

# Cash & Counseling Moves Into the Mainstream

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ALLIANCE FOR  
HEALTH REFORM

**F**or more than a decade, policymakers virtually ignored what some analysts believe is the granddaddy of health policy challenges—long-term care. But those concerned about the aging of America have now begun paying close attention to strategies that can ease long-term care costs while providing appropriate support for frail elders and persons with disabilities.

One approach winning support on Capitol Hill and in a number of states is the public-private Medicaid demonstration program known as “Cash and Counseling,” which allows certain Medicaid beneficiaries to control directly how money is spent on their behalf.

The concept began in the late 1990’s, funded by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services (HHS). An initial three-state demonstration was considered successful enough to be expanded to 12 other states in 2004.

In the 2005 Deficit Reduction Act, Congress took another step to expand the scope of the program, including provisions that will allow states to cover the costs of self-directed personal care services—including those provided by family members—without having to seek a federal waiver.

## **How Cash and Counseling Came About**

Cash and Counseling draws its inspiration from the independent living movement launched in the 1960’s by disability rights advocates. Some of these advocates argued that individuals, if equipped with adequate funding, were better at organizing their own services than agencies contracting with state and local governments to provide home care. In particular, advocates wanted beneficiaries to control personal care services—assistance with bathing, feeding and other activities of

daily living. Such services are an optional Medicaid benefit under federal law.

More than 30 years later, federal and state officials decided to test this premise directly in a large-scale, three-state demonstration program. Operating in New Jersey, Arkansas and Florida, the demonstration included diverse populations of Medicaid beneficiaries requiring long-term care.

In all three states, the study population included beneficiaries age 65 and older, including those with dementia, and 18 to 64-year-olds with disabilities. In Florida, the demonstration also included a thousand children with developmental disabilities. The results were tracked and evaluated by Mathematica Policy Research, which measured access to services, health outcomes, and costs.

More than 6,700 people participated in the initial demonstration program. Each state operated its demonstration under a Section 1115 waiver granted by the Centers for Medicare and Medicaid Services (CMS). Section 1115 waivers are designed to be budget-neutral, and allow states to bypass a range of Medicaid’s statutory requirements, including one that would normally prohibit Medicaid officials from creating individualized budgets controlled by beneficiaries.

Beneficiaries (or their designated advocates) were permitted to use their monthly budgets to hire personal assistants of their own choice—often a family caregiver—and to purchase certain items and services aimed at promoting independence and allowing them to continue living in their own homes.

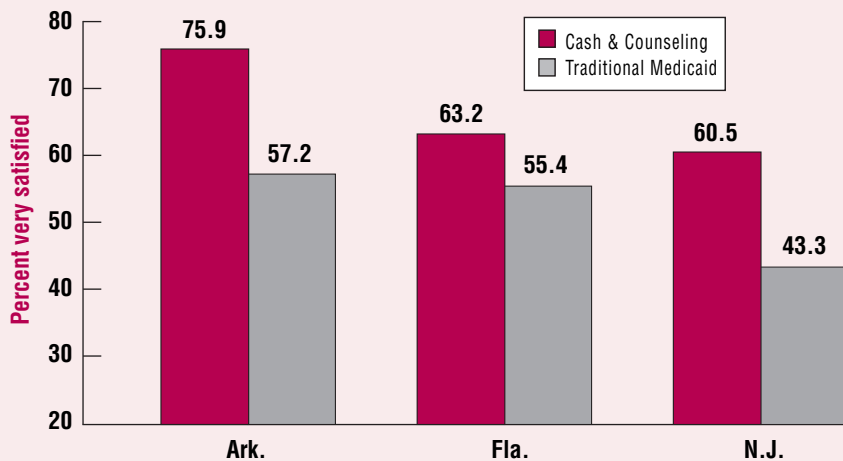
The states counseled beneficiaries about how to manage their budgets and purchases. States also helped beneficiaries pay payroll taxes and comply with other legal requirements that apply when hiring a

## **Fast Facts**

- ▲ Through “Cash and Counseling,” Medicaid provides a monthly allowance controlled by the beneficiary.
- ▲ The amount of the Cash and Counseling allowance is determined after assessing the beneficiary’s need for community-based long-term care services.
- ▲ Cash and Counseling began with Medicaid demonstration projects in New Jersey, Arkansas and Florida. Twelve additional states are now implementing similar programs under Medicaid waivers.
- ▲ Access to personal care services (e.g., help with bathing, feeding and transferring) was generally found to be better among Cash and Counseling beneficiaries than those enrolled in traditional Medicaid.
- ▲ With one exception (elderly beneficiaries in Florida), all groups of beneficiaries enrolled in Cash and Counseling demonstration projects reported more satisfaction with their care arrangements than those receiving agency services.
- ▲ Family caregivers in Cash and Counseling were also generally likelier to report less physical and emotional strain.
- ▲ By the end of the program’s second year, total Medicaid costs for beneficiaries in Cash and Counseling were 8 to 12 percent higher than for beneficiaries receiving agency services in New Jersey and Florida. This is probably because Cash and Counseling beneficiaries typically got all the hours of personal care services they were authorized.

