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Consumer Preferences for a Cash Option Versus Traditional Services:

Telephone Survey Results From New Jersey Elders and Adults

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The Cash and Counseling Demonstration and Evaluation (CCDE) is a policy-driven evaluation of the basic belief that most people, including the elderly, want a say in matters that affect their daily lives. The evaluation is comparing cost, quality, and satisfaction of consumers receiving traditional personal care services with those receiving a consumer-directed cash benefit and information services. This article presents results from a telephone survey conducted as background research to assess the preferences of elders and adults with disabilities for a cash option versus traditional services in New Jersey, one CCDE demonstration state. This preference study provides information about consumer perceptions and attitudes, need for help or training with service management tasks, and outreach messages to emphasize when promoting a consumer-directed cash option.

"Because the more I can do for myself . . . I am so much happier." (Consumer)

"If I had the option to have a family member or a friend come in, it would be a blessing. . . . there are family members who don't have a job and who know my needs and would be able to care for me." (Consumer)

"I would be able to hire somebody . . . and pay them. I like that." (Consumer Representative)

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 meals. However, 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. The Cash and Counseling Demonstration and Evaluation (CCDE; see Note 1) is at its heart a policy-driven evaluation of this basic belief. The CCDE is a test of one of the most unfettered forms of consumer-directed services—offering

Medicaid consumers a cash allowance in lieu of agency-delivered services. The evaluation is comparing cost, quality, and satisfaction of consumers receiving traditional personal care services with those receiving the cash option. (For a detailed description of the CCDE design, please refer to Mahoney, Simone, & Simon-Rusinowitz, 2000.)

This article reports on background research conducted to inform the three-state (Arkansas, Florida, and New Jersey; see Note 2) CCDE design and further our understanding about implementing consumer-directed services. Efforts to better understand the intricacies of implementing consumer-directed services, especially in the aging community, have only recently begun (Simon-Rusinowitz, Bochniak, Mahoney, & Hecht, 2000a, 2000b). Early in the CCDE development, program planners realized they were lacking key information essential to program implementation—data indicating consumers' preferences for a consumer-directed cash option versus traditional agency-delivered services. For that reason, the University of Maryland Center on Aging conducted telephone surveys and focus groups in each demonstration state to assess consumers' preferences. This article reports findings from the survey in New Jersey.

Background

The idea of consumer-directed services originated over two decades ago among younger persons with disabilities in the disability rights and independent living movements (DeJong, Batavia, & McKnew, 1992). The aging community began to adopt consumer-direction principles more recently when a coalition between the aging and younger disability communities emerged in the mid-1980s (Ansello & Eustis, 1992; Mahoney et al., 1986; Simon-Rusinowitz & Hofland, 1993). Interest in consumer choice expanded among some aging leaders in the early 1990s, due in part to a belief that consumer-directed care may lead to much-needed cost savings (Simon-Rusinowitz et al., 2000b). The emphasis on consumer choice and control in the language of the 1994 Health Security Act (Kapp, 1996) exemplifies this increased interest.

Typically, personal assistance services (PAS) are financed by public or private third-party payers in one of three ways: (a) cash benefits (payments to qualified clients or their representative payees), (b) vendor payments (a case manager determines the types/amounts of covered services and arranges for and pays authorized providers to deliver the services), and (c) vouchers (clients use funds for authorized purchases). In the United States, most existing public programs that finance personal care services follow the vendor payment model where the program purchases services for consumers from authorized vendors (i.e., service providers or equipment suppliers; see Note 3).

Cash allowance programs are currently small because they involve "state-only" funds. States cannot use Medicaid to fund cash allowances that permit clients to purchase their own services because of federal restrictions on direct payments to clients. Until recently, the prohibition on cash payments to Medicaid clients has rarely been questioned. However, many state program officials have come to share the concerns of disability rights advocates who want programs that promote consumer choice (such as a consumer-directed cash benefit program) rather than those that may foster dependency in the name of consumer protection and/or public accountability (Litvak, Zukas, & Heumann, 1987; Litvak & Kennedy, 1990, 1991; Velgouse & Dize, 2000). Additionally, state officials have a strong interest in achieving program economies. Most Medicaid personal care programs mandate that case managers (registered nurses and/or social workers) assess clients, develop and monitor care plans, and authorize provider payments. Case management can be expensive, and researchers and administrators question whether it should be uniformly required (Geron & Chassler, 1994; Jackson, 1994).

