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# Consumer Preferences for a Consumer-Directed Cash Option Versus Traditional Services

## Telephone Survey Findings of Florida Elders and Adults with Physical Disabilities

*This report evaluates the findings of a telephone survey inquiring into the preferences of Florida elders and adults with physical disabilities with regard to various options for receiving assistance and services.*

**By Sharon M. Desmond,  
Kevin J. Mahoney, Lori Simon-  
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Today, in most states, whether you are an elderly individual or a younger person with disabilities, if you need Medicaid assistance to perform major activities of daily living (ADLs) like bathing, dressing, toileting, transferring, or eating you will not have much say over who helps you, when they come, or what they actually do. However, for many years, people from the disability community have been saying, “If I had more control over my services, my quality of life would improve and I could meet my needs for the same amount of money or less.” The Cash and Counseling Demonstration and Evaluation (CCDE)<sup>1</sup> 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 consumers a cash allowance in lieu of agency-delivered services.

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This article reports on background research conducted to inform the three-state (Arkansas, Florida, and New Jersey) CCDE design and further our understanding about implementing consumer-directed services. A consumer-directed approach to services encourages maximum consumer choice and control to people needing assistance with ADLs and other personal care tasks. Efforts to better understand the intricacies of implementing consumer-directed services, especially in the aging community, have only recently begun.<sup>2</sup> Early in the CCDE development, program planners realized that key information essential to program implementation was lacking—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 in each demonstration state to assess consumers' preferences. This article reports findings from the survey conducted in Florida.

As this preference survey provides background information for the CCDE, we begin with a brief description of the CCDE and existing personal assistance services to provide a context for the Florida findings. Although the survey results guided several aspects of program development, we focus on one application—guidance in developing communications and social marketing materials to assist Florida in its efforts to inform consumers about the project. We also highlight key policy issues addressed by the survey.

## Background

The idea of consumer-directed services originated more than two decades ago among younger people with disabilities in the disability rights and independent living movements.<sup>3</sup> 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.<sup>4</sup> Interest in consumer choice expanded among some aging leaders in the early 1990s, in part due to a belief that consumer-directed care might lead to much needed cost savings.<sup>5</sup> The emphasis on consumer choice and control in the language of the 1994 Health Security Act<sup>6</sup> exemplifies this increased interest.

Typically personal assistance services are financed by public or private third-party payers in one of three ways:

1. Cash benefits (payments to qualified clients or their representative payees);
2. Vendor payments (a case manager determines the types/amounts of covered services, and arranges for and pays authorized providers to deliver the services); and
3. 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).<sup>7</sup>

Cash allowance programs are currently very 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.<sup>8</sup> 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.<sup>9</sup>

The cash and counseling model offers a cash allowance and information to clients so they can purchase the services, assistive devices, or home modifications that best meet their individual needs. In theory, consumers who shop for the most cost-effective providers would then (through such savings) have funds to purchase additional services.<sup>10</sup> To determine the effectiveness of this consumer-directed option, the CCDE was designed. The evaluation compares cost, quality, and satisfaction of consumers receiving traditional personal care services with those receiving the cash option.<sup>11</sup>

## Determining Consumers' Preferences for a Cash Option

Little research exists to indicate clients' preferences for consumer directed programs, specifically the cash option. This information was essential to help the

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

Policy makers, program planners, and others have speculated that age would be a strong indicator of interest in a consumer-directed option (i.e., younger consumers would be more likely to be interested). 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.<sup>12</sup> However, there is much more to be learned about age-specific preferences for consumer direction in general, and particularly for a cash option. Additionally, there is scant information regarding other 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.<sup>13</sup> More recently, Sciegaj and Kyriacou<sup>14</sup> 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.

In the present study, Florida elders and adults with physical disabilities who are receiving Medicaid Home and Community-Based Waiver 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 and surrogates choosing the cash option versus traditional services and identify reasons for their choices;
3. Identify demographic and background characteristics of consumers and surrogates with specific preferences;
4. Identify cash option features that are attractive or unattractive to consumers and surrogates;
5. Identify what information consumers and surrogates need to decide whether to choose the cash option;

6. Identify consumers' and surrogates' needs for counseling and support services; and
7. Develop strategies to market the cash option.

## Methods

### Sample

There were 950 adults with physical disabilities 18 to 64 years of age and 11,499 adults 65 and older who received services in 1997 from Florida's Aging and Disabled Waiver Program. Based on this population, and using the relevant standard error formula to insure adequate power, a sample size of 273 adults 18 to 64 years of age and 330 adults 65 and older was needed. It was assumed phone numbers would be at least 80 percent accurate and that the response rate would be 20 percent. Florida forwarded the names and phone numbers of 368 randomly selected adults 18 to 64 years of age with physical disabilities and 2,344 randomly selected older adults (65 and older) to the University of Maryland's Interdisciplinary Health Research Lab (IHRL).

### Instrumentation

A survey measuring client perceptions of the cash option was developed. It consisted of four sections:

1. Type of services received and satisfaction with those services (34 items);
2. Perceptions regarding the cash option (32 items);
3. Consumer demographic and background variables (35 items); and
4. Perceptions and demographics of surrogates (33 items).

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 benefit. Then, subsequent survey items informed respondents about various cash option features and support services. The questionnaire contained two attitudinal subscales—satisfaction with services (7 items) and willingness to assume responsibility for personal assistance services (6 items). Background variables included a measure of functional status based on ADLs, an assessment of overall physical health, the individual's living arrangement, number of informal caregivers, and experience interviewing, training, hiring, or supervising workers, among others.

Content validity of the survey was established via an expert panel ( $n = 7$ ) knowledgeable in aging, disabilities, and survey design and evaluation. In addition, the survey was pilot tested with three disabled and elderly individuals to assess administration time as well as acceptability and understandability of the items. A pilot test with 120 clients was also conducted to determine internal consistency and reliability of the subscales (both were reliable, .73 and .79). Finally, the instrument was translated into Spanish, and then back-translated, to insure accuracy and enable Spanish-speaking consumers' participation. We expected to have a large number of Spanish-speaking respondents in Florida, given the large Hispanic population in the state. However, only 63 surveys were conducted in Spanish.<sup>15</sup>

### **Procedures**

The randomly selected potential participant phone files from Florida were entered into the MacIntosh Computer-Assisted Telephone Interview (MaCATI) system. Telephone interviews took place in 1997 from September through November. On average, interviews lasted 40 minutes. Individuals were called up to six times before they were considered nonrespondents. If respondents were unable to answer survey items themselves (for a variety of reasons, including language barriers, communication difficulties, or other health problems), they provided the interviewer with the name and phone number of a surrogate responder (a friend or relative). A series of questions were then used to identify surrogates and the type of decisions they helped the consumer make (i.e., financial, medical, living arrangements, or all). Surrogates were instructed to represent the consumer and respond to survey items with the consumer present, so the consumer could clarify responses if necessary.

