

Determining Consumers' Preferences for a Cash Option: New York Telephone Survey Findings

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Introduction

As long-term care expenditures have risen, policymakers have sought new ways to control costs while maintaining or increasing consumer satisfaction. Concurrently, there is increasing interest among the aging and disability communities in consumer-directed care (Kapp, 1996; Simon-Rusinowitz & Hofland, 1993; Ansello & Eustis, 1992; Mahoney, Estes, & Heumann, 1986), which is exemplified in the language of the 1994 Health Security Act (H.R.3600, Kapp, 1996). One consumer-directed model, "cash and counseling," offers a cash allowance and information services to persons with disabilities enabling them to purchase the 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 additional and more personalized services (Kapp, 1996). To determine if this is so, the cash and counseling model will be evaluated via a four-state demonstration project the Cash and Counseling Demonstration and Evaluation (CCDE). The CCDE is 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).

The purpose of this article is to present findings from a telephone survey conducted in New York, the largest of the demonstration states, to assess consumers' preliminary interest in the cash option when compared to traditional services. The telephone survey was undertaken to discover how many clients might be interested in the cash option and to identify their demographic, background, and attitudinal characteristics for social marketing and communication purposes. The results of this survey were also used to guide the design of supportive counseling services and to ascertain what information consumers needed to make an informed decision regarding the cash and counseling option. So survey findings can be interpreted in context, we will first provide a little background information on the CCDE as well as information about existing personal care programs. Finally, key policy issues will be discussed.

Existing Personal Assistance Service Programs

Personal assistance services (PAS) encompass a range of human and technological assistance provided to persons with disabilities who need help with activities of daily living (ADL's), including bathing, dressing, toileting, transferring and eating, and/or instrumental activities of daily living (IADL's), such as housekeeping, cooking, shopping, and laundry. Public or private third-party payers can use any of three PAS financing methods: cash benefits (payments to qualified clients or their representative payees); vendor payments (a case manager determines the types/amounts of covered services and arranges for and pays authorized PAS providers to deliver these services); and vouchers (clients use funds for authorized purchases). The CCDE will evaluate the impact of cash benefits.

In the United States, most existing public programs that finance PAS including such major funders as Medicaid's optional personal care services benefit and home and community-based long-term care (HCBS) waiver programs follow a vendor payment model. That is, the program purchases services for consumers from authorized vendors (i.e., service providers or equipment suppliers). In some programs, the list of covered services and authorized vendors is quite restricted. Other programs may have a broader range of covered services, adding adult day care, transportation, home modifications, and assistive devices. Clients may sometimes hire workers themselves (i.e., workers not employed by home health agencies) to be their in-home aide.

Until recently, the prohibition on direct 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 PAS programs that promote consumer choice and avoid program rules that may foster dependency in the name of consumer protection and/or public accountability (Litvak, Zukas, & Heumann, 1987; Litvak et. al., 1990; Litvak et. al, 1991). In addition, state officials have a strong interest in achieving program economies. Most Medicaid PAS 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 (Jackson, 1994; Geron & Chassler, 1994). Hence, reasons for the growing interest in a cash option are savings on program administration and enhanced consumer empowerment.

Cash allowance programs are currently very small because they involve "state-only" funds. Up until this demonstration, states could not use Medicaid to fund cash allowances that permit clients to purchase their own services because of federal restrictions on direct payments to clients. Consequently, it hasn't been possible to evaluate large programs with a cash option. This policy-driven demonstration and rigorous evaluation will provide information about the costs, benefits, and implementation issues involved in a cash option so state and federal policymakers can make informed decisions about whether and how to implement this long-term care model.

Demonstration and Evaluation Design

As the national program office for this large project, the University of Maryland Center on Aging (UMCA) directs and coordinates the demonstration, oversees the evaluation, and provides technical assistance to the demonstration states. The national program office works in conjunction with the project Management Team comprised of project officers from the Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation, the evaluation team leader from Mathematica

Policy Research, Inc., and advisors from the National Council on the Aging, the Health Care Financing Administration (HCFA), and the Social Security Administration.

In the winter of 1996/97, Arkansas, Florida, New Jersey, and New York each received grants of up to \$500,000 from RWJF to implement programs offering Medicaid PAS consumers the choice of a cash benefit instead of agency-delivered care. Some major program characteristics are:

- States will include both elders and younger adults with disabilities. Florida will also include children with developmental disabilities.
- Arkansas, New Jersey, and New York are offering a cash alternative to their Medicaid Personal Care Option, while Florida will include its Medicaid Home and Community-Based Care waivers.
- Funds must be used for personal assistance services: i.e., personal care workers and home renovations and/or assistive devices. Each participant will develop a plan for the use of the cash. Funds can be carried over from month to month for large purchases or other personal care needs.
- Each state will determine the cash payment amount. States are generally planning to follow current assessment and care planning practices, establish the value of the individual care plan, and offer a cash amount based on the amount consumers would receive in the traditional program. The average monthly benefit in traditional programs varies greatly by state, as confirmed by the four demonstration states: Arkansas (\$320), Florida (\$389, weighted average for different programs), New Jersey (\$910), and New York (\$1,580 in state fiscal year 1996).
- Counseling services are an integral part of the demonstration. They will include services to help consumers decide whether to select the cash option and, for cash option participants, an array of supportive services to help them manage employer responsibilities (such as hiring and training workers, arranging emergency backup, paying workers and employer taxes, etc.) or locate home modification subcontractors, etc. A fiscal intermediary service will be available to assist with accounting and payment tasks.

The evaluation is comprised of two components. The first is an experimental design in which interested consumers are randomly assigned to the cash option (treatment group) or the traditional services program (control group). The second is a process evaluation to study program implementation. The evaluation will compare outcomes for consumers in the treatment and control groups with respect to cost, quality, client satisfaction, and use of counseling services. The evaluation will also examine the impact of the cash option on formal and informal caregivers.