The cash and counseling model offers a cash allowance and information services to clients so they can purchase personal care services, assistive devices, or home modifications that best meet their individual needs. Information services include assistance with cash management tasks such as hiring, training, and managing workers as well as payment responsibilities. In theory, consumers who shop for the most cost-

effective providers may then (through such savings) have funds to purchase additional services (Kapp, 1996).

Determining Consumers' Preferences for a Cash Option

There is scant information regarding demographic and background characteristics that may influence interest in consumer direction. For example, studies have found greater informal care and less nursing home use among some minority groups compared to their White counterparts, providing speculation that preferences for consumer direction may differ among racial and ethnic groups (Rimer, 1998; Tennstedt & Chang, 1998; Wallace, Levy-Storrs, Kington, & Anderson, 1998). More recently, Sciegaj and Kyriacou (2000) found that consumers' preferences for types of personal assistance services (consumer directed, negotiated care managed, and traditional case managed services) varied among racial/ethnic groups. Policymakers, program planners, and others have speculated that age is a strong indicator of interest in a consumer-directed option (i.e., younger consumers would be more likely to be interested). Although research on consumers' preferences for consumer-directed services is limited, there is evidence that consumers of all ages, including elders, would like to be more involved in directing their care (Barnes & Sutherland, 1995; Benjamin & Matthias, 2001; Benjamin, Matthias, & Franke, 1998; Doty, Kasper, & Litvak, 1996; Eustis & Fischer, 1992; Glickman, Brandt, & Caro, 1994). However, there is much more to be learned about age-specific preferences for consumer direction in general, and for a cash option in particular.

In the present study, New Jersey elders and adults with physical disabilities who were receiving Medicaid personal care services were randomly selected to participate in a telephone survey assessing their perceptions regarding the cash option. Specifically, we wanted to

1. determine preferences for consumer-directed services and the cash option,
2. determine the percentage of consumers/surrogates choosing the cash option versus traditional services and identify reasons for their choices,
3. identify demographic and background characteristics of consumers/surrogates with specific preferences,
4. identify cash option features that are attractive/unattractive to consumers and surrogates,
5. identify what information consumers/surrogates need to decide whether to choose the cash option,
6. identify consumers'/surrogates' needs for counseling and support services, and
7. develop strategies to market the cash option.

Method

The total population of Medicaid personal care clients in New Jersey in 1996 was 10,760. There were 7,532 people age 65 and older and 3,228 between the ages of 18 and 64. Based on this population and using the standard error formula to ensure adequate power for both age groups, a sample size of 320 older clients and 265 younger clients was required.

Focus group discussions that took place in two CCDE states, New York and Florida, guided survey development. The 96 focus group participants were organized into 11 groups, including adult consumers with disabilities under age 65, adult consumers with disabilities age 65 and older, and adult surrogate decision makers (for a full discussion of focus group results, see Zacharias, 1997a, 1997b).

The research team developed a 139-item survey (using items from other related instruments where appropriate) to measure consumer and surrogate perceptions of the cash option. The survey consisted of four primary sections:

1. satisfaction with current homemaker home health aide services (27 items),
2. perceptions regarding the cash and counseling option (33 items),
3. consumer demographic and background variables (44 items), and
4. perceptions and demographics of surrogates (35 items).

The survey contained four attitudinal subscales:

1. Satisfaction with Worker Characteristics (six items),
2. Satisfaction with Availability of Workers (four items),
3. Overall Satisfaction with Personal Care Services (nine items), and
4. Willingness to Assume More Responsibility (six items).

To explain the cash option, interviewers read a scenario about a woman who needed personal care services and described several different ways she could use her cash benefit. Subsequent survey items informed respondents about various cash option features and support services.

Content validity of the survey was established via an expert panel ($n = 7$) knowledgeable in the areas of aging, disabilities, or survey design and evaluation. In addition, we pilot tested the survey with three disabled and elderly individuals to assess administration time as well as acceptability and understandability of the items. Finally, the instrument was translated into Spanish, and then back translated, to ensure accuracy and enable Spanish-speaking consumers' participation. There were 49 New Jersey respondents who completed the Spanish version of the survey.

The randomly selected potential participant phone files from New Jersey were entered into the MacIntosh Computer Assisted Telephone Interview system. Telephone interviews took place from July through September of 1997 and lasted an average of 40 minutes. Individuals were called up to six times before they were considered nonrespondents. If respondents felt unable to answer survey items themselves, they provided the interviewer with the name and phone number of a surrogate responder (a friend or relative). A series of questions identified surrogates and the type of decisions they helped the consumer make (i.e., financial, medical, living arrangements, or all of the above). Interviewers instructed surrogates to represent the consumer and to respond to survey items with the consumer present so the consumer could clarify responses if necessary (see Note 4).

