The Future of Cash and Counseling: The Framers' View

*Kevin J. Mahoney, Nancy Wiener Fishman, Pamela Doty, and
Marie R. Squillace*

Objective. This paper reflects on the progress of the original Cash and Counseling states, and shows how this model has spread, how it has evolved over time, and what is left to improve. It then discusses the generalizability of the Cash and Counseling approach beyond long-term care and ventures some thoughts on what still needs to be learned. Finally, this paper suggests some of the contingencies that could affect the diffusion of this innovation.

Data Sources/Study Setting. Drawing from ten years of experiences with the fifteen Cash and Counseling states, plus their analyses of current trends and future opportunities and threats, the framers of the Cash and Counseling model reflect on future directions.

Study Design. This paper is essentially a policy-driven analysis of how the Cash and Counseling model has been sustained and disseminated, how it is likely to develop, and what still needs to be learned.

Principal Findings. The basic Cash and Counseling model appears adaptable to different state environments and populations, but that hypothesis will be severely tested as more and more states seek to replicate. As one step to promote flexibility while capturing and preserving the essence of the model that led to such promising research results, the Cash & Counseling National Program Office developed a "Vision Statement".

Conclusions. The Cash and Counseling approach is not for everyone, but it is clearly a choice many participants desire. Its development merits monitoring.

Key Words. Consumer direction, federal and state policy, cash and counseling

---

The Supreme Court's 1999 Olmstead decision made it clear that state long-term care systems must provide a continuum of services that allows people to live where and how they want. But how do we achieve this reform?

Cash and Counseling appears to be part of the solution. Already this promising model is spreading—spurred with funding from the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human

Services (DHHS). In an environment nurtured by President Bush's New Freedom Initiative, the Cash and Counseling option has drawn attention; The Systems Change Grants for Community Living, which provide seed money to states, have played a key part in building the support and infrastructure necessary to support such major systems change. Now, as numerous states attempt to create a more balanced long-term care delivery system and move toward Medicaid reform, Cash and Counseling has gained bi-partisan recognition and credibility.

Despite this broad support, questions remain. The literature is full of stories detailing the difficulties states have in implementing innovative policy changes even under the best of circumstances (Sparer 2004). Will Cash and Counseling be any different? Even with the research results from the controlled experiment, doubters, and even some detractors, remain. Many home care agencies, care managers, union organizers, and state budget officials continue to question whether the Cash and Counseling option can be adapted for their states without running into quality problems, negatively affecting paid workers, or increasing state home care costs. It will be important to assess the expansion experience to examine how the model evolves in different environments and contexts and whether it is still able to generate such positive outcomes.

Meanwhile, in this paper we want to reflect on the progress the original states have made as the completion of the demonstration and evaluation and show how this model has spread to other states, how it has evolved over time, and what is left to improve. Then, we will discuss the generalizability of the Cash and Counseling approach beyond long-term care. We will venture some thoughts on what still needs to be learned and where we hope to be in 10 years. Finally, we will suggest some of the contingencies, such as the block-granting of Medicaid or persistent state budget problems, that could affect the diffusion of this innovation.

Address correspondence to Kevin J. Mahoney, Ph.D., Boston College Graduate School of Social Work, 314 Hammond Street, Chestnut Hill, MA 02467. Nancy Wiener Fishman, R.N., M.P.H., is with The Robert Wood Johnson Foundation, Princeton, NJ. Pamela Doty, Ph.D., is with the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Washington, DC. Marie R. Squillace, Ph.D., is with the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Disability, Aging and Long-Term Care Policy, Washington, DC.

DEVELOPMENTS IN THE ORIGINAL STATES

Each of the original Cash and Counseling states has moved to make this model a regular part of its delivery system. This is not easy since these states are currently dependent on Section 1115 research and demonstration waivers which must be renewed every 5 years. The states must maintain budget neutrality as defined by the Centers for Medicare and Medicaid Services (CMS), and, at the time of renewal, the state must comply with any revisions in federal policy that have occurred since its last waiver was granted. Furthermore, there is no assurance that waivers can be extended indefinitely. But, beginning in 2007 states will have the option, made possible under Section 6087 of the Deficit Reduction Act of 2005, of building the Cash and Counseling option directly into their regular Medicaid State Plans.

