How Caregivers and Workers Fared in Cash and Counseling

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Objectives. To assess the effects of Cash and Counseling on Medicaid beneficiaries' primary informal caregivers and describe the experiences of their directly hired workers.

Study Setting. Beneficiaries in Arkansas, Florida, and New Jersey voluntarily enrolled in the demonstration and were randomly assigned to 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). Beneficiaries identified their primary informal caregiver during a baseline interview and their primary paid worker during a 9-month follow-up interview.

Data Sources. Data were collected through telephone interviews with caregivers and workers. These interviews were conducted about 10 months after beneficiaries' random assignment, between February 2000 and May 2003, depending on the state.

Data Analysis Methods. We estimated program effects with regression and logit models and compared the mean characteristics of directly hired workers and agency workers, by state.

Principal Findings. Compared with caregivers in the control group, those in the treatment group had modestly to substantially better outcomes for measures of satisfaction with care, worry, and physical and financial strain. For hours of care and emotional strain, outcomes in the treatment group were similar to or somewhat better than those in the control group. Directly hired workers reported greater satisfaction with wages, similar satisfaction with working conditions, and similar rates of injuries as agency workers. Workers who were related to the beneficiary reported more emotional strain than agency workers.

Conclusions. Cash and Counseling can lessen some of the burden associated with caring for a child or adult with disabilities. The experiences of hired workers suggest consumer direction is a sustainable option, but support networks for workers might be a welcome program improvement.

Key Words. Cash and Counseling, family caregivers, personal care workers, long-term care

In light of evidence that Cash and Counseling improved beneficiary satisfaction and quality of life, this paper examines how the model worked for two other important groups: (1) the family and friends providing the most unpaid

assistance to beneficiaries when those beneficiaries enrolled in the demonstration; and (2) the workers hired directly by beneficiaries who were randomly assigned to the demonstration treatment group.

There are good reasons to study these groups. Most Medicaid beneficiaries who have disabilities rely on informal (unpaid) caregivers for most of their assistance with personal care, and society relies on unpaid caregivers to help beneficiaries live in the home or community as long as possible. Medicaid supplements informal assistance with paid supportive services. However, if paid services are unsatisfactory or too inflexible to meet beneficiaries' needs, the burden to compensate usually falls on informal caregivers, potentially causing them emotional, financial, and physical strain. Furthermore, although beneficiaries in the demonstration treatment group continued to receive informal care while enrolled in Cash and Counseling, a key feature of program participation was being able to hire workers of one's choosing, train and supervise them, and determine their wages, schedule, and tasks. Although consumer empowerment is the primary objective of Cash and Counseling, the viability of the model hinges on the willingness of family, friends, and others to work for self-directing consumers. Thus, understanding the rewards and hardships of consumers' directly hired workers is also important.

We used telephone survey data to (1) estimate the impacts of Cash and Counseling on the well-being of caregivers who were beneficiaries' *primary informal caregivers at baseline*, and (2) describe the experiences and job conditions of the workers who were hired by treatment group consumers and were their *primary paid workers at follow-up*. Both groups of caregivers were interviewed about 10 months after beneficiaries enrolled in the demonstration.

PREVIOUS RESEARCH

Informal caregivers pay an emotional, financial, and physical price for being perpetually on-call and having obligations to other family members and employers (American Medical Association, Council on Scientific Affairs 1993; Schulz and Beach 1999; National Alliance for Caregiving and AARP 2004; Rabow, Hauser, and Adams 2004; Zarit 2004). Compared with noncaregivers,

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caregivers are more likely to have health problems and chronic conditions, need time off from work, and lack health insurance (Ho et al. 2005). Despite these burdens, many caregivers say they derive great satisfaction from their work (Andren and Elmstahl 2005).

Paid home care workers also face difficult conditions. They do demanding work for low pay, few fringe benefits, and poor prospects for advancement (Stone and Wiener 2001; Yamada 2002). They often feel isolated from their supervisors and peers, lack authority to take initiative, and desire more information about their client's condition and care objectives (Eustis, Kane, and Fischer 1993). Turnover among home care workers is high, although research suggests that worker satisfaction could be improved—and turnover reduced—with greater pay, supervision, and support (Feldman 1993). Even without such improvements, however, home care workers find certain aspects of their jobs rewarding, including flexible schedules (Eustis, Kane, and Fischer 1993) and close relationships with their clients (Karner 1998; Piercy and Woolley 1999).

While the literature on caregivers and home care workers is abundant, few studies have examined the interplay between consumer direction and caregivers and/or workers. According to a review of consumer-directed programs in several countries, allowances let caregivers effectively coordinate the beneficiary's care, and workers hired under consumer direction report positively about their relationships with beneficiaries and their work environments (Tilly, Wiener, and Cuellar 2000). Also, a consumer-directed family support program was shown to improve caregiver satisfaction and self-efficacy (Heller, Miller, and Hsieh 1999). However, in the most comprehensive study to date of workers hired under consumer-direction, in California's In-Home Supportive Services (IHSS) program, the findings were somewhat mixed. Compared with agency workers, workers hired directly by consumers (1) received 30 percent less in wages and were less likely to receive fringe benefits; (2) were less satisfied with their pay, but were highly satisfied with their jobs; (3) had closer relationships with their clients, but more emotional strain; (4) were less likely to have been trained to provide personal care, but more likely to feel well informed about their client's needs (Benjamin and Matthias 2004).

