



U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy



THE FEDERAL ROLE IN THE MOVE TOWARD CONSUMER DIRECTION

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Office of the Assistant Secretary for Planning and Evaluation

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Office of Disability, Aging and Long-Term Care Policy

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

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The opinions and views expressed in this report are those of the author. They do not necessarily reflect the views of the Department of Health and Human Services.

The origins of "Cash and Counseling" as an example.

Since the early 1990s, the Office of Disability, Aging, and Long-Term Care Policy (DHHS), a division of the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services (DHHS), has made consumer direction in long-term care a major focal point of our policy research agenda. The largest and most visible of its research initiatives on consumer-directed services is the Cash and Counseling Demonstration and Evaluation, a large-scale social experiment designed to explore the possibilities and test the limits of consumer direction in publicly funded (Medicaid) home and community-based services programs. Mahoney and colleagues describe this project in detail in this issue. This article is intended to provide historical perspective on the federal government's involvement in the Cash and Counseling Demonstration and Evaluation as an example of the federal role in consumer direction. Specifically, the article describes how previous research and analysis led to DALTCP's interest in sponsoring this social experiment and shaped our thinking about its purpose and design.

The immediate antecedents of Cash and Counseling can be found in the long-term-care proposals included in President Clinton's 1993 Health Care Reform Plan. However, in a deeper sense, understanding where the idea came from requires situating this project in the context of a research tradition that includes previous and ongoing federally sponsored research on "consumer-direction," interest in learning from foreign models of providing publicly funded home- and community-based services, and reflection on the lessons learned from previous social experiments focusing on home- and community-based "alternatives to institutional care," in particular, the Channeling Demonstration.

Although Cash and Counseling is the centerpiece of DALTCP's research agenda on consumer direction, the project is not ours alone. The design and implementation of the demonstration and its controlled experimental design evaluation would have been impossible had DALTCP, a small research and policy analysis office with limited resources, not been able to enter into and sustain a complex partnership involving a major private philanthropy, multiple federal agencies both within and outside of the Department of Health and Human Services, several states (and multiple agencies within each of those states), two universities, an independent research organization, a major national advocacy group, as well as numerous private consultants.

It is particularly important to acknowledge the key role of the Robert Wood Johnson Foundation in joining us to sponsor Cash and Counseling as well as the RWJF's sponsorship of related research and demonstration projects that have influenced the experiment. Certainly, without the foundation's financial support, there would be no Cash and Counseling Demonstration and Evaluation. Although DALTCP is a cofunder with the RWJF of the rigorous scientific evaluation, the RWJF has provided all of the funding for the demonstration itself; that is, the planning and implementation grants to the participating states as well as funding for oversight, coordination, and

technical assistance provided by or through the national program office for Cash and Counseling at the University of Maryland Center on Aging. Kevin Mahoney, national program office director, and Lori Simon-Rusinowitz, deputy director, have provided indispensable day-to-day leadership. We also appreciate the willingness of four states, Arkansas, New York, New Jersey, and Florida, to participate as demonstration sites. Although New York was unable to continue, Arkansas, New Jersey, and Florida have gone the distance from planning to implementation; indeed, Arkansas is approaching completion of the evaluation phase of its demonstration (December 31, 2000).

The cooperation of several other federal agencies in granting “research and demonstration” waivers or exemptions to laws and regulations applying to Medicaid, Supplemental Security Income (SSI), Food Stamps, and other means-tested government benefits also merits recognition. The Health Care Financing Administration approved Medicaid waivers under Section 1115 of the Social Security Act. Waivers were required to permit Medicaid funds that otherwise would have purchased personal care services under the Medicaid state plan (New Jersey, Arkansas) or 1915 (c) home- and community-based services (Florida) to be paid out as monthly cash allowances available to beneficiaries instead of as reimbursements to service providers. These “1115” waivers were also necessary to permit Medicaid beneficiaries to use their cash benefits to purchase disability-related goods and services not otherwise covered under Medicaid and to suspend the prohibitions against certain family members (spouses and parents of minor children, whose income and assets are deemed available to Medicaid beneficiaries for purposes of financial eligibility determinations) being paid caregivers.

