Implementation Issues for Consumer-Directed Programs: Comparing Views of Policy Experts, Consumers, and Representatives

Lori Simon-Rusinowitz, MPH, PhD
Lori N. Marks, PhD
Dawn M. Loughlin, PhD
Sharon M. Desmond, PhD
University of Maryland

Kevin J. Mahoney, PhD
Boston College

B. Lee Zacharias, MSW
The Zacharias Group

Marie R. Squillace, PhD
National Council on Aging

Ann Marie Allison, MA
Arthur Andersen

SUMMARY. An increasing number of aging community providers and consumers support consumer-direction (CD) in long-term care services. In regard to devolution, consumer-direction goes beyond the usual ap-

[Haworth co-indexing entry note]: "Implementation Issues for Consumer-Directed Programs: Comparing Views of Policy Experts, Consumers, and Representatives." Simon-Rusinowitz, Lori et al. Co-published simultaneously in *Journal of Aging & Social Policy* (The Haworth Press, Inc.) Vol. 14, No. 3/4, 2002, pp. 95-118; and: *Devolution and Aging Policy* (ed: Francis G. Caro, and Robert Morris) The Haworth Press, Inc., 2002, pp. 95-118. Single or multiple copies of this article are available for a fee from The Haworth Document Delivery Service [1-800-HAWORTH, 9:00 a.m. - 5:00 p.m. (EST). E-mail address: getinfo@haworthpressinc.com].

10.1300/J031v14n03_06

proach of shifting responsibilities from the federal government to state governments to bring programs "closer to the people." Consumer-direction goes even further by placing resources directly in the hands of consumers.

Yet, many questions remain unanswered regarding how to implement CD personal assistance services in general, and especially for older persons. This article describes the importance of examining views from multiple key stakeholders involved in implementing CD programs. We report on three background studies that have informed the Cash and Counseling Demonstration and Evaluation (CCDE) design and implementation–policy expert interviews as well as surveys and focus groups with consumers and representatives. As a fourth data source, we drew upon experiences in designing the CCDE and initial results from the first year of implementation. Each of the three studies on its own provided essential information for planning the CCDE. However, when we examined the studies together, and added CCDE design and implementation experiences, views expressed by the different stakeholders formed a type of multi-perspective "dialogue" that expanded our knowledge about implementing CD services. We hope this increased knowledge will help expand the availability of such services for consumers of any age who want to direct their own care.

KEYWORDS. Community-based long-term services, consumer-directed services, cash benefit

INTRODUCTION

I like being able to have a say in who . . . cares for me. (Elderly Arkansas consumer)

I would be able to hire somebody . . . and pay them. I like that. (New Jersey representative)

I feel a lot more comfortable with my friends helping me out. (Adult Arkansas consumer)

Most people want to have a say in matters that affect their daily lives. Elders and people with disabilities share this desire, especially when it comes to how and when they receive help with intimate personal care such as bathing, dressing, using the toilet, and preparing their meals. Yet, traditional programs that provide such help often lack a significant consumer-direction focus that allows or encourages consumers to be in charge of their services. This paper addresses issues in implementing consumer-directed services. Our goal is to expand our knowledge about this important topic by comparing the views of key stakeholders involved in consumer-directed (CD) programs (i.e., people having an interest in such programs). We hope that increased knowledge about implementing CD programs will help expand the availability of such services.

Consumer-direction for persons needing assistance with activities of daily living (ADLs) and other personal care tasks originated over two decades ago among younger persons with disabilities in the disability rights and independent living movements (DeJong, Batavia, & McKnew, 1992). More recently, the aging community began to adopt CD principles that maximize consumer choice and control when a coalition between the aging and younger disability communities emerged in the mid-1980s (Simon-Rusinowitz & Hofland, 1993; Ansello & Eustis, 1992). Interest in consumer choice expanded among some aging leaders in the early 1990s, in part due to a belief that CD care may lead to cost savings (Simon-Rusinowitz et al., 2000). For many years, people from the disability community have believed that having more control over their services would enable them to meet their needs and improve the quality of their lives for the same amount of money or less than required by traditional services. The Cash and Counseling Demonstration and Evaluation (CCDE) is a policy-driven evaluation of these beliefs. The CCDE is a test of one form of CD services–offering consumers a cash allowance and information services in lieu of agency-delivered services.

On a continuum of CD services offering differing levels of decision-making, control, and autonomy, a cash allowance is one of the more unrestricted forms of CD services (Stone, 2000). "Cash and Counseling" enables consumers to purchase services, assistive devices, or home modifications that best meet their needs. In principle, cash allowances maximize consumer choice and promote efficiency as consumers who shop for the most cost-effective providers may be able to purchase more services (Kapp, 1996). In regard to devolution, consumer-direction goes beyond the usual approach of shifting responsibilities

from the federal government to state governments. Devolution to states is designed to bring programs "closer to the people" as states can be more responsive to individual needs than a more removed federal government. Consumer-direction goes even further by placing resources directly in the hands of consumers.

We need to know more about how this approach works. The CCDE, co-sponsored by The Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, seeks to learn whether this approach can increase consumer choice and control costs by empowering persons with disabilities to purchase the assistance they need to be as independent as possible. This three-state social experiment is taking place in Arkansas, Florida, and New Jersey Medicaid programs under Section 1115 Research and Demonstration Waivers granted by the Centers for Medicare and Medicaid Services. Elders (over age 65) and adults (age 18-64) are included in all states. Children with developmental disabilities are included in Florida.

