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Designing the Cash and Counseling Demonstration and Evaluation

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Objective. The Cash and Counseling Demonstration and Evaluation (CCDE) was designed as an experiment in shifting the paradigm in home and community-based long-term care from a professional/bureaucratic model of service delivery to one emphasizing consumer choice and control. The experimental intervention was an individualized budget offered in lieu of traditional Medicaid-covered services, such as agency-delivered aide services or a plan of care developed and coordinated by a professional case-manager, which typically involves authorization for several different providers to deliver a range of services. Within the spending limits established by their budgets, program participants were largely free to choose the types and amounts of paid services and supports they judged best able to meet their disability-related personal assistance needs.

Study Population. Medicaid beneficiaries in selected states who volunteered to participate. In all of the participating state Medicaid programs, beneficiaries eligible to participate included elders and younger adults with chronic disabilities and, in one state, adults and children with mental retardation/developmental disabilities could also participate. Minor children and adults with cognitive impairment could participate via representatives (family or friends who agreed to assist them in managing their services or to act as their surrogate decision-makers).

Data Sources. Members of the CCDE management team describe the rationale for and implications of key design decisions.

Study Design. Key design decisions included the choice of research methodology (random assignment of CCDE participants in each state to treatment and control groups), selection of the state sites (AR, FL, NJ, NY), and the need for the CCDE to comply with federal waiver requirements for Medicaid research and demonstration projects.

Principle Findings. The CCDE design was successfully implemented in three of the four state Medicaid programs selected for participation.

Conclusions. The successful implementation of the CCDE (results from the evaluation are reported elsewhere) led to replication efforts in other states. The CCDE also inspired changes in Medicaid law and policy, including the 2002 "Independence Plus" Initiative by the Centers for Medicare and Medicaid and sections of the Deficit Reduction Act of 2005 intended to promote consumer-direction in Medicaid.

Key Words: Consumer direction, Medicaid home and community-based services, personal assistance services.

Coverage of personal assistance services for Medicaid program participants with long-term functional disabilities has been available since the late 1960s, but, during the 1980s, coverage options were expanded and more states elected to offer these services. Over the past quarter century, program participants' access to these benefits has greatly expanded. When personal care services (PCS) were first offered as an optional state plan benefit, in 1968, coverage was limited to in-home aide services and followed a "medical model" that required physician authorization and nurse supervision. Congress eliminated these federal requirements in 1993 in response to a campaign by disability-rights activists. They successfully argued that, whereas medical conditions cause disability and make PCS medically necessary, which provides the rationale for medical insurance coverage, a physician is not needed to make a disability determination and PCS themselves are not "medical" and should not be regulated as such. Nevertheless, many states continued to mandate physician authorization and nurse supervision and, as of the mid-1990s when the CCDE was being designed, approximately half of the 33 states and federal territories offering Medicaid PCS stipulated that only licensed home health care agencies could provide them.

In 1981, Congress enacted new legislative authority under which states could petition U.S. Department of Health and Human Services for greater flexibility to offer home and community-based alternatives to institutional care. Whereas state plan PCS coverage had largely been restricted to elders and younger adults in need of "hands-on" help with basic self-care (such as bathing, dressing, getting into and out of bed), home and community-based services (HCBS) provided under 1915(c) waivers allowed for a much broader range of disability-related services and supports, including services that were clearly more "social" than "medical." In addition to in-home aide services, HCBS waiver programs could offer services in other settings (e.g., day care), protective supervision for persons with cognitive impairment ("companion" services), services for family caregivers (e.g., "respite"), habilitation and "prevocational" services for persons with mental retardation/developmental

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disabilities (MR/DD), transportation, assistive devices, and home modifications—and virtually any other service states thought might prevent institutional placement.

In addition, HCBS waiver programs could be targeted to Medicaid beneficiaries with disabilities other than the elderly and younger adults with physical disabilities; most especially, to children and adults with MR/DD. States could also decide which services to offer to which groups. Some chose to offer many services; others limited coverage to only a few or even only one service (personal care aide services). By the mid-1990s, every state had at least one HCBS waiver program (often several). HCBS waivers contributed greatly to the drive to "deinstitutionalize" persons with MR/DD from large state institutions. Nationally, two-thirds of HCBS waiver spending goes toward services for Medicaid beneficiaries with MR/DD. HCBS waiver programs emphasize professional case-management. "Case managers" (usually nurses or social workers) develop individualized "care plans," which means that they decide (subject to state coverage rules and limits) which services, in what amounts, from among the services the state has chosen to put "on the menu" will be authorized as appropriate for each program participant. Many states also have "provider qualifications" that require aide services to be provided by agencies or otherwise limit the providers eligible for Medicaid reimbursement. Proponents of consumer-directed PCS believe such requirements overshadow what federal law identifies as a key purpose of the Medicaid program—attaining or retaining families' and beneficiaries' "capability for independence and self-care."