Of the 2,712 randomly selected names and phone numbers sent to the IHRL, 899 were unusable numbers (i.e., not in service, wrong locale, business phone, person no longer receiving services, etc.), 813 refused to participate, 257 were not used because the appropriate sample size had been reached, and 743 completed the survey (48 percent response rate). One hundred and sixty-five of the 743 individuals who completed the survey were "partial completes," meaning they had answered up to and including the item that asked about their interest in the cash option. A total of 578 respondents actually completed the entire survey, and 43 of those responded in Spanish.

Nonrespondents were asked why they did not want to participate in the survey prior to ending the interview, and the two most frequent reasons given were that the individual was too sick, disabled, or old ( $n = 235$ , 34 percent), or that she or he was not interested in participating in any survey ( $n = 179$ , 26 percent). Other reasons were that the consumer was not interested in changing services ( $n = 60$ , 9 percent) or not interested in discussing her or his personal care services ( $n = 60$ , 9 percent). We were able to determine if nonrespondents differed from participants based on age and average amount of money the state spent on services over a nine-month period, from July 1, 1996 through March 31, 1997. Age and cost data were provided to the researchers via the phone files sent by Florida. There was a significant difference ( $p < .01$ ) between participants ( $n = 743$ ) and nonrespondents ( $n = 697$ ) on both variables. The average amount of money spent on services over the nine months for participants was \$2,581 (SD = \$2,312), compared to \$2,217 (SD = \$1,980) for nonrespondents. Participants were also younger than nonrespondents; mean ages were 68.7 years (SD = 16.2) and 77.4 years (SD = 12.0) respectively.

## **Results**

### **Description of the Sample**

Between 579 and 591 respondents provided consumer demographic and background information. The sample size varied slightly due to missing data on a particular item. The majority of consumers were female (80 percent), had a high school education or less (73 percent), and were 65 years of age or older (66 percent) (Exhibit 1). Fifty-eight percent were Caucasian, 24 percent were African American, and 12 percent identified themselves as Hispanic. Forty-five percent were widowed, while 20 percent were divorced. Ninety-one percent reported having been employed, although the majority of these individuals were currently retired (71 percent). A majority had an informal caregiver (61 percent), and 33 percent had an informal live-in caregiver. Thirty-four percent had experience hiring, firing, or interviewing workers, while 44 percent had experience supervising or training workers (Exhibit 1).

Consumers were asked to rate their overall health status, and 74 percent rated it "fair" or "poor," compared to 24 percent who rated it "good," "very good," or "excellent." A measure of functional

**Exhibit 1.** Demographic and Background Characteristics of Florida Elderly and Adult Consumers

Demographic Variable	N	(%)
Adult Consumers (18 to 64)	199	(34.0)
Elderly Consumers (65 and older)	387	(66.0)
<b>Gender</b>		
Male	120	(20.3)
Female	470	(79.7)
<b>Race/Ethnicity</b>		
African American/Black	143	(24.2)
Native American/Alaskan Native	5	(00.8)
Asian	2	(00.3)
Hispanic	69	(11.7)
Caucasian/White	343	(58.0)
Biracial	8	(01.4)
Don't know/Refused question	21	(03.5)
<b>Education level</b>		
Less than high school	267	(45.5)
High school graduate	160	(27.3)
Trade or vocational school	8	(01.4)
Some college	81	(13.8)
Baccalaureate degree	32	(05.5)
Some graduate school	5	(00.9)
Graduate degree	10	(01.7)
Don't know/Refused question	24	(04.1)
<b>Marital status</b>		
Married	84	(14.4)
Widowed	262	(44.8)
Divorced	118	(20.2)
Separated	34	(05.8)
Single	80	(13.7)
Live with partner	1	(00.2)
<b>Living arrangement</b>		
Alone	292	(49.9)
With spouse and/or children	179	(30.6)
With friend, partner, or relative	113	(19.3)
Other	1	(00.2)
<b>Do you own your own home?</b>		
Yes	208	(35.6)
No	371	(63.4)
Don't know/Refused question	6	(01.1)
<b>Demographic Variable</b>		
<b>N (%)</b>		
<b>Do you have an informal caregiver?</b>		
Yes	358	(61.2)
No	223	(38.1)
Don't know/Refused question	4	(00.6)

*(continued)*

**Exhibit 1. Demographic and Background Characteristics of Florida Elderly and Adult Consumers (cont'd)**

Does informal caregiver live with you?		
Yes	193	(33.0)
No	168	(28.7)
No informal caregiver	222	(37.9)
Don't know	2	(00.3)
Have you ever been employed?		
Yes	529	(90.7)
No	49	(08.4)
Don't know/Refused question	5	(00.8)
Consumer employment status (if ever employed)		
Employed part time	4	(00.7)
Unemployed	131	(24.5)
Retired	380	(71.0)
Homemaker	6	(01.1)
Volunteer	2	(00.4)
Don't know/Refused question	12	(02.2)
Any experience hiring, firing, or interviewing any type of worker?		
Yes	196	(33.5)
No	375	(64.1)
Don't know/Refused question	14	(02.5)
Any experience supervising or training any type of worker?		
Yes	257	(44.1)
No	310	(53.2)
Don't know/Refused question	16	(02.8)
Current overall physical health		
Excellent	18	(03.1)
Very good	19	(03.3)
Good	103	(17.7)
Fair	192	(32.9)
Poor	238	(40.8)
Don't know/Refused question	13	(02.2)
Disability level		
Mild	288	(49.7)
Moderate	153	(26.4)
Severe	138	(23.8)
Length in program		
0–6 months	32	(04.3)
6–11 months	49	(06.6)
1–2 years	209	(28.2)
3 years or more	424	(57.1)
Don't know	28	(03.8)

status was also obtained, using the five ADLs (bathing, dressing, transferring, toileting, and eating). Consumers were asked if they needed help with each activity and could respond “yes,” “no,” or “sometimes.” A “yes” response received a score of 1, a “no” a 0, and a “sometimes” a 0.5. The functional-status scale could thus range from 0 to 5. Individuals who scored between 0 and 1.5 were considered mildly disabled (50 percent), those who scored between 2 and 3.5 were labeled moderately disabled (26 percent), and those with a 4 or 5 were determined to be severely disabled (24 percent). Finally, 742 respondents answered the item regarding how long they had been in the Florida Home Care program. The majority (57 percent,  $n = 424$ ) had been in the program more than three years, 28 percent ( $n = 209$ ) had participated one to two years, and the remainder were enrolled for an even shorter period of time (Exhibit 1).

### **Services Received and Satisfaction Levels**

Either 742 or 743 respondents answered the items concerning services received, as one person discontinued the survey during this sequence of questions. Respondents were asked if they currently received each of 14 different services provided by Florida’s Home Care program. They were also asked how much of the service they received and if they were satisfied with it. A majority of consumers received 3 services—case manager (73 percent,  $n = 543$ ), homemaker (72 percent,  $n = 531$ ), and personal care (61 percent,  $n = 454$ ) (Exhibit 2). The percentage of consumers who obtained other services ranged from 4 percent ( $n = 26$ ), who received caregiver training and support, to 40 percent ( $n = 294$ ), who received home-delivered meals. The vast majority of consumers who received each service were satisfied with the service. Rates of satisfaction ranged from a high of 94 percent ( $n = 257$ ), who were satisfied with consumable medical supplies, to a low of 75 percent ( $n = 21$ ), who were satisfied with caregiver training and support (Exhibit 2). The number of services clients received ranged anywhere from 0 to 10, with a distribution mode of 3 services received (23 percent,  $n = 168$ ). The average number of services received was 3.68 ( $SD = 1.85$ ). Analysis revealed a significant ( $p < .01$ ) negative association between number of services received and interest in the cash option. Descriptive statistics and frequencies for services received are presented in Exhibit 3.

