



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



THE CASH AND COUNSELING DEMONSTRATION:

AN EXPERIMENT IN CONSUMER-DIRECTED PERSONAL ASSISTANCE SERVICES

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Office of the Assistant Secretary for Planning and Evaluation

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THE CASH AND COUNSELING DEMONSTRATION: An Experiment in Consumer-Directed Personal Assistance Services

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The "Cash and Counseling" Demonstration/Evaluation is a large-scale public policy experiment designed to test the feasibility and assess the advantages and disadvantages of a consumer-directed approach to the financing and delivery of personal assistance services (PAS). The intent is to give Medicaid eligible persons with disabilities more choice about and control over the PAS they require. The experimental intervention is a cash benefit which allows recipients to make more of their own decisions about and arrangements for personal attendant and related personal assistance services. Classical experimental design methodology (i.e., random assignment of volunteer participants to treatment and control groups) will be employed to identify and evaluate the effects of the experimental intervention in a scientifically rigorous manner.

The Robert Wood Johnson Foundation (RWJF), a private charitable organization located in Princeton, New Jersey, has provided funding for development of the demonstration and for support of a National Program Office located at the University of Maryland Center on Aging. The National Program Office is responsible for overall project management and technical assistance to the participating states. The RWJF and the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services (OASPE/DHHS) are co-sponsors of the evaluation research component, which will be conducted under the oversight of the University of Maryland Center on Aging by Mathematica Policy Research. Kevin Mahoney, Ph.D., is the Project Director and Lori Simon-Rusinowitz, Ph.D., is the Deputy Project Director at the University of Maryland Center on Aging. Barbara Phillips, Ph.D., heads the evaluation team at Mathematica Policy Research.

Four states will participate as Cash and Counseling Demonstration sites: Arkansas, New Jersey, New York, and Florida. Each of these states has received close to \$500,000 in planning and implementation grants from the Robert Wood Johnson Foundation. The states were chosen through a competitive process in which 17 states submitted initial letters of intent. Ten states were invited to submit full proposals; from these the four finalists were selected.

In New York, Arkansas, and New Jersey, demonstration participants will be recruited from among those Medicaid clients whose services are covered under the personal care services optional benefit. In Florida, participants will be recruited from among Medicaid clients who are enrolled in the 1915© home and community-based long-term care waiver program. In all four states, both older (aged 65 and above) and younger adults (aged 18 to 64) with disabilities will be recruited to participate. In addition, in Florida only, there will be a third target group of demonstration participants comprised of children with disabilities and their parents.

Because the experimental intervention is a cash benefit and Medicaid law does not permit direct cash payments to clients, the state Medicaid programs participating in the Cash and Counseling Demonstration must obtain special "1115" research and demonstration waivers from the Health Care Financing Administration. Other federal agencies (the Social Security Administration and the Food Stamps Program run by the

Department of Agriculture) must also grant permission under their research and demonstration authority so that cash benefits in lieu of services will not be counted as income or assets for purposes of determining recipients' eligibility for income support (SSI) or Food Stamps.

DESIGN OF THE DEMONSTRATION

In each of the four states, a fixed number of Medicaid-eligible individuals with long-term functional disabilities will be recruited to participate in the Cash and Counseling Demonstration. Although some participants are expected to be newly enrolled clients, the large majority will be persons who are already receiving Medicaid-financed PAS via the existing service delivery system. Because the evaluation incorporates a classical experimental design to test the effects of the new approach to service delivery, Cash and Counseling volunteers must be willing to accept random assignment to the treatment or control group. That is, they must agree to participate knowing that they will receive a cash payment in lieu of traditional services if assigned to the treatment group, but that only half of all participants will be assigned to the treatment group. The control group members will continue to be restricted to receiving the traditional service package which includes only attendant care in three of the states, available only from a limited number of authorized vendor agencies.

Cash and Counseling aims to maximize the degree of consumer direction available to Medicaid clients who use PAS services. In the traditional, professionally managed service delivery system, nurses and/or social workers assess clients' disabilities and associated care needs, then develop care plans. Typically, the professionals themselves have limited service options, with the result that care plans, though developed for particular individuals, tend to look very much alike, except that individuals with higher levels of disability receive larger amounts of the standard services. Professionals also arrange for the services in the care plan to be provided through one or more authorized provider agencies, which bill Medicaid for reimbursement after the services have been delivered. In Cash and Counseling, professionals will play a more limited role: they will continue to perform eligibility assessments and act as financial gatekeepers by establishing the amount of the cash benefit payment, based on an eligibility clients' severity of disability and related needs for assistance. However, the treatment group participants will be permitted to use their cash benefits to purchase a wide range of disability-related goods and services from the providers and suppliers they personally select--within the limits established by the fixed monthly dollar amount provided to each recipient. Thus, participants will not be restricted to purchasing personal attendant services but will also be able to buy transportation services, assistive technologies, home and vehicle modifications (such as lifts and ramps), adult day care, and respite services. The only restriction is that the services or products purchased must address disability-related needs; the cash payments may not be used as a general income supplement. Cash benefit recipients will meet with counselors who will help them develop their cash management plans and provide other advice. For example, a counselor might offer suggestions about how to recruit an attendant, including how to interview and choose among several applicants for the job. Treatment group members will be required to account, periodically, for how they spend their cash benefits.