This paper describes how the principal funders of the CCDE and its management team ("we" in the text that follows), which included the authors of this paper, designed an intervention that both (1) was faithful to models of consumer direction proposed by disability activists, and (2) could be "operationalized" in light of state and federal laws and political considerations. The paper covers the period from late 1994 to late 1998, when demonstration enrollment began.

THE FRAMEWORK OF THE INTERVENTION

What may now be considered the hallmarks of Cash and Counseling programs—participant choice and control, use of a monthly budget, and access to counseling and fiscal services—came into place not automatically but through the interplay of idealism, compromise, and creativity.

Choice and Control

From the start, defining the CCDE intervention as a "cash" benefit was primarily intended to give Medicaid beneficiaries with disabilities the same degree of choice and control over how to best meet their needs for home- and community-based services as private payers have. Although the CCDE model represents a paradigm shift in the delivery of long-term care, it adheres to the original intentions of the Medicaid program. When Medicaid was enacted into law in 1965, Congress chose not to create a separate service system for the poor but instead to give low-income Americans the ability to purchase services from the same health care providers (hospitals, physicians, nursing homes, etc.) that other Americans used. In the case of home and community-based long-term care, however, Medicaid financing and the program's provider qualifications created a service system primarily dependent on Medicaid funding. Thus, there developed a marked divergence between the service providers used by Medicaid beneficiaries and others. Although a majority of chronically disabled elders living in the community do not receive paid care (perhaps because they cannot afford to pay privately and do not qualify for public coverage), a higher percentage of disabled elderly who do use paid care pay privately than receive Medicaid-financed services. (According to the 1999 National Long-Term Care Survey, 52 percent of elders with paid helpers reported that they or their relatives paid out-of-pocket—as compared with 15 percent who reported having Medicaid coverage and 28 percent who received Medicare-covered home health services.) Private payers are free to make whatever arrangements they choose for hiring aides and national data also indicate that disabled elders and their families frequently invest in other goods and services (including simple technologies and home modifications, such as grab bars and railings) that reduce dependence on human help (both paid and unpaid). In contrast, Medicaid reimburses only providers that meet program qualifications, which are often "medical" (licensing, certification, professional training, and supervision, etc.). Such requirements can cause Medicaid providers to be more expensive and less available than those hired privately. However, the quality of their work may not be better, and could actually be worse, given the lack of control the consumer has over how the services are delivered.

During the 1960s and 1970s, disability rights activists such as Ed Roberts and Judy Heumann developed the "independent living model" of personal assistance services. The model stressed the importance of a person's right to hire, fire, schedule, train, supervise and, wherever possible, participate in paying personal care attendants (DeJong 1983; DeJong, Batavia, and McKnew 1992; Eustis 2000). This model was later renamed "consumer-directed personal assistance services" (CD-PAS). In the 1980s, the World Institute on Disability, a think tank founded by Roberts and Heumann, called for an expansion of the concept of CD-PAS to encompass a cash benefit. If participants actually paid their attendants, it would be quite clear that they, not the public program, were their attendants' employers (Litvak et al. 1987).

The designers of the CCDE were committed to offering choice and control to *all* adults in the target population, including those who, due to cognitive impairments, were not able to manage the care themselves, but had concerned family members or guardians who would do so for them. Much debate ensued over this issue, out of concern that it was not really "consumer" directed care if the consumer could not make decisions, and concerns that some consumers might be taken advantage of. Nonetheless, the importance of being as inclusive as possible, the possible legal challenges to denying some consumers the right to enroll, and the difficulty of deciding who could or could not manage their own care adequately led to the prohibition of any screening of consumers for suitability for the program. Any otherwise eligible Medicaid beneficiary, who volunteered for the program, or their designated representative, could participate in the demonstration.

A Monthly Budget

The participating states were allowed to choose which Medicaid home care benefits they wished to "cash out" through the allowance. Arkansas and New Jersey elected to limit participation to persons eligible for the state plan PCS benefit and cashed out only these aide services. Florida open participation to enrollees in three different HCBS waiver programs (for the elderly and for children and adults with developmental disabilities) and cashed out an array of services covered under these waivers.