Five other items related to consumer satisfaction were included on the survey, as well as the 7-point satisfaction subscale. One indication of satisfaction is whether a consumer has had to dismiss a worker; 23 percent ( $n = 171$ ) of these respondents had this experience. Of those, 53 percent ( $n = 91$ ) stated the reason for dismissal was that the worker wasn’t doing a good job. An additional 23 percent ( $n = 39$ ) indicated the worker “had a bad attitude,” 10 percent ( $n = 17$ ) said they didn’t get along with the worker, and 8 percent ( $n = 14$ ) stated their worker stole from them. Another sign of satisfaction has to do with consumers’ perception of the adequacy of hours of home care services they receive. A majority of respondents (55 percent,  $n = 394$ ) believed the number they received was “just about right,” while 28 percent ( $n = 201$ ) stated they were “a little low” and 14 percent ( $n = 103$ ) said “much too low.” Finally, 2 percent ( $n = 2$ ) said the number of hours they received was too high, and an additional 2 percent ( $n = 2$ ) did not have an opinion.

Fifty-seven percent of respondents ( $n = 411$ ) stated they were satisfied with the availability of home care services in an emergency, while 15 percent ( $n = 105$ ) were dissatisfied and 24 percent ( $n = 171$ ) chose the “don’t know” option for this item. Five percent ( $n = 33$ ) stated the question wasn’t applicable. We asked consumers if one of the things they didn’t like about their services was that the consumer and worker did not speak the same language. Nine percent of respondents ( $n = 66$ ) agreed with this statement, and the remainder either didn’t know, said the statement wasn’t applicable, or disagreed (82 percent,  $n = 610$ ).<sup>16</sup>

Satisfaction was also measured via the seven-item subscale mentioned previously. Three items were positively worded with the following stem: “One of the things I like most about my current home care services is:” followed by (a) the worker, (b) the schedule, and (c) that the agency makes sure the worker is doing her/his job. Four items were negatively worded with the stem: “One of the things I really don’t like about my home care services is:” followed by (a) the time of day my worker arrives, (b) my lack of control over the services, (c) that the agency doesn’t inform me of changes being made, and (d) that my worker is not properly trained. Positive responses to the first three items and negative responses to the last four each received a score of 1, resulting in a satisfaction subscale score that ranged from 0 (most



**Exhibit 2. Services Received and Satisfaction with Services Among Florida Elderly and Adult Consumers**

Service	Receives Service		Satisfied with Service	
	N	(%)	N	(%)
Case manager services				
Yes	543	(73.1)	490	(90.7)
No	158	(21.3)	25	(04.6)
Don't know	42	(05.7)	25	(04.6)
Case aide services				
Yes	150	(20.2)	132	(89.8)
No	578	(77.8)	6	(04.1)
Don't know	15	(02.0)	9	(06.1)
Homemaker services				
Yes	531	(71.6)	437	(82.8)
No	209	(28.2)	69	(13.1)
Don't know	2	(00.3)	22	(04.2)
Personal care services				
Yes	454	(61.1)	401	(88.5)
No	285	(38.4)	38	(08.4)
Don't know	4	(00.5)	14	(03.1)
Adult day health services				
Yes	60	(08.1)	54	(90.0)
No	675	(91.0)	4	(06.7)
Don't know	7	(00.9)	2	(03.3)
Home modification services				
Yes	177	(23.9)	160	(90.4)
No	563	(75.9)	13	(07.3)
Don't know	2	(00.3)	4	(02.3)
Chore services				
Yes	106	(14.3)	85	(80.2)
No	632	(85.2)	13	(12.3)
Don't know	4	(00.5)	8	(07.5)
Respite services				
Yes	142	(19.2)	129	(90.8)
No	571	(77.2)	7	(04.9)
Don't know	27	(3.6)	6	(04.2)
Personal emergency response system services				
Yes	264	(35.6)	236	(90.1)
No	473	(63.7)	6	(02.3)
Don't know	5	(00.7)	20	(07.6)
Consumable medical supplies				
Yes	273	(36.8)	257	(93.5)
No	461	(62.1)	15	(05.5)
Don't know	8	(01.1)	3	(01.1)
Counseling services				
Yes	72	(09.7)	64	(88.9)
No	667	(89.9)	3	(04.2)
Don't know	3	(00.4)	5	(06.9)
Nutritional services				
Yes	39	(05.3)	36	(92.3)
No	697	(93.9)	3	(07.7)
Don't know	6	(00.8)	0	(00.0)
Home delivered meals				
Yes	294	(39.6)	232	(78.9)
No	447	(60.2)	42	(14.3)
Don't know	1	(00.1)	20	(06.8)
Caregiver training and support				
Yes	26	(03.5)	21	(75.0)
No	687	(92.7)	4	(14.3)
Don't know	28	(03.8)	3	(10.7)

**Exhibit 3.** Descriptive Statistics for Services Received

Service Received	Min	Max	Mean	SD	Median	Mode	N
Case manager services (contacts per month)	1	33	2.00	3.66	1	1	394
Case aid services (hours per week)	1	50	7.30	8.23	5	3	128
Homemaker services (hours per week)	1	49	3.93	3.64	3	2	515
Personal care services (hours per week)	1	50	5.87	5.12	5	3	433
Adult day health service (hours per week)	1	56	3.93	2.74	10	2	53
Home modifications (number ever)	1	13	1.94	1.57	1	1	166
Chore services (hours per month)	1	25	4.51	5.92	2	1	84
Respite service (days per month)	1	28	5.63	5.17	4	4	122
Personal emergency response service (times ever)	1	60	3.27	6.47	2	1	120
Consumable medical supplies (times per month)	1	30	1.72	2.93	1	1	236
Counseling services (hours per week)	1	23	2.35	4.11	1	1	49
Nutritional service (times ever)	1	12	3.29	2.45	3	1	32
Home delivered meals (hours per week)	1	14	4.25	2.20	5	5	287
Caregiver training and support (times per month)	1	36	7.15	9.91	2	1	13

dissatisfied) to 7 (most satisfied). Eighty-one percent of respondents who answered all seven items (573/706) scored a 4 or higher on this subscale.

**Interest in the Cash Option**

Valid responses for the item concerning interest in the cash option were received from 511 consumers and 43 surrogates answering on behalf of the consumer. Approximately 59 percent ( $n = 301$ ) of consumers answering for themselves indicated interest in the cash option, with an additional 20 percent ( $n = 102$ ) indicating they were not sure of their interest (Exhibit 4). When examining responses of surrogates who answered for consumers, 49 percent ( $n = 21$ ) indicated that the consumer would be interested while 26 percent ( $n = 11$ ) were not sure of the consumer's interest level. Finally, surrogates were asked for their own opinion; 62 percent ( $n = 31$ )

stated they liked the idea of the cash option, while 24 percent ( $n = 12$ ) said they didn't know (Exhibit 4). Overall, 58 percent (322/554) of the consumers and 62 percent (31/50) of the surrogate respondents were interested in the cash option.