Among the many activities conducted during the project planning phase (e.g., completing a HCFA 1115 Research and Demonstration Waiver application to allow participants to receive cash payments and pay legally responsible relatives), the UMCA has been conducting background research that will guide program development and social marketing activities. Enrollment will begin sometime in 1999.

Assessing Consumers' Preferences for a Cash Option

Little research exists to indicate:

- how many consumers (or surrogate decisionmakers) would choose a cash option;
- what consumer characteristics might indicate who would choose cash vs.

- agency-based PAS; and
- what cash option features are attractive/unattractive to consumers and surrogates.

This information is essential to help the demonstration states design various cash option components (including counseling services) and social marketing approaches that will enable consumers and surrogates to make an informed choice between the cash option and their current program.

The demonstration states' communications and social marketing tasks are critical to achieving the CCDE's goals and are somewhat daunting for several reasons. As indicated by pre-survey focus groups, the cash option is quite different from traditional services and consumers often have difficulty understanding such a new and different concept. For consumers who have not completed high school, this communication effort is especially challenging. In addition, even those consumers who decide they like the cash option and feel qualified to try it will need to overcome fears and concerns about changing a service that is so important to their daily lives.

By their very nature, major social experiments push states to enroll many consumers (to have a sufficient sample size for hypothesis testing) during a relatively short period of time. Under the design proposed by Mathematica, New York has 1 year to enroll 3,750 current consumers from a population of approximately 65,000 clients (as reported in the period June-August 1996), plus 3,750 new consumers coming into the Medicaid program. Under current plans, two-thirds of all New York enrollees will be randomized to the treatment group that receives cash and one-third to the control group. Consequently, as mentioned earlier, the UMCA designed a three-part study to assess consumers' preliminary interest in a cash option. The RWJF provided funding to support this additional effort.

Consumers' Preferences for Consumer-Direction: Existing Research and Theory

Policymakers, program planners, and others have speculated that age would be a strong indicator of interest in a consumer directed model i.e., younger consumers would be more likely to select a consumer-directed cash option. While 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. In a small study of Minnesota home care clients (20 under age 65 and 34 over age 65), Eustis and Fischer (1992) found that while younger clients were more apt to take charge of their services, about one-third of older clients took charge of their care in at least three ways (e.g., participating in activities such as care plan development and hiring and training a worker.) Glickman, Brandt, and Caro (1994) surveyed 883 older Massachusetts home care clients to assess their interest in becoming more involved in managing their care. A substantial minority of clients said they would be willing to assume more responsibility in hiring, paying, scheduling, supervising, and firing their workers ranging from a high of 39 percent willing to schedule their workers to a low of 24 percent willing to fire a worker.

In a study comparing 1,432 California home care clients in independent provider and agency contract models, Barnes and Southerland (1995) found that when consumers had the amount of management responsibility they wanted (regardless of their age), they were happier with their worker's reliability and quality of service. Kasper, and Litvak (1996) compared satisfaction with care among 879 older Medicaid personal care clients in three states (Michigan, Maryland, and Texas) with varying degrees of consumer direction. Clients were significantly more satisfied with their services in programs that permitted more consumer control.

In addition to limited knowledge regarding the impact of age on consumers' preferences for consumer direction, there is little information regarding other demographic and background characteristics that may influence interest in consumer direction. Glickman and colleagues (1994) provide some guidance they found an association between client willingness to assume responsibility for directing a home care worker and the following client characteristics:

- prior experience directing an in-home worker,
- greater length of time receiving home care services,
- greater involvement in directing a home care worker, and
- lower levels of satisfaction with their home care services.

Research indicating differences in long-term care service use and care giving patterns among some minority groups i.e., greater informal care and less nursing home use among some minority groups compared to their white counterparts offers reason to speculate that preferences for consumer direction may differ among racial and ethnic groups (Tennstedt & Chang, 1998; Wallace, Levy-Storms, Kington, & Anderson, 1998; Rimer, 1998).

However, limited information about consumers' preferences for consumer direction, and specifically the cash option, point to the need to further understand many unanswered questions. Most importantly, what types of consumers and surrogates, and how many, would choose the cash option given the opportunity? In addition, what would their reasons be for this choice?

Preference Study Design and Purposes

A three-part study consisting of pre-survey focus groups, telephone surveys, and post-survey focus groups was developed to:

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

We wanted to survey at least 382 of the 65,000 clients in New York who received personal care services between June and August of 1996. New York provided almost

4,200 randomly selected personal care client names and phone numbers to the University of Maryland Interdisciplinary Health Research Laboratory (IHRL) so they could be called and invited to participate. A 139-item valid and reliable questionnaire was developed to measure consumer and surrogate perceptions of the cash option, using items from other related surveys where appropriate as well as input from 11 different consumer and surrogate focus groups conducted in New York and Florida. (If you are interested in a full discussion of focus group findings, please see Zacharias [1997a, 1997b].) We also translated the survey into Spanish so Spanish speaking consumers and surrogates could participate.

The survey consisted of four primary sections:

- satisfaction with current personal care services (27 items),
- perceptions regarding the cash option (33 items),
- demographic and background variables (44 items), and
- perceptions and demographics of surrogates (35 items).

Within these sections were four attitudinal subscales which measured satisfaction with worker characteristics, satisfaction with the availability of workers, overall satisfaction with personal care services, and willingness to assume more responsibility for one's care. To explain the cash option, interviewers read a scenario about a woman, Mrs. Green, who needed personal care services. The scenario described several different ways she could use her cash benefits. In addition, subsequent survey items informed respondents about various cash option features and support services. Background variables included a measure of functional status based on five activities of daily living (ADL's), an assessment of overall physical health, number of informal caregivers, and experience interviewing, training, hiring, or supervising workers.