Although choice and control hinges on receipt of a cash benefit in the CD-PAS model, it soon became apparent that giving CCDE participants a cash benefit in the form of a monthly check would pose significant practical problems. The first problem is that an unrestricted cash benefit of more than a token value would appear to be an increase in the beneficiary's personal income or assets. If income or assets rise above allowable limits, eligibility for Medicaid and other means-tested public programs, such as supplemental security income, food stamps, and subsidized housing, is lost. In the short term, we addressed this problem by obtaining research and demonstration waivers from the relevant federal agencies—the Centers for Medicare and Medicaid, the Social Security Administration, and the Department of Agriculture. Under the waivers, the CCDE allowance is not counted as income or assets. In addition, the CCDE allowance is to be deposited in a separate bank account to clearly distinguish it from beneficiaries' income and assets (Doty 2000). However, the necessity of these short-term solutions raised questions about whether an unrestricted cash payment approach could ever be widely replicated and eventually "mainstreamed," assuming the evaluation results proved favorable.

A second problem in giving an unrestricted cash payment to beneficiaries was that neither federal nor state Medicaid officials were willing to cede such a great degree of control over public funds to beneficiaries. Some senior federal officials worried that beneficiaries might use the cash benefit to buy liquor, lottery tickets, cigarettes, or illegal substances, or that family members would exploit the beneficiary and use the benefit themselves. For their part, state officials were prepared to loosen, but not eliminate, Medicaid coverage restrictions. They supported requirements that program participants use the CCDE cash benefit only to meet health and disability-related needs, not to cover general living expenses or buy luxury items. Even paying for education or training seemed inappropriate uses of Medicaid funds. Finally, state officials wanted to prevent program participants from inadvertently wasting their CCDE allowances by using them to purchase goods or services that Medicaid or other public programs already covered.

The final barrier to giving cash directly to beneficiaries was the resistance of the Medicaid fiscal intermediaries in the participating states. Fiscal intermediaries are private firms, serving as administrative contractors that operate state Medicaid Management Information System (MMIS) and associated claims payment operations. For a myriad of technical reasons having to do with the complexities and costs of making software and other changes to MMIS designed to process providers billings electronically, these contractors balked at mailing benefit checks to, or making electronic deposits to the personal bank accounts of, CCDE participants. The extra costs the fiscal intermediaries would have charged to retool their systems again raised more questions about whether cash payments could ever become widespread, even if the evaluation findings were positive.

In the end we decided that, in lieu of a direct cash payment, CCDE would provide participants with a prospectively paid monthly budget that would be managed by a fiscal-services provider at the direction of the beneficiary or a designated representative. Lest this form of consumer-directed care be too far removed from the original idea of a direct cash payment, we also decided to offer beneficiaries two options. First, they would be allowed to receive their allowance in cash each month from the fiscal-services provider if they agreed to be trained and tested on fiscal responsibilities and submit to a periodic audit (and retained receipts for all purchases with the allowance). Second, beneficiaries would be able to receive a cash advance each month of up to 10 or 20 percent of the monthly allowance for incidental purchases, such as taxi fare, that could not readily be invoiced in advance. Consumers would pay for the bulk of their expenses by submitting invoices (or timesheets, for workers' wages) to the fiscal services provider, which would write the checks. The first option was decidedly unpopular with beneficiaries—only a handful among thousands chose to manage the allowance themselves. Most chose to receive the modest cash advance, although a sizeable number took none of their allowance in cash and had all of their eligible expenses paid for directly by the fiscal agent.

Counseling and Fiscal Services

The "counseling" component of CCDE refers to assistance and advice that participants may receive from designated program staff about making and implementing a plan to spend the monthly budget. Fiscal services include serving as consumers' agents, for purposes of filing payroll taxes and check writing (Flanagan 1994). Considerable effort was put into providing technical assistance to assure that the organizations states contracted with for fiscal services filed payroll taxes correctly. Early on, we contacted officials at the Internal Revenue Service to clarify policies and procedures and this collaboration is ongoing.

Counseling became part of the CCDE experiment when Jim Firman, President of the National Council on Aging and coiner of the term "Cash and Counseling," and others argued persuasively that not offering participants supportive guidance from professionals was tantamount to making them "sink or swim." Whether or how much professional guidance program participants and families actually need to access appropriate services is a matter of ongoing debate: some experts consider professional help critical; others argue that case-management is an expensive service which Medicaid has overemphasized. We considered giving beneficiaries access to counseling services—but not requiring their use—so that we could study whether, how much, and what kinds of services beneficiaries actually wanted. Again, however, it proved impractical to make the counseling component purely discretionary. Medicaid officials were understandably unwilling to forgo all independent oversight of how program participants spent public funds. Thus, as CCDE planning progressed, it became mandatory for counselors (New Jersey used the term "consultants") to review program participants' purchasing plans to assure that all intended purchases of goods and services were within state guidelines. If any planned purchases seemed questionable, the counselor was to inform the participant that state officials needed to decide.

