adults with severe physical disabilities at risk of institutionalization remain in their own homes by subsidizing the cost of personal attendant services. It allows participants to hire their attendants. The Hart-Supported Living program provided grants that enabled people with disabilities to live in the community by allowing them to decide what supports and services to buy and to arrange and manage their services. The Traumatic Brain Injury Trust Fund allowed people with brain injuries to direct their services and hire workers.

But many people with disabilities—including frail older adults and people with intellectual or developmental disabilities—were not covered by these programs, which were operated under federally approved Medicaid waivers that let states test ways to deliver and pay for Medicaid-funded services. In 2004, Kentucky passed legislation creating the Consumer-Directed Option in the state’s Medicaid waiver programs.

Cash & Counseling Steps In

With a $250,000 grant from the Cash & Counseling national program, 38 Kentucky launched the Consumer-Directed Option and expanded participant-directed services to more people with disabilities.

The Consumer-Directed Option is a participant-directed program involving three Kentucky departments: Medicaid Services, Mental Health/Mental Retardation Services, and Aging and Independent Living. Kentucky amended three waivers and launched the Consumer-Directed Option in 2006, starting with older adults and children with disabilities (under the 1915(c) home and community-based services waiver). By 2007, the state had also included people with acquired brain injury (under the acquired brain injury waiver) and people with intellectual or developmental disabilities (under the supports for community living waiver). It also created the Community Directed Option Branch within the Department for Aging and Independent Living to manage the program.

38 Grant ID 52103 ($233,120; October 1, 2004 to June 30, 2008).
Support brokers from Kentucky’s Area Agencies on Aging and Independent Living counsel the participants, providing both some traditional case management services and additional services specifically related to self-directed care (for example, guidance in how to hire employees). These agencies also provide services that help older adults remain in their homes. Case managers monitor overall health and well-being of program participants.

Financial services managers from Kentucky’s Area Development Districts helped participants manage the paperwork required to pay an employee’s wages and withhold taxes. They also monitored timesheets and budgets (the Area Development Districts provide financial management services for the Area Agencies on Aging and Independent Living and the state).

**Challenges in Implementing the Community-Directed Option**

Kentucky faced significant challenges in implementing the Consumer-Directed Option and developing the necessary infrastructure to support the program, which led to slower than expected implementation and lower than expected enrollment. Changes in leadership and responsibility for the program, the blurred roles of the support brokers and case managers (and their lack of experience working with people with brain injuries and developmental disabilities), and getting the assessments necessary to enroll people, were among these challenges.

**Changes in State Leadership and Program Management**

While participating in the *Cash & Counseling* program, Kentucky elected a new governor and had four different Medicaid directors. In addition, while the Department for Medicaid Services was responsible for the Consumer-Directed Option, it initially contracted with the Department for Mental Health, Developmental Disabilities, and Addiction Services to design the infrastructure for the program and then switched to contracting with the Department for Aging and Independent Living to implement the option. Both Medicaid and Aging and Independent Living had to approve policies.

The Department for Aging and Independent Living in turn contracted with the local Area Agencies on Aging and Independent Living to handle program operations. But the state was behind schedule in implementing the Consumer-Directed Option and did not allow enough time to train staff at these agencies. In moving the contracts for the program to different agencies, the state frequently changed policies and procedures and many issues were not adequately addressed. Support brokers and financial services managers were frustrated and concerned about their ability to serve participants. Participants were also frustrated.
To address problems among state agencies and community organizations, the Department for Aging and Independent Living developed a procedures manual and distributed it to all state departments involved with the Consumer-Directed Option, and trained staff. The department also developed provider guidelines to answer questions and alleviate concerns, and hired a nurse consultant and social workers to troubleshoot issues for the local Area Agencies on Aging and Independent Living.

To reduce confusion among potential participants, project staff established a toll-free number for information about the program and the Area Agencies on Aging and Independent Living updated and distributed brochures and used other outreach activities to get the new information to potential participants and others.

**Blurred Roles and Lack of Relevant Experience Among Staff**

The blurred roles of the support brokers and case managers was another challenge. Kentucky uses support brokers to provide both counseling and case management services, but the state did not clearly define their differing roles. In most of the Area Agencies on Aging and Independent Living, support brokers did not do, or want to do, the broader monitoring tasks involved in case management. Some did not have case management experience. This led to a lack of case management services for Consumer-Directed Option participants. Project staff provided more training and information for support brokers through conference calls and its website, and it revised the policy and procedures manual. Staff also reassigned support brokers who did not meet the qualifications to be case managers.

The support brokers also lacked experience working with people with brain injuries and developmental disabilities. Aging and Independent Living brought in case managers from Community Mental Health Centers and trained them in the support broker tasks to work with these Consumer-Directed Option participants.

