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Experiences of Workers Hired Under Cash and Counseling: Findings from Arkansas, Florida, and New Jersey

Final Report

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CONTENTS

CONTENTS *(continued)*

Page

TABLES

TABLES *(continued)*

Table **Page**

EXECUTIVE SUMMARY

The well-being of paid workers is an important consideration often overlooked in consumer-directed programs. Medicaid supportive services for people 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 that these workers may not have enough 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. They may also find their jobs emotionally draining because they are usually friends or relatives of their clients.

This study describes the experiences of workers hired under consumer direction in the Cash and Counseling Demonstration, using results from all three participating states—Arkansas, Florida, and New Jersey. Demonstration enrollment, which occurred between December 1998 and July 2002, was open to interested adult beneficiaries eligible for personal care services (PCS) under their state Medicaid plan (in Arkansas and New Jersey) and to interested adults and children receiving home- and community-based services under a waiver (in Florida). After a baseline survey, enrollees were randomly assigned to direct their own personal assistance as Cash and Counseling consumers (the treatment group) or to receive services as usual from agencies (the control group). Cash and Counseling consumers had the opportunity to manage a monthly allowance, which they could use to hire their choice of caregivers or to buy other services or goods needed for daily living. Each state's program differed somewhat from the others in how it was implemented, the size of the allowance, and how the allowance could be used. All three states, however, kept the basic Cash and Counseling principle of providing an allowance with limited constraints and helping the consumer develop a spending plan to manage the funds.

Consumers' primary paid workers were contacted by telephone about one month after being identified by the consumers in their nine-month postenrollment interview. Within about a month after being identified, the primary paid workers were called and asked to complete the Cash and Counseling Caregiver Survey. These workers, who were also the consumer's primary informal caregiver at baseline (about 40 percent of the workers for the treatment group), were also asked questions related to their role as informal caregivers. From their survey responses we constructed measures describing (1) the worker's characteristics and relationship with the consumer, (2) the type, timing and amount of paid and unpaid care provided during the past two weeks, along with perceptions of working conditions, (3) whether the worker received training, and (4) worker well-being, including wages, fringe benefits, stress, and satisfaction. We focused on describing the experiences of the directly hired workers for the treatment group, using agency workers' experiences as a benchmark.

Results

In our examination of workers hired by adults, the majority of directly hired workers were related to the consumer (ranging from 58 percent in Florida to 78 percent in Arkansas), and about 80 percent provided unpaid care to the consumer before the demonstration began. As a result, these workers often fulfilled the roles of both informal caregiver and employee. They provided many hours of unpaid care (an average of 26 hours per week in each state) and care during nonbusiness hours. Because they were not bound by agency rules or other state regulations, they could help with a variety of health care tasks.

There were two areas in which directly hired workers fared worse than agency workers: (1) emotional strain and (2) the level of respect they received from the consumer's family and friends. However, these differences were due to their being related to the care recipient, not to being directly hired by the consumer, as the levels of well-being of nonrelated directly hired workers were nearly identical to those of agency workers. For example, 47 percent of directly hired workers who were related to the consumer reported suffering little or no emotional strain, compared to 57 percent of agency workers, and 57 percent of nonrelated directly hired workers. Similarly, 35 percent of directly hired workers who were related to the consumer desired more respect from the consumer's family and friends, compared to 19 percent of agency workers and 19 percent of nonrelated directly hired workers. Thus, the greater strain for related workers appears to be caused not by their hired status, but by other aspects of their relationship to the consumer. The high proportion of directly hired workers (about 90 percent) 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. Compared to agency workers, directly hired workers were paid, on average, $1 per hour more (about 15 percent) in Florida and New Jersey and 30 cents less per hour (about 5 percent) in Arkansas. In all three states, more than 40 percent of directly hired workers were very satisfied with their wages and fringe benefits, compared to only about 20 percent of agency workers. While only about half of directly hired workers received training in the health care or personal care they provided, nearly all felt fully prepared to do their jobs and were well-informed about the consumer's condition. Injury rates for both agency workers and directly hired workers were very low (averaging less than five percent across all three states). Compared to agency workers, injury rates were higher for directly hired workers in Arkansas, and lower for this group of workers in New Jersey. When differences in total hours of care provided were taken into account, caregivers hired by Cash and Counseling consumers were no more likely than agency workers to suffer injuries from caregiving.

Finally, both agency workers and directly hired workers were quite satisfied with their overall working conditions and the supervision they received. Our findings were remarkably consistent among workers in all three states, even though the states served different target populations and had different restrictions concerning who consumers could hire. Moreover, results for the workers hired on behalf of children in Florida were similar to the results for those hired by adults in Florida.

Implications

Despite the satisfaction that workers hired under Cash and Counseling had with their work arrangements, compensation, and relationship with the care recipient, there remain some concerns about workers' well-being and willingness to continue in their role over a longer period. There are several improvements that the program could possibly make. First, counselors/consultants might give educational materials to hired workers to lessen the concern that consumers or workers could be injured because so few workers receive training in how to do their jobs. Second, counselors could be made aware of local caregiver support groups and sources of information (such as books, websites, or informational brochures) on how to deal with stress related to caring for a family member or friend, and then trained to refer caregivers to them. Third, the state could prepare materials (printed or videotaped) for consumers and their families, alerting them to the fact that workers often feel that the consumer and the consumer's family don't respect the work they do. These materials could suggest ways to minimize such tensions.

Finally, while both related and unrelated hirees have high levels of satisfaction under the program, that conclusion begs the following question: Could this highly successful program benefit far more consumers if it provided a list of people who wanted to become workers to interested consumers who were unable to hire family members or friends? Furthermore, such a listing could help program participants find suitable replacements if their current hired workers were unable or unwilling to continue in the positions. On the other hand, offering such a list could create opposition from the states' home care industry and could put the state at risk of lawsuits if a worker hired from the state's list abused the consumer in some way. States may also wish to consider whether more support and training should be offered to family caregivers to help them avoid the situation of feeling unappreciated and emotionally strained. These efforts could help the workers remain in the job longer, perhaps until the consumer no longer wished or was able to continue living at home.

INTRODUCTION

Medicaid supportive services for people with disabilities have traditionally been provided through government-regulated home care agencies. Agency care provides consumers with important benefits (such as formally trained and supervised workers), but it sometimes limits consumers' choices about how and when their care is provided. Moreover, agency worker shortages sometimes make it difficult for consumers to receive all of the care they are authorized to receive. 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.

While the movement toward consumer direction is growing—with an estimated 139 publicly funded consumer-directed programs in 1999 (Flanagan 2001)—the well-being of paid workers is often overlooked. Because directly hired workers do not have an agency affiliation, some policymakers are concerned that these workers may not have enough 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. They may also find their jobs emotionally draining because they are usually friends or relatives of their clients.