We conducted preference surveys and focus groups to help determine the content of the counseling and fiscal services to be provided (Mahoney et al. 2004; Simon-Rusinowitz, Mahoney, Zacharias et al. 2005). Medicaid beneficiaries who indicated a potential interest in participating in the experiment said the ability to employ their choice of home care workers was one of the demonstration's most attractive features. Typically, focus group participants and survey respondents were confident they could hire, fire, and supervise their workers and make good decisions about other goods and services that would meet their needs for personal care. They did worry, however, about their ability to handle paperwork, file taxes correctly, and keep records of how they spent the allowance each month. So serious were the doubts of these focus group participants and survey respondents that we became worried enrollment into the demonstration would be low. We had to assure prospective participants that counselors would be available to help them with paperwork and tracking their spending, and that fiscal-service providers would handle their responsibilities as employers, by filing tax documents and withholding taxes if they chose to hire workers.

When the demonstration states began training counselors, they recruited primarily individuals with social services backgrounds (not necessarily MSWs). Counselors in Arkansas and New Jersey did not come from the ranks of traditional "case managers" whereas Florida only permitted current HCBS waiver program case managers to become "counselors." Some counselors (especially those with experience in traditional case management) were more likely than others to doubt that program participants eligible to enroll in the CCDE (in particular, elders) would be able to direct their own services without a lot of professional help. Some also assumed that beneficiaries who needed extensive assistance in developing a monthly spending plan (arithmetic was particularly challenging) were also unsuited to other aspects of consumer direction. Some of these counselors failed to give beneficiaries the initial help they needed. When it became evident that many participants were taking much longer than expected to plan for and start receiving the allowance, we used focus groups of counselors, evaluation surveys of participants and counselors, and process evaluation interviews with state officials to improve the provision of counseling. The participating states reconsidered how much counseling should be required for purposes of oversight; how much they should pay counselors to ensure that they provide enough, but not too much, assistance; and what types of counselor assistance self-directing program participants and families need or find most useful. Despite differences across states in the provision of counseling, treatment group members in all three states reported high satisfaction with the counseling they received. State program administrators drew their own conclusions: Arkansas now requires less counseling, whereas Florida revised counselor training to try to ensure counselors would provide enough. New Jersey determined that counseling would be improved if counselors worked for the same organization that provided the fiscal/employer agent services. Thus, debate continues over how much and what type of counseling is needed.

TESTING THE INTERVENTION IN A DEMONSTRATION SETTING

Designing the framework of the intervention and figuring out how to test it were largely concurrent processes. After the CCDE management team and funders identified demonstration elements that would not be negotiable with states, and after evaluation requirements for sample size and enrollment periods were established, site selection was mostly a process of elimination. Thereafter, two obstacles delayed implementation of the demonstration: determining how to meet federal budget neutrality requirements, and assuaging concerns that the demonstration would induce demand for Medicaid PCS or home- and community-based waiver services. After discussing the design requirements that states had to meet in order to be selected as demonstration sites, we will discuss in greater detail the obstacles that had to be overcome in order for the selected states to receive federal "waiver" approval to implement their demonstration programs.

Nonnegotiable Demonstration Elements and State Selection

Randomized Design. From the earliest stages of planning, there was never any doubt that the CCDE would employ controlled experimental design. The funders anticipated that the extent of consumer choice and control accorded the experimental program participants could be controversial. As the "gold standard" of scientifically rigorous evaluation, a controlled experimental design would increase the credibility of the research findings, whether favorable or unfavorable. This would be especially important if the findings contradicted the conventional wisdom or expectations of likely critics (traditional providers) or proponents (consumer advocates).

Committing to controlled experimental design was nevertheless a bold move. It significantly increased research and demonstration costs, in time and money (Greenberg, Shroder, and Onstott 1999). The decision to employ controlled experimental design methods imposed significant caseload requirements on participating states. Mathematica Policy Research Inc., the independent evaluator of the demonstration, calculated that each state needed to enroll at least 2,000 volunteer participants to detect moderately sized program effects and conduct subgroup analyses.

Participating states knew that agreeing to implement a controlled experimental design was a nonnegotiable condition for selection as CCDE sites. Initially, state officials were ambivalent. They made clear that, had they been allowed to decide, they would have preferred a different type of evaluation. (With hindsight, state officials agreed that the advantages of controlled experimental design outweighed the disadvantages and proved their worth.) State officials seemed most worried about the possible political repercussions of random assignment. In particular, they believed they might come under pressure if disappointed control group members lobbied elected officials to get them re-assigned to the treatment group.