The Social Security Administration and the U.S. Department of Agriculture also agreed to exempt participants in the treatment group from rules related to means-testing that might otherwise have jeopardized treatment group members’ eligibility for cash assistance (SSI) payments and Food Stamps. Both agencies have statutory authority to relax these rules in the interests of research, contingent on impact analyses being performed. Although both agencies were highly willing to cooperate, some time-consuming, detailed work was required to decide exactly what types of information the evaluation needed to collect to determine the demonstration’s impact on recipients of SSI and Food Stamps. Less formalized understandings were also reached with the Department of Housing and Urban Development (HUD) and the Department of Education to ensure that cash benefits for disability-related services provided under the Cash and Counseling Demonstration would not adversely affect recipients otherwise eligible for low-income housing or income-related educational and vocational rehabilitation benefits.

In sum, policy research involving social experimentation on a large scale requires a considerable investment not only of finances but in team building and teamwork. Leadership and management of the Cash and Counseling Demonstration and Evaluation--which also has been a team enterprise--require holding firm to the original goals of the research and protecting the scientific integrity of its design and methodology while also negotiating for the project’s survival and successful implementation within a socio-political-economic environment that is in constant flux.

THE MOVE TOWARD CONSUMER DIRECTION

Consumer direction is a concept that came out of the organized disability rights (“independent living”) movement. In 1987, the World Institute on Disability (WID), a research organization that serves as a “think tank” for the national disability rights movement, published a report entitled *Attending to America* (Litvak, Zukas, and Heumann, 1987). With funding from several private foundations, WID had attempted to survey all state-level public programs, regardless of funding source (e.g., Medicaid, Title III of the Older Americans Act, Title XX/Social Services Block Grant, state revenues) that provided personal attendant services, as of 1984, to adults (18 and older) with disabilities, except programs only for people with mental retardation or other developmental disabilities. *Attending to America* not only published individual and aggregate descriptive information about these programs, it also evaluated them based on the “independent living” philosophy of personal assistance services, also referred to as “consumer direction.” A 14-point scale was used to measure the extent of consumer direction available in each program. Key criteria included whether or not public program clients could hire, train, schedule, supervise, dismiss, and pay or participate in paying their personal care attendants directly rather than being required to obtain the services through licensed home health/homecare agencies (the “medical model”). The report concluded that approximately 50 percent of publicly funded attendant care programs permitted some amount of consumer direction, but that only a handful truly exemplified the independent living philosophy.

In 1989, WID received funding from the National Institute for Disability and Rehabilitation Research in the Department of Education to replicate the national survey of personal assistance programs, as of 1988. The Office of the Assistant Secretary and DALTCP decided to take advantage of the opportunity to study variation across states in how they administered the Medicaid personal care services optional benefit. We were interested in contracting with WID to explore why some states had elected to finance personal care services only through a “medical model,” requiring attendant care to be provided by certified home health or licensed homecare agencies, whereas other states permitted or required Medicaid beneficiaries to hire, fire, and supervise their own attendants. The research was relevant to policy because the Health Care Financing Administration (HCFA) was in the process of writing regulations for the personal care services optional benefit. A draft Notice of Proposed Rulemaking circulated for comment reflected HCFA’s intent to assert greater federal control over how states administered Medicaid-funded personal care services. The preamble described the proposed rule as based on a “modified medical model.” Both philosophically and operationally, it discouraged consumer-directed modes of service delivery.

DALTCP’s contract with WID called for case studies of six state Medicaid personal care services programs, including site visits, as well as specialized analyses of data from the 1988 attendant care survey, comparing Medicaid-funded personal care services programs across states and with attendant care financed by other federal and

state or state-only programs. While the research was under way, we learned that the Commonwealth Fund Commission on the Elderly Living Alone, based at Johns Hopkins University, was also conducting research on the Medicaid personal care option. The Commonwealth Commission, WID, and DALTCP agreed, informally, to coordinate our efforts. As a result, the Commonwealth Commission decided to conduct its surveys of Medicaid beneficiary satisfaction with personal care services in three of the states where WID was doing case studies. This experience suggested some of the benefits of government and a foundation engaging in joint research, even though this particular partnership came about in an unplanned fashion and was never formalized.

WID's analyses of the 1988 survey data on attendant care programs found that 46 percent of these Medicaid programs either required or permitted Medicaid beneficiaries to hire and manage their own attendants directly. The case studies suggested that cost effectiveness, more than a philosophy of promoting independence and autonomy for people with disabilities, was the primary motivation when states chose to encourage or to require "consumer-directed" modes of service delivery. However, in one state, officials also expressed the view that encouraging Medicaid beneficiaries to hire attendants from within their social networks (family, friends, and neighbors) helped sustain natural support systems. States that required attendant care to be provided through agencies were found to be highly concerned about potential liability for poor quality care and had greater confidence than states that favored consumer direction in the efficacy of assuring quality through licensing and related regulatory requirements.