Arkansas, Florida, and New Jersey have all received federal approval to extend their waivers for another 5 years. In fact, Arkansas is in the process of applying for its second renewal! The State of Florida has enacted legislation making consumer-directed care an option for all of its Medicaid waivers, subject, of course, to federal approval. At the time of Section 1,115 waiver renewal each of these states was able to drop random assignment and move to a formula where budget neutrality was based on a comparison of trends in state spending with and without the consumer directed option. This change in the formula meant that hundreds of individuals who had wanted to manage their own services were able to do so.

Speaking on behalf of the original states at a July 29, 2005 congressional briefing sponsored by the alliance for Health Reform, William Ditto, New Jersey's Director of the Division of Disability Services, said "Cash and Counseling works. People like it. Whereas participant-direction is not for everyone, those who do participate get the services they need, when they need them and they are prudent purchasers. Traditional home care agencies are important to the system and participant-direction does not impact them adversely" (Ditto 2005). Arkansas' Governor Mike Huckabee, speaking at a Consumer Direction Conference in Washington, DC on June 10, 2001 went even further stating, "People thought this would be rampant with fraud or abuse, that there would be exploitation of the individual but we found in Arkansas instead of seeing widespread fraud and abuse, its really been able to empower families—it's perhaps curtailed it [fraud]. . . . One hundred percent of our participants are satisfied with the program, ninety-three percent would recommend the program to other people, ninety-two percent know the person they hired and were very happy with that. . . . We see this is a model for other states; it doesn't

serve the need of every client and we understand that and I think that's the beauty of it; its not meant to supplant, but only to supplement other options that are out there for the client. . . . While there are many people who are saying this can't work, here in Arkansas we're proving that it can."

The original states have not stopped at the status quo. Each has used the occasion of waiver renewal to embed consumer direction in their delivery system; each has made some programmatic changes to streamline and increase the efficiency of their operations based on evaluation findings. But they have not stopped there. Arkansas has infused the principles of consumer direction throughout all of its home and community-based service programs and they have received funding from the DHHS Office of the Assistant Secretary for Planning and Evaluation (ASPE) to implement "Next Choices," expanding the concept of Cash and Counseling to individuals wishing to transfer out of nursing facilities. This expansion is scheduled to take place in 2006. The State of Florida has developed its "Florida Freedom Initiative," broadening the Cash and Counseling approach using waivers from CMS and the Social Security Administration to allow adults with developmental disabilities to keep additional assets and income so that they can escape poverty if they return to work.

HORIZONTAL EXPANSION: REACHING THE TIPPING POINT SO THAT EVENTUALLY EVERY STATE WILL OFFER THIS OPTION

With clear interest from at least 28 other states, the funders did not rest content with this successful demonstration in three states. They made the critical decision to try and bring the idea to scale by funding replications in a critical mass of states—believing that if every state could view some peer state as having successfully implemented this major policy change we would eventually see this option in every state (Gladwell 2002; Greenhalgh et al. 2004). In this section, we will describe the expansion initiative and discuss some of the broader ways Cash and Counseling has affected the development of home and community-based services across the nation.

In October 2004, RWJF, in collaboration with ASPE and the Administration on Aging (AOA), funded a new initiative to replicate the Cash and Counseling program in 11 additional states. The states each received 3-year grants of approximately \$250,000, which covered start-up costs such as dedicated personnel, training, outreach materials, and computer system enhance-

ments. (As a general rule, these foundation funds were eligible for federal Medicaid match.) In addition, each state received an array of technical assistance through the National Program Office at Boston College. The Medicaid funds that consumers managed were the same funds that would have gone to agencies providing care for these same individuals.

The 11 new Cash and Counseling State Programs are: Alabama, Iowa, Kentucky, Michigan, Minnesota, New Mexico, Pennsylvania, Rhode Island, Vermont, Washington, and West Virginia.

New states were chosen by the funding agencies and a national advisory committee. Criteria for selection included looking for programs that were designed to serve both the aging and disability communities, had adequate enrollment potential, demonstrated a clear understanding of the Cash and Counseling model and awareness of other home and community-based services in their state, had experience with Medicaid waivers, had a strong record of interagency communication, had a realistic implementation plan and a commitment by significant leadership to roll out this program.

In January 2005, the Retirement Research Foundation made it an even dozen states by funding the Illinois Department on Aging and providing them sufficient funds to purchase technical assistance from the Cash and Counseling National Program Office at Boston College.