Early in the planning phase, consideration was given to carrying out the random assignment in a manner that would minimize so-called "control group rage." In the alternative scenario (an approach previously employed in a Dutch experiment with "individual budgets"), eligible beneficiaries would have been randomly assigned without prior knowledge or consent to (1) a group allowed to choose between directing their own services or receiving traditional services, or (2) a group that could receive only agency services as usual. After a vigorous debate, the CCDE management team decided to enroll into the demonstration only those eligible Medicaid beneficiaries who knowingly volunteered for the CCDE and consented to randomization. Enrollees randomly assigned to the treatment group would have the opportunity to receive the CCDE allowance; those assigned to the control group would rely on Medicaid PCS or home- and community-based waiver services as usual. This design was selected because it maximized the utility of random assignment by ensuring a high participation rate among treatment group members—a necessary condition for adequate statistical precision if a limited number of consumers enrolled, and a more cost-efficient approach given the need to collect survey data on sample members. It also increased the likelihood that states would be able to recruit sufficient numbers of demonstration participants who would be willing to be interviewed and for whom accurate contact information would be available.

A Willingness to Take Some Risks. In addition to agreeing to implement a randomized experiment with sufficient numbers of enrollees, states selected to participate in the CCDE would have to be willing to participate in some bold experimentation. To the management team and funders, this meant willingness to mount a large-scale demonstration within Medicaid. States that would consider only small pilot tests—for example, including only a state-funded program or only the state's share of Medicaid funding—were disqualified. States also had to agree to recruit elderly Medicaid beneficiaries into the demonstration, in addition to younger adults. Because many elders have physical frailties and cognitive impairments, their suitability for consumer direction has long been debated by policymakers; the CCDE was meant to generate definitive evidence to resolve this debate. Selected states had to demonstrate a willingness to grant CCDE participants a great deal of choice. For example, in addition to hiring workers of their choice, they had to be allowed to purchase assistive equipment and make home modifications that would enhance their independence. Selected states would be required to allow CCDE participants to hire family members as paid caregivers if they chose to—a controversial issue in many states (Linsk et al. 1992; Simon-Rusinowitz, Mahoney, and Benjamin 1998; Simon-Rusinowitz, Mahoney, Loughlin et al. 2005). Finally, states in which more than small numbers of beneficiaries already hired/fired and supervised individual workers were considered less desirable test sites for the CCDE. The funders preferred to test the Cash and Counseling model in states where the contrast between traditional Medicaid PCS and the experimental alternative would be greatest.

The Successful Candidates. Seventeen states submitted letters of intent to apply for CCDE grants; 11 were invited to submit full proposals; and, in summer 1996, four were selected for site visits. These four were Arkansas, Florida, New Jersey, and New York. Arkansas and New Jersey both had well-developed interventions and strong leadership. Florida and New York were particularly attractive because they had large numbers of potential enrollees.

Florida also was of interest because it proposed to include both children and adults with MR/DD in its target population, and was "cashing out" a wider range of services covered under their waiver program, including some skilled services, and supplies (such as adult diapers). New York was attractive because it had a rich service package and diverse population. Other states were dropped from consideration because it was felt they could not meet sample size requirements for the evaluation or they were unwilling to comply with some of the nonnegotiable aspects of the demonstration. Although the CCDE funders had originally intended to select only two states to participate in the demonstration, after the site visits they were convinced to include all four that were visited. More states would give CCDE results a greater likelihood of being perceived as applicable to other states and some insurance in case one or more states pulled out of the demonstration. This proved a prescient decision; New York dropped out of the demonstration before implementation (Sciegaj, Simone, and Mahoney 2007).

Choosing the Best Way to Meet Budget Neutrality Requirements

To implement the CCDE, the management team and participating states had to apply for a Section 1115 waiver of certain federal Medicaid requirements. The Centers for Medicare and Medicaid Services (CMS) has statutory authority to grant such waivers, but the federal Office of Management and Budget (OMB) holds veto power. Since the early 1980s, OMB has insisted that Section 1115 waiver demonstrations be budget-neutral to the federal government. In fact, proponents of consumer-directed personal assistance have long emphasized its potential cost efficiency. For state officials, cost efficiency means spending proportionately less on overhead expenses and more on direct services. OMB requirements are stringent, however, and many demonstration programs have failed to meet them.

The measurement of budget neutrality in Section 1115 waiver demonstrations generally follows established protocol based on analysis of historic costs. First, a trend factor is calculated using 5 years of state claims data. The trend factor equals the average annual Medicaid expenditure growth rate for the services that will be affected by the demonstration. If federal budget analysts consider the state-specific trend factor to be excessive, a lower trend factor based on the CMS actuarial projections of future national Medicaid expenditure growth is used instead. Second, state-specific base-year costs are trended forward to establish per member, per month (PMPM) average annual cost caps for each year of a 5-year waiver period.

