Effects of Cash and Counseling on Personal Care and Well-Being

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Objective. To examine how a new model of consumer-directed care changes the way that consumers with disabilities meet their personal care needs and, in turn, affects their well-being.

Study Setting. Eligible Medicaid beneficiaries in Arkansas, Florida, and New Jersey volunteered to participate in the demonstration and were randomly assigned to receive an allowance and direct their own Medicaid supportive services as Cash and Counseling consumers (the treatment group) or to rely on Medicaid services as usual (the control group). The demonstration included elderly and nonelderly adults in all three states and children in Florida.

Data Sources. Telephone interviews administered 9 months after random assignment.

Methods. Outcomes for the treatment and control group were compared, using regression analysis to control for consumers' baseline characteristics.

Principal Findings. Treatment group members were more likely to receive paid care, had greater satisfaction with their care, and had fewer unmet needs than control group members in nearly every state and age group. However, among the elderly in Florida, Cash and Counseling had little effect on these outcomes because so few treatment group members actually received the allowance. Within each state and age group, consumers were not more susceptible to adverse health outcomes or injuries under Cash and Counseling.

Conclusions. Cash and Counseling substantially improves the lives of Medicaid beneficiaries of all ages if consumers actually receive the allowance that the program offers.

Key Words. Consumer direction, Cash and Counseling, Medicaid, elderly, disabled, developmental disability, personal care services, unmet needs

Medicaid beneficiaries who have disabilities and receive supportive services from home care or case management agencies often have little control over who provides their care, when they receive it, and how it is delivered. Under Cash and Counseling, consumers could arrange services as they saw fit.

Greater flexibility and autonomy were expected to result in greater satisfaction and reduced unmet needs. On the other hand, eliminating agency supervision raised concerns about consumer safety. States considering adopting consumer-directed models need to understand how such programs affect the care that consumers receive. This article presents findings about the effects of Cash and Counseling on the types and amount of personal assistance services received by demonstration participants, as well as on their satisfaction with care, unmet needs, and incidence of adverse health events.

PREVIOUS RESEARCH

The term “consumer direction,” when applied to personal care services, is used to refer to a variety of program models. These range from consumers having more say over the acceptability of the agency worker assigned to them, to the freedom to spend a monthly allowance in whatever way they feel will best enable them to remain in the community. The largest consumer directed program in the United States is in California, which allows consumers to hire relatives, but restricts consumer control to purchases of personal assistance. Cash and Counseling is at the most flexible end of the spectrum, allowing consumers the freedom to use their allowance to purchase household appliances, modify their homes or cars, set the wage rate of workers they hire, hire relatives as their workers, hire workers to perform a wide range of household activities as well as personal care, and even take a small proportion in cash for incidental expenses. The article by Phillips and Schneider (2007) provides a fuller description of the broad and flexible benefits that states had to provide under Cash and Counseling and their decisions about how much discretion to allow counselors in spending plans.

Research on the effect of consumer direction on service use is limited. One study suggests that consumers can buy more hours of service under consumer direction because privately provided services cost less than those provided by agencies (Miltenberg, Ramakers, and Mensik 1996). Some researchers (for example, Grana and Yamashiro 1987; Osterle 1994; Benjamin and Matthias 2001) have found that, when given a choice, consumers tend to

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hire family members and friends; other research (Cameron and Firman 1995) has found that consumers hire mostly workers who were not family or friends. Several studies have examined the effect of consumer direction on well-being. According to a study of consumer direction in California, participants in the In-Home Supportive Services (IHSS) program who directed their own care reported better outcomes than their counterparts who relied on agency-directed services in terms of their sense of security, unmet needs, technical quality of care, ability to pursue desired activities, and general satisfaction (Benjamin, Matthias, and Franke 2000). Other research showed that a cash subsidy program for children with developmental disabilities enhanced life satisfaction (Meyers and Marcenko 1989) and a consumer-directed family support program for adults with developmental disabilities reduced participants' unmet needs (Heller, Miller, and Hsieh 1999). However, because these studies did not use random assignment, the results could be due to unmeasured differences between the groups they compared. Moreover, consumers might have different experiences under Cash and Counseling than under other consumer-directed programs, because the Cash and Counseling program had many unique features (such as the flexibility of the allowance and the counseling component).

EXPECTED EFFECTS

Given Cash and Counseling's intent to be flexible and consumer friendly, we expected that, *compared with control group members*, Cash and Counseling treatment group members would:

- Be more likely to be receiving paid assistance at follow-up.
- Be more likely to buy assistive equipment, supplies, and home and vehicle modifications.
- Receive different amounts of both paid care and unpaid care. (The amounts of care could be greater or lesser, depending on whether consumers substitute equipment for human assistance and on how easy [or difficult] it is to obtain workers.)