Assessing the well-being of workers hired under consumer direction and addressing their concerns is critical, because the consumer-directed model is sustainable only if workers are satisfied with it. While care recipients who manage their own care appear to be much more satisfied than consumers who receive agency care (Benjamin and Matthias 2000; Foster et al. 2003; Carlson et al. 2005), the primary reason given for dropping out of a consumer-directed option is difficulty finding or keeping a worker (Schore and Phillips 2004). Moreover, turning to

consumer direction and tapping consumers' family members and friends as additional sources of labor could help solve the serious worker shortage. In this report, we use results from all three states participating in the Cash and Counseling demonstration—Arkansas, Florida, and New Jersey—to assess the experiences of workers hired under consumer direction.[1]

A NEW APPROACH TO MEDICAID PERSONAL ASSISTANCE

As one model of consumer-directed supportive services, Cash and Counseling provides a flexible monthly allowance to Medicaid beneficiaries who volunteer for the program and are randomly assigned to the evaluation's treatment group. They can use this allowance to hire their choice of workers, including family members, and to purchase other services and goods (as states permit). Cash and Counseling requires that consumers develop plans showing how they would use the allowance to meet their personal care needs. It also provides counseling and fiscal assistance to help consumers make these plans and then manage their responsibilities. Consumers who cannot manage their care themselves, or prefer not to, may designate a representative, such as a family member, to help them or to do it for them. These features make Cash and Counseling adaptable to consumers of all ages and with all levels of ability.

With funding from the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation and with waivers from the Centers for Medicare & Medicaid Services, the Cash and Counseling Demonstration and Evaluation was implemented in three states—Arkansas (IndependentChoices), Florida (Consumer Directed Care), and New Jersey (Personal Preference Program). The National Program Office for the demonstration, at Boston College and the

[1] This report repeats the findings for Arkansas reported in Dale et al. 2003a. See Simon-Rusinowitz et al. (2005) for a comparison of family and nonfamily caregivers in Arkansas.

University of Maryland, coordinated the overall demonstration, provided technical assistance to the states, and oversaw the evaluation. Because their Medicaid programs and political environments differ considerably, these states were not required to implement a standardized intervention, although they did have to adhere to the basic Cash and Counseling tenets of flexibility in the use of the allowance and support to make it possible for all consumers to participate.

KEY FEATURES OF THE THREE DEMONSTRATION PROGRAMS

As they began their demonstrations, Arkansas, Florida, and New Jersey all wanted to determine whether the Cash and Counseling model was politically, operationally, and economically feasible in their state environments and whether consumers would receive adequate care. Arkansas stressed increasing access to care more than the other states did, because its home care workers were in unusually short supply, particularly in rural areas.

The programs of all three states shared key features, but they also differed in important ways. This section and Table C.1 summarize the main features of the three programs.

1. Eligible Population, Enrollment, and Allowance

Arkansas and New Jersey "costed out" (provided an allowance in lieu of) Medicaid state plan personal care to elderly adults and nonelderly adults with physical disabilities.[2] Florida costed out all goods and services covered under its Medicaid home- and community-based waiver program (such as behavioral therapy, personal care supplies, and personal care) for qualified elderly adults, nonelderly adults with physical disabilities, and children and adults with developmental disabilities.

[2] Some adults in Arkansas and New Jersey had developmental disabilities, but these people cannot be differentiated from those with other disabilities.

Another important distinction between the three state programs involved whether beneficiaries had to be enrolled in the traditional program to participate in Cash and Counseling. In Florida, beneficiaries had to already be receiving some costed-out waiver services to be eligible for the demonstration, and, in New Jersey, beneficiaries had to have applied for agency PCS and been assessed as eligible to receive them. Only these people were invited to participate in the program.[3] However, Arkansas allowed anyone who was eligible for Medicaid personal care to enroll and used a letter from the governor to inform all Medicaid beneficiaries in the state of this option. None of the states screened eligible consumers for appropriateness; rather, consumers were allowed to enroll if they (or their representatives) felt they could manage the Cash and Counseling program.[4]

Due to the substantial cross-state differences in the services covered, the maximum hours of care allowed, and wage rates, the median monthly allowance varied widely across the three states, from $313 in Arkansas to $1,097 in New Jersey, with Florida falling between these two extremes ($829). In spite of the name of the program, consumers did not actually receive much of the allowance in cash. Rather, consumers (or their representatives) had to develop a spending plan specifying the goods and services to be purchased for them with the allowance. Only goods and services related to the consumer's disability were permissible; however, the states usually took a broad view in assessing what purchases to allow (for example, they permitted the purchase of microwave ovens and washing machines). Spending plans could include small amounts of cash—up to 10 percent of the allowance in Arkansas and New Jersey and up to 20

[3] These requirements limited the likelihood of consumers enrolling in the demonstration who would not have sought or accepted agency services but who were interested in receiving a flexible monthly allowance.

[4] The Section 1115 special terms and conditions had an express provision that people with cognitive disabilities could not be deliberately excluded from participation but should be given the support needed to self-direct.

percent in Florida—to be paid to the consumer for incidental expenses (such as taxi fare) for which invoicing was impractical. In general, invoices had to be submitted for checks to be written; consumers were not given accounts that they could write checks against, as with a private bank account.

To prevent abuse of the allowance, all three programs verified worker time sheets and check requests against spending plans before disbursing funds. In Florida and New Jersey, the fiscal staff was responsible for this verification; in Arkansas, a counselor was responsible for it. Counselors in Arkansas and Florida also checked receipts for expenditures under the allowance. (New Jersey did not require consumers to keep receipts.) Arkansas required receipts for everything except incidental expenses. Florida required that counselors review receipts for incidental expenses, and the fiscal agent reviewed receipts for all purchases made by the few consumers who assumed responsibility for fiscal tasks themselves.

Consumers were allowed to hire relatives. A waiver of federal regulations permitted the hiring of "legally responsible" relatives (spouses, parents of minors, and legal guardians, who by law were responsible for the consumers' safety and welfare). Florida and New Jersey exercised this waiver, but Arkansas did not. Consumers who hired workers became their employer of record. To avoid a conflict of interest, Arkansas and New Jersey did not allow the same person to serve as both representative and worker.[5]

2. Counseling and Fiscal Services

In all three Cash and Counseling programs, consumers were offered the assistance of counselors (called "consultants" in Florida and New Jersey) and of a fiscal agent. Counselors

[5] Florida originally allowed the same individual to serve as the consumer's worker and representative, but it no longer permits this.

interacted with consumers to (1) review initial and revised spending plans and ensure that they included only permissible goods and services, (2) help with employer functions, (3) monitor consumers' health, and (4) monitor the uses of the allowance (in Florida and New Jersey). Florida and New Jersey required that state- or district-level staff review *all* spending plans. Arkansas required such review only if a plan contained an item that was not on a preapproved list. Counselors in all three programs advised consumers about recruiting, hiring, training, supervising, and (if necessary) firing workers. Counselors were required to telephone and visit consumers periodically to monitor their condition and their use of the allowance. While the frequency of required calls and visits varied across programs, counselors provided additional monitoring and problem-solving calls and visits as needed.