**The Alliance for Health Reform, with support from the Robert Wood Johnson Foundation, held a Capitol Hill briefing on the Medicaid “Cash and Counseling” program. This issue brief draws from information presented at that briefing, and recent policy developments.**

**Beneficiaries Very Satisfied  
With Care Arrangements  
(Cash & Counseling vs. Traditional Medicaid)**



SOURCE: Cash and Counseling National Program Office (<http://198.87.1.54/abtAnalysis.aspx>)

personal assistant. To ensure that money was spent as authorized, state fiscal agents and counselors oversaw purchases made by beneficiaries each month.

Kevin Mahoney of Boston College, national director of the Cash and Counseling program, called it “one of the ... ultimate forms of consumer direction, one where the consumer gets to manage an individualized budget very broadly.”

**Five Steps in Getting Started**

Mahoney explained that the demonstration followed a five-step model. First, beneficiaries’ need for services was assessed and a care plan was developed to meet their identified needs. Second, a monthly allowance reflecting the monetary value of the services in the care plan was calculated for each person (the “cash” portion of Cash and Counseling). An amount (around \$150 per month per person) was then subtracted to offset the costs of counseling and fiscal administrative services.

Third, a state agency representative discussed the care plan with the beneficiary and family members, explaining the program’s two possible options: receiving the monthly allowance or instead, receiving services through traditional Medicaid. Those beneficiaries wishing to participate in the demonstration were then randomly assigned to one of the two options.

In steps four and five, beneficiaries receiving the monthly allowance worked with counselors to create a cash management plan that helped them organize their services.

**Access, Health Outcomes, and Satisfaction with Services**

In each of the three demonstration states, Cash and Counseling beneficiaries clearly benefited on at least one important measure. (A series of reports about the demonstration’s findings are available at the national program office website—[www.cashandcounseling.org](http://www.cashandcounseling.org).) Asked whether they had received paid care services in the past two weeks, beneficiaries controlling their own budgets said “yes” much more often than traditional Medicaid beneficiaries.

The effect was especially striking in Arkansas, where only 6 percent of Cash and Counseling beneficiaries reported that they had not received services from a paid helper. In contrast, 24 percent of beneficiaries enrolled in traditional Medicaid reported having no paid helper.

One possible explanation that is that labor shortages of home care workers may have hampered delivery of agency services; another is the possibility that under-funding of community-based agency services in traditional Medicaid may have caused access problems.

Cash and Counseling participants with paid helpers were also more likely than traditional Medicaid beneficiaries to report having a caregiver (1) live with them, (2) help with personal care and (3) provide help on weekends. Health outcomes at nine months were not significantly different between the Cash and Counseling and the traditional Medicaid groups.

Satisfaction rates among beneficiaries and family caregivers were also measured. Beneficiaries with monthly allowances were far more likely to report that they were satisfied with their care arrangements than were those receiving agency services. (See chart, “Beneficiaries Very Satisfied with Care Arrangements.”). Family caregivers also reported less emotional, physical, and financial strain.

**Cost Comparisons**

In the first year, beneficiaries with monthly allowances spent significantly more on personal care than those receiving agency services – generally up to the limit permitted by their monthly allowances. Spending on personal care for beneficiaries receiving agency services was lower largely because these beneficiaries received fewer hours of home care on average than were authorized in their care plans.

Outside of personal care, spending on other long-term care services, including home health

services, was moderately lower among beneficiaries who received a monthly allowance.

Total Medicaid costs after two years were 8 to 12 percent higher among those with monthly allowances in New Jersey and Florida; in Arkansas, costs did not differ significantly between the two beneficiary groups.

However, recent data from Arkansas show that by the third year, nursing home admissions in the Cash and Counseling group had declined substantially, generating cost savings of 18 percent relative to beneficiaries in traditional Medicaid.

### **The New Jersey Experience**

William Ditto, director of the New Jersey Division of Disability Services, has overseen that state's Cash and Counseling program from the design through the final evaluations. "The program works," he said. "It works very well ... for some people under some circumstances."

Ditto emphasized, however, that the monthly allowance model is not appropriate for all persons, such as isolated frail elderly people and others without relatives or neighbors who can help them manage their program. For such individuals, Ditto argued that states should continue to make traditional provider agency services available.

One interesting lesson from the demonstration, Ditto said, is that many families with monthly allowances turned out to be "prudent purchasers" who maximized the benefit of their allowances. For example, families of beneficiaries with cognitive impairment "were not getting the kind of services that they needed (under traditional Medicaid). We were getting [recipients] four or five hours of homemaker/home health aide [assistance] a day. It wasn't really cutting it for [families] ... they were up all night because they had to worry about somebody wandering away."

