Vulnerable Populations

Determining Personal Care Consumers' Preferences for a Consumer-Directed Cash and Counseling Option: Survey Results from Arkansas, Florida, New Jersey, and New York Elders and Adults with Physical Disabilities

Kevin J. Mahoney, Lori Simon-Rusinowitz, Dawn M. Loughlin, Sharon M. Desmond, and Marie R. Squillace

Objective. To assess Medicaid consumers' interest in a consumer-directed cash option for personal care and other services, in lieu of agency-delivered services.
Data Sources/Study Setting. Telephone survey data were collected from four states from April to November 1997. Postsurvey focus groups were conducted in four states in 1998. Early implementation experiences are drawn from three states from 1999 to 2002.
Study Design. Participants ($N = 2{,}140$) were selected for a structured telephone survey interview from a probability-sampling frame of current Medicaid consumers in Arkansas, Florida, New Jersey, and New York. Key variables include interest in the cash option, demographic and background characteristics of consumers, as well as previous experience and training needed. Postsurvey focus groups were also conducted with current Medicaid consumers.
Data Collection/Extraction Methods. Interviewers read the telephone survey from computer screens and entered responses directly into the database of the Macintosh *Computer Assisted Telephone Interview* software. Data were analyzed using *SPSS* 10.0 (www.spss.com) for Windows.
Principal Findings. Cash option interest was positively associated with experience hiring and supervising workers, more severe levels of disability, having a live-in caregiver, living in Florida, and minority status. Age of the client was also a significant factor.
Conclusions. There is significant interest in the cash option, although interest varies among subgroups of consumers. Future research should continue to evaluate interest in the cash option among different groups of consumers, as well as actual experience with the option when the Cash and Counseling Demonstration and Evaluation (CCDE) evaluation findings are completed.

Key Words. Long-term care policy, consumer direction, consumer preferences, cash allowance

> Mrs. Green needs personal care because of arthritis and heart trouble. She can do some things for herself, but she needs some help bathing, dressing, and preparing meals. In the Cash and Counseling option, she could receive cash every month to pay for help with these tasks, and she could choose the services and the workers. For example, if she wishes, Mrs. Green can use her money to pay her niece to help her bathe and dress in the morning and prepare some meals. She could pay the high school girl who lives downstairs to prepare her dinner and help her get ready for bed in the evening. Mrs. Green may also use the money to buy some special equipment like grab bars that will make her more independent. She, not an agency, gets to make these decisions about her needs and care.

For many years, persons from the disability community have suggested that if people like Mrs. Green had more control over services, their quality of life would improve. The Cash and Counseling Demonstration and Evaluation (CCDE) is a test of this belief, comparing cost, quality, and satisfaction of Medicaid consumers receiving traditional personal care services with those receiving the cash option. 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. It operates under Section 1115 Research and Demonstration waivers granted by the Centers for Medicare and Medicaid Services (CMS).

Early in the CCDE development, program planners realized that key information essential to program implementation was lacking: data detailing consumers' preferences for a consumer-directed cash option versus traditional agency-delivered services. This article reports on background research conducted to inform the design of the CCDE in Arkansas, Florida, New Jersey, and New York (although only Arkansas, Florida, and New Jersey proceeded to implementation), and to further our understanding about implementing consumer-directed services in other states.

The Cash and Counseling Demonstration and Evaluation (CCDE) is cosponsored 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 Centers for Medicare and Medicaid Services (CMS) granted Section 1115 research and demonstration waivers to the demonstration states and CMS provides continuing oversight and technical assistance.

Address correspondence to Lori Simon-Rusinowitz, M.P.H., Ph.D., University of Maryland Center on Aging, 2360 HHP Bldg., College Park, MD 20742. Kevin J. Mahoney, Ph.D., is with Boston College, Graduate School of Social Work, Chestnut Hill, MA. Dawn M. Loughlin, Ph.D., is with the University of Maryland Center on Aging, College Park, MD. Sharon M. Desmond, Ph.D., is with the University of Maryland, Department of Public and Community Health, College Park, MD. Marie R. Squillace, Ph.D., is with the U.S. Department of Health and Human Services, Administration on Aging, Washington, DC.

BACKGROUND

The idea of consumer-directed services originated more than three decades ago among younger persons with disabilities in the disability rights and independent living movements (DeJong, Batavia, and McKnew 1992). The aging community, comprised of aging leaders, elders, and others with an interest in aging issues, began to adopt consumer-direction principles more recently when a coalition between the aging and younger disability communities emerged in the mid-1980s (Ansello and Eustis 1992; Mahoney, Estes, and Heumann 1986; Simon-Rusinowitz and Hofland 1993). Interest in consumer choice expanded among some aging leaders in the early 1990s, in part due to a belief that consumer-directed care may lead to much-needed cost savings (Simon-Rusinowitz et al. 2000). The emphasis on consumer choice and control in the language of the 1994 Health Security Act (H.R. 3600, 1994; Kapp 1996) exemplifies this increased interest.