HYPOTHESES

As intended, Cash and Counseling favorably affected consumers. It also was intended to benefit their primary informal caregivers and provide a rewarding experience to directly hired workers. It could be, however, that the model's

effects on consumers came at the expense of those who helped them. To assess the forms of burden and/or satisfaction that might be associated with caring for a consumer who choose to direct his or her own supportive services, our analysis examined the following outcomes and types of outcomes:

- Whether got paid for providing assistance.
- Hours of assistance provided.
- The quality of the relationship with the consumer.
- Satisfaction with and worries about care quality.
- Emotional, physical, and financial strain.
- Compensation (if any).
- Satisfaction with working conditions.
- Training and preparedness.

We also hypothesized that outcomes for caregivers and hired workers might vary across states because of differences in benefit levels, eligible populations, whether consumers were allowed to hire spouses, and the availability of family members to become hired workers. In addition, we examined differences between subgroups of caregivers defined by beneficiary age group and whether caregivers were paid for caregiving during the follow-up period. For hired workers, we compared the experiences of those who were related to the consumer with those who were unrelated.

SAMPLES AND METHODS

The analyses presented in this paper are based on two, somewhat overlapping samples. The sample for the impact analysis consists of caregivers who were identified during beneficiaries' baseline telephone interview as the one person (if any) who had given the beneficiary the most unpaid assistance during the previous week with personal care, household and community tasks, and routine health care at home. Sample sizes were 1,433 in Arkansas; 1,193 in New Jersey; and 1,042 and 829 in Florida for caregivers of adults and children, respectively. Overall response rates were 84 percent for caregivers associated with treatment group members and 78 percent for those associated with control group members. Caregivers typically were female (roughly 80 percent in each state) and related to their care recipient (roughly 90 percent in each state; not shown). At least half the caregivers in each state's sample were married

(50–60 percent), some had dependent children (20–30 percent), and many were employed when the care recipient enrolled in the demonstration (40–50 percent). Only a small percentage of primary informal caregivers were the spouses of adult care recipients (6–8 percent).

The sample for the descriptive analysis consists of workers who were identified during beneficiaries' 9-month follow-up interviews as the one paid person (if any) who helped the most with personal care, household and community tasks, and routine health care at home during a 2-week period shortly before the interview. Workers for the treatment group were only included in the study if they were hired with the Cash and Counseling allowance and their beneficiary was still enrolled in the program. For agency workers identified by control group members, we sought target sample sizes of 300 completed interviews in Arkansas and New Jersey and 400 in Florida. Ultimately, interviews were completed by 391 directly hired workers and 281 agency workers in Arkansas, 382 directly hired workers and 308 agency workers in New Jersey, and 520 directly hired workers and 416 agency workers in Florida, combining those for adults and children. Response rates were similar in each state, averaging 95 percent for directly hired workers and 79 percent for agency workers. About 40 percent of the caregivers in the impact analysis were also in the descriptive analysis because they became the consumer's primary paid worker.

In the caregiver analysis, means for continuous outcome measures, such as hours of care provided, were predicted with ordinary least squares regression models. Means for binary outcome measures were predicted with logit models. All models controlled for consumers' baseline characteristics and caregivers' demographic characteristics. The descriptive analysis of primary paid workers simply compares the unadjusted means for directly hired workers and agency workers. Many of the outcome measures in both analyses were derived from survey questions with four- or five-point scales (for example, degree of satisfaction). After examining frequencies and determining that binary measures would not obscure important information, we generally converted each scale into two binary measures—one for the most favorable rating (very satisfied) and one for an unfavorable rating (somewhat or very dissatisfied). See Brown and Dale (2007), for a more detailed description of data collection and analytic methods.

RESULTS

In interpreting the evaluation results, it is important to note that the proportions of treatment group members that actively participated in a Cash and

Counseling program—by developing and executing an allowance spending plan—ranged considerably by state. Only 55 percent of Florida adults participated in this way, compared with 72 percent of Florida children, 75 percent of New Jersey consumers, and 88 percent of Arkansas consumers. Moreover, the proportions of primary informal caregivers in the treatment group that were paid for caregiving during the follow-up period varied by state—from 56 percent in Arkansas, to 42 percent in New Jersey, to 29 and 21 percent in Florida for adults and children, respectively.

In the following pages, we (1) present program impacts that were estimated over all responding caregivers of treatment and control group members; (2) examine the extent to which impacts differed by whether treatment group caregivers became paid workers; and (3) describe the experiences of consumers' directly hired workers. Space limitations prevent us from presenting data on all the outcomes measured for the evaluation. Thus, our text and tables focus on outcomes that are most germane to the objectives of Cash and Counseling and policymakers, regardless of the size and direction of any treatment-control differences. Data on the full set of outcomes are available from the authors.

