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**The Experiences of  
Workers Hired Under  
Consumer Direction in  
Arkansas**

*Final Report*

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## EXECUTIVE SUMMARY

An important consideration that is often overlooked in consumer-directed programs is the well-being of paid workers. Medicaid supportive services for individuals with disabilities have traditionally been provided through home care agencies. In contrast, under the Cash and Counseling model of consumer-directed care, beneficiaries hire and pay workers directly, deciding who provides their care, when they receive it, and how it is delivered. Because directly hired workers do not have an agency affiliation, some policymakers are concerned they may not have sufficient training, supervision, and support, and may not receive adequate wages. In addition, the emotional and physical well-being of directly hired workers may be at risk because of the workers' lack of training and support; also, because these workers are usually the friends or relatives of their clients, they may find their jobs emotionally draining.

This study describes the experiences of workers hired under consumer direction, using results from the first Cash and Counseling demonstration, Arkansas' IndependentChoices. This demonstration included Arkansans who were at least 18 years old and eligible for personal care services under the state Medicaid plan. After voluntarily enrolling in the demonstration (between December 1998 and April 2001), individuals were randomly assigned to direct their own personal assistance as IndependentChoices consumers (the treatment group) or to receive services as usual from agencies (the control group). IndependentChoices consumers could use a monthly allowance to hire their choice of caregivers, including friends or relatives (except spouses), or to buy other services or goods needed for health and personal care. At their follow-up interview, a sub-sample of consumers (including mainly those who responded to the survey after September 2000) were asked to identify their "primary paid worker." Our analysis focuses on these primary paid workers.

Within about a month after being identified, primary paid workers were called to complete the Cash and Counseling Caregiver Survey. Those workers who were also the consumer's primary informal caregiver at baseline (about 45% of the workers for the treatment group) were administered a longer survey instrument that also included questions related to their role as informal caregivers. From their survey responses, we constructed measures describing the worker's characteristics and relationship with the consumer; the type, timing and amount of care provided during the past two weeks; perceptions of working conditions; whether the worker received training; and worker well-being, including wages, fringe-benefits, stress, and satisfaction. We focus primarily on describing the experiences of the "directly hired workers" for the treatment group; we use agency workers' experiences as a benchmark.

Directly hired workers were generally the relatives or close friends of the consumer, often fulfilling the roles of both informal caregiver and employee. They provided many hours of unpaid care and care during non-business hours. Because they were not bound by agency rules or other state regulations, they were able to assist with a variety of health care tasks. Compared to agency workers, directly hired workers who were related to the consumer were more likely to feel emotional strain and were more likely to desire greater respect than they were receiving from the consumer's family. In contrast, the well-being of non-related directly hired workers was very similar to that of agency workers. Thus, the greater strain for related workers appears

to be due to other aspects of the relationship between these hired workers and the consumers, rather than to their being hired. The high proportion of directly hired workers (91%) who report getting along very well with the consumer is further evidence that being hired has not caused or exacerbated emotional or relationship problems for workers.

In general, the Cash and Counseling model does not appear to create adverse consequences for caregivers through either a lack of training or poor compensation. Directly hired workers were paid about the same wage on average as agency workers, but expressed substantially greater levels of satisfaction with their compensation. When differences in total hours of care provided were taken into account, caregivers hired by IndependentChoices caregivers were no more likely than agency workers to suffer physical injury or strain from caregiving, despite their being much less likely to receive training. Finally, both agency workers and directly hired workers were quite satisfied with their overall working conditions. Thus, workers hired under IndependentChoices appear to be as pleased with the program as consumers are.

While Medicaid supportive services for individuals with physical dependency needs have traditionally been provided by home care agency workers, under the Cash and Counseling model of consumer-directed care, beneficiaries make their own decisions about their care. They develop and manage individual budgets, and when they choose to use some of that allowance for personal assistance workers, they set wage rates and hire and pay workers directly; they decide who provides their care, when they receive it, and how it is delivered. Because directly hired workers do not have an agency affiliation, some policymakers are concerned that they might not have sufficient training, supervision, or support to perform their job appropriately. These deficiencies could adversely affect the emotional and physical well-being of directly hired workers. Also, workers who are the friends or relatives of the consumer might find that being paid to care for a loved one can create difficulties in their relationship with the consumer or other family members.

It is important to study the welfare of workers under consumer-directed care, as this model is sustainable only if workers have positive experiences. In this paper, we use data obtained from the first Cash and Counseling demonstration, Arkansas' IndependentChoices, to assess the experiences of directly hired workers. We describe the types and amount of care that paid workers provide, the training and supervision they receive, their working conditions, and their well-being. We also consider how the worker-consumer relationship affects key outcomes. While this study is not an impact analysis, we use the experiences of agency workers as a benchmark for comparison of the experiences of directly hired workers. Thus, this analysis should enable policymakers to assess whether directly hired workers fare at least as well as agency workers. We do not expect, however, that agency workers and directly hired workers will necessarily have similar experiences, as most directly hired workers are the relatives or

friends of the consumer, serving as part employee, part informal (unpaid) caregiver. This personal relationship will clearly influence caregivers' outcomes.

## **A. BACKGROUND**

### **1. New Model of Medicaid Personal Assistance**

About 1.2 million individuals receive disability-related supportive services in their homes (LeBlanc et al. 2001; and Kitchener and Harrington 2001), mostly from government-regulated agencies whose professional staff select, schedule, and monitor the quality of services. However, a growing percentage handle the responsibilities themselves (Velgouse and Dize 2000).

As one model of consumer-directed supportive services, Cash and Counseling provides a flexible monthly allowance that consumers can use to hire their choice of workers (including relatives) and to purchase other services and goods that meet their personal assistance needs (any restrictions on which are set by states). Cash and Counseling also provides counseling and fiscal assistance to help consumers plan and manage their responsibilities and allows them to designate representatives (such as family members) to make decisions on their behalf. These features make the model adaptable to consumers of all ages and with all types of impairments.

With funding from the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, the Cash and Counseling Demonstration and Evaluation was implemented in three states—Arkansas, Florida, and New Jersey. Because of variations in their Medicaid programs and political environments, the demonstration states were not required to implement a standardized intervention, but they did have to adhere to basic Cash and Counseling tenets (as summarized above). Unsurprisingly, the resulting programs differed in their particulars. For this reason, each program is being evaluated separately, by Mathematica Policy Research, Inc. (MPR).

## **2. Cash and Counseling in Arkansas**

Arkansas designed IndependentChoices as a voluntary demonstration for adults over 18 who were eligible for personal care services (PCS) under its Medicaid plan. The state hoped to use the demonstration as a way to gauge the demand for consumer-directed personal assistance and assess its practicability. It also hoped the program would be better than agencies at serving individuals during non-business hours and in rural parts of the state, where agencies and agency workers were scarce (Phillips and Schneider 2002). Enrollment and random assignment began in December 1998 and continued until the evaluation target of 2,000 enrollees (about 11 percent of Arkansas PCS users, 26 percent of which are new to PCS) was met, in April 2001.<sup>1</sup>

Prospective enrollees were told what their monthly allowance would be should they be assigned to the treatment group to direct their own PCS. (The average allowance was \$320 a month, which was based about 40 hours of services, the average recommendation of care plans.) Those who wanted to use a representative were asked to name one. Arkansas required all prospective enrollees to agree that they would use agency services should they be assigned to the control group. Beneficiaries who decided to enroll completed a baseline telephone interview and were then randomly assigned to the treatment or control group.

After random assignment, control group members continued relying on agency services or, if newly eligible for Medicaid PCS, received a list of home care agencies to contact for first-time

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<sup>1</sup> To receive Medicaid PCS, an Arkansan must (1) be categorically eligible for Medicaid; (2) live in his or her own residence or in a community-based residence, group or boarding home, or residential care facility; and (3) have physical dependency needs related to the activities of daily living and a physician's prescription for personal care (Arkansas Medicaid Program 1998). Slightly more than 18,000 Medicaid beneficiaries received personal care services in Arkansas in 1998, when Cash and Counseling was introduced (Nawrocki and Gregory 2000). Intake for the program was longer than one year, and there may have been a net flow into the program. Thus, 11 percent represents the maximum percentage of eligible recipients who enrolled in IndependentChoices.

services. Treatment group members were contacted by an IndependentChoices counselor, who helped them develop acceptable written plans for spending their allowance. Arkansas consumers could use their allowance to hire workers (except spouses or representatives) and set the hourly rate for their wages. They could also use the allowance to purchase other services or goods related to their personal care needs, such as supplies, assistive devices, and home modifications. They were required to keep receipts for all but incidental expenditures, which could not exceed 10 percent of the allowance.

With very few exceptions, consumers chose to have the program's fiscal agents maintain their accounts, write checks, withhold taxes, and file payroll tax returns for their workers. Most also called upon program counselors for advice about hiring, training, and supervising workers. In addition to helping consumers manage their responsibilities, counselors monitored consumer satisfaction, safety, and use of funds through initial home visits, monthly telephone calls, reassessment visits, and reviews of spending plans, receipts, and workers' time sheets (Schore and Phillips, 2002).

## **B. RESEARCH QUESTIONS**

From previous research, we do know *whom* consumers hired under IndependentChoices. Specifically, most treatment group members hired at least one family member (Dale et al. 2002). Although about one-third of treatment group members hired only nonrelatives as paid caregivers, program staff and counselors reported that few treatment group members hired strangers (Phillips and Schneider 2002). Also, few consumers hired agency aides, and only rarely did different consumers hire the same worker.

One previous study of another program, the California In-Home Supportive Services Program (IHSS), assessed the experiences of workers hired under a different consumer-directed model (Doty et al. 1999). In this paper, we examine some outcome measures, such as the total



hours and timing of care that workers provided, that were not analyzed by Doty et al. (1999). While many of our other research questions, are similar to those investigated by Doty et al., it is important to note that the IndependentChoices programs is somewhat different from the IHSS program. In particular, in the IHSS program, consumers were assigned to receive consumer-directed services in certain counties because agency-directed services were not available; in counties where both agency services and consumer-directed services were available, case managers assigned people to receive one type or the other. Case managers were more likely to assign people to receive consumer-directed services if they had severe disabilities (and therefore required more hours of care), required paramedical assistance, or were likely to be able to recruit a worker. In contrast, under IndependentChoices, consumers who volunteered for the demonstration were randomly assigned to receive the cash allowance option or agency-directed care. Thus, workers' experiences could be different under these two programs.