A chart summarizing the target populations, types of waivers, and other key features for each of these states can be found in Table 1. As the reader can see, five of the 12 states (including many of the largest) planned to implement the model in pilot counties while the remainder planned to cover the whole state, and each state has a target of at least 400 individuals managing individualized budgets by the end of the grant period.

In general, the plan is for states to use the first year of their grants to hire staff, build the infrastructure, and obtain their Medicaid waivers from the CMS; the second to get underway and their third to get 10–15 percent of their target population (or at least 400+ individuals) onto individualized budgets. As we approach the end of the first full year of funding we see that Minnesota, Kentucky, Vermont, and West Virginia have gotten their waivers and Minnesota has actually begun enrollment.

Ten of the 12 states have decided to seek 1915(c) (the most common form of funding for home and community-based services) as opposed to 1115 research and demonstration waivers, (the only exceptions are Vermont and Alabama). In general, the states made this decision in order to avoid the lengthy period of time which is typically needed to negotiate terms and conditions for 1115 waivers, participate in a CMS readiness review, and assure

Table 1: Cash and Counseling Replication States at a Glance—August 2006

Funder	Alabama Cash and Counseling	Illinois: My Choices	Iowa Consumer Choices Option	Kentucky Independence Plus	Michigan Self-Determination in Long-Term Care	Minnesota Consumer Directed Community Supports	New Mexico Mt. Via (My Way)	Pennsylvania Cash and Counseling	Rhode Island Personal Choice	Vermont Flexible Choices	Washington New Freedom	West Virginia Personal Options
Target date of implementation	January 07	November 06	October 06	September 07	October 06	March 05	September 06	January 07	March 06	August 06	September 06	October 06
Populations served	Elderly and Adult Disabled Medicaid personal care recipients	Elderly and Adult Community Care Program participants, Medicare and non-Medicaid eligible seniors	Elderly and Adult Disabled Medicaid personal care recipients	Elderly, Adult Disabled, MR/DD, Acquired Brain Injury, Medicaid personal care recipients	Elderly and Adult Disabled Medicaid personal care recipients	Elderly and Adult Disabled Medicaid personal care recipients	Elderly and Adult Disabled Medicaid personal care recipients. New clients with TBI	Elderly, Adult Disabled, AIDS, technology dependent, MR (aged 3+ years) Medicaid personal care recipients	Elderly and Adult Disabled, PARI and Elderly Medicaid recipients and RIDEA's Co-Pay Program	Disabled recipients of Medicaid long term care services	Elderly and Adult Disabled Medicaid Aged and Disabled Waiver	Elderly and Adult Disabled Medicaid Aged and Disabled Waiver
Waiver	Primary	None at first	1915c	1915c	1915c	1915c	1915c	1915c	1915c	1115	1915c	1915c
Departments involved	Department of Senior Services (In collaboration with) Alabama Department of Rehabilitation Services and Alabama Department of Public Health (West Alabama)	Department of Aging	Department of Human Services (In Collaboration With) University of Iowa's Employment Policy Group	Department of Medicaid Services	Department of Community Health	Department of Human Services	Department of Aging and Long Term Care Services	Governor's Office of Health Care Reform (In collaboration with) Departments of Aging and Public Welfare	Department of Human Services	Department of Aging and Independent Living	Department of Social and Health Services (In collaboration with) Bureau of Medical Services	Primary Bureau of Senior Services (In collaboration with) Bureau of Medical Services
Territory covered	Seven counties	Four areas (rural, urban, small cities, mixed)	Statewide	Statewide	Four Area Agencies on Aging (sites comprise 26 counties)	Statewide	Statewide	14 counties	Statewide	Statewide	King County, Seattle, five counties in southern WA, Vancouver, rural areas	Statewide
Enrollment targets	90	500	400	400 (?)	600	1,257	1,000	400	450	250	200	350
Program innovation award received	N/A	N/A	N/A	N/A	N/A	Expanding consumer-directed services to caregivers of seniors under Title III-E and possibly other OAA programs.	Develop outreach materials for hard-to-reach Native American and Asian populations.	N/A	N/A	N/A	N/A	N/A

RWJF, Robert Wood Johnson Foundation; OAA, Older Americans Act.

budget neutrality. They made this decision although they knew that they could not offer even a modest 10 percent of the allowance in cash—an option which had proven very attractive in the original states and which allowed consumers to cover miscellaneous expenses (such as taxi rides or incontinency supplies) for which a requisition did not make sense. These 10 states elected to apply for the 1915(c) waiver even though 1915(c) rules raised design issues ranging from the requirement of having provider agreements with every entity the consumer wanted to do business with, to requirements to offer comparable services to all beneficiaries. The Cash and Counseling expansion states are applying for their 1915(c) waivers at the very time that CMS is revising and standardizing the 1915(c) application template and review process. This unanticipated event has greatly increased the time and effort needed to secure a 1915(c) waiver, but the process has raised and helped to address many questions regarding how this innovative model can be integrated into an ongoing waiver program.