Estimated Program Impacts on Caregivers

Hours of Assistance. Caregivers provided a great deal of assistance during the 2-week period we asked about. The average was more than 100 hours in 2 weeks, or at least 7 hours per day (Table 1). Except in New Jersey, however, treatment group caregivers consistently reported providing fewer hours of assistance than their control group counterparts. Although none of the estimated effects were highly significant, the pattern suggests that Cash and Counseling, not chance, probably drove the differences.

New Jersey's atypical results were driven by the caregivers of nonelderly adults (age group data not shown). Caregivers for nonelderly adults in the treatment group reported about 20 more hours of care than those in the control group during the period we asked about. (Results for the caregivers of elderly consumers in New Jersey were quite similar to those for Arkansas and Florida adults.)

Satisfaction with and Worries about Care Quality. In all three states, treatment group caregivers were substantially more satisfied with care recipients' overall care. Specifically, treatment group caregivers were 18–20 percentage points more likely than control group caregivers to say they were very satisfied with the care recipients' help from home care workers, family and

Table 1: Estimated Effects on Hours of Care Provided by Primary Informal Caregivers, by State (2-Week Reference Period)

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
Total hours of assistance				
Predicted treatment group mean	106.6	123.7	123.2	150.1
Predicted control group mean	117.0	132.7	113.3	155.0
Difference	- 10.4	- 9.0	9.9	- 4.9
<i>p</i> -value	.089	.111	.057	.353
Among live-in caregivers				
Predicted treatment group mean	140.1	139.5	148.4	154.1
Predicted control group mean	153.0	149.3	140.1	159.9
Difference	- 12.9	- 9.8	8.3	- 5.8
<i>p</i> -value	.035	.069	.279	.227
Among visiting caregivers				
Predicted treatment group mean	61.9	48.9	84.8	—*
Predicted control group mean	68.9	54.0	72.5	—
Difference	- 7.0	- 5.1	12.3	—
<i>p</i> -value	.164	.676	.090	—
Number of respondents	1,433	1,193	1,042	829

*Only 30 of the primary unpaid caregivers for Florida children were visiting caregivers; hence, results are not presented for this small group.

Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Hours were measured over the most recent 2-week period preceding the interview that the consumer was not in a hospital or nursing home. Means were predicted with ordinary least squares models.

Source: MPR's caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

friends, and organizations providing home-delivered meals, transportation, and similar services (Table 2). Furthermore, treatment group caregivers were only half as likely as control group caregivers to be dissatisfied with such arrangements.

We asked caregivers how often they worried about insufficient care, safety, and theft when they were not with the care recipient (and someone else may have been helping him or her). Overall, substantial proportions of caregivers said they worried, but treatment group caregivers were less likely than control group caregivers to worry quite a lot. The observed differences were large and statistically significant in each state, ranging from about 20 to 30 percent of the control group means for caregivers of adults and children. Effects were similar at the other end of the scale, with caregivers in the

Table 2: Estimated Effects on Primary Informal Caregivers' Satisfaction with and Worries about Care Quality, by State

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
How satisfied with care recipient's overall care arrangements				
Very satisfied				
Predicted treatment group percent	60.8	47.9	51.6	42.3
Predicted control group percent	42.7	29.8	31.7	22.0
Difference	18.1	18.1	19.9	20.3
p-value	< .001	< .001	< .001	< .001
Dissatisfied				
Predicted treatment group percent	9.1	15.7	13.3	14.6
Predicted control group percent	22.8	27.5	32.2	36.9
Difference	- 13.7	- 11.8	- 18.8	- 22.4
p-value	< .001	< .001	< .001	< .001
When not with care recipient, worried quite a lot that:				
Recipient did not have enough help				
Predicted treatment group percent	35.8	47.8	52.2	47.2
Predicted control group percent	53.5	60.5	70.2	64.7
Difference	- 17.6	- 12.7	- 18.0	- 17.6
p-value	< .001	< .001	< .001	< .001
Recipient's safety was at risk				
Predicted treatment group percent	39.3	43.1	53.5	43.5
Predicted control group percent	53.4	52.3	64.8	57.3
Difference	- 14.1	- 9.2	- 11.3	- 13.8
p-value	< .001	.001	< .001	< .001
Someone would take recipient's belongings				
Predicted treatment group percent	14.0	22.2	24.9	25.0
Predicted control group percent	20.3	29.2	30.3	34.7
Difference	- 6.3	- 7.0	- 5.5	- 9.7
p-value	.001	.005	.041	.002
Number of respondents	1,433	1,193	1,042	829

Primary informal caregivers are those providing the most unpaid care to care recipients at base-line. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Percents were predicted with logit models.

Source: MPR's caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

treatment group being more likely than those in the control group to say they worried only rarely or not at all about these aspects of care quality (not shown).