In this paper, we focus in particular on workers' training and supervision, working conditions, and well-being. The policy concern about whether directly hired workers receive adequate training without the support of an agency is important. Doty et al. (1999) found that workers hired under consumer direction were less likely than agency workers to report receiving training in performing household chores and in bathing and transferring their client, but more likely to report receiving training on providing paramedical assistance. Workers who have not received training on the correct way to lift or care for patients could become injured on the job. Another policy concern is the potential adverse effect of the working arrangement on the workers' well-being. Without the support of an agency, workers might receive inadequate wages or have to work in an unsafe environment. They might also suffer from emotional strain due to providing care for people they love. Indeed, Doty et al. (1999) found that, relative to agency workers, workers hired under consumer direction received lower wages, were less likely to

receive fringe benefits, and had closer relationships with their clients, but also did not fare as well in terms of emotional well-being.

We also examine the patterns of the timing, hours, and types of care provided under IndependentChoices. From Dale et al. (2003), we know that consumers are more likely to receive care during non-business hours under IndependentChoices than through agencies. However, providing care during these hours could be burdensome for the workers. Another important issue is whether directly hired workers are more likely to provide care that requires the performance of certain types of health care tasks. Doty et al. (1999) found that workers under consumer direction were more likely than agency workers to report providing paramedical assistance, including help with medications or injections. Agency rules designed to limit liability and state regulations in Arkansas prevent agency workers from performing nursing tasks, such as giving medications (they are permitted to remind people to take their medications). Workers hired under consumer direction are exempt from these state regulations and therefore would not be prohibited from providing certain types of health care assistance.

Finally, because workers who are related to the consumer often fulfill dual roles of informal caregivers and employees, we would expect their experiences to be different from those of non-related workers. Therefore, for key outcomes, we will compare the experiences of related and non-related directly hired workers. We also examine briefly which types of workers appear to have better or worse experiences under IndependentChoices.

## **C. METHODS**

### **1. Data Collection**

This analysis draws primarily on data from two computer-assisted telephone surveys: (1) a baseline survey of all treatment and control group members, and (2) a survey of the “primary paid workers” hired by treatment group members and the agency workers for control group

members. During the nine-month follow-up survey, we asked a subsample of approximately 420 treatment group and 360 control group members (primarily those interviewed after September 2000) to identify the paid worker who, at the time of that survey, was helping the most with personal care, chores and activities around the house and in the community, and routine health care at home. Although the members of the subsample did not constitute a random sample of all treatment and control group members, the baseline characteristics of this subset of consumers were fairly comparable to those of the treatment and control group as a whole.<sup>2</sup> About a month after completing the nine-month follow-up survey with consumers, we interviewed the primary paid workers whom the subsample of consumers had identified for the Cash and Counseling Caregiver Survey. Those paid workers who were also the consumer's primary informal caregiver at the time of demonstration enrollment—about 45 percent of the paid worker sample—were administered a longer version that also included the questions pertaining to their roles as informal caregivers. On average, the survey took about 20 minutes to complete. About 94 percent of workers for the treatment group and 78 percent of agency workers for the control group that we attempted to contact responded. (For the treatment group, we attempted to contact only workers who had been hired with the allowance.)

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<sup>2</sup> The decision to fund and implement a paid worker survey was made after the consumer nine-month survey was in progress. All those consumers who were interviewed for the nine-month survey after September 2000 were asked to identify a paid worker. We also identified the primary paid workers of a subsample of the consumers who completed the nine-month survey prior to September 2000, based on their responses to a supplemental survey. The subsample of consumers who were administered the supplemental survey included those who had responded to the nine-month survey most recently. Thus, those consumers who enrolled in IndependentChoices later (and were therefore surveyed later) were more likely than were consumers who enrolled earlier to have been asked to identify a worker for the paid worker survey. Although the consumers whose paid workers were included in our sample were generally similar to the consumers whose paid workers were not in the sample, they differed in some ways; for example, they were less likely to be older than age 80, more likely to live alone, and less likely to have a representative.

In the final sample, 391 workers for treatment group members and 281 workers for control group members responded to the survey. We refer to the primary paid workers for the treatment group as “directly hired workers” and to those for the control group as “agency workers.” However, 1 percent of the workers for the control group reported that they were paid directly by the consumer (presumably through a private source), and another 1 percent were hired by the consumer through a Medicaid waiver program, Alternatives, which allowed a beneficiary’s relatives and friends to become certified providers and receive payment for providing care. Also, agencies were allowed to hire the relatives of their clients, but they rarely did.

## **2. Descriptive Measures**

The survey data allow us to construct measures that describe the workers’ characteristics as well as their experiences, as shown in Appendix Table A.1. In general, the measures describe only the experiences of workers caring for the IndependentChoices sample member. (For example, they describe the hours the worker spent caring for the sample member, but not the hours spent taking care of any other individuals.) In summary, our measures describe:

- Worker and consumer characteristics, including the worker-consumer relationship
- Working conditions, including (1) factual measures, such as the workers’ wages and fringe benefits, and (2) the workers’ perceptions about the working conditions
- The training and preparation that workers received for job
- The pattern of care provided, including the type, amount, and the timing of care provided during the “past two weeks”<sup>3</sup> (that is, the two weeks preceding the primary paid worker interview)

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<sup>3</sup> Directly hired workers reported the number of hours of care they were paid for and the number of hours of total care they provided. However, they did not differentiate tasks they were paid for from tasks that they provided informally. Likewise, they did not report (and likely did not keep track of) whether the hours the time they worked during non-business hours were paid or unpaid.

- The worker’s physical and emotional well-being

We derived many of these measures (for example, degree of satisfaction) from survey questions that have four-point scales. To maintain simplicity in presenting the results, we collapsed these scales into two binary measures—one for the most favorable rating (very satisfied and one for an unfavorable rating (somewhat or very dissatisfied)).<sup>4</sup>

### **3. Methods for Analysis**

Because this analysis is intended to describe the experiences of directly hired workers, we present the means for each measure, along with *t*-tests indicating whether the mean for one group (such as agency workers) and the mean for another group (such as directly hired workers) differ. We present means, rather than regression-adjusted results, because we are often interested in comparisons that do *not* net out the differences due to the characteristics of the workers that were hired. For example, we draw comparisons between workers who were related to the consumer and workers who were not.

While we do not present regression results in the main body of the paper, we estimated regressions to determine whether there were differences between agency workers and directly hired workers after controlling for consumer and worker characteristics. In general, the regression-adjusted differences between directly hired and agency workers were similar to the unadjusted differences reported in the paper (see Table A.5).

In addition, we estimated the effect of worker characteristics, consumer characteristics, and the worker-consumer relationship on key outcomes for the workers hired directly by the

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<sup>4</sup> Before collapsing the responses, we examined frequencies for individual response categories responses to each of the questions to make sure that using two binary variables would not obscure important findings.

treatment group. These key outcomes include worker satisfaction, whether the worker received training, whether the worker desired more respect from the consumer or the consumer's family, and the worker's level of emotional strain. These results are shown in Appendix Table A.4. In general, there were few consistent patterns across outcome measures that we could draw from the regression results. The characteristics for which we found the strongest relationship to key outcomes were the consumer-worker relationship and living arrangements. Therefore, after examining outcomes for the full sample, we compare key outcomes for workers who are related to the consumer to those workers who are not related, and we compare workers who lived with the consumer to those who did not.

### **Sample Description: Characteristics of Workers and Their Care Recipients**

*Consumer Characteristics.* As with the consumer sample in general, most consumers whose workers were paid to provide assistance were white and female (Table A.2). Half the consumers who received care from agency workers and 44 percent who were cared for by directly hired workers reported being in poor health. Two-thirds of each group reported functional limitations, such as with getting in and out of bed.

Although consumers receiving care from directly hired workers and consumers receiving care from agency workers were similar along most dimensions, we found one notable difference between the two groups. Thirty-eight percent of the consumers with directly hired workers were “new” to personal assistance services; that is, they were not receiving paid assistance at baseline. In contrast, only 21 percent of the consumers with agency workers were new to personal assistance services. This difference is due to the fact that control group members who were new to personal assistance services were much less likely than were treatment group members to have

a paid caregiver by the time of the nine-month follow-up survey (and therefore did not have a worker who could be included in this sample).

***Worker Characteristics.*** In some respects, workers who were hired directly and agency workers were similar (Table 1). The majority of both groups were aged 40 to 64, and over 80 percent were at least 10 years younger than the consumer they cared for. Most had at least a high school education, although agency workers were somewhat more likely than directly hired workers to have graduated from high school (79 percent and 71 percent, respectively). Nearly all agency workers (97 percent) and the great majority of directly hired workers (84 percent) were female.

Because treatment group members generally hired friends and family, there are some striking differences between directly hired workers and agency workers. Specifically, 78 percent of directly hired workers were related to the consumer, and nearly half (49 percent) were the daughter or daughter-in-law. About 27 percent of directly hired workers lived with the consumer at the time of the caregiver survey, and nearly all these live-in workers had lived with the consumer before the demonstration began (not shown). Before the demonstration began, 84 percent of directly hired workers had provided help with routine health care, personal care, or household tasks, and 45 percent had been the consumer's primary informal caregiver.<sup>5</sup> In contrast, few agency workers were related to the consumer (about 6 percent), lived with the consumer (4 percent), or were the primary informal caregiver prior to the demonstration (5 percent). During the two weeks prior to the Caregiver survey, 40 percent of directly hired

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<sup>5</sup> The consumer's primary informal caregiver is defined as the caregiver who provided the greatest number of hours of unpaid care to the consumer.