Telephone interviews with New York Medicaid personal care recipients took place between April and June 1997. On average, interviews lasted 40 minutes. If consumers felt unable to answer survey items themselves, they provided the interviewer with the name and phone number of a surrogate responder. A series of questions were then asked of the surrogates to determine the type of decisions they helped consumers make (i.e., financial, medical, living arrangements, and medical).

Four hundred and ninety-three surveys were completed in New York, yielding a 23 percent response rate (493 completed surveys out of 2,181 eligible names). Of the almost 4,200 names and phone numbers New York provided, 600 were used in the pilot test, over 1,200 were unusable numbers (i.e., wrong locale, answering machine, busy line, etc.), and almost 1,800 refused to participate. The primary reasons individuals gave for refusing to participate were:

- language barrier (33%: other than English, consumers were most likely to speak Spanish or Russian),
- no interest in completing any survey (16%), and
- feeling too sick, disabled, or old (15%).

Because of the large number of non-English speaking respondents, we calculated a second response rate where these individuals were excluded, resulting in a 32 percent response rate.

To determine whether respondents were similar to those who refused to participate, we compared a sample of these two groups on two items, age and dollars spent on services per year. There were no differences between responders and refusers in the amount spent on services; both groups averaged about \$15,500 per year in Medicaid personal care

expenditures. However, on average, participants were younger than refusers, 69 years of age compared to 74 years.

Findings

The majority of consumers were female (77%), had a high school education (39%) or less (35%), were 65 years of age or older (63%), lived alone (61%), and did not have experience hiring, firing, or interviewing workers (71%) or supervising or training workers (60%). Forty-six percent were widowed and 23 percent were single. Forty-seven percent were Caucasian, 31 percent were African American and 12 percent identified themselves as Hispanic. Seventy percent of consumers rated their overall health status as "fair" or "poor," while 28 percent rated it "good," "very good," or "excellent." A measure of functional status was obtained, based on the five ADL's (bathing, dressing, toileting, transferring, and eating). Individuals scoring between 0 and 1.5 were considered to be mildly disabled (52%), those scoring between 2 and 3.5 were considered moderately disabled (24%), and those scoring between 4 and 5 were considered severely disabled (24%).

Examination of the surrogate sample (n=105) revealed they were younger than consumers (82% were less than 65 years of age) and had higher levels of education (60% reported at least some college). Fifty percent were currently married and 60 percent reported they lived with a spouse or children. The majority of surrogates were relatives of consumers (83%) and female (65%). The racial/ethnic background of surrogates was similar to that of consumers.

Interest in the Cash Option

Approximately 40 percent (n=155) of consumers answering for themselves indicated interest in the cash option, with an additional 22 percent (n=85) indicating they were not sure of their interest (Table 1). When examining responses of surrogates who answered for consumers, 41 percent (n=37) thought the consumer would be interested and 19 percent (n=17) were not sure. Finally, surrogates were asked for their own opinion: 56 percent (n=58) liked the idea of the cash option, 15 percent (n=16) indicated they didn't know, and 28 percent (n=29) did not think it was a good idea. Overall then, 40 percent of consumers and 56 percent of surrogates were interested in the cash option.

Consumers differed in their interest in the cash option depending on their age, gender, and race/ethnicity. Fifty-five percent of consumers under age 65 were interested in the option, compared to 31 percent of those 65 and older. Likewise, a larger percentage of male respondents were interested in the option when compared to females, 57 percent versus 35 percent. Finally, more African American consumers were interested in the option (47%) when compared to Hispanic (39%) and Caucasian (36%) consumers.

Table 1
Interest in the Cash Option by Respondent Status

	Interested N%	Not Sure N%	Not Interested N%
Consumer answering for him / or herself ^(a)	155 (40.3)	85 (22.1)	145 (37.7)
Surrogate answering for consumer ^(b)	37 (40.7)	17 (18.7)	37 (40.7)
Surrogate answering for him / or herself ^(c)	58 (56.3)	16 (15.5)	29 (28.2)

(a)N=385 (b)N=91 (c)N=103

Table 2
Variables that Predict Interest in the Cash Option

Characteristic	Significance	Exponent (B)*/ Odds Ratio
Willingness to Assume Responsibility Subscale **	.0000	1.39
Satisfaction with Program Subscale **	.0000	.74
Desired Level of Involvement with Services	.0004	2.74
Gender	.0013	2.58
Race / Ethnicity	.0045	2.06

*Exponent beta is used instead of an odds ratio with continuous variables

** Continuous variable

We looked at other demographic and background variables to see if consumers who were interested in the option differed on these variables when compared to those who were not interested. We found married consumers were most likely to be interested in the cash option (53% were interested) followed by separated (50%), single (48%), divorced (46%), and widowed (31%) consumers. Fifty-two percent of those who lived with a spouse or children and 50 percent of those who lived with a friend, partner, or relative indicated interest, compared with 34 percent of those who lived alone. Consumers who wanted more involvement with their current personal care services were more likely to be interested in the cash option (64%); when compared to those who wanted the same or less involvement, only 30 percent of these consumers were interested in the option. Consumers who had experience hiring, firing, or interviewing workers and those who had experience supervising or training workers were more likely to be interested in the cash option (64% and 56%); when compared with those who did not have such experiences, only 33 percent and 31 percent, respectively were interested in the option.

Consumers who had an informal caregiver living with them were more likely to be interested in the cash option when compared to those who did not have an informal live-in caregiver: 55 and 40 percent respectively. Consumers who described their relationship with their personal care worker as "very close" were less likely to be interested in the option than those who described the relationship as other than "very close" (32% vs. 43%). For example, rather than reporting their relationship as "very close," they may have described it as an "employee-employer" relationship, "unfriendly," or even "hostile." Consumers who rated their disability level as "severe" were more likely to be interested in the option (53%) than those who rated their disability level as "moderate" (36% of these consumers were interested) or "mild" (37% were interested).