Emotional, Financial, and Physical Strain. In addition to being more satisfied than control group caregivers with the care that consumers were receiving, treatment group caregivers tended to fare better personally. They were

somewhat less likely than control group caregivers to say that caregiving limited their privacy or social lives, and (except in Florida) were somewhat less likely to say that caregiving caused them a great deal of emotional strain (giving a rating of four or five on a five-point scale; Table 3). Treatment group caregivers were much more likely than control group caregivers to be very satisfied with their own lives and much less likely to be dissatisfied (Table 3). The proportions of very satisfied treatment group caregivers were roughly a third larger than the control group proportions among those caring for adults, and 55 percent larger among those caring for children. Moreover, the proportions of dissatisfied treatment group caregivers were smaller by nearly half in Arkansas, New Jersey, and Florida for children's caregivers, and by one-fourth in Florida for adults' caregivers.

Cash and Counseling seemed to alleviate caregivers' perception of financial strain in all three states and both Florida age groups. In Arkansas, the proportion of caregivers reporting a great deal of financial strain as a result of caregiving was 13 percentage points (nearly 40 percent) smaller than the control group proportion, while in Florida and New Jersey the treatment group proportions were about one-fourth smaller than the control group proportions (Table 3). Similarly, treatment group caregivers were substantially more likely than control group caregivers to report little or no financial strain in each state (not shown).

In all three states, substantial proportions of adults' caregivers said caregiving adversely affected their choice and performance of jobs, but some problems were less prevalent in the treatment group. For example, while at least 38 percent of control group caregivers in each state said they had not looked for a job or another job—although they wanted to—since their care recipient enrolled in the demonstration, the proportions of treatment group caregivers reporting this problem were 7–15 percentage points smaller than the control group proportions in each state. Among Arkansas and New Jersey caregivers who were working for pay (other than for their care recipient) when interviewed, those in the treatment group were less likely than those in the control group to say they missed work or arrived late because of caregiving.

Treatment group caregivers were substantially less likely than control group caregivers to report a great deal of physical strain, and to have suffered physical health problems as a result of caregiving (Table 3). They also were less likely to rate their health as fair or poor, as opposed to good or excellent, than their control group counterparts. These differences in physical well-being measures were large (20–30 percent of the control group mean) and consistent across states and both Florida age groups.

Table 3: Estimated Effects on Primary Informal Caregivers' Emotional, Financial, and Physical Strain, by State

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
Emotional strain				
Caregiving caused great deal of emotional strain				
Predicted treatment group percent	26.8	35.7	42.3	39.4
Predicted control group percent	34.3	38.6	49.4	41.6
Difference	-7.5	-2.9	-7.1	-2.2
p-value	.002	.286	.017	.495
Caregiving limits privacy				
Predicted treatment group percent	38.7	52.3	41.1	61.0
Predicted control group percent	52.7	57.1	50.5	65.9
Difference	-14.1	-4.8	-9.4	-4.9
p-value	<.001	.084	.001	.125
Caregiving limits free time/social life				
Predicted treatment group percent	52.5	66.9	54.8	80.9
Predicted control group percent	63.8	73.3	60.1	81.6
Difference	-11.3	-6.5	-5.3	-0.7
p-value	<.001	.008	.061	.778
Very satisfied with own life				
Predicted treatment group percent	51.3	47.0	51.6	36.9
Predicted control group percent	39.9	35.2	37.5	23.8
Difference	11.4	11.8	14.1	13.2
p-value	<.001	<.001	<.001	<.001
Dissatisfied with own life				
Predicted treatment group percent	13.1	16.7	15.2	16.7
Predicted control group percent	23.2	22.8	27.3	31.1
Difference	-10.1	-6.1	-12.2	-14.4
p-value	<.001	.008	<.001	<.001
Financial strain				
Caregiving caused great deal of financial strain				
Predicted treatment group percent	22.4	29.9	30.0	43.7
Predicted control group percent	35.7	38.9	38.6	55.6
Difference	-13.3	-9.0	-8.6	-11.9
p-value	<.001	.001	.001	<.001
Wanted to look for a job but did not due to caregiving				
Predicted treatment group percent	23.5	35.1	33.9	52.7
Predicted control group percent	38.6	41.8	44.1	57.0
Difference	-15.1	-6.7	-10.3	-4.3
p-value	<.001	.011	<.001	.192
Missed work or arrived late due to caregiving				
Predicted treatment group percent	48.6	60.9	53.6	84.0
Predicted control group percent	60.6	67.1	65.8	82.6
Difference	-12.0	-6.2	-12.2	1.4
p-value	.001	.095	.002	.657

continued

Table 3. *Continued*

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
Physical strain				
Caregiving caused great deal of physical strain				
Predicted treatment group percent	23.0	28.4	31.7	34.5
Predicted control group percent	32.0	38.8	41.8	42.1
Difference	-9.0	-10.4	-10.1	-7.6
<i>p</i> -value	<.001	<.001	<.001	.020
Physical health has suffered due to caregiving				
Predicted treatment group percent	23.6	32.7	30.7	41.8
Predicted control group percent	34.3	44.9	40.3	55.4
Difference	-10.7	-12.2	-9.6	-13.6
<i>p</i> -value	<.001	<.001	.001	<.001
Current health was fair/poor relative to peers				
Predicted treatment group percent	35.5	31.8	30.3	27.4
Predicted control group percent	46.7	39.6	42.3	36.8
Difference	-11.2	-7.8	-12.0	-9.4
<i>p</i> -value	<.001	.004	<.001	.003
Number of respondents	1,433	1,193	1,042	829

Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Percents were predicted with logit models.