This article describes the importance of examining views from key stakeholders involved in implementing CD programs. We report on three studies that have informed the CCDE design and implementation. These studies included a variety of methodologies and distinct sample groups to assess diverse views from key stakeholders. As a fourth data source, we drew upon experiences in designing the CCDE and initial results from the first year of implementation. While these three studies and CCDE experience speak about a cash allowance, many issues that are addressed are applicable to other types of CD programs.

BACKGROUND

Implementing Consumer-Directed Programs

Consumer-directed programs that encourage maximum consumer choice and full participation in community activities are a shift in focus for programs serving older persons, which have traditionally been more paternalistic in nature and focused on a more limited goal of keeping older persons in their own homes and out of nursing homes. Increased choice and control is likely to increase satisfaction with care and quality of life (Ansello & Eustis, 1992; Doty, Kasper, & Litvak, 1996; Kapp, 1996; Simon-Rusinowitz & Hofland, 1993). Although an increasing number of aging community providers and consumers support more

consumer control and choice within service delivery, many questions remain unanswered regarding how to implement CD personal assistance services (PAS) in general, and especially for older persons (Doty, Kasper, & Litvak, 1996; Kapp, 1996; Mahoney, Estes, & Heumann, 1986; Simon-Rusinowitz & Hofland, 1993). For example, researchers are exploring appropriate approaches to assessing consumers' preferences regarding their services and assuring high quality services in CD programs–critical implementation issues (Davis, Schneider, Kunkel, & Applebaum, 2001; Geron, 2000; Degenholtz, Kane, & Kivnick, 1997).

Views of Key Stakeholders Involved in Implementing CD Programs

Consumer-direction is an innovative approach that could challenge the way long-term care is delivered. While many service providers and consumers have been excited by CD, as with any system change, there has been resistance to the concept. For example, service providers who felt threatened about losing clients to the cash option were likely to express doubt about and resistance to this program. According to Green and Kreuter's health promotion planning model (1999), people will appreciate and support health innovations and policies if they can see clearly how such efforts address their concerns and contribute to the quality of their lives.

This model stresses the principle of participation to ensure the involvement of the people intended to benefit from a proposed program. Green and Kreuter (1999) describe a "social assessment" process that involves gathering information from multiple sources to expand the understanding of people regarding the quality of their own lives. They explain that lay people may view health from different perspectives than do professionals. Professionals tend to focus on the objective indicators of health, while lay people tend to emphasize subjective indicators such as social, emotional, spiritual, and cultural dimensions of health (Green & Kreuter, 1999). All perspectives are necessary for successful program planning. This principle was clearly demonstrated by the CCDE background research. The perspectives of policy experts as well as those of consumers and/or their representatives (relatives or friends), expressed in surveys and focus groups, guided program planners in designing the project. These varied perspectives were sometimes supportive of one another, while at other times there was tension among them.

The social assessment process includes two imperatives. The first is a pragmatic imperative: Joint participation is necessary when tackling today's complex health problems. Community members have insights

and knowledge that professionals may not have. Also, community involvement may encourage community buy-in to program innovations. The second is a moral imperative: including community members in the planning process shows respect for potential program participants. Green and Kreuter (1999) emphasize the importance of planning *with* community members, rather than *for* communities. While Green and Kreuter's planning process has been applied extensively in the health promotion field, its application to an aging and disability social experiment is new to our knowledge.

The Key Stakeholders

To represent key stakeholders in designing CD services, we gathered information from multiple perspectives and used a variety of methodologies. First, we interviewed 20 policy experts from the aging and disability arenas. Participants included state program administrators and leaders in home- and community-based services from multiple settings. Next, we conducted focus groups and surveys with consumers and/or representatives in the Demonstration states who would be eligible to participate in the CCDE. The experts were able to contribute insights about the political and health care provider climate, and consumers/representatives added a dimension that enabled program planners to design a CD program that could serve them well. Views from additional stakeholders came from the fourth data source in this study, actual CCDE experiences in designing the Demonstration and first year implementation data. This source brings firsthand experiences of Demonstration state staff, policymakers, traditional personal care agencies, and the project management team (composed of the project funders, project directors, evaluation specialists, and others).

Various stakeholders had different roles in this process. Policy experts were asked to raise issues and concerns about implementing CD services, and speak about the perspectives of consumers, providers, payers, and policymakers. Thus, policy experts' comments represent their own views as well as predictions about these four constituencies. Consumers and representatives were asked to share their preferences about a CD cash option. Program planners then considered the information provided by these studies to find solutions to the concerns and preferences raised by policy experts, consumers, representatives, and others. These various roles illustrate how a "dialogue," or even some tension, among key stakeholders became part of the program planning and design process.

METHODS

Descriptions of the Three Studies[1]

Policy Expert Interviews. Telephone interviews were conducted with 20 policy experts from the aging and disability communities. The research questions were designed to assess implementation issues when adopting a CD approach to aging services and to address issues as they relate to consumers, providers, payers, and policymakers. Nine participants had experience specifically in aging issues; ten participants described working with both elders and younger persons with disabilities; and one participant had experience only with disability issues. Policy experts were affiliated with the federal government (2), state government (1), universities (7), other research settings (2), national associations (3), one private foundation, and one health insurance company. Three experts were private consultants. Interviews were conducted between September 1996 and August 1997. The interviews ranged in length from 25 to 125 minutes, and averaged 76 minutes. Refer to Simon-Rusinowitz et al., 2000, for a detailed description of the policy expert study.