**Getting the Necessary Assessments for Enrollment**

Getting the assessments necessary to enroll people in the Consumer-Directed Option was difficult, because the home health agencies that had been doing this work lost money on the assessments, which they performed for a fee below cost in the expectation of then providing the services identified as needed in the assessments. They had no incentive to assess people who chose the Consumer-Directed Option. Sometimes, agencies would not even complete assessments when people indicated they wanted to self-direct or they would not give people information about the Consumer-Directed Option.

The Department for Aging and Independent Living changed its policies to allow support brokers to conduct assessments of people who chose the Consumer-Directed Option, provided training on how to do this, and hired a registered nurse to review the
assessments. Project staff also invited representatives of the home health agencies to serve on the Consumer-Directed Option Advisory Board and asked Kentucky Home Health Care Agencies to send a memo to the home health agencies clarifying the facts about the consumer-directed option and defining their responsibility to tell clients about it.

**Giving More People With Disabilities in Kentucky Choice and Control Over Personal Assistance Services**

Despite these challenges, Kentucky’s Consumer-Directed Option introduced participant-directed services to frail older adults with disabilities and people with intellectual or developmental disabilities, and expanded these services for other adults with physical disabilities. By September 2009, the state had enrolled 3,150 people. By December 2012, about 6,800 people with disabilities were enrolled in the Consumer-Directed Option, including about 2,100 older adults who probably would otherwise need to live in nursing homes. Aside from the humanitarian benefits of the option, the state is saving money by paying for personal assistance services instead of nursing home care, and also not exceeding nursing home capacity.

Kentucky has expanded the Consumer-Directed Option to two other programs that also cover people with intellectual or developmental disabilities (using the Michelle P. waiver) and people with brain injuries (using the long-term care brain injury waiver).

“Just about everybody is pleased with their services. They have control over when, where, and who is providing those services,” said Evan Charles, an internal policy analyst in the Community Options Branch of the Department for Aging and Independent Living and the Consumer-Directed Option’s lead staff member. The Consumer-Directed Option is especially beneficial for people with significant disabilities, who would probably need to live in an institution if not for the extra support and care they are getting from family members hired through the option, according to Tonia Wells, manager of the Community Options Branch.

The state has also streamlined and standardized the Consumer-Directed Option. For example, The Department for Aging and Independent Living originally handled billing and reimbursement and budget approval. Now, Medicaid Services handles these tasks, which has increased efficiency and made the program more responsive to the Area Agencies on Aging and Independent Living and the Area Development Districts. The Department for Aging and Independent Living developed standardized timesheets and support-brokers case notes.

“Overall, this program has been a huge success for Kentucky. The majority of our folks have thrived. But we have a lot to learn and work on,” said Wells.
MINNESOTA FOCUSES ON ATTRACTING OLDER ADULTS TO PARTICIPANT-DIRECTED SERVICES IN MEDICAID

Minnesota has offered a menu of home and community-based services to vulnerable older and disabled people, through a variety of federal waiver programs and state-funded programs since 1997. (Waivers granted by CMS let states test ways to deliver and pay for health care services in Medicaid.) While several programs allowed people to hire their own workers to provide personal assistance services, they were not available statewide. Only one program, called Consumer-Directed Community Supports, targeted to people with mental impairment and related conditions, let people control the budget for their services.

Minnesota Joins Cash & Counseling

In October 2004, the state of Minnesota received a $350,000 grant from the Cash & Counseling national program to expand the Consumer-Directed Community Supports program to cover more people and more areas of the state.39

In Minnesota's Consumer-Directed Community Supports, a case manager (for people in fee-for-service programs) or care coordinator (for people in managed care) works with the participant to make decisions and plan care, and provides referrals to support planners and financial management services. Support planners, independent professionals who are certified by the state of Minnesota, help participants enroll, and help them write the plan for services, and hire and manage the workers who provide the care. Participants can hire family members, friends, and neighbors as workers and support planners.

Financial management services include paying the workers who provide services, deducting appropriate taxes, and filing with the IRS. Program staff in Minnesota encouraged participants to use financial management services. Most used a model in which an agency is a joint employer with the participant and handles payroll and billing.

Expanding Participant-Directed Services Statewide

Minnesota used its Cash & Counseling national program grant to expand the Consumer-Directed Community Supports program to make participant-directed services available statewide in all of its home and community-based services waiver programs, the Alternative Care program (a state program that helps low-income older adults remain in their communities), and two managed care programs: Minnesota Disability Health Options and Minnesota Senior Health Options. (Minnesota Disability Health Options ended in December 2010.)