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

Cash allowance programs have typically been 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 had 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 (Litvak and Kennedy 1991; Velgouse and Dize 2000). In addition, state officials have a strong interest in achieving program economies. Most Medicaid personal care programs mandate that case managers (registered nurses or social workers), develop and monitor care plans and authorize provider payments. Case management can be expensive, and researchers and administrators question whether it should be uniformly required (Geron and Chassler 1994; Jackson 1994).

The cash and counseling model offers a cash allowance and information services to clients so they can purchase personal care services, assistive devices, or home modifications that best meet their individual needs. Information services include assistance with cash management tasks such as hiring, training, and managing workers as well as payment responsibilities. In theory, consumers who shop for the most cost-effective providers may then (through such savings) have funds to purchase additional services (Kapp 1996).

Determining Consumers' Preferences for a Cash Option

Program planners wondered if those with severe disabilities would be able to manage the cash option tasks, and have also suggested that younger consumers would be more interested in consumer-directed services. However, there is scant information regarding demographic and background characteristics that may influence interest in consumer direction. Sciegaj and Kyriacou (2000) found that consumers' preferences for types of personal assistance services (consumer-directed, negotiated care managed, and traditional case managed services) varied among racial/ethnic groups. There is also evidence that consumers of all ages, including elders, would like to be more involved in directing their care (Barnes and Sutherland 1995; Benjamin and Matthias 2001; Doty, Kasper, and Litvak 1996).

In this study, which synthesizes data gathered from 2,140 consumers from four states, we asked the following general research questions: (1) What demographic and background characteristics influence a consumer's interest in a cash option? and (2) What types of supports are needed by consumers who want to participate in the cash option? Given speculations that older consumers would not be interested in a consumer-directed program (Simon-Rusinowitz et al. 2000), we were also concerned specifically with addressing the question: What are the effects of age on interest and willingness to participate in a cash option? These findings helped the demonstration states to design their programs and are expected to guide future programs as well.

Methods

Participants

Clients aged 65 and older, and adults with physical disabilities aged 18 to 64, were selected from a probability-sampling frame of all Medicaid personal care

clients in each of the four states. For a more detailed description of methodologies and individual state results see Desmond et al. (2001), Mahoney et al. (in press), Mahoney et al. (1998), and Simon-Rusinowitz et al. (1997). We allowed for surrogate representation in completing the surveys, so that more consumers' views would be represented. Overall, surrogate respondents made up 17 percent of respondents. However, surrogates were asked to have the consumer present, if possible, and to obtain or clarify the responses they made on behalf of the consumer. Surrogates were also explicitly asked and reminded to answer *for* the consumer when the consumer could not be present, and to answer for themselves only when the question called for their own opinions.

Instrument

Survey development was guided by focus group discussions that took place in 1996–1997 in New York and Florida. The 96 focus group participants (elders aged 65 and older, adults with physical disabilities aged 18–64, and surrogate decision makers), were organized into 11 groups. Discussion topics included consumer satisfaction with current Medicaid PAS services and consumer and surrogate reactions to a consumer-directed cash option and the tasks associated with the option. The research team then developed similar survey instruments for each state, assessing demographics, attitudes toward cash option tasks, and interest in a cash option. Content validity was established via a panel ($n = 7$) with expertise in aging, disabilities, and survey design and evaluation. The survey was tested with three disabled and elderly individuals to assess administration time, language appropriateness, and understanding of the items. The instruments in New York, New Jersey, and Florida were translated into Spanish, and then translated back, to insure accuracy and to enable Spanish-speaking consumers and surrogates to participate.

To explain the cash option, interviewers read the vignette that introduced this article and then asked if the consumer would be interested in such an option. We were concerned most with identifying consumers who would likely be open to more information about the option (interested or unsure), versus those who knew they were not interested. We also assessed loss of variance in the model due to the collapse of these categories, comparing a saturated model that included all three categories of interest to one in which the interested/unsure categories were collapsed. Given the relatively small chi-square difference ($p > .01$), categories were collapsed for analysis in the direction of theoretical interest and interested/not sure versus not interested.

The survey also included a measure of functional status based on five activities of daily living (ADLs): bathing, dressing, using the toilet, transferring, and eating. Consumers were asked if they needed help with each of the five tasks, and could respond "yes," "no," or "sometimes." A "yes" response received a score of 1, a "no" response a 0, and a "sometimes" response a 0.5. Individuals scoring from 0 to 1.5 were considered mildly disabled, those scoring from 2 to 3.5 were considered moderately disabled, and those scoring from 4 to 5 were considered severely disabled. Other background variables assessed in the survey included: age (collapsed by decade), race/ethnicity, gender, marital status, home ownership, history of employment, and self-rated health (excellent, very good, good, fair, poor). We recorded whether a surrogate or consumer responded to the survey, and the state in which the consumer resided. Consumers were asked if they had an informal caregiver, and if that informal caregiver lived in. Consumers were asked if they had any experience hiring or firing workers, and in a separate question, if they had any experience supervising or training workers. Consumers who indicated that they had experience with hiring and firing also tended to respond yes to the question about supervisory experience. These responses were recoded into one dichotomous variable: any experience with hiring, firing, supervising, or training workers, versus no experience in the four areas.