Telephone Surveys. Surveys with consumers and representatives were conducted in Arkansas, New York,[2] New Jersey, and Florida. Medicaid personal care clients were randomly selected from the total Medicaid personal care clients in those states. The sample size and response rate for each state were: Arkansas (n = 491, 34%), New York (n = 493, 31%), New Jersey (n = 683, 60%), and Florida (n = 743, 50%).[3]

A 139-item instrument was developed to measure consumer and representative perceptions of a cash option. The survey assessed consumers' satisfaction with current PAS, perceptions about the cash option, and demographic and background variables, as well as representatives' perceptions and demographics. Telephone interviews took place between April and November 1997. On average, interviews lasted 40 minutes. If respondents felt unable to answer survey items themselves, they provided the interviewer with the name and phone number of a representative responder. Items were worded so it was very clear to representatives when they were answering for the consumer and when they were providing their own opinions. Refer to Simon-Rusinowitz et al., 1997; Mahoney et al., 1998; Mahoney et al., 2002; and Desmond et al., 2001 for detailed descriptions of the telephone surveys.

Focus Groups. Focus groups with consumers and representatives were conducted prior to the telephone surveys to guide survey develop-

ment. In addition, a series of focus groups was conducted after the surveys to help explain survey findings.

Eleven focus groups with a total of 96 participants were conducted in Westchester County and New York City, NY, and in Tampa, FL, in late 1996 and early 1997. These groups were conducted to: determine consumer satisfaction with current Medicaid personal care, introduce the concept of the cash option, gauge consumer and representative reactions to the program features, determine consumer and representative reactions to the cash option tasks, and determine if there are certain demographic characteristics that affect one's desire to participate in the cash option. Focus group participants included adults with physical disabilities under age 65, elders over age 65, and representatives who assist in decision-making with consumers who are unable to make all decisions for themselves. A second series of 16 focus groups, with a total of 95 consumer and representative participants, was conducted after the telephone surveys to obtain further explanation of survey findings. Refer to Simon-Rusinowitz et al. (in progress) for a full discussion of focus group findings.

Implementation Data. Initial observations from CCDE planning activities and experience from the first year of implementation in Arkansas were considered in this study, including preliminary findings from a survey of early Arkansas consumers who had been in the cash option for nine months (Brown & Foster, 2000). Survey participants included 194 individuals who enrolled in the Arkansas demonstration between its inception (December 1998) and June 1999, were randomly assigned to receive the cash allowance, and completed a nine-month follow-up interview between September 1999 and March 2000. The telephone survey had a 90% response rate. It included descriptive information about cash option consumers and well as consumer outcomes in four areas: program participation; uses of cash, goods, and services; hiring of caregivers; and satisfaction.

Procedures for the Secondary Analysis

In this secondary analysis, we began by identifying and examining common themes expressed by different stakeholders across the data sources. (In this retrospective analysis, each data source did not necessarily address each topic discussed.) We noted that in many cases, policy experts and consumers had different perspectives about CD principles–exhibiting a tension between the differing perspectives. They expressed different views about whether consumers would be willing to

participate in CD services, whether consumers would be able to manage CD services, and whether CD services could be successfully implemented.

Each of the three background studies on its own provided essential information for planning the CCDE. However, when we examined the studies together, and added CCDE design and implementation experiences, views expressed by the different stakeholders formed a type of multi-perspective "dialogue" about CD. In this dialogue, for instance, policy experts sometimes expressed concerns, and the issues about which they were concerned were then "resolved" by consumers and program planners during the often-challenging program development phase of the CCDE. At the same time, ideas for CD implementation were often expanded as a result of comparing views from the stakeholders.

FINDINGS

> *It's offering you the same options that you're getting. The only difference is that you're in charge.* (Florida elder)

This section reports results from the four data sources that illustrate the need to compare multiple views among stakeholders regarding CD services. Policy experts, consumers and their representatives, and Demonstration staff expressed differing views about the topics discussed in this article. These contradictory views could have presented barriers in designing the CCDE had we not examined the responses of all involved. Stakeholders' concerns and eventual solutions to those concerns about consumers' ability to manage CD services, fraud and abuse, consumer training, and worker shortages are presented and summarized in Table 1.

Stakeholders' Concerns About Consumers' Ability to Manage CD Services

Experts were concerned about allowing individuals who could not manage CD tasks independently to participate in the CCDE. Although project implementers initially shared this concern, they decided that they did not want to exclude any individuals who could benefit from the program. Implementers looked for ways to be inclusive and decided to allow a surrogate or representative for individuals who need assistance with decision-making. The CCDE includes all consumers interested in the cash option, regardless of disability level, and allows representa-

tives to assist consumers who cannot manage all consumer tasks independently.

Policy experts expressed further concerns about how to identify whether consumers can manage CD services because procedures to assess consumers' skills in managing CD services were not clearly defined. Their thoughtful statements illustrated this difficult issue. "There is also the question of how you determine the skill levels of the consumers in managing CD services. . . . " "An issue also is how you determine for whom CD services are appropriate and desired, and for whom they are not." Using a representative addresses these issues.

Policy experts, consumers, and representatives were concerned about the need to serve consumers with a variety of needs, preferences, and impairments. They discussed differences in the level of interest in CD, specifically the cash option, depending on consumers' demographic and background characteristics such as age. Experts pointed out that consumers evolve and their needs change; thus, there is a need for multiple, flexible programs (8).[4] "People evolve through their lives. They have different wants and needs . . . programs should reflect the ability to evolve."

Differences in Interest Level by Age Groups. Policy experts predicted that consumers and providers might be resistant to CD services for elders. Experts reported that payers and policymakers' paternalistic thinking has made it difficult for them to accept an independent living philosophy for elders who have a wide range of health care needs (17). One expert added, "The potential for a more unstable health care condition of older people has been the rationale [of policymakers] for using agencies rather than a CD approach."