39 Grant ID 52105 ($350,000; October 1, 2004 to December 31, 2007).
The Centers for Medicare & Medicaid Services approved adding Consumer-Directed Community Supports to the state’s array of home and community-based services waiver programs in March 2004, before the state joined Cash & Counseling. At that time, the Minnesota Department of Human Services began implementing a plan to expand the service option statewide for:

- People with acquired or traumatic brain injury (under the brain injury waiver)
- Children and adults who are chronically ill and would otherwise need hospital-level care (under the community alternative care waiver)
- Children and adults who would otherwise need nursing home-level care (under the community alternatives for disabled individuals waiver)
- Children and adults with developmental disabilities or related conditions (under the developmental disabilities waiver)
- People age 65 and older who are eligible for Medicaid and need nursing home-level medical care but choose to live in the community (elderly waiver)
- People age 65 and older who are eligible for Medicaid and enrolled in Medicare Parts A and B (Minnesota Senior Health Options)
- Family or other caregivers of older adults and adults with Alzheimer disease and related disorders, grandparents caring for grandchildren, and grandparents or other relatives caring for disabled adults (National Family Caregiver Support Program)

Minnesota used its Cash & Counseling national program grant to focus on increasing enrollment in Consumer-Directed Community Supports services among older adults through the elderly waiver and the alternative care waiver, and also adults under the Community Alternatives for Disabled Individuals Waiver program, and family caregivers under the National Family Caregiver Support Program. The state also focused on using Cash & Counseling funds and technical assistance to build the infrastructure to sustain this service option.

**Challenges in Enrolling Older Adults, and Effective Solutions**

**Many Potential Participants Were Satisfied With Existing Agency Services**

Minnesota’s Cash & Counseling grant staff found that older adults were generally satisfied with the traditional system, in which agencies determined which services were needed and hired workers to provide those services. They had strong relationships with their case managers or care coordinators, whom they relied on, and they had little incentive to learn about or enroll in Consumer-Directed Community Supports. “We
wanted to jumpstart the use of this model for older adults,” said Jane E. Vujovich, state program administrator at the Minnesota Department of Human Services.

**Ambivalence Among Staff, and Competing Priorities for Their Time**

Enrollment was also hampered because many case managers, care coordinators, and other staff from the lead agencies were skeptical that Consumer-Directed Community Supports was appropriate for older adults, and they had competing priorities for their time. The lead agencies are Minnesota’s 87 counties, nine managed care organizations, and eight area agencies on aging (which provide services that help older adults remain in their homes, including counseling people who are interested in self-direction programs).

At the time that Consumer-Directed Community Supports was being implemented statewide, Minnesota was also implementing its Minnesota Senior Health Options managed care program across the state. In addition, case managers and care coordinators were helping to enroll eligible people in the Medicare Part D drug benefit and in Medicaid programs for people eligible for both Medicaid and Medicare. Because of their heavy workload, and the many programs they were working on, it took a long time for staff to really understand Consumer-Directed Community Supports.

**A Multifaceted Strategy to Overcome the Challenges**

To boost enrollment in Consumer-Directed Community Supports among older adults, the Minnesota Department of Human Services contracted with three Centers for Independent Living covering 29 counties to help with outreach and enrollment. Project staff conducted regional meetings, developed educational materials, and provided ongoing information and training for case managers and care coordinators through videoconferences, conferences, and meetings.

As they worked on the *Cash & Counseling* grant, over time project staff gained expertise in Consumer-Directed Community Supports, and could better counter objections from the lead agencies. These activities also helped build the infrastructure for the option.

The Centers for Independent Living were strong advocates and champions of Consumer-Directed Community Supports, says Vujovich, and “could talk directly one-on-one to an interested participant and give them unbiased information and really be able to articulate how it worked.”

The centers used direct mail, telephone calls, and in-person visits to inform eligible people about Consumer-Directed Community Supports.

Project staff developed many educational materials for consumers, case managers, care coordinators, providers in the aging network, and others. They also created a Web page with Consumer-Directed Community Supports information, tools, resources, and
participant stories and a video, kiosk card, and flowcharts to briefly describe Consumer-Directed Community Supports.

Staff from the Minnesota Department of Human Services and the three Centers for Independent Living jointly developed regional meetings with local stakeholders to address enrollment and consumer education issues, and roles and responsibilities. The department also provided technical assistance to case managers and care coordinators, support planners, financial service management entities, and others.

To build the infrastructure for financial management services, project staff asked financial management services entities to teach participants about the services they provided. They also trained case managers, care coordinators, support planners, and staff from financial management services entities about the different models of financial management services.

**Seeing Results: Helping Older Adults with Disabilities Stay at Home**

Minnesota had 868 enrollees in Consumer-Directed Community Supports as of September 30, 2009. Older adult participants and their families were enthusiastic about the service option and voiced a strong desire to keep it a viable and growing option in Minnesota, according to staff at the Minnesota Department of Human Services.

