

One possible approach for making long-term-care systems more consumer-directed is to provide the consumer with a cash alternative. Advocates have touted the possible advantages of this approach, while nay-sayers have worried about the potential for abuse and questioned the claims of cost savings. This article describes the Cash and Counseling Project, a large-scale demonstration project with a rigorous, policy-driven evaluation built into it. Written prior to the project's actual implementation, this article specifically reviews the major evaluation questions, and the state selection process.

Cash and Counseling Demonstration and Evaluation Start-Up Activities

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As the costs of various types of long-term care have continued to rise, policymakers and others have sought new ways to control costs while maintaining or increasing consumer satisfaction. Concurrently, there is increasing interest among the aging and disability communities in models of consumer-directed health care. Among the models is "cash and counseling," in which cash allowances, coupled with information services, are paid directly to persons with disabilities, enabling them to choose and purchase the services they feel would best meet their needs.

The Cash and Counseling initiative of The Robert Wood Johnson Foundation (RWJF) seeks to provide more autonomy to consumers of long-term-care services while controlling health care costs by empowering persons with disabilities to purchase the assistance they require in performing their activities of daily living. The evaluation of this program is being cosponsored with the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation,

BACKGROUND

Cash allowances exemplify a model of consumer-directed care that emanated from the disability rights and independent living movements. In principle, cash allowances maximize consumer choice and promote efficiency because consumers who shop for the most cost-effective providers may be able to purchase more services (Kapp, 1996).

Personal assistance services (PAS) encompass a range of types of human and technological assistance provided to persons of any age who require help with basic activities of daily living, including bathing, dressing, transferring, toileting, and eating, and/or such instrumental activities of daily living as housekeeping, meal preparation, shopping, laundry, money management, and medication management. In principal, public programs, private insurance companies, or other third-party payers can finance PAS through any of three methods:

1. Cash benefits: Dollar amounts are paid directly to qualified beneficiaries or their representative payees.
2. Vendor payments: The types and amounts of covered services are determined by nurse and/or social work case managers, who then arrange for and pay authorized PAS providers to deliver these services.
3. Vouchers (also termed coupons or stamps) and related methods such as debit accounts: To ensure that funds are used only for authorized purposes, constraints are placed on what beneficiaries can purchase.

This demonstration will measure the differential impacts of cash benefits. This article provides an overview

Mahoney and Simon-Rusinowitz

of the Cash and Counseling Demonstration and the critical research questions the evaluation is designed to answer.

DESCRIPTION OF EXISTING PERSONAL ASSISTANCE SERVICE (PAS) PROGRAMS

In the United States, most existing public programs that finance PAS—including such major funding sources as Medicaid’s optional personal care services benefit and home and community-based long-term-care waiver programs [also known as 19 15(c) and (d) waivers or as Section 2176 waivers]—follow the vendor payment model. That is, the program purchases services on behalf of beneficiaries from authorized vendors (i.e., service providers or equipment suppliers). In some programs, the list of covered services and authorized vendors from whom services may be purchased is quite restricted. In other programs, the range of covered services may be much broader, encompassing, for example, adult day care, transportation services, home modifications, and assistive technologies as well as in-home aide/attendant care. In addition, clients may be permitted to recruit independent providers (i.e., individuals who are not employees of home health agencies) to be their in-home aides/attendants. In some programs, independent providers may be family members, friends, or neighbors and are not necessarily required to have prior training or credentials.

Application of a “medical model” of services financing and delivery to PAS has resulted in a strong emphasis on professional case management. Just as physicians serve to both enable and control patients’ access to medical treatment, it has been assumed that professionally trained case managers (registered nurses and/or social workers) are similarly needed to facilitate and gatekeep disabled persons’ access to PAS. The nurse/social worker’s role in assessment, care planning, and ongoing case management is often accorded a status equivalent or analogous to the physician’s role in diagnosing illnesses and conditions, prescribing the appropriate medications, procedures or other treatments, and doing appropriate follow-up. Accordingly, most Medicaid programs that finance PAS services mandate the involvement of professional nurses and/or social workers beyond the eligibility determination phase at least to develop care plans and authorize program payments to qualified PAS service providers.

Until recently, the prohibition on direct payments to Medicaid beneficiaries in any and all circumstances has rarely been called into question. One reason is that most state and local program administrators would prefer to avoid becoming embroiled in the sort of political controversy around allegations of fraud that the Supplemental Security Income (551) program is currently experiencing in respect to payments for disabled children. Medicaid administrators are aware that politicians and

the public are sensitive to allegations of welfare fraud and that, because the program’s eligibility criteria are keyed to cash assistance eligibility standards, Medicaid’s image is that of a “welfare” program. Historically, Medicaid officials at federal and state levels have attempted to maintain an aura of integrity around the program and an inviolability associated with professional medical authority.