Bivariate analyses were conducted to assess factors associated with interest in the cash option. Cases were included in the bivariate analysis if respondents had answered the interest in the cash option item and the specific demographic or background variable being examined. Consumers differed significantly ( $p < .001$ ) in their interest in the cash option based on their age. There were 189 consumers under age 65 who answered the item regarding interest level, and of these, 71 percent ( $n = 135$ ) were interested in the option, 12 percent ( $n = 23$ ) were not certain of their interest, and 16 percent ( $n = 31$ ) were not interested. Examination of the 355 consumers

**Exhibit 4.** Interest in the Cash Option by Respondent Status

Respondent Status	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
Consumer answering for self	301	(58.9)	102	(20.0)	108	(21.1)
Surrogate answering for consumer	21	(48.8)	11	(25.6)	11	(25.6)
Surrogate answering for self	31	(62.0)	7	(14.0)	12	(24.0)

age 65 and older who answered the item showed 51 percent (n = 182) were interested, 25 percent (n = 89) were not sure, and 24 percent (n = 84) were not interested in the option.

Consumer interest also differed significantly ( $p < .01$ ) by level of disability, as measured by the activities of daily living scale. There were 122 consumers with severe, 146 with moderate, and 270 with mild disability levels who also answered the interest item. Consumers with more severe disabilities were more likely to be interested in the option. Seventy-one percent of consumers with the severe disability rating were interested compared to 57 percent of those with the moderate rating and 55 percent of those with the mild rating. Consumer interest did not differ significantly by gender, race, level of education, marital status, living arrangement, home ownership, having ever been employed, current employment status, length of time in the Florida Home Care program or self-rating of overall health status.

Consumers who desired more involvement with their current personal care services (n = 215) were significantly more likely to be interested in the cash option compared to those who desired the same or less involvement (n = 292) (73 percent versus 49 percent,  $p < .001$ ). Consumers who reported having experience hiring, firing, or interviewing workers (n = 187) and consumers who had experience supervising or training workers (n = 245) were significantly more likely to be interested when compared to those who did not have such experience (71 percent versus 53 percent and 68 percent versus 51 percent, respectively) ( $p < .001$ ).

Consumers who reported having an informal caregiver (n = 331) were significantly more likely ( $p < .01$ ) to be interested in the cash option when

compared to those who did not have one (n = 209), (63 percent versus 52 percent). For those who have an informal caregiver, no significant difference in interest was found based on whether the informal caregiver lived with the consumer or not. Consumers who felt the number of hours of home care service were much too low (n = 89) were more likely to be interested in the option than those who felt the hours were a little low (n = 164) or those who indicated the hours were just about right (n = 284) (75 percent versus 67 percent versus 49 percent,  $p < .001$ ). Consumers dissatisfied with the availability of home care workers in an emergency (n = 83) were more likely to be interested in the cash option when compared to those who were not sure of their satisfaction with this service (n = 143) or those who were satisfied (n = 301) (70 percent versus 56 percent versus 55 percent,  $p < .05$ ).

Respondents were asked if they would be willing to sign up for the program even if, due to randomization procedures, there was a chance they might not get into the program. Of those who indicated interest in the program, 80 percent (n = 258) were willing to sign up, and of those who indicated they were unsure of their interest in the program, 35 percent (n = 40) were 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 that the amount was close to what the state now pays the agency. Of those interested in the option, 59 percent thought it was more important to know the exact amount, while for those unsure of their interest (n = 113) and those not interested (n = 119), the corresponding percentages were 54 percent and 33 percent, respectively ( $p < .001$ ).

Examination of the surrogate subsample found that their interest in the option differed significantly by age, with the 29 surrogates under 65 more likely to be interested (79 percent) versus the 17 surrogates 65 or older (35 percent) ( $p < .01$ ). Surrogate interest in the option did not differ significantly by gender, race, level of education, marital status, relationship to consumer, or current living arrangement.

### **Attractive Cash Option Characteristics**

Consumer ratings of the importance of various program characteristics differed significantly by level of interest in the cash and counseling option for each

of the four program characteristic items. Consumers who indicated interest ( $n$  varied from 319 to 321 by question) were more likely than those not interested ( $n$  varied from 115 to 117 by question) to consider it important to be able to hire their current worker (76 percent versus 44 percent), to pay their worker more money (67 percent versus 29 percent), to know a group of other consumers who were participating (74 percent versus 29 percent), and to be able to back out of the cash and counseling option if they so desired (83 percent versus 58 percent) ( $p < .001$ ) (Exhibit 5). Significant differences were also found by consumer age for three of these

**Exhibit 5.** Consumers' Perceptions of the Importance of Cash Option Characteristics by Interest Level

Cash Option Characteristic	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
<b>Hire current worker</b>						
Important	246	(76.4)	58	(51.3)	52	(43.7)*
Don't know	26	(08.1)	33	(29.2)	21	(17.6)
Not important	42	(13.0)	16	(14.2)	34	(28.6)
Not applicable	06	(01.9)	06	(05.3)	09	(07.6)
Refused question	02	(00.6)	—	—	03	(02.5)
<b>Pay worker more</b>						
Important	216	(67.1)	45	(39.8)	35	(29.4)*
Don't know	65	(20.2)	50	(44.2)	27	(22.7)
Not important	32	(09.9)	13	(11.5)	44	(37.0)
Not applicable	06	(01.9)	04	(03.5)	09	(07.6)
Refused question	03	(00.9)	01	(00.9)	04	(03.4)
<b>Know a group of other consumers</b>						
Important	238	(73.9)	63	(55.8)	35	(29.4)*
Don't know	26	(08.1)	26	(23.0)	20	(16.8)
Not important	52	(16.1)	21	(18.6)	51	(42.9)
Not applicable	05	(01.6)	03	(02.7)	11	(09.2)
Refused question	1	(00.3)	—	—	02	(01.7)
<b>Ability to back out of program</b>						
Important	267	(82.9)	79	(69.9)	69	(58.0)*
Don't know	22	(06.8)	24	(21.2)	17	(14.3)
Not important	27	(08.4)	06	(05.3)	21	(17.6)
Not applicable	03	(00.9)	04	(03.5)	09	(07.6)
Refused question	03	(00.9)	—	—	03	(02.5)

\*  $p < .001$

program characteristics, with consumers under 65 (n varied from 197 to 198) more likely than those 65 or older (n varied from 376 to 380) to consider it important to hire their current worker (74 percent versus 56 percent) ( $p < .001$ ), to pay their worker more money (62 percent versus 46 percent) ( $p < .01$ ), and know a group of other consumers in the program (69 percent versus 53 percent) ( $p < .01$ ). When examining surrogate responses concerning these important program characteristics, no significant differences were found by interest in the cash option or age of respondent.