Contrary to the view that elders would be uninterested in CD services, survey data revealed that a substantial proportion of elders over age 65–one-third to one-half–were interested in this approach to services. Many older focus group participants expressed interest in the cash option and felt they would have no problem handling the tasks. "I think it would be great . . . I would have the control over who was going to come into my home, and what they were going to do . . ." (Florida elder). In addition, preliminary findings indicate that 73% (n = 194) of Arkansas CCDE participants were elderly (which mirrors Arkansas' eligible personal care population since about three-fourths of the participants are elderly) (Brown & Foster, 2000). This experience is consistent with an evaluation of the California In-Home Supportive Services, a CD program, in which more than half of the participants were elderly (Benjamin & Matthias, 2001; Doty et al., 1999).

TABLE 1. Implementation Issues for Consumer-Directed PAS Programs: Comparing Stakeholders' Views and Experiences. Background Research to Support the Cash and Counseling Demonstration and Evaluation

Summary of Findings

Key Issues	Policy Expert Views	Consumer/Representative Survey Results	Consumer/Representative Focus Group Results	Experiences in CD Programs
Concerns about consumers' ability to manage CD services and the need for flexible programs to meet diverse consumers' preferences.	• Concerned about excluding individuals who could not manage CD tasks. • Predicted that older consumers may not want CD services. • Expressed need for flexible programs to include diverse consumers.	• One-third to one-half of elders were interested in CD approach. • African American and Hispanic consumers were more interested in C&C than were Caucasians.	• Many older participants expressed interest and felt they would have no problem handling tasks. • African American and Hispanic participants felt their cultures have strong family networks and emphasize caring for family members.	C&C Experience: • Created role of a representative for consumers needing help with employer tasks. • Preliminary findings show that 73% of AR C&C Demonstration consumers are elderly. • Consumers who knew someone to hire as a worker have done best in the cash option. Finding a worker may be easier in a community with strong family networks. CA IHSS Experience (Doty et al., 1999): • Over half of consumers in the evaluation were elders (over 65).
Concerns about family decisions truly representing consumers accurately.	• Concerned that family decision-making may not represent consumer accurately.	• A family member or friend completed the survey for 17% of consumers. • Representatives were able to differentiate between their views and views of consumers.	• One focus group respondent stated that she would "change her mother's mind" in order to convince her mother to agree with her daughter's choices.	• The nine-month CCDE report shows that about half of AR participants are represented by family or friends. • This issue needs to be studied further.

TABLE 1 (continued)

Key Issues	Policy Expert Views	Consumer/Representative Survey Results	Consumer/Representative Focus Group Results	Experiences in CD Programs
Concerns about fraud and abuse.	• Concerned that consumers unable to manage tasks could be vulnerable to fraud, abuse, and neglect. • Providers fear liability based on bad decisions made by consumers. • Concerned that even rare cases of fraud/abuse could cause bad publicity.	• Respondents were aware of cash option challenges and most (3/4) stated they would want training and/or assistance with employer tasks.	• Some felt they could handle employer tasks, others were interested in training or assistance.	• Early implementation experience in AR shows that fears of fraud and abuse were unwarranted. • CA IHSS (Doty et al., 1999) evaluation generally supports this experience.
Concerns about level and type of training needed.	• While some believed that training is important, some were concerned that too much training could make a CD program seem overly complicated.	• Most consumers/representatives (80%) said they would like a fiscal intermediary (FI) to help handle bookkeeping tasks.	• Participants were willing to be trained or assisted with tasks. • Some saw contact with peers as a means to problem solving.	• Almost all AR consumers have used an FI to handle bookkeeping tasks.
Concerns about worker shortages.	• Concerns about availability of trained service providers, quality of care, and obtaining backup services.	• Consumers and representatives also acknowledge need for help in finding workers and backup workers. • Respondents wanted to pay their workers more than agency wages.	• Respondents wanted to pay their workers more than agency wages.	• In AR, 78% of cash option paid workers are relatives. In the CA IHHS evaluation, almost half of the paid workers in the CD model were relatives and about a quarter were friends/neighbors.

On the other hand, focus group discussions provided an explanation of why some older consumers were not interested in the cash option. For example, older consumers may not have been as interested initially as younger consumers since older consumers reported being more satisfied with current PAS than younger consumers. Many believe PAS enables them to remain in their homes. "I couldn't live in my apartment if I didn't have a homemaker," stated one Florida elder. A New York representative demonstrated the centrality of this desire for elders to be able to remain in their homes by saying, "The best thing about it (the cash option) is being able to keep your loved ones . . . in their own surroundings."

The focus groups revealed a possible explanation for the higher rate of younger consumer interest in the cash option. Younger consumers sometimes see PAS operating for agency convenience, not consumer needs. As one Florida consumer under age 65 stated, "Most nursing agencies want you to be home every day. Homebound you can't go to school. . . . So if you're trying to advance yourself . . . the system is really working against you. . . ."

Differences in Interest Level by Ethnic/Racial Groups. Following up on experts' statements about the need for flexibility in PAS to include all interested consumers, survey data revealed ethnic and racial differences in consumers' levels of interest in CD programs. According to survey data, African American and Hispanic consumers were more interested in the cash option than were Caucasians. Multivariate analyses demonstrated that consumers' race/ethnicity predicted their interest in the cash option in Arkansas, New Jersey, and New York. Focus group participants offered preliminary explanations of why African American and Hispanic consumers were more interested in the cash option than were Caucasians. African American and Hispanic participants felt their cultures tend to have stronger family networks and emphasize caring for family members. ". . . They are more caring. They got that family value . . . when it comes to sticking together, mostly they are really tight" (New Jersey African American representative).