Source: MPR's caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

Subgroup Results. Although treatment group caregivers fared better than control group caregivers across most indicators of satisfaction and well-being, caregivers assisting nonelderly adults in New Jersey were an exception to the pattern. In this subgroup, treatment group caregivers provided more total hours of assistance than did control group caregivers; moreover, the treatment group seemed not to enjoy the favorable effects on other outcomes (not shown). This finding suggests that if caregivers provide more assistance to care recipients under consumer direction than they would otherwise, their own well-being may not improve. In contrast, if Cash and Counseling enables caregivers to reduce their care hours, they are more likely to benefit emotionally, physically, and financially and, thus, have a better quality of life.

Impacts by Payment Status at Follow-up

Across key measures of caregiver satisfaction and well-being, both unpaid and paid treatment group caregivers had significantly better outcomes than control

group caregivers, but most impact estimates were substantially larger for paid than unpaid caregivers (not shown). Differences between paid (or unpaid) caregivers in the treatment group and all caregivers in the control group must be cautiously interpreted, however. Because of the selection bias inherent in the decision to become paid or remain unpaid, we cannot determine whether differences in impact estimates for these groups were due to payment or to unobserved differences between the groups. For example, it may be that caregivers who became paid had had more responsibility, on average, for arranging care recipients' personal care than caregivers who remained unpaid, and that caregivers accustomed to responsibility benefited most from Cash and Counseling. In addition, some of the caregivers who did not become paid workers were providing care to treatment group consumers who never received the program allowance, whereas all caregivers who were paid by consumers were caring for allowance recipients. Given that Cash and Counseling would not have affected outcomes for caregivers of allowance nonrecipients, the observed differences between caregivers who did and did not become paid workers overstate the effects of becoming paid. That is, the estimated effects of Cash and Counseling on informal caregivers who were not paid are attenuated by the inclusion of caregivers of treatment group members who did not participate in the program, but no such attenuation occurs in the estimates for caregivers who did become paid workers. Treatment group caregivers who were not paid for caregiving at the time of their interview were asked why. Although caregivers in all three states most commonly said they helped out of love, devotion, or family tradition, substantial proportions said they did not know they could be paid—9 percent in Arkansas, 14 percent in Florida, and 15 percent in New Jersey.

Descriptive Analysis of Directly Hired Workers

The remainder of this section focuses on workers hired directly by treatment group consumers. Control group members, of course, were not expected to hire workers during the follow-up period, but we use the experiences of a sample of their agency workers as a benchmark for workers in the treatment group.

Worker Characteristics. Directly hired workers and those employed by agencies were strikingly similar in a couple of ways and notably different in others. More than 80 percent of workers in both groups were female (not shown), roughly one-third or more were 18–39 years old, and roughly one-half or more were 40–64 years old (Table 4). However, directly hired workers

Table 4: Characteristics of Primary Paid Workers, by State (Percentages)

	Adults						Children	
	Arkansas			Florida			New Jersey	
	Directly Hired Workers	Agency Workers		Directly Hired Workers	Agency Workers		Directly Hired Workers	Agency Workers
Age (Years)								
18-39	37.1	34.2		25.2	33.3**		35.9	34.7
40-64	54.5	57.7		62.4	62.0		58.9	61.7
65-79	8.2	7.5		11.7	4.3		5.0	2.3
≥ 80	0.3	0.7		0.7	0.4		0.3	1.3
Same race as consumer	90.7	79.6**		83.6	60.2**		84.4	54.5**
Family and work situation								
Married	51.7	51.3		50.2	52.6		51.4	49.3
Has children	35.6	47.0**		29.9	41.6**		40.4	47.5
Currently has job other than caregiving	39.7	20.1**		40.3	21.2**		42.1	22.6**
Relationship to consumer								
Related	78.3	NA		58.4	NA		70.9	NA
Not related, but knew consumer before demonstration	16.4	NA		25.8	NA		19.1	NA
Did not know consumer before demonstration	5.4	NA		15.8	NA		10.0	NA
Lives with consumer	39.4	NA		46.3	NA		40.1	NA
Is primary informal caregiver	44.5	NA		35.2	NA		46.1	NA
Provided consumer with informal care before demonstration	84.4	NA		69.7	NA		79.6	NA
Maximum sample size	391	281		298	255		382	308

*Mean for directly hired workers different from that of agency workers at the .05 level.

**Mean for directly hired workers different from that of agency workers at the .01 level.

Sample sizes vary slightly for each measure due to item nonresponse.

NA, not applicable for agency workers. A small proportion of agency workers (less than 5 percent) were related to consumers, lived with them, or provided unpaid care to them before the demonstration.