“This program has been a godsend,” said Violet Hamilton, wife and caregiver to her husband Harold, who was 70 when he enrolled in Consumer-Directed Community Supports. Harold lost his sight to diabetes and had been getting personal care services from an agency every day while Violet worked.

But his diabetes kept spiraling out of control because neither he nor his agency-employed aides recognized when he was in danger of going into diabetic shock. Violet was the only person who spotted the signs and symptoms quickly enough to prevent this. Also, the aides could not give Harold his pills or his insulin or take him to doctors’ appointments. Through Consumer-Directed Community Supports, Harold was able to hire Violet to provide personal assistance services and to pay her enough that she could afford to give up her job.

“Minnesota is very much committed to self-directed services. The work we did as part of Cash & Counseling was one piece in our effort to build this model into our system. It helped to give us momentum on the aging side,” said Vujovich.

Consumer-Directed Community Supports has allowed participants to stay in their homes for longer and couples to stay together. Family caregivers who have quit work to care for
a family member are now being paid. And participants are getting quality home and community-based care from familiar, trusted workers. The service option has been especially helpful in rural areas where agency personal care workers are limited and in enabling people from other cultures to find workers who speak their language.

**Continuing to Build Participant Direction**

Since the *Cash & Counseling* grant ended in December 2007, the Minnesota Department of Human Services has “kept going,” according to Vujovich, building on the work done during the program through another grant project, and in services funded by the Administration for Community Living for older adults and other people with disabilities.

Under a Nursing Home Diversion Modernization Program grant from the federal Administration for Community Living (2007–09), the Department of Human Services has worked with the University of Minnesota to develop and validate a standardized screening tool to identify people at high risk of moving into assisted living or a nursing home. Project staff pilot tested the tool with the service providers and clients of three area agencies on aging. At-risk people are referred to the state’s evidence-based programs (e.g., chronic disease management) that can help mitigate their risks.

The state is also working with the areas agencies on aging to redirect the use of some of their funding from the Administration for Community Living for participant-directed services—where people who have incomes above Medicaid thresholds pay part of the costs themselves—and to educate people about the cash and counseling option.

Minnesota also participates in the Veteran-Directed Home and Community-Based Services Program, which lets veterans manage their own flexible spending budgets for personal care services, and to choose the goods and services that best meet their needs; hire and supervise their workers, including family and friends; and buy things or services that help them live more independently.

Lastly, the Minnesota Department of Human Services is developing a standardized assessment for community-based services that can be used by staff from all health plans and has been providing more training for staff on participant-directed services, including a series of learning modules that will also be available to potential participants and their families.
PENNSYLVANIA CONFRONTS CHALLENGES TO CREATE STRONGER SELF-DIRECTED PERSONAL ASSISTANCE SERVICES

The state of Pennsylvania has allowed Medicaid recipients with physical disabilities to make decisions about their personal assistance services since 1984. This included allowing them to hire, manage, pay, and fire workers. Since then, Pennsylvania has added options for self-directed personal assistance services through eight 1915(c) home- and community-based services waiver programs, including the aging and attendant care waivers. Waivers granted by the Centers for Medicare & Medicaid Services let states test ways to deliver and pay for health care services in Medicaid.

These self-directed programs let participants choose and hire workers but did not give them control over the services they received or let them buy things to support their independent living. Also, not all programs were available statewide.

With a $196,798 grant from the Cash & Counseling national program, Pennsylvania had planned to develop and implement a cash and counseling program, called Services My Way, in its aging waiver program statewide and in six other waiver programs in some counties.

Challenges in Developing and Implementing Services My Way

From the start, Pennsylvania experienced many significant challenges with Services My Way. In the end, the state was able to offer the program only to Medicaid beneficiaries who were eligible for the aging and the attendant care waivers—people over the age of 60 and people ages 18 to 59 with physical disabilities who met the level of care needed for placement in a nursing home or a special rehabilitation facility, respectively.

Strife within the state government and lack of previous oversight of financial management services were key challenges for Pennsylvania. The Governor’s Office of Health Care Reform, established in 2003 to improve health and long-term living services in Pennsylvania, submitted the proposal and was managing the grant. But the office had no authority over the agencies that operated the waiver programs related to Services My Way, and these agencies were suspicious of—and resistant to—initiatives coming out of the Governor’s Office of Health Care Reform.

“They could not come to a consensus on what they wanted the program to look like,” said Virginia Brown, the original project manager for the grant in the Governor’s Office of Health Care Reform (as of December 2012, Brown was director of the Bureau of Individual Support in the Department of Public Welfare’s Office of Long-Term Living).