Consumers were asked whether particular program characteristics (i.e., getting services when you want them, hiring whomever you want including a friend or relative, and buying different services) would make them interested in the cash option. For each program characteristic, interested consumers were significantly ( $p < .001$ ) more likely to say the

characteristic made them more interested in the program when compared to those who weren't sure of their interest and those who were not interested (Exhibit 6).

Surrogates were also asked a series of questions to ascertain reasons for their interest in the cash option. Those interested in the option were significantly ( $p < .001$ ) more likely to agree with the reason stated when compared to those not sure of their interest or not interested (Exhibit 7). For example, interested surrogates were more likely to believe the consumer would like to participate, that the cash option would offer more choice, flexibility and independence to the consumer and themselves, and that they would use the cash option to hire a friend or relative. Surrogates interested in the cash option were also significantly more likely to be willing to hire a personal care worker, show the worker what to do, arrange a worker's schedule, and pay a worker

**Exhibit 6.** Consumers' Reasons for Interest in the Cash Option by Actual Interest Level

Reason for Interest	<u>Consumer Interest in Cash and Counseling Option</u>					
	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
<b>Get services when you want</b>						
Interested	296	(91.9)	63	(55.8)	34	(28.6)*
Don't know	11	(03.4)	27	(23.9)	13	(10.9)
Not interested	15	(04.7)	20	(17.7)	67	(56.3)
Not applicable	—	—	03	(02.7)	04	(03.4)
Refused question	—	—	—	—	01	(00.8)
<b>Hire whomever you want</b>						
Interested	295	(91.6)	66	(58.4)	24	(20.2)*
Don't know	07	(02.2)	23	(20.4)	06	(05.0)
Not interested	16	(05.0)	20	(17.7)	84	(70.6)
Not applicable	02	(00.6)	04	(03.5)	04	(03.4)
Refused question	02	(00.6)	—	—	01	(00.8)
<b>Buy different services</b>						
Interested	290	(90.1)	70	(61.9)	31	(26.1)*
Don't know	15	(04.7)	21	(18.6)	04	(03.4)
Not interested	15	(04.7)	18	(15.9)	80	(67.2)
Not applicable	01	(00.3)	04	(03.5)	03	(02.5)
Refused question	01	(00.3)	—	—	01	(00.8)

\*  $p < .001$

**Exhibit 7.** Surrogates' Reasons for Interest in the Cash Option by Interest Level

Reason for Interest	<u>Surrogate Interest in Cash and Counseling Option</u>					
	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
<b>Thinks consumer would like to participate</b>						
Agree	20	(62.5)	01	(14.3)	01	(08.3)*
Disagree	01	(03.1)	01	(14.3)	09	(75.0)
Not applicable	01	(03.1)	01	(14.3)	—	—
Don't know	10	(31.3)	04	(57.1)	02	(16.7)
<b>Cash could offer more choice, flexibility, and independence for consumer</b>						
Agree	22	(68.8)	02	(28.6)	02	(16.7)*
Disagree	02	(06.3)	02	(28.6)	09	(75.0)
Don't know	08	(25.0)	03	(42.9)	01	(08.3)
<b>Cash could offer more choice, flexibility, and independence for the surrogate</b>						
Agree	25	(78.1)	03	(42.9)	02	(16.7)*
Disagree	—	—	—	—	09	(75.0)
Don't know	07	(21.9)	04	(57.1)	01	(08.3)
<b>Would like cash option to interview and hire workers</b>						
Agree	28	(90.3)	03	(42.9)	01	(08.3)*
Disagree	—	—	01	(03.2)	08	(66.7)
Don't know	02	(06.5)	04	(57.1)	03	(25.0)
<b>Would like cash option to hire a friend or relative</b>						
Agree	24	(77.4)	04	(57.1)	02	(16.7)*
Disagree	05	(16.1)	01	(14.3)	09	(75.0)
Don't know	02	(06.5)	02	(28.6)	01	(08.3)

\*  $p < .001$ 

( $p < .001$ ), as well as to fire and supervise a worker ( $p < .05$ ). No significant differences were found for the surrogate's willingness to perform duties associated with the cash option by the age of the surrogate. Finally, surrogates were asked if they thought the cash option would make it easier or harder on them. Thirty-four percent ( $n = 16$ ) believed the option would make their job easier, while 17 percent ( $n = 8$ ) believed it would be harder.

### **Services Consumers Want to Purchase**

Respondents were asked about their interest in purchasing various services, and again, those interested in the cash option were significantly ( $p < .001$ ) more likely to want to purchase each of the services when compared to those not interested or not sure of their interest level. For example, a majority of respondents interested in the option ( $n = 301$ ) wanted to purchase more hours of service (80 percent,  $n = 240$ ),

housekeeping services (80 percent, n = 240), transportation services (70 percent, n = 209), respite care services (62 percent, n = 185), laundry services (59 percent, n = 176), grab bars or shower equipment (55 percent, n = 166), and wheelchairs or other equipment (50 percent, n = 151) (Exhibit 8). A majority of those not sure of their interest in the option (n = 102) were interested in purchasing housekeeping services

**Exhibit 8.** Services Consumers Would Like to Purchase by Cash Option Interest Level

Services Would Like to Purchase	<u>Consumer Interest in Cash and Counseling Option</u>					
	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
More hours of service						
Yes	240	79.7	48	47.1	23	21.3*
No	61	20.3	54	52.9	85	78.7
Grab bars or shower equipment						
Yes	166	55.1	31	30.4	15	13.9*
No	135	44.9	71	69.6	93	86.1
Adult day health program						
Yes	107	35.5	19	18.6	14	13.0*
No	194	64.5	83	81.4	94	87.0
Home modifications						
Yes	138	45.8	22	21.6	13	12.0*
No	162	53.8	80	78.4	95	88.0
Transportation services						
Yes	209	69.4	48	47.1	28	25.9*
No	92	30.6	54	52.9	80	74.1
Laundry services						
Yes	176	58.5	40	39.2	25	23.1*
No	125	41.5	62	60.8	83	76.9
Housekeeping services						
Yes	240	79.7	57	55.9	37	34.3*
No	61	20.3	45	44.1	71	65.7
Respite care						
Yes	185	61.5	33	32.4	24	22.2*
No	116	38.5	69	67.6	84	77.8
Wheelchairs and other equipment						
Yes	151	50.2	34	33.3	28	25.9*
No	150	49.8	68	66.7	80	74.1

\* p < .001

(56%,  $n = 57$ ) (Exhibit 8).

Consumers under 65 ( $n = 199$ ) were significantly more likely than those 65 or older ( $n = 387$ ) to be interested in purchasing home modification services (41% versus 26%) and laundry services (55% versus 37%) ( $p < .001$ ), as well as grab bars and shower equipment (47% versus 35%), transportation services (60% versus 47%), and housekeeping services (68% versus 56%) ( $p < .01$ ). Consumers under age 65 were also more likely to be interested in purchasing more hours of service (64% versus 54%), adult day health services (32% versus 23%), and wheelchairs or other equipment (46% versus 36%) ( $p < .05$ ).