Source: MPR'S caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

were much more likely than agency workers to be of the same race as the care recipient and to have a job in addition to caregiving. While less than 5 percent of agency workers in each state were related to or lived with the care recipient, most directly hired workers (54–78 percent) were related to the care recipient. Typically, directly hired workers were the consumers' daughters or sons (not shown; see Dale and Brown 2005 for details on the consumer–worker relationship). In Florida and New Jersey, consumers could hire spouses, but less than 3 percent in each state did (not shown). About 30 percent of the primary paid workers for children in Florida were the child's parents. Finally, many directly hired workers (39–47 percent) lived with the care recipient, and relatively few (5–21 percent) did not know the care recipient before the demonstration.

Hours Worked, Compensation, and Job Satisfaction. In the three states and both Florida age groups, directly hired workers were paid for less than half the hours of care they provided, on average (Table 5). They provided 38–47 total hours of care, depending on the state, and were paid for 12–20 of them. In Florida and New Jersey, the directly hired workers of adult treatment group consumers were paid 10–15 percent (about \$1.00) more per hour on average than agency workers serving the control group. In Arkansas directly hired workers were paid about 4 percent less per hour than agency workers. As part-time employees, almost no directly hired workers received fringe benefits, but few agency workers did either. One-third of directly hired workers were occasionally paid late, but few were ever paid less than they were owed. In all three states, directly hired workers were twice as likely as agency workers to say they were very satisfied with their compensation despite the similarity in wages. The two groups of workers were similarly likely to be very satisfied with their overall working conditions (reported by 70–89 percent of workers) and very few (3 percent at most) were dissatisfied.

Training and Preparedness. Only 50–55 percent of directly hired workers said that they received formal training in personal care, compared with at least 8 in 10 agency workers; however, directly hired workers were at least as likely to say they felt well informed about the care recipient's conditions and service needs (Table 5).

Physical Strain and Injury. Between 17 and 30 percent of directly hired workers reported a great deal of physical strain as a result of caregiving,

Table 5: Primary Paid Workers' Hours of Care, Compensation, Training and Preparedness, and Satisfaction, by State

	Adults						Children	
	Arkansas			Florida			New Jersey	
	Directly Hired Workers	Agency Workers [†]	Directly Hired Workers	Agency Workers [†]	Directly Hired Workers	Agency Workers [†]	Directly Hired Workers	Agency Workers [†]
Hours of care provided per week (percent)								
Average paid hours	12.5	11.7	19.9	16.2**	20.3	18.9	18.6	22.8*
Average unpaid hours	25.7	NA	26.5	NA	26.5	NA	21.2	NA
Total hours	38.2	NA	46.4	NA	46.8	NA	39.7	NA
Compensation								
Hourly wage (dollars)	6.07	6.30***	10.26	9.03**	9.84	8.53***	11.81	11.33
Received fringe benefits (percent)	1.6	20.6**	3.5	16.5**	4.6	24.2**	1.0	8.6**
Paid for travel time [†] (percent)	5.8	57.8**	7.3	21.2**	6.9	15.1**	7.5	7.1
Ever paid late (percent)	35.1	NA	29.2	NA	30.8	NA	29.8	NA
Ever paid less than owed (percent)	6.7	NA	5.1	NA	6.8	NA	2.8	NA
Training and preparedness								
Received personal care training	49.9	93.5***	54.7	95.5***	55.3	98.6***	54.8	82.6***
Feels well-informed about care needs	89.7	82.6***	87.4	82.2	89.9	89.2	93.2	93.2
Satisfaction with:								
Wages and fringe benefits								
Very satisfied	44.6	22.2**	50.7	22.9**	41.4	19.1**	61.6	23.0**
Not satisfied	15.6	37.5**	16.3	38.0**	16.9	41.8**	8.4	41.0**

Working conditions overall									
Very satisfied	83.4	81.8	85.3	82.6	79.3	69.9**	88.7	84.7	
Not satisfied	1.0	2.1	1.0	2.4	1.3	3.3	1.4	2.5	
Physical strain									
Great deal of physician strain	16.9	15.1	29.6	33.9	28.4	42.0**	21.2	32.5*	
Suffered any injury	3.6	1.4	5.7	4.3	3.7	6.5	8.6	4.9	
Emotional strain									
At least some emotional strain	39.8	29.9**	52.5	40.9**	59.8	58.0	56.0	48.8	
Consumer's family and friends needed to be more respectful	37.1	22.4**	21.4	16.5	29.2	18.9**	21.6	12.4*	
Maximum sample size	391	281	298	255	382	308	222	164	

*Responses for agency workers pertain only to the care the workers provided to the consumers who identified them during the 9-month follow-up survey as their primary worker.

†Among those living apart from consumer.

*Mean for directly hired workers different from that of agency workers at the .05 level.

**Mean for directly hired workers different from that of agency workers at the .01 level.

NA, not applicable. Only the handful of agency workers who were related to the consumer provided unpaid care to the consumer. Questions about being paid late or less than owed were not asked of agency workers.