The self-directed changes consumers make were expected to improve consumer satisfaction, reduce unmet needs, and enhance quality of life. However, critics argue that quality of care, adverse events, and health problems could worsen if managing the allowance or recruiting caregivers proves too burdensome, if the loss of nurse supervision leads to problems going

undetected, if qualified caregivers are not available for hire, or if consumers purchase too little assistance. Supporters contend that there is no evidence that nurse supervision of caregivers in the traditional agency model provides more safeguards against adverse health events than the consumer-directed model, in which the consumer, the family, the caregivers, and the counselors can detect and address any health problems that arise. In terms of the effect of consumer direction on consumer well-being, we expected that, compared with control group members, treatment group members would:

- Have fewer unmet needs for supportive services.
- Be more satisfied with their paid caregivers.
- Be more satisfied with their overall care arrangements and quality of life.
- Have no more injuries or other adverse health outcomes.

When interpreting the findings below, readers should bear in mind that “consumer direction” does not mean that consumers act entirely on their own. Many consumers in the treatment group chose representatives to help them make decisions about the program and act on their behalf.¹ Elderly consumers, younger adults with developmental disabilities, and, of course, children, were most likely to use a representative—typically a family member. Overall, some consumers made decisions alone, others designated a representative to make decisions for them, and many others made joint decisions with the representative. While we cannot assess the extent of representative involvement, Cash and Counseling differs greatly from the traditional model in that the decisions are not made by agencies or others not of the consumer’s choosing.²

DATA AND METHODS

Outcome Measures

Outcome measures were drawn from the consumer 9-month follow-up survey. To measure service use, we asked consumers about the types and amounts of paid and unpaid personal care they received during the past 2 weeks. We also asked about their purchase of supplies (Florida only) and equipment, and about any home and vehicle modifications they made during the 9-month period since enrollment. To measure the quality of care received, we asked questions about (1) unmet needs for PCS (and care supplies), (2)

satisfaction with paid caregivers, (3) satisfaction with overall care arrangements, (4) life satisfaction, and (5) adverse events and health problems. Many of our outcome measures were derived from survey questions with four-point scales (for example, degree of satisfaction). After first examining frequencies and determining that binary measures would not obscure important findings, we generally converted each four-point scale into two binary measures—one for the most favorable rating (very satisfied) and one for an unfavorable rating (somewhat or very dissatisfied). While most of our other outcome measures are straightforward, two merit additional explanation.

Total Hours of Care. The survey asked about the total hours of care provided during the past 2 weeks for up to three visiting paid caregivers, three visiting unpaid caregivers, two live-in paid caregivers, and two live-in unpaid caregivers. To determine the total hours of help provided, we summed up the hours each worker provided for both the individual and for the entire household, across all paid and unpaid visiting and live-in caregivers.

Paid Hours of Care. The survey asked treatment group consumers to report the total number of hours of care that each of their caregivers provided and the number of those hours for which the caregiver was paid. Control group members were also asked about the hours of work provided by each of their paid caregivers, but we assumed that visiting agency workers were paid for all the help they provided to control group sample members. For the small number of control group consumers who had a paid worker living with them, we imputed the portion of total hours of care that were paid, using data collected on the Cash and Counselor Caregiver survey to estimate the fraction of total hours that live-in workers for the control group were paid for.

Nine-Month Survey Sample

The 9-month survey was administered between September 1999 and May 2003. We attempted to interview all sample members, including those who had disenrolled from Cash and Counseling and were no longer receiving the allowance (most of whom had returned to traditional agency-directed services).

Although we encouraged adult sample members to respond to our 30-minute surveys themselves, many were unable to respond or insisted that a family member respond for them. In such cases, we asked to speak to the

person who was most knowledgeable about the sample member's care. For children, the desired respondent was the parent, and measures of satisfaction represent the parents' viewpoint. The use of proxy respondents was widespread at baseline and at follow-up (more than 40 percent). For adults, proxies were asked to indicate the sample member's level of satisfaction. However, if proxy respondents did not think they could respond about the sample member's satisfaction with care, or the consumer was mentally unable to form an opinion (due to severe cognitive impairment) we skipped the questions about the consumer's satisfaction with paid care. We did not pose questions about the consumer's satisfaction or unmet needs to proxy respondents who were also paid caregivers for the sample member because they may not have been able to give objective answers to such questions. Thus, these outcome measures were missing for sample members with proxies who were also paid caregivers. This restriction affected the treatment group far more than it did the control group. (Note that, because representatives generally could not be paid to provide care under the program, a representative could be a proxy respondent and if so, was asked questions about the consumer's satisfaction with paid care.) The percentage of the treatment group with proxies who were paid workers ranged from 9 percent (for the nonelderly in New Jersey) to 26 percent (for the elderly in Arkansas) (see Brown and Dale 2007). In the analysis, we controlled for use of proxies at baseline and performed sensitivity tests to assess the effects of proxy responses on our findings.