In recent years, however, many state program officials have come to share the concerns of disability rights advocates about public program rules and regulations that may, in effect, foster dependency in the name of consumer protection and/or public accountability. In addition, state officials have a strong interest in achieving program economies. Case management can be expensive; researchers and administrators are beginning to question whether it should be universally required (Geron & Chassler, 1994; Jackson, 1994). Hence, reasons for the growing interest in experimenting with cash allowance alternatives include both savings on program administration and enhanced consumer empowerment. As a result, disabled clients might obtain much the same services at lower cost or, alternatively, a broader clientele might be served and/or more intensive services provided to those clients in need without increasing total program expenditures.

Most of the current programs that offer a “cash benefit” do not fully achieve one of the main objectives of a true cash and counseling program, i.e., integration of

Cash allowance programs may include a variety of counseling options.

consumer choice and control in all aspects of home and community-based care. This is because case managers, not consumers, have a major role in deciding who gets cash, how much, and how the money can be used. Programs from abroad, especially Germany and the Netherlands, come closest to the cash and counseling approach we desire to test (Cameron & Firman, 1995). In these countries, consumers decide whether or not a cash benefit is best for them and then make final decisions concerning what services will best meet their individual needs,

A handful of states has introduced administrative flexibility by providing cash benefits to those persons with disabilities who wish to negotiate service arrangements entirely on their own, or more commonly, with the assistance of case management. Cash allowance programs may include a variety of counseling options to assist consumers in managing their services. For example,

counseling may assist consumers in locating, screening, managing, and training providers, and in paying payroll taxes.

Existing cash allowance programs are currently very small because they involve "state only" funds. Federal statutes prohibit direct payments to beneficiaries, so no state is currently able to use Medicaid as a funding source for cash allowances to permit beneficiaries to purchase their own services on the open market. Although voucher approaches have been frequently discussed, no states appear to have actually implemented any. However, a few states (e.g., Delaware) have implemented a related approach termed the *debit account*, in which funds are deposited in a bank account (on behalf of the consumer) and, after satisfying various third-party accountability requirements, consumers are authorized to write checks on those accounts to pay PAS providers.

THE CASH AND COUNSELING DEMONSTRATION AND EVALUATION PROGRAM

Plans called for two to four states to be selected to receive grants from The Robert Wood Johnson Foundation of up to \$500,000 each for the implementation of cash and counseling programs for the delivery of personal assistance services. In January 1996, the University of Maryland issued a request for proposals. The following are some of the major characteristics of a cash and counseling program, as described in the proposal, for which RWJF will provide funding:

- The experimental mode for the demonstration states will be to allow clients to choose cash payments in lieu of traditional case-managed services.
- States will be expected to include both elderly and younger adults with disabilities in the demonstration. States may propose the inclusion of other groups, such as disabled children.
- States will be expected to operate the demonstration program for a period of at least 18 months to provide adequate time for participant enrollment and experience.
- Evaluation protocol specifications, based on a rigorous experimental design with randomized control and treatment groups, will be built into the process for selecting demonstration states. States must agree to participate in this design.
- To the fullest extent permissible under law and regulations governing the Health Care Financing Administration's (HCFA) authority to grant Medicaid "1115" research and demonstration waivers, as well as requirements for other means-tested programs such as SSI and food stamps, minimal restrictions will be placed on disabled beneficiaries' use of cash benefits.
- The experimental demonstration programs may (but need not) be implemented statewide; however, participating states will be required to provide sufficient participants to meet minimum

requirements for the evaluation research component.

- Demonstration participants who receive PAS benefits in cash will be locked out from receiving any additional PAS via Medicaid.
- States may use Medicaid 1915 (c) or (d) waivers as the primary funding source for traditional PAS, or rely primarily on the Medicaid personal care option. State-funded programs may also be included.
- The amount of the cash payment has not been set in advance. The formula for establishing the amount of the cash payment, the period the payment must cover (e.g., a month), the frequency for reviewing the adequacy of this payment, etc., will be established in conjunction with the chosen states.
- States will need to develop an effective, impartial approach for informing potential participants of their opportunity to take part in this demonstration. As this presentation is critical, a pilot phase may be necessary.
- The availability of counseling services is integral to a consumer-directed approach and to this demonstration. At a minimum, counseling involves helping consumers to decide whether to choose the cash option and how they might best spend the money available to them. Counselors should give consumers the facts and options they need to make informed choices for themselves. It should be up to the consumer to decide whether to have total control over the "who, what, where, when, and how" of PAS or to consult with, collaborate with, or delegate certain aspects of decision making and ongoing management to someone else.
- In addition to these basic services, the state also may want to offer a range of optional supportive services, including but not limited to: care coordination services; recruitment of workers; screening of workers; training of the consumer and worker; back-up or emergency services; assistance with tax forms and insurance paperwork; and supervising or monitoring functions as desired by the consumer. A variety of agencies could theoretically provide counseling, including Area Agencies on Aging; Centers for Independent Living; consumer organizations serving older people or persons with disabilities; and case management organizations committed to consumer-directed services. Minimum criteria regarding counseling services will need to be established by demonstration states.