The influence of Cash and Counseling has been even broader than the programs we developed directly. Drawing from the lessons of Cash and Counseling and another RWJF initiative, “Self-Determination for Persons with Developmental Disabilities,” CMS in 2001 developed the “Independence Plus” model application or template to expedite the process for states wishing to implement consumer-directed programs. As of the end of 2005, eight states (over and above the Cash and Counseling states) have secured Independence Plus waivers. In 2005, CMS went a step further incorporating consumer direction directly into the new application form for all 1915(c) home and community-based waivers. This means that from this day forward, every 1915(c) application will automatically have to address questions about the degree of consumer direction and participation.

Still at a congressional hearing on July 29, 2005, speaking on behalf of all the Cash and Counseling states, William Ditto, New Jersey’s Director of the Division of Disability Services, asked that states be able to implement these proven programs without waivers. Two approaches for accomplishing this end have been promoted. The first, proposed by the State of New Jersey in an October 31, 2001 letter to CMS, requests confirmation that Medicaid’s personal care benefit need not be limited to hands-on human assistance and the states have the right to define Medicaid’s personal care benefit to also include goods and services prescribed in an approved care plan. The second, contained in Section 6087 of the 2005 Budget Reconciliation Act, creates a new Section 1915(j) which allows states to offer a “Cash and Counseling” option under their regular Medicaid State Plans. Interim regulations are expected late in 2006.

PROGRAM IMPROVEMENTS: WHAT ARE THE REMAINING BARRIERS?

Learning from the problems encountered by the original states and responding to the challenges of growing in new environments has fostered a culture of continuous quality improvement (CQI). Some of the early examples of this learning environment include special reports on Workers' Compensation rules in all 50 states and best practices for protecting workers and consumers against the risks of injury on the job (Flanagan 2004); a legal treatise on liability issues for consumers, paid workers, counselors, fiscal management agencies, and government entities (Hughes and Sabatino 2004); focus groups and surveys of nonparticipants to better understand their motivations and how that might affect future outreach, program operations, and overall demand (Simon-Rusinowitz et al. 2005); and case studies of states deciding whether to allow payment to family caregivers (Simon-Rusinowitz et al. forthcoming). One significant study also took a more in-depth look at how individuals used their individual budgets to purchase goods and services and not just human assistance for meeting personal assistance needs (Meiners et al. 2004). All of these studies can be viewed at www.cashandcounseling.org.

That is not to say that we do not have many challenges ahead. Let us focus on six critical issues and how we are tackling them.

1. *Adapting the Principles of Consumer Direction When the Participant Is Not Fully Able to Self-Direct.* In the course of the original experiment, states learned that many individuals who were capable of expressing important preferences but not able to manage an individualized budget on their own (e.g., persons with some developmental disabilities or persons with Alzheimer's disease) could profit from the flexibility afforded through the Cash and Counseling model if they were allowed to appoint a representative to assist them. Others, especially among the elderly, just felt more comfortable having a representative at least at the start. Whereas states have made good progress developing criteria for when representatives are needed and how they should be monitored, these policies need to be evaluated and refined.

2. *Dealing with Worker Shortages and Linking Participants and Workers When Informal Networks Lack Individuals Willing to Take on the Paid Worker Role.* Clearly, Cash and Counseling worked for individuals with family, friends, and neighbors ready to fill the paid worker role. In each of the original states, at least 84 percent of all the participants chose people they knew to be their workers. But we know that those who did not have workers at hand frequently had trouble locating appropriate people, and we know that numbers of people

did not participate for the same reason. We have begun to explore a number of forms of formal and informal registries. It seems clear that registries can be administratively burdensome to operate, and some worry about the liability of recommending prospective workers. Clearly, a registry needs to be used and updated regularly in order to be useful. One promising approach, being developed by Rewarding Work Resources Inc. in collaboration with the University of Massachusetts Medical School, can be viewed at www.rewardingwork.org, a web-based recruitment website. The site is not a registry and does no screening or reference checks on personal assistants. Individuals have the option to request and pay for a Criminal Offender Record Information report through the website but are advised to use all of their usual screening and background checking to assure that candidates are qualified. This consumer-directed recruitment website has already proved successful in a handful of states and is capable of reaching nationwide (D. O'Connor, personal communication, October 12, 2005).