Cash benefit recipients will be permitted to carry over monies not spent from month to month, provided these funds are maintained in a special account. This will enable treatment group members to maintain emergency reserves for times when they may need more attendant hours than usual or to save toward a special purchase (such as an assistive device). In order to ensure public accountability, cash payment recipients will be required to document how they spend their funds and to keep receipts for purchases. Each state will develop its own monitoring plan. Consumers will be required to seek prior approval for unusual purchases. For example, one elderly consumer who participated in a focus group said that she might like to purchase a bicycle so that her grandchild could do grocery shopping and run errands for her, rather than having a paid attendant perform these tasks.

Although consumers will be permitted to pay their personal attendants directly, they will be required to comply and to document compliance with FICA and other tax requirements (which may include workers compensation and unemployment benefits in some states, depending on how much treatment group members pay per quarter or per year to individual employees). It is anticipated that many--perhaps most--Medicaid clients who are assigned to the treatment group and receive cash payments will choose to access the services of a fiscal intermediary to withhold and pay taxes for the home care workers they hire.

HISTORICAL BACKGROUND AND CONTEXT

Personal assistance services encompass a range of types of human and technological assistance provided to persons with disabilities of any age who require help with basic activities of daily living (ADL's), including bathing, dressing, transferring, toileting, eating, and/or such instrumental activities of daily living (IADL's) such as housekeeping, meal preparation, shopping, laundry, money management, and medication management. For most persons with disabilities who require PAS, the core service is regular help with ADL and/or IADL tasks provided by a personal assistant (also referred to as a personal care aide or attendant). However, other products and services such as assistive devices, home modifications, home-delivered meals, adult day care, and handicapped transportation services may supplement or, in some instances, substitute for attendant care.

The primary source of funding for PAS for low income persons with disabilities is the Medicaid program. Coverage for PAS under state Medicaid programs is optional, but virtually every state provides access to PAS either through the Medicaid personal care services (PCS) benefit and/or one or more 1915© home and community-based services (HCBS) waiver programs. When PAS is financed through the PCS benefit, the *only* service offered is attendant care. When PAS is financed under an HCBS waiver, a broader menu of disability-related products and services is likely to be available, but it is often the service providers--including provider agencies specializing in "case management" services--who decide which services will be provided. Case managers also contract with home health and home care agencies, adult day care providers, meals-on-wheels providers, emergency alarm vendors, assistive technology suppliers, and others to provide the goods and services specified in the care plan. Often, case managers must choose from a limited number and range of authorized vendors.

A number of state Medicaid programs (e.g., Oregon, Washington, Wisconsin, Michigan, Maryland, and California) already permit Medicaid clients to hire independent providers--individuals who are not employees of home health or home care agencies--to be their personal attendants. Some states permit clients to hire family members, friends, and neighbors to be their aides or attendants, although Medicaid funds may not be used to pay for attendants who are clients' spouses or the parents or legal guardians of clients who are minor children.

New York has made a "direct hire" option available for the past 15 years in New York City on a limited basis primarily for persons with disabilities under age 65 through an organization called *Concepts for Independence*. Under this model, Concepts for Independence serves as the employer of record for home care attendants hired directly by clients (Flanagan, 1997). Although Medicaid relates to Concepts for Independence as if it were the same as any licensed home care agency, it is actually a kind of client cooperative developed and run by persons with disabilities. Its founders were--and many current members still are--politically active in the disability rights and independent living movements. In 1995, New York enacted legislation that creates an entitlement for

Medicaid home care attendant clients to "consumer-directed care"--that is, to be able to hire their own attendants directly. Because of this law, availability of consumer-directed services is slowly beginning to spread beyond New York City.

However, the majority of state Medicaid personal care services and 1915© waiver programs still require that attendant care be provided under the auspices of licensed home care agencies or Medicare/Medicaid certified home health agencies. Not infrequently, there is only one agency authorized to provide services in a given geographic area. Consumers who are dissatisfied with the quality or reliability of the services they are receiving can ask the agency to send a different worker, but if consumers are dissatisfied with the agency management's response to complaints, there may be little recourse open to them if this is the only authorized provider agency in their area.

Disability rights advocates have long argued that persons with disabilities, who find themselves forced by circumstances of illness or accident to depend on others for help with routine daily activities, should be enabled and empowered to be as independent and autonomous as possible with regard to managing their own services. Advocates argue that public programs ought not mandate service delivery modes that cause persons with disabilities to be unnecessarily dependent on professional or bureaucratic authorities.