Some believed that the cash option could bring much-needed jobs (as PAS workers) to African American and Hispanic communities. "It would be an income for someone else . . . some want to work and really need to work and can't get a job simply because they are African American and not a graduate or college student . . . " added an African American representative in Arkansas. Experience in Arkansas indicates slightly higher participation among African Americans than expected from the racial composition of the eligible personal care client population.

Concerns About Family Decisions Truly Representing Consumers

Experts pointed out that family members' participation in managing CD services could raise questions about the extent to which the consumer is actually directing the care. This issue was seen as a barrier to implementing CD services (7). "The preference and plans made . . . by any family member on behalf of the person with the disability might not be what they want." "A barrier is . . . disagreements . . . within families." Background research results and early CCDE implementation reports show that a significant proportion of consumers had representatives who completed their surveys (17%, n = 2140 in background research, and 50%, n = 194 in early CCDE implementation findings), demonstrating that this could be an important concern. Survey results indicate that representatives often expressed different views when speaking for consumers vs. when speaking for themselves, indicating that they were able to differentiate between their own views and the views of consumers. To the contrary, one focus group respondent stated that she would "change her mother's mind" in order to convince her mother to agree with her caregiving daughter.

Concerns About Fraud and Abuse

Policy experts were also concerned that consumers would not be able to handle CD tasks and therefore could be vulnerable to fraud and abuse. Experts reported that providers fear they may be liable for bad decisions made by consumers directing their own care (4). ". . . Agencies didn't want to provide services to people . . . because they were afraid that if the worker didn't show up that the person would be at risk. Then, the agency would be at risk." In addition, the New Jersey CCDE manager reported this issue as a major concern expressed when training consultants to assist consumers.

Experts also discussed payers' fears about client safety. They fear that people will be taken advantage of or be neglected. Experts predicted that payers and policymakers might resist implementing CD programs due to these fears about client and provider safety (11). "Even if fraud and abuse are very rare, one single case can cause so much damage. . . . " They added, "States need to think through . . . how to ensure quality . . . [policymakers] also don't want to be [in the headlines] with a scandal." The New Jersey CCDE manager's experience presenting this new program option throughout the state also illustrates the extent of

this concern. His often-repeated experience was, "I say cash, they say fraud."

Experts reported that payers and policymakers also have concerns about accountability for cash payments and legal liabilities associated with CD programs (21). Among these concerns, "Payers will be concerned with . . . how the money is spent." One expert added, "[Payers] want to reduce administrative involvement but . . . they don't want to let go of the strings."

Experts were also concerned about whether consumers would pay their workers' taxes. They believed that consumers are limited in their knowledge of how to be an employer (19). "You have to take on this consumer role . . . in a time of great stress and impaired capacity." Thus, "Consumers [need] training [in] how to manage services [and] deal with the tax and liability issues."

Experts also warned that consumers should be aware of their vulnerability and need to be willing to assume the risks associated with managing their own care (6). "When you assume personal responsibility you also have to assume risk and that gets into who is liable for problems that may occur."

Survey data show that both consumers and representatives interested in the cash option system seem to be aware of the challenges and potential difficulty in those tasks. In all four states surveyed, more than three-fourths of consumers and representatives interested in the cash option stated that they would want training or help with payroll taxes, deciding how much to pay a worker, and doing a background check on the worker. Consumers' and representatives' strong desire for help or training demonstrates their willingness to handle consumer tasks appropriately.

First-year implementation data from Arkansas demonstrate that these fears of fraud and abuse are exaggerated. The majority of consumers have representatives and use fiscal intermediaries. There have been no reported cases of fraud and abuse. There was one instance of consumer self-neglect and that was addressed by requiring a representative for the consumer. Consumers report satisfaction with their services–93% stated they would recommend the program to others, and 82% reported that the cash option has improved their lives. None considered themselves to be worse off. The Arkansas experience is consistent with findings from an evaluation of the California In-Home Supportive Services program (IHSS), which reported that consumers in a CD program had higher ratings of client satisfaction, empowerment, and quality of life than con-

sumers receiving traditional services (Doty, Benjamin, Mathias, & Franke, 1999).

Concerns About Level and Type of Training Needed

Stakeholders suggested that consumer training could address concerns about fraud and abuse, including liability for payroll taxes and misuse of the cash benefit. Most (80%) survey respondents said they would like to use a fiscal intermediary to help in handling payroll taxes, and would like training and support to help decide on pay, conduct background checks on workers, and interview workers.

Focus group findings added further support to survey results about consumers' and representatives' willingness to seek assistance with CD tasks. Participants had some concerns about finding and interviewing workers. Handling payroll tasks elicited the greatest concern and widest range of reactions. Participants with financial experience thought they could do payroll tasks with no training. One Florida participant stated, "I never worked outside the home, but I handled the money . . . I'm very interested in it (the cash option)." Those who were unsure about their abilities to handle payroll tasks willingly expressed their desire for training and support.

Experts speculated that too much training could be a barrier to implementing CD. In addition to the cost of training, one expert stated, "We could kill [this movement] by making it feel complicated, by suggesting that you have to have some sort of an advanced course in personal management. That you need to know so many things."

Concerns About Worker Shortages

Experts reported that in a CD program, consumers and providers often have concerns about the availability of trained service providers and obtaining emergency backup services. Experts predicted that this would also be a concern in the independent provider setting (2). ". . . We are wrestling with a shortage of backups and the nonexistence of a pool of capable personal assistants."

Another potential barrier to the availability of competent personal assistants is that independent providers have unique implementation issues such as being responsible for their own working conditions, adequate wages, benefits, and job security (8). "It's interesting about all the workers' issues coming up around CD . . . I think a lot of [agencies] use

on-call labor pools who are poorly paid and get no benefits and are construed as working for themselves."

