Putting the Consumer First: An Introduction and Overview

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If anything best describes recent trends in the complex world of long-term care (LTC), it is the growth of interest and investment in home and community-based services (HCBS). Various forces have driven efforts to shift from disproportionate investment in nursing homes to a more diversified set of institutional and noninstitutional services, including home-based services, day care, respite services, case management, and others. The Cash & Counseling Demonstration and Evaluation reported in this Special Issue examines a new approach to the provision of increasingly important home-based personal assistance services (PAS) to people with disabilities of all ages.

Because most people with LTC needs now live in community settings, especially at home, there has been a growing demand for enhanced supportive services at home—in particular, for “personal care” or “personal assistance” services. PAS include help with activities of daily living (ADLs) such as bathing, dressing, eating, and toileting, along with instrumental activities of daily living (IADLs) like cooking, shopping, and housekeeping. These individualized services may make the difference between living independently at home and needing support in congregate or institutional settings (LaPlante, Harrington, and Kang 2002).

Most people with personal assistance needs receive help from unpaid family members, but other options have emerged for those without adequate sources of informal assistance. Private home care agencies provide paid personal assistance in the market place, and public programs provide these services to those with low-incomes and thus limited capacity to purchase routine help privately. While there are now several such public programs, including those funded under the Older Americans Act, the Social Services Block Grant, and state-only sources, by far the most important are financed through the Medicaid program. Medicaid funds PAS modestly through its home health benefit and more generously through HCBS waivers and the optional state plan personal care services benefit. Recent analysis indicates that an estimated

13–15 million persons needed PAS in 2004. Among these, just over four million needed paid (formal) services (Kaye et al. 2006) with one to 1.5 million of these receiving PAS through Medicaid benefits and waivers.

The Cash & Counseling Demonstration was designed to provide a more consumer-centered alternative to the traditional model of PAS delivery by home care agencies. PAS (like most home-based services) typically are provided by agencies that send nurses, therapists, and aides into the home to deliver both medically related home health services and more supportive PAS. For example, when a Medicaid applicant is deemed eligible for PAS, he or she is referred to an authorized provider agency that assigns a worker and schedules service visits. The agency also defines allowable tasks, monitors worker performance, processes any complaints, arranges backup, and otherwise manages service delivery (Benjamin 2001). Critics of the agency-based model argue that all of these decisions are more likely to be made on the basis of agency interests than in response to recipient needs. For example, workers may be in short supply and are assigned as available and rotated as needed, disrupting both nascent and long-standing service relationships. Scheduling is done by the agency with what may be limited regard for recipient preferences about when help is most needed. Timely visits may be sacrificed for agency needs without asking or informing clients beforehand or arranging back-up services. For liability reasons, agency workers are constrained in the tasks they may perform. What training workers receive may involve doing assistance tasks in a prescribed way, even if not compatible with recipient preferences. More generally, critics charge that the professional-agency model tends to assume that people with physical limitations must also have other limitations that restrict their analytical capacities and ability to express preferences and make sound decisions about services.

In consumer-directed approaches, like Cash & Counseling, many of these choices and responsibilities are shifted to the recipient or “consumer.” Consumer direction assumes that most supportive services are essentially nonmedical, low-technology services that do not require either extensive worker training or external monitoring. Instead, the consumer can decide which services are needed, when and how they are delivered, and by whom. In arranging assistance, the consumer may be free to choose a family member or friend to be their personal assistant. From this perspective, consumers should be empowered to make all or most service decisions, and

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physical (and even cognitive) limitations should not be barriers to expressing preferences and making decisions about services so personal and fundamental to their quality of life. The Cash & Counseling model is a more intensive variant of “consumer directed care,” in the sense that it places in the hands of consumers direct control of monthly *cash* allotments and considerable discretion to purchase any services or goods they consider essential. In this model, recipients can manage their cash directly or pay a small fee to have a certified fiscal agent manage fund accounting. The *counseling* part of the program involves professionals who are available to provide consumers with information and advice as they assume the role of “employer” in managing funds and services.