3. Training for Support Brokers, Fiscal Management Agencies, Consumers, and Paid Workers: States face the difficult choice of relying on existing care managers and helping them make the paradigm shift from a medical model where the professional makes the key decisions to a consumer-driven system, or developing a new parallel system to provide supports brokerage. In either case, serious attention needs to be devoted to training the support brokers. With CMS funding, channeled through MEDSTAT, faculty at the Boston College Graduate School of Social Work have developed and tested the first modules for such a curriculum (McInnis-Dittrich, Simone, and Mahoney 2006). It remains to be seen if curricula such as this can be made available to states across the nation moving to consumer-directed systems.

Equally complicated issues remain regarding training for fiscal management agencies, consumers, and for that matter, paid workers and informal caregivers. Training is clearly needed; but given the dispersion of consumers with disabilities and the lack of uniformity in their training needs, one size will not fit all. We can take comfort in the results from the controlled experiment showing that health outcomes were the same or better for consumers who hired their own workers and the workers themselves felt better prepared than agency workers. Even though injuries and physical strain were similar to agency workers, we cannot be satisfied. Training for consumers and for workers needs to be on the front burner, but we need to develop flexible approaches that are tailored to individual needs. To constrain costs and to be feasible we need to utilize training already available in the community and

take advantage of distance learning opportunities. Over time, research is needed on who needs training, when, what type, and how much.

4. *Assuring Quality in a Consumer-Directed Program Environment:* Another critical area is the design of a quality management system and a CQI approach for consumer-directed services. Such a strategy needs to recognize that the consumer is in charge, still there must be accountability for the use of public funds. With the assistance of the Scripps Gerontology Center at the Miami University in Ohio, we have designed “A Guide to Quality in Consumer-Directed Services,” which discusses how to design quality into the program and then manage for quality using techniques ranging from monitoring the achievement of consumer goals to CQI committees. Appendices in this report catalogue the monitoring methods used by each of the original states. This guide can be found at www.cashandcounseling.org. During the replication process we intend to update this guide building on the CMS “Quality Framework” for all waiver services. As outcome indicators and performance benchmarks are critical for CQI, we have completed work on a minimum data set of Performance Indicators, which all the Cash and Counseling states have agreed to collect.

One serious quality issue in the original demonstration was the length of time it took a consumer who had opted for the individualized budget to actually start receiving the allowance. To the extent this problem was due to the time consuming process of developing, approving, and revising spending plans it seemed that a web-based system offered great promise. During the first year of working with the new states, we set out to develop a web-based “Consumer Direction Module” that will allow faster communication not only in developing individual budgets, but also in recording support broker interventions, allowing states to monitor unexpended allowances, and giving consumers “real time reports” on how much of their allowance remains available. Whereas only about a third of the elderly currently use computers, many use representatives to help develop and manage their budgets. Furthermore, as Baby Boomers age the number of computer-literate consumers will increase.

5. *Increasing Involvement of Consumers at the Policy and Program Operation Levels:* A key to the success of models like Cash and Counseling seems to be the ability to meaningfully involve consumers and their families in policy formulation, the design of the program including pretesting of various forms and procedures, the CQI process and the evaluation—including surveys to ascertain participant satisfaction with key elements of the program. Consumers have also regularly reported a desire to learn from others who have had

parallel experiences. Toward the end of the original demonstration, small amounts of RWJF monies were allotted to Arkansas, Florida, and New Jersey to develop model peer counseling efforts where consumers helped other consumers decide whether the Cash and Counseling option was right for them and how to develop spending plans and locate workers, etc. We hope in the years ahead to build on these efforts, empowering consumers to play an active role in program operation and policy making.