Experts pointed out that independent providers might find it difficult to coordinate the employment and tax regulations of the multiple programs in which an individual might participate (4). "Trying to coordinate [program rules] with a multi-problem individual who might cross over many programs . . . the providers might feel that they are at risk if they do things around CD rather than the regulation that the payer defined."

Surveys revealed that most consumers and representatives also acknowledge a need for help in finding workers and emergency backup workers. In fact, worker shortages have created difficulties in all three Demonstration states. Both surveys and focus groups showed that respondents wanted to pay their workers more. Consumers interested in the cash option were significantly more likely than those uninterested in the cash option to consider being able to pay their worker more money an important program feature.

DISCUSSION AND RECOMMENDATIONS

This section reviews new ideas about implementing CD services learned from the various perspectives reported in this study and makes recommendations about implementing CD programs.

Views from Multiple Stakeholders

The process of considering differing views from a variety of stakeholders resulted in a creative solution addressing concerns about consumers' abilities to manage CD services. Policy experts raised issues about identifying those consumers capable of managing CD services and focused on screening out consumers not able to be self-directing. CCDE program designers, in efforts to develop a solution to these potential problems, also acknowledged these issues. Their concerns were threefold: they did not want to exclude consumers who wanted to try a CD program; they were under pressure to meet enrollment requirements for the Demonstration; and they were worried about burdensome appeals/lawsuits from consumers who were told they could not participate. Hence, they chose an approach that would include all consumers, regardless of their abilities to be completely self-directing–the use of representatives. While this concept has been accepted in the develop-

mental disabilities community for many years, it is new to CD programs and the aging community.

Investigate Messages to Change Attitudes of Some Stakeholders

Despite findings that many elders are interested in CD and are managing CD services, some stakeholders maintain their beliefs that elders are not interested in or capable of managing a CD program (Benjamin & Matthias, 2001; Brown & Foster, 2000; Mahoney et al., 2002). In designing their outreach and enrollment programs, the CCDE states have had to consider these beliefs about elders when determining who would be most effective in outreach and enrollment efforts. As previously mentioned, CD programs for elders are fairly new, and acceptance of this approach requires a paradigmatic shift from thinking about elders in a traditional, paternalistic manner (i.e., elders are frail and need to be taken care of) to being open to the possibility that some elders and their representatives may be interested in the choice and autonomy offered by a CD program. Clearly, it will be important to select outreach workers who are open to this concept for all consumers, including elders.

Stakeholders' concerns about fraud and abuse have been cited as another barrier to implementing CD programs. Information from the multiple data sources revealed many solutions or "antidotes" to consumer fraud and abuse. In response to policy experts' concerns, several CCDE features (i.e., training, representatives, and fiscal intermediaries) were designed to help deter fraud and abuse. Early implementation experience in Arkansas demonstrates that widespread fraud and abuse have not materialized. Survey and focus group data indicated that the majority of consumers and representatives were interested in and willing to participate in training to learn necessary employer skills and planned to utilize a fiscal intermediary service for payroll tasks. Representatives provide support for the most vulnerable consumers who are unable to manage all employer tasks independently; training empowers consumers and representatives with needed skills; and the fiscal intermediary limits the amount of cash in consumers' hands, while assuring that employer and employee taxes will be paid. In addition, all consumers, including those with representatives, are monitored by CCDE consultants.

CCDE as One Solution to a Shortage of Qualified PAS Workers

Policy experts, state CCDE staff, and consumers and representatives have all expressed concerns about the shortage of qualified PAS work-

ers in an economy with low unemployment. This labor shortage is creating problems for agencies and consumers who try to hire independent workers. The perspectives from different stakeholders about this issue have led to several key social marketing messages that present the cash option as one approach to addressing the worker shortage.

First, survey and focus group data indicated that consumers and representatives are attracted to the idea that they can pay their workers more than they receive while employed by agencies. Consumers and representatives were acutely aware of the difficulty of finding and keeping good workers, and wanted to be able to pay competitive wages.

Second, consumers are likely to be attracted to the idea that they may receive services sooner in the cash option than in traditional services, especially if they are in a location that is difficult to serve. Agencies are not always able to serve their consumers immediately due to the worker shortage, especially those in rural areas who require much travel time for staff.

Home care agencies are important stakeholders in the CCDE, and state CCDE staff have worked to gain cooperation from these agencies. As predicted by policy experts and state CCDE staff, home care agencies initially viewed the cash option as a threat to their businesses. Yet, agencies were having difficulty serving clients due to labor shortages. Consequently, they have responded positively to marketing messages that encourage them to refer "hard to serve" consumers to the cash option. Consumers may be difficult to serve for a number of reasons (e.g., location, need for evening and weekend hours not usually offered by agencies), and these consumers may have their needs met in a more satisfactory manner by hiring workers independently.

Hiring consumers' relatives and friends as PAS workers is a way to expand the worker supply as this approach taps new worker sources who may not have entered the PAS labor force. Many of these new PAS workers will provide personal care for a family member out of devotion and caring, but would not have otherwise done so. Early findings about cash option participants in Arkansas indicated that the majority of consumers (78%) have hired relatives as paid workers; 15% hired a friend, neighbor, or church member; and few have hired strangers. There is also the possibility that paid relatives and friends will find this work satisfying and continue in the workforce when their relatives/friends no longer need their services. This approach to expanding the PAS worker labor force is potentially attractive to agencies, program administrators, and policymakers.