HISTORICAL CONTEXT FOR CONSUMER DIRECTION

Like most innovations, the conceptualization of Cash & Counseling emerged out of multiple sources or streams of experience. While the fuller story of the birth of the demonstration and evaluation will be told in the papers that follow, at least four sources seem to merit mention up front. First, as early as the 1950s a few public programs appeared that incorporated the idea that service recipients might receive cash or some flexible equivalent rather than a set of defined services arranged by vendors and paid for by government. Second, from the 1970s onward, the pursuit of a more recipient-centered alternative to agency-based, medically managed home care was a central theme for younger disability activists in the independent living (IL) movement. Third, the success of other reform efforts by IL activists set the stage for a new dialogue between aging and disability leaders and new enthusiasm for “nontraditional” approaches to HCBS. Finally, the growing costs of the LTC components of federal and state Medicaid budgets whetted the appetites of policy makers for approaches that might reduce average beneficiary costs.

Since the 1950s, the Veterans Administration has been authorized under federal law to provide additional payments (beyond income benefits) to eligible veterans with disabilities so they can purchase PAS. Since the late 1950s, the State of California has provided a monthly service benefit for the hiring of personal attendants, first with state-only funding to a small number of eligibles and later as a Medicaid plan benefit. Later, other states began establishing small-scale programs that left service decisions to the recipient.

Young disability activists in the 1970s were the first to notice these programs, to conceptualize this as a new and (for them) preferred way to think about services, and to integrate this approach into the idea of “IL.” Many of

these activists had major physical disabilities, and their survival and longevity had resulted from vast improvements in medical care. Yet, in their view, the success of physicians and nurses in medical settings did not justify the extension of medical-professional authorization and direction of basic supportive services delivered at home. When outside acute and rehabilitation settings, younger activists with disabilities demanded a service benefit in which they were given resources (or control of them) and were free to design and implement PAS based on their own lifestyles and preferences (Batavia, DeJong, and McKnew 1991).

Disability activism was a crucial element in the passage of the Americans with Disabilities Act in 1990. That success freed up activist energy to turn to other issues, primarily expansion of PAS linked with consumer choice to direct their own services. These developments caught the attention of leaders of the other recipient group with a keen interest in PAS, namely the elderly. Since the mid-1980s, policy dialogue had begun between these two groups, which despite many common interests, have some divergent views about the direction of public policy reform (Eustis and Fischer 1992). The Clinton health care reform process in the 1990s brought together scholars and policy makers in disability and aging research, and the latter came to learn about and embrace consumer-directed approaches (see Doty paper in this issue). Importantly, the seeds had been sown earlier by scholars in aging who argued that professionals were wrong to assume that as we grow older, we became more passive and less interested in making choices. Instead, they argued that as aging can magnify physical issues, bolstering psychological vitality by encouraging older people to express their preferences and make choices became more significant, not less (Rodin 1986; Cohen 1988).

Finally, federal and state policy makers had watched and fretted while Medicaid steadily consumed greater public dollars and became a program covering many low-income families with children but allocating most of its resources to the elderly, disabled, and LTC services. Knowing that expanding LTC costs were driven by nursing home expenditures made HCBS seem even more salient. Knowing that home-care costs were also rising steadily made innovative approaches to the payment, organization, and delivery of PAS more appealing.

The language of consumerism pervades current health care reform discussions. While it may be tempting to view all consumer-centered initiatives as similar, there are some important differences across acute and LTC. "Consumer-driven health care" is an approach that seeks a more active and informed patient role in medical decision making, primarily at the point of acute

care utilization. This approach is based on assumptions that medical patients tend to make poorer decisions because (a) they are inadequately informed; (b) they confront barriers to effective communication between providers and patients due to differences in culture, language, socio-economic status, or underlying assumptions about service provision (Fennell 2005); and (c) they do not experience the burden of payment fully enough. Advocates for proposals like “health savings accounts” argue that higher deductibles, stronger incentives to avoid high-cost, low-benefit care, and better performance data will yield more prudent patient decisions, more satisfying care, and lower costs.