Procedure and Response Rate

The department responsible for the program in each state mailed letters to inform consumers about the telephone survey, to explain the Cash and Counseling program, and to encourage participation in the study. Data for all four states were collected in telephone interviews conducted between April and June of 1997 in Arkansas and New York, July through September of 1997 in New Jersey, and September through November of 1997 in Florida. The average interview was approximately 40 minutes.

Response rates (number of respondents/number contacted) for each state were calculated with and (without) inclusion of those who could not respond to the survey due to language barriers. Response rates were: Arkansas: 34 percent, (34 percent), Florida: 48 percent, (50 percent), New Jersey: 38 percent, (55 percent), and New York: 23 percent, (31 percent). Two reasons for refusals that were commonly observed were: (1) feeling too sick, too disabled, or too old, and (2) no interest in answering any survey. We compared a sample of these two groups in each state on two variables: age and average amount of Medicaid personal care expenditures (over 12 months in

New York; 6 months in Arkansas; and 9 months in New Jersey and Florida). Respondents were younger ($p < .05$) on average than nonrespondents in all four states, and Medicaid personal care expenditures were slightly higher for respondents versus nonrespondents in New Jersey and Florida.

Postsurvey Focus Groups

The second set of 16 focus groups with a total of 93 participants was conducted in 1998 in Florida, New York, New Jersey, and Arkansas after the telephone surveys were completed. These focus groups were organized on the basis of race/ethnicity, age (younger and older than 65), and also on consumer/surrogate status. Participants viewed a video describing the cash option and the subsequent focus group discussions were audiotaped, videotaped, and transcribed. In addition to the original topics covered in the moderator's guide, new and recurrent themes emerged from the discussions. These themes were noted and text was clustered under the moderator's topics and the new themes.

RESULTS

Consumer Demographic Characteristics

There were 1,783 consumers and 357 surrogates for consumers who participated in the survey. Table 1 presents sample characteristics by state. Women represented the vast majority of consumers in each state, ranging from 77 percent to 89 percent. The majority of consumers in each state were over age 60. The racial composition was primarily Caucasian (47–61 percent) and African American (26–48 percent). Most consumers were widowed, separated, or divorced (63–78 percent), and reported living alone (51–61 percent). Many had less than a high school education (41–85 percent).

Although many constants were observed across the states, Arkansas sometimes presented as the outlier. Eighty-five percent of the Arkansas sample had less than a high school education; and more than half (52 percent) were over 80 years old. While African American and Hispanic minorities were represented in each of the other states, in Arkansas nearly half (48 percent) of respondents were African American and none were Hispanic. Respondents in Arkansas were also the least likely to report ever having been employed, and to report having experience hiring, firing, supervising, or training workers, although they were the most likely to report home ownership.

Table 1: Demographic and Background Characteristics of Consumers by State

	Arkansas		Florida		New Jersey		New York	
	N = 470	%	N = 554	%	N = 640	%	N = 476	%
Gender								
Male	51	10.9	110	20.1	149	23.3	111	23.3
Female	419	89.1	437	79.9	491	76.7	365	76.7
Age								
20–29	1	0.2	8	1.5	42	6.7	15	3.2
30–39	4	0.9	24	4.4	53	8.4	21	4.5
40–49	12	2.6	43	7.9	56	8.9	33	7.1
50–59	23	4.9	70	12.9	61	9.7	62	13.2
60–69	54	11.6	113	20.8	104	16.5	85	18.2
70–79	129	27.7	131	24.2	156	24.8	123	26.3
80–89	173	37.2	120	22.1	126	20.0	101	21.6
90–99	69	14.8	33	6.1	31	4.9	28	6.0
Race/Ethnicity								
Caucasian	212	50.2	321	60.7	283	46.6	221	49.7
African American	203	48.1	135	25.5	225	37.1	151	33.9
Hispanic	0	0	58	11.0	76	12.5	56	12.6
Other	7	1.7	15	2.8	23	3.8	17	3.8
Education								
Less than high school	399	84.9	267	48.1	316	48.3	193	41
High school graduate	48	10.2	160	28.8	211	32.3	174	36.9
Some college	12	2.6	81	14.6	81	12.4	56	11.9
B.A./B.S.	6	1.3	32	5.8	23	3.5	28	5.9
Some graduate school	2	0.4	5	0.9	3	0.5	4	0.8
Graduate degree	3	0.6	10	1.8	20	3.1	16	3.4
Marital Status								
Married or live with partner	56	12.0	81	15.1	49	7.7	55	11.6
Widowed, divorced, or separated	364	77.9	385	71.6	400	62.6	310	65.1
Single never married	47	10.1	72	13.4	190	29.7	111	23.3
Living Arrangement								
Alone	279	56.9	292	49.9	371	54.4	302	61.3
With spouse or children	139	28.4	179	30.6	122	17.9	113	22.9
With friend, partner, or relative	70	14.3	113	19.3	182	26.7	67	13.6
Other	2	0.4	1	0.2	7	1.0	11	2.2
Home Ownership								
Yes	201	42.9	197	36.6	70	11.0	50	10.5
No	267	57.1	341	63.4	567	89.0	425	89.5
Ever Employed								
Yes	327	70.2	493	91.8	504	79.1	401	84.4
No	139	29.8	44	8.2	133	20.9	74	15.6
Informal Caregivers								
Yes: live-in	82	17.5	171	31.5	148	23.2	85	18.0
Yes: non–live-in	199	42.5	162	29.9	233	36.5	164	34.7
No informal caregiver	187	40.0	209	38.6	257	40.3	224	47.4

continued

Table 5. (Contd.)