Interest in the cash and counseling option was also related to how old the consumer was when he/she first acquired a disability. However, age of onset was also related to the consumer's current age, and when current age was controlled by looking at this relationship for each age group separately (those 65 and over and those 64 and under), age of onset of disability no longer affected interest in the cash option. There was a slight trend for those in the 65 and over age group who had acquired their disability before age 30 to be more interested in the option when compared to those 65 and older whose disability was acquired at a later age, but no similar trend was noted for the 64 and younger age group.

Consumer interest in the cash and counseling option did not differ by education, home

ownership, presence or absence of informal caregivers, or current or former employment status. Similarly, interest did not differ by rating of overall health, number of personal care workers, number of new personal care workers in the past 12 months, length of time in the program (less than vs. greater than 3 years) or number of personal care workers dismissed (one vs. more than one).

Respondents were asked if they would be willing to sign up for the cash option even if due to randomization procedures there was a chance they might not get in. Of those interested in the option, 83 percent were still willing to sign up. Respondents were also asked if it would be more important to know the exact amount of money they would receive under the cash and counseling option or to know the amount was close to what the state now pays for their care. Fifty percent of those interested in the option thought it was more important to know the exact amount of money they would receive, compared to 33 percent of those not sure of their interest and 32 percent of those who were not interested.

Examination of the surrogate subsample (n=105) found their interest in the option differed by age, with surrogates 64 and younger more likely to be interested (58%) versus those 65 and older (50%). Surrogate interest also differed by race; 73 percent of the African American surrogates, 54 percent of Caucasian surrogates, and 50 percent of Hispanic surrogates stated they were interested in the option. Surrogate interest also differed by education interest levels generally rose with level of education from less than high school (29% interested) to graduate degree (71% interested).

A multivariate analysis (logistic regression) was conducted to predict consumer interest in the cash option. Predictor variables included the demographic items race, age, education, and gender, the four attitude subscales, and the significant predictors of interest identified via bivariate analyses presented above. Interest in the cash option was collapsed to test for differences between those who showed some interest in the option (i.e., "interested" and "not sure" respondents) versus those who showed no interest (the "not interested" respondents). The most important variable predicting consumers' interest in the cash option was the "willingness to assume responsibility" subscale (Table 2), which measured readiness to hire, train, schedule, pay, supervise, and fire one's own worker. Consumers' general satisfaction with their current personal care services (i.e., satisfaction with worker, schedule, and provider agency) was another important factor in predicting interest. Consumers with lower satisfaction scores were more likely to be interested in the cash option.

Table 3
Consumer and Surrogate Perceptions of the Importance of Cash Option
Characteristics by Interest Level

	Cash and Counseling Interest Level		
	Interested N%	Not Sure N%	Not Interested N%
CONSUMERS: How important is it to:			
Hire Current Worker			
Important	132 (69.1)	52 (51.5)	94 (52.8)***
Don't Know	15 (07.9)	29 (28.7)	27 (15.2)
Not Important	44 (23.0)	20 (19.8)	57 (32.0)
Pay Worker More Money			
Important	135 (71.4)	40 (40.0)	65 (37.4)***
Don't Know	27 (14.3)	42 (42.0)	45 (25.9)

Not Important	27 (14.3)	18 (18.0)	64 (36.8)
Know a group of others who are participating			
Important	137 (72.9)	57 (56.4)	51 (29.3)***
Don't Know	15 (08.0)	26 (25.7)	24 (13.8)
Not Important	36 (19.1)	18 (17.8)	99 (56.9)
Be able to back out of cash option			
Important	158 (84.0)	67 (65.7)	102 (58.3)***
Don't Know	13 (06.9)	27 (26.5)	26 (14.9)
Not Important	17 (09.0)	8 (07.8)	47 (26.9)

SURROGATES: How important is it to: Interested Not Sure Not Interested
N% N% N%

Hire Current Worker			
Important	47 (81.0)	09 (56.3)	17 (58.6)***
Don't Know	02 (03.4)	06 (37.5)	01 (03.4)
Not Important	09 (15.5)	01 (06.3)	10 (34.5)
Pay Worker More Money			
Important	35 (60.3)	06 (37.5)	13 (44.8)***
Don't Know	10 (17.2)	08 (50.0)	03 (10.3)
Not Important	13 (22.4)	02 (12.5)	12 (41.4)
Know a group of others who are participating			
Important	43 (74.1)	07 (43.8)	05 (17.2)***
Don't Know	02 (03.4)	08 (50.0)	02 (06.9)
Not Important	13 (22.4)	01 (06.3)	21 (72.4)
Be able to back out of cash option			
Important	55 (94.8)	11 (68.8)	17 (58.6)***
Don't Know	00 (00.0)	05 (31.3)	02 (06.9)
Not Important	03 (05.2)	00 (00.0)	09 (31.0)

***p < .001

Consumers' desired level of involvement with their personal care services also predicted interest in the option. Those who wanted more involvement in determining the amount and type of services they currently receive were almost three times as likely to be interested in the option when compared to those who wanted the same or less involvement with their current services. The next most important variable, which predicted interest, was gender. Males were about two and a half times as likely to be interested in the option as females, although this could partially be due to age, as female respondents were more likely to be 65 or older when compared to males. Finally, African American consumers were twice as likely to be interested in the option as white or Latino consumers. These five factors (Table 2) predicted with 85 percent accuracy consumers who were either interested or not sure of their interest in the cash option and with 62 percent accuracy those who indicated they were not interested (overall 76% accuracy). No other factors or combination of factors were found to significantly improve upon this prediction rate.