---

40 Grant ID 52100 ($195,798; October 1, 2004 to February 28, 2009).
Lack of consensus delayed the work and left the state unable to prepare the necessary waivers to implement Services My Way for adults with physical disabilities and developmental disabilities. After a period during which waivers were submitted and then withdrawn, the state was only able to amend the aging and attendant care waivers to do a pilot demonstration in 21 counties.

Since Pennsylvania had a history of offering self-directed services and comprehensive benefits to Medicaid recipients covered by the aging and attendant care waivers, Services My Way held limited appeal to key stakeholders: potential participants, state staff, and the personal assistance workers and staff from area agencies on the aging who were already working with participants in the existing self-directed programs. The area agencies on aging in Pennsylvania provide services that help older adults remain in their homes, including counseling people who are interested in self-directed programs.

Potential participants were afraid Services My Way would negatively affect their ability to hire workers. State and other staff did not understand the idea of giving participants a budget to manage, and there were inconsistencies among agencies in the ways staff understood their roles in self-directed programs, with some traditionally taking a very hands-off approach. To increase buy-in, project staff met with other state staff, potential participants, and staff from provider organizations and the area agencies on aging to explain the program. They also made presentations, conducted focus groups, created an advisory committee composed of stakeholders, established several workgroups, and provided training to state staff.

The biggest challenge related to the financial management services component of the program. The state required the agencies that were providing home care services under seven waiver programs to also provide financial management services such as disbursing funds, withholding and filing taxes, and processing time sheets. But the state had been providing little oversight of the financial management services entities and had little understanding of how they operated. The state agencies responsible for the waiver programs did not assess or monitor the financial management services and had different expectations for the providers and different policies for reimbursing them.

There was also an inherent conflict of interest in expecting the agency that provided home care services to also help people hire and supervise their workers. “It all boiled down to having the conflict of interest of having the financial management being provided by the service agency because they would self-refer,” said Brown. This resulted in few people being told about Services My Way.

Brown and other project staff began looking at better options for financial management services. After working with an expert from the Cash & Counseling national program office, they met with a group of stakeholders and put together standards, implemented in December 2008, for financial management services entities.
Launching Services My Way

The pilot Services My Way program for Medicaid recipients covered by the aging and attendant care waivers started in July 2009 in 21 counties. Pennsylvania had enrolled only two participants as of September 30, 2009. Services My Way became available statewide in July 2011, after the state amended the aging and attendant care waivers to expand the program statewide. As of December 2012, about 75 Medicaid beneficiaries were enrolled in Services My Way through the aging and attendant care waivers.

Services My Way gives participants a flexible budget within which they can design a service plan and choose the goods and services they need to continue living at home. It gives people who are already self-directing their services more choices than they had before, such as deciding how much to pay workers and when to give them a raise, and buying things that are not allowed through other programs. Participants can hire a friend, neighbor, or other trusted person (including a family member but not the spouse) as their worker.

A service coordinator from a local area agency on aging helps participants develop and implement their plan. The fiscal management services providers from other self-directed programs help them with the paperwork required to pay an employee’s wages and withhold taxes and with receiving and disbursing program funds.

Addressing the Challenges: Creating Stronger Self-Directed Services

Despite the many challenges Pennsylvania faced during its participation in the Cash & Counseling program, the state is moving toward stronger self-directed services. Identifying and correcting the issues with the financial management services was key.

Along with establishing the standards for financial management services providers, in December 2012, Pennsylvania transitioned to a single provider for these services. “We’re truly hoping that with this move to a statewide vendor of financial management services we will finally have some legitimacy to the program, that people will be offered the choice of budget authority because there will no longer be the conflict,” said Brown.

The work done to develop Services My Way and participate in Cash & Counseling also helped state staff, providers, and participants better understand the role of giving people the authority to determine their own priorities for allocating their budget.

“We would also like to see the model grow, and see about expanding it into some of our other waiver programs,” said Brown. The state plans to collect data on participants in Services My Way for use in decisions about expanding the model.
## Project List

### Project List for the Demonstration Phase

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Project Director</strong></td>
<td>Sandra Barrett</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Project Director</strong></td>
<td>Tom Reimers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

|---|---|---|---|---|

41 Contact information is included only for those projects whose directors were interviewed for the sidebars to this report.
ID 43761 (October 2001–August 2002) $99,492

**Project Director**
William A.B. Ditto, MSW, LSW

*Health Research, Inc. (Menands, N.Y.)*
New York *Cash & Counseling Program*
ID 30279 (October 1996–December 1998) $157,552

**Project List for the Replication Phase**

**State of Alabama Department of Senior Services (Montgomery, Ala.)**
Alabama *Cash & Counseling Program*
ID 52116 (October 2004–March 2008) $247,853