Consumers in all three programs were offered assistance with fiscal tasks, including the payroll functions of an employer (such as preparing and submitting payroll tax returns) and writing checks. A consumer who demonstrated the ability to assume responsibility for these fiscal tasks was allowed to do so. Florida and New Jersey required that consumers pass a fiscal skills examination, while Arkansas program staff individually assessed the ability of each consumer who applied for responsibility for all fiscal tasks. In Arkansas and Florida, a few consumers assumed responsibility for all fiscal tasks, but none did so in New Jersey.

3. Research Questions and Previous Research

This report explores how hired workers fare under consumer direction, using the experiences of agency workers as a benchmark. We examine four questions:

1. How many hours of care do workers provide, and what compensation do they receive?
2. How satisfied are workers with their working conditions, supervision, and scheduling?

3. What preparation and training do workers receive?
4. How do workers fare emotionally and physically, and how does worker well-being vary by different consumer-worker relationships and living arrangements?

Literature on home care workers has shown that these workers have emotionally and physically demanding jobs, yet they receive low wages and few benefits or opportunities for advancement (Stone and Wiener 2001; Yamada 2002). Although these workers do find relationships with their clients rewarding and appreciate the flexible schedules, they often feel isolated from their supervisors and peers, lack authority to take initiative, and would like to have more information about their clients' conditions and care objectives (Eustis et al. 1993). However, these findings for home care workers, who generally are employed by agencies, may not be applicable to the workers hired under consumer direction, many of whom are consumers' close relatives or friends. Similarly, the stress, depression, and health problems that unpaid family caregivers face are well documented (Schulz and Beach 1999; National Alliance for Caregiving and AARP 2004; American Medical Association, Council on Scientific Affairs 1993). However, because they are paid, the workers hired under consumer direction may have outcomes different from those of unpaid caregivers.

Only one study other than Cash and Counseling (Benjamin and Matthias 2004) has quantitatively assessed the experiences of workers hired under consumer direction in the United States. According to this study of California's In-Home Supportive Services (IHSS) program, compared to agency workers, workers hired under consumer direction:

- Received wages that were 30 percent lower and were less likely to receive fringe benefits
- Were less satisfied with their pay but reported similar, high levels of job satisfaction
- Had closer relationships with their clients but did not fare as well in terms of emotional strain

- Were less likely to report receiving training in personal care but were more likely to report receiving informal training tailored to specific recipients and were more likely to feel well informed about clients' needs

Finally, within the consumer-directed model, related workers were more likely to have close relationships with the beneficiaries, but they also experienced more emotional strain than did unrelated workers.

Although we examined measures similar to the ones in Benjamin and Matthias (2004), the Cash and Counseling program and the IHSS program are somewhat different. First, under IHSS, people who had severe disabilities (and, therefore, required more hours of care), who required paramedical assistance, or who were likely to be able to recruit workers were more likely to be assigned to receive consumer-directed services. In contrast, under Cash and Counseling, consumers volunteered for the demonstration and were randomly assigned to receive the cash allowance option or agency-directed care. Thus, the self-directed care recipients under Cash and Counseling should be similar to control group consumers receiving agency care. Second, unlike Cash and Counseling, the IHSS program did not include a counseling component. Third, consumers in the Cash and Counseling program had more flexibility in how they used the allowance (for example, they could purchase other services and goods), which could affect the well-being of workers. Fourth, the state set wage rates under the IHSS program, whereas consumers set wage rates under Cash and Counseling. Finally, under consumer direction, workers in the IHSS program were paid to provide an average of 28 hours a week to the consumer they cared for, whereas in Cash and Counseling the average worker provided about 12 hours of paid care per week in Arkansas and 20 hours per week in Florida and New Jersey.

The differences between the two programs could lead to differences in the workers' experiences, although it is difficult to predict in which direction. For example, the counseling

component might result in a greater difference between hired workers and agency workers in job satisfaction than was observed in the IHSS program. However, workers' job satisfaction might suffer if consumers become overly demanding as a result of being counseled on how to get what they want from workers.

METHODS

1. Data Collection

After the demonstration began, funding became available to conduct a survey of workers in all three states. In the nine-month follow-up survey of consumers who completed their interview in September 2000 or later, consumers were asked to provide contact information for their primary paid worker, defined as the paid individual who was helping the most with personal care, chores and activities, and routine health care at home during the week before the interview.[6] Workers for the treatment group were only included in the study if they were hired with the allowance. Our sample includes the primary paid workers for the treatment group, who we refer to as "directly hired workers," and the workers in the control group, who we refer to as "agency workers." However, the agency workers group includes a few control group workers who reported being hired directly by the consumer, mainly in Arkansas, where another waiver program, Alternatives, allowed consumers to hire family members.

Starting in September 2000, we tried to contact all the primary paid workers that sample members had identified for the Caregiver Survey.[7] Response rates were similar in each state,

[6] In Arkansas, the nine-month survey began in September 1999, so a supplemental survey was administered to identify the workers of some of the consumers who responded to the survey between September 1999 and September 2000.

[7] We set a target of 300 agency workers in Arkansas and New Jersey and 400 in Florida. In Florida and New Jersey, we stopped contacting workers after we met these targets; in Arkansas, the target for agency workers was never met.

averaging 79 percent for agency workers and 95 percent for directly hired workers across the three states. The final sample includes the 391 directly hired workers and 281 agency workers in Arkansas, the 520 directly hired workers and 416 agency workers in Florida, and the 382 directly hired workers and 305 agency workers in New Jersey who responded to the Caregiver Survey. In the analysis presented in the text for Florida, we include only those 298 directly hired workers and 255 agency workers who cared for adults. The 222 directly hired workers and 164 agency workers who cared for children are analyzed separately in Appendix B, because the experience of those caring for children may differ markedly from that of caregivers for adults.

The sample is not representative of all workers who provided paid care to consumers, for two reasons. First, we only surveyed directly hired workers who were hired with the allowance. Because there were delays in starting the allowance in Florida and New Jersey, some treatment group members had not yet hired workers by the time of the Caregiver Survey. Second, the sample is a snapshot of workers providing paid care to consumers nine months after their enrollment, so it excludes workers who may have been hired by the treatment group members who disenrolled from the program by nine months after enrollment (33 percent in Arkansas and 38 percent in Florida and New Jersey).[8]

2. Descriptive Measures

From the survey data, we constructed measures that describe the workers' characteristics and their experiences. The measures describe only the experiences the workers had while caring

[8] While about 30 to 50 percent of the disenrollees had died or become ineligible for PCS or Medicaid, many (50 percent in Arkansas, nearly 60 percent in New Jersey, and 70 percent in Florida) initiated their own disenrollment. Some of these disenrollees may have had problems with their worker, but the number of such cases is likely to be small. Less than 10 percent of the treatment group sample in each state attributed their disenrollment to problems with employer responsibilities (Schore and Phillips 2004; Foster et al. 2004a; Foster et al. 2004b).

for the Cash and Counseling sample member. In general, we report the proportion of cases giving the most favorable rating (for example, "very satisfied").