State and federal program administrators are becoming more aware that traditional modes of service delivery may unintentionally presume a high level of personal incompetency on the part of aged/disabled beneficiaries and foster excessive dependency in the name of consumer protection and/or public accountability. Moreover, program administrators also have a strong interest in achieving program economies. Often 30 to 40 percent of the hourly rates paid to home health and home care agencies go toward administrative overhead rather than toward wages and benefits paid to direct care workers (i.e., the personal attendants). Case management services are also expensive. An initial assessment and periodic reassessments of functional disability and need for services are required to determine program eligibility and authorize benefit amounts. However, program administrators are beginning to question--beyond the "gatekeeping" function--whether ongoing professional case-management (to develop a care plan, locate and arrange services, and monitor service providers) is universally required. Many consumers and/or family members could perform these ongoing service management tasks for themselves. Thus, encouraging consumer direction could lower the cost of services by reducing administrative expenses. This would mean that the same clientele could obtain the same services more cost effectively, or, alternatively, a broader clientele could be served and/or more intensive services provided to those clients in need without increasing total program expenditures.

THEORETICAL FRAMEWORK FOR THE EVALUATION

There is a growing body of research literature suggesting that although Medicaid clients who receive personal assistance services are generally satisfied with the services they receive, satisfaction increases in relation to the amount of personal choice and control that clients perceive themselves to have (Doty, Kasper, & Litvak, 1997). The degree of choice or control that clients are able to exercise can be conceptualized along several dimensions. These include:

- the ability to access advice as needed or desired--as opposed to being required to have a "case manager" who consults with the client in preparing the care plan but who holds the decision-making authority;
- the choice to receive attendant services through an agency or from an independent provider;
- the opportunity to participate in hiring, training, scheduling, and paying one's own attendants; and
- the freedom to purchase goods and services other than personal attendant care, especially assistive technologies and home and vehicle modifications that promote greater independence and autonomy by reducing the need for human assistance.

The potential benefits of Cash and Counseling include:

- promoting consumer choice and control over personal assistance services;
- increasing access to reliable, qualified home care workers willing to work flexible schedules, by permitting consumers to hire virtually anyone of their choosing, including family, friends, and neighbors if they so desire; and
- reducing administrative overhead and stretching scarce public dollars to cover more direct services.

Accordingly, the project's goals are to:

- test the feasibility of a cash payment alternative to traditional agency provided services and to determine what percentage of Medicaid clients, with what characteristics (e.g., younger versus older, more versus less severely disabled) are potentially interested in an optional cash benefit;
- to find out whether consumers who receive cash benefits without experiencing too much difficulty and what supportive services they may want or require;
- to explore whether and to what extent consumers' use of services differs when they have cash and make their own choices rather than having services arranged for them by home care agency employed nurses or by case managers employed or under contract to state/county government; and

- to measure the differential effects, if any, of receiving cash benefits as contrasted with traditional services on consumer and family caregiver satisfaction, public program costs, and health outcomes.

PLANNING AND IMPLEMENTATION SCHEDULE FOR THE DEMONSTRATION

The Cash and Counseling Demonstration/Evaluation is being carried out in three phases:

- **Phase I** (from October 1, 1995 to October 1, 1996) has been completed. It involved the selection of the participating states and the evaluation contractor.
- **Phase II** (from October 1, 1996 through August 1998) is nearing completion. It involves:
 - the creation of detailed demonstration and evaluation designs for each state,
 - conducting focus groups and consumer preference studies to estimate consumer take-up rates and to aid the development of an outreach/marketing plan to recruit participants,
 - application for and approval of HCFA "1115" research and demonstration waivers, and
 - coordination with other federal agencies to ensure that Cash and Counseling Demonstration participants are exempted from negative impacts of the cash benefit on eligibility for other federal programs, such as Food Stamps or SSI.
- **Phase III** (anticipated to begin in September 1998) will involve:
 - enrollment of consumers in the demonstration (open enrollment for 1 year), including personalized outreach to potential participants to inform them of their eligibility to participate,
 - baseline interviews with and randomization of participants to treatment and control groups,
 - interviews with treatment group members to learn of their initial experiences in managing the cash benefit approximately 3 to 4 months after enrollment,
 - followup interviews with treatment and control group members and supplementary interviews with family caregivers, and paid workers at 8 months,
 - interviews with state officials and other stake holders for an implementation process report,
 - tracking of various cost and health outcome measures through claims and other administrative data sources through 1 year following enrollment for each participant, and
 - analysis of the data and the writing and dissemination of a final report.

Medicaid clients who participate in the Cash and Counseling Demonstration will be followed for purposes of the evaluation for 1 year; however, treatment group members may continue to receive cash benefits in lieu of traditional services for at least 1 additional year.

For further information about the Cash and Counseling Demonstration, you may contact the federal project officer: Pamela Doty, Ph.D., Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Room 424E, 200 Independence Avenue, S.W., Washington, D.C., 20201. (Telephone: (202) 690-6172, E-mail: PDoty@OSASPE.DHHS.GOV).

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