The Commonwealth Fund Commission surveys of Medicaid beneficiaries aged 65 and older who used personal care services found that beneficiaries who reported having more choice and control over hiring and managing their attendants reported greater satisfaction with their attendant services than did beneficiaries reporting less choice and control. Satisfaction with attendant care was greatest among Medicaid personal care services users in the state where the program was the most "consumer-directed."

The results of the WID and Commonwealth Commission studies were widely disseminated shortly after the studies were completed in 1991-92. DALTCP organized briefings for HCFA and the staff of the Office of Planning and Evaluation. The findings were also reported to the larger Washington, D.C., community of health and long-term-care policy analysts at a health policy forum sponsored by George Washington University. The findings were also published in *ASPE Research Notes* (circulated primarily within the government) as well as in a professional journal (Doty, Kasper, and Litvak, 1996). Although it is seldom easy to document the direct effects on policy making of policy research, there is reason to believe that these studies and follow-up research affected legislation that Congress passed in 1993 that eliminated certain requirements that critics felt imposed a medical model on personal care services, and that they also influenced HCFA's subsequent approach to writing regulations and guidelines for Medicaid personal care services. The final rule on personal care services published in 1997 preserved and even expanded the discretionary authority of states to provide for consumer direction and a 1999 official Medicaid transmittal explicitly stated that states could choose consumer-directed service-delivery modes.

The results from the WID case studies also generated hypotheses about the advantages and disadvantages of consumer-directed models of service delivery that DALTCP was interested in testing. To do so would, however, require DALTCP to sponsor research on a larger scale, involving statistically representative data and multivariate quantitative analyses comparing the outcomes of consumer-directed and more traditional models of service. In 1994, DALTCP put out a competitive request for contract to compare consumer-directed and professional management models of personal assistance services delivery in the context of California's In-Home Supportive Services (IHSS) program. The contract was awarded to the University of California, Los Angeles (A.E. Benjamin, principal investigator) (see Benjamin and Matthias, this issue). The study, which involved interviews with over 1,000 IHSS recipients and over 600 consumer-directed and agency-employed workers found that both service-delivery models had positive outcomes overall. However, the consumer-directed model had significantly better outcomes on six of fourteen client-related outcome measures having to do with satisfaction with services, empowerment, and quality of life. The professional management (agency) model did not outperform the consumer-directed model on any outcome measures. (Benjamin, Matthias, and Franke, 1998; Doty et al., 1999). Although these findings were not yet available during the early design phase of Cash and Counseling, the evaluation contractor drew on the survey instruments developed for the California study, which will facilitate comparison of the California study findings with those that eventually emerge from Cash and Counseling.

Also, in 1994, DALTCP sponsored the first of what was to become a series of studies by Susan Flanagan (then with the MedStat Group) focusing on tax and labor law issues that affected state administration of consumer-directed personal assistance programs (Flanagan, 1994; Flanagan and Green, 1997). This research included a descriptive overview of twenty-two consumer-directed personal assistance services programs in sixteen states. The states and their programs were selected because they represented variations within consumer-directed service-delivery models. Over the years, DALTCP has been able, through Susan Flanagan's research and consultation, to establish an ongoing relationship with the U.S. Internal Revenue Service that has led to improvements in policies and procedures with regard to tax filings for client-employed personal attendants and other in-home workers. Susan Flanagan has provided technical assistance to all of the Cash and Counseling states in designing the fiscal intermediary services, awarding contracts to fiscal intermediary organizations, and monitoring their performance after implementation. Fiscal intermediary services are made available to assist treatment group members with using their cash allowances to purchase disability-related goods and services, including paying wages to and making tax filings on behalf of their client-hired attendants. Consumer-friendly training manuals have been designed for treatment group participants who elect to take on full employer responsibilities themselves.