3. Methods for Analysis

We present the means (or distributions) for a variety of outcome measures, along with *t*-tests (or chi-square tests) indicating whether they are different for directly hired workers and agency workers by more than might be expected by chance. We conducted analyses separately for each state. We limit the analyses presented in the text to those workers who cared for adults. (As noted, Appendix B shows similar analyses for the workers who cared for children in Florida.) We also estimated the effect of worker characteristics and consumer characteristics on key outcomes. We do not report those results here, however, as few characteristics were significantly related to outcomes, and there was no consistent pattern across outcome measures. The only variables that were significantly related to outcome measures were those that described the consumer-worker relationship and living relationship. Therefore, after examining outcomes for the full sample in each state, we compare key outcomes for workers who were related to consumers with those for unrelated workers, and we compare workers who lived with the consumers with those who did not. For this analysis, we combined the workers for all three states in the adult samples together.

4. Sample Description: Characteristics of Workers and Their Care Recipients

Consumer Characteristics. As with the consumer sample in general, most consumers in each state whose workers were paid to provide assistance (whether by an agency or by the consumer) were white and female (Table A.1). Most had functional limitations. For example, two-thirds of each group reported that they needed help getting in and out of bed, and about 90 percent needed help bathing.

The proportion of adult consumers who were nonelderly (younger than age 65) in Florida (more than 60 percent) was much greater than in the other two states (about 25 percent in Arkansas and 45 percent in New Jersey). In addition, more than 90 percent of those under age 60 in Florida were participants in the Developmental Disabilities waiver (not shown). Thus, most of the nonelderly consumers in Florida had developmental disabilities, whereas elderly consumers in Florida, and both elderly and nonelderly consumers in Arkansas and New Jersey, primarily had physical disabilities. Therefore, the percentage reporting that they were in poor health was greater in New Jersey (about 40 percent of all consumers) and in Arkansas (about 47 percent), than in Florida (26 percent).

A sizable minority of consumers did not have any paid personal care workers during the week before the consumer baseline survey. This may have been because these consumers were new to personal care (in Arkansas), had enrolled but not yet received personal care (in New Jersey), or only received waiver services other than personal care (in Florida). In all three states, it also may have been because labor shortages or other idiosyncratic events (such as illness) prevented consumers from receiving help that week. The percentage of workers who served consumers lacking paid assistance before baseline was highest in Arkansas (38 percent of directly hired workers and 21 percent of agency workers), followed by Florida (21 percent of directly hired workers and 9 percent of agency workers)[9] and New Jersey (17 percent of directly hired workers and 7 percent of agency workers). Cash and Counseling greatly increased the likelihood that consumers receive any paid personal care (Carlson et al. 2005). Therefore, it is not surprising that more directly hired workers than agency workers in this sample were caring for consumers who did not have paid assistance before the baseline survey.

[9] Consumers in Florida who did not receive paid personal care generally received other services (such as therapy) under the waiver. Nearly all consumers in Florida received at least some services.

There are also other differences between the consumers cared for by agency workers and those cared for by directly hired workers. The sample is not representative of all consumers, as it excludes consumers who did not have a worker at nine months postenrollment and those in the treatment group who had a worker who was not hired with the allowance. In New Jersey, compared to consumers cared for by agency workers, consumers cared for by directly hired workers were less likely to live alone, had more functional impairments, and were less likely to be Hispanic. In Florida and Arkansas, the prospective allowance amounts were greater for consumers cared for by directly hired workers than for those cared for by agency workers.

Worker Characteristics. Most directly hired workers in each state were friends or relatives of the consumer. However, there were some differences across states in the consumer-worker relationship, due primarily to the different consumer populations served. For example, in Florida, fewer directly hired workers were related to the consumer than in the other two states, perhaps because fewer had family members living nearby. Specifically, 58 percent of directly hired workers in Florida were related to the consumer, compared to 71 percent in New Jersey and 78 percent in Arkansas (Table 1). In Florida, directly hired workers were more likely to be parents, and less likely to be children, than in the other two states. This was because Florida had a much higher proportion of nonelderly adults than did Arkansas or New Jersey and because nearly all of these nonelderly adults came from Florida's waiver program for people with developmental disabilities. In each state, the most commonly hired relative was a daughter or son, with 49 percent hiring a son or daughter in Arkansas, 42 percent in New Jersey, and 20 percent in Florida. In Florida, 19 percent hired a parent, compared to 9 percent in New Jersey and 3 percent in Arkansas. In Florida and New Jersey, consumers could hire spouses. In these states, however, less than three percent of directly hired workers were married to the consumer they cared for. Before the demonstration began, about 80 percent (ranging from 70 percent in

TABLE 1

WORKER CHARACTERISTICS

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Worker Age				***		
18 to 39	37.1	34.2	25.2	33.3	35.9	34.7
40 to 64	54.5	57.7	62.4	62.0	58.9	61.7
65 to 79	8.2	7.5	11.7	4.3	5.0	2.3
80 or older	0.3	0.7	0.7	0.4	0.3	1.3
10 or more years younger than consumer	82.6	82.2	42.0	47.1	70.9	71.1
High School Graduate	70.8	78.7**	82.1	79.3	78.0	71.5*
Female	84.4	97.2***	81.2	92.2***	82.5	97.7***
Race		*		***		***
White	60.3	55.4	68.4	51.4	47.9	27.0
Black	35.1	42.1	22.9	36.0	29.0	38.5
Other	4.6	2.5	8.8	12.6	23.1	34.5
Same race as consumer	90.7	79.6***	83.6	60.2***	84.4	54.5***
Family and Work Situation						
Married	51.7	51.3	50.2	52.6	51.4	49.3
Has children	35.6	47.0***	29.9	41.6***	40.4	47.5*
Currently has job other than caregiving	39.7	20.1***	40.3	21.2***	42.1	22.6***
Consumer-Worker Relationship						
Related to consumer	78.3	n.a.	58.4	n.a.	70.9	n.a.
Not related, but knew consumer before demonstration	16.4	n.a.	25.8	n.a.	19.1	n.a.

TABLE 1 *(continued)*

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Did not know consumer before demonstration	5.4	n.a.	15.8	n.a.	10.0	n.a.
Worker is consumer's:						
Spouse	0.0	n.a.	2.0	n.a.	2.6	n.a.
Parent	3.3	n.a.	18.8	n.a.	8.9	n.a.
Daughter or son	48.6	n.a.	19.5	n.a.	41.9	n.a.
Sister or brother	5.9	n.a.	7.4	n.a.	5.5	n.a.
Grandparent	0.0	n.a.	2.0	n.a.	0.3	n.a.
Grandchild	11.3	n.a.	1.7	n.a.	7.3	n.a.
Other relative	9.2	n.a.	7.1	n.a.	4.5	n.a.
Living/Caregiving Arrangements						
Lives with consumer	39.4	n.a.	46.3	n.a.	40.1	n.a.
Is primary informal caregiver	44.5	n.a.	35.2	n.a.	46.1	n.a.
Provided consumer with informal care prior to demonstration	84.4	n.a.	69.7	n.a.	79.6	n.a.
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

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

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

*Mean or distribution for directly hired workers different from that of agency workers at .10 level.
**Mean or distribution for directly hired workers different from that of agency workers at .05 level.
***Mean or distribution for directly hired workers different from that of agency workers at .01 level.