Our analysis includes the respondents to the 9-month consumer survey. The sample size was 1,739 adults in Arkansas (59.6 percent proxy), 1,465 adults (49.7 percent proxy) in New Jersey, and 1,547 adults (64.5 percent proxy) and 859 children (100 percent proxy [parent] respondents) in Florida. Response rates averaged 88 percent for the treatment group and 83 percent for the control group across all three states. (See Brown and Dale 2007, for further information on the survey sample.)

Results are presented for seven state-age group combinations. Arkansas and New Jersey are each separated into two age groups: nonelderly adults (ages 18–64) and elderly adults (ages 65 and older). Florida results are presented separately for three age groups: children (ages 3–17), nonelderly adults (ages 18–59), and elderly adults (ages 60 and older). In the Florida sample, all children and about 90 percent of the nonelderly adults had developmental disabilities; the remainder had physical disabilities. The great majority of all sample members in Arkansas and New Jersey were eligible for personal care because of physical disabilities.

Analysis

Although random assignment ensures that the treatment and control groups should be similar, restricting the sample to enrollees with available data on a given outcome could create differences between the two groups. Therefore, we estimated logit models (for binary outcome measures) or ordinary least squares regression models (for continuous outcome measures) that controlled for consumers' baseline characteristics (such as their demographic characteristics, health and functioning, satisfaction with care and life, unmet needs, and whether they had a proxy respondent). Our impact estimates equal the difference between the two means of predicted values for sample members, the first assuming each was in the treatment group, the second assuming each was in the control group. The *p*-value on the treatment status variable was used to assess statistical significance of the impact on any given outcome. See Brown and Dale (2007) for details.

Our impact estimates measure the effects of consumers having the *opportunity* to receive the monthly allowance (by virtue of their being assigned to the treatment group), regardless of whether they actually received it. While the estimated effects of the program would be larger if we had excluded those who did not receive the allowance, this exclusion would have introduced unmeasured differences between the treatment and control groups.

Given the large number of outcome measures examined in this study, we took a conservative approach to distinguishing between statistically significant treatment-control differences that were likely to be program effects and those probably due to chance. In general, statistically significant estimates (at the .05 level) suggesting *favorable* effects of the program were not considered to be true program effects unless they followed a pattern across related measures and/or across states (see Brown and Dale 2007). Because we did not want to dismiss any potential negative consequences, any results suggesting the program had *adverse* effects were not subject to these more rigorous criteria.

RESULTS

Participation Rates at 9 Months

There were sizable differences across states in the proportion of treatment group members reporting that they were receiving the allowance at the time of the 9-month survey. Among adult treatment group members still living in the community (i.e., not in a hospital or nursing home), roughly three-quarters in Arkansas and 61 percent in New Jersey said they had received the allowance

in the month of, or preceding, the interview. In Florida, 69 percent of children in the sample were receiving the allowance at 9 months, according to their parents. Among adult treatment group members living in the community in Florida, the percentage receiving the allowance at 9 months was somewhat lower for the nonelderly (54 percent) and much lower for the elderly (39 percent). In each state and age group, a small percentage of consumers not receiving the allowance at 9 months had received it at some point, but then disenrolled from the program. (The denominators in these participation rates include all treatment group members living in the community.)

There were a variety of reasons that consumers did not receive an allowance within the first 9 months. For example, some consumers had difficulty finding someone to hire (which is a requirement of getting a spending plan approved). Others expected their counselors to lead them through the process, while the counselors assumed that the consumers should direct the process. See Phillips et al. (2003) for more details.

In each state and age group, the vast majority of consumers receiving an allowance used it to hire and pay workers (Schore et al. 2007). While most consumers hired family members, about a third of consumers in each state who hired workers employed only nonrelatives. Most of these unrelated workers were friends or neighbors of the consumers.

Effect on the Use of Care

For six of the seven state–age groups we examined, the treatment group was significantly more likely than the control group to be receiving paid personal assistance during a 2-week reference period preceding the 9-month interview (Table 1). The difference was largest in Arkansas, where many beneficiaries faced limited access to services due to worker shortages, but it also was sizable in New Jersey and in Florida (except in the case of elderly consumers). Ninety percent or more of the treatment and control groups in every state and age group were receiving some unpaid assistance at 9 months (not shown; see Carlson et al. 2005). The total number of hours of care received (paid and unpaid) was consistently *lower* for the treatment group than for the control group, although the differences were small for most groups and statistically significant only among younger adults in Arkansas and older adults in Florida. The treatment group received significantly *more* hours of paid care, with the exception of nonelderly adults in Arkansas (whose control group mean was increased by 20 percent by six outliers) and elderly adults in Florida. For every state and age group, the control group had a very large number of unpaid