Table 4
Consumers Who Want Help or Training with Task by Cash and Counseling Interest Level

Would you want help or training with any of the following tasks?	Cash and Counseling Interest Level		
	Interested N%	Not Sure N%	Not Interested N%
Finding a worker			
Yes	119 (62.0)	54 (54.0)	78 (45.6)***
Don't Know	13 (06.8)	21 (21.0)	24 (14.0)
No	60 (31.3)	25 (25.0)	69 (40.4)
Interviewing a worker			
Yes	98 (51.0)	48 (47.5)	78 (45.1)***
Don't Know	06 (03.1)	16 (15.8)	13 (07.5)
No	88 (45.8)	37 (36.6)	82 (47.4)
Doing a background check			
Yes	138 (72.6)	59 (58.4)	92 (53.5)***
Don't Know	07 (03.7)	18 (17.8)	08 (04.7)
No	45 (23.7)	24 (23.8)	72 (41.9)
Deciding how much to pay a worker			
Yes	146 (76.4)	63 (61.8)	91 (52.9)***
Don't Know	05 (02.6)	19 (18.6)	15 (08.7)
No	40 (20.9)	20 (19.6)	66 (38.4)
Knowing what to do if a worker didn't show			
Yes	125 (65.4)	63 (61.8)	91 (52.9)***
Don't Know	07 (03.7)	15 (14.7)	14 (08.1)
No	59 (30.9)	24 (23.5)	67 (39.0)
Firing a worker if necessary			
Yes	84 (44.2)	53 (52.0)	87 (50.6)***
Don't Know	05 (02.6)	16 (15.7)	14 (08.1)
No	101 (53.2)	33 (32.4)	71 (41.3)
Payroll and taxes			
Yes	149 (78.0)	64 (62.7)	84 (48.6)***
Don't Know	04 (02.1)	16 (15.7)	18 (10.4)
No	38 (19.9)	22 (21.6)	71 (41.0)

Note: N may vary slightly due to missing data *p < .05, **p < .01, ***p < .001

Attractive Program Features and Services Consumers Want to Purchase

Consumer and surrogate ratings of the importance of various program characteristics differed by level of interest in the cash option for each of four program characteristic items. Interested consumers were more likely than those not interested to consider it

important to be able to hire their current worker (69% vs. 53%), pay their worker more money than he/she currently receives (71% vs. 37%), back out of the cash option if they desired (84% vs. 58%), and know a group of other consumers participating in the option (73% vs. 29%) (Table 3). Similar differences were found between the interested and not interested surrogates (Table 3). Differences were also found by age when examining the importance of these program characteristics to consumers and surrogates. Consumers 64 and younger were more likely than those 65 and older to consider each characteristic important. For surrogates, those 64 and younger were more likely than the older group to consider it important to know other participating consumers.

Consumers were also asked whether particular program characteristics would make them interested in the cash option. Features they were specifically asked about included the ability to "get services on the days and times you want them," "hire whomever you wanted to provide services, even a friend or relative," and "use the money to buy different services or make home modifications." Eighty-nine percent of those interested in the option stated each of these features contributed to their interest in the option. These same characteristics were appealing to only 14 to 19 percent of the consumers not interested in the option.

Surrogates were also asked a series of questions to determine reasons for their interest in the cash option, and surrogates interested in the option were much more likely to be interested in these specific characteristics when compared to those not sure of their interest and those not interested. Anywhere from 74 to 88 percent of surrogates interested in the option agreed with the various items, compared to just 3 to 17 percent of those not interested. To elaborate, the majority of interested surrogates agreed the cash option would offer more flexibility to both the consumer (88%) and themselves (86%). They also liked the idea of being able to interview and hire the worker (83%) and being able to hire a friend or relative (74%). In addition, 74 percent of the interested surrogates believed the consumer would like to participate in the option.

Finally, surrogates were asked if they thought the cash option would make it easier or harder on them; 32 percent believed the option would make their job easier while 37 percent thought it would be harder. However, again, those surrogates interested in the option were much more likely to think it would make their job easier (55%) when compared to the not sure and not interested groups. Also, interested consumers were more willing to take on the tasks related to managing personal care workers (like scheduling, hiring, and supervising, among others).

Respondents were asked about their interest in purchasing various services, including more hours of personal care service; grab bars or equipment to help in the shower; wheelchair, motorized scooter, hospital bed, or chair lift; home remodeling services; exercise equipment; transportation services; laundry services; and housekeeping services. Again, those interested in the cash option were much more likely to want to purchase the various services when compared to those not interested or those not sure of their interest level. The services a majority of the respondents interested in the option wanted to purchase included more hours of service (66%), wheelchairs or other equipment (52%), and transportation services (65%).

Consumers 64 and younger were more likely than those 65 and older to be interested in purchasing more hours of service (52% vs. 39%), grab bars or shower equipment (36% vs. 21%), home remodeling service (29% vs. 11%), exercise equipment (28% vs. 16%), and transportation services (55% vs. 35%). The two age groups did not differ in their interest in purchasing wheelchairs or other equipment.

Consumer and Surrogate Training and Support Needs

Seven different tasks associated with the cash option were included in the survey and the majority of consumers wanted assistance or training in each of these areas. However, those interested in the cash option were more likely to want help or training on each task when compared to the other two groups (Table 4). They were more likely to want help with payroll taxes (78%), deciding how much to pay a worker (76%), doing a background check on a worker (73%), what to do when a worker doesn't show (65%), finding a worker (62%), interviewing a worker (51%), and firing a worker (44%). For those not sure of their interest in the cash option, the need for help or training was most acute for assistance with payroll taxes (63%), followed by what to do when a worker doesn't show (62%), and deciding how much to pay a worker (62%) (Table 4). For those not interested in the cash option, the largest percentage believed they would need help doing a background check (54%), followed by determining what to do when a worker didn't show (53%), and deciding how much to pay a worker (53%) (Table 4). When comparing consumers by age group, those 65 and older were more likely to indicate the need for help or training with interviewing a worker while those 64 and younger were more likely to want help doing a background check on a worker.