Florida to 84 percent in Arkansas) of directly hired workers had informally helped the consumer with routine health care, personal care, or household tasks, and 35 to 46 percent had been the consumer's *primary* informal caregiver.[10]

In some respects, directly hired workers and agency workers were similar. Most workers in both groups were ages 40 to 64, and, in Arkansas and New Jersey, most were at least 10 years younger than the consumer they cared for. Because Florida served more nonelderly adults, only 42 percent of directly hired workers and 47 percent of agency workers were 10 or more years younger than the consumer. Nearly all agency workers (more than 90 percent in each state) and most directly hired workers (more than 80 percent in each state) were female. There were some notable differences between agency workers and directly hired workers, however. About 40 percent of directly hired workers in each state held jobs other than caregiving, compared to about 20 percent of agency workers. Finally, many more directly hired workers than agency workers were members of the same racial or ethnic group as the consumer they cared for, probably because most directly hired workers were relatives.[11]

RESULTS

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, which we use as a benchmark. The most common

[10] The consumer's primary informal caregiver is defined as the caregiver who provided the greatest number of hours of unpaid care to the consumer at the time of the baseline survey.

[11] Few agency workers were relatives of the consumers (six percent in Arkansas, three percent in Florida, and two percent in New Jersey), lived with the consumer (less than five percent in each state), or were the consumer's primary informal caregiver before the demonstration (less than four percent in each state). Because consumers usually do not know the agency workers before the workers start providing care to them, the differences in consumer-worker relationships are obvious and, therefore, are not presented in Table 1.

reason 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 for which they were paid. 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. 2005) 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 they provided in the two weeks before the interview, most also provided unpaid care. In fact, directly hired workers provided an average of more than 25 hours of unpaid care per week in each of the three states (Table 2). Over a quarter of directly hired workers in each state provided more than 40 hours of unpaid care per week; only 26 percent in Arkansas, 34 percent in New Jersey, and 41 percent in Florida provided no unpaid care. (The differences between states in the percentage of workers providing unpaid care closely correspond to the percentage of workers related to the consumer in each state, as related workers were much more likely than unrelated workers to provide unpaid care. See Subsection 8, Key Outcomes, by Consumer-Worker Relationship, for results on the number of hours of unpaid care provided by related and unrelated workers.) The large amount of unpaid care that directly hired workers provided likely reflects the fact that nearly 80 percent of them (ranging from 70 percent in Florida to 84 percent in Arkansas) provided at least some care to the consumer informally before the demonstration.

In Florida, directly hired workers provided an average of about 20 hours of paid care per week to the sample member, about 4 hours more per week, on average, than their agency

counterparts (Table 2). In New Jersey, directly hired workers also provided an average of about 20 hours of paid care per week to the sample member, an hour per week more than the average for agency workers. In Arkansas, the two types of workers provided similar amounts of paid assistance, averaging approximately 12 hours per week. In Arkansas and Florida, the distribution of paid hours was different for directly hired workers and agency workers. In both states, directly hired workers were less likely than agency workers to provide 1 to 7 hours of paid care per week, but more likely to provide 8 to 20 hours of care per week (in Arkansas) and 21 or more hours of care per week (in Florida).

2. Compensation and Job Satisfaction

In Florida and New Jersey, directly hired workers received wages of about $10 per hour, over $1 an hour more than the average agency worker in their state. In contrast, in Arkansas, directly hired workers received an average hourly wage of $6.07, slightly (but significantly) less than the average agency worker wage of $6.30 an hour. Directly hired workers and agency workers might receive different wages for a variety of reasons. For example, consumers in New Jersey and Florida may have paid higher wages to directly hired workers in order to attract a higher quality worker, or because they chose to pay higher wages instead of fringe benefits. Consumers in Arkansas may have tended to pay directly hired workers lower wages than agency workers because the vast majority of directly hired workers were family members, many of whom did not primarily depend on income from their caregiving job.

More agency workers (ranging from 17 percent in Florida to 24 percent in New Jersey) than directly hired workers (less than 5 percent) received fringe benefits. However, most of these directly hired workers would be considered part-time employees, providing an average of 12 to 21 hours of care per week, and, in general, many part-time employees are ineligible for benefits. (The monthly benefit was seldom large enough in any of the states to permit a consumer to hire a

TABLE 2

HOURS OF CARE PROVIDED AND COMPENSATION

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers	Agency Workers[a]	Directly Hired Workers	Agency Workers[a]	Directly Hired Workers	Agency Workers[a]
Hours of Care Provided per Week						
Average paid hours	12.5	11.7	19.9	16.2***	20.3	18.9*
Average unpaid hours	25.7	n.a.	26.5	n.a.	26.5	n.a.
Total hours	38.2	n.a.	46.4	n.a.	46.8	n.a.
Distribution of Paid Hours per Week (Percent)		***		***		
0	0.8	0.0	1.9	0.0	0.0	0.0
1 to 7	18.3	30.9	23.1	36.3	6.9	10.9
8 to 20	73.3	59.3	37.2	38.3	51.5	53.0
21 to 30	4.7	6.9	18.6	11.3	28.7	26.5
Over 30	2.8	2.9	19.3	14.1	13.0	9.6
Distribution of Unpaid Hours per Week (Percent)						
0	26.4	n.a.	40.9	n.a.	33.6	n.a.
1 to 7	17.2	n.a.	7.4	n.a.	14.3	n.a.
8 to 20	15.3	n.a.	11.2	n.a.	12.4	n.a.
21 to 40	13.9	n.a.	13.0	n.a.	12.4	n.a.
Over 40	27.2	n.a.	27.5	n.a.	27.3	n.a.
Compensation						
Hourly wage (dollars)	6.07	6.30***	10.26	9.03***	9.84	8.53***
Received fringe benefits (percent)	1.6	20.6***	3.5	16.5***	4.6	24.2***
Paid for travel time (percent)[b]	5.8	57.8***	7.3	21.2***	6.9	15.1***
Ever paid late (percent)	35.1	n.a.	29.2	n.a.	30.8	n.a.
Ever paid less than owed (percent)	6.7	n.a.	5.1	n.a.	6.8	n.a.
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

TABLE 2 *(continued)*

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

[a]Responses for agency workers pertain only to the care they provide to the consumer who identified them as their primary worker on the nine-month follow-up survey.