### **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, respondents interested in the cash option ( $n$  varied from 312 to 318 by item) were significantly ( $p < .001$ ) more likely to want help or training on each task when compared to the other two groups (Exhibit 9). They were more likely to want help doing a background check on a worker (82 percent), deciding how much to pay a worker (79 percent), assistance with payroll taxes (77 percent), and knowing what to do when a worker doesn't show (73 percent). No significant differences were found for the need for help or training on these tasks by the age of the consumer.

Examination of surrogates' perceptions, when responding to the items about their training needs, found no significant differences in need for help or training by interest level in the cash option on six of the seven tasks. However, surrogates interested in the cash option ( $n = 31$ ) and those not certain of their interest ( $n = 7$ ) were significantly ( $p < .05$ ) more likely to indicate a need for help in knowing what to do if a worker did not show up than were those not interested in the option ( $n = 9$ ), (84 percent versus 86 percent versus 44 percent,  $p < .05$ ) (Exhibit 10).

### **Additional Information Needed**

Overall, before deciding whether to be involved in the cash option, the majority of consumers, regardless of their interest level, wanted more information. However, there were statistically significant differences ( $p < .001$ ) among the three interest-level groups

on each of these items—respondents were even more likely to want information if they stated they were interested in the option or not certain. Specifically, when asked if they needed to know more financial details, 92 percent ( $n = 293$ ) of those interested, 87 percent ( $n = 96$ ) of those not sure, and 69 percent ( $n = 75$ ) of those not interested answered “yes” (overall 86 percent). When asked if they needed to know whether their current worker could be retained, 85 percent ( $n = 268$ ) of those interested, 82 percent ( $n = 90$ ) of those not sure, and 77 percent ( $n = 82$ ) of those not interested responded “yes” (overall 83 percent). When asked if they needed to know how other current benefits they received would be affected, the percentage breakdown was 95 percent ( $n = 300$ ), 86 percent ( $n = 95$ ), and 84 percent ( $n = 86$ ) respectively (overall 91 percent). Finally, when asked if they needed to know more about their rights and responsibilities under the cash option, 96 percent ( $n = 305$ ) of the interested consumers, 92 percent ( $n = 101$ ) of those not sure, and 84 percent ( $n = 85$ ) of those not interested responded “yes” (overall 93 percent). There were no statistically significant differences in need for more information by age of respondents. Again, the majority of respondents (84 percent to 93 percent) wanted additional information, regardless of their age.

### **Discussion and Recommendations**

Survey results provide Florida with information about the type of services their clients actually receive and satisfaction with those services. Results have guided Florida in designing numerous aspects of the cash option; however, this discussion will focus on the implications of survey findings for Florida's communications and social marketing efforts, as well as policy issues.

Approximately three-fourths of Florida consumers received case management, homemaker, and personal care services, and 40 percent received home-delivered meals. There was a negative association between number of services received and interest in the cash option; as the number of services decreased, respondents were more likely to be interested in the option. It is possible these respondents believe they may receive more services with the cash option, as they would have more control, personally deciding which services to purchase. Alternatively, individuals who receive many services may be loath to give up case management, as the sheer number of ser-



**Exhibit 9. Consumers Who Want Help or Training with Task by Cash Option Interest Level**

Task Want Help With	<u>Consumer Interest in Cash and Counseling Option</u>					
	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
<b>Help finding a worker</b>						
Yes	193	64.8	66	67.3	51	52.0*
No	95	31.9	15	15.3	36	36.7
Don't know	10	3.4	17	17.3	11	11.2
<b>Help interviewing a worker</b>						
Yes	170	57.0	51	52.0	43	45.3*
No	120	40.3	31	31.6	45	47.4
Don't know	8	2.7	16	16.3	7	7.4
<b>Help doing a background check</b>						
Yes	242	82.3	75	76.5	50	52.6*
No	47	16.0	13	13.3	36	37.9
Don't know	5	1.7	10	10.2	9	9.5
<b>Help deciding how much to pay</b>						
Yes	237	79.0	72	73.5	49	51.0*
No	52	17.3	11	11.2	36	37.5
Don't know	11	3.7	15	15.3	11	11.5
<b>Help if worker didn't show</b>						
Yes	215	73.1	67	68.4	53	56.4*
No	74	25.2	19	19.4	31	33.0
Don't know	5	1.7	12	12.2	10	10.6
<b>Help firing worker</b>						
Yes	150	50.2	45	45.9	42	44.7*
No	146	48.8	39	39.8	46	48.9
Don't know	3	1.0	14	14.3	6	6.4
<b>Help with payroll taxes</b>						
Yes	228	76.5	67	68.4	47	49.5*
No	61	20.5	18	18.4	39	41.1
Don't know	9	3.0	13	13.3	9	9.5

\* p &lt; .001

vices they receive requires much coordination and the complexity of operationalizing the cash plan may be greater.

Satisfaction with current services was measured in several ways, and it appears that the vast major-

ity of Florida consumers were very satisfied with their current services (75 percent to 94 percent), and 81 percent scored a 4 or higher on the 7-point satisfaction subscale, indicating they were satisfied. However, it appears dissatisfaction with specific char-

**Exhibit 10.** Surrogates Who Want Help or Training with Task by Cash Option Interest Level

Task Want Help With	<u>Surrogate Interest in Cash and Counseling Option</u>					
	Interested		Not Sure		Not Interested	
	N	(%)	N	(%)	N	(%)
<b>Finding worker</b>						
Yes	20	64.5	4	57.1	7	70.0
No	10	32.3	1	14.3	2	20.0
Don't know	—	—	1	3.2	2	28.6
<b>Interviewing worker</b>						
Yes	17	54.8	4	57.1	3	37.5
No	12	38.7	1	14.3	5	62.5
Don't know	2	6.5	2	28.6	—	—
<b>Doing background check</b>						
Yes	24	77.4	4	57.1	5	55.6
No	6	19.4	1	14.3	4	44.4
Don't know	1	3.2	2	28.6	—	—
<b>Deciding how much to pay</b>						
Yes	24	77.4	5	71.4	4	44.4
No	5	16.1	1	14.3	5	55.6
Don't know	2	6.5	1	14.3	—	—
<b>What to do if worker doesn't show</b>						
Yes	26	83.9	6	85.7	4	44.4*
No	5	16.1	1	14.3	5	55.6
<b>Firing worker if doesn't work out</b>						
Yes	12	38.7	2	28.6	4	44.4
No	18	58.1	3	42.9	5	55.6
Don't know	1	3.2	2	28.6	—	—
<b>Payroll taxes</b>						
Yes	22	71.0	5	71.4	6	66.7
No	8	25.8	1	14.3	2	22.2
Don't know	1	3.2	1	14.3	1	11.1

\* p &lt; .05

acteristics of current services creates more interest in the cash option. If consumers believed the services they currently received were much too low, they were more likely to be interested in the cash option. Also, if they were dissatisfied with the availability of

a worker in an emergency situation, they were significantly more likely to be interested in the cash option. Florida can be very pleased with the high level of consumer satisfaction. For social marketing and enrollment purposes however, it would not be

sufficient for Florida to focus on dissatisfied consumers as they are in the minority.

