Is Consumer Direction Appropriate for Everyone Who Wants It? Experience from the Cash & Counseling Demonstration and Evaluation.

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Introduction

Today, whether you are an older or a younger person with disabilities, if you need assistance to perform major activities of daily living (ADLs) like bathing, dressing, using the toilet, transferring or eating, you may not have the opportunity to direct your own care, to decide who helps you, when they come, or what they actually do. However, for many years, persons from the disability community have suggested that with more control over these types of services, their quality of life would improve.

The Cash & Counseling Demonstration and Evaluation (CCDE) has been, at its heart, a policy-driven evaluation of this basic belief. The CCDE tested one of the most unfettered forms of consumer-directed services—offering Medicaid consumers of all ages in Arkansas, Florida and New Jersey a cash allowance (of comparable worth) in lieu of agency-delivered services. The evaluation compared cost, quality and satisfaction of consumers who received traditional personal care services with those who received the cash option.[1]

Using their cash benefit, participants in the CCDE were able to choose who provided very personal and essential services, as well as when and how they were provided. For example, consumers could hire a friend or relative, who knows their preferences, to help them on evenings or weekends. Consumers could also use their benefit to buy other services that would increase their independence (e.g. transportation, home modifications, and assistive devices). Counseling and bookkeeping were offered to help consumers manage their services.

The growing interest in this cash and counseling model is evidenced both by the three original CCDE states who have made the program permanent, and by the additional 28 states that responded with letters of intent when invited to submit proposals for participating in the second, expanded phase of the CCDE. However, some policymakers are concerned that consumer-direction is not appropriate for everyone. They fear that some consumers may not be able to handle the associated responsibilities, such as hiring a worker or handling payroll records. They have raised questions about the burden such tasks may place upon some consumers, such as consumers with severe mental or physical disabilities, or the frail elderly. This report addresses those concerns based on the experience of the three original CCDE states, drawing on pre-enrollment preference surveys, program evaluation surveys, consumer focus groups and in-depth participant interviews.

[1] The CCDE has been co-sponsored by the Robert Wood Johnson Foundation (RWJF) and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (DHHS/ASPE). It operates under section 1115 Research and Demonstration waivers granted by the Centers for Medicare and Medicaid Services (CMS). For a detailed description of the CCDE design, see Mahoney, Simone, and Simon-Rusinowitz, 2000. Data collection for the CCDE has been completed and all evaluation reports are available at www.cashandcounseling.org.

The CCDE Data Sources

Prior to CCDE implementation, the University of Maryland Center on Aging conducted a three-part study to determine consumers' preferences for a cash option. Researchers initially conducted pre-survey focus groups, followed by a telephone survey of a random selection of over two thousand consumers or their proxy respondents. The survey sought to determine consumers' levels of interest in the program and reasons for their interest or disinterest. Finally, post-survey focus groups sought to expand understanding of key survey findings. These preference study findings informed the Demonstration states' program design and social marketing efforts (Mahoney, et al. 2004; Simon-Rusinowitz, et al 2005).

The CCDE program implementation phase was a randomized trial in which approximately 3,300 participants received the cash benefit and an equal number received traditional services. This evaluation-driven Demonstration included quantitative evaluation surveys of consumers, workers, and others conducted by Mathematica Policy Research, Inc. In addition researchers at the University of Maryland Baltimore County conducted in-depth interviews with a subset of cash option "care units" (i.e. consumers, workers, and consultants). This issue brief includes findings from all of these quantitative and qualitative data sources.

The Cash & Counseling Participants

During the CCDE, in-home interviews were conducted with Cash & Counseling cash option "care units" (i.e. a consumer and/or representative of a consumer receiving the cash option, a paid worker, and a cash option consultant) in each of the three demonstration states. Although there is no "typical" Cash & Counseling participant, Mr. Nelson and Mrs. Rose (as described below by the interviewers, represent the types of people that the program served. (Note: All consumer names have been disguised to protect anonymity.)