[b]Among those living apart from consumer.

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

*Mean or distribution for directly hired workers different from that of agency workers at .10 level.
**Mean or distribution for directly hired workers different from that of agency workers at .05 level.
***Mean or distribution for directly hired workers different from that of agency workers at .01 level.

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. Even for agency workers, however, fringe benefits were rare.

Among those who did not live with the consumer, only six to seven percent of directly hired workers were paid for their travel time. Agency workers were more likely to be paid for their travel time, although the percentage varied greatly by state, ranging from 15 percent in New Jersey to 58 percent in Arkansas, with agency workers in Florida (21 percent) falling between these two extremes.

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, about a third of directly hired workers in each state did report that their pay had been delayed over the past two weeks; however, few (five to seven percent) reported ever being paid less than they were owed. Thus, nearly all directly hired workers eventually received all the pay they were expecting. (We did not ask these questions of agency workers, as it was assumed that agencies generally paid workers on time and correctly. In the IHSS study, however, 5 to 6 percent of agency workers reported having payment problems (Doty et al. 1999).)

Despite receiving modest (and sometimes late) pay and almost no fringe benefits, an average of 45 percent of directly hired workers across all three states reported being very satisfied with their wages and benefits (ranging from 41 percent in New Jersey to 51 percent in Florida) (Table 3). Only about 16 percent in each state reported being dissatisfied. In contrast, an average of about 20 percent of agency workers in each state reported being very satisfied with their wages

TABLE 3

SATISFACTION WITH WORKING CONDITIONS

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Satisfaction:						
With Wages and Fringe Benefits						
Very satisfied	44.6	22.2***	50.7	22.9***	41.4	19.1***
Not satisfied	15.6	37.5***	16.3	38.0***	16.9	41.8***
With Working Conditions Overall						
Very satisfied	83.4	81.8	85.3	82.6	79.3	69.9***
Not satisfied	1.0	2.1	1.0	2.4	1.3	3.3*
Is Satisfied with Supervision of Care						
Strongly agrees	86.4	84.3	87.9	88.0	87.0	83.2
Disagrees	2.3	2.6	1.6	4.6*	2.0	4.1
Is Satisfied with Amount of Feedback on How Care Is Provided						
Strongly agrees	88.3	82.2**	86.4	86.2	89.7	88.1
Disagrees	1.6	2.2	1.7	2.8	0.5	2.1*
Asked to Do Things to Which They Had Not Agreed	1.8	7.5***	2.7	3.2	2.6	6.2**
Close Supervision Interfered with Work	3.1	2.9	3.1	3.2	2.9	4.0

TABLE 3 *(continued)*

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Has a Lot of Flexibility in Scheduling Care						
Strongly agrees	77.1	72.7	81.2	79.9	79.8	76.4
Disagrees	8.6	11.4	8.2	7.4	9.1	7.3
Ever Had Disagreement Regarding Schedule	2.1	3.2	1.7	5.2**	2.9	4.2
Must Hurry to Meet All Consumer's Needs						
Strongly agrees	21.4	16.0*	25.9	23.4	35.4	32.4
Disagrees	63.9	68.7	58.5	67.7**	49.3	53.5
Worker Responsible for Providing Back-Up Care	53.3	n.a.	41.3	n.a.	44.5	n.a.
Somewhat or Very Difficult to Arrange Back-Up Care	19.2	n.a.	21.5	n.a.	17.0	n.a.
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable for agency workers.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

and fringe benefits; about twice as many 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 compared to agency workers. This probably is due, in part, to the fact that so many directly hired workers had been providing unpaid care—they are satisfied to be receiving even modest pay for some of the work they had previously done entirely for free. Also, because more directly hired workers had jobs other than caregiving, they may not have been as dependent on their pay from caregiving as agency workers.

3. Satisfaction with Working Conditions

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 in Arkansas and Florida reported being very satisfied with their working conditions. Similarly, 79 percent of directly hired workers in New Jersey report being very satisfied with their working conditions; however, agency workers in New Jersey reported somewhat lower levels of satisfaction, with only 70 percent being very satisfied with their working conditions.

The supervision of agency workers and directly hired workers is somewhat different in that 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, similar percentages of directly hired workers and agency workers (about 87 percent of both types of workers in each state) were very satisfied with the supervision they received. Compared to agency workers, directly hired workers were more satisfied with the amount of feedback they received on how care was provided in Arkansas, and were less likely (in Arkansas and New Jersey) to report having been asked to do things to which they had not agreed. Finally, similar percentages (approximately three percent in all three states)

of both directly hired workers and agency workers reported that close supervision interfered with their work.

In each state, more than 70 percent of workers in both groups were satisfied with the flexibility of their schedules, and few reported scheduling disagreements with their client. Directly hired workers in Arkansas and Florida, however, were more likely to report having to hurry to meet the consumer's needs, perhaps 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.

As another satisfaction issue, directly hired workers often have to find back-up care when they cannot come to work. In the three states, a sizable percentage of directly hired workers in the sample (ranging from 41 percent in Florida to 53 percent in Arkansas) were responsible for obtaining back-up care, and about 20 percent in each state reported having at least some difficulty arranging it. (We did not ask agency workers this question, as we assumed that agency workers would not be responsible for providing their own back-up care. However, in focus groups, some agency workers reported that they did have to provide their own back-up care.)

4. Pattern of Care Provided

Because most directly hired workers also were informal caregivers, it is not surprising that many of them provided care during nonbusiness hours. In each state, about half provided care before 8:00 A.M. on weekdays, more than 70 percent provided evening care, and more than 80 percent provided weekend care (Table A.2). In contrast, less than a third of agency workers in each state provided early morning care, evening care, or care on weekends; the exception was that about 45 percent of agency workers in Florida provided care on the weekends. In interpreting these results, we cannot determine whether hours for which workers were paid were business or nonbusiness hours. Workers were asked whether they provided care during times of

the day and week, but were not asked whether they were *paid* for the hours that they worked during those times. 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 mostly during business hours and the unpaid caregiver providing care mostly during nonbusiness hours. Under Cash and Counseling, *consumers* experienced only modest increases (of about five percent) in the likelihood of receiving any (paid or unpaid) help during the early mornings, evenings, or weekends. During nonbusiness hours, most members of the control group who could not obtain paid help apparently still received at least some informal care (Carlson et al. 2005). This reflects the fact that many caregivers have jobs and can provide care only during nonbusiness hours.

5. Type of Care Provided

More than 87 percent of all directly hired workers and agency workers in each state provided personal care and household care. However, although most directly hired workers (83 percent in Arkansas, 81 percent in Florida, and 92 percent in New Jersey) provided help with routine health care, a smaller percentage of agency workers provided this type of help (Table 4). In particular, in each state, more than 70 percent of directly hired workers helped their client take medicine. About two-thirds helped with range-of-motion or other exercises (ranging from 56 percent in Arkansas to 77 percent in New Jersey), and about a quarter helped their client care for pressure sores or other chronic wounds. Sizable percentages (ranging from 29 percent in Florida to 42 percent in Arkansas and New Jersey) helped with special foot care needed because of poor circulation. Fewer directly hired workers helped with technical health care tasks such as taking care of a feeding tube, colostomy, or urinary catheter, probably because these medical needs were less prevalent in our sample.