Of the 3,207 randomly selected names and phone numbers sent to the researchers, 930 were unusable numbers (i.e., no answer, wrong locale, business phone, not in service), 457 participants refused to take part, 643 were unable to participate because of a language or hearing difficulty, 494 were never called as the appropriate sample size had been reached, and 683 completed the survey (response rate = 38%). Of those who completed the survey, 526 were clients answering for themselves and 157 were surrogates answering for consumers. The response rate was also recalculated excluding non-English speaking respondents as we were unable to determine their willingness to participate. The response rate then changed from 38% to 60%.

The most frequent reason given for nonparticipation was that there was a language barrier ($n = 506$, 46%) and the most common languages identified were Spanish and Russian (see Note 5). Other common reasons for not participating were that the individual was too sick, disabled, or old ($n = 197$, 18%), that she or he was not interested in participating in the survey ($n = 115$, 11%), or that he or she was not interested in changing his or her home care services ($n = 107$, 10%). Ninety-two individuals (8%) simply hung up without providing a reason.

We were able to compare participants and nonrespondents on age and average amount of money the state spent on services in the past year. (Age and cost data were provided to the researchers via the phone files sent by New Jersey.) There was a significant difference ($p < .01$) between participants ($n = 683$) and nonrespondents ($n = 1,100$) on both variables. Nonrespondents had less money spent on their services ($M = \$3,956$, $SD = \$2,618$ vs. $M = \$4,903$, $SD = \$7,659$) and they were older ($M = 74.9$, $SD = 14.2$ vs. $M = 62.9$, $SD = 19.8$).

Results

Sample

At least three fourths of New Jersey consumers were female, had been employed in the past, did not own their own home, and had a high school education or less. Fifty-seven percent

were age 65 or older. Almost half were Caucasian and a little more than one third were African American. Approximately two thirds were either widowed or single and more than one half lived alone. Finally, approximately two thirds rated their overall health status as fair or poor (see Table 1).

A measure of functional status was obtained based on the five activities of daily living (bathing, dressing, transferring, toileting, and eating). Consumers were asked if they needed help with each of the tasks and could respond "yes," "no," or "sometimes." A response of "yes" received a score of 1; "no," a score of a 0; and "sometimes," a score of 0.5. The functional status scale could thus range from 0 to 5; individuals scoring between 0 and 1.5 were considered to be mildly disabled, those scoring between 1.6 and 3.5 were considered moderately disabled, and those scoring between 3.6 and 5 were considered severely disabled. Fifty-seven percent of consumers scored in the mild disability category, 23% at the moderate level, and 20% were considered severely disabled.

Demographic information was also collected for surrogates. Examination of this sample ($n = 157$) revealed the majority were relatives of the consumer, female, Caucasian (25% were African American), younger than consumers (74% were less than 65 years old), and had higher levels of education (52% had at least some college). Eighty-three percent ($n = 130$) of surrogates helped the consumer with personal care decisions, 12% ($n = 19$) assisted with language problems, 3% ($n = 5$) assisted with hearing problems, and 2% ($n = 3$) did not identify what type of assistance they provided.

Interest in the Cash Option

Forty-two percent of consumers (whether answering for themselves or with surrogate assistance) stated they were interested in the cash option (see Table 2). Surrogates were asked about their own personal opinion on this item, and 56% said they were interested. Chi-square analyses indicated consumer interest differed significantly ($p < .05$) by age, gender, and ethnicity. More consumers under age 65 were interested (57%), yet almost one third (32%) of those age 65 and older were interested. Males were more interested than females (53% vs. 39%), and Hispanics and African Americans were more interested than Caucasians (51%, 45%, and 38%, respectively).

Additional chi-square analyses were conducted on the other demographic and background variables, by level of interest in the cash option. Six variables were significant ($p < .05$). Examination of marital status indicated consumers who were separated were most likely to be interested in the cash option (56%), followed by those who were single (47%), married (46%), divorced (44%), and widowed (35%). When looking at consumer living arrangement, 51% of those who lived with a spouse or children and 48% of those who lived with a friend, partner, or relative indicated interest, compared to 37% of those who lived alone.