Ethnic/Racial Differences in Interest in Consumer-Directed Programs

The policy experts clearly stated the need to design programs flexible enough to meet the needs of diverse consumers. (They were not asked to comment on differing levels of interest in CD by racial/ethnic groups, and no experts raised this issue.) The telephone surveys revealed that African American and Hispanic consumers and representatives were more interested in the cash option than Caucasian consumers. In follow-up focus groups, African American and Hispanic consumers and representatives indicated that their cultures tend to have strong family networks that emphasize caring for one another. It is reasonable to conclude that consumers from closely-knit families and communities would have an easier time than consumers with fewer connections in achieving the first, critical step in a CD program–locating and hiring a worker. Thus, the strong networks of African American and Hispanic consumers may contribute to their increased interest in the cash option. Yet, the experience in Arkansas indicates only slightly higher participation among African American consumers than expected from the racial composition of the eligible personal care population, and less than expected based on preference study findings. We need to learn more about this issue.

Appropriate Levels of Consumer/Representative Training

Stakeholders were concerned about offering appropriate levels of training for consumers and representatives. Determining the "right" amount of training requires balancing the need to teach CD skills (i.e., performing employer tasks) with the need to keep the program manageable. As policy experts astutely indicated, making the program feel overcomplicated could kill it. Yet, the temptation to teach consumers and representatives as much as possible is great since consumer training is an important "antidote" to the major fraud and abuse concerns expressed by policymakers, program administrators, and others.

Recent focus groups with Florida case managers demonstrated some difficulties that occur when a program seems complicated. While they were complimentary about Florida's training materials, consultants thought the program was complicated and required a great deal of time to learn. As they felt burdened by their existing caseloads, they were overwhelmed at the prospect of learning a new program option that would add to their responsibilities. The case managers believed that

consumers, particularly frail elders, would be overwhelmed by the program. These training issues need further attention.

Conclusion and Research Recommendations

Investigating the views of key stakeholders has revealed significant implementation issues for conducting CD programs, in general, and specifically cash allowance programs, and at least three areas for further research. This study has emphasized the need for investigating the role of representatives in CD programs, ethnic/racial differences in consumers' interest in CD, and effective training for consumers, representatives, and consultants. First, we need to understand better the role of representatives and examine whether they are truly representing consumers. How do representatives learn their role? How is the effectiveness of this role assessed? These questions have implications for numerous aspects of program design and evaluation, including training programs for participants and quality assurance priorities. A program cannot be truly consumer-directed unless representatives are eliciting consumers' views.

Second, we are just beginning to learn about the role of race and ethnicity in preferences for CD programs. Finally, in regard to training, we need to learn more about behavior-change efforts in regard to helping some professionals achieve a paradigm shift from a focus on dependency in a traditional home care model to a focus on consumer empowerment in a CD model. We also need to learn more about effective training for consumers and consultants to teach necessary skills while avoiding an overly complicated program. We look forward to learning more about these important issues as the CCDE continues and in follow-up research.

NOTES

1. The three studies are described in detail in reports and publications from each project. Interested readers can refer to the citations in this section to identify individual reports/publications.
2. New York was a Demonstration state early in the CCDE.
3. This survey consisted of Florida elders (age 65 and older) and adults with physical disabilities (age 18-64 years). Adults and children with developmental disabilities were surveyed separately.
4. The number in parentheses indicates the number of statements related to each topic addressed by the experts. Not all experts commented on each topic; however,

some experts provided multiple, distinct comments related to a topic. Thus, the number of comments may exceed the number of experts interviewed (20).

AUTHOR NOTES

Lori Simon-Rusinowitz is Deputy Director of the Cash and Counseling Demonstration and Evaluation (CCDE) at the University of Maryland Center on Aging and a faculty member in the Department of Public and Community Health. Her research focus has been in the field of aging and disability policy issues for the past 15 years. As Director of Research for the CCDE, Dr. Simon-Rusinowitz has overseen a three-part study of consumers' preferences for consumer-directed personal care as well as other components of the Demonstration and Evaluation.

Dr. Simon-Rusinowitz can be contacted at National Program Office, University of Maryland Center on Aging, HHP Building, College Park, MD 20742 (E-mail: ls119@umail.umd.edu).

Lori N. Marks is an adjunct faculty member for the University of Maryland, Department of Family Studies, and serves as a research consultant for the Cash and Counseling Demonstration and Evaluation.

Dr. Marks can be contacted at 9905 DePaul, Bethesda, MD 20817.

Dawn M. Loughlin has been involved in research design and program development in the fields of health and health policy since 1987–as a developmental psychologist, counseling program developer, and statistical analyst. She is currently a faculty research assistant with the University of Maryland, Center on Aging.

Dr. Loughlin can be contacted at National Program Office, University of Maryland Center on Aging, HHP Building, College Park, MD 20742.

Sharon M. Desmond is Associate Professor in the Department of Public and Community Health at the University of Maryland. She has participated in the Cash and Counseling Demonstration and Evaluation preference study survey team since 1997.

Dr. Desmond can be contacted at the Department of Public and Community Health, University of Maryland, College Park, MD 20742.

Kevin J. Mahoney is a faculty member at the Boston College Graduate School of Social Work where he serves as Associate Professor as well as National Program Director for the Cash and Counseling Demonstration and Evaluation, a policy-driven evaluation of one of the most unfettered forms of consumer direction of personal assistance services. During his 28-year career in gerontology and long-term care, Dr. Mahoney has served in a number of policymaking and administrative positions in the state governments of Connecticut and California. Prior to coming to Boston College in 1999, he held academic appointments at Yale University, the University of Connecticut, the University of California-San Francisco and the University of Maryland.