PROGRAM EVALUATION

The project evaluation will be designed and implemented by Mathematica Policy Research, Inc., the external evaluator hired and supervised by the National Program Office at the University of Maryland Center on Aging (UMCA). The evaluation design will be refined in consultation with the states selected for the demonstration. The following section describes the evaluation goals, research questions, and project parameters.

Evaluation Design

This evaluation will have two major components: a classical experimental design using randomized treatment and control groups and a process evaluation to study program implementation.

It is anticipated that the demonstration and associated evaluation research data collection will address research questions pertaining to differential outcomes with respect to cost, quality, and client satisfaction between traditional PAS services and alternative choice modalities. The research will not include an evaluation of the effectiveness of various counseling services. Data from each state study will be analyzed separately. The evaluation is not designed to combine data from the demonstration states.

Key Research Questions

The evaluation research effort will entail developing research questions and formulating hypotheses to measure differential impacts/outcomes between a traditional model of PAS and a model in which clients are offered the opportunity to select a cash payment in lieu of services. The evaluator will examine a broad range of questions, however, the preeminent research questions are:

1. Do treatment group members use significantly different types and amounts of services than control group members receiving traditional PAS?
2. Are the programmatic and administrative costs for treatment group members significantly different than those costs for control group members receiving traditional PAS?
3. Do treatment group members experience a different level of consumer satisfaction and quality of care (including adverse health and functional outcomes) than control group members receiving traditional PAS?
4. What counseling services are offered to clients receiving cash payments? Which clients take advantage of additional supports offered, such as counseling, provider training, and provider payrolling? What is the client's assessment of the value of the counseling services?

The following questions elaborate on these preeminent research areas:

1. What are the differential characteristics of clients who elect to participate in the demonstration (i.e., indicate a willingness to accept either services or the cash experimental alternative versus those who are unwilling)?
2. What is the impact of cash payments on the service use patterns of people with disabilities?
3. What is the impact of the cash payment option on public and private expenditures?
4. Are clients with particular characteristics more likely to drop out of the cash treatment group; i.e., ask to be transferred back to the traditional services program?
5. What is the impact of the cash payment option on individual client outcomes related to quality of care/quality of life? How well were clients' needs met? Were there behavioral impacts?
6. What do recipients say they like/dislike about the various payment modalities to which they are or have been exposed (cash or services)?
7. How much and what kinds of abuse, if any, were encountered in cash payment programs in comparison to traditional service programs?

Supplementary Research Questions

Client Preferences

1. What percentages of clients express a preference for cash over services, initially (at baseline)?
2. What are the differential characteristics of clients who prefer cash benefits to services and vice versa?
3. Do preferences at baseline have any predictive power with respect to outcomes? For example, are individuals who report a strong preference for cash at baseline more likely than others to report high client satisfaction if they are allowed to choose cash, and to express less satisfaction if they are assigned to the traditional services program? Are those who prefer cash more likely to purchase different types or amounts of services? Alternatively, are such individuals also more self-managing and more proactive in their relationships with case managers in the traditional services program, i.e., more likely to express their service preferences more actively to case managers and have those preferences been taken into account in care planning?

Informal and Formal Caregiver Impacts/Outcomes

1. What is the impact of the cash payment option on informal caregivers? Do the number of hours and/or types of care they provide change? Are paid hours substituted for unpaid? Is there any effect on burnout or stress?

2. What is the impact of the cash payment option on formal caregivers? Are there payment problems? Are workers paid a fair wage? Do formal agency providers lose market share?
3. Did the experimental intervention affect the supply of formal service providers and the cost of services?

Health Impacts/Outcomes

1. Do treatment group members use significantly different types and amounts of hospital, physician, and nursing home services than control group members receiving traditional PAS?

Implementation Issues

1. What was the reaction to the demonstration from the formal provider community? How did the states involve the provider community in the implementation process?
2. What was the reaction to the demonstration from legislators, policymakers, and advocates in the community?
3. How did program administrators and case managers react to cash payments? Were there regional differences?
4. How did the states determine the kind and amount of counseling services that would be available to clients receiving cash payments? How was payment for counseling determined? What problems, if any, were encountered in developing and implementing the counseling services?
5. To what extent and in what specific ways did the cash interventions differ from the services program in each of the participating states? How was the amount of the cash payment set? How were prospective clients informed of the cash payment option?
6. What is the effect of cash on assessment/reassessment and care planning? How often were redeterminations needed? How significant were the care plan changes? How did this compare to the traditional system?
7. How do cash recipients identify and choose PAS providers/suppliers as compared to how service arrangements are made in traditional service programs?
8. Whom do cash recipients rely on for advice and counsel in decisions concerning PAS purchase? How do these sources of advice and counsel differ as compared to those relied on by recipients of traditional services?
9. Under what circumstances do cash allowances work for cognitively impaired beneficiaries?
10. What accountability mechanisms work best to maintain client autonomy

and satisfaction while preserving public trust and reducing probability of abuse?