**Project Director**
Jean Stone

**State of Iowa Department of Human Services (Des Moines, Iowa)**
Iowa *Cash & Counseling Program*
ID 52108 (October 2004–March 2008) $239,366

**Project Director**
Eileen Creager

**State of Kentucky Department for Medicaid Services (Frankfort, Ky.)**
Kentucky *Cash & Counseling Program*
ID 52103 (October 2004–June 2008) $233,120

**Project Director**
Tonia Wells
(502) 564-6930 ext. 3498
toniaa.wells@ky.gov

**State of Michigan Department of Community Health (Lansing, Mich.)**
Michigan *Cash & Counseling Program*
ID 52102 (October 2004–March 2008) $249,303

**Project Director**
Michael J. Head, MSW, CSW
State of Minnesota Department of Human Services (Saint Paul, Minn.)
Minnesota Cash & Counseling Program
ID 52105 (October 2004–December 2007) $350,000

Project Director
Jane E. Vujovich, BA
(651) 451-3966
jane.vujovich@state.mn.us

State of New Mexico, Aging and Long-Term Services Department (Santa Fe, N.M.)
New Mexico Cash & Counseling Program
ID 52106 (October 2004–June 2008) $347,260

Project Director
Marise McFadden, MPA
(505) 246-9988 ext. 8131242
marise.mcfadden@xerox.com

Commonwealth of Pennsylvania Governor’s Office (Harrisburg, Pa.)
Pennsylvania Cash & Counseling Program
ID 52100 (October 2004–February 2009) $196,798

Project Director
Virginia Davies Brown
(717) 783-4510
virbrown@pa.gov

State of Rhode Island Department of Human Services (Cranston, R.I.)
Rhode Island Cash & Counseling Program
ID 52101 (October 2004–December 2007) $238,147

Project Director
Dianne Kayala, MS

State of Vermont Agency of Human Services, Department of Disabilities, Aging, and Independent Living (Waterbury, Vt.)
Vermont Cash & Counseling Program
ID 52110 (October 2004–September 2008) $237,342

Project Director
Merle Edwards-Orr
State of Washington Department of Social and Health Services (Olympia, Wash.)
Washington Cash & Counseling Program
ID 52109 (October 2004–March 2008) $249,602

Project Director
Dan K. Murphy

State of West Virginia Bureau of Senior Services (Charleston, WV)
West Virginia Cash & Counseling Program
ID 52104 (October 2004–September 2007) $250,000

Project Director
Julie Shelton

APPENDIX 2

Demonstration Phase Evaluation Methodology

The Effects of the Cash and Counseling Approach on Medicaid Beneficiaries

To evaluate the effects of the cash and counseling approach on Medicaid beneficiaries, the evaluators at Mathematica:

- Interviewed Medicaid beneficiaries before they were randomized into the treatment (cash and counseling) and control (traditional agency services) groups
- Compared outcomes for the treatment and control groups, regardless of whether a particular treatment group member actually received the monthly allowance. Some consumers never received their allowances, so this intent-to-treat approach understates the impacts of actual participation in the program.
- Surveyed, by telephone, treatment and control group participants nine months after they enrolled in the program to collect data on well-being and outcomes. This covered the types and amounts of care received, unmet care needs, satisfaction with care, health and functioning, quality of life, and incidence of adverse outcomes (e.g., falls or pressure sores).

The Effects of the Cash and Counseling Approach on Medicaid Costs and Services

To evaluate the effects of the cash and counseling approach on Medicaid costs and service use, the evaluators used Medicaid and Medicare claims data for the two years after enrollment.
**The Effects of the Cash & Counseling Approach on Caregivers**

To evaluate the effects of the *Cash & Counseling* approach on caregivers, the evaluators:

- Conducted 10-month follow-up telephone surveys with the primary *unpaid* caregivers identified by participants when they enrolled.

- Surveyed by telephone the person participants identified as the primary *paid* caregiver. This could be a directly hired worker or an agency worker. At their nine-month follow-up survey, participants identified their primary paid caregiver during the two previous weeks. For agency workers, the evaluators stopped after interviewing 300 people, the target sample size.

- Compared the experiences of the workers hired by consumers and agency workers on working conditions, stress levels, and satisfaction, using data from the telephone surveys.

**How the Cash & Counseling Program Operated: The Implementation Analysis**

To evaluate how the *Cash & Counseling* program operated, the evaluators:

- Visited the states and discussed the program with staff, state officials, and representatives from the personal care industry (such as leaders of agency associations or trade groups in the state).

- Reviewed administrative data from the states.

- Surveyed the treatment group participants by telephone.

- Surveyed counselors by mail.