In 1996, DALTCP cosponsored (with the American Association of Retired Persons, the National Association for Home Care, and the American Nurses Association) a national conference through the National Institute on Consumer-Directed Long-Term

Services (a partnership of the World Institute on Disability and the National Council on Aging) to explore “nurse delegation” and related approaches to revising state nurse practice acts to permit people with disabilities who require paraprofessional or paramedical services (e.g., medication management, bowel and bladder care) to exercise more choice and control in arranging to have these needs met (Wagner, Nadash, and Sabatino, 1997). DALTCP also provided financial support, through the Administration on Aging, for *Consumer Choice*, a quarterly newsletter published by the National Institute on Consumer-Directed Long-Term Services, to disseminate information about consumer-directed research, demonstrations, policies, programs, and practices.

THE IDEA FOR "CASH AND COUNSELING"

Interest within DALTCP in sponsoring a social experiment to test the limits of “consumer direction” via the mechanism of a cash benefit--the “Cash and Counseling” Demonstration and Evaluation--arose in late 1994 and early 1995. The impetus for the demonstration can be traced to the long-term-care proposals included in President Clinton’s 1993 healthcare financing reform plan. Robyn Stone, who led the Health Care Reform Task Force’s long-term-care working group had become, in the fall of 1993, the Deputy Assistant Secretary for DALTCP. Several DALTCP staffers (including Mary Harahan and myself) participated in the working group. Simi Litvak of WID was among a number of temporary consultants from outside the government who joined the working group. WID had long championed a cash benefit alternative to home-care services that would allow individuals who were eligible for publicly funded personal assistance services to become their own “case managers.” At the same time, within DALTCP, both Robyn Stone and I had studied the use of cash allowances to finance home- and community-based services in other countries, and Mary Harahan had speculated, since her days as federal manager of the National Channeling Demonstration, about whether, for some percentage of severely disabled elders and their caregivers, a cash benefit or voucher might not be a less costly and more efficacious alternative to a case-managed service package.

The expanded home-and community-based services program that emerged as the key feature of the president’s proposed legislation with respect to long-term-care services contained several provisions intended to enhance consumer choice and control. For example, states that accepted funding for these services under the enhanced federal matching rate proposed in the president’s plan would also have had to agree to offer services through both consumer-directed and homecare-agency delivery modes. This requirement would have ensured access to a consumer-directed service-delivery model for beneficiaries both interested in and capable of self-directing, but at the same time, it would also have prevented states from pursuing cost-efficiency (or advocacy-driven ideology) to the point of imposing consumer direction on Medicaid beneficiaries who preferred and whose needs could be better met through professionally managed services. The proposed legislation also would have allowed

states, at their discretion, to offer self-directing consumers maximum choice and control by providing benefits in the form of a cash allowance in lieu of specific defined services.

By October 1994, it had become clear that the bill containing the president's healthcare and long-term-care reform proposals would not pass Congress. Indeed, it appeared that, in the near term, no fundamental reforms of the long-term-care financing and delivery system were likely to occur at the federal level. Robyn Stone and the DALTCP staff who had served with her on the long-term-care working group began to consider how to prepare for the next round of serious debate about long-term-care reforms, which seemed likely to be postponed perhaps as much as a decade or so into the future. If there was any silver lining discernable in the dark cloud of disappointment following defeat of the president's long-term-care reform proposals, it was that the working group's efforts had brought some exciting ideas to the fore that could benefit from experimental testing, such as allowing states to offer beneficiaries in public programs a cash-benefit alternative to case-managed services for home- and community-based long-term care. Whereas DALTCP's interest in sponsoring a demonstration along the lines of Cash and Counseling grew directly out of the consumer-directed long-term-care reform proposals that were included in the president's healthcare reform legislation, we recognize that many others outside the government made seminal contributions. Significant new ideas seldom originate from any single source, nor can they be credited to any one individual.

CONCLUSION

From a federal perspective, the Cash and Counseling Demonstration and Evaluation is an outgrowth of and beneficiary of lessons learned from years of previous research on "consumer-direction" and of serious reflection on the meaning and significance of earlier social experiments with financing and delivering home- and community-based services. Cash and Counseling represents a highly visible test of the effects of maximizing consumer choice and control over the supportive services that elderly and younger people with disabilities need to meet their needs for assistance in the community. However, Cash and Counseling also represents a hopeful effort on the part of its federal sponsors to move beyond the impasse at which the policy debate on home- and community-based services has seemingly been stuck for nearly two decades. Cash and Counseling is an experiment that puts the responsiveness of public programs to the needs and preferences of low-income people with disabilities front and center, instead of defining the main or only value of home- and community-based services in terms of providing cost-effective "alternatives" to institutional care.

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