	Arkansas		*Florida*		*New Jersey*		*New York*	
	N = 470	*%*	*N = 554*	*%*	*N = 640*	*%*	*N = 476*	*%*
Overall Health								
Excellent	13	2.8	14	2.6	24	3.8	11	2.4
Very good	38	8.3	17	3.2	47	7.5	29	6.2
Good	88	19.3	96	18.0	139	22.1	92	19.7
Fair	121	26.5	176	33.1	217	34.6	161	34.5
Poor	197	43.1	229	43.0	201	32.0	173	37.1
Score on Activities of Daily Living Scale								
Mild	265	57.1	266	51.4	371	58.8	248	52.7
Moderate	150	32.3	137	26.4	140	22.2	115	24.4
Severe	49	10.6	115	22.2	120	19.0	108	22.9
Experience Hiring, Firing, Supervising, or Training Workers								
Yes	106	22.7	263	49.3	238	37.5	191	40.8
No	360	77.3	270	50.7	396	62.5	277	59.2
Interest in Cash Option								
Interested	147	31.3	322	58.1	269	42.0	192	40.3
Don't know	116	24.7	113	20.4	126	19.7	102	21.4
Not Interested	207	44.0	119	21.5	245	38.3	182	38.2

Consumer Interest in the Cash Option

Direct cross-tabulations of interest in the cash option by age, as presented in Table 2, showed high levels of interest throughout the life span, especially during the middle years. To assess demographic and background variables that predicted interest in the cash option a hierarchical series of multivariate logistic regression equations were computed. When through forward selection, six variables contributed to the fit of the model, a main effects model was chosen. No additional variables or two-way interactions significantly increased the fit of the model (Model $X^2 = 250.54$, 18 *df*, $p < .001$, $n = 1{,}910$). The six variables were: consumer age; experience hiring, firing, supervising, or training a worker; having an informal caregiver; severity of disability (ADL); the state in which the consumer resides; and consumer race/ethnicity.

Age effects were assessed with deviation contrasts. That is, each group was examined with reference to the average interest among all groups except the examined group. Odds of showing some interest among consumers in their twenties, fifties, and sixties were not significantly different from the average odds on interest for all other consumers. However, compared to the average odds on interest for all other consumers, consumers in their thirties had 1.9 times higher odds, and those in their forties had 1.7 times higher odds,

Table 2: Consumer Interest in the Cash Option and Desired Level of Involvement by Consumer Age

Consumer Age		*Interest in Cash Option*				*Desired Level of Involvement*				
		Interested	*Don't Know*	*Not Interested*	*Total*	*More Involvement*	*Same Involvement*	*Less Involvement*	*Don't Know*	*Total*
20–29	Count	36	9	21	66	22	30	1	3	56
	Percent within consumer age	54.5	13.6	31.8	100	39.3	53.6	1.8	5.4	100
30–39	Count	63.0	21.0	18.0	102	53.0	39.0	2.0	7.0	101
	Percent within consumer age	61.8	20.6	17.6	100	52.5	38.6	2.0	6.9	100
40–49	Count	90.0	23.0	31.0	144	62.0	68.0	1.0	10.0	141
	Percent within consumer age	62.5	16.0	21.5	100	44.0	48.2	0.7	7.1	100
50–59	Count	130.0	31.0	55.0	216	92.0	116.0	5.0	7.0	220
	Percent within consumer age	60.2	14.4	25.5	100	41.8	52.7	2.3	3.2	100
60–69	Count	177.0	72.0	107.0	356	115.0	219.0	3.0	24.0	361
	Percent within consumer age	49.7	20.2	30.1	100	31.9	60.7	0.8	6.6	100
70–79	Count	208.0	121.0	210.0	539	153.0	342.0	3.0	48.0	546
	Percent within consumer age	38.6	22.4	39.0	100	28.0	62.6	0.5	8.8	100
80–89	Count	158.0	134.0	228.0	520	137.0	335.0	12.0	52.0	536
	Percent within consumer age	30.4	25.8	43.8	100	25.6	62.5	2.2	9.7	100
90–99	Count	50.0	38.0	73.0	161	42.0	104.0	3.0	22.0	171
	Percent within consumer age	31.1	23.6	45.3	100	24.6	60.8	1.8	12.9	100
	Total									
	Count	912.0	449.0	743.0	2104	676.0	1,253.0	30.0	173.0	2132
	Percent within consumer age	43.3	21.3	35.3	100	31.7	58.8	1.4	8.1	100

on showing some interest in the cash option. On the other hand, for consumers in their seventies, the odds of showing some interest versus not being interested were decreased by a factor of .76, for those in their eighties odds were decreased by a factor of .66, and for those in their nineties odds were decreased by a factor of .48, as compared to the average odds on showing interest for other consumers.