TABLE 1  
CHARACTERISTICS OF PRIMARY PAID WORKERS  
(Percentages)

Characteristics	Agency Workers	Directly Hired Workers
Age (Years)		
18 to 39	33.8	37.1
40 to 64	57.7	54.5
65 to 79	7.5	8.2
80+	0.7	0.3
≥10 Years Younger than Consumer	82.2	82.6
High School Graduate	78.6	70.8***
Female	97.2	84.4***
Race		
White	55.4	60.3
Black	42.1	35.1
Other	2.5	4.6
Same Race as Consumer	79.6	90.7***
Held Job Other than Caregiving at Time of Caregiver Survey	20.1	39.7***
Relationship to Consumer		
Related to consumer	6.4	78.3***
Not related, but knew consumer prior to demonstration	20.6	16.4
Did not know consumer prior to demonstration	73.0	5.4***
Type of Relationship to Consumer		
Parent	0.0	3.3***
Daughter/daughter-in-law/son/son-in-law	3.2	48.6***
Sister/sister-in-law/brother/brother-in-law	1.8	5.9***
Grandchild	1.1	11.3***
Other relative	0.4	9.2***
Living/Care Arrangement		
Lives with consumer	4.3	27.4***
Was consumer's primary informal caregiver prior to demonstration	4.6	44.5***
Helped consumer with care prior to demonstration	— <sup>a</sup>	84.4
<b>Sample Size</b>	<b>281</b>	<b>391</b>

SOURCE: Caregiver Survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

<sup>a</sup> Question not asked of agency workers.

<sup>b</sup> The consumer's primary informal caregiver was identified during the Consumer Baseline Survey.

\*Directly hired workers different from agency workers at .10 level, two-tailed test.

\*\*Directly hired workers different from agency workers at .05 level, two-tailed test.

\*\*\*Directly hired workers different from agency workers at .01 level, two-tailed test.



workers held jobs other than caregiving, compared with 20 percent of agency workers. Finally, more directly hired workers than agency workers were members of the same racial or ethnic group as the consumer they cared for (91 percent and 80 percent, respectively); this difference is likely due to the fact that most directly hired workers were relatives.

## **D. RESULTS**

In the following examination of the employment experiences of directly hired workers, we use the experiences of agency workers as a benchmark. However, because most directly hired workers were relatives or friends of the consumer and were providing care informally before the demonstration began, their experiences are likely to be different from those of agency workers. Indeed, prior to the demonstration, 95 percent of directly hired workers knew the consumer, and 84 percent were providing informal care to the consumer. The most common reason that these informal caregivers gave for becoming paid workers was that it was “an opportunity to be paid for tasks that I had already been doing.” After the demonstration began, most directly hired workers continued to provide large amounts of unpaid care to the consumer, in addition to the hours they were paid for. In short, the experiences of directly hired workers may be more similar to those of informal caregivers than to those of agency workers. A companion report (Foster et al. 2003b) compares the outcomes of the predemonstration primary informal caregivers who became paid workers to those who did not become paid.

### **1. Hours of Care Provided**

Although directly hired workers were paid for some hours of care that they provided in the two weeks preceding the interview, most also provided unpaid care. In fact, 74 percent of directly hired workers provided at least some unpaid care (Table 2). The average directly hired

TABLE 2  
 PRIMARY PAID WORKERS' AVERAGE HOURS OF CARE  
 PROVIDED PER WEEK  
 (Percentages)

	Agency Workers	Directly Hired Workers
<b>Paid Hours Provided per Week</b>		
Average Number	11.8	12.5
Distribution		
0 to 7	30.9	19.2
8 to 14	44.7	61.4
>14	24.4	19.4
<b>Unpaid Hours Provided per Week</b>		
Average Number	3.7	25.7***
Distribution		
0	92.0	26.4
1 to 14	3.3	28.1
15 to 35	.7	16.1
36 to 84	2.2	22.2
>84	1.8	6.9
<b>Total Hours Provided per Week</b>		
Average Number	15.4	38.2***
Distribution		
0 to 14	70.2	26.9
15 to 35	24.4	33.7
36 to 84	3.3	28.9
>84	2.2	10.5
<b>Sample Size</b>	<b>275</b>	<b>360</b>

SOURCE: Caregiver Survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Workers were asked how many hours of care they provided during the two weeks preceding the survey. Their responses were divided in half to compute the average hours of care they provided per week. The hours that live-in workers provided include hours of care provided to the consumer and hours of assistance that benefited the household (including the consumer), such as cooking, preparing meals, and doing laundry.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

worker was paid for less than one-third of the hours of care provided per week (12.5 paid hours divided by 38.2 total hours). Seven percent of directly hired workers provided an average of more than 84 hours of unpaid care per week during the two weeks preceding the interview (including hours provided for the whole household as well as for the consumer),<sup>6</sup> and the average directly hired worker provided 26 hours of unpaid care per week.<sup>7</sup> In contrast, only 8 percent of agency workers provided any unpaid care, and most of the agency workers who provided a nontrivial amount of unpaid care were related to the consumer. Specifically, the 6 percent of agency workers who were related to the consumer provided an average of more than 50 hours of unpaid care per week, whereas those who were not related provided an average of less than half an hour of unpaid care per week (not shown). The large amount of unpaid care that directly hired workers provided likely reflects the fact that 84 percent of them provided at least some care to the consumer informally before the demonstration.<sup>8</sup>

Both directly hired and agency workers provided similar amounts of paid assistance, averaging approximately 12 hours a week (Table 2). However, the distribution of hours of paid

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<sup>5</sup> Live-in workers were asked how many hours they spent on tasks that benefited the whole household, such as preparing meals and doing housework, laundry, shopping, and yard work. They were also asked the number of hours spent on tasks that benefited the consumer only, such as routine health care, personal care, or transportation. Our measures for hours of care include the hours these workers provided both for the consumer and for the consumer's household.

<sup>7</sup> Workers were asked about the hours of care that they provided during the past two weeks. Their responses were divided by two to compute the hours provided per week.

<sup>8</sup> The fact that 84 percent of directly hired workers provided care informally to the consumer prior to the demonstration but only 75 percent provided unpaid care at the time of the Caregiver Survey indicates that some no longer provided unpaid care. While this suggests that there was some substitution of paid for unpaid care, about 9 percent of the primary informal caregivers for the *control* group at baseline were no longer providing any care at the time of the Caregiver Survey (Foster et al. 2003b). Thus, the proportion of workers who were providing unpaid help prior to the consumers' enrollment in IndependentChoices and who stopped doing so after the cash alternative became available is quite similar to the proportion who would be expected to have stopped providing unpaid assistance even if the cash alternative were not available.

care differed, with directly hired workers less likely than agency workers to provide very few or very many hours of care. Nineteen percent of directly hired workers provided fewer than 7 hours of paid care a week to the sample member, compared with 31 percent of agency workers; conversely, 19 percent of directly hired workers provided more than 14 hours of paid care a week to the sample member, compared with 24 percent of agency workers.

Finally, because directly hired workers provided so many hours of unpaid care, they also provided more than twice as many total hours of care (paid and unpaid) than did agency workers. Directly hired workers cared for the sample member for an average of 38 hours a week, whereas agency workers averaged approximately 15 hours a week.

## **2. Compensation and Job Satisfaction**

Directly hired workers and agency workers received similar wages, although directly hired workers were less likely to receive fringe benefits. Directly hired workers received an average hourly wage of \$6.07, slightly (but significantly) less than the average agency worker wage of \$6.31 an hour (Table 3). However, the average weekly wages of the two groups were virtually identical, with both groups earning an average of approximately \$77 a week for caring for the sample member (\$153 over the past two weeks).

Although only a minority of workers received any fringe benefits, a greater percentage of agency workers (21 percent) than directly hired workers (2 percent) received fringe benefits as part of their caregiving job. The percentage of directly hired workers receiving fringe benefits is quite small. However, most of these workers would be considered part-time employees, providing an average of 12 hours of care per week, and part-time employees of many organizations are ineligible for benefits. (The monthly benefit was seldom large enough in

TABLE 3

COMPENSATION AND SATISFACTION WITH WORKING CONDITIONS

	Agency Workers	Directly Hired Workers
<b>Compensation</b>		
Hourly Wage (Dollars)	\$6.31	\$6.07***
Total Pay over Past Two Weeks (Dollars)	\$152	\$153
Received Some Fringe Benefits (Percent)	20.6%	1.6%***
Paid for Travel Time (Percent, Among Visiting Workers Only)	57.8%	5.8%***
<b>Job Satisfaction<sup>a</sup></b>		
With Wages and Fringe Benefits (Percent)		
Very satisfied	22.2%	44.6%***
Not satisfied	37.5%	15.6%***
With Working Conditions Overall (Percent)		
Very satisfied	81.8%	83.4%
Not satisfied	2.1%	1.0%

SOURCE: Caregiver survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers.

<sup>a</sup> Fringe benefits could include health insurance, life insurance, disability insurance, paid sick leave, paid vacation, paid holidays, free housing, free use of consumer's car, or free meals.

<sup>b</sup> Respondents were asked whether they were very satisfied, somewhat satisfied, somewhat dissatisfied, or very dissatisfied. "Not satisfied" includes those who were somewhat or very dissatisfied. "Somewhat satisfied" is not shown.

\*Significantly different from agency workers at the .10 level, two-tailed test.

\*\*Significantly different from agency workers at the .05 level, two-tailed test.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

Arkansas to permit a consumer to hire a full-time worker.) In contrast, agency workers usually would have cared for more than one person and may have worked full-time or at least enough hours to be eligible for benefits. Furthermore, small employers (such as the consumers in this program) rarely can afford to provide benefits such as health insurance or retirement plans, whereas larger entities can negotiate more favorable rates and can spread the fixed costs of such benefits over more employees. Among those who did not live with the consumer, 58 percent of agency workers, but only 6 percent of directly hired workers, were paid for their travel time.