The CCDE management team, the states, CMS, and OMB agreed early on, however, *not* to measure budget neutrality according to the usual method. Instead, they hoped to take advantage of the CCDE's experimental design by comparing treatment group costs with control group costs. The assumption was that control group costs were the best measure of what Medicaid costs would be if no demonstration took place. However, the official "1115" waiver terms and conditions for measuring budget neutrality differed from how treatment/control group costs were compared in the evaluation. Medicaid costs for services other than PCS, home health care, and HCBS were not taken into consideration. In contrast, the evaluation cost comparisons included all Medicaid and Medicare costs (though all costs were compared for only 1 year following each participant's enrollment into the demonstration). Almost all elderly demonstration participants and many younger adults with physical disabilities were dually eligible and most of their hospital and other acute medical expenses were Medicare-covered.

Also, unlike the evaluation, the official budget neutrality measure only counted PMPM costs for home care in the months when any such costs were incurred. In other words, comparisons of home care costs of treatment and control members only included months in which treatment group members spent at least *some* (but not necessarily all) of their available funds and control group members received at least *some* (but not necessarily all) of the traditional home care services authorized in their care plans.

The exclusion of all other Medicaid (and Medicare) costs from the official budget neutrality formula meant that if either treatment or control group members PMPM spending for home care was significantly greater, no "offsets" to achieve budget neutrality could be applied if there were also savings from significantly lesser use of other services (e.g., nursing home care). Indeed, the evaluation subsequently found that both in New Jersey and, especially, Arkansas, treatment group members' greater use of home care was associated with reduced use of nursing home care. It was therefore necessary, at a minimum, for the official formula to exclude months in which demonstration participants did not incur—and, indeed, could not possibly have incurred—home care costs because they spent the entire month in a nursing home or hospital. Although the budget neutrality formula did not directly include nursing home costs (or hospital cost covered by either Medicare or Medicaid), it tacitly recognized the inappropriateness of crediting the traditional service system with "savings" if, in fact, control group members had no home care costs because they were in an institutional setting for the entire month.

But why exclude from the comparative home care cost calculations all months in which participants incurred no home care costs but did not spend the month as an inpatient; that is, when they were residing in the community, just not receiving paid home care? By so doing, the budget neutrality formula implicitly acknowledged that demonstration participants who had been assessed according to program rules as "needing" paid care should be receiving at least *some* Medicaid-funded home care in any given month in which they were alive, still Medicaid eligible, had not been found to no longer meet coverage criteria, and were residing in the community.

It is true that considerable ambiguity surrounds the determinations of "need" for paid home care. If a Medicaid beneficiary undergoes a professional needs assessment and, based on the results, is authorized to receive a given amount does that mean that he or she needs *exactly* that, no more, no less? It seems plausible that some, perhaps even many, beneficiaries authorized to receive a certain number of hours (or other "units") of Medicaid-covered care might suffer no measurable harm from receiving a few fewer—or might demonstrably benefit from receiving more. Indeed, the evaluation found that, on average, control group members who received services did not receive their full allotment in a given month and treatment group members, on average, spent less than their entire allowances.

It becomes more difficult, however, to rationalize the failure of demonstration participants judged to need paid care to receive any, whether they are control group members who receive no traditional home care or treatment group members who do not make any purchases using their budgeted funds for one or more months. If individuals with chronic disabilities fail to access any paid home care in a given month while residing in the community rather than in a nursing home or hospital, should this be interpreted ex post facto to mean that no paid home care was actually "necessary" and its nondelivery represents a cost savings? (In New Jersey and Arkansas, coverage criteria for state plan PCS do not even require a "nursing home" equivalent level of disability.) The official budget neutrality formula recognized that using less than the fully authorized amount of paid home care could save Medicaid money, but that paying for any amount of home care (large or small) will always result in higher Medicaid costs than no care whatsoever. As such, no experimental intervention could reasonably be expected to facilitate access to any amount of paid home care for less than or equal to the zero cost associated with no use of such services.

Nevertheless, the decision to base budget neutrality calculations on PMPM treatment-control group comparisons remained fraught with unforeseen difficulties for states. Under the standard budget-neutrality protocol, state

Medicaid program administrators know *in advance* the waiver cost caps they cannot exceed. This is a clear managerial advantage. Had the standard approach been used in CCDE, program administrators could easily have set the dollar value of the CCDE allowance so as not to exceed the preestablished PMPM cost limits.

Instead, because budget neutrality would be judged by comparing treatment/control group actual costs *retrospectively*, CCDE project managers had to try to predict what percentage of their authorized services control group members would actually receive. State project managers were advised to research the average shortfall between authorized services and actual services delivered in a recent period (in other words, they were to compare expected versus actual costs) and to discount CCDE allowances accordingly.