Consumers who indicated any experience hiring, firing, supervising, or training workers had 2.5 times higher odds on showing some interest in the cash option as contrasted with those without such experience ($p < .001$). For consumers with an informal caregiver who did not live in, the odds of showing some interest were 1.4 times higher, and for consumers with a live-in informal caregiver the odds of showing some interest were 1.9 times higher, when each group was compared to the odds of interest among those who had no informal caregiver ($p < .001$).

Consumers who were classified in the severe range of the ADL scale had 1.5 times higher odds of being interested in the cash option, as compared to those in the mild range ($p < .05$), although there was no increase in odds on showing interest for those consumers with moderate disability. Using New Jersey as the comparison state, consumers in New York and Arkansas were not significantly different in their relative odds of showing some interest, however consumers in Florida had 2.4 higher odds of showing some interest in the cash option. African American respondents had 1.9 times higher odds, and Hispanic consumers had 1.6 times higher odds of showing some interest in the option, as compared to Caucasian consumers ($p < .001$).

Consumers Willingness to Perform Tasks and Desired Level of Involvement

To further address age-related capacities and interests, six questions that concerned the consumer's willingness to perform tasks associated with the cash option were examined by consumer age: hiring, showing a worker what to do, scheduling, supervising, paying a worker, and firing a worker. Table 3 presents these results. In each case, a curvilinear relationship appeared, similar to the independent effect of age on interest in the cash option, with willingness generally peaking in the thirties through fifties. However, willingness remained high even in the later decades. With the exception of hiring a worker, more than 60 percent of respondents in their sixties, seventies, and eighties were willing to perform these cash option tasks.

Another survey question concerned consumers' desired level of involvement in determining the amount and type of services, asking if the

Table 3: Consumers' Willingness to Perform Cash Option Tasks by Age

	Hire Worker		*Show Worker What to Do*		*Schedule Worker*		*Supervise Worker*		*Pay Worker*		*Fire Worker*	
Age	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*	*N*	*%*
20–29	27	47.4	41	77.4	38	73.1	34	64.2	33	63.5	39	73.6
30–39	53	53.0	84	85.7	73	74.5	76	79.2	69	70.4	79	81.4
40–49	88	64.7	115	87.1	111	83.5	106	79.1	108	80.0	100	73.5
50–59	134	60.9	191	88.8	181	83.4	172	79.6	161	73.2	175	79.5
60–69	156	43.7	303	86.6	271	78.3	262	75.3	240	68.0	250	71.2
70–79	233	42.9	454	84.5	367	68.0	384	71.0	348	64.1	362	66.2
80–89	212	40.3	410	78.5	331	63.8	349	67.2	322	62.3	322	61.7
90–99	60	36.1	117	72.2	88	54.3	91	57.2	91	57.2	98	60.9
Total	963	45.7	1,715	82.9	1,460	70.6	1,474	71.3	1,372	66.1	1,425	68.3

consumer desired more, less, or the same level of involvement. A cross-tabulation of age by desired level of involvement (see Table 2) indicated a similar pattern—with desire for more involvement peaking in the thirties through fifties, but still significant percentages (25–32 percent) for consumers over age 60.

Consumer Need for Help or Training

Although the majority of consumers were willing to complete the tasks associated with the cash option, they also indicated a need for help or training. Consumers were asked, if they were to choose the cash option, would they want help or training with: finding a worker, interviewing a worker, doing a background check, deciding how much to pay a worker, firing a worker, and payroll tasks. Results for those who expressed some interest in the cash option (interested or unsure) are presented in Table 4. Although there were statistically significant differences by age category for each variable, no obvious pattern for these differences emerged and the desire for help or training on tasks was high in all age groups.

Discussion and Recommendations

Interest in the Cash Option and Age

One of the survey's major research questions concerned age as a factor influencing interest in the cash option. We noted that the youngest group

Table 4: Need for Help or Training with Cash Option Tasks among Consumers Expressing Some Interest in the Cash Option, by Age of Consumer