6. *Sustaining a Lasting Learning Community of States Interested in Sharing Promising Practices and Fostering Consumer Direction:* We are also trying to learn what factors help sustain these innovations. One element may be organizational. Years after the conclusion of the original demonstration, the original Cash and Counseling states still see the need to meet regularly. Arkansas, Florida, and New Jersey have offered significant time assisting the new states, but they have also valued peer consultation for themselves. The result has been the creation of the alliance of Consumer Directed State Programs. Such an alliance has helped these states gain a legitimate place at the policy table, working with CMS to improve the waiver application process, but it also bodes well for the day when outside funding for a National Program Office is more modest and the states will need to assist and counsel each other. This alliance is not limited to Cash and Counseling states, and it is cognizant that consumer direction is but one option in an effective delivery system. Still, it recognizes that there are particular issues when consumers take the lead and states need to share insights to continually improve.

Before ending this section, it is important to reflect on some of the challenges to the diffusion of this model and some of the contingencies one might anticipate.

Sparer (2004) has discussed the difficulties of implementation in periods of prosperity, but what about during economic downturns? There is no doubt that when resources (human or financial) are scarce, states must select from among competing priorities. Already the difficulties local agencies have had with the implementation of the Medicare Part D prescription benefit have cut into the reserves they intended to use to implement consumer-directed care. Furthermore, the tighter the budget, the more scrutiny budget officers will give making sure that Cash and Counseling will not add costs. The cost findings from the controlled experiment suggested that this model does not need to cost states more, but that will not be enough. During hard budget times, states will be trying to assure budget neutrality and many options for cutting costs (such as having the consumer shoulder more of the support service costs) could make the consumer-directed option less attractive.

One might also wonder what the impact would be if reformers were ever successful in block-granting Medicaid (Kousser 2002; Lambrew 2005). We can only guess at the answer to this question, although early long-term care system reformers like Vermont, Florida, and Kentucky have used the opportunity to embrace elements of consumer direction. At this moment in time disability rights and consumer choice are supported by strong social movements. We hypothesize that states with strong consumer advocacy groups will be more likely to accent consumer directed approaches for the delivery of supports and services. As more choices devolve to the states, it will be important to assess what changes evolve in this model or its key components (such as the roles of support brokers and financial management services) and to monitor outcomes and performance utilizing data from the standardized Performance Indicators the Cash and Counseling states will be collecting.

EXPANSION TO OTHER POPULATIONS

We are frequently asked to reflect on whether the lessons of Cash and Counseling are directly transferable to other service delivery systems. Our answer has been one of caution. Whereas the value of self-determination, the import of flexibility and the desirability of the option of receiving assistance from individuals with whom one has a loving, trusting relationship have been clearly established, this demonstration was limited to nonmedical services which family members typically provide for one another. Furthermore, it was limited to chronic, as opposed to acute, care so there was much greater stability in the need for services and supports and it was, therefore, far easier to develop individualized budgets and care plans. Finally, Cash and Counseling was always viewed as a choice. Consumers could opt for the traditional system at any time.

Under what circumstances can one generalize from our results? We believe that wherever the service environment differs dramatically from the conditions under which we tested Cash and Counseling, a new test is desirable. A number of areas for expanding the individualized budget approach have already been advanced. Let us examine five of them.

One of the simplest is to the aging network programs administered under the Older Americans Act (OAA). As one of the largest providers of home and community-based care for older persons and their caregivers in the United States, the AOA has taken a keen interest in consumer direction in general and Cash and Counseling in particular. Furthermore, the three-state-

controlled experiment was successful in dispelling the myth that the elderly would not be interested in or benefit from the Cash and Counseling approach. The best example was in Arkansas, where nearly 73 percent of all enrollees were elderly. Many State and Area Agencies on Aging are involved in leading the RWJF replication or state-funded Cash and Counseling projects. For example, Minnesota received an additional \$100,000 from RWJF to extend the Cash and Counseling model to OAA Programs.

Another area where testing is underway is in Medicare's home health benefit where Congress has authorized the Section 648 Demonstrations to see if the benefits associated with Cash and Counseling can accrue to long-term home health beneficiaries under Medicare. During the planning stage it has become clear that there are far fewer long-term home health recipients than there were before the Balanced Budget Act of 1997, and it will be tricky to isolate the budget for home health aides now that Medicare's home health budget (which includes skilled nursing, home health aides, and various therapies) has been capitated.

The federal Substance Abuse and Mental Health Services Administration, guided by recommendations of the President's New Freedom Commission on Mental Health and the "New Freedom Initiative," is looking at how the principles of Cash and Counseling can be adapted for use with persons with severe mental health problems. Preliminary research conducted at the Boston College Graduate School of Social Work shows that a substantial number of Cash and Counseling participants had mental health diagnoses and, although they were more likely to utilize representatives, their outcomes were positive (C. Shen, personal communication, October 17, 2005).