- Mr. Donald Nelson is a 44 year-old married, African American man. He lives with his wife Florence who serves as his representative. He has a non-family caregiver, Christine Clark, who works 21 hours, spread over 5 days a week. After Ms. Clark leaves, one of the Nelson's two daughters comes to watch Mr. Nelson until Mrs. Nelson returns from work to assume his care. The Nelsons live on the second floor of a three story apartment building in a residential area in urban New Jersey. Although the neighborhood is a bit run-down, the Nelson's apartment is clean and nicely decorated. Mr. Nelson lost his ability to speak after suffering a stroke in 1999. His right side is paralyzed and he wears a brace to help him walk. He needs assistance with both IADLs and ADLs and spends much of his time in bed. The Nelsons were interviewed while sitting at a small kitchen table. During the interview Mrs. Nelson was taking care of her young grandson, who was polite and well-behaved. Mr. Nelson followed the conversation by responding with simple nods, but had to be prompted to stay engaged by Mrs. Nelson who tries to keep her

husband as involved as possible (San Antonio, Eckert, Niles, & Siegel, 2003).

- Mrs. Pearl Rose is an eighty-seven year old white woman who lives alone in a single-family home in an urban area in Arkansas. She was wearing a nightgown and a robe and covered with a blanket during the interview. Mrs. Rose was interviewed with her daughter Ruth, and several other daughters in the house. Her youngest daughter, Ellen, who lives next door, is her paid personal care worker. Mrs. Rose is very friendly, with a good sense of humor. She had difficulty answering some of the questions because of diminished hearing and memory so her daughter helped repeat the questions and discussed the questions with her. Mother and daughter traded quips and teased each other during the interview. Mrs. Rose has several serious medical problems. She is fed through a feeding tube because she aspirates food into her lungs. She is also prone to pneumonia and has a blocked artery in her heart which is inoperable because of her age. Several of her daughters live nearby and provide 24 hour a day care. Mrs. Rose is never left alone, even at night. She has a loving extended family that see that she is cared for although Mrs. Rose tries to maintain her independence as much as possible. Her daughter explains how her family works together: "There are four girls and three husbands and it takes all of us and a cousin. That way we take care of it, and we know she's taken care of (Eckert, San Antonio, & Siegel, 2001)."

Consumer Interest in a Cash Option: Preference Study Findings

The CCDE is based on the premise that the cash option is a choice, in which a consumer like Mr. Nelson or Mrs. Rose will be able to select either the cash option or traditional agency services. On a system level, a consumer-directed option is not intended to replace traditional services, as this approach is unlikely to be desirable to all consumers. In fact, while there was substantial consumer interest (ranging from 31% to 58%) across four states that were surveyed prior to the demonstration, between 21% and 44% of respondents felt at that time that they were definitely not interested in the cash option and between 20% and 25% were unsure (Mahoney, et al. 2004).

Interest among Older Consumers

In light of policymakers' concerns about the appropriateness of the cash option for elderly consumers, one of the CCDE preference survey's major research questions inquired specifically about age as a factor influencing consumers' interest in the cash option. Although interest in the cash option did tend to decline with age, a high percentage (30%-50%) of consumers aged 60 and older (like Mrs. Rose) were interested. In addition, many consumers aged 60 and older desired more involvement than they currently have in determining the type and amount of their services (25%-32%). Consumers' willingness to complete individual tasks associated with a cash option (such

as hiring a worker, or supervising a worker) ranged from 36% to 87% depending upon the task and age group (Mahoney, et al. 2004).

Consistent with the preference survey findings, young and older consumers participating in pre-demonstration focus groups indicated various levels of interest in the cash option. Among consumers of all ages, some liked and some disliked the idea of a consumer-directed cash option (Simon-Rusinowitz, et al 2005).

"…you're in charge. You're the one that dictates what these people are going to do for your care". (Florida Elder)

"I think it would be best for us to keep our program like it is. They might not give you enough money to pay for this stuff. Then …you haven't got anything". (Florida Elder)

"Already we're dealing with our medication, we're dealing with our doctors, we're dealing with our families… this is just the worst. (New York Consumer < 65)

"This is a great program. …it puts me in a position of not being beholden and not being under someone else's thumb". (New York Consumer < 65)

Interest among Consumers with Varying Levels of Disability

The pre-demonstration preference study also found that those consumers with more severe disability (those who needed assistance with more activities of daily living) were more likely to be interested in the option when compared to those with mild or moderate disabilities (Mahoney, et al. 2004). When asked to explain why consumers with more severe disabilities showed more interest in the cash option, post-survey focus group participants offered poignant insights, suggesting that consumers with severe disabilities might be especially excited about the cash option's flexibility and control (Simon-Rusinowitz, et al 2005).