Source: MPRS caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

although few (3–9 percent) reported being injured since they began providing paid care (Table 5). Their injury rates were generally similar to rates reported by agency workers, but hired workers in New Jersey and Florida (for children only) were significantly less likely than agency workers to report great physical strain. Furthermore, the difference in work-related injuries in Arkansas (significant at the .10 level) disappeared when we used a regression model to control for the fact that directly hired workers provided significantly more hours of care, in total, than agency workers.

Emotional Well-Being. Across states, 40–60 percent of the directly hired workers reported at least some emotional strain as a result of caregiving. Directly hired workers were significantly more likely than agency workers to report emotional strain in Arkansas and Florida and were more likely to say that they received too little respect from the care recipient's family and friends in Arkansas and New Jersey (Table 5). More than three-fourths of the workers hired by adults in all three states said they had a very close relationship with their care recipient compared with, at most, 54 percent of agency workers (not shown).

These differences in emotional strain and desire for more respect appeared to be driven by the high likelihood that directly hired workers were related to care recipients. After pooling data in the adult samples across states to yield adequate sample sizes, we found that reports of emotional strain and lack of respect were about the same for agency workers as they were for workers hired by consumers to whom they were not related (Table 6). By contrast, workers hired by family members were more likely than these other groups to report great emotional strain and lack of respect. Unrelated hired workers also received higher wages, were more likely to receive training, and provided far fewer unpaid hours of care than did related workers. Thus, emotional strain is not associated with being hired by a self-directing consumer, per se, but with being hired by a family member.

DISCUSSION

Caregivers who provided the most unpaid assistance to beneficiaries at baseline devoted a great deal of time to caregiving at follow-up, and many reported emotional, physical, and financial strain. Nonetheless, compared with caregivers in a randomly assigned control group, those in the treatment group had

Table 6: Selected Paid Worker Outcomes, by Consumer–Worker Relationship

	<i>Directly Hired Workers</i>		<i>Agency Workers</i>
	<i>All Related</i>	<i>All Unrelated</i>	
Working conditions			
Hourly wage (dollars)	8.3**	9.1	7.9
Satisfied with wages (percent)	46.3	42.5	21.3
Satisfied with working conditions (percent)	82.1	83.3	82.4
Training and preparedness			
Received personal care training	45.9**	71.9	96.0
Feels well informed about care needs	89.9	87.3	84.8
Worker well-being (percent)			
Little or no emotional strain	46.5**	56.8	56.7
Consumer needed to be more respectful	19.0**	13.0	14.4
Consumer's family and friends needed to be more respectful	34.6*	18.9	19.3
Hours of care provided (number)			
Paid hours	17**	19	16
Unpaid hours	34**	7	2
Maximum sample size [†]	751	320	844

*Related workers different from unrelated workers at the .05 level, two-tailed test.

**Related workers different from unrelated workers at the .01 level, two-tailed test.

[†]Data for the primary paid workers for adults from all three states are combined here to provide adequate sample sizes for comparisons across subgroups of directly hired workers defined by their relationship to the consumer.

Sample sizes vary slightly for each measure due to item nonresponse.

Source: MPR'S caregiver interview conducted in Arkansas between February 2000 and April 2002, in Florida between May 2001 and May 2003, and in New Jersey between September 2000 and June 2003.

modestly to substantially better outcomes for measures of satisfaction, worry, and physical and financial strain. For hours of care and emotional strain, outcomes in the treatment group were similar to or better than those in the control group. Most impact estimates were quite similar across states and across age groups in Florida.

The programs' positive effects probably stemmed from several factors. Great financial strain may have been less common for treatment group caregivers who, unlike their control group counterparts, became paid workers, gained flexibility to do other paid work, or had lower out-of-pocket expenses if consumers spent their program allowance on care-related supplies. They may have worried less about safety and theft because consumers hired workers they knew and trusted. When consumers hired other workers, treatment group caregivers may have been able to forego physically demanding tasks, especially if caregivers themselves were frail. Also, when consumers hired

other workers, their informal caregivers may have received respite that reduced their emotional strain. Indeed, other research has found that caregiver well-being improves when caregivers are able to maintain leisure time (Lopez, Lopez-Arrieta, and Crespo 2005).

Program effects on caregivers generally were larger in Arkansas than in the other two states. This may be because the Arkansas treatment group had the largest proportions of active participants (those who developed and executed an allowance spending plan) and caregivers that became paid workers. As noted, in Florida and New Jersey, about 15 percent of caregivers who remained unpaid said they were not aware they could have been paid, compared with 9 percent of caregivers in Arkansas. Differential program effects also may have stemmed from the states' target populations. The emotional strain experienced by caregivers of children and young adults with primarily developmental disabilities, such as Florida enrolled, may differ from that experienced by adults with primarily physical disabilities, such as Arkansas and New Jersey enrolled, in ways that consumer direction would not address. Program effects on well-being were also somewhat smaller for caregivers in New Jersey, particularly for those helping nonelderly adults. These were the only caregivers providing more hours of assistance than their control group counterparts, on average. The nature of the relationship between caregiver burden, the age of the care recipient, and the hours of care provided merits further research.