Table 1: Paid and Unpaid Care Received, by Age Group

	<i>Arkansas</i>		<i>Florida</i>			<i>New Jersey</i>	
	<i>18-64</i>	<i>65+</i>	<i>3-17</i>	<i>18-59</i>	<i>60+</i>	<i>18-64</i>	<i>65+</i>
Percent reporting receiving paid personal care in last 2 weeks [†]							
Treatment	94.5	94.2	79.3	76.4	94.0	91.6	93.9
Control	67.8	78.8	65.1	64.2	91.2	78.7	81.9
Difference	26.7**	15.4**	14.2**	12.2**	2.8	12.9**	12.0**
<i>p</i> -value	<.001	<.001	<.001	<.001	.176	<.001	<.001
Total hours of care in past 2 weeks [‡]							
Treatment	96.7	124.0	237.2	187.5	139.9	145.2	133.2
Control	119.8	133.3	246.8	188.7	158.4	149.9	142.9
Difference	-23.1*	-9.4	-9.5	-1.2	-18.6*	-4.7	-9.7
<i>p</i> -value	.014	.185	.228	.878	.042	.612	.283
Paid hours of care in past 2 weeks [‡]							
Treatment	23.1	22.7	39.5	39.4	28.0	38.8	39.1
Control	23.0	18.2	29.6	28.9	32.9	33.2	31.2
Difference	0.2	4.5**	9.9**	10.5**	-4.9	5.6*	7.9**
<i>p</i> -value	.959	.001	<.001	<.001	.140	.023	<.001
Unpaid hours of care in past 2 weeks [‡]							
Treatment	73.6	101.3	197.7	148.1	111.8	106.5	94.2
Control	96.8	115.1	217.1	159.8	125.6	116.7	111.7
Difference	-23.2**	-13.8*	-19.4**	-11.7	-13.7	-10.2	-17.6*
<i>p</i> -value	.008	.036	.009	.130	.109	.242	.034
Made any equipment purchase or home or vehicle modification							
Treatment	60.2	55.0	86.0	65.5	78.2	47.4	47.4
Control	49.6	54.5	83.6	66.2	81.1	42.5	42.6
Difference	10.7**	0.5	2.4	-0.7	-2.9	4.9	4.8**
<i>p</i> -value	.013	.855	.292	.797	.300	.149	.039
Maximum sample size	471	1,259	859	805	727	677	778

*Significantly different from zero at the .05 level, two-tailed test.

**Significantly different from zero at the .01 level, two-tailed test.

[†]Sample is restricted to consumers residing in the community at the time of the 9-month interview (about 95% of the nonelderly and 90% of the elderly in each state). Means were predicted using logit models.

[‡]Means predicted using ordinary least squares regression models. Analysis includes only those with complete data for every component of total hours (about 90% of the sample in each state).

Source: Nine-month evaluation interview conducted by Mathematica Policy Research Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

hours of care, accounting for 80–85 percent of their total hours of care. The treatment group also reported high levels of unpaid hours, but consistently less than the control group for consumers of all ages in all three states. The treatment group's lower number of unpaid hours essentially offset its higher number of paid hours observed in most state–age groups.

Nonelderly treatment group members were more likely than control group members to receive paid help with various types of care, and more likely to purchase equipment or supplies, but no such differences were observed for the elderly. Nonelderly treatment group members in Arkansas were much more likely than their control group counterparts to be receiving paid help with eating, transferring in and out of bed, toileting, other personal care, shopping, transportation, and “other things around the house or community” (such as yardwork or heavy housework) (not shown; see Carlson et al. 2005). Treatment–control differences in New Jersey were smaller, but generally positive and statistically significant. Among the nonelderly in Florida, the treatment group was more likely than the control group to receive assistance with “other things around the house or community,” but the two groups were similar in the other types of assistance received. Finally, there were few significant treatment–control differences on equipment purchases or home or vehicle modifications, and observed differences were inconsistent across states and age groups (see Carlson et al. 2005).

Unmet Needs

Except for elderly consumers in Florida, treatment group members were much less likely than control group members to report unmet needs, and much more likely to report high satisfaction with their paid care. Table 2 summarizes these results, by signifying a statistically significant treatment–control difference ($p < .05$) that favors the treatment group with a “+” (moderate difference) or “++” (large difference).³ Table 3 provides some illustrative estimates for representative outcomes in each the following categories: unmet needs, satisfaction with paid caregivers, satisfaction with overall care, and life satisfaction.

Despite the services and sizable amounts of unpaid care received, one-quarter to one-half or more of treatment and control group members reported unmet needs for help with personal care, help around the house, help with routine health care, and help with transportation (Table 3). For most measures, however, Cash and Counseling enabled the treatment group to reduce those unmet needs by 10–40 percent below the incidence for the control group.