"The more disabled you are, the less disabled you want to be. If you can manage your own care to any degree of normalcy, it helps you to be like the rest of the world." (Florida Consumer)

"…you have a say so in your life again. You have no control over your life…It gives you a sense of independence that you are somebody, you're not just a number in a file cabinet somewhere." (Florida Consumer)

Interest Among Consumers with Varying Backgrounds and Experience

The preference study showed that regardless of age or level of disability, consumers who already had a caregiver, or especially a live-in caregiver, were more likely to be interested in a cash option. Hispanic and African-American respondents also showed greater levels of interest (Mahoney, et al. 2004). It is reasonable to assume that consumers who already have an informal worker, and 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.

Consumers of all ages and types and levels of disability vary as well in their life experiences. Those who had hired or supervised workers, or had familiarity with

bookkeeping tasks, also showed greater interest, perhaps feeling better equipped to perform the tasks associated with the cash option. However, the training and instruction provided by cash option consultants (see below) may also encourage or empower consumers who lack such experience.

Finally, pre-demonstration preference survey data also indicated that a majority of consumers interested in the cash option wanted help or training with payroll and taxes. This finding was important in the process of approving the CMS (then HCFA) waiver for the CCDE, as it reassured HCFA officials and others that consumers would either use a bookkeeping service to pay workers and taxes (thereby decreasing the amount of cash they have on hand), or participate in skills training to learn payment tasks.

Consumer Experience with the Cash Option: The Demonstration

Description of Participants

Based on the pre-demonstration preference survey and focus group findings, as well as their experience with consumers, program staff in the three demonstration states did not screen applicants for appropriateness for the CCDE.[2] In keeping with the inclusive philosophy of consumer direction, they employed a self-selection process that relied on consumers' evaluations of the appropriateness of the program for their own needs. Approximately 10%-15% of eligible consumers volunteered for the program.

Like Mr. Nelson and Mrs. Rose, participants across the three states were diverse in many ways and represented a variety of backgrounds, as well as types of disabilities. Of Arkansas participants, 84% did not graduate from high school and 40% were rural residents. In New Jersey, 29% of non-elderly adult and 41% of elderly adult demonstration participants were of Hispanic origin. Florida was unique because, due to the nature of the program that was cashed out, ninety percent of non-elderly adult participants were consumers with developmental, as opposed to physical disabilities. The Florida program also included children with developmental disabilities and their representatives.

CCDE Evaluation Results

What the diverse CCDE participants did have in common, however, was a high degree of satisfaction with the cash option program. In their statistical analysis of CCDE nine-month survey data, evaluators provided separate sub-analyses for adult and elderly populations in Arkansas, Florida and New Jersey, and concluded with regard to all of the adult participants, that "Among the non-elderly in all three states, the treatment group had significantly fewer problems, and were significantly more satisfied, with their paid caregivers, than did the control group." Similar results were reported for elderly consumers in the three states. Assessing all of the measures of satisfaction with the quality of care received, the evaluators further concluded that, "Cash and Counseling was successful in all three demonstration states, and for both elderly and non-elderly adult participants, on many dimensions – most importantly in the goal of improving the participants' perceived quality of life." (Carlson et al., 2004)

[2] Program planners also rejected a screening process due to concerns about discrimination claims.

In more personal terms, Mrs. Nelson described her satisfaction with Mr. Nelson's directly hired (non-family) worker and with the program: "It helps me because I have a steady worker. We got to select the one that we wanted, and I don't have one on one day and the next couple of days we would have somebody else, and you know, setting the hours yourself for what you need, so it helps him a lot… Yes. I think that this works very consistent. At the other point, it was like a week that I didn't have a home health care person, you know, it's hard when you have to go to work and try to find somebody at the last minute to come in, or they will send somebody else. [Now] he has a reliable person. It is someone that he likes, you know. I am comfortable with the fact of leaving him, you know, under her care, and she is a trustworthy person."

Mrs. Rose's daughter describes her satisfaction her own and her sisters' participation in their mother's care: "Us four girls accept each other for who we are and what we are and we get along great....We are very close when it comes to Momma. We try to keep her comfortable and happy." Ellen feels that, "I would rather her be here, be close, and us know that she's taken care of, than to worry about someone that might not be taking care of her."