Consumers who desired more involvement in arranging and scheduling their current personal care services were sig-

TABLE 1
Demographic and Background Characteristics of
New Jersey Consumers

Characteristic	N	(%)
Age of consumer		
Under age 65	286	(41.9)
65 or older	391	(57.2)
Don't know	1	(0.1)
Refused question	5	(0.7)
Gender		
Male	164	(24.0)
Female	519	(76.0)
Race/ethnicity		
African American/Black	233	(34.1)
Native American	9	(1.3)
Asian	7	(1.0)
Hispanic	82	(12.0)
Caucasian/White	312	(45.7)
Biracial	7	(1.0)
Don't know	18	(2.6)
Refused question	15	(2.2)
Education		
Less than high school	316	(46.3)
High school graduate	211	(30.9)
Trade or vocational school	16	(2.3)
Some college	81	(11.9)
Baccalaureate degree	23	(3.4)
Some graduate school	3	(0.4)
Graduate degree	20	(2.9)
Don't know	12	(1.8)
Refused question	1	(0.1)
Consumer marital status		
Married	51	(7.5)
Widowed	271	(39.7)
Divorced	103	(15.1)
Separated	43	(6.3)
Single	213	(31.2)
Partnered	1	(0.1)
Refused question	1	(0.1)
Consumer living arrangement		
Alone	371	(54.3)
With spouse and/or children	122	(17.9)
With friend, partner, or relative	182	(26.6)
Other	7	(1.0)
Refused question	1	(0.1)
Do you own your own home?		
Yes	73	(10.7)
No	607	(89.3)
Don't know	3	(0.4)
Do you have informal caregivers?		
Yes	414	(60.9)
No	266	(39.1)
Don't know	3	(0.4)

(table continues)

(Table 1 continued)

Characteristic	N	(%)
Does informal worker live with you		
No informal caregiver	266	(38.9)
Yes	175	(25.6)
No	239	(35.0)
Don't know	1	(0.1)
Refused question	2	(0.3)
Have you ever been employed?		
Yes	522	(76.4)
No	158	(23.1)
Don't know	2	(0.3)
Refused question	1	(0.1)
Consumer employment status		
Never employed	158	(23.1)
Employed full-time	6	(0.9)
Employed part-time	13	(1.9)
Unemployed	131	(19.2)
Retired	349	(51.1)
Full-time student	2	(0.3)
Part-time student	1	(0.1)
Homemaker	8	(0.1)
Volunteer	4	(0.6)
Don't know	7	(1.0)
Refused question	4	(0.6)
Any experience hiring, firing, or interviewing any type of worker?		
Yes	159	(23.3)
No	514	(75.3)
Don't know	6	(0.9)
Refused question	4	(0.6)
Any experience supervising or training any type of worker?		
Yes	224	(32.8)
No	451	(66.0)
Don't know	6	(0.9)
Refused question	2	(0.3)
Current overall physical health		
Excellent	26	(3.8)
Very good	50	(7.3)
Good	152	(22.3)
Fair	226	(33.1)
Poor	215	(31.5)
Don't know	6	(0.9)
Refused question	8	(1.2)

Note. N = 683.

nificantly more likely to be interested in the cash option (62%), compared to those who desired the same or less involvement (33%). Similar percentages regarding interest were found when comparing those who had experience hiring, firing, or interviewing workers to those who did not (63% vs. 35%) and comparing those who reported experience supervising or training workers to those without such experience

TABLE 2
Interest in the Cash Option by Respondent Status

Respondent status	Interested		Not sure		Not interested	
	N	(%)	N	(%)	N	(%)
Consumers answering for self	216	(42.1)	101	(19.7)	196	(38.2)
Surrogates answering for consumers	53	(41.7)	25	(19.7)	49	(38.6)
Surrogates answering for themselves	87	(55.8)	21	(13.5)	48	(30.8)

(57% vs. 35%). Finally, consumers who reported dismissing a homemaker or home health aide were more likely to indicate interest in the cash option compared to those who had never dismissed an aide (52% vs. 38%).

Respondents were asked if they would be willing to sign up for the program even if there was a chance they would not get in because of randomization procedures. Seventy-eight percent of consumers interested in the program were willing to sign up, and 35% of those who indicated they were not sure of their interest were willing to sign up. Respondents were also asked if it would be necessary to know the exact amount of money they would receive under the cash option or if it would be sufficient to know that the amount was close to what the state now pays their agency. Among consumers interested in the option, 53% stated it was necessary to know the exact amount and 31% said knowing the amount was close to what the state now pays was sufficient.