Satisfaction with Paid Caregivers

In all state–age groups except for elderly adults in Florida, treatment group members were significantly more likely than control group members to report positive experiences with their paid caregivers. Treatment group members

Table 2: Summary of Results on Satisfaction with and Quality of Paid Care

	Arkansas		Florida			New Jersey	
	18-64	65+	3-17	18-59	60+	18-64	65+
Unmet needs for help with							
Daily living*	++		++	+		+	++
Household activities [†]	++	+	++	+			++
Transportation [‡]	++	+	+			+	++
Routine health care [§]			++	+		++	++
Paid caregiver							
Neglected consumer	++	++	++			++	+
Was rude or disrespectful	++					++	
Took something without asking	++	+				+	
Gave unwanted help							
Consumer very satisfied with relationship	++	++	++	++	+	++	++
Satisfaction with overall assistance							
Help with daily living tasks ^{*,}	++	+	++	++		++	++
Help around house/community [†]	++	++	++	++		++	++
Routine health care ^{§,}	++	++	++	++			++
Transportation aid [‡]	++	++	++	++		++	++
Overall care arrangements ^{**}	++	++	++	++		++	++
Very satisfied with life	++	++	++	++	+	++	++
Percentage of treatment group currently receiving allowance (among those in community) (%)	77	72	69	54	39	61	61
Sample size for impact analyses (maximum)	439	1,048	796	746	625	637	680

*Daily living activities include eating, dressing, toileting, transferring, and bathing.

[†]Household activities include preparing meals, doing laundry, doing housework, and doing yard work. Help doing things around the house and community does not include help with transportation.

[‡]Transportation includes transportation to and from a physician's office, shopping, school, work, and social and recreational activities.

[§]Routine health care includes help with medications, checking blood pressure, and doing exercises.

^{||}Effects were estimated by pooling the two adult age groups and including an age $\times$ treatment status interaction term in the model.

^{**}Includes arrangements for unpaid and paid help with personal care, activities around the house and community, routine health care, community services, transportation, and for use of care-related equipment.

+Signifies statistically significant treatment-control difference ($p < .05$) that favors the treatment group and is modest (less than 10 percentage points and less than half the size of the control group proportion or its complement).

++Signifies statistically significant treatment-control difference ($p < .05$) that favors the treatment group and is large (at least 10 percentage points or at least half the size of the control group proportion [pc] or its complement [$1 - pc$]).

Source: Nine-month evaluation interview conducted by Mathematica Policy Research Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey. Sample sizes differ from Table 1 because those with proxy respondents who were paid caregivers were excluded from these analyses. See Brown and Dale (2007).

Table 3: Unmet Needs and Satisfaction with Care and Life

	<i>Arkansas</i>		<i>Florida</i>			<i>New Jersey</i>	
	<i>18-64</i>	<i>65+</i>	<i>3-17</i>	<i>18-59</i>	<i>60+</i>	<i>18-64</i>	<i>65+</i>
Has unmet needs for help with daily living activity [†]							
Treatment	25.8	35.9	32.8	26.7	42.8	46.1	44.1
Control	41.0	36.5	44.6	33.8	46.5	54.5	57.7
Difference	-15.2**	-0.7	-11.8**	-7.1*	-3.7	-8.4*	-13.7**
<i>p</i> -value	.001	.823	<.001	.014	.336	.028	<.001
Very satisfied with way paid caregiver helped around house/community [‡]							
Treatment	90.4	87.3	85.3	85.4	70.4	84.4	78.9
Control	64.0	68.3	73.1	70.9	66.1	66.0	58.8
Difference	26.4**	19.0**	12.3**	14.5**	4.3	18.4**	20.1**
<i>p</i> -value	<.001	<.001	.001	.001	.351	<.001	<.001
Very satisfied with overall care arrangements [§]							
Treatment	71.0	68.3	56.4	68.2	50.0	51.9	56.5
Control	41.9	54.0	26.8	48.0	46.9	35.0	36.6
Difference	29.2**	14.3**	29.7**	20.2**	3.1	16.9**	19.9**
<i>p</i> -value	<.001	<.001	<.001	<.001	.463	<.001	<.001
Very satisfied with way spending life							
Treatment	43.4	55.5	51.9	63.5	35.9	37.5	47.1
Control	22.9	37.0	28.7	50.2	27.9	21.0	25.3
Difference	20.5**	18.5**	23.2**	13.3**	8.0*	16.5**	21.9**
<i>p</i> -value	<.001	<.001	<.001	.001	.049	<.001	<.001
Sample size	439	1,048	796	746	625	637	680

Note: Means were predicted using logit models. Sample sizes for some variables in this table were smaller because of differences in item nonresponse and skip patterns.

[†]Daily living activities include eating, dressing, toileting, transferring, and bathing.

[‡]Help doing things around the house/community does not include help with transportation.

[§]Includes arrangements for unpaid and paid help with personal care, activities around the house and community, routine health care, community services, transportation, and for use of care-related equipment.

*Significantly different from zero at the .05 level, two-tailed test.

**Significantly different from zero at the .01 level, two-tailed test.

Source: Nine-month evaluation interview conducted by Mathematica Policy Research Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

were generally less likely to report problems with their caregiver, such as neglect, being disrespectful, and taking things without asking (Table 2). In all seven state-age groups, the treatment group was significantly more likely to report being very satisfied with their relationship to the paid caregiver. Finally, in all but one state-age group, treatment group members were much more likely than those in the control group to report being satisfied with the way their paid caregivers helped with daily living activities, things around the

house, routine health care, and transportation 9 months after enrollment. Once again, the one group showing few significant differences is elderly consumers in Florida.