### **Identifying Interested and Uncertain Consumers and Surrogates**

It is likely Florida can achieve its evaluation enrollment requirement by focusing on individuals who indicated an initial interest in the cash option—54 percent of the sample was interested. In addition, 23 percent of respondents stated they were unsure of their interest in the cash option. These individuals may decide to enroll if their concerns are satisfactorily addressed. When surrogates were asked if the consumer would be interested in the cash option, 49 percent said “yes,” but when asked if they were personally interested, an even higher percentage said “yes” (62 percent). It is unclear why surrogates believed fewer consumers would be interested in the option than they were themselves. Perhaps this is simply an indication that surrogates truly tried to answer for the consumer and did not allow their personal opinion to color the consumer's choice.

One of the survey's major research questions inquired about age as a factor influencing interest in the cash option. Although there was a significant difference in interest in the cash option between the younger (< 65) and older ( $\geq$  65) age groups (71 percent versus 51 percent), a high percentage of older consumers were interested. (Younger surrogates were also more likely to be interested in the option when compared to older surrogates (79 percent versus 35 percent)). These findings support the work of others,<sup>17</sup> who suggest that there may be sizable interest in consumer-directed services among older clients. In Florida this was certainly the case. Therefore, social marketing efforts should focus on consumers of all ages, not just younger consumers. Bivariate analyses indicated that in Florida (unlike the other three demonstration states) there were no significant differences in interest in the cash option based on race or gender. Surrogates also did not differ significantly on any of the demographic variables, with the exception of age as previously mentioned. This may make social marketing efforts easier given the broader potential client base.

There were significant differences among those interested, not interested, or not sure of their interest on a variety of variables. For example, those who were severely disabled were more likely to be inter-

ested in the option when compared to those who were mildly or moderately disabled. Prior to data collection, there was speculation regarding this variable. Some believed the most disabled individuals would not be able to manage all the tasks associated with the option and that the majority of those participating would be only mildly disabled. However, the data did not support this speculation; perhaps severely disabled consumers were especially excited about the flexibility and control offered via the cash option. Age of onset of disability also significantly increased interest level; the younger the age of onset, the more likely the consumer was to be interested in the cash option. However, age of onset of disability was also related to the consumer's current age ( $p < .001$ ). When current age was statistically controlled for using partial correlation, the relationship between age of onset and interest in the cash option was no longer significant ( $p > .60$ ).

Thirty-four percent of Florida consumers had experience hiring, firing, and interviewing workers, and 44 percent had experience supervising and training workers. Those who had these experiences were significantly more interested in the cash option when compared to those who had not. Perhaps those with past experience supervising, training, or hiring others (in any capacity) are more comfortable taking on some of the tasks related to the cash option, as they already know they can be successful.

Survey data indicated the highest level of interest in the cash option was among surrogate decision makers when expressing their own views (62 percent) followed by consumers answering for themselves (60 percent). In addition, respondents who had an informal caregiver were more interested in the cash option when compared to those who did not. These findings may be related, as surrogate decision makers are likely to be informal caregivers. Florida 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 informal caregiver—how does the presence of this individual influence a consumer's decision to select or not select a cash option? One possible explanation is that the informal caregiver could serve as the emergency back-up person if the paid worker didn't show up, 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.

### **Communications and Social Marketing Messages to Emphasize**

An important factor to further explore in relation to social marketing efforts is educational level. Forty-six percent of Florida consumers had less than a high school education, and 27 percent were high school graduates but did not go on to college. These findings serve as potent reminders 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 or trainers).

The survey data offer detailed guidance in assisting Florida in the development of communications and social marketing materials, and more importantly, provide direction for designing the cash option. For example, the majority of interested consumers thought it would be important to hire their own worker, to pay the worker more money if they desired, to know a group of others participating in the program, and to be able to back out of the program if they wished.<sup>18</sup> In fact, being able to back out of the program was important to a majority of all consumers (70 percent to 83 percent), regardless of interest level. Obviously, having a safety net (i.e., being able to back out without being penalized) is critical. This was expected, as change is difficult for people, even a desired change. This may be especially true for personal assistance services as they are essential to daily living and functioning. Finally, consumers appear to appreciate the importance of social support when embarking on a change.

Seventy-six percent of interested consumers wanted to be able to hire their current worker. This consumer preference has important implications for Florida. It is understandable that once consumers have a worker they like they would want to continue with that person, especially as focus-group findings indicated many consumers had unsatisfactory experiences before finding a worker they liked. However, this desire poses difficult organizational issues. It is possible provider agencies may try to limit this practice. In addition, a worker may need full-time employment but only work part-time 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 the existing arrangement.

Surrogates' reasons for being interested in the cash option also offer messages to include when addressing that group. Surrogates' interest in the cash option was significantly related to their willingness to assume responsibility for employer tasks, a concept to highlight in social marketing messages. Materials should be sure to highlight the surrogate's ability to interview and hire workers (even a friend or relative), the possibility that the cash option would make things easier for surrogates, increase flexibility for both consumers and surrogates, as well as provide potential benefits to the consumer.

Effective social marketing materials also need to address the consumer's ability to "get services on the days and at the times you want," "hire whomever you want to provide personal care services, even a friend or a relative," and "buy different services," as the vast majority of interested consumers found these program characteristics appealing. The majority of consumers interested in the cash option wanted to purchase more hours of service, house-keeping services, and transportation services, so each of these should also be included in social marketing materials.

Consumers interested in the cash option were more likely to express a need for help or training in employer tasks. Social marketing materials should be sure to inform consumers that they could have help or training with the most requested tasks. 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: consumers' rights and responsibilities under the cash option, assurance that other current benefits would not be affected, cash option financial details, and an explanation of how the current worker would be affected.

### **Policy Issues**

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

Fraud and abuse concerns, related to the possibility that consumers and/or their families might misuse the cash benefit or be exploited by others,<sup>19</sup> must also be considered. While the demonstration needs to address these concerns, procedures to minimize fraud and abuse must 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 or their workers. Florida survey data indicate these possibilities are limited as a majority of consumers and surrogates interested in the cash option (77 percent and 71 percent, respectively) said they wanted help or training with payroll and taxes. Most clients are likely to elect to have the payroll and tax withholding for their workers done by accounting professionals. This would greatly reduce the amount of cash consumers receive and manage.<sup>20</sup> Those consumers electing not to use accounting professionals will need to participate in a training program and pass a skills test in payroll tasks. Any training program Florida develops must take into consideration that 46 percent of respondents did not complete high school and only 27 percent graduated from high school.

One may also question whether the cash benefit will be adequate to provide the level of service that consumers need as Florida offers a relatively small benefit level (\$389 monthly is the weighted average for different programs). This may be especially pertinent for severely disabled consumers with high levels of need. While it is not possible to comment on the adequacy of the benefit until the evaluation is complete, it is important to note that the amount of the cash benefit will approximate the dollar amount spent on the consumer's current service plan (and will be based upon the same assessment process used in the traditional program). The evaluation will compare cost, quality, and satisfaction with service in both the cash option and traditional services and will be able to compare adequacy of service in both models.