In retrospect, the CCDE management team and the states did not take sufficiently into account the possible implications of self-selection on control group costs. All demonstration enrollees were volunteers. It seems quite likely that some of them may have been motivated to join the demonstration because they were dissatisfied with traditional Medicaid services for one reason or another. If their reasons included greater-than-average difficulty accessing traditional services, then CCDE volunteers randomized to the control group would use fewer traditional services, and have lower home care expenditures, than would be reflected in states' calculations of authorized or expected costs.

In any case, the question of whether and by how much to discount CCDE allowances to adjust for the authorized services that control group members would not receive from traditional service providers presented state program administrators with a dilemma. On one hand, states could not afford to incur the financial penalties CMS would impose if they failed to satisfy the budget neutrality test. On the other hand, if they discounted CCDE allowances too steeply, they could undercut the potential of CCDE to offer some Medicaid beneficiaries a means of overcoming the access and quality problems they experienced in the traditional service system.

There was much discussion and debate over whether discounting was indeed necessary to assure federal waiver budget neutrality and was justifiable administratively (i.e., procedurally fair). Florida and Arkansas officials chose to apply discounts. Arkansas, the state with the least generous Medicaid personal care benefits, actually applied the steepest discounts. Over the course of the demonstration, the Arkansas discount had to be increased because the shortfall between authorized and delivered services for control group members proved to be much greater than expected (and much greater in Arkansas than in either New Jersey or Florida). New Jersey officials elected not to discount benefits; they concluded that consumers typically received benefits quite close to what was authorized, on average, and hoped to get enough savings from reducing administrative overhead to make benefit discounts unnecessary.

Avoiding the "Woodwork Effect"

Late in summer 1997, while OMB was reviewing the CCDE's application for a Section 1115 research and demonstration waiver, agency analysts began to insist that the Department of Health and Human Services and the demonstration states develop a plan to prevent people from applying for Medicaid PCS or HCBS solely because they wanted to receive the program allowance. OMB analysts speculated that a "woodwork effect" might emerge in the CCDE due to the presumed attractiveness of the cash allowance. In addition, OMB objected to allowing spouses and parents of minor children to become paid workers under CCDE. OMB argued that the opportunity to pay these immediate family members would induce Medicaid beneficiaries to enroll in the demonstration when they otherwise could have continued to rely on free (to Medicaid) sources of care.

The stalemate with OMB took a year to resolve. It was eventually overcome when each state agreed to limit the ratio of "new" to "continuing" Medicaid eligibles allowed to volunteer for the CCDE. The ratios were based on historical analysis of the typical percentage of users of PCS or HCBS in a given year that had not received those benefits during the previous year. In reality, no woodwork effect was possible in Florida because only beneficiaries already in HCBS waiver programs—for which there was a 2-year waiting list—were eligible to volunteer for the CCDE. In New Jersey, new applicants for Medicaid PCS had to apply for benefits through a traditional agency provider before they were told about the CCDE opportunity and could enroll in the program. Only in Arkansas were *all* Medicaid beneficiaries informed about the CCDE program, and if determined eligible for PCS by a state-employed nurse, could volunteer for the CCDE and go directly into the experimental program if randomly assigned to the treatment group.

For its part, OMB agreed to compromise on the issue of payments to spouses and the parents of minor children: New Jersey and Florida were permitted to offer this option; Arkansas and New York (which subsequently dropped out of the CCDE) had not planned to do so and therefore readily agreed that they would not.

Enforcement of "Budget Neutrality"

Participating states were able, over time, to satisfy the "1115" budget neutrality terms and conditions that were mutually agreed upon by CMS, OMB, and the states (Florida's MR/DD Consumer-Directed Care programs experienced the most difficulty). All states were allowed to continue their programs by extending and amending their "1115" waivers beyond the original 5-year term. Because none of the states exceeded the enrollment limits for newly eligible beneficiaries, concerns about a potential "woodwork effect" faded. From the states' own perspective, the 1115 "budget neutrality" standard had to be met but state officials themselves judged success by other standards. It was more important to them that Cash and Counseling prove more cost-effective in achieving program goals (such as reducing unmet need and preventing/postponing nursing home use) than traditional services and more cost efficient in terms of spending proportionately less on overhead and more on direct services.

It is important to bear in mind, for purposes of policy implications, how the official test of budget neutrality differed from the evaluation's treatment/control group cost comparisons. In addition to the key differences already discussed, CMS measured budget neutrality over a longer time frame (the entire 5-year waiver period), which not only permitted, but rewarded states for making "mid-course corrections" to achieve budget neutrality.