	Finding a Worker		*Interviewing a Worker*		*Doing a Background Check*		*Deciding Pay*		*Help When Worker Doesn't Show Up*		*Firing a Worker*		*Help with Payroll*	
Age	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%	*N*	%
20–29	29	72.5	23	57.5	33	82.5	30	75.0	23	57.5	23	57.5	31	77.5
30–39	50	61.7	38	46.3	64	78.0	58	70.7	53	64.6	37	45.1	63	76.8
40–49	71	64.0	52	46.8	94	84.7	82	73.9	77	69.4	46	41.4	93	83.8
50–59	96	60.0	82	51.3	126	79.7	124	77.5	110	68.8	70	43.8	125	78.1
60–69	148	60.7	129	52.7	175	72.0	191	78.3	166	68.3	112	45.7	189	77.5
70–79	218	66.7	193	59.0	229	70.2	260	79.5	226	69.3	187	57.2	243	74.5
80–89	166	58.2	165	57.7	203	71.0	214	74.3	207	72.6	157	54.7	213	74.7
90–99	56	66.7	47	56.6	59	71.1	61	72.6	62	73.8	52	62.7	55	65.5
Total	834	62.6	729	54.6	983	74.0	1,020	76.3	924	69.4	684	51.2	1,012	76.0

surveyed, those in their twenties, had less interest in the cash option than those slightly older. Younger people may not yet have gained the confidence to deal with the financial and interpersonal tasks associated with the cash option. Interest rose substantially among consumers in their thirties, remaining high throughout the midlife period (ages 30–60). Although interest in the cash option did decline after age 60, a high percentage of older consumers were still interested. In addition, a high percentage of consumers aged 60 and older desired more involvement in determining the type and amount of their services (25–32 percent). Consistent with these survey findings, focus group participants indicated various levels of interest in the cash option among young and older consumers. Some consumers of all ages liked and disliked the idea of a consumer-directed cash option.

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

> This is a great program. … [I]t puts me in a position of not being beholden and not being under someone else's thumb. (New York Consumer, <65)

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

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

Seventy-two percent of Arkansas demonstration consumers ($n = 2{,}008$) are elderly, which mirrors the proportion of elders in the Arkansas Medicaid personal care consumer population that is eligible to choose the cash option. Fifty-four percent of the first 231 New Jersey demonstration consumers are elderly (Brown and Foster 2001). Clearly, communication efforts should focus on consumers of all ages, not just younger consumers.

Interest in the Cash Option and Level of Disability

Those who were severely disabled were more likely to be interested in the option when compared to those who were mildly or moderately disabled. Prior to data collection, some program planners believed that the most disabled individuals would not be able to manage all of the cash option tasks and that the majority of those participating would be only mildly disabled. However, the data did not support this speculation; perhaps consumers with severe disabilities were especially excited about the cash option's flexibility and control.

When asked to explain why consumers with more severe disabilities were more interested in the cash option, focus group participants offered poignant insights.

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

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

Interest in the Cash Option and Experience with Cash Option Tasks

Those who had experience hiring, firing, supervising, or training workers (37 percent) were significantly more interested in the cash option when compared to those who did not have these life experiences. It is likely that those with past experience with these tasks (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.

While the focus groups did not directly address experience hiring, supervising, or training, they did address consumers' perceived abilities to perform cash option tasks. Participants varied in their perceived abilities to manage these tasks, although most looked at the cash option tasks as steps to greater independence and control over their lives. In regard to finding a worker, those consumers who felt able to manage this task reported ideas such as gaining "access to names through ads" and "putting up signs at the schools that are training home health aides."

Payroll tasks elicited the greatest concern and widest range of reactions among focus group participants. Some participants—those tending to have previous workplace experience handling similar tasks—thought they could readily take on payroll responsibilities without training. Others were willing to handle these tasks, but wanted training and support to do so.

> I never worked outside the home, but I handled the money all the time. I'm very interested in it (the cash option). (Florida Consumer)

> I'd want training to do it (payroll tasks) myself. I'd want them to cover me on how to do it until I learned how to do it, and then I'd take care of it myself. (Arkansas Representative).

Interest in the Cash Option among Consumers with an Informal Caregiver

Even after controlling for their level of disability, respondents who had an informal caregiver, and particularly an informal caregiver who lived in, were more interested in the cash option than were those who did not. One explanation is that the informal caregiver could serve as the emergency back-up person if the paid worker did not show up, an important concern often expressed by consumers. In some cases, consumers may see their informal caregiver as a potential paid worker, relieving the consumer of the responsibilities of the interviewing and hiring process. Hiring a worker was the task that consumers in each age group expressed the least willingness to do. The CCDE findings in Arkansas and preliminary New Jersey findings support the tendency of consumers to hire family members or friends (Brown and Foster 2001; Dale et al. 2003). More than three-quarters of Arkansas consumers chose a family member and another 16 percent opted for a friend, neighbor, or church member. In early results from New Jersey, more than over three-quarters of the first 81 consumers who hired caregivers hired family members. Thirty-seven percent hired friends, neighbors, or church members. (Note: These percentages total more than 100 percent because consumers frequently hire more than one worker.)

Focus group findings further illuminate consumers' views about being able to hire a family member or friend, who may be already helping them with personal care needs.

> For once, your family member can actually help you and get paid. (New Jersey Representative)

> (Hiring a family member or friend) would be a blessing…there are family members who don't have a job and who know my needs and would be able to care for me. (New Jersey Consumer)

> I'd rather trust someone in the family that's capable. (New York Representative)

Hiring a relative or friend would enable consumers to hire someone of the same ethnicity, an important factor for African Americans and Hispanics.