Without agency support, policymakers might be concerned that directly hired workers would not be paid in a timely manner or might be paid less than they were owed. In fact, 35 percent of directly hired workers did report that their pay had been delayed over the past two weeks; however, only 7 percent reported ever being paid less than they were owed (not shown). Thus, the vast majority of directly hired workers eventually received all the pay they were expecting. (These questions were not asked of agency workers, as it was assumed that agencies generally paid workers on time and correctly.)

Despite receiving modest (and sometimes late) pay and almost no fringe benefits, about 45 percent of directly hired workers reported being very satisfied with their wages and benefits; only 16 percent reported being dissatisfied. In contrast, 22 percent of agency workers reported being very satisfied with their wages and fringe benefits, whereas 38 percent reported being dissatisfied. Thus, although policymakers might be concerned that directly hired workers receive inadequate wages and benefits, the workers themselves are fairly satisfied with their compensation, especially in comparison with agency workers. The directly hired workers' higher level of satisfaction with their wages and fringe benefits is likely due in part to the fact that so many of them had been providing unpaid care; they are satisfied to be receiving even modest pay for work for which they had previously done for free. Also, the directly hired

workers might have viewed their pay as a supplement to their family income, and many who received health insurance from another job or their spouse's job may not have resented the lack of fringe benefits.

Finally, it is notable that the modest wages of these workers do not seem to dampen their overall perception of their working conditions. More than 80 percent of both directly hired workers and agency workers reported being very satisfied with their working conditions.

### **3. Pattern of Care Provided**

Because most directly hired workers also were informal caregivers, it is not surprising that many of them provided care during non-business hours. Fifty percent provided care before 8 AM on weekdays, 71 percent provided evening care, and 85 percent provided weekend care (Table A.3). In contrast, only 21 percent of agency workers provided care before 8 AM on weekdays, 12 percent provided evening care, and 16 percent provided weekend care. Thus, few agency workers provided care outside normal business hours. Note that in interpreting these results, we cannot determine the hours for which workers were paid (that is, for business or for non-business hours). These results reflect the directly hired workers' role as both employee and informal caregiver, and the fact that many such workers live with the consumer (see Table 8 for care provided by live-in workers during non-business hours). In contrast, nearly all of these control group members whose agency worker was interviewed had both paid caregivers and unpaid caregivers, with the paid (agency) worker providing care during business hours, and the unpaid caregiver providing care during non-business hours. Under IndependentChoices, *consumers* experienced only modest increases (of around 5 percentage points) in the likelihood of receiving any (paid or unpaid) help during the early mornings, evenings, or weekends; during non-business hours, most members of the control group who could not obtain paid help apparently received at least some informal care (Dale et al. 2003).

#### **4. Type of Care Provided**

Nearly all directly hired workers and agency workers provided personal care and household care. However, although most directly hired workers (83 percent) provided help with routine health care, only 59 percent of agency workers provided this type of help (Table 4). In particular, 76 percent of directly hired workers helped their client take medicine, 56 percent assisted with range-of-motion or other exercises, 26 percent helped their client care for pressure sores or other chronic wounds, and 42 percent assisted with special foot care necessary as a result of poor circulation. Fewer directly hired workers assisted with technical health care tasks such as taking care of a feeding tube, colostomy, or urinary catheter, likely because these medical needs were less prevalent in our sample.

One might be concerned that directly hired workers are not fully qualified to perform many of these health care tasks. However, we found no evidence that consumers' health suffered as a result of the care they received during the demonstration. In fact, in a companion analysis, Foster et al. (2003a) showed that IndependentChoices' consumers were less likely than control group members to have pressure sores develop or worsen and less likely to experience shortness of breath.

In nearly every area we examined, directly hired workers were much more likely than agency workers to provide specific types of health care. This difference was not surprising, since agency workers were prohibited from performing many health care tasks. However, even though few consumers in the control group received assistance with health care tasks from agency workers, many may have received help from informal caregivers. Indeed, Dale et al. (2003) found that there was no difference between the treatment and control groups in the likelihood that consumers received assistance with routine health care from any (paid or unpaid) caregiver.



TABLE 4  
TYPE OF CARE PROVIDED DURING PAST TWO WEEKS  
(Percentages)

	Agency Workers	Directly Hired Workers
Type of Assistance		
Any routine health care	59.4	82.6***
Personal care	94.6	94.1
Household care	93.5	98.3
Provided company	— <sup>a</sup>	94.1
Health Care Tasks Provided		
Taking medicine	23.1	75.8***
Caring for pressure sores or other chronic wounds	10.4	26.3***
Use/care of feeding tube	1.8	4.4*
Care of urinary catheter	6.1	5.3
Care of colostomy	1.1	2.5
Range of motion/other exercise	36.3	55.8***
Care of ventilator or other care of the lungs	5.4	11.7***
Special care of feet	27.7	42.2***

SOURCE: Caregiver Survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample size is 281 for agency workers and 391 for directly hired workers.

<sup>a</sup> Question not asked of agency workers.

\*Significantly different from agency workers at the .10 level, two-tailed test.

\*\*Significantly different from agency workers at the .05 level, two-tailed test.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

## **5. Training and Preparedness for Work**

Directly hired workers do not appear to receive training comparable to that of their agency counterparts. Only half the directly hired workers who provided routine health care reported receiving any health care training; in contrast, 95 percent of agency workers who provided routine health care received such training (Table 5). About 90 percent of both agency workers and directly hired workers who received health care training reported that the training was “hands on”: the worker performed the task while the trainer watched. Similarly, only about half the directly hired workers who assisted in personal care received training in it, whereas nearly all agency workers received such training. Again, most workers received hands-on training. Finally, virtually all agency workers received their training in personal and health care from a health care provider (not shown). Among those directly hired workers who reported receiving any training, 86 percent were trained by a health care provider, and the rest were trained by the consumer or the consumer’s family or friends.

In interpreting these results, it is important to remember that, although many directly hired workers did not report receiving training, the vast majority (84 percent, see Table 1) had been caring for the consumer before the demonstration began. These workers already may have known how to take care of their consumers, and those who were shown how to perform certain tasks while they provided informal (unpaid) care (rather than when they became paid) may not have reported that they were “trained.” Indeed, like agency workers, nearly all the directly hired workers (97 percent, Table 5) “felt fully prepared to meet expectations in helping the consumer.” Furthermore, more directly hired workers than agency workers (90 percent versus 83 percent) reported that they were well informed about the consumer’s condition.

TABLE 5  
 TRAINING AND PREPAREDNESS FOR WORK  
 (Percentages)

	Agency Workers	Directly Hired Workers
<b>Training</b>		
Received Any Health Care Training	95.2	51.7***
Of Those Receiving Health Care Training:		
Received classroom training	89.7	62.4***
Received hands-on training	89.7	89.8
Received Any Personal Care Training	93.5	49.4***
Of Those Receiving Personal Care Training:		
Received classroom training	85.7	59.4***
Received hands-on training	85.7	90.8
<b>Preparedness<sup>a</sup></b>		
Is Well-Informed About Consumer's Condition and Services		
Strongly agrees	82.6	89.7***
Disagrees	5.3	2.8
Feels Fully Prepared to Meet Expectations in Helping Consumer		
Strongly agrees	95.7	96.7
Disagrees	0.0	0.5

SOURCE: Caregiver Survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers.

<sup>a</sup> Respondents were asked whether they strongly agree, somewhat agree, somewhat disagree or strongly disagree. "Disagrees" includes those who somewhat disagreed or strongly disagreed. "Somewhat agrees" is not shown.

\*Significantly different from agency workers at the .10 level, two-tailed test  
 \*\*Significantly different from agency workers at the .05 level, two-tailed test.  
 \*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

Finally, results from a companion analysis suggest that consumers received satisfactory health care under IndependentChoices (Foster et al. 2003a) in spite of their workers' apparent lack of training. Directly hired workers' access to the consumer's family health care provider could partially account for why consumers received adequate health care. About 44 percent of directly hired workers consulted the consumer's doctor with health care questions, and 12 percent consulted the consumer's nurse (not shown). In contrast, 72 percent of agency workers consulted the home care agency with health care questions, while few consulted with the consumer's doctor or nurse (9 percent and 4 percent, respectively).

## **6. Supervision and Scheduling**

The supervision of agency workers and directly hired workers is somewhat different. Agency nurses periodically supervise agency workers in the home, while directly hired workers report being supervised mainly by the consumer and consumer's representative or family. Despite the differing nature of the supervision received, similar percentages of directly hired workers and agency workers (84 and 86 percent, respectively, Table 6) were satisfied with the supervision they received. However directly hired workers expressed greater satisfaction with the amount of feedback they received on how care was provided, and they were less likely to report having been asked to do things to which they had not agreed. Compared to agency workers, directly hired workers' may have been more satisfied with the feedback they received because they had closer (and perhaps better) relationships with the consumer. Finally, similar percentages (approximately 3 percent) of both directly hired workers and agency workers reported that close supervision interfered with their work.

Over 70 percent of workers in both groups were satisfied with the flexibility of their schedules, and few reported scheduling disagreements with their client. However, directly hired workers were more likely to report having to hurry to meet the consumer's needs, perhaps

TABLE 6  
SUPERVISION AND SCHEDULING  
(Percentages)

	Agency Workers	Directly Hired Workers
<b>Supervision</b>		
Is Satisfied with Supervision of Care		
Strongly agrees	84.3	86.4
Disagrees	2.6	2.3
Is Satisfied with Amount of Feedback on How Care Is Provided		
Strongly agrees	82.2	88.3**
Disagrees	1.6	2.1
Asked to Do Things Not Agreed to	7.5	1.8***
Close Supervision Interfered with Work	2.6	3.1
<b>Scheduling</b>		
Has a Lot of Flexibility in Scheduling Care		
Strongly agrees	72.7	77.1
Disagrees	11.4	8.5
Ever Disagreed About Schedule	3.2	2.1
Must Hurry to Meet All Consumer's Needs		
Strongly agrees	16.0	21.4*
Disagrees	68.7	63.9
<b>Back-Up Care</b>		
Is Responsible for Arranging Backup Care	— <sup>b</sup>	53.3
Somewhat or Very Difficult to Arrange Backup Care	— <sup>b</sup>	19.2

SOURCE: Caregiver survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers.