Evaluators asked the following key questions in the implementation analysis:

- **Targeting of the program:**
  - Which beneficiaries would be offered the program?
  - How did the states determine program eligibility?
  - How did the states promote the program to potentially eligible people?

- **Operational aspects:**
  - How did the states define and implement the counseling component of the program?
  - How did they set allowances, what restrictions did they place on uses of the allowance, how was allowance use monitored?
— How did states provide the fiscal services that helped consumers meet their obligations as employers?

- Performance measures:
  — What were the programs’ level of success in enrolling and starting consumers on allowances?
  — How frequent was fraud or abuse?
  — To what extent did consumers like the program?
  — What program features did counselors and consumers find to be particularly attractive or unattractive?

APPENDIX 3

How the States Demonstrated Budget Neutrality

Source: Pamela Doty, PhD, ASPE

Under the terms of the Medicaid Section 1115 waiver authority for the demonstration, each of the three program states was required to demonstrate that Medicaid expenditures with the program were no higher than expenditures without the program.

Staff at the Centers for Medicare & Medicaid Services (CMS) monitored budget neutrality according to what had been negotiated between CMS and the federal Office of Management and Budget and the three Cash & Counseling states for inclusion in the 1115 waiver terms and conditions. Essentially the treatment group’s average spending from their budgets and on related Medicaid community care services could not exceed the control group members’ Medicaid cost of claims paid for a set of core services per month—including the personal care or home- and community-based services whose anticipated costs served as the basis for treatment group members’ budget amounts.

Per-member-per-month cost calculations for individual members of each group only included months in which any such services were received or in which any spending from treatment group members’ budgets occurred. States had insisted that the budget neutrality test not include physician, hospital, or other in-patient services so it was important to compare costs in such a way that Medicaid savings were not inappropriately credited when treatment or control group members became ineligible for community care because of hospital or nursing home use. Although these comparative costs were monitored on a quarterly basis, whether or not the budget neutrality requirement was met was determined on the basis of comparative treatment/control group costs over the entire initial waiver period and any subsequent four-year maximum waiver renewal periods.
New Jersey satisfied budget neutrality every quarter as long as the 1115 waiver remained in effect. In contrast, early on, Arkansas experienced worrisomely higher costs for treatment compared to control group members. Arkansas officials took steps to reduce treatment group costs and in the final waiver closeout report, CMS credited it with savings. In the case of Florida there appears never to have been an official determination regarding the budget neutrality of the state’s cash and counseling program given that need for such a determination was mooted by Congress’ enactment of the Deficit Reduction Act provisions of 2005 which permitted states to offer cash and counseling alternatives without having to demonstrate budget neutrality.

APPENDIX 4

The Aging Network in the United States

State units on aging are state and territorial government agencies that administer, manage, design, and advocate for benefits, programs, and services for older adults and their families and, in many states, for adults with physical disabilities. They provide the opportunities and supports for people to live independent, meaningful, productive, dignified lives.

Area agencies on aging are public or private nonprofit agencies designated by the state to address the needs and concerns of all older people at the regional and local levels. They coordinate and offer services that help older adults remain in their homes, if that is their preference, aided by services such as Meals on Wheels and homemaker assistance.

The Aging and Disability Resource Centers is a collaborative effort of the U.S. Administration for Community Living and CMS to streamline access to long-term care. The center supports state efforts to develop one-stop shop centers in local communities that help older adults and people with disabilities make informed decisions about their service and support options and serve as the single point of entry to the long-term-care system.

APPENDIX 5

More Findings From the Replication Phase Evaluation

Findings Regarding Challenges and Lessons Learned in the Planning and Design Stages

Independent evaluator Janet O’Keeffe, DrPH, RN, reported the following challenges states faced in designing the program components: counseling, financial management services, and individual budgets.
Counseling

- **Providing counseling services in a self-direction program generally entails some change in the role of traditional case managers.** Many of the states learned that they could not expect all case managers to support these changes. The more changes in the traditional role of case managers that the new program entails, the more likely it is that the state will face challenges, particularly if case managers provide counseling services and handle enrollment in the new program.

States need to determine the extent of case manager support for changes in their role before designing the counseling service. If case managers are resistant after receiving initial information, education, and training, states may want to consider other approaches, such as having a distinct role for counselors that will not alter the role of traditional case managers.

If case managers and counselors have separate and distinct roles, however, program staff and participants must understand these roles. Conducting joint training for counselors and case managers is one way to do this.