On the private side, long-term care insurers have expressed considerable interest in how flexible, individualized budgets might be utilized to attract purchasers for private policies. Certainly, a number of private insurers have pioneered so-called disability benefits where eligible policyholders receive a monthly cash benefit once the insured event has been triggered. Research by Marc Cohen shows the high level of satisfaction with these policies (Cohen et al. 1999). But, insurers, recognizing the relative popularity of such policies, have been watching the research on Cash and Counseling to answer their own questions on how this approach influences satisfaction, unmet needs, health outcomes, overall life satisfaction, costs, caregiver burn-out, and the types and amounts of personal assistance services and nursing home care received. As evidenced by regular presentations at the Private Long-Term Care Insurance annual conference, private insurers have also been interested in practical

lessons on developing the infrastructure of support brokers and fiscal management agencies required for this form of consumer-directed care.

Finally, as managed care organizations (MCOs) get more deeply involved in delivering long-term care their interest in consumer direction grows. Meiners et al. (2002), in a study examining MCO attitudes toward and practices in consumer direction, found that although the majority of the responding MCOs were found to be practicing some form of consumer direction, the experience is limited and underdeveloped. Two areas of concern seem to be most important in an organization's decision to adopt a consumer choice or consumer-direction model: the balance of concerns about unprofitability and the perceived interest and benefit of the clients. These same authors found that, in certain predictable situations, MCOs were also interested in the individualized budget approach exemplified by Cash and Counseling (Mahoney et al. 2003).

RESEARCH AGENDA

Many questions remain to be answered including: Will the favorable results in the original states persist over time? What are the long-term cost implications of this model—particularly given the proven reductions in informal caregiver stress and the favorable health outcomes? What patterns of switching back and forth between traditional agency services and consumer-directed options will emerge? Will later adopters remain faithful to the original model? Will different consumer groups enroll at different rates? Will results continue to be positive?

To make it easier to answer research questions involving the original demonstration we have worked to make the data from the three-state-controlled experiment available to researchers and policymakers on an unprecedented scale. Not only are there public use tapes, but we have constructed an interactive website (see www.cashandcounseling.org) which will allow stakeholders to learn about the data, view descriptive statistics, and perform simple cross-tabs at their own pace on their personal computers.

One of the first uses of this data has been to initiate subgroup analyses to determine how Cash and Counseling affected various subgroups such as those with mental health diagnoses or Alzheimer's disease and to see if Cash and Counseling's results were different for various ethnic and cultural groups.

CONCLUSION

The question is no longer whether persons with disabilities are capable of self-direction or whether there is a role for family and friends to play as paid providers of personal assistance services. The Cash and Counseling Demonstration and Evaluation offers convincing evidence that Cash and Counseling is an important option that improves quality of life. Cash and Counseling fits well with our economy and is consistent with American values—we all desire choice and control.

No doubt there will be struggles as we move from a small number of states receiving significant amounts of technical assistance to a large number of states receiving more modest help. It will be interesting to observe the variations on the basic Cash and Counseling model that evolve in unique state environments, and to study whether new generations of the model can continue to produce such positive results. It will be interesting to see if opposition coalesces as this option is seen as more than a demonstration.

Already it is clear that evolving in a 1915(c) regulatory environment may limit the flexibility evinced in the original demonstration. For that reason, it will be important to monitor the progress of Section 1915(j) now that the Cash and Counseling model can become part of the regular Medicaid State Plans. The delivery system, culture, and personalities are different in every state. The basic Cash and Counseling model appears adaptable to different state environments and populations, but that hypothesis will be severely tested as more and more states seek to replicate this approach. Certainly other innovations (such as PACE or the S/HMO) have altered as they spread. This can be a sign of the robustness of the model, but it may also be a sign that basic tenets are being watered down. As the model is mainstreamed and regulated, it will be a challenge to remain flexible. For instance, support brokerage could quickly be laden with so many rules it becomes a new form of care management. As one step to capture and preserve the essence of the model that led to such promising research results, the Cash and Counseling National Program Office developed a “Vision Statement” which can be accessed on www.cashandcounseling.org.