<sup>a</sup> Respondents were asked whether they strongly agree, somewhat agree, somewhat disagree or strongly disagree. "Disagrees" includes those who somewhat disagreed or strongly disagreed. "Somewhat agrees" is not shown.

<sup>b</sup> Question not asked of agency workers.

\*Significantly different from agency workers at the .10 level, two-tailed test

\*\*Significantly different from agency workers at the .05 level, two-tailed test.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

because many held other jobs, or because they had to provide more hours than they were being paid for as part of their family responsibility for the consumers' overall welfare.

Finally, directly hired workers usually had to resolve one work-related issue that agency workers presumably were not responsible for: directly hired workers often have to find backup care when they cannot come to work. Fifty-three percent of the directly hired workers in the sample were responsible for obtaining backup care, and 19 percent reported having at least some difficulty arranging for it. (We did not ask agency workers this question, as we assumed that agency workers would not be responsible for providing their own backup care.)

## **7. Worker Well-being**

Most workers experienced little physical strain as a result of their jobs, and the amount of such strain reported by workers in the two groups was similar. About two-thirds of both directly hired workers and agency workers reported little or no physical strain; conversely, only 15 percent of agency workers and 17 percent of directly hired workers reported a great deal of physical strain (Table 7). Few were physically hurt on the job, although directly hired workers were more likely than agency workers to be injured as a result of caring for the sample member (4 percent and 1 percent, respectively). The directly hired workers' lack of personal care training might have contributed to their higher rate of on-the-job injury. In addition, directly hired workers might have been more likely to be injured while caring for their client simply because they spent so much more time delivering that care. If we take into account the number of hours of work provided (by weighting the observations on workers by the total number of hours of care they provided to the sample member), directly hired workers were slightly (although not significantly) less likely than agency workers to be injured.

TABLE 7  
WELL-BEING OF PRIMARY PAID WORKERS  
(Percentages)

	Agency Workers	Directly Hired Workers
<b>Physical Strain and Injuries</b>		
Level of Physical Strain		
Little or none (1 or 2)	68.3	65.2
A great deal (4 or 5)	15.1	16.9
Any Injury	1.4	3.6*
Any Injury (Observations Weighted by Hours of Care Worker Provided to Consumer)	5.7	4.6
<b>Relationship with Consumer</b>		
Caregiver and Consumer Get Along Very Well	94.4	91.4
Had Very Close Relationship with Consumer	54.5%	84.7%***
<b>Emotional Strain</b>		
Level of Emotional Strain		
Little or none (1 or 2)	70.1	60.2***
A great deal (4 or 5)	8.9	15.2**
Ever Had Disagreement with Consumer About Schedule	3.2	2.1
Consumer Needs to Be More Respectful	12.4	16.1
Consumer's Family Needs to Be More Respectful	22.4	37.1***

SOURCE: Caregiver survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers.

\*Significantly different from agency workers at the .10 level, two-tailed test.  
 \*\*Significantly different from agency workers at the .05 level, two-tailed test.  
 \*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

Both agency workers and directly hired workers reported positively about their relationships with the consumer. Over 90 percent of both agency workers and directly hired workers reported that they got along very well with the consumer. Also, 85 percent of directly hired workers, and 55 percent of agency workers, reported having a very close relationship with the consumer.

Although most workers in both groups also reported little or no emotional strain, a larger share of directly hired workers reported suffering a great deal of emotional strain (15 percent and 9 percent, respectively). Directly hired workers also fared somewhat worse than agency workers in terms of the respect they reported receiving from the consumer and the consumer's family. (With directly hired workers, the consumer's family is typically the worker's own family). In particular, 37 percent of directly hired workers, compared with 22 percent of agency workers, reported that the consumer's family needed to be more respectful. Part of the reason that directly hired workers felt more emotional strain and were more likely to feel the consumer's family should be more respectful could be that most directly hired workers were related to the consumer. Family dynamics and relationships are likely to color the experiences of directly hired workers in many ways. Next, we explore the effect of the worker-consumer relationship on workers' experiences in more detail.

## **8. Key Outcomes, by Consumer-Worker Relationship**

In this section, we examine whether the experiences of directly hired workers varied by whether they were related to the consumer and whether their experiences differed by whether they lived with their consumer. Our primary goal in this section is to compare key outcomes across different types of directly hired workers. However, we also show these outcomes for agency workers, in order to provide a benchmark for directly hired workers, very few of whom are related to the consumer they care for.



Overall, both related and non-related directly hired workers reported high levels of satisfaction with their working conditions. Eighty-four percent of related workers and 81 percent of non-related workers reported being “very satisfied” with their working conditions (Table 8). However, directly hired workers related to the client fared worse on two measures of well-being than directly hired workers who were not related. Specifically, related workers were more likely to report that they suffered much emotional strain (17 percent compared to 10 percent). Among related workers, those who lived with the consumer reported higher levels of emotional strain than those who did not. Even among workers who did not live with the consumer, related workers felt more strained than did non-related workers. Similarly, 41 percent of related workers, but only 23 percent of non-related workers, reported that the consumer’s family needed show more respect. Related live-in workers fared the worst, as fully half the workers in this group (but only 34 percent of related workers who did not live with their client) felt that the consumer’s family did not show enough respect.

Interestingly, non-related directly hired workers and agency workers (the great majority of whom were not related to the consumer) reported similar levels of well-being. In particular, workers in both groups reported similar levels of emotional strain and similar amounts of respect from the consumer and the consumer’s family. Thus, the differences in well-being between directly hired and agency workers appear to be driven entirely by the worker’s relationship with the consumer.

Finally, we find that related directly hired workers provided an average of 29 hours of unpaid care per week, many more than the 12 hours of unpaid care per week provided by unrelated directly hired workers. This difference is driven by the large number of hours of unpaid care (49) provided by related workers who live with the consumer. However, even among workers who did not live with the consumer, those who were related to the consumer

TABLE 8  
 SELECTED OUTCOME MEASURES BY WORKER/CLIENT RELATIONSHIP  
 (Percentages)

	Directly Hired Workers						Agency Workers
	Related Workers			Non-related			
	Live-In	Not Live-In	All Related	Live-In	Not Live In	All Non-related	
<b>Working Conditions</b>							
Satisfied with Wages	41.8	47.5	44.9	43.8	43.3	43.4	22.0
Satisfied with Working Conditions	84.1	83.9	84.0	87.5	79.7	81.2	84.0
<b>Worker Well-Being</b>							
Little or No Emotional Strain	51.1	63.7	58.0	43.8	73.5	67.9*	70.2
Much Emotional Strain	19.0	14.9	16.7	25.0	5.9	9.5*	8.9
Consumer's Family Needs to be More Respectful	50.4	33.7	41.0	37.5	18.8	22.5***	22.4
Consumer Needs to be More Respectful	20.6	13.6	16.7	31.3	9.5	13.9	12.4
<b>Patterns of Care Providers</b>							
Total Hours per Week	62.2	23.7	41.6	76.4	14.6	24.7***	15.4
Paid Hours per Week	13.2	11.7	12.4	12.3	12.7	12.6	11.8
Unpaid Hours per Week	49.0	12.0	29.2	52.1	1.9	12.1***	3.7
Help During Nonbusiness Hours	99.3	86.1	92.2	100.0	53.4	62.4***	32.4
<b>Maximum Sample Size</b>	<b>138</b>	<b>168</b>	<b>306</b>	<b>16</b>	<b>69</b>	<b>85</b>	<b>281</b>

Note: Sample sizes vary slightly for each measure due to item non-response.

\*Related workers different from non-related workers at .10 level, two-tailed test.

\*\*Related workers different from non-related workers at .01 level, two-tailed test.

\*\*\*Related workers different from non-related workers at .01 level, two-tailed test.

provided many more hours of unpaid care (12.0) than those who were not related (1.9).<sup>9</sup> Related directly hired workers also were much more likely than non-related directly hired workers to provide care during non-business hours. This difference is due partly to the high percentage of related workers who lived with their client, as almost all live-in workers provided care during non-business hours. However, even among workers who live apart from the consumer, related workers were more likely than non-related workers to provide care during non-business hours.

## **E. DISCUSSION**

### **1. Summary and Policy Implications**

As expected, most directly hired workers were relatives or close friends of the consumer. These caregivers fulfilled the roles of both employee and informal caregiver, providing many hours of unpaid care, despite the fact that consumers could not hire their spouse or any relative that was acting as their representative. Compared with agency workers, directly hired workers were more likely to provide care during non-business hours; the fact that many directly hired workers lived with the consumer facilitated the provision of such care. Directly hired workers were also more likely to assist with a variety of health care tasks. Because they were not bound by agency rules or other state regulations, they were in a better position to do so. While most members of the control group did receive assistance with health care tasks and care during non-business hours (Dale et. al 2003), this care was provided primarily by informal caregivers rather than by agency workers.

While directly hired workers felt more emotional strain and lack of respect than agency workers, the reason for this difference was not that consumers make poor employers, but rather

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<sup>9</sup> The hours of unpaid care include those provided only for the consumer and those provided for the whole household.

that directly hired workers were typically the consumer's close family members. Among directly hired workers, those who were related to the consumer (particularly those who lived with the consumer) were the most likely to experience emotional strain and feelings of not being respected. There were no differences between agency workers and *non-related* directly hired workers in the levels of emotional strain and lack of family respect.

Why do related workers seem to fare worse than non-related workers in terms of these measures of their well-being? The most obvious explanation is that related workers experience more emotional strain simply because taking care of a loved one is emotionally draining. Related workers may have also desired more respect from the consumer's family because the consumer's family is also their *own* family. Family members involved in caring for family members may take each other's efforts for granted. Also, family members who provide only unpaid care may resent the fact that another family member is being paid for the help they provide. This resentment could breed a lack of respect for the efforts of the paid worker. Finally, the well-being of related live-in workers may have suffered partly because they also provided substantial amounts of unpaid care, often at odd hours, which perhaps made them feel that they were "on call" all hours of the day and night.