“Consumer direction” in LTC starts elsewhere. In this view, consumers of PAS already know their preferences and are quite capable of translating them into service decisions, sometimes with the aid of advice from peers, friends, or professional counselors. Because, with agency services, providers make service decisions based on their own preferences and traditions and not the recipients’, consumer-directed approaches are designed not to re-train and incentivize recipients but to provide them opportunities to act as the informed consumers they already are.

Consumer-directed approaches have generated both enthusiasm and skepticism among academics, policy makers and advocates. Their appeal has several dimensions. They are relatively simple to administer, so that they seem less “bureaucratic” and more directly responsive to citizens needs and thus appeal politically to both antigovernment and propublic program interests. These approaches are person- and family-centered, as control of service resources and decisions is shifted from professionals to recipients and their informal care systems. They provide flexibility and allow people in need to make adjustments in services (e.g., scheduling) and modify the home environment (e.g., purchase assistive equipment) as their needs change.

On the other hand, critics of consumer direction cite doubts about the motivation and capacity of older, frail, perhaps cognitively impaired recipients to make appropriate service decisions, skepticism about the hiring of family members whose motives for receiving public dollars have been questioned, concerns about whether the interests of workers are underplayed in these models (Wilner 2000) and uncertainty about how quality of care will be monitored, among others. Some (but not all) of this skepticism is rooted in our welfare history, in which Americans have always doubted the willingness and ability of low-income people (however “deserving”) to responsibly manage public funds.

CASH AND COUNSELING

With funding from the Robert Wood Johnson Foundation, the Cash & Counseling Demonstration was designed and implemented in three states (Arkansas, Florida, and New Jersey) between 1999 and 2003. Simultaneously, an evaluation was designed and implemented by Mathematica Policy Research Inc. (MPR) with support from the federal Department of Health and Human Services' Office of the Assistant Secretary for Planning and Evaluation. The Demonstration enrolled Medicaid beneficiaries with PAS needs older than 65, adults age 18–64, and (in one state) children with disabilities. Those who agreed to participate in the demonstration were randomly assigned to the experimental services option (i.e., Cash & Counseling) or to usual care (agency-based services as provided through Medicaid). By all accounts, the MPR evaluation team worked closely with the demonstration planners in designing sampling and data collection procedures and in completing the evaluation.

The papers in this special issue describe the process of conceptualization and design of the Cash & Counseling Demonstration and Evaluation, the implementation of the demonstration across three states, the design of the evaluation, the experiences of participants in the demonstration, analysis of the various program effects, consumer case studies from the demonstration states, and the initial and anticipated impact of the demonstration experiences and evaluation results on funders and states.

The first three papers provide historical background on the emergence of consumer direction as a policy priority and the process of design and implementation of the demonstration and evaluation. The paper by Knickman and Stone recounts the various forces that brought consumer direction to the attention of a large foundation and a federal agency with long histories of supporting LTC reform and research. From the viewpoint of the key decision makers in these organizations, this paper also describes the development of a genuine collaboration between these private and public partners, including their parallel commitments to an innovative demonstration and a rigorous evaluation. The paper by Doty, Mahoney, and Simon-Rusinowitz describes the process of fielding this demonstration, some of the challenges presented by the funders' commitment to use experimental design with random assignment, key elements of the intervention and the issues that accompanied design decisions, as analyzed by key program leaders. The paper by Phillips and Schneider describes the process by which the three demonstration states implemented the demonstration, within the context of national guidelines that left some discretion for state choice about eligibility, allowable goods and

services, amount of the allowance, and other key features. These papers set the stage for discussion of the evaluation and its results.