11. How do take-up rates for public PAS benefits differ (if at all) following the start-up of the demonstration?

PROGRAM DIRECTION AND TECHNICAL ASSISTANCE

The UMCA national program office will be responsible for providing technical assistance to states both in the preliminary phase in which states determined whether or not they wish to be considered for participation, and during the planning and implementation stages of the demonstration. The center will also supervise the work of the evaluation subcontractor. The National Council on the Aging (NCOA), which is conducting ongoing research on cash and counseling programs in the U.S. and Europe, has an advisory role in the administration of the demonstration/evaluation project.

ELIGIBILITY AND SELECTION CRITERIA

Plans called for two to four states to participate. In fact, four states were selected to participate in the Cash and Counseling program. Each state will receive a planning and implementation grant of up to \$500,000, funded by the Robert Wood Johnson Foundation. The first stage of the state selection process, a letter of intent submitted to the University of Maryland Center on

The state's commitment and level of interest were the first criteria.

Aging, was completed by March 1, 1996. From those 17 states submitting a letter of intent, 10 were invited to complete a full application, and 4 (Arkansas, New York, Florida, and New Jersey) were given full site visits. Representatives of RWJF, UMCA, the federal Department of Health and Human Services, Mathematica, and NCOA reviewed state applications. However, the Robert Wood Johnson Foundation made the final selection of states participating in the demonstration, choosing all four states receiving site visits. Program operations will commence in the Spring of 1998. Applications were reviewed using the following eligibility and selection criteria:

Applicant's commitment and interest: The state's commitment and level of interest (as exhibited through the involvement of the Governor's office and the legislature, the cooperation of all key state agencies, the state's financial contribution, and the participation of consumers and providers in the planning process) were the first criteria.

Populations/programs included in the demonstration:

At a minimum, the project should include the elderly and younger persons with a disability. It is expected that Medicaid-funded PAS will be one component of the demonstration.

Size of client population: The client population, including clients in Medicaid Home and Community-Based Service waivers, Medicaid Personal Care, and state-funded PAS programs, should total in the thousands. Final recommendations on the appropriate sample size will come from the evaluator, but it appears that at least 5,000 potential participants (approximately 4,000 existing and 1,000 new) will be needed by the second year of operation. Ideally, a single entry point for all clients will be developed (e.g., one assessment process and entrée to services), but at a minimum, common data elements should be collected.

Adherence to the evaluation protocol: A rigorous evaluation, using a classical experimental design in which willing participants will be randomly assigned to the treatment or control groups, will be an integral part of the demonstration.

Degree of similarity between existing programs and Cash and Counseling intervention: If the current system includes large programs that offer similar benefits, it may be difficult to isolate the effects of Cash and Counseling. Some argue that because cash may, to a large extent, be used to hire independent providers or informal caregivers (including family members), the demonstration should exclude states with large existing programs emphasizing independent providers. Others argue that for states to be “ready to go,” they must have piloted some aspects of the demonstration and developed some of the counseling or fiscal intermediary infrastructure. Thus, one view of an optimal demonstration state would be a state that does not have a large, independent provider-based program, and has previously implemented a pilot project assessing consumer-directed PAS. This prior experience would improve a state’s “readiness to go” without confounding the experiment.

“1115” Medicaid waiver application:

Although Medicaid law currently prohibits direct payments to recipients, Medicaid is the predominant source of public financing for state PAS programs for the elderly and disabled. Therefore, participating states will be required to obtain an “1115” research and demonstration waiver from HCFA. The agency has provided the sponsors of the Cash and Counseling program with assurances of its willingness, in principle, to grant the necessary research waivers.

CONCLUSION

One possible approach, one important option, for making long-term-care systems more consumer-directed is to provide the consumer with a cash alternative.

Advocates have touted the possible advantages of this approach, while nay-sayers have worried about the potential for abuse and questioned the claims of cost savings. This Cash and Counseling Project is a large-scale demonstration and includes a rigorous, policy-driven evaluation of this concept. Through the foresight of the Robert Wood Johnson Foundation and the federal Department of Health and Human Services we hope to provide the consumer with a cash alternative to services, and state and federal policymakers with critical insights into the costs and benefits of this approach, as well as with practical insights into how such a program can best be implemented.

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