It is important to remember that the greater strain felt by family members who became paid workers was not necessarily *caused* by their becoming a paid worker. In this analysis, we did not test whether the individuals who were hired under consumer direction would have felt lower levels of strain if they had not become paid workers. However, from research reported in a companion paper, we know that primary informal caregivers at baseline who subsequently became paid workers suffered *less* emotional strain than did those who remained unpaid (Foster et al. 2003b).

Notably, directly hired workers (both related and non-related) reported quite favorable perceptions of their working conditions. Most were very satisfied with both their overall working conditions and the supervision they received. The vast majority reported getting along very well with their client. The fact that directly hired workers report high levels of satisfaction with their working conditions, in spite of feeling emotional strain, is consistent with the experiences of workers hired under the IHSS program (Doty et al. 1999). These findings are also consistent with the reports of workers hired under IndependentChoices who participated in focus groups. Many of these workers said that although their jobs were demanding, they felt “blessed” by having the opportunity to take care of a loved one and said that their jobs were quite gratifying (Zacharias 2002).

Although directly hired workers were less likely than agency workers to receive fringe benefits and received slightly lower hourly wages, the total pay received over the past two weeks was comparable for the two groups. More important, directly hired workers were quite satisfied with their wages and fringe benefits (much more so than agency workers), probably because many directly hired workers had cared for their client without pay prior to the demonstration. Directly hired workers provided so many hours of unpaid care that the actual amount of their hourly wages and fringe benefits may not have been that important; rather, they appreciated the fact that they received some pay rather than none at all. Also, caregiving is a second job for many directly hired workers; thus, their wages from caregiving may be supplementing their income from another job. The fact that directly hired workers report such high levels of satisfaction may reduce policymakers’ possible concerns about such workers feeling exploited because of low levels of compensation or poor working conditions. These results also suggest that paying family members to provide care previously provided by agencies will not exacerbate caregiver burnout and may actually ameliorate such problems.

Some aspects of the working environment under consumer direction may be cause for concern. Many directly hired workers reported that they did not receive training for the health care or personal care they provided. Whether a lack of training is a problem is unclear. Relatives may be well versed in the health care needs of their family members, and consumers may be able to direct their own workers to meet their specific needs. Indeed, the vast majority of consumers' directly hired workers had been caring for the consumer prior to the demonstration, and most reported that they were well prepared to assist them. Both the workers and their clients may have felt that training was unnecessary, as the workers were simply continuing to perform tasks they had been doing for years. It does not appear that worker safety was harmed due to the lack of training, as directly hired workers and agency workers experienced similar levels of physical strain and injuries related to caregiving, after controlling for the total number of hours of care that they provided. Moreover, it does not appear that *consumer* safety was jeopardized by the absence of formal training, as Foster et al. (2002a) found that IndependentChoices did not increase the likelihood (and for some outcomes decreased the likelihood) that a consumer would experience an adverse event or health problem.

Finally, policymakers might be concerned that a sizable portion of workers were responsible for arranging backup care but had difficulty doing so. Agency workers presumably would not face this problem. However, agencies in Arkansas were having difficulty providing backup care during the study period, so it is unclear whether the consumer would be more or less likely to receive backup care if the worker was employed by an agency.

## **2. Limitations**

This study is limited in that we have no way of knowing how these hired workers would have fared in the absence of the demonstration; therefore, it cannot measure in a rigorous manner the “impacts” of consumer-directed care on workers. This is because consumers, not workers,

were randomly assigned to the treatment or control group. Rather, the study can describe the experiences only of directly hired workers in this sample and compare them to those of agency workers as a benchmark. Furthermore, the sample used more heavily represents those who worked for consumers who enrolled later in the demonstration and is not necessarily representative of all workers in the demonstration. Because we did not collect baseline data on workers, we do not know whether workers for consumers who enrolled later differed from workers for consumers who enrolled earlier.

Our findings also may be limited in that they pertain to one consumer-directed care program in one state. The results may not be generalizable to other states or other programs. Other programs may have features that differ from those of IndependentChoices. For example, the Florida Cash and Counseling program allows children to participate; both Florida and New Jersey allow spouses to serve as paid workers; Florida cashes out home- and community-based services in addition to personal care; and other states may have more generous or less generous personal assistance benefits than Arkansas. Also, our results may not pertain to programs where consumers hire primarily workers who are *not* their relatives or friends. Despite these limitations, the results from study of the program in Arkansas suggest that workers hired under consumer direction can be very satisfied with their experiences and do not suffer physical or emotional hardship beyond what might be expected for individuals providing care to a relative.

### **3. Future Research**

In this paper, we examined only a single dimension of consumer-directed care. Other evaluation reports (some of which we have mentioned) are available or will be available to provide a fuller picture of IndependentChoices. Some of these papers used survey data to examine the program's effects on the quality of care consumers receive, their use of personal assistance services, and the well-being of the consumers' primary informal caregiver at the time

of program enrollment. Other papers will use claims-based data to assess how IndependentChoices affected the cost of personal assistance, as well as the use and cost of services covered by Medicaid and Medicare. Still other papers will describe the implementation of the program. Finally, the findings from the Arkansas Cash and Counseling program will be compared with the findings from the program in the two other demonstration states, Florida and New Jersey.



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## APPENDIX

In this appendix, we present tables and results that are not available in the text. As noted in the body of the report, Table A.1 provides a complete list of the measures used in our analysis. Table A.2 shows the characteristics of the consumers who had workers in this sample. Table A.3 shows the timing of care that directly hired and agency workers provided, as discussed in the text. Table A.4 presents regression estimates on the effects on key outcomes of worker characteristics, consumer characteristics, and the worker-consumer relationship. Table A.5 compares adjusted and unadjusted differences in outcomes between directly hired workers and agency workers. Finally, Table A.6 provides a comparison of informal caregivers who became paid and those who remained unpaid.

### Regression Results

**Relationship between characteristics and outcomes for directly hired workers.** Some types of directly hired workers will probably have less-satisfactory experiences than others, as a result either of their own characteristics or of those of the consumer they are caring for. For example, workers who are more educated may need less training; those who have other jobs or children may feel more stress; and those caring for consumers who need more assistance may feel less satisfied with their working conditions. To investigate which types of directly hired workers have better or worse experiences than others, we regressed some key outcome measures on the following characteristics:

- The worker's relationship to the consumer and whether the worker lives with the consumer
- The consumer's demographic characteristics (age, sex, race, education, whether lives alone)

## TABLE A.1

### DESCRIPTION OF MEASURES

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#### **Worker and Consumer Characteristics**

Worker demographic characteristics; whether worker was consumer's primary informal caregiver at baseline  
Consumer demographic characteristics, health status, functional status, whether received personal assistance services at baseline, whether had supervisory experience, whether had representative

#### **Consumer/Worker Relationship**

Whether worker and consumer are related, live together, are within 10 years of age, are the same race

#### **Compensation and Working Conditions**

Compensation: hourly wage; whether received fringe benefits; total pay during two weeks preceding the survey

Whether very satisfied (or dissatisfied) with wages and fringe benefits, overall working conditions

#### **Pattern of Care Provided During Two Weeks Preceding the Survey**

Type of care: whether provided assistance with personal care, household tasks, kept consumer company or provided help with specific health care tasks

Hours of paid, unpaid, and total care provided for the consumer and for the consumer's household

Timing of care: before/after business hours, weekends

#### **Training and Preparedness for Work**

Whether received any health care training; type of health care training received

Whether received any personal care training; type of personal care training received

Percentage strongly agreeing (or disagreeing) with statement:

I am usually well informed of the consumer's condition and other services he receives.

I feel prepared to do what is expected of me in helping the consumer.

#### **Supervision and Scheduling**

Whether supervision interferes with work

Percentage strongly agreeing (or disagreeing) with statement:

I am satisfied with the supervision I received for the help I give the consumer.

I have to hurry to get everything done when helping consumer.

I have a lot of flexibility in scheduling the things I do to help the consumer.

I am satisfied with the amount of information I get on whether the consumer liked the way I helped him.

Whether worker is responsible for obtaining backup care; difficulty of arranging backup care

TABLE A.1 (continued)

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**Caregiver Well-being**

Caregiver/consumer relationship and emotional strain

Whether worker and consumer get along very well

Whether worker feels consumer needs to be more respectful

Whether worker feels consumer's family and friends need to be more respectful

Whether worker felt high (or little to no) emotional strain due to caregiving

**Physical strain and injuries**

Whether reported high (or little to no) physical strain due to caregiving

Whether reported any injury or injury serious enough to see doctor while caring for sample member

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TABLE A.2  
 BASELINE CHARACTERISTICS OF CONSUMERS  
 (Percentages)

Characteristic	Cared for by Agency Workers	Cared for by Directly Hired Workers
Age (Years)		
18 to 39	5.3	7.2
40 to 64	16.0	21.7*
65 to 79	40.9	38.9
80+	37.7	32.2
Female	80.4	78.0
Race		
Hispanic	1.1	1.5
White	60.7	60.5
Black	35.0	33.9
Other	4.3	5.7
Lives Alone	34.2	34.3
Had Unmet Need for Personal Care	63.8	59.4
Is in Poor Health	49.6	44.0
Unable to Get in and out of Bed Without Help in Past Week	66.8	62.7
Appointed a Representative	46.3	39.6*
Had Supervisory Experience	55.7	53.2
Did Not Receive Paid Personal Care Assistance During Week Before Baseline	20.7	37.6***
<b>Sample Size</b>	<b>281</b>	<b>391</b>

SOURCE: Baseline Evaluation Interview Conducted by Mathematica Policy Research, Inc. between December 1998 and April 2001.

\*Sample member cared for by directly hired workers different from sample member cared for by agency workers at .10 level, two-tailed test.