Workers hired under Cash and Counseling had mostly favorable perceptions of their jobs. Most were very satisfied with their overall working conditions and many were satisfied with their compensation. Nearly all said they got along very well with the care recipient. These findings were remarkably consistent across states and Florida age groups even though states served different target populations and had different hiring restrictions.

Directly hired workers did report more emotional strain than agency workers. Strain was more common among workers hired by family members, however, than it was among others. In fact, the prevalence of emotional strain was about the same among paid workers who were not related their care recipient as it was among agency workers. Nonetheless, consumers and the family members they hired both reported getting along very well with each other, and program counselors did not report observing frayed family relationships under Cash and Counseling. (See Carlson et al. [2007] and Schore, Foster, and Phillips [2007]).

The fact that directly hired workers report high levels of satisfaction with their working conditions, despite feeling emotional strain, is consistent with

the experiences of workers hired under the IHSS program (Benjamin and Matthias 2004). These findings also are consistent with the reports of workers hired under Arkansas's Cash and Counseling program who, in focus groups, said that, although their jobs were demanding, they felt "blessed" by having the opportunity to take care of a loved one and that their jobs were quite gratifying (Zacharias 2002). In other research, home care workers have reported that having close relationships with consumers and flexible schedules are appealing aspects of their job (Eustis, Kane, and Fischer 1993). Thus, it is not surprising that directly hired workers are quite satisfied with jobs that have these desirable characteristics.

Our findings, and those of other researchers, address some common concerns about consumer direction. The training and supervision that agencies provide to their workers are seen by some as critical omissions of consumer-directed models because they might be detrimental to care quality. Workers hired under both Cash and Counseling and under the IHSS program in California were far less likely than agency workers to be formally trained in the tasks they performed. Nonetheless, under both programs, these workers felt well informed about consumers' care needs. Moreover, both the Cash and Counseling and the IHSS program had satisfactory safety records. Under Cash and Counseling, treatment group members were no more prone than control group members to adverse events and health problems, and had a significantly lower incidence for some such problems (Carlson et al. 2007). Likewise, beneficiaries in the IHSS program were no more likely to experience safety problems if they received consumer directed, rather than agency directed, services (Benjamin, Matthias, and Franke 2000).

Although critics of consumer direction may worry that consumers would not pay workers adequately, directly hired workers earned almost as much per hour as agency workers in Arkansas (within 5 percent) and more per hour (10–15 percent) in New Jersey and Florida. Compared with agency workers, they were more satisfied with their wages. While those hired in the IHSS program were less satisfied than agency workers with pay and career opportunities, this was likely not a result of consumers exploiting workers, but rather a result of the state setting a wage for hired workers in the consumer-directed program that was 30 percent less than their agency counterparts (Benjamin and Matthias 2004).

Our findings have limitations. First, they pertain to one model of consumer direction and may not be generalizable to models with different features, particularly those that do not let consumers hire family members (although variation across states ameliorates this concern somewhat). Second,

given the relatively short duration of our follow-up period, we do not know whether the positive experiences reported by paid and unpaid caregivers will persist. Third, although the demonstration's randomized design allows us to be quite confident in the results of our impact analysis, we cannot rule out the possibility that some caregivers for treatment group members might have inflated reports on some outcomes, such as their own health status, because Cash and Counseling brought them other benefits and they wanted the program to continue. (Conversely, some caregivers for control group members may have overstated their dissatisfaction or burden because they were disappointed that their care recipient was not randomly assigned to the treatment group.) Fourth, the descriptive analysis of directly hired workers was not representative of all workers who provided paid care to consumers. Workers who were hired and quit (or were fired) or whose care recipient disenrolled from Cash and Counseling before the 9-month consumer follow-up survey were not included in the study. Such workers may well have been less satisfied with their working conditions than were those in our sample.

Finally, having data on additional caregiver and worker characteristics would have enriched our analysis. For example, data on caregivers' and workers' baseline health status and levels of strain would have helped us determine how Cash and Counseling affects subgroups defined by those characteristics.

Our findings suggest several lessons for programs. Clearly, the sooner interested consumers begin receiving the allowance and directing their care, the sooner they and their caregivers might benefit. Thus, programs should give consumers whatever assistance they need to develop their allowance spending plans, and perhaps hold program counselors responsible for starting most consumers on the allowance by a certain time. Second, because many caregivers benefited from becoming paid workers, programs must accurately inform consumers about hiring policies. For consumers who cannot or do not want to hire family members, states may want to consider developing worker registries as a resource. Finally, workers experiencing emotional strain might benefit from caregiver support networks, which programs could organize or publicize.

As states and the federal government seek to increase Medicaid beneficiaries' ability to live at home, attention must be paid to the burden society places on front-line caregivers. The expanding availability of Medicaid supportive services, made possible in recent years through the federal New Freedom Initiative and Systems Change grants and through state efforts, is intended to help the nation's cadre of family caregivers. Judging from the

experiences of our three-state study sample, letting interested consumers direct their own personal care—whether or not they decide to hire family members as workers—is one way of reducing some types of caregiver burden, while providing a satisfactory experience to the workers whom consumers choose to hire.

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