TABLE 4

TYPE OF CARE PROVIDED

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Provided:						
Any routine health care	82.6	59.4***	81.2	70.6***	91.6	86.4**
Personal care	94.1	94.6	89.6	88.1	95.7	94.7
Household care	98.9	93.5***	96.9	87.3***	99.2	98.0
Company	94.1	n.a.	91.7	n.a.	91.9	n.a.
Provided Assistance with						
Medicine	75.8	23.1***	70.1	25.5***	81.4	54.1***
Pressure sores	26.4	10.4***	18.5	12.8*	23.8	9.3***
Feeding tube	4.4	1.8*	7.5	7.6	4.6	3.6
Urinary catheter	5.3	6.1	7.1	10.4	6.6	7.3
Colostomy	2.5	1.1	3.2	2.0	2.5	1.7
Range of motion	55.8	36.3***	62.5	52.4**	76.8	71.3
Ventilator	11.7	5.4***	11.4	7.6	13.9	9.9
Special care of the feet	42.2	27.7***	28.5	25.9	42.4	42.2
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

TABLE 4 *(continued)*

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

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, Carlson et al. (2005) showed that, under Cash and Counseling, treatment group members in one or more states were *less* likely than control group members to fall, develop contractures, have respiratory infections, experience shortness of breath, or have urinary infections.

For nearly every outcome 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 help with health care tasks from agency workers, many may have received help from informal caregivers. Indeed, Carlson et al. (2005) found that there was no difference between the treatment and control groups in the likelihood that consumers received help with routine health care from any caregiver (paid or unpaid).

6. Training and Preparedness for Work

Directly hired workers do not appear to receive training comparable to that of their agency counterparts. About 60 percent of the directly hired workers who provided routine health care reported receiving any health care training (ranging from 52 percent in Arkansas to 69 percent in Florida) (Table 5). In contrast, in each state, at least 95 percent of agency workers who provided routine health care received such training. About 90 percent of both directly hired workers and agency workers who received health care training reported that the training was "hands-on"—the worker performed the task while the trainer watched (not shown). 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 who received personal care training had hands-on training. Finally, nearly all agency workers received their training in personal and

TABLE 5

TRAINING AND PREPAREDNESS FOR WORK

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Received Any Health Care Training	51.7	95.2***	69.2	95.6***	58.4	98.5***
Received Any Personal Care Training	49.9	93.5***	54.7	95.5***	55.3	98.6***
Preparedness for Job						
Is well informed about consumer's condition and services						
Strongly agrees	89.7	82.6***	87.4	82.2*	89.9	89.2
Disagrees	2.8	5.3	3.4	7.4**	1.9	2.7
Feels fully prepared to meet expectations in helping consumer						
Strongly agrees	96.7	95.7	95.6	96.0	94.7	96.4
Disagrees	0.5	0.4	1.3	2.4	0.5	0.3
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

health care from a health care provider. Among those directly hired workers who reported receiving any training, about 85 percent in each state were trained by a health care provider, and the rest were trained by the consumer or the consumer's family or friends (data not shown in tables).

In interpreting these results, it is important to remember that, although many directly hired workers did not report receiving training, most (at least 70 percent in each state; Table 1) had been caring for the consumer before the demonstration began. Those who had been 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 (about 96 percent) "felt fully prepared to meet expectations in helping the consumer" (Table 5). Furthermore, in all three states, more than 80 percent of all workers (both directly hired and agency) reported that they were well informed about the consumer's condition. In Arkansas and Florida, the percentage of directly hired workers who were well informed about the consumer's condition was significantly higher than the percentage of agency workers.

Finally, results from a companion analysis suggest that consumers received satisfactory health care under Cash and Counseling (Carlson et al. 2005) 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. A sizable percentage of directly hired workers (ranging from 35 percent in Florida to 44 percent in Arkansas, not shown) consulted the consumer's doctor with health care questions. In contrast, agency workers most often turned to the home care agency with health care questions (with 49 percent in Florida and 77 percent in Arkansas consulting the agency), while less than 10 percent in each state consulted the consumer's doctor (not shown).

7. Worker Well-Being

In general, workers in Florida and New Jersey reported more physical strain than those in Arkansas. About 30 percent of directly hired workers in Florida and New Jersey reported a great deal of physical strain, compared to 17 percent of directly hired workers in Arkansas (Table 6). Conversely, 46 percent of directly hired workers reported little or no physical strain in Arkansas, compared to 36 percent in Florida and 39 percent in New Jersey. These differences across states could be due to differences in the consumer's characteristics and care needs. Only in New Jersey were there significant differences in the level of physical strain reported by directly hired and agency workers, with agency workers reporting higher levels of physical strain. For example, 42 percent of agency workers in New Jersey reported suffering a great deal of physical strain, compared to 28 percent of directly hired workers.[12]

Few workers were physically hurt on the job, but there were some differences in the likelihood of injury for directly hired workers and agency workers. Directly hired workers were significantly more likely than their agency counterparts to be injured as a result of caring for the sample member in Arkansas (four and one percent, respectively) but significantly less likely to be hurt caring for the sample member in New Jersey (four versus seven percent, respectively). Directly hired workers might have been especially likely to be injured while caring for their client simply because they spent so much more time delivering that care. When we controlled statistically for the total number of hours of work provided to the sample member, directly hired

[12] We also examined key measures of worker well-being separately in Florida for those who served the nonelderly (those under age 60), who generally had developmental disabilities, and the elderly, who tended to be frail or physically impaired. Among those who served the nonelderly, directly hired workers suffered significantly less physical strain than agency workers, with 24 percent of directly hired workers and 35 percent of agency workers reporting a great deal of physical strain (Table B.9). Similarly, directly hired workers who served children in Florida also reported less physical strain than their agency counterparts (Table B.6). No such difference was observed for the workers serving elderly Floridians.

TABLE 6

WORKER WELL-BEING

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)	Directly Hired Workers (Percent)	Agency Workers (Percent)
Physical Strain						
Little or none	45.8	52.2	36.4	40.6	38.6	27.7***
Great deal	16.9	15.1	29.6	33.9	28.4	42.0***
Injuries						
Suffered any injury	3.6	1.4*	5.7	4.3	3.7	6.5*
Suffered any injury, after controlling for hours of care provided	1.8	1.3	3.2	4.8	3.0	10.0***
Suffered injury serious enough to see doctor	1.0	0.0*	0.7	1.2	0.0	0.7
Emotional Strain						
Little or none	60.2	70.1***	47.5	59.1***	40.2	42.0
A great deal	15.2	8.9**	25.1	26.7	31.2	35.6
Consumer-Worker Relationship						
Caregiver and consumer get along very well	91.4	94.4	93.1	92.8	87.1	80.8**
Has very close relationship with consumer	83.8	53.5***	77.4	49.3***	75.7	34.3***
Consumer needs to be more respectful	16.1	12.4	16.1	13.0	19.2	17.5
Consumer's family and friends need to be more respectful	37.1	22.4***	21.4	16.5	29.2	18.9***
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

workers in each state were no more likely (and, in New Jersey, were much less likely) to be injured while caring for the consumer than their agency counterparts.