> Hispanics know how to pick up a fruit or a vegetable…I prefer Hispanic because…you could say, buy me something, and they know. (New Jersey Hispanic Elder)

Interest in the Cash Option among Florida Consumers

Independent of the other factors that were examined, Florida consumers were more likely to be interested in the cash option. While we are unable to draw conclusions at this time about this effect, we can speculate that many Florida elderly residents have relocated to the state, and possibly these Florida consumers are a self-selected group who tend to be more independent or self-confident by nature. Another reason for increased interest among Florida residents could be differences in service and delivery patterns in their current program. This is an important consideration for states now considering a cash option program.

Interest in the Cash Option and Race/Ethnicity

Finally, African American and Hispanic consumers showed higher levels of interest in the option when compared to Caucasian consumers. This finding supports literature that suggested that preferences for consumer direction may vary by racial/ethnic group.

In focus group discussions, African American and Hispanic consumers and representatives were asked to explain reasons why their communities may have great interest in the cash option. Participants described strong family networks that emphasize caring for one another.

> They got that family value …When it comes to sticking together, mostly they are really tight. (New Jersey African American Representative)

> We're very interested, and our families, we want to have them in our homes. (New Jersey Hispanic Representative)

The ability to feel independent and in control may also be a source of pride for African American and Hispanic participants. In addition, the cash option could bring much-needed jobs (as personal care workers) to these communities.

> We've been dependent on the government so long. A program comes along like this, it seems like heaven. (Arkansas African American Consumer)

> It would be an income for someone else…some want to work and really need to work and they can't get a job…there are some ladies out there who would be glad to sit with the elder person, to have an income. (Arkansas African American Representative)

It is also reasonable to conclude that consumers from closely knit families and communities would have an easier time than consumers with fewer

connections in achieving the first, critical step in a counseling demonstration program—locating and hiring a worker. Although the literature suggested, survey findings predicted, and postsurvey focus groups confirmed higher levels of interest among minority consumers, Arkansas' experience reports only slightly higher participation among minority consumers versus nonminority consumers. Further research is needed to explore why substantially higher levels of initial interest in the cash option among minority consumers are reflected in only slightly higher enrollment rates.

Policy Issues

Findings about consumers' level of interest in a consumer-directed cash option may assist policymakers when deliberating the advantages and disadvantages of a national consumer-directed PAS program, such as MiCASA—the Medicaid Community Attendant Services Act of 1977–HR2020 (www.adapt.org/casa/toc.htm). Based on the assumption that all eligible consumers would want such a program, policymakers often fear overwhelming unmet need leading to exorbitant costs (Glazier 2001). However, the preference study findings and CCDE experience thus far confirm that this assumption is inaccurate, as a sizeable percentage of the eligible population would not be interested in a consumer-directed option.

Fraud and abuse concerns, related to the possibility that consumers or their families might misuse the cash benefit or be exploited by others (Doty 1997), must also be considered. The vast majority of consumers who were interested in the cash option wanted help or training with various cash option tasks—this type of training and assistance can serve as a deterrent to misuse and exploitation. For example, misuse of the cash benefit includes the possibility that consumers might not pay their taxes or their workers. Our data indicate that a majority of consumers interested in the cash option wanted help or training with payroll and taxes. This finding was important in gaining CMS (then HCFA) waiver approval for the CCDE, as it reassured HCFA officials and others that consumers would either use a bookkeeping service to pay workers and taxes, or participate in skills training to learn payment tasks. Experience in Arkansas is consistent with this finding, because almost all consumers are using a bookkeeping service.

We learned from focus group participants that the ability to hire a friend or family member as a paid worker was an important reason for interest in a cash option. Findings from Arkansas and New Jersey show that the vast majority of consumers are hiring relatives and friends, despite policymakers'

concerns about the quality of care provided by friends or relatives who may lack formal training. Arkansas evaluation results negate policymakers' concerns, as these workers provided care that was at least as safe as agency workers and on some measures their care had better outcomes (Foster et al. 2003). Forthcoming reports from New Jersey and Florida will further our understanding about the quality of services when friends and relatives become paid providers. As part of the CCDE, a research team is developing quality assurance procedures consistent with consumer-directed principles to monitor the quality of services provided by all workers, including friends and relatives.

SUMMARY

Survey findings have guided Arkansas, Florida, and New Jersey, and are intended to guide other states, in designing a cash option and developing communications and training materials. As the CCDE evaluation results are completed, we will learn how consumers fare in three specific cash option program designs. Combined with consumer preference data, these evaluations will offer further lessons about how to implement consumer-directed programs in a "real-world" setting.

REFERENCES

Ansello, E. F., and N. N. Eustis. 1992. "A Common Stake? Investigating the Emerging Intersection of Aging and Disabilities." *Generations* 16 (1): 5–8.

Barnes, C., and S. Sutherland. 1995. *Context of Care, Provider Characteristics, and Quality of Care in the IHSS Program: Implications for Provider Standards.* Interim Report to the California Department of Social Services. Sacramento: Institute for Social Research, California State University.

Benjamin, A. E., and R. E. Matthias. 2001. "Age, Consumer Direction and Outcomes of Supportive Services at Home." *Gerontologist* 41 (5): 632–42.