Examination of surrogates' perceptions, when they were answering for themselves (n=103), found differences by interest level in need for help or training on 5 of the 7 tasks. Surrogates interested in the cash option, versus those not certain and those not interested, were more likely to indicate a need for help or training with payroll taxes (86% vs. 63% vs. 42%) (Table 5). They were also more likely to want help or training doing a background check on a worker (79% vs. 69% vs. 41%), deciding how much to pay a worker (78% vs. 63% vs. 35%) finding a worker (76% vs. 50% vs. 38%), and knowing what to do when a worker doesn't show (71% vs. 50% vs. 35%) (Table 5).

Overall, before deciding to be involved in the cash option, the majority of consumers (regardless of their interest level) wanted more information. However, respondents were even more likely to want additional information if they were interested in the option or not certain of their interest. Specifically, when asked if they needed to know more financial details, 94 percent of those interested, 96 percent of those not sure, and 54 percent of those not interested answered "yes" (overall 80%). When asked if they needed to know whether their current worker could be retained, 84 percent of those interested, 84 percent of those not sure, and 69 percent of those not interested responded "yes" (overall 79%). When asked if they needed to know how other current benefits they receive would be affected, the percentage breakdown was 99 percent, 93 percent, and 72 percent respectively (overall 88%). Finally, when asked if they needed to know more about their rights and responsibilities under the cash option, 98 percent of the interested consumers, 98 percent of those not sure, and 71 percent of those not interested responded "yes" (overall 88%).

Table 5
Surrogate Need for Help or Training with Task by Cash Option Interest Level

Would you want help or training with any of the following tasks?	Cash and Counseling Interest Level		
	Interested N%	Not Sure N%	Not Interested N%
Finding a worker			
Yes	44 (75.9)	08 (50.0)	11 (37.9)***
Don't Know	00 (00.0)	05 (31.3)	01 (03.4)

No	14 (24.1)	03 (18.8)	16 (55.2)
Interviewing a worker			
Yes	26 (44.8)	07 (43.8)	09 (31.0)
Don't Know	00 (00.0)	02 (12.5)	01 (03.4)
No	32 (55.2)	07 (43.8)	18 (62.1)
Doing a background check			
Yes	46 (79.3)	11 (68.8)	12 (41.4)*
Don't Know	01 (01.7)	01 (06.3)	01 (03.4)
No	11 (19.0)	04 (25.0)	15 (51.7)
Deciding how much to pay a worker			
Yes	45 (77.6)	10 (62.5)	10 (34.5)***
Don't Know	02 (03.4)	03 (18.8)	01 (03.4)
No	11 (19.0)	03 (18.8)	17 (58.6)
Knowing what to do if a worker didn't show			
Yes	41 (70.7)	08 (50.0)	10 (34.5)**
Don't Know	00 (00.0)	02 (12.5)	01 (03.4)
No	17 (29.3)	06 (37.5)	17 (58.6)
Firing a worker if necessary			
Yes	24 (41.4)	03 (18.8)	07 (24.1)
Don't Know	01 (01.7)	01 (06.3)	02 (06.9)
No	33 (56.9)	11 (68.8)	19 (65.5)
Payroll and taxes			
Yes	50 (86.2)	10 (62.5)	12 (41.4)**
Don't Know	00 (00.0)	01 (06.3)	01 (03.4)
No	08 (13.8)	04 (25.0)	15 (51.7)

Note: N may vary slightly due to missing data *p < .05, **p < .01, ***p < .001

Discussion and Recommendations

Survey results will guide New York in designing numerous aspects of the cash and counseling demonstration; however, this discussion will focus on the implications of survey findings for New York's critical communications and social marketing efforts. Survey data will help provide answers to three broad questions:

- How can New York reach those consumers and surrogates most interested in the cash option?
- What messages should New York emphasize in its communications and social marketing efforts?
- What issues need to be explored further in the post-survey focus groups?

Targeting Interested and Uncertain Consumers and Surrogates

Frequency data obtained in this survey can clearly guide New York's social marketing

efforts. Findings indicate that New York should be able to achieve evaluation enrollment targets by focusing on those individuals who indicated an initial interest in the cash option (40% of responding consumers). In addition, 21 percent of consumers were unsure of their initial interest in the cash option. New York will need to use data from the survey and followup focus groups to learn more about what information is needed to help the "unsure" population make a well-informed decision to choose the cash option or stay with their current program. Also, knowing that 35 percent of respondents had less than a high school education and 39 percent had not gone beyond a high school education serves as a reminder that outreach and training materials must be simple and straightforward (and/or many consumers may need the assistance of surrogates and direct contact with counselors).

We found that males were more interested in the cash option than females (57% vs. 35%). In addition, African Americans were more interested than Latinos and Caucasians (47%, 39%, and 36% respectively). However, the vast majority of the New York sample was female (77%) and was about equally divided between Caucasians (47%) and African Americans and Latinos combined (43%). So, although more males and African Americans are interested in the option, females and Caucasians are more prevalent in the consumer population. Therefore, New York program officials need to learn more about which cash option features are appealing to women and Caucasians, which was addressed during the post-survey focus groups. These discussions were designed to learn more about the reasons behind consumers' preferences as they vary by race and gender.

One of the survey's major research questions inquired about age as a factor influencing interest in the cash option; we found younger consumers to be more interested than elders (55% vs. 31%). However, a sizable minority of elders were interested in the cash option. This information guides New York to include both age groups in social marketing efforts; however, program workers need to focus on reaching the younger group (who make up a smaller proportion of consumers receiving services in New York) and learning more about factors that would help uncertain elders feel comfortable with the cash option.