To prevent consumer exploitation by others (and subsequent suffering of ill effects), the cash option

allows and encourages the use of surrogate decision makers to represent consumers who are unable to make all decisions independently. (Surrogates are not paid for their assistance.) While there are many questions to consider regarding surrogate decision makers, we know from the Florida survey that 9 percent of consumers utilized surrogates and 62 percent of surrogates responding for themselves (versus 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—even 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 vast majority of consumers who were interested in the cash option wanted these support services. In Florida, all consumers and surrogates will be required to participate in a training program.

Florida 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 consumers are likely to hire friends or relatives as their workers. Policy makers 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<sup>21</sup> 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, Texas, and Maryland 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.<sup>22</sup> The Florida survey indicates the CCDE will further our understanding about the quality of services when friends and relatives become paid providers.

## Summary

This article has presented results from a telephone survey conducted to assess the preferences of elders and adults with physical disabilities for a cash option versus traditional services in Florida, one

demonstration state in the CCDE. The telephone survey was conducted as background research. Survey findings have guided Florida in designing the cash option and developing much needed communications, training, and social marketing materials. These efforts are essential to informing Florida consumers about the cash option so they can make thoughtful

decisions about choosing a consumer-directed option or staying in the traditional program. As the CCDE continues, we will not only learn how consumers fare in the cash option, but also how this rigorous social experiment will offer valuable lessons about how to implement consumer-directed programs in a “real world” setting.

## Endnotes

1. The CCDE is cosponsored by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation.
2. Lori Simon-Rusinowitz et al., *The Status of a Common Agenda Between the Aging and Disability Communities: Where Has It Been? Where Is It Going? Views from Policy Experts*, in ANNUAL REVIEW OF ETHICS, LAW, AND AGING, at 85-106 (Marshall Kapp ed., 2000).
3. Gerben DeJong et al., *The Independent Living Model of Personal Assistance in National Long-Term Care Policy*, 16 GENERATIONS 89-95 (1992).
4. Edward F. Ansello & Nancy N. Eustis, *A Common Stake? Investigating the Emerging Intersection of Aging and Disabilities*, 16 GENERATIONS 5-8 (1992); UNIV. OF CAL. & WORLD INST. ON DISABILITY, TOWARD A UNIFIED AGENDA: PROCEEDINGS OF A NATIONAL CONFERENCE ON DISABILITY AND AGING (C.W. Mahoney et al. eds., 1986); Lori Simon-Rusinowitz & B.F. Hofland, *Adopting a Disability Approach to Home Care Services for Older Adults*, 33 GERONTOLOGIST 159-67 (1993).
5. Simon-Rusinowitz et al., *supra* note 2.
6. Health Security Act, H.R. 3600, 103d Congress (2d Sess. 1994), S1757, 103d Congress (2d Sess. 1994), cited in Marshall Kapp, *Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services*, 4 ELDER L.J. 55-97 (1996).
7. Much of this background section comes from background materials written by Pamela Doty, the CCDE's project officer at DHHS, ASPE.
8. SIMI LITVAK ET AL., WORLD INST. ON DISABILITY, ATTENDING TO AMERICA: PERSONAL ASSISTANCE FOR INDEPENDENT LIVING, A SURVEY OF ATTENDANT SERVICE PROGRAMS IN THE UNITED STATES FOR PEOPLE OF ALL AGES WITH DISABILITIES (1987); SIMI LITVAK & J. KENNEDY, WORLD INST. ON DISABILITY, NEW MODELS FOR THE PROVISION OF PERSONNEL ASSISTANCE SERVICES app. B (1990); SIMI LITVAK & J. KENNEDY, WORLD INST. ON DISABILITY, POLICY ISSUES AND QUESTIONS AFFECTING THE MEDICAID PERSONAL CARE SERVICES OPTIONAL BENEFIT (1991).
9. S. GERON & D. CHASSLER, CONN. CMTY. CARE, GUIDELINES FOR CASE MANAGEMENT PRACTICE ACROSS THE LONG-TERM CARE CONTINUUM (1994); M.E. JACKSON, RATIONING CASE MANAGEMENT: SIX CASE STUDIES (1994) (report prepared for the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services).
10. Kapp, *supra* note 6.
11. For a detailed description of the CCDE design, see Kevin J. Mahoney et al., *Early Implementation Lessons from the Cash and Counseling Demonstration and Evaluation*, 24 GENERATIONS 41-46 (2000).
12. C. BARNES & S. SUTHERLAND, CAL. STATE UNIV., CONTEXT OF CARE, PROVIDER CHARACTERISTICS, AND QUALITY OF CARE IN THE IHSS PROGRAM: IMPLICATIONS FOR PROVIDER STANDARDS (Apr. 17, 1995); A.E. BENJAMIN ET AL., U.C.L.A., COMPARING CLIENT-DIRECTED AND AGENCY MODELS FOR PROVIDING DISABILITY-RELATED SUPPORTIVE SERVICES AT HOME (Sept. 1998); Pamela Doty et al., *Consumer-Directed Models of Personal Care: Lesson from Medicaid*, 74 MILBANK MEMORIAL FUND 377-409 (1996); Nancy N. Eustis & L.R. Fischer, *Common Needs, Different Solutions? Younger and Older Homecare Clients*, 16 GENERATIONS 17-22 (1992); L.L. GLICKMAN ET AL., UNIV. OF MASS., SELF-DIRECTION IN HOME CARE FOR OLDER PEOPLE (1994).
13. Sharon Tennstedt & Bei-Hung Chang, *The Relative Contribution of Ethnicity versus Socioeconomic Status in Explaining Differences in Disability and Receipt of Informal Care*, 53B(2) J. GERONTOLOGY SOC. SCI. S61-70 (1998); Steven P. Wallace et al., *The Persistence of Race and Ethnicity*, 53B(2)

- J. GERONTOLOGY SOC. SCI. S104–112 (1998); S. Rimer, *Blacks Carry Load of Care for Their Elderly*, N.Y. TIMES, Mar. 15, 1998, at 1.
14. Mark Sciegaj & C.K. Kyriacou, *Study Examines Racial and Ethnic Differences in Preferences for Consumer Direction*, 4(4) CONSUMER CHOICE NEWS 5 (Spring 2000).
  15. Recent welfare reform legislation enacted close to the time the survey was conducted may have increased fear within the Hispanic population, thus creating reluctance to respond.
  16. We anticipated a language problem in Florida with many English-speaking workers and Spanish-speaking clients, or the other way around, so having only 9 percent of respondents state they had language difficulties was unexpected.
  17. BARNES & SUTHERLAND, *supra* note 12; Doty et al., *supra* note 12; Eustis & Fischer, *supra* note 12; GLICKMAN ET AL., *supra* note 12.
  18. Younger consumers were also significantly more likely than older consumers to believe the first three characteristics mentioned above were important.
  19. Pamela Doty, U.S. D.H.H.S., internal briefing paper addressing possible fraud and abuse issues in the cash option (1997) (unpublished).
  20. *Id.*
  21. BARNES & SUTHERLAND, *supra* note 12; BENJAMIN ET AL., *supra* note 12.
  22. Doty et al., *supra* note 12.