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## 2009 HSR Impact Awardee

# Cash and Counseling Evaluation Changes Policymakers' Approach to Consumer Directed Care

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### THE ISSUE

Many Medicaid beneficiaries needing help with daily living activities have long sought greater control over their personal care, but federal and state policymakers have resisted, fearing that beneficiaries would be vulnerable to abuse or inadequate care. Policymakers were also concerned about possible adverse effects on those who would be hired and on the family caregiving network. The Cash and Counseling Demonstration was designed to examine such effects under a relatively unfettered form of consumer direction, offering beneficiaries in three states an allowance to hire and direct workers of their own choosing instead of using traditional agency-supplied services.

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Mathematica's evaluation of the Medicaid Cash and Counseling Demonstration altered policymakers' thinking about consumer-directed care, leading the federal government to pass legislation encouraging

it, and states to incorporate it into their Medicaid programs. Primary Investigator, Randall Brown, and a team of Mathematica researchers and programmers, conducted the research and partnered with funders, state program directors and journal editors to disseminate the highly impactful findings on this innovative approach to providing home-based personal assistance to Medicaid beneficiaries who are frail or have disabilities. The demonstration and the evaluation were funded jointly by the Robert Wood Johnson Foundation and the office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services.

Participants enrolled in the Medicaid Cash and Counseling Demonstration managed a monthly allowance to purchase assistance with routine daily living activities from sources other than traditional home care agencies. They could also purchase equipment or home modifications to facilitate independent living. The goal was to increase beneficiaries' control over and satisfaction with personal care by allowing them to decide what services they wanted, who (including possibly family members) would provide them, and how and when the services would be provided, while limiting Medicaid spending to what their authorized care would have cost from an agency. Another important goal was to reduce the burden of unpaid family caregivers who provide the majority of the care that beneficiaries receive.

The program was implemented as a demonstration in Arkansas, Florida, and New Jersey between 1998 and 2004. Approximately 2,000 adults in each state (plus 1,000 Florida children), who volunteered for the study, were randomly assigned to participant or control groups. Mathematica's evaluation investigated effects on consumers, unpaid caregivers, hired workers, and Medicaid costs. Participants typically hired relatives, but about one-third hired only unrelated individuals.

Researchers found large, statistically significant, favorable effects on unmet needs, satisfaction with care, and quality of life for all three states, for both elderly and nonelderly adults, and for children with developmental disabilities in Florida. More than half of participants in each state reported that the program had improved their lives a great deal. Participants' rates of adverse health events related to caregiving were similar to or lower than controls.' Participants' primary unpaid caregivers reported significantly less physical, emotional, and financial stress than control group caregivers, lower rates of adverse health effects from caregiving, and greater satisfaction with life. Participants' nursing home use was reduced 18 percent in Arkansas.

Workers hired under the program also fared well compared to agency workers, reporting higher satisfaction with their pay and similar rates of job-related injuries and physical strain. The evaluation found that the program participants had higher Medicaid expenditures for personal care than controls, but lower expenditures for other Medicaid services. It also found that in two states, the reason for participants' higher expenditures was that control group members received far less services than had

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*Risk-Based (continued)*

been authorized, while in the third state the participants received substantially higher allowances than their initial care plans recommended.

The findings were disseminated quickly to different stakeholders through publications, congressional briefings, press releases, webcasts to states, audiotapes for legislators, and presentations at conferences attended by state officials. The first peer-reviewed findings were published as “web exclusives” in *Health Affairs* in 2004 to get them out quickly. Findings on family caregiver effects and the experiences of hired workers were published in *The Gerontologist*. A *Medical Care* article showed the reduction in nursing home use. A special ten-paper issue of *Health Services Research* was commissioned, describing the origins of the program, implementation challenges, and all program effects. Reprints of all publications, and short, informal Issue Briefs, were distributed broadly to state Medicaid directors and to federal policy makers. The National Program Office for Cash and Counseling used the research extensively in promoting the program to state Medicaid directors and federal legislators.

**Research Impact**

Assured that this type of consumer direction is safe and that costs of the program could be controlled, policymakers made changes to improve the lives of thousands of Medicaid beneficiaries and their caregivers:

- Congress included a provision in the Deficit Reduction Act of 2005 permitting states to offer Cash and Counseling without burdensome waivers, and provided incentives to use the model to transition nursing home residents into the community.
- In January 2008, the Centers for Medicare & Medicaid Services (CMS) issued a proposed rule to allow more beneficiaries nationwide to direct their personal assistance services.
- Twelve more states adopted Cash and Counseling programs, and over half the remaining states have adopted or are developing related alternatives to traditional services.

**What is health services research?**

Health services research is the multidisciplinary field of scientific investigation that studies how social factors, financing systems, organizational structures and processes, health technologies, and personal behaviors affect access to health care, the quality and cost of health care, and ultimately our health and well-being. Its research domains are individuals, families, organizations, institutions, communities, and populations.

— *AcademyHealth, June 2000*

**SELECTED PUBLICATIONS**

Putting Consumers First in Long-Term Care: Findings from the Cash & Counseling Demonstration and Evaluation. A Special Issue of *Health Services Research*. A.E. Benjamin and M. L. Fennell (editors). Vol. 42, No. 1, February 2007. Contains

10 papers on the program’s origins; implementation; impacts on consumers, caregivers, and costs; and dissemination.

A comprehensive list of publications, provided by Primary Investigator Randall Brown, is available on the AcademyHealth Web site at [www.academyhealth.org/cashandcounselingimpactreferences.htm](http://www.academyhealth.org/cashandcounselingimpactreferences.htm)

**RELATED READINGS ON CASH AND COUNSELING**

Glendinning, C., et al. “Evaluation of the Individual Budgets Pilot Programme: Final Report.” Heslington, York: Social Policy Research Unit, University of York, 2008. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_089505](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089505)

Phillips, B., K.J. Mahoney, and L. Foster. “Implementation Lessons on

Basic Features of Cash & Counseling Programs.” Boston, MA: Cash & Counseling National Program Office, April 2007. <http://www.cashandcounseling.org/resources/20070404-152907/ImplementationLessons.pdf>

**Web Site:** Numerous references to publications and presentations on implementation issues and research regarding Cash and Counseling: [www.cashandcounseling.org/index.html](http://www.cashandcounseling.org/index.html)

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Many reviewers also made valuable comments on drafts of project reports.