Two other key factors require further exploration to guide social marketing efforts. Survey data indicate the highest level of interest in the cash option 56 percent is among surrogate decision makers when expressing their own views. In addition, consumers who live with their informal caregiver are more interested in the cash option than those without this arrangement. It is possible these two variables are related, as the surrogate decision maker is likely to be an informal caregiver. New York needs to learn more about the reasons for surrogates' high level of interest in the cash option, as well as their role in working with a consumer to choose the cash option. The same is true for the role of a live-in informal caregiver: How does the presence of this individual influence a consumer's decision to select a cash option? One possible explanation is that the informal caregiver could serve an emergency backup role if the paid worker doesn't come to work an important concern expressed by consumers. Without support from informal caregivers, many consumers may lack the confidence to take on the additional responsibilities required in the cash option. Another explanation may be that the consumer would want to hire the informal caregiver as a paid worker. Further understanding of the surrogate and informal caregiver roles can help New York develop social marketing messages that address high levels of interest among surrogate decision makers and consumers with a live-in informal caregiver.

Communications and Social Marketing Messages to Emphasize

Two consumer attributes that strongly predicted interest in the cash option were consumers' willingness to perform employer tasks needed to direct their own care and

consumers' desire to be more involved in determining the amount and types of services they receive. At first glance, these two characteristics may appear to be quite similar, and possibly proxy indicators for interest in the cash option. However, closer scrutiny illuminates possible differences between these two attributes. Some consumers may want more say in the types and amounts of services they receive and at the same time be unwilling to conduct some or all employer tasks needed to direct their own care. For example, they may feel strongly about being able to specify key aspects of their service (e.g., who provides what service, when, and how much) and want others to carry out some or all of their wishes. Their desire for more involvement may boil down to a desire to assess their own needs and (help) develop a plan which others can implement, as opposed to a wish to carry out employer tasks such as hiring and paying a worker. Once again, the post survey focus groups were designed to further explore these concepts.

Surrogates' interest in the cash option was also related to their willingness to assume responsibility for employer tasks a concept to highlight in social marketing materials. In addition, surrogates' interest in the cash option was related to a belief that this option would make it easier on them. Among interested surrogates, even those who thought the cash option would be harder believed their extra effort would be worthwhile. Knowing this, the post-survey focus groups explored how the cash option could be easier for surrogates and, if extra effort would be required, which specific aspects make the exertion worthwhile.

Cash option characteristics attractive to interested consumers provide further direction regarding social marketing messages and, more importantly, direction for designing the cash option. For example, effective materials would address the ability to "get services on the days and at the times you want" and "hire whomever you want to provide personal care services, even a friend or a relative," as the vast majority of interested consumers found these program characteristics appealing. The attractiveness of being able to hire one's own worker is consistent with the finding that consumers who described their relationship with their personal care worker as "very close" were less likely to be interested in the option when compared to those who described the relationship as other than "very close." As the survey addressed the possibility of hiring "a friend or a relative," the followup focus group discussion differentiated between either a friend or relative to learn if consumers find one more appealing than the other. Pre-survey focus groups indicated some negative feelings about hiring relatives. Finally, interested consumers also found the ability to "buy different services" an attractive program feature.

Surrogates' reasons for being interested in the cash option also offer messages to include when addressing that group. Materials should definitely highlight the ability to interview and hire workers, increased flexibility for consumers and surrogates, and the cash option's potential benefits for the consumer.

Consumers and surrogates provided consistent information regarding cash option features they found attractive, providing further direction about messages to include in social marketing materials for both groups. Consumers and surrogates who were interested in the cash option were most likely to think it was important to have peer support from others in the cash option. They also wanted to know that, should they feel the need or want, they could pay their worker more than the worker currently receives and that they could back out of the cash option if they wanted to return to the traditional program. There were differences between older and younger consumers regarding the importance of these features, with consumers under 65 more likely to consider each feature important.

Finally, interested consumers and surrogates considered it important to be able to hire their current worker should they choose the cash option. This information is a strong message that the state needs to address this difficult issue in its social marketing efforts.

Pre-survey focus group participants frequently described problems with former workers and explained that when they had a worker they liked they wanted to continue with that person. Yet, difficult organizational issues are likely to interfere with this consumer preference. Most important, provider agencies and/or union contracts may limit this practice. In addition, a worker may need fulltime employment and only work parttime hours for a specific consumer. This issue is likely to be less important for new consumers entering the Medicaid program, as they would be less attached to an existing arrangement.

Consumers interested in the cash option were more likely to express a need for help or training in employer tasks. Social marketing materials should inform consumers they can have help or training with the most requested tasks, which included: payroll taxes, help deciding how much to pay a worker, doing a background check on a worker, and what to do when a worker doesn't show, as well as finding, interviewing, and firing a worker. Older and younger consumers differed only slightly regarding their need for training or help, indicating minimal need to address this issue differently by age groups. Social marketing materials should inform surrogates they can have help or training with the same tasks; however, materials would highlight a slightly different order to reflect the priorities of surrogates interested in the cash option: i.e., help or training with payroll taxes, doing a background check, deciding how much to pay a worker, finding a worker, what to do when a worker doesn't show, as well as interviewing and firing a worker.

As the majority of consumers wanted more information before deciding whether to choose the cash option, social marketing materials and in-person communication should be as specific as possible regarding the following issues (listed in order of importance):

- how other current benefits would be affected,
- consumers' rights and responsibilities under the cash option,
- cash option financial details, and
- how the current worker would be affected.

When survey respondents were asked whether it was more important to know the exact amount or that the amount was close to what the state now pays the agency, half of those interested in cash thought it was more important to know the exact amount. It was therefore important to test materials explaining the financial details in the post-survey focus groups.

Cash and counseling project planners have had some concern about the difficulty of explaining randomization to consumers and the possibility that randomization would be a deterrent to choosing the cash option. Survey findings dispel these concerns to a large degree, as 83 percent of those interested in the cash option were willing to sign up even if there was a chance they might not be selected. However, it was important to test materials explaining randomization during the post-survey focus groups to be sure they were clearly understood.

Six additional issues were explored in the New York followup focus group discussions.