\*\*\*Sample member cared for by directly hired workers different from sample member cared for by agency workers at .01 level, two-tailed test.

TABLE A.3  
TIMING OF CARE PROVIDED  
(Percentages)

	Agency Workers	Directly Hired Workers
Before 8 AM Weekdays	21.2	49.5***
After 6 PM Weekdays	11.5	70.5***
On Weekends	16.2	84.7***
Any Non-business Hours	32.4	85.7***

SOURCE: Caregiver Survey conducted by Mathematica Policy Research, Inc. caregiver survey between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

TABLE A.4

EFFECT OF CONSUMER CHARACTERISTICS, WORKER CHARACTERISTICS, AND CONSUMER-WORKER RELATIONSHIP  
ON KEY OUTCOMES FOR DIRECTLY HIRED WORKERS  
(Percentages)

	Suffered Little or No Emotional Strain		Suffered Much Emotional Strain		Desires More Respect from Consumer's Family		Desires More Respect from Consumer		Very Satisfied with Wages and Fringes		Very Satisfied with Working Conditions		Received Health Care Training (Among Those Providing Health Care)		Received Personal Care Training (Among Those Providing Personal Care)	
	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value
<b>Worker-Consumer Relationship</b>																
Worker lives with consumer	-1.304	0.003	1.932	0.012	1.527	0.001	1.467	0.028	-0.312	0.440	-0.632	0.247	-0.620	0.191	-0.777	0.088
Worker related to consumer, does not live in	-0.533	0.183	1.277	0.076	1.136	0.013	0.535	0.407	-0.047	0.899	-0.155	0.751	-0.902	0.051	-0.766	0.071
<b>Consumer Demographic Characteristics</b>																
Age 40 to 64	0.808	0.153	-0.339	0.693	-0.160	0.779	0.070	0.942	0.716	0.204	0.384	0.593	0.364	0.566	-2.460	0.032
Age 65 to 79	1.326	0.021	0.100	0.907	-0.170	0.764	0.289	0.775	0.796	0.155	1.261	0.082	-0.176	0.784	0.457	0.444
Age 80+	0.710	0.219	0.331	0.710	-0.075	0.896	1.379	0.177	0.357	0.527	0.865	0.225	-0.676	0.304	-0.690	0.232
Female	-0.185	0.553	0.919	0.060	0.294	0.372	-0.391	0.360	-0.333	0.276	-0.260	0.525	0.058	0.859	-0.588	0.318
Nonwhite	-0.223	0.640	0.418	0.541	0.419	0.377	0.354	0.620	-0.484	0.256	0.045	0.937	-0.820	0.123	0.055	0.862
<b>Has Less than High School Education</b>																
Has Less than High School Education	0.234	0.466	-0.680	0.139	-0.078	0.815	-0.271	0.579	0.366	0.248	0.390	0.365	-0.158	0.660	-0.021	0.966
<b>Lives Alone</b>																
Lives Alone	0.674	0.043	-0.695	0.167	-0.589	0.079	-0.676	0.146	-0.049	0.876	0.234	0.581	-0.560	0.111	0.072	0.828
<b>Consumer's Health and Functioning</b>																
Needs transfer help	0.401	0.285	-0.547	0.308	0.318	0.395	0.161	0.754	0.191	0.599	0.011	0.982	-0.245	0.544	-0.596	0.078
Needs bath help	1.162	0.015	-1.495	0.035	-0.458	0.360	-0.024	0.971	0.679	0.146	0.304	0.601	-0.158	0.766	-0.308	0.424
Needs toilet help	-0.194	0.616	0.314	0.577	0.023	0.952	-1.039	0.055	-0.186	0.618	1.061	0.033	-0.333	0.436	-0.032	0.949
Fair health	-0.036	0.920	-0.073	0.890	0.000	1.000	0.484	0.328	-0.214	0.528	-0.033	0.945	0.282	0.451	0.194	0.630
Poor health	-0.322	0.348	0.834	0.096	0.083	0.813	-0.133	0.788	-0.249	0.455	-0.347	0.459	0.045	0.902	0.246	0.493
<b>Consumer Need for Decision-Making Support</b>																
Consumer Has Representative and Survey Proxy	-0.182	0.591	0.578	0.228	0.091	0.786	0.599	0.197	-0.660	0.051	-0.413	0.365	0.199	0.576	0.150	0.668
Consumer Has Representative, No Survey Proxy	-0.450	0.270	0.536	0.356	0.029	0.944	1.009	0.052	-0.261	0.502	-1.068	0.031	0.708	0.090	1.266	0.003



TABLE A.4 (continued)

	Suffered Little or No Emotional Strain		Suffered Much Emotional Strain		Desires More Respect from Consumer's Family		Desires More Respect from Consumer		Very Satisfied with Wages and Fringes		Very Satisfied with Working Conditions		Received Health Care Training (Among Those Providing Health Care)		Received Personal Care Training (Among Those Providing Personal Care)	
	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value
Help Consumer Received in Week Prior to Baseline																
Has 2 unpaid helpers	-0.216	0.519	-0.198	0.689	-0.337	0.307	0.121	0.780	0.191	0.551	0.195	0.646	-0.807	0.026	0.257	0.465
Has 3 or more unpaid helpers	-0.152	0.636	0.125	0.781	-0.229	0.468	-0.443	0.327	-0.054	0.861	0.415	0.320	-0.217	0.525	-0.475	0.167
Had any paid help prior to baseline	0.193	0.513	-0.367	0.383	-0.168	0.577	0.200	0.633	0.301	0.293	0.350	0.358	0.331	0.316	-0.543	0.100
Consumer's Work Experience																
Supervisory Experience	-0.047	0.865	0.545	0.172	-0.131	0.637	-0.063	0.874	0.305	0.242	0.436	0.229	0.179	0.529	0.512	0.103
Length of Time Consumer Receiving PCS																
Received PCS for < 1 year	-1.078	0.094	1.577	0.151	-0.641	0.346	-0.892	0.377	0.569	0.381	-0.356	0.682	0.263	0.719	-0.750	0.273
Received PCS for 1 to 3 years	-0.727	0.265	0.829	0.470	-1.180	0.092	-0.985	0.328	-0.041	0.950	-0.782	0.362	-0.209	0.773	0.961	0.182
Received PCS for 3+ years	-0.683	0.298	1.988	0.069	-0.418	0.542	-0.492	0.621	-0.293	0.657	-0.609	0.482	0.155	0.830	0.398	0.579
Consumer's Unmet Need, Access to Care, and Satisfaction																
Unmet personal care need	-0.422	0.155	-0.128	0.762	0.347	0.255	0.073	0.864	-0.050	0.861	-0.417	0.295	-0.195	0.547	1.130	0.118
Unmet transportation need	-0.210	0.461	0.324	0.416	-0.092	0.744	0.717	0.074	-0.261	0.332	-0.044	0.902	-0.234	0.442	0.304	0.316
Unmet household need	0.739	0.020	0.092	0.840	-0.477	0.134	0.105	0.811	0.020	0.949	-0.434	0.318	0.098	0.765	0.316	0.278
Lives in rural area	-0.016	0.958	-0.011	0.979	-0.216	0.487	0.366	0.413	0.242	0.416	0.455	0.257	0.483	0.143	-0.260	0.418
Lives in urban area but transportation difficult or high crime	-0.182	0.573	-0.016	0.972	0.375	0.252	0.514	0.259	-0.187	0.547	0.551	0.185	0.155	0.654	0.419	0.182
Consumer satisfied with help and equipment	0.193	0.513	-0.367	0.383	-0.168	0.577	0.200	0.633	0.301	0.293	0.350	0.358	0.331	0.316	-0.543	0.100
Consumer's primary informal caregiver employed	-0.932	0.014	1.083	0.065	-0.403	0.262	-0.807	0.093	0.671	0.059	-0.331	0.499	0.808	0.041	0.098	0.801
Consumer's Enrollment in Independent Choices																
7 to 11 hours in care plan	-0.771	0.049	0.997	0.088	-0.068	0.852	-0.955	0.051	0.448	0.214	-0.348	0.477	0.129	0.747	0.223	0.422
12+ hours in care plan	-0.932	0.014	1.083	0.065	-0.403	0.262	-0.807	0.093	0.671	0.059	-0.331	0.499	0.808	0.041	0.098	0.801
Enrollment month in 2000 or 2001	-0.022	0.942	-0.072	0.867	-0.115	0.692	0.529	0.209	-0.108	0.695	-0.134	0.730	0.311	0.311	0.838	0.030
Consumer's Reason for Enrollment:																

TABLE A.4 (continued)

	Suffered Little or No Emotional Strain		Suffered Much Emotional Strain		Desires More Respect from Consumer's Family		Desires More Respect from Consumer		Very Satisfied with Wages and Fringes		Very Satisfied with Working Conditions		Received Health Care Training (Among Those Providing Health Care)		Received Personal Care Training (Among Those Providing Personal Care)	
	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value	Parameter Estimate	P-value
Paying family important	-0.493	0.231	0.680	0.288	0.703	0.092	0.640	0.301	-0.188	0.613	0.591	0.245	0.730	0.074	0.013	0.964
Time of day received help important	-0.180	0.605	0.106	0.837	-0.175	0.616	0.215	0.640	-0.020	0.952	0.561	0.197	0.221	0.542	0.459	0.256
Type of help received important	-0.245	0.540	0.856	0.186	-0.200	0.618	-0.761	0.149	-0.132	0.728	-0.617	0.259	0.273	0.512	-0.162	0.653
Worker Characteristics																
Worker interest in being paid	-0.039	0.893	0.071	0.860	0.225	0.426	0.737	0.065	-0.417	0.135	-0.294	0.416	-0.372	0.220	0.080	0.843
Worker age 18 to 39	0.315	0.565	-0.164	0.836	0.375	0.516	1.469	0.084	0.084	0.873	1.649	0.014	1.886	0.004	-0.436	0.139
Worker age 40 to 64	0.496	0.299	-0.261	0.713	0.288	0.573	0.247	0.738	-0.310	0.508	0.996	0.064	0.980	0.081	1.305	0.028
Worker nonwhite	0.956	0.048	-0.346	0.613	0.068	0.888	0.166	0.816	-0.215	0.614	-0.817	0.146	1.185	0.029	0.767	0.129
Worker female	-0.078	0.831	-0.585	0.227	0.035	0.924	-0.807	0.113	0.691	0.052	-0.582	0.240	0.864	0.029	0.181	0.712
Worker high school graduate	-0.989	0.001	0.809	0.064	-0.280	0.325	-0.638	0.113	-0.013	0.962	-0.437	0.257	0.518	0.084	1.158	0.003
Worker married	-0.444	0.096	0.179	0.644	0.306	0.263	0.398	0.313	0.301	0.243	-0.436	0.218	0.377	0.193	0.667	0.023
Worker has kids	-0.173	0.610	-0.080	0.867	-0.079	0.815	-0.075	0.870	-0.522	0.106	-0.249	0.575	-0.432	0.243	-0.197	0.469
Worker has other job	0.058	0.831	-0.142	0.722	-0.197	0.478	0.075	0.849	0.455	0.083	0.421	0.241	0.477	0.102	-0.470	0.189

NOTE: Parameters were estimated with logit models. Outcome measures based on workers' responses to MPR's Caregiver Survey, administered about 10 months after consumers enrolled in the demonstration. Maximum sample size is 372. Sample sizes vary slightly from measure to measure due to item nonresponse.