Based on surveys of the informal caregivers (primarily mothers) of children with disabilities in Florida, Foster, et al (2004) found that adults whose children were cash option participants were "more likely to be very satisfied with their child's care and with the way they were spending their own lives". Referencing earlier results from the Arkansas cash option demonstration, they concluded that "Interested consumers, be they adults, or children and their parents, and their primary informal caregivers, fared better under consumer- directed programs than they did under programs with a more traditional approach to providing Medicaid personal care services or other home and community based benefits".

Some Consumers Returned to Traditional Services or Had Difficulty

While the cash option worked well for the majority of participants, approximately a quarter of participants in each state disenrolled from the program, in the majority of cases prior to actually receiving the cash allowance (Foster, et al., 2005). In Arkansas, for example, among those who gave reasons for voluntary disenrollment, the most frequent reason was that the allowance was not enough. Other common reasons were that the consumer had changed his/her mind, had difficulty understanding the program, was satisfied with traditional services or had problems with employer responsibilities. Some consumers felt that the program had too many rules (Schore & Phillips, 2002).

The in-depth interviews with care units offer insight into those consumers who encountered some problems. In general, consumers who had a relative or friend available to hire as a worker were most successful in the cash option. For example, in Arkansas,, Mrs. Wright had difficulty finding an appropriate worker as she would only hire a worker who agreed to wear a dress or skirt on the job. For religious reasons, she believed it was inappropriate for women to wear pants. Mrs. Wright used her cash benefit to make critical home modifications and purchase other items until she found a personal care worker who met her specifications. In Florida, Mr. Beall hired his daughter and granddaughter as his personal care workers, and then expected that a portion of their

wages be used to buy his groceries. Although the consultant explained that his workers were not obligated to use their wages for his purchases, he insisted otherwise. The consultant planned to ask Mr. Beall to return to the traditional program if he continued to make this demand (San Antonio & Niles, 2005). In New Jersey, Mr. Maimoni had a difficult personality and was not able to keep workers although, a quadriplegic in need of daily care, he was in trouble if his workers quit. He was still more satisfied with his services in the cash option program than those offered by the traditional agency, as he was able to use his cash benefit to modify his van, giving him the ability to come and go as he pleased. This freedom to leave his small, dark apartment was of utmost importance to him.

Why the Cash Option was Successful for Most Consumers

Consumer Supports

Despite problems for some, the cash option worked well for a wide variety of consumers. A range of supports contributed to this success. Consumers who felt unable or unwilling to manage the cash option tasks could appoint a representative. Representatives act in the interest of the consumer as advocates, decision makers, and managers of the care plan and the cash benefit. The range of tasks performed by representatives include communicating with the program office, handling consumer finances and program paperwork, coordinating services, making medical decisions, hiring and managing caregivers, purchasing assistive devices or personal care items for the consumer, and monitoring the quality of care. [3] Representatives were formally appointed or acted in an informal arrangement, and some consumers had family members who acted as representatives, but were not formally designated as such. Informal representatives provided the same help to consumers as did formal representatives, but worked with consumers who were able to participate and make choices about their care.

For example, Mrs. Rose's daughter scheduled the caregiving of one paid agency worker, a directly-hired family caregiver, a visiting nurse, and six unpaid family caregivers in order to provide constant care for her mother.

Mr. Nelson's speech impediment did not allow him to talk about what his wife does as his representative. As Mrs. Nelson says, "He does better with yes and no questions." Mrs. Nelson thinks that it is important for her husband to have her as his representative. She explains: "I guess because I think that he can't answer the questions and I have to try to explain to him what the program is about, the difference between this and the home health care service that he had before. He pretty much understands. I mean you have to keep saying it over and over again, you know, but…. he wants to make sure that he understands. He may not understand what you are saying, you know, and this way even if he doesn't understand, later on he will ask me, okay, what did she say?"

Program consultants also worked with consumers to develop or change cash plans, monitor progress, and answer questions about the program. Consultants provided advice,

[3] Adult consumers could choose anyone to act as a representative with the exception of a paid caregiver. This restriction avoided a conflict of interest as the representative often handled supervisory or payroll tasks. This restriction did not apply to Florida children as parents could assist their child in both roles (although this policy has recently changed).

program information and explanation, and monitored quality of care. Consumers and representatives discussed spending plans with their consultants who also provided informal training in budgeting, planning, and recruiting and hiring caregivers. Consumers called their consultants with questions about timesheets or other paperwork. Some consumers needed more contact with consultants, while others required only minimal attention from consultants and had no difficulty independently managing their caregivers or the cash plan.

