Executive Summary
Cash & Counseling

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 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. The Robert Wood Johnson Foundation (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. RWJF funding runs through August 2015.

Read the full report.  
Learn more about the program here.

**CONTEXT**

Frail older adults with disabilities and other people with disabilities historically had little say about who provided them with home care services, or when or how services were provided. For example, most home care agencies offered services only during regular working hours on weekdays.

RWJF has a history of supporting initiatives to improve the care and support of people with chronic illnesses and disabilities, including initiatives that promote independent living and lower the cost of long-term care. Under one approach, called cash and counseling, the government gives people the option of managing a budget (equal to what traditional providers would have received) to pay for goods and services that best meet
their functional assistance needs; it also pays for counseling to help them manage their services.

THE PROGRAM AND ITS RESULTS

The *Cash & Counseling* national program was a joint venture between RWJF and the DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE). RWJF and ASPE collaborated in all phases of the program including funding, selecting sites and designing the evaluation. Kevin Mahoney, PhD, MSW, directed the program. *Cash & Counseling* included a demonstration phase followed by a replication phase.

As the program was ending, RWJF and The Atlantic Philanthropies established the National Resource Center for Participant-Directed Services at Boston College School of Social Work in April 2009.

The Demonstration Phase: October 1996 to June 2003

Three states—Arkansas, Florida, and New Jersey—completed the demonstration phase, which included a rigorous evaluation involving random assignment of participants into a treatment (cash and counseling) and control group. Mathematica Policy Research conducted the evaluation.

Both RWJF and ASPE believed that the idea of giving people cash would require strong evidence that participants or their families did not misuse the money and that their care needs would be met. “It had to be a controlled experiment that was run with the highest scientific standards to get people to pay attention,” said Program Director Mahoney.

With help from the national program office and federal officials, staff in the demonstration states secured federal research and demonstration waivers, which allowed them to offer nontraditional Medicaid services (cash and counseling) so long as the services cost no more than traditional personal assistance services.

After a professional assessment of their needs, each cash and counseling participant prepared a written plan for spending the budget in permissible ways. A counselor (often a social worker) monitored the consumer’s well-being and use of the budget. The consumer submitted bills for allowable goods and services, which were paid for by a fiscal agent (also called a bookkeeper). Both the counselor and the fiscal agent helped the consumer manage the budget and supervise and pay caregivers.

Program staff assured participants that if they joined and got randomized to the treatment group, and continued to qualify for Medicaid coverage, they could be part of the program for at least two years. This was important because some worried they would no sooner join and the state would close the program, which would be very disruptive to their lives.
Results of the Demonstration Phase

The demonstration states enrolled 6,583 Medicaid beneficiaries (including the treatment and the control group). Key findings from the evaluation were incorporated into a 2007 report, Choosing Independence: An Overview of the Cash & Counseling Model of Self-Directed Personal Assistance Services provided by RWJF. The results and methodology were also disseminated more broadly in a special issue of the journal Health Services Research devoted to Cash & Counseling.¹ The key findings, which were typically found to hold for each of the three states, and for both the older and non-older participants in the program, are:

- The cash and counseling approach “significantly reduced the unmet needs of Medicaid consumers who require personal assistance services.” Ten percent to 40 percent fewer treatment group participants reported unmet needs compared with control group participants.

- Cash and counseling participants “experienced positive health outcomes.” Participants were no more likely to experience care-related health problems than those receiving traditional agency services. On about one-third of the measures examined, participants in the treatment group were significantly less likely to experience care-related problems.

- The cash and counseling approach “improved quality of life for participants and their caregivers.” Participants 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, and half as likely to say they were dissatisfied.

- “Medicaid personal care costs were somewhat higher” under cash and counseling, “mainly because enrollees received more of the care they were authorized to receive than the control group did.” At the same time increased personal care costs were partially offset by savings in institutional and other long-term care. Among program participants in Arkansas who were already receiving personal care at the time of enrolling in the cash and counseling study, nursing home admissions were 17 percent lower than in the control group, resulting in net savings to Medicaid.²

- The demonstration and evaluation were effective and influential, according to Randall S. Brown, PhD, the evaluator. Based on the favorable findings, the Centers for Medicare & Medicaid Services (CMS) changed its regulations, making it much easier for states to obtain waivers and allowing states to offer a cash and counseling consumer-directed alternative in Medicaid personal care services programs. States no longer had to get additional waivers to offer consumer-directed budgets within

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¹ See Health Services Research, 42(1.2), February 2007.
otherwise approved waiver programs for Home and Community-Based Services for individuals who qualified for institutional care.

CMS also began encouraging states to include consumer-directed options in new programs funded via Money Follows the Person grants, designed to help consumers transition out of nursing homes and other institutions and back to the community.

- **The influence of the study led to its selection for the 2009 Health Services Research Impact Award**, which 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.

### The Replication Phase: November to July 2009

Based on the positive state demonstration experience, participant responses, and evaluation findings, RWJF and ASPE supported an expansion of the program to other states. Twelve states participated in the replication, 11 funded by RWJF, and one, Illinois, funded by the Retirement Research Foundation.

Janet O'Keeffe, DrPH, RN, conducted a process evaluation focused on lessons learned from the replication states.

### Results of the Replication Phase

National program office staff reported the following results from the replication:

- **The 12 states enrolled 10,235 Medicaid recipients as of September 2009, and all of them made their programs permanent.**

- **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.**

- **Participant-directed services are now available in all 50 states.**

O'Keeffe reported the following lessons and conclusions from the replication phase:

- "Involving participants and a broad range of stakeholders in the planning, design, and implementation of a new program is essential."

- "Delineate roles and establish an effective and efficient communication system." This involves developing a formal communication strategy, which should address specific concerns raised by state officials, caregivers, agency providers, and program participants.

- "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 believes it is well worth doing.”

THE RESOURCE CENTER SUPPORTS AND SPREADS PARTICIPANT-DIRECTED SERVICES

The National Resource Center for Participant-Directed Services was initially directed by Kevin Mahoney, but Richard Petty, MBA, took over in November 2014.

The center uses lessons from the Cash & Counseling program to deliver technical assistance to participant-directed programs; offer training and toolkits on building participant-directed options; coordinate research and policy efforts to spark the expansion of programs; and support participants and caregivers through a National Participant Network.

Its National Inventory of Participant Direction Programs provides outcome measures to determine whether the center’s work is having an impact on the field, 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. The Facts and Figures report, which shares highlights and general findings from the National Inventory, is available on the center’s website. The 2013 inventory shows 835,000 participants in 277 programs across the country.

Key projects of the center are training and technical assistance to the VA Medical Centers for its Veteran-Directed Home and Community-Based Services Program and a demonstration and evaluation of self-direction in behavioral health, co-funded by RWJF, the federal Substance Abuse and Mental Health Services Administration, and the New York State Health Foundation.

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. Findings of the studies include:

● A lack of standardized requirements
● Inconsistent service coordinator training
● A lack of quality indicators and data reporting
Program Management
National Program Office: Boston College
Program Director: Kevin Mahoney, PhD, MSW
Resource Center Director: Richard Petty, MBA