### **The Federal Perspective**

Michael O'Grady served as a top advisor to HHS Secretary Michael Leavitt in health and disability, among other areas, before leaving the federal government in October 2005.

At the briefing, O'Grady asserted that the Cash and Counseling demonstration offers important lessons for Medicaid modernization, and for the "sleeping giant" of how to deliver and pay for cost-effective long-term care services.

Another promising feature of the demonstration, O'Grady said, is the flexibility afforded to

beneficiaries with monthly allowances to "decide what they really need and how to get it in the best way." (See box, "Tanya and Rhonda's Story.") Yet another plus is the potential for broad use of allowances by beneficiaries who have widely varying disabilities.

But like other panelists, O'Grady stressed that the Cash and Counseling model is not a panacea. As more and more baby boomers approach retirement, he said, "we need to...protect the Medicaid dollars by helping people [who are middle class] figure out some ways...to pre-fund their own care." Encouraging the purchase of long-term care insurance would be one way to do so, he said.

### **Outstanding Issues**

Not everyone agrees that Cash and Counseling has limitless potential. Some in the disability community, for example, worry that some states may not set the value of monthly allowances at levels that are adequate to meet the needs of people with more severe disabilities. In fact, the monthly allowances in the three initial states varied widely, from about \$300 in Arkansas to \$1,000 in Florida and \$1,300 in New Jersey.

If careful assessments are not done, skeptics say, beneficiaries in some states could wind up with skimpy allowances that are driven more by state budget constraints than by a desire to ensure that the needs of beneficiaries with complex needs are met.

Now the second wave of states—Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, Pennsylvania and Illinois—is launching Cash and Counseling programs.

### **Tanya and Rhonda's Story**

One individual benefiting from Cash and Counseling is Tanya Dickens, whose experience was narrated in a short film clip that was aired at the Capitol Hill briefing. Born in 1971, Tanya was diagnosed with mental retardation as a child, and became eligible for Medicaid services that included recreation activities at a day care center. However, Tanya's mother, Rhonda Sloan, decided that her daughter might gain a greater measure of independence through the Cash and Counseling demonstration, and the family was selected to receive a monthly allowance.

Part of the allowance was used to hire a companion who accompanied Tanya in local excursions within their Florida community. When Tanya showed an interest in animals, the two approached a local pet store and after a period of training and volunteering, Tanya was hired. In the future, Rhonda hopes that her daughter will be able to live a more independent life, "probably with a roommate [and] with the right kind of services and help."

Robert Wood Johnson's vice president James Knickman cautioned that the original three-state findings should not be over-interpreted.

"This demonstration took place with basically non-medical services—the types of services people provide for their own family members," he said. "It is clearly a matter of choice [for beneficiaries who] had the option to stay in the traditional system. They could return at any time." Moreover, he said, it is easier to set a beneficiary's allowance to cover long-term chronic care services than would be the case with medical services.

Within organized labor, the Service Employees International Union, which represents many nurses and home care workers, has cautioned that Cash and Counseling could produce a new work force of poorly compensated workers with few, if any, fringe benefits and employment protections.

It is true that Cash and Counseling aides often do not have fringe benefits. But federal officials point out that in two of the three states, beneficiaries who hired personal aides paid these workers slightly

higher wages on average than were paid to agency workers. And Cash and Counseling aides reported higher overall satisfaction rates than did agency workers.

New Jersey's William Ditto said that CMS could provide greater incentives for states to use the Cash and Counseling monthly allowance model by broadening the definition of services that can be delivered as part of Medicaid's optional personal care benefit. At present, the personal care benefit covers only human assistance, not equipment, goods and other services.

O'Grady noted that CMS has "tried to do the heavy lifting" to move Cash and Counseling further into mainstream Medicaid. For example, the agency has revised the home and community-based services waiver application to include the self-direction and individual budget concepts embodied in Cash and Counseling.

One thing is certain: The strong interest in Cash and Counseling is a sign that Medicaid's powerful role in financing long-term care services for millions of frail elders and persons with disabilities is headed for change.

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The Alliance is a nonpartisan, not-for-profit group committed to the education of journalists, elected officials and other shapers of public opinion, helping them understand the roots of the nation's health care problems and the trade-offs posed by various proposals for change.

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## **Expert Sources**

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▲ <b>Patrick Morrissey</b> , <i>Sidley Austin Brown and Wood</i>	202/736-8228
▲ <b>Michael O'Grady</b> , <i>NORC/University of Chicago</i>	202/223-7933

## **Websites**

▲ <b>Alliance for Health Reform</b>	<a href="http://www.allhealth.org">www.allhealth.org</a>
▲ <b>Center for Health Transformation</b>	<a href="http://www.healthtransformation.net">www.healthtransformation.net</a>
▲ <b>Cash and Counseling Nat'l Prog Office (incl. link to state websites)</b>	<a href="http://www.cashandcounseling.org">www.cashandcounseling.org</a>
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