Mrs. Nelson is satisfied with the consultant relationship and reported: "She is very nice. She came over and did all the paperwork. She was a lot of help. She even calls periodically to see how things are going, you know, to make sure that the worker is getting paid and that everything is being done for him that needs to be done… She gave me her number. She stopped by I think once this March. If I have a problem, I will call her or I will call them."

Mrs. Rose, due to her extensive family support, needed less consultant support than some consumers. According to Mrs. Rose's program consultant: "...her daughter is right behind her, and then one of her other daughters, I believe, lives across the street or something from her. They provide a lot of care for her and a lot of family members around... And then as far as requests and things like that, I have not had a lot of requests for personal items and different things like that; mostly it is just calling them to make sure that everything is going well and usually they say yes, everything is going fine. They may call me to say, well my mom didn't feel well today and we may have to take her to the doctor or something like that, but ... the difference is the amount of family members around this participant."

As another support feature, fiscal agencies were available to handle bookkeeping and payroll tasks, and almost all consumers chose to use these services. The fiscal agencies relieved consumers of the task that many of the preference study participants had found to be the most daunting – handling payroll responsibilities. In sum, program consultants, formal and informal representatives and fiscal intermediary agencies make it possible for consumers with different needs to participate in a cash option program with a variety of different arrangements.

Consumer Creativity and Program Flexibility

Another reason for the success of the CCDE with diverse consumers is that CCDE consumers exhibited a great deal of creativity in their use of program funds. Most consumers combined both paid and unpaid care – combining public and private resources to achieve the maximum benefit from the program. Some consumers used funds set aside from their monthly budget to purchase a wide variety of equipment, goods and services that increased their independence. Often the pay received by the caregiver contributed to the overall household budget

As another of Mrs. Rose's daughters explained: "...it helps us more than you guys would ever know because little things are expensive and it really helps us in that category. Even though you all are paying us two hours to take care of her, it is not really ours. It takes care of little things. It goes to buy her personal stuff. It really helps a lot because it is expensive. She really doesn't get a whole lot per month, so it really helps us more than you will ever know."

The flexibility of the cash option allows it to work well for diverse populations, by allowing room for a series of consumer choices. CCDE consumers make the initial choice to participate in a cash option program. More importantly, on the most personal level, they make the program work for them by making further choices about the specific implementation of their care.

Mr. Nelson's paid worker described the hours she worked to the interviewers – a schedule that clearly reflected Mr. Nelson's needs: "Two in the morning and two in the afternoon. Except on Friday when he goes to therapy. He goes to the doctor on Friday. Then I work extra hours because he has transportation up and I wait and transportation back. That will be about four or five in the afternoon, instead of three or four, something like that."

Consumers work with their support team to choose the amount, the type and the timing of the care they receive. They choose how and when to supplement their paid human assistance with unpaid assistance, or with appropriately chosen equipment, goods or services. As their needs fluctuate or change due to increasing or decreasing disability, for example, or simply due to changes in circumstances, the program offers consumers the flexibility to reconsider these decisions and restructure the amount of support or type of assistance they require.

Conclusion

Is consumer direction appropriate for everyone who chooses it? Certainly in the realm of consumer services there are no absolutes. It would be naïve to assume that the program would always work perfectly for everyone. For example, a consumer could have difficulty finding a worker on his/her own, or determine that the program required too much involvement and opt out. For that reason, it is important that the option to return to traditional services be available.

It is also possible, for example, that a consumer could mis-use their benefit, or be taken advantage of by an unscrupulous worker, including a family member or friend. However, there were almost no instances of fraud or abuse noted during the CCDE. The ongoing involvement of a comprehensive system of supports, including the consultant, the fiscal agency, and the consumer's representative (when necessary), all served to increase the chances that a problem could be prevented, or be quickly recognized and addressed.

What does the future hold for consumers who want to choose a consumer-directed option? A cash option PAS program may not be appropriate for every consumer, and not every consumer will choose to participate. However, the high levels of satisfaction reported by the diverse participants in the CCDE have demonstrated that a cash option program has the potential to be appropriate and successful for any consumer who chooses it.

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