The Cash and Counseling approach is not for everyone, but it is clearly a choice many participants desire. In the end, the story of Cash and Counseling is the story of individuals and families who have more control over their lives, more flexibility to address their particular needs and preferences, and more opportunities for integration with their communities and significant others.

ACKNOWLEDGMENTS

This article was made possible with funding from the RWJF, the U.S. DHHS Office of the ASPE, and the AOA.

REFERENCES

- Cohen, M., J. Miller, E. Murphy, and M. Weinrobe. 1999 "A Descriptive Analysis of Patterns of Informal and Formal Caregiving among Privately Insured and Non-Privately Insured Disabled Elders Living in the Community." Final Report to Department of Health and Human Service Office of Disability, Aging and Long-Term Care Policy and The Robert Wood Johnson Foundation Home Care Research Initiative. Waltham, MA.
- Ditto, W. 2005 "Cash & Counseling: Part of the Long-Term Care Answer?" Presented at Alliance Health Reform Sponsored Meeting of the Congressional Briefing Held in Washington, DC. Available at www.kaisernetwork.org
- Flanagan, S. A. 2004 "Accessing Workers' Compensation Insurance for Consumer-Employed Personal Assistance Service Workers: Issues, Challenges and Promising Practices June 7" [accessed on February 20, 2006]. Available at http://www.cashandcounseling.org/resources/20060113-121929/wc_final_report_narrative.pdf
- Gladwell, M. 2002. *The Tipping Point: How Little Things Can Make a Big Difference*. Boston: Little, Brown and Company.
- Greenhalgh, T., G. Robert, F. Macfarlane, P. Bate, and O. Kyriakidou. 2004. "Diffusion of Innovations in Service Organizations: Systematic Review and Recommendations." *Milbank Quarterly* 82 (4): 581–629.
- Hughes, S. L., and C. P. Sabatino. 2004 "Addressing Liability Issues in Consumer-Directed Personal Assistance Services (CDPAS) January" [accessed on February 20, 2006]. Available at <http://www.cashandcounseling.org/resources/20051205-111452/CDocumentsandSettingsVITALEBDesktopcclibAddressingLiability.doc>
- Kousser, T. 2002. "The Politics of Discretionary Medicaid Spending, 1980–1993." *Journal of Health Politics, Policy and Law* 27 (4): 639–71.
- Lambrew, J. M. 2005. "Making Medicaid a Block Grant Program: An Analysis of the Implications of Past Proposals." *Milbank Quarterly* 83 (1): 41–63.
- Mahoney, K. J., M. R. Meiners, D. M. Shoop, and M. R. Squillace. 2003. "Cash and Counseling and Managed Long-Term Care?" *Care Management Journals* 4 (1): 18–22.
- McInnis-Dittrich, K., K. Simone, and K. Mahoney. 2006. "Consultant Training Program" [accessed on September 5, 2006]. Available at <http://www.cashandcounseling.org/resources/20060602-113610/>
- Meiners, M. R., D. M. Loughlin, M. D. Sadler, and K. J. Mahoney. 2004. "Clarifying the Definition of Personal Care: Findings on the Purchase of Equipment, Goods, and Services under the Cash and Counseling Demonstration and Evaluation Cash Option in Arkansas and New Jersey" [accessed November 20, 2006].

Available at <http://www.cashandcounseling.org/resources/20060126-102403/ClarifyingtheDefinition.pdf>

- Meiners, M. R., K. J. Mahoney, D. M. Shoop, and M. R. Squillace. 2002. "Consumer Direction in Managed Long-Term Care: An Exploratory Survey of Practices and Perceptions." *Gerontologist* 42 (1): 32–8.
- Simon-Rusinowitz, L., K. J. Mahoney, B. L. Zacharias, L. N. Marks, and D. M. Loughlin. 2005. "Consumer Focus Groups Inform Program Design and Communication Efforts." *Care Management Journals* 6 (2): 56–65.
- Simon-Rusinowitz, L., G. Martinez Garcia, D. Martin, M. DeBarthe Sadler, J. Tilly, L. N. Marks, D. M. Loughlin, and K. J. Mahoney. Forthcoming. "Hiring Relatives as Caregivers in Two States: Developing an Education and Research Agenda for Policymakers." *Journal of Health and Social Policy*.
- Sparer, M. S. 2004. "States and the Politics of Incrementalism: Health Policy in Wisconsin during the 1990s." *Journal of Health Politics, Policy and Law* 29 (2): 269–91.