Dr. Mahoney can be contacted at Boston College School of Social Work, McGuinn Hall 132, Chestnut Hill, MA 02467.

B. Lee Zacharias is President of the Zacharias Group. She has moderated and written reports for most of the focus groups conducted for the Cash and Counseling Demonstration and Evaluation.

Ms. Zacharias can be contacted at 441 N. Pownal Rd., New Gloucester, ME 04260.

Marie R. Squillace is Senior Researcher for the National Council on the Aging. Her research has focused primarily on health and long-term care issues with specific interest in long-term care financing and organization. Most recently, Dr. Squillace is in-

volved in efforts to transfer models of consumer-direction from the disability arena into the aging service system and in exploratory research to understand and gauge interest in approaches to consumer-direction in managed care.

Dr. Squillace can be contacted at Mariners Cove, 308 I Forbes St., Annapolis, MD 21401.

Ann Marie Allison obtained her master's degree from the University of Maryland in Career Counseling, Education, and Personnal Services. She worked with the Cash and Counseling Demonstration and Evaluation as a graduate assistant when she was a master's degree student. Since graduating, Ms. Allison has been working in various areas of organizational development as a manager in Human Resources at Arthur Andersen.

Ms. Allison can be contacted at 4845 Chevy Chase Drive, Chevy Chase, MD 20815.

REFERENCES

Ansello, E., & Eustis, N. (1992). A common stake? Investigating the emerging intersection of aging and disabilities. *Generations*, *16*, 5-8.

Benjamin, A. E., & Matthias, R. E. (2001). Age, consumer direction, and outcomes of supportive services at home. *The Gerontologist*, *41*(5), 632-642.

Brown, R., & Foster, L. (2000). Cash and counseling: Early experiences in Arkansas. Mathematica Policy Research, Inc., Issue Brief, Dec., No. 1. Princeton, NJ.

Davis, S., Schneider, B., Kunkel, S., & Applebaum, R. (2001). Quality monitoring in consumer directed care programs. Draft. Scripps Gerontology Center, Miami University, Oxford, OH.

Degenholtz, H., Kane, R. A., & Kivnick, H. Q. (1997). Care-related preferences and values of elderly community-based LTC consumers: Can case managers learn what's important to clients? *The Gerontologist*, *37*(6), 767-776.

DeJong, G., Batavia A., McKnew, L. (1992). The independent living model of personal assistance in national long-term care policy. *Generations*, *16*, 89-95.

Desmond, S. M., Mahoney, K. J., Simon-Rusinowitz, L., Shoop, D. M., Squillace, M. R., & Fay, R. A. (2001). Consumer preferences for a consumer directed cash option versus traditional services. Telephone survey findings of Florida elders and adults with physical disabilities. *Elder's Advisor*, *3*(1), 1-22.

Doty, P., Benjamin, A. E., Matthias, R. E., & Franke, T. M. (1999). In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery. USDHHS Office of the Assistant Secretary for Planning and Evaluation, Contract #100-94-0022.

Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. *Milbank Memorial Fund*, *74*(3), 377-409.

Geron, S. M. (2000). The quality of consumer-directed long-term care. *Generations*, *24*(3), 66-73.

Green, L. W., & Kreuter, M. W. (1999). *Health Promotion Planning: An Educational and Ecological Approach*. Third Edition. Mountain View, CA: Mayfield Publishing Company.

Kapp, M. (1996). Enhancing autonomy and choice in selecting and directing long-term care services. *The Elder Law Journal*, *4*(1), 55-97.

Mahoney, C., Estes, C., & Heumann, J. (Eds.) (1986). *Toward a Unified Agenda: Proceedings of a National Conference on Disability and Aging*. San Francisco: University of California and World Institute on Disability.

Mahoney, K. J., Desmond, S. M., Simon-Rusinowitz, L., Shoop, D. M., Squillace, M. R., & Fay, R. A. (2001). Consumer preferences for a consumer directed cash option versus traditional services. Telephone survey findings of New Jersey elders and adults with disabilities. In press, *Journal of Disability Policy Studies*.

Mahoney, K. J., Simon-Rusinowitz, L., Desmond, S. M., Shoop, D. M., Squillace, M. R., & Fay, R. A. (1998). Determining consumers' preferences for a cash option: New York telephone survey results. *American Rehabilitation*. *24*(4) 24-36.

Mahoney, K. J., Simon-Rusinowitz, L., Loughlin, D. M., Desmond, S. M., & Squillace, M. R. (2002). Determining personal care consumers' preferences for a consumer-directed "Cash and Carry" option: Survey results from Arkansas, Florida, New Jersey, and New York elders and adults with physical disabilities. Submitted for publication to the *Journal of the American Public Health Association*.

Simon-Rusinowitz, L., Bochniak, A. M., Mahoney, K. J., & Hecht, D. (2000). Implementation issues for consumer-directed programs: Views from policy experts. In Kapp, M. B. (Ed.), *Ethics, Law, and Aging Review*, *Volume 6*. New York: Springer Publishing. 107-129.

Simon-Rusinowitz, L., & Hofland, B. (1993). Adopting a disability approach to home care services for older adults. *The Gerontologist*, *33*(2), 159-167.

Simon-Rusinowitz, L., Mahoney, K., Desmond, A., Shoop, D., Squillace, M., & Fay, R. (1997). Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review 19*(2), 73-96.

Simon-Rusinowitz, L., Mahoney, K. M., Zacharias, B. L., & Marks, L. N. (In Progress). Consumer and representative focus groups inform program design and communication efforts. For submission to *The Gerontologist*.

Stone, R. I. (2000). Consumer direction in long-term care. *Generations*, *24*(3), 5-9.