Overall Satisfaction

When asked about satisfaction with their overall care arrangements, treatment group members were significantly more likely than controls to report that they were very satisfied. The treatment–control difference in the proportion of nonelderly adults in Arkansas and in Florida that was very satisfied with their care overall exceeded 20 percentage points, but this difference was half that size or less among elderly adults, and not statistically significant in Florida (Table 3). The estimated differences for the two age groups in New Jersey were comparable to each other—between 16 and 20 percentage points. Moreover, treatment group members were far less likely to be dissatisfied with their care arrangements.

Satisfaction with Life

On what is perhaps the most important measure of the value of Cash and Counseling, treatment group members were 25–90 percent (8–23 percentage points) more likely than control group members to say that they were very satisfied with their lives (Table 3). Again, the treatment group was significantly less likely to report dissatisfaction.

Adverse Outcomes

None of the 11 measures of health problems or adverse events examined showed worse outcomes for the treatment group than the control group, for any of the seven state–age groups. These measures included whether the consumer: fell; saw a physician due to a fall; saw a doctor because of a cut, burn, or scald; was injured while receiving paid help; had contractures develop or worsen; had bedsores develop or worsen; had shortness of breath develop or worsen; had a urinary tract infection; had a respiratory infection; was in poor health; and was hospitalized or in a nursing home during the past 2 months. We show four of these measures in Table 4 (see Carlson et al. 2005 and Foster et al. 2004 for all results). Furthermore, for nearly one-third of the 77 comparisons, the treatment group was significantly *less* likely to experience health problems. The significant differences revealed no consistent pattern across measures, age groups, and states, but they were sizeable, ranging from 20–50 percent of control group means.

Table 4: Care-Related Health Problems and Events

	<i>Arkansas</i>		<i>Florida</i>			<i>New Jersey</i>	
	<i>18-64</i>	<i>65+</i>	<i>3-17</i>	<i>18-59</i>	<i>60+</i>	<i>18-64</i>	<i>65+</i>
Had a fall							
Treatment	28.4	19.0	27.3	14.5	17.5	18.7	13.2
Control	28.7	18.6	36.2	17.5	19.7	28.0	20.4
Difference	-0.4	0.4	-8.9**	-3.0	-2.2	-9.3**	-7.2**
<i>p</i> -value	.931	.869	.004	.235	.468	.004	.009
Contractures developed/worsened							
Treatment	26.0	15.9	9.4	9.0	20.0	24.5	17.5
Control	25.2	19.7	13.4	14.0	21.9	28.1	27.1
Difference	0.8	-3.9	-4.0*	-5.0*	-2.0	-3.7	-9.6**
<i>p</i> -value	.826	.089	.049	.021	.534	.269	.002
Bedsore developed/worsened ^{†,‡}							
Treatment	5.9	7.5	3.0	4.1	7.9	9.0	7.2
Control	12.6	6.8	6.0	5.9	9.3	13.0	7.1
Difference	-6.7*	0.7	-3.0*	-1.8	-1.4	-4.1	0.1
<i>p</i> -value	.012	.640	.033	.252	.511	.094	.970
Had a urinary tract infection [‡]							
Treatment	19.4	18.2	2.5	7.7	19.5	16.6	15.7
Control	21.6	21.0	6.0	11.7	21.5	19.4	15.8
Difference	-2.2	-2.8	-3.5*	-4.0*	-2.0	-2.8	-0.1
<i>p</i> -value	.560	.230	.011	.043	.516	.329	.966
Sample size	462	1,164	857	808	696	668	742

Means were predicted using logit models. Sample sizes for some variables in this table were smaller because of differences in item nonresponse and skip patterns.

[†]Effects were estimated by pooling the two adult age groups and including an age $\times$ treatment status interaction term in the model.

[‡]For Florida children, impact could not be estimated from the logit model. Results presented are the unadjusted means and treatment-control differences.

*Significantly different from zero at the .05 level, two-tailed test.

**Significantly different from zero at the .01 level, two-tailed test.

Source: Nine-month evaluation interview conducted by Mathematica Policy Research Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

DISCUSSION

The message from the consumers' perspective is clear—Cash and Counseling led to a major improvement in their care and overall well-being. By allowing beneficiaries to hire family members and friends during a time when agency workers were in short supply, it increased consumers' ability to obtain the paid care for which they were eligible. The control and flexibility offered

by the program greatly increased consumers' satisfaction with the help they received and with their overall quality of life. Consumers under Cash and Counseling appeared to receive care at least as good as that provided by agencies, in that they had the same or an even lower incidence of care-related health problems.