Brown, R., and L. Foster. 2001. "Cash and Counseling: Early Experiences in New Jersey." Mathematica Policy Research, Inc., C&C Memo-1093, July 16. Princeton, New Jersey.

Dale, S., L. Foster, R. Brown, B. Phillips, J. Schore, and B. Carlson. 2003. "The Experiences of Consumers, Caregivers and Workers under Arkansas' IndependentChoices." Paper presented at the 2003 Joint Conference of the National Council on Aging and the American Society on Aging. March 14, Chicago.

DeJong, G., A. I. Batavia, and L. McKnew. 1992. "The Independent Living Model of Personal Assistance in National Long-Term Care Policy." *Generations* 16 (1): 89–95.

Desmond, S. M., K. J. Mahoney, L. Simon-Rusinowitz, D. M. Shoop, and M. R. Squillace. 2001. "Consumer Preferences for a Consumer Directed Cash Option versus Traditional Services: Telephone Survey Findings of Florida Elders and Adults with Physical Disabilities." *Elder's Advisor* 3 (1): 1–22.

Doty, P. 1997. "Internal Briefing Paper Addressing Possible Fraud and Abuse Issues in the Cash Option." U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Unpublished.

Doty, P., J. Kasper, and S. Litvak. 1996. "Consumer-Directed Models of Personal Care: Lesson from Medicaid." *Milbank Memorial Fund* 74 (3): 377–409.

Foster, L., R. Brown, B. Phillips, J. Schore, and B. L. Carlson. 2003. "Improving the Quality of Medicaid Personal Assistance through Consumer Direction." *Health Affairs* Web Exclusive March 26, pp. W3-162–75 Available at http://content.healthaffairs.org/cgi/content/full/htthaff.w3.162v1/DC1/

Geron, S. and D. Chassler. 1994. *Guidelines for Case Management Practice across the Long-term Care Continuum.* Technical Report. Connecticut Community Care, Inc.

Glazier, R. E. 2001. "The 'Re-Invention' of Personal Assistance Services." *Disability Studies Quarterly* 21 (2).

H.R. 3600, 103rd Congress, 2d Session 1994; S1757, 103d Congress, 2d Session 1994, Health Security Act. As cited in M. Kapp, 1996, "Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services," *Elder Law Journal* 4 (1): 55–97.

Jackson, M. E. 1994. *Rationing Case Management: Six Case Studies.* Report prepared for the Department of Health and Human Services Office of the Assistant Secretary for Planning and Evaluation.

Kapp, M. 1996. "Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services." *Elder Law Journal* 4 (1): 55–97.

Litvak, S., and J. Kennedy. 1991. *Policy Issues and Questions Affecting the Medicaid Personal Care Services Optional Benefit.* Contract no. HHS-100-89-0025. Oakland, CA: World Institute on Disability.

Mahoney, C. W., C. L. Estes, and J. E. Heumann, eds. 1986. *Toward a Unified Agenda: Proceedings of a National Conference on Disability and Aging.* San Francisco: University of California and World Institute on Disability.

Mahoney, K. J., S. M. Desmond, L. Simon-Rusinowitz, D. M. Shoop, and M. R. Squillace. In press. "Consumer Preferences for a Cash Option versus Traditional Services: Telephone Survey Results from New Jersey Elders and Adults." *Journal of Disability Policy Studies.*

Mahoney, K. J., L. Simon-Rusinowitz, S. M. Desmond, D. Shoop, M. A. Squillace, and B. S. Fay. 1998. "Determining Consumer Preferences for a Cash Option: New York Telephone Survey Findings." *American Rehabilitation* 24 (4): 24–36.

Sciegaj, M., and C. K. Kyriacou. 2000. "Study Examines Racial and Ethnic Differences in Preferences for Consumer Direction." *Consumer Choice News* 4 (4): 5.

Simon-Rusinowitz, L., M. A. Bochniak, M. A. , K. J. Mahoney, and D. Hecht. 2000. *The Status of a Common Agenda between the Aging and Disability Communities: Where Has It Been? Where Is It Going? Views from Policy Experts. Annual Review of Ethics, Law, and Aging.* New York: Springer.

Simon-Rusinowitz, L., and B. F. Hofland. 1993. "Adopting a Disability Approach to Home Care Services for Older Adults." *Gerontologist* 33 (2): 159–67.

Simon-Rusinowitz, L., K. J. Mahoney, S. M. Desmond, D. Shoop, M. A. Squillace, and B. S. Fay. 1997. "Determining Consumer Preferences for a Cash Option: Arkansas Survey Results." *Health Care Financing Review* 19 (2): 73–96.

Simon-Rusinowitz, L., K. J. Mahoney, B. L. Zacharias, and L. N. Marks. In Progress. "Cash and Counseling Demonstration Evaluation: Focus Groups Inform Design of a Consumer Directed Cash Option."

Velgouse, L., and V. Dize. 2000. "A Review of State Initiatives in Consumer-Directed Long-Term Care." *Generations* 24 (3): 28–33.