First, successful communications and social marketing efforts depend on knowing the sources of credible (and unreliable) information for consumers and surrogates. For example, should social marketing efforts utilize certain well-regarded community organizations?

Second, it was very important to test draft materials to be sure they would be effective for a population primarily comprised of people with a high school education or persons not completing high school.

Third, the timing of presenting various issues was also important to test. For example, what messages are critical "door openers" to be included in general introductory materials? What information should be included in followup communication?

Fourth, it was necessary to learn when consumers/surrogates wanted hands-on assistance as opposed to training that would allow them to function independently. Specifically, the focus groups assessed consumers' and surrogates' views about the fiscal intermediary role.

Fifth, New York needed to determine if it would be necessary and/or feasible to develop separate materials for specific segments of the population (i.e., according to gender, race, age, surrogate or consumer viewpoint, etc.). Although this question is related to resources and deadlines, it was tested in the focus groups.

Sixth, given that "language barrier" was identified as the primary reason for refusing to participate in the survey, language needs must be addressed. The focus groups were designed to assist New York in developing and translating materials for non-English speaking participants.

Policy Issues

The CCDE is a policy-driven project addressing numerous policymaker concerns. While comprehensive recommendations will not be available until the evaluation is complete, the New York preference survey offers insight into policy issues concerning the importance of offering consumers a choice of PAS options, as well as insights regarding potential fraud and abuse and service quality concerns.

The CCDE is based on the premise that the cash option is a choice available to those consumers who want consumer direction. It is not intended to replace traditional services, as the cash option is unlikely to be appropriate for or desirable to all consumers. The New York survey findings support this perspective. Although 40 percent of all respondents expressed a preliminary interest in the cash option (a sizable amount), the remaining were uncertain or not interested.

Fraud and abuse concerns relate to the possibility that consumers and/or their families might misuse the cash benefit or be exploited by others (Doty, 1997). While the demonstration must and will address these concerns, procedures to minimize fraud and abuse must also maintain the consumer empowerment principles being tested in the CCDE. Overly restrictive measures could negate the effect of the consumer-directed intervention.

Misuse of the cash benefit includes the possibility that consumers might not pay taxes for their workers. New York survey data indicate these possibilities are limited, as a majority of consumers and surrogates interested in the cash option (78% and 86%, respectively) said they would want help or training with payroll and taxes. More precisely, most clients are likely to elect to have these services performed by accounting professionals. This would greatly reduce the amount of cash consumers actually need to manage (Doty, 1997). Those consumers electing not to use accounting professionals will need to participate in a training program and demonstrate the skill to handle payroll tasks.

To prevent consumer exploitation by others (and subsequent suffering of ill effects), the cash option allows/encourages the use of surrogate decision makers to represent consumers who are unable to make all decisions independently. While there are many questions to consider regarding surrogate decision makers, we know from the New York

survey that 21 percent of consumers used surrogates and that 56 percent of these surrogates, when responding for themselves vs. representing a consumer, were interested in the cash option. In the event of possible exploitation by a surrogate, it is important to note that under the cash option counselors will have a role in monitoring all consumers including those with surrogates.

For those consumers functioning independently (without surrogates), the cash option training and support services offer further protection against consumer exploitation. When asked whether they would want help or training with various cash option tasks, the majority of consumers were interested in these support services, especially those that expressed interest in the cash option.

New York survey respondents found the ability to "hire whomever you want to provide personal care services, even a friend or relative," an attractive feature of the cash option. This finding indicates that many consumers are likely to hire friends or relatives as their workers. Policymakers often raise concerns about the quality of care provided by friends or relatives, as they may lack formal training. Yet, two studies of California's In-Home Support Services program (Bames & Sutherland, 1995; Benjamin, Mathias, & Franke, 1998) found that consumers rated family members and friends as more reliable than workers who were strangers. In addition, a study of elderly Medicaid personal care recipients in Michigan found that client satisfaction was related to several indicators of greater client control and, specifically, to Michigan's policy of encouraging clients to hire family, friends, and neighbors as attendants (Doty, Kasper, & Litvak, 1996). The CCDE will further our understanding about the quality of services when friends and relatives become paid providers.

In regard to the research question about consumers' age as an indicator of interest in the cash option, it is important to assess this question on an ongoing basis as aging baby boomers the next generation of elders are likely to be more interested in consumer direction than today's older population. While the New York survey found 31 percent of elders are interested in the cash option, younger consumers were 1.32 times as likely to be interested as elder consumers. This trend could shift in coming years as baby boomers have grown up with the consumerism movement and they will most likely carry this perspective into their later years. This trend may be especially true for the next generation of elders who have aged with a disability. Many baby boomers that have had early onset disabilities have grown accustomed to independent living principles and they are likely to want to continue directing their care as they age. The survey data hint at this possibility, as there was a slight trend for consumers over age 65 who had acquired their disability before age 30 to indicate a greater interest in the cash option than elders who acquired a disability at a later age.

Summary

This article has presented results from a telephone survey conducted to assess consumers' preferences for a cash option vs. traditional services in New York, one demonstration state in the CCDE. The telephone survey was conducted as background research to guide project development. Survey findings will guide New York in designing the cash and counseling option and developing much needed communications and social marketing materials. These efforts are essential to informing New York consumers about the cash option so they can make informed decisions to choose a consumer-directed option or stay in the traditional program. The authors look forward to continued learning about consumers' interest in and satisfaction with a cash option (vs. traditional services) when the demonstration is implemented and the choice becomes real, not theoretical.

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Notes

1. Much of this section comes from background materials written by Pamela Doty, the CCDE's project officer at DHHS/ASPE, during the project development phase.
2. For a more detailed discussion of procedures and statistical analyses, please refer to the full New York State report, entitled "Determining Consumers' Preferences for a Cash Option: A Report on New York Telephone Survey Findings."