- **States need to ensure that counselors understand the target population and to have enough counselors available to meet its needs.**

Financial Management Services

- **Designing financial management services and obtaining a provider, a key to the success of a new budget authority option, was a major challenge for many states, which recommend that others:**
  - Allow sufficient time and resources to hire the financial management service provider(s)
  - Get the best technical assistance available in order to save money in the long run
  - Have a financial management service subject matter expert who understands the internal revenue service, state contracting protocols, and program requirements on staff or as a consultant

Individual Budgets

- **“Designing the methodology for individual budgeting and dealing with concerns about the new program’s costs were major challenges for the states.”** While Medicaid does not require a self-direction program to be budget neutral relative to traditional services delivery, state legislatures and budget offices may require program staff to demonstrate that the new program will not cost more than the traditional service delivery system.”

- **“Program staff must also be prepared to spend a considerable amount of time educating all stakeholders about the budget methodology—how the amount of money in the budget is determined.”** Since participants in the traditional service
system in many states are not receiving all of their authorized services, but may do so once they can hire their own workers and purchase the goods and services they need, some states felt they had to discount the budget, which led to negative perceptions about the program in several states and slowed enrollment in others.”

Nine of the 12 replication states reported challenges related to individual budgets, most frequently, negative perceptions about the adequacy of the budget and concerns that the new program would cost more than the current program.

Negative views about the sufficiency of the budget slowed enrollment in Iowa, Minnesota, and Vermont.

- **States are concerned that a new self-direction program could cost more than the traditional service system, but if the cost differential is due to the failure of participants to receive their authorized services in the traditional system, states need to figure out a way to address this problem.**

**Findings Regarding Lessons Learned in the Implementation/Enrollment Stage**

- Communication often takes much longer than anticipated and it is important to set aside sufficient time and resources to plan and design materials for diverse populations and to involve the target audiences in these activities.

- **Communication strategies specific to enrollment are:**
  - Outreach and education to ensure that all people who are eligible know about the new program
  - Providing sufficient information to enable potential participants to decide if the new program is right for them

- **States should examine others’ communication strategies (e.g., letters, brochures, and outreach videos) but be aware that strategies that are successful in one state may not always work in another.**

- “To ensure a smooth enrollment process, states need to be flexible, address problems quickly, and be prepared to change policies and procedures as better ways of doing things become clear. What seems logical in theory may not work in practice.”

- **Dedicated enrollment staff can help to increase enrollment, particularly when a program is first implemented.** If a state cannot afford ongoing dedicated staff, it should consider paying for such staff during the first six months of a new program.

- A simple and efficient enrollment process is essential.
APPENDIX 6

More Lessons Learned


- Unless counselors aggressively seek to help consumers establish their spending plans within a short period after enrollment, many consumers who want to direct their own care might not ever do so.
  - The very low proportion of Florida’s elderly beneficiaries who participated suggests that states may have to develop incentives for counselors and may have to train counselors to encourage and help consumers develop their spending plans within a few months of enrollment.
  - Arkansas’s method of requiring counselors to get consumers started on the cash allowances within 45 days was particularly effective.

- The program’s favorable effects on participants may not be realized or, if realized, may not be sustained, if many participants are unable to hire workers, or if stress leads hired family workers to quit.
  - To help participants find or replace workers, states should consider establishing worker registries or providing lists of hired workers who would like to work for more participants.
  - States should also consider providing resources, such as brochures and referrals, to help participants’ relatives cope with the emotional stress of caregiving, and with the lack of respect they reported perceiving from other family members.

More Lessons From the National Program Office

- States cannot just rely on handbooks and other technical assistance support materials when implementing a participant-directed program; they also need staff who understand labor and tax laws and how to adapt to new ways of delivering services. While Developing & Implementing Participant Direction Programs & Policies: A Handbook received positive feedback, states also needed to master relevant laws and adapt to new ways of delivering services such as managed long-term care.

- Streamlined and simplified implementation of participant-directed programs is necessary before this model can become the default way of doing business in home- and community-based services. Participant-directed programs are quite complex. States should take advantage of existing infrastructure when developing these programs.
NATIONAL PROGRAM OFFICE BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Articles


Health Services Research, 42(1.2), 2007. Special Issue: “Putting Consumers First in Long-Term Care: Findings From the Cash & Counseling Demonstration and Evaluation.”


**Books**


**Reports**


Kafka B, Nerney T, Mahoney KJ, McGaffigan E, Adams K, Frane L, and Oxford M. *Guiding Principles for Partnerships with Unions and Emerging Worker Organizations When Individuals Direct Their Own Services and Supports*. Available online.


Communication or Promotion

www.bc.edu/schools/gssw/nrcpds. The website of the National Resource Center for Participant-Directed Services, which includes an overview of the center’s services and provides content and tools on participant-directed services, issue briefs, presentations, and more. Chestnut Hill, MA: National Resource Center for Participant-Directed Services at Boston College.

Toolkits


EVALUATION BIBLIOGRAPHY

Articles


**Reports**


*Cash & Counseling*. Chestnut Hill, MA: Boston College. Available [online](#).