TABLE A.5

COMPARISON OF ADJUSTED AND UNADJUSTED PERCENTAGES FOR DIRECTLY  
HIRED WORKERS AND AGENCY WORKERS, SELECTED MEASURES OF  
WORKER SATISFACTION AND WELL-BEING  
(Percentages)

	Agency Workers (Unadjusted Percentage)	Directly Hired Workers (Unadjusted Percentage)	Unadjusted Difference	Adjusted Difference
<b>Worker Satisfaction</b>				
Very satisfied with working conditions	81.8	83.4	1.8	.2
Very satisfied with wages and fringe benefits	22.2	44.6	22.4***	21.4***
Strongly Agrees: Is Satisfied with Supervision	84.3	86.4	2.1	2.4
<b>Emotional Strain</b>				
Level of Emotional Strain				
Little or none	70.1	60.2	-9.9***	-9.5**
A great deal	8.9	15.2	5.3**	7.5***
Consumer Needs to Be More Respectful	12.4	16.1	3.7	4.5
Consumer's Family Needs to Be More Respectful	22.4	37.1	14.7***	14.4***
<b>Level of Physical Strain</b>				
Little or none	68.3	65.2	-3.1	-5.0
A great deal	15.1	16.9	1.8	3.6

SOURCE: Caregiver survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: Sample sizes vary from measure to measure due to item nonresponse. The maximum sample sizes are 281 for agency workers and 391 for directly hired workers. "Adjusted percentages" were calculated from estimated logit models that controlled for consumer baseline characteristics.

\*Significantly different from agency workers at the .10 level, two-tailed test.

\*\*Significantly different from agency workers at the .05 level, two-tailed test.

\*\*\*Significantly different from agency workers at the .01 level, two-tailed test.

TABLE A.6  
ESTIMATED EFFECTS OF BECOMING A PAID WORKER ON  
CAREGIVER WELL-BEING AND SATISFACTION  
(Percentages)

	Estimated Effect of Independent Choices on Primary Informal Caregivers who:	
	Became Paid (P-Value)	Remained Unpaid (P-Value)
<b>Physical Health Has Suffered as a Result of Caregiving</b>	-19.7*** (.000)	.3 (.918)
<b>Level of Emotional Strain</b>		
Little or none	11.7*** (.000)	-2.0 (.555)
A great deal	-12.7*** (.000)	-0.7 (.827)
<b>Total Hours of Care Provided</b>	-3.1 (.537)	-14.8*** (.014)

SOURCE: Caregiver survey conducted by Mathematica Policy Research, Inc. between February 2000 and May 2002.

NOTE: The estimated effects of becoming paid (remaining unpaid) are the differences in predicted means for treatment group caregivers who became paid workers (remained unpaid) and those for control group caregivers.

\*Significantly different from control group caregivers at the .10 level, two-tailed test.  
 \*\*Significantly different from control group caregivers at the .05 level, two-tailed test.  
 \*\*\*Significantly different from control group caregivers at the .01 level, two-tailed test.

- The consumer's health and functioning indicators (whether needs help with various activities, self-rating of health)
- The consumer's need for decision-making support (has representative, had proxy complete the interview)
- Paid and unpaid help consumer received prior to enrollment
- The consumer's experience as supervisor
- Length of time the consumer has received PCS
- The consumer's unmet needs, living situation
- Whether the primary informal caregiver was employed
- Hours of care in the consumer's care plan
- The consumer's reason for enrollment
- The worker's characteristics (age, sex, race, education, marital status, whether has children, whether has another job)

Many hypotheses could be formulated concerning what relationships might be expected between these characteristics and the worker's emotional strain, satisfaction with wages and working conditions, and desire for more respect from the consumer or the consumer's family. However, they are difficult to test, given the high correlation among many of the characteristics and the modest sample size (391). Thus, we find few statistically significant relationships in our analyses. The most noteworthy findings (see Appendix Table A.4) are:

- Workers were less satisfied with working conditions when the consumer was under age 40.
- Workers of those consumers who needed limited decision-making support (defined as consumers who had a representative but were able to respond to the survey themselves) were less satisfied with working conditions, more likely to feel that they lacked respect from the consumer, and more likely to receive both health care and personal care training than the workers of consumers who did not need any decision-making support.<sup>1</sup>

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<sup>1</sup> Workers who needed the most decision-making support (defined as consumers who had a representative and a proxy survey respondent) generally did not have significantly different

- Workers age 65 and over were less satisfied with working conditions and less likely to be trained.
- Workers related to the consumer, particularly those who live with the consumer, had more emotional strain and were more likely to feel they lack respect from the consumer's family.
- Workers for consumers whose primary informal caregiver was employed had more emotional strain.
- Workers for consumers with more hours in care plan had more emotional strain.

These findings suggest that workers' jobs are more difficult when the consumer needs some decision-making support, when the consumer needs more assistance, and when other sources of unpaid assistance are scarcer. As discussed in the text, workers who are related to the consumer and who live with the consumer do not fare as well in terms of some measures of emotional well-being as workers who are not related. Other relationships between worker or consumer characteristics and the worker's well-being may exist, but they cannot be detected with the available sample.

**Adjusted versus unadjusted differences in outcomes between directly hired workers and agency workers.** We estimated logit models to test whether the unadjusted differences in the percentages of agency workers and the percentages of directly hired workers experiencing each outcome persisted after controlling for the consumer's baseline characteristics. These baseline measures included demographic characteristics, health and functioning, use of personal assistance, satisfaction with care, unmet needs, reasons for enrollment in the demonstration, and year of enrollment. We used the estimated coefficients from these logit models to calculate the

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*(continued)*

outcomes from those who did not need any such support. One exception was that workers who needed the most decision-making support were the least likely to be satisfied with their compensation.

average predicted probability that the binary outcome variable takes a value of 1, first with each sample member assumed to be in the treatment group, and then in the control group. Table A.5 shows the adjusted percentages (derived from these logit models) as well as the actual (unadjusted) percentages of agency workers and directly hired workers that experienced selected outcomes. The differences between agency workers and directly hired workers in the adjusted percentages are quite similar to the differences in the unadjusted percentages. Thus, it is clear that differences between consumers in the treatment group who have hired workers and consumers in the control group who have agency workers are not the source of differences in outcomes between the two groups of workers.

**Comparison of key outcomes for primary informal caregivers who became paid and those who remained unpaid.** In a companion report, Foster et al. (2003b) compared the predicted means<sup>2</sup> for control group members' primary informal caregivers and treatment group members' primary informal caregivers who (1) became paid workers, and (2) remained unpaid. Table A.6 presents the predicted means for selected outcomes reported in Foster et al. (2003b). As shown, those primary informal caregivers for the treatment group who became paid workers were significantly *less* likely than the primary informal caregivers for the control group to report emotional strain or to suffer a decline in their physical health. In contrast, primary informal caregivers for the treatment group who remained unpaid reported levels of emotional strain and physical well-being similar to those of primary informal caregivers for the control group. These findings suggest that informal caregivers who became paid fared better both emotionally and physically than those who remained unpaid. However, these findings may also be due to

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<sup>2</sup> These means were predicted from logit models that controlled for the consumer's baseline characteristics and the primary informal caregiver's demographic characteristics.

preexisting, unmeasured differences between the types of caregivers that became paid workers and those that remained unpaid. For example, healthier informal caregivers may have been more likely to become paid workers, and therefore report fewer emotional or physical problems than those who did not become paid. (We did not have baseline measures of the caregivers' emotional or physical well-being.) Also, since spouses cannot be hired under IndependentChoices, the two groups of informal caregivers differ on this dimension as well. If spouses feel more strain than other unpaid caregivers, then this could lead to the finding that informal caregivers who do not become paid experience more strain than those who do.

Finally, those primary informal caregivers who became paid workers provided similar total hours of care as the primary informal caregivers for the control group. In contrast, those primary informal caregivers for the treatment group who remained unpaid provided significantly fewer total hours of care than the primary informal caregivers for the control group. This suggests that under IndependentChoices, the consumers' who did not hire their primary unpaid caregivers hired other workers to relieve their primary unpaid caregiver of some responsibilities. This is consistent with an ethnographic study conducted by Eckert et al. (2002) in which IndependentChoices' consumers reported that they liked the fact that the program allowed them to provide some relief to family members who had given them so much unpaid assistance. It is also possible, however, that those unpaid caregivers who became paid were providing more care at baseline than those who remain unpaid. Thus, some of the difference in the hours of care provided by paid and unpaid caregivers could be due to preexisting differences between the two groups in the amount of assistance they had been providing before the demonstration.