CASH AND COUNSELING TODAY

Five to 8 years after enrolling their first participants, the experimental programs in all three of the pioneer CCDE states remain in operation—though not at the peak level of enrollment reached during the evaluation. However, despite highly favorable evaluation results (described elsewhere in this issue), none of the three states has yet been able to negotiate the transition from offering Cash and Counseling via experimental demonstrations to making it available as a standard option for beneficiaries eligible for Medicaid long-term care at home. Instead, the three states have received Section 1115 waiver extensions and amendments to allow their programs to continue.

The time required and conditions imposed to obtain approval to drop random assignment delayed program expansion. Florida's program was authorized to drop random assignment but not permitted to expand enrollment beyond previous control group members. Arkansas and New Jersey received permission to end random assignment and enroll new participants. Their programs currently show Medicaid savings when measured against Section

1115 budget neutrality standards derived from historical Medicaid costs and annual expenditure growth rates.

Since May 2002, CMS has used its administrative discretion to permit states to offer self-directed budgets under Section 1915(c) waivers. Florida now plans to make its demonstration program permanent by incorporating consumer-directed budgets into 1915(c) waiver programs. However, until recently, only the 1115 waivers allowed spouses or parents of young children to become paid caregivers and 1115 waivers are still required to give "cash" directly to Medicaid beneficiaries. Until new legislative authority goes into effect, 1115 waivers remain the only mechanism under which CMS will allow a Cash and Counseling alternative to be offered when the financing mechanism is state-plan Medicaid PCS rather than an HCBS waiver.

Currently, only a few thousand of an estimated 1.2 million Medicaid beneficiaries receiving home care participate in Cash and Counseling programs. However, the Deficit Reduction Act of 2005 contains provisions (effective January 2007) intended to make it easier for states to offer self-directed alternatives to traditional Medicaid services. CMS will need to issue regulations and interpretive guidance to states. Looking toward the future, it will be necessary to address, at both federal and state levels, a number of program operational challenges. For example, states have found it difficult to sustain and grow the infrastructure of providers of counseling and fiscal services that facilitate consumer direction. Fewer organizations than anticipated have been willing to take on the mission of supporting self-directing Medicaid beneficiaries and develop the necessary expertise to perform effectively as fiscal/employer agents. Unless such difficulties are resolved, they are likely to impede expansion of Cash and Counseling options, even as interest in offering Cash and Counseling options both within and beyond Medicaid continues to grow. For example, the 2006 reauthorization of the Older Americans Act includes "Choices for Independence," a new program inspired by the CCDE to promote consumer-directed service options for disabled elders living in the community who cannot afford the paid care they need but are not poor enough to qualify for Medicaid.

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REFERENCES

DeJong, G. 1983. "Defining and Implementing the Independent Living Concept." In *Independent Living for Physically Disabled People*, edited by N. Crewe and I. K. Zola, pp. 4–27. San Francisco: Jossey-Bass.

DeJong, G., A. J. Batavia, and L. B. McKnew. 1992. "The Independent Living Model of Personal Assistance in National Long-Term Care Policy." *Generations* 16 (1): 89–95.

Doty, P. 2000. "The Federal Role in the Move toward Consumer Direction." *Generations* XXIV 111: 22–7.

Eustis, N. 2000. "Consumer-Directed Long-Term Care Services: Evolving Perspectives and Alliances." *Generations* XXIV 111: 10–5.

Flanagan, S. A. 1994. *Consumer-Directed Attendant Care Services: How States Address Tax, Legal, and Quality Assurance Issues.* Cambridge, MA: Medstat.

Greenberg, D., M. Shroder, and M. Onstott. 1999. "The Social Experiment Market." *Journal of Economic Perspectives* 13 (3): 157–72.

Linsk, N. L., S. M. Keigher, L. Simon-Rusinowitz, and S. E. England. 1992. *Wages for Caring: Compensating Family Care of the Elderly.* New York: Praeger.

Litvak, S., H. Zukas, and J. Heumann. 1987. *Attending to America.* Berkeley, CA: World Institute on Aging.

Mahoney, K. J., L. Simon-Rusinowitz, D. M. Loughlin, S. M. Desmond, and M. R. Squillace. 2004. "Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey and New York Elders and Adults with Physical Disabilities." *Health Services Research* 39 (3): 643–63.

Sciegaj, M., K. Simone, and K. Mahoney. 2007. "State Experiences with Implementing the Cash and Counseling Demonstration and Evaluation Project: The Case of New York." *Journal on Aging and Social Policy* (forthcoming).

Simon-Rusinowitz, L., K. Mahoney, and A. E. Benjamin. 1998. "Payments to Families Who Provide Care: An Option That Should Be Available." *Generations* 2 3(Fall): 69–75.

Simon-Rusinowitz, L., K. J. Mahoney, D.M Loughlin, and M. D. Sadler. 2005. "Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation." *Marriage and Family Review* 37 (1/2): 83–105.

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.