Logistic regression was conducted to determine which variables best predicted consumer interest in the cash option. Variables included in the analysis were selected consumer demographic items (race, age, education, and gender), the four Attitude subscales, and predictors of interest identified via bivariate analyses ($p < .25$) (having an informal caregiver, level of disability, age at onset of disability, experience hiring or firing a worker, experience supervising or training a worker, having ever dismissed an aide, marital status, living arrangement, employment status, and desired level of involvement in services). Interest in the cash option was collapsed to test for significant differences between those who showed some interest in the option ("interested" and "not sure" respondents) versus those who responded "not interested."

The best predictor of consumers' interest in the cash option was ethnicity (Hispanics were almost four times as likely as Caucasians and to be interested in the option, and African Americans were almost twice as likely as Caucasians). Consumers age 64 and younger were 2.7 times as likely as those age 65 and older to be interested in the cash option. Consumer willingness to perform tasks associated with managing personal care workers was also a significant predictor. These tasks

were measured using the Willingness to Assume Responsibility subscale and included willingness to (a) hire your own home care worker, (b) show your worker what to do, (c) schedule your worker, (d) supervise your worker, (e) pay your worker, and (f) fire your worker if she or he was not doing a good job.

Consumers' general satisfaction with current personal care services was another factor that predicted interest. Lower satisfaction scores were associated with interest in the cash and counseling option. The Satisfaction subscale was composed of the following items:

"One of the things I like most about my services is"

1. my worker,
2. the schedule,
3. that my worker "lives in,"
4. that the agency makes sure the worker is doing his or her job, and
5. the time of day my worker arrives.

"One of the things I really don't like is"

6. my lack of control over the services,
7. that the agency doesn't inform me of changes being made,
8. that my worker isn't properly trained, and
9. that my worker and I don't speak the same language.

Although some were phrased in the negative, these items were coded so that higher scores indicated greater satisfaction with services.

Consumers' desired level of involvement with current personal care services also predicted interest in the option. Respondents who wanted more involvement determining the amount and type of services they then received were 1.4 times more likely than those who desired the same or less involvement to be interested in the option (see Table 3).

The five factors previously described (willingness to assume responsibility, age of consumer, general satisfaction with personal care services, race of consumer, and desired level of involvement) predicted with 82% accuracy consumers who were either interested or not sure of their interest in the cash option and with 65% accuracy those who were not interested (overall 76% accuracy). No other factors or combination of factors were found to significantly improve this prediction rate.

Attractive Program Features

Consumers interested in the cash option were significantly ($p < .001$) more likely to find each program characteristic important than those who were not interested or not sure of their interest (see Table 4). For example, 76% of interested consumers thought it was important to know a group of other consumers, whereas only 55% of those not sure and 21% of

TABLE 3
Variables That Predict Interest in the Cash Option

Characteristic	Significance	Odds ratio/ Exp β
Willingness to Assume Responsibility subscale	.001	1.666
Age (under age 65 vs. 65 or older)	.001	2.696
Satisfaction with Worker subscale	.001	0.671
Race		
African American vs. Caucasian	.05	1.697
Hispanic vs. Caucasian	.001	3.846
Desired level of involvement with current services (more vs. same or less)	.05	1.391

those not interested in the cash option thought that characteristic was important. Similar findings were noted when examining surrogates' perceptions of program characteristics (see Table 5). There were also significant differences related to age—younger consumers were more likely than older consumers to consider it important to know a group of other participants (64% vs. 45%, $p < .001$) and to be able to back out of the cash option (84% vs. 77%, $p < .05$).

Consumers were asked about the reasons for their interest in the cash option. When asked whether the ability to "get services on the days and times you want them" would make them interested in the option, 88% of those interested, 45% of those not sure of their interest, and 11% of those not interested said it would. Participants responded similarly when asked about being able to hire whomever they want and being able to buy services different from what they currently receive (see Table 6).

Surrogates were also asked a series of questions about the reasons for their interest in the cash option. Compared to the other two groups (surrogates not sure of their interest and those who weren't interested), surrogates interested in the option were significantly ($p < .001$) more likely to be interested in these specific characteristics. Interested surrogates were more likely to believe the cash option would offer more flexibility for them and the consumer, that the consumer would like to participate, and that they would like to be able to use the money to interview and hire a worker (see Table 7).

Finally, surrogates were asked if they thought the cash option would make it easier or harder on them, and a similar percentage agreed to each response: 32% ($n = 49$) believed the option would make their job easier, 34% ($n = 52$) believed it would be harder, and 34% ($n = 52$) were not sure. Surrogates who were interested in the cash option were significantly ($p < .001$) more likely to believe the option would make things easier for them.