Our findings are similar to the findings reported in previous research, even though past studies examined programs that included different features and populations than Cash and Counseling did. For example, the IHSS program (the largest consumer-directed program in the United States) provided a more generous benefit, did not include counseling, and purposively assigned individuals (including those with the most severe disabilities and those requiring paramedical assistance) to receive consumer direction (Benjamin and Matthias 2001). Nonetheless, consumers under both the IHSS program and under Cash and Counseling in all three states experienced fewer unmet needs, higher levels of satisfaction, and higher quality of life than consumers receiving agency care. Similar to research on the IHSS program, we also found that both younger and older beneficiaries can reap the benefits of consumer direction—in spite of some policymakers' concerns that consumer-direction might not be appropriate for the elderly (Benjamin and Matthias 2001).

Consumers' high level of satisfaction under Cash and Counseling may have been mainly due to their receiving paid care from someone close to them rather than from strangers. However, it is unlikely that *all* of the positive outcomes that consumers experienced were attributable to the familiarity of their paid caregiver. Rather, the reduction in unmet needs and in adverse events that consumers experienced under Cash and Counseling suggests that the paid care provided by these family members and friends was of higher quality than agency care.

One could argue that, when consumers use a representative to help make decisions about their care, or to make decisions on their behalf, it is not really "consumer direction." However, children and adults with serious developmental disabilities or cognitive problems could not possibly direct their own care. People responsible for their care do it for them. Regardless of how these care decisions are made, Cash and Counseling can still be accurately described as a consumer-directed program, because the decisions are not being made by an agency, but by the consumer or the consumer's advocate. Advocates for people with disabilities view the allowed use of representatives as a strength of the program, in that it enables participation by those not able to make such decisions entirely on their own, but who might benefit greatly from the program.

The increased access to paid care did not result in consumers receiving more *total* hours of care. Family and friends might have been paid for some care that they (or other family members) otherwise would have provided free, as the total number of hours of care that beneficiaries received under Cash and Counseling were similar to (or lower than) those the control group received. However, the reduction in unmet needs that beneficiaries experienced under Cash and Counseling suggests that paid care may have been provided more efficiently than the care provided under the traditional program. For example, workers may have saved time by performing tasks concurrently—such as bathing the consumer while the dinner they prepared was cooking—instead of having an agency worker perform one of these tasks. Also, agency workers are typically restricted from performing certain tasks, such as administering medication or providing transportation, while workers for the treatment group would not face such restrictions. Finally, some consumers purchased equipment—such as microwaves to prepare their own meals—that may have decreased their need for human assistance. Thus, the consumer-directed model allows consumers to design more appropriate, flexible, and responsive services that better meet their needs.

The magnitude of program effects varied considerably across states and age groups, for each of the three types of measures examined. While significant favorable impacts were found for both younger and older adults in general (except for Florida's elderly), impacts on the younger adults tended to be larger in each state for satisfaction with care, unmet needs, and caregiver behaviors. The sole exception to this pattern was for unmet needs in New Jersey, where the favorable program impacts were larger for the older adults. These findings across age groups are consistent with those in Benjamin et al. (2000), in which age was a significant factor for some outcomes and not others. Across states, impacts tended to be largest in Arkansas, similar or smaller in New Jersey, and consistently smaller for Florida, among both younger and older adults. Florida is the only one of the three states to provide the program to children, and impacts were consistently larger for them than for either younger or older adults in the state.

The differences across states and age groups is essentially what should be expected from the proportions of treatment group members getting an allowance—that is, the proportion actually getting the intervention. For example, the absence of effects for the elderly in Florida seems likely to be due to the fact that only 39 percent of elderly treatment group members were receiving their allowance at that time. Any favorable program effects on elderly consumers in Florida who were receiving the allowance were not large enough

to produce a statistically significant treatment–control group difference in the full sample of randomized consumers. In contrast, about 69 percent of children and 54 percent of nonelderly adults in Florida, over 70 percent of elderly and nonelderly treatment group members in Arkansas, and 61 percent of both age groups in New Jersey were receiving allowances. Thus, much less attenuation of program effects occurs in Arkansas and New Jersey, or for Florida children.

Several differences in program operations may explain differences in the proportion receiving the allowance at 9 months. One explanation is that treatment group members in Florida were expected to initiate contact with their counselors, whereas Arkansas's and New Jersey's program counselors took more initiative in getting treatment group members started. Arkansas in particular required counselors to have spending plans developed for most consumers within 45 days after enrollment. Elderly participants in Florida may have moved there upon retirement, and, with fewer family members nearby, may have had difficulty finding a worker to hire. In Florida and New Jersey, program applicants were receiving agency care or had been assessed for care before random assignment. Thus, all sample members were already receiving (or about to receive) services, making it less urgent to obtain the allowance. See Phillips et al. (2003) for a more thorough discussion of differences across states in the proportion of consumers receiving an allowance.

Limitations

Despite the rigorous experimental design, our findings have some limitations. First, the estimated program effects depend, in part, on whether the local supply of home care workers in the area was adequate to meet the demand for services during the period studied. Had the evaluation been carried out at another time or in other states, the results might have differed.