The next six papers examine program effects as determined by the evaluation across different sets of actors and using diverse methods. The paper by Brown (principal investigator for the evaluation team at MPR) and Dale describes key elements of the evaluation research design and how various methodological issues were resolved. The paper discusses research questions, data sources, random assignment, measurement, analytical methods, and design limitations and issues. The following paper by Schore, Foster, and Phillips describes consumer baseline characteristics and experiences in the implementation of the demonstration and evaluation. The authors describe who received the cash allowance and how they spent it as well as how consumers in the experimental group adapted to their assigned roles as employers.

The next three papers present the primary evaluation findings on program effects of the cash option compared with usual services. The paper by Carlson and colleagues examines effects on recipient personal care utilization and well-being, including unmet needs, service and life satisfaction, and adverse outcomes. Analysis is done separately for each of the three states and for three age groups; the findings indicate strong positive effects for those assigned to the Cash & Counseling intervention, compared with controls. The paper by Dale and Brown addresses program effects on Medicaid costs for program enrollees in the three states. Using Medicaid claims data, the authors show that because access to paid care was increased, personal care expenditures were higher for the treatment group but that these were partially offset by savings in other Medicaid services. The authors discuss some complex patterns across treatment and control groups and across states that seemed to influence utilization and costs. The last paper in this set by Foster, Dale, and Brown analyzes program effects not on recipients but on their informal caregivers and directly hired (paid) workers. Both informal and paid caregivers in the treatment group reported better outcomes on measures of satisfaction, worry, and strain than those in the control group. However, directly hired workers who were related to recipients reported more emotional strain than agency workers.

The last paper on program effects presents illustrative case histories of six consumers and their families; this paper by San Antonio and colleagues helps put “real faces” on otherwise impersonal data from the evaluation. The paper describes consumers drawn from the treatment group, the service issues they faced, the limits of their resources before the demonstration, how the intervention altered the kinds of goods and services they were able to purchase, the impact of the intervention, and any issues they faced in Cash & Counseling.

The final paper by Mahoney and colleagues, describes policy developments as the completion of the demonstration and evaluation. The authors include representatives from the demonstration leadership team and from the foundation and federal funders. All continue to be involved in Cash & Counseling as a second round of funding has extended the demonstration to additional states. The paper assesses recent developments in the original three states as well as in the 12 new states now implementing Cash & Counseling. The authors consider the future of consumer-directed approaches in LTC and cite both anticipated challenges and promising developments as they look ahead.

This special issue concludes with two thoughtful commentaries by Joshua Wiener and Peter Kemper. Wiener, a well-known scholar in the field, places the Cash & Counseling model into a comparative perspective by discussing some established European approaches to expanding consumer choice in LTC. Another prominent scholar, Kemper carefully reviews the findings reported in this issue and reflects on their meaning, significance, and limitations.

FINAL THOUGHTS

Close to two decades ago, *HSR* published a special issue (Kemper et al. 1988) on the evaluation of the National Long-Term Care Demonstration (better known as *Channeling*), which was arguably the most prominent of a series of early community care demonstration programs aimed at expanding and analyzing the substitution of community-based services for nursing home care among older people with functional disability. The evaluation team was led by Peter Kemper and including others (Brown, Phillips, Schore) who went on to guide the Cash & Counseling Evaluation. At the heart of this early demonstration was comprehensive case management provided by trained professionals and formal in-home services delivered by home care agencies. While the field continues to struggle with persistent questions about public-private roles, service supply, funding, and the organization and delivery of services (Feder, Komisar, and Niefeld 2000), it is also striking how much has changed over time in our thinking about service provision. In some sense, the Cash & Counseling Demonstration was designed to reduce the roles of case managers and home care agencies in the delivery of supportive in-home services and to shift attention to the recipient as consumer, employer, and case manager. In a real sense, our policy goals are the same, but we have shifted our thinking

about preferred means to address them. It remains to be seen whether two decades from now scholars are still interpreting and debating the findings of Cash & Counseling as they have those from Channeling. What is apparent is that this special issue presents important findings from Cash & Counseling that merit careful attention and discussion.

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