Second, we did not directly observe the care provided under the Cash and Counseling program but relied on survey responses. Because personal care is nonmedical and the consumer is an important judge of its quality, our reliance on self-reports of satisfaction, unmet needs, adverse outcomes, and health problems is appropriate. Nonetheless, it is possible that some control group members exaggerated their dissatisfaction, because they were disappointed by not being assigned to the treatment group. Although some treatment group members may have experienced health hazards not reflected in survey data, their Medicaid and Medicare expenditures for acute care were not different from the control group's (Dale and Brown 2005).

A third limitation is that program effects on unmet needs and on purchase of equipment and supplies may be underestimated because the survey asked only *whether* the consumer had unmet needs or purchased equipment. Data on the severity or number of unmet needs or the amount spent on equipment, supplies, or home modifications might have enabled us to observe differences in amounts as well as probabilities of these outcomes. However, such measures were deemed too difficult to gather reliably from a survey.

The survey was designed so that proxy respondents who were also paid workers were not asked the questions about the consumer's satisfaction with paid care (i.e., these respondents were not asked to assess their own performance). Because this circumstance was far more common in the treatment group than in the control group, impacts for these measures may not be based on statistically equivalent comparison groups. This could result in biased estimates if the control variables in our regression models did not adequately account for the influence of any preexisting differences between the two groups. However, sensitivity tests showed positive and statistically significant effects on outcomes for the subset of sample members who responded themselves.

Findings may also be limited by our relatively short follow-up period. The limitation of a short duration follow-up could be addressed to some extent in future studies. For example, consumers in the program could be tracked to observe how long they remain in the program and interviewed at disenrollment to determine why they were leaving the program. Consumers who remained in the program for a few years could also be interviewed to assess whether the high rates of satisfaction expressed at 9 months attenuate, as the novelty of the program wears off, hired workers quit for various reasons, and consumers' care needs increase with their frailty levels. While no longer-term findings for satisfaction and unmet needs are available, a paper by Dale and Brown (2006) shows that favorable effects of the program on nursing home use in Arkansas grow in the second and third years after enrollment.

This study also could not examine the sensitivity of the favorable effects to specific program features. For example, if consumers were not permitted to take any of the allowance in cash for incidentals, would that reduce the favorable effects on unmet needs? The importance of allowing consumers to use the allowance to purchase equipment and supplies is also unclear, since relatively few consumers did so.

Finally, our evaluation relies on a single survey instrument to assess service-use and quality outcomes. The wording of questions was varied to

apply to children; however, the instrument was developed with the PCS needs of adult beneficiaries foremost in mind. That said, when responding to several open-ended survey questions, few treatment group parents reported purchasing non-PCS services or said they hired specialized service providers.

These limitations notwithstanding, this analysis was based on a rigorous research design and yielded estimated program effects that were large, compelling, consistent across numerous types of measures, and widespread across subgroups. In fact, the significant differences between the treatment and control groups understate program effects on *participants* because many in the treatment group were not actively managing their own care at the time of the 9-month follow-up survey. Overall, our results provide unambiguous evidence that Cash and Counseling substantially improved the amount and quality of paid personal assistance from the perspective of consumers, with no discernible adverse effects on safety or health.

Policy Implications

Our analysis suggests that the program works well for children and for elderly adults, as well as nonelderly adults, if they receive the monthly allowance that Cash and Counseling offers. States wishing to implement similar programs should be aware of some operational lessons raised by Phillips et al (2003) as part of this evaluation. Of particular relevance for this paper, the time from enrollment to receipt of the allowance varies considerably, and in some cases the consumer never began receiving the allowance. This shortcoming can be reduced by developing mechanisms to help consumers identify workers (such as worker registries) and by efficient program structure and procedures.

Based on the favorable findings from this evaluation, all three Cash and Counseling states have renewed their waivers, allowing the programs to continue. Moreover, the evidence from the demonstration has convinced many states to implement a Cash and Counseling program of their own, or adopt principles from it. By taking advantage of the lessons learned from the demonstration, these states may be able to achieve for their Medicaid beneficiaries the same gains in well-being as demonstration participants experienced. While no rigorous or comprehensive evaluation of the new programs is planned, the national program office will be monitoring the experiences of consumers who enroll in them. These new programs will provide the opportunity to investigate some of the questions about Cash and Counseling that have yet to be answered.

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NOTES

1. In Arkansas, about one-fourth of nonelderly adults appointed a representative before enrolling; the proportion was much higher (86 percent) in Florida, where over 90 percent of this age group had developmental disabilities. For the elderly, 49 percent of Arkansas enrollees and 71 percent of Florida enrollees appointed a representative. New Jersey did not require sample members to report use of representatives until after random assignment.
2. It should be noted that the high proportion of control group members who had designated a representative before being randomly assigned makes clear that reliance on family members for important care decisions is a common process for Medicaid beneficiaries receiving personal care.
3. "Large" differences are those that are either greater than 10 percentage points or greater than half the mean value for the control group. All other statistically significant differences are considered "moderate."

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