Both agency workers and directly hired workers gave positive reports on their relationships with the consumer. In both Arkansas and Florida, about 90 percent of both directly hired workers and agency workers reported that they got along very well with the consumer. While nearly all workers in New Jersey also gave positive reports on their relationship with the consumer, a greater percentage of directly hired workers (87 percent) than agency workers (81 percent) said that they got along very well with the consumer. In addition, more than 75 percent of directly hired workers in each state reported having a very close relationship with the consumer, probably because many were related to the consumer. Far fewer agency workers (ranging from 34 percent in New Jersey to 54 percent in Arkansas) reported having a very close relationship with the consumer.

Although most workers in both groups also reported little or no emotional strain, fewer directly hired workers than agency workers reported suffering little or no emotional strain in Arkansas (60 and 70 percent, respectively) and Florida (48 and 59 percent, respectively). In Arkansas, directly hired workers also were significantly more likely than agency workers to report suffering much emotional strain (15 versus 9 percent). In New Jersey, no such difference was observed, but both types of workers reported levels of emotional strain that were higher than those in the other two states.

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. (For directly hired workers, the consumer's family typically is also the worker's own family.) In particular, 37 percent of directly hired workers in Arkansas (compared to 22 percent of agency workers) and 29 percent in New Jersey (compared to 19 percent of agency workers) reported that the

consumer's family and friends needed to be more respectful. In Florida, for the full adult sample, the percentage of directly hired workers reporting that the consumer's family and friends needed to be more respectful (21 percent) was much lower and not significantly greater than that of agency workers (17 percent). In Florida, however, fewer directly hired workers were related to the consumer than in the other two states. Nonetheless, among those who served the elderly in Florida, a greater share of directly hired workers (26 percent) than agency workers (13 percent) desired more respect from the consumers' family and friends (Table B.9).[13] Indeed, 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 consumer-worker 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 by whether they lived with the consumer. Our primary goal in this section is to compare key outcomes across different types of directly hired workers. We also show these outcomes for agency workers (few of whom are related to the consumer they care for), so that the outcomes of agency workers and nonrelated directly hired workers can be compared. To increase cell sizes, we present results pooled for the three states; results were similar when we analyzed each state separately. Finally, while we only report

[13] Among those who served children in Florida, directly hired workers were more likely to desire respect from the consumer's family and friends as well (Table B.6).

selected outcomes in this section, Table A.3 provides a comprehensive list of outcome measures for directly hired workers, by whether the consumer was related to the worker.

Overall, both related and nonrelated directly hired workers reported high levels of satisfaction with their working conditions. More than 80 percent of each category of directly hired workers report being "very satisfied" with their overall working conditions (Table 7). Related workers were somewhat (although not significantly) more likely than unrelated workers to be very satisfied with their compensation, in spite of the fact that the average hourly wage for related workers ($8.34) was significantly less than that of unrelated workers ($9.11).[14]

The lack of formal training among directly hired workers is mainly concentrated among related workers, probably because related workers received training informally, while on the job. However, regardless of their relationship with the consumer, more than 85 percent felt well informed about the consumer's condition, and nearly all felt well prepared for their jobs (not shown).

Directly hired workers who were related to, or lived with, the client fared worse on several measures of well-being than directly hired workers who were not related. First, related workers reported higher levels of emotional strain than nonrelated workers. In particular, 26 percent of all related workers were likely to report that they suffered much emotional strain, compared to 19 percent of nonrelated workers. Among related workers, emotional strain was particularly high among those who lived with the consumer. Second, related workers were more likely than nonrelated workers to report a lack of respect from the consumer and the consumer's family and friends. Nineteen percent of related workers, compared to only 13 percent of nonrelated

[14] This difference in hourly wages was even more pronounced in the Florida children's sample, where nonrelated workers earned an average of nearly $13 per hour, over $2 an hour more than the average for related workers (Table B.7).

TABLE 7

SELECTED OUTCOMES BY CONSUMER-WORKER RELATIONSHIP, ALL THREE STATES COMBINED

	Directly Hired Workers						
	Related			Unrelated			
	Live-In	Not Live-In	All Related	Live-In	Not Live-In	All Unrelated	Agency Workers
Working Conditions							
Hourly wage (dollars)	8.64	7.98	8.34***	7.63	9.29	9.11	7.93
Very satisfied with wages (percent)	45.5	47.1	46.3	48.8	41.5	42.5	21.3
Very satisfied with working conditions (percent)	80.0	84.4	82.1	85.4	83.0	83.3	82.4
Training and Preparedness for Job (Percent)							
Received health care training	53.7	54.2	53.9***	69.2	73.2	72.5	96.7
Received personal care training	43.7	48.7	45.9***	70.0	72.2	71.9	96.0
Is well informed about consumer's condition	90.8	88.9	89.9	95.1	86.1	87.3	84.8
Worker Well-Being (Percent)							
Little or no emotional strain	40.8	53.0	46.5***	41.5	59.1	56.8	56.7
Much emotional strain	29.3	21.6	25.7**	26.8	17.5	18.7	23.8
Consumer needs to be more respectful	22.9	14.5	19.0**	19.5	12.0	13.0	14.4
Consumer's family and friends need to be more respectful	40.9	27.4	34.6***	31.7	17.0	18.9	19.3
Hours of Care Provided (Per Week)							
Paid hours	19	14	17**	22	18	19	16
Unpaid hours	53	12	34***	48	2	7	2
Maximum Sample Size	**404**	**347**	**751**	**41**	**279**	**320**	**844**

TABLE 7 *(continued)*

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

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

*Related workers different from unrelated workers at the .10 level, two-tailed test.
**Related workers different from unrelated workers at the .05 level, two-tailed test.
***Related workers different from unrelated workers at the .01 level, two-tailed test.

workers, reported desiring more respect from the consumer. Similarly, 35 percent of related workers, but only 19 percent of nonrelated workers, reported that the consumer's family and friends needed to show more respect. Related live-in workers fared the worst, as 41 percent of the workers in this group (but only 27 percent of related workers who did not live with their client) felt that the consumer's family and friends did not show enough respect.

Interestingly, nonrelated directly hired workers and agency workers (nearly all of whom were not related to the consumer) generally 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 workers 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 34 hours of unpaid care per week, many more than the 7 hours of unpaid care per week that unrelated directly hired workers provided. This difference is driven by the large number of hours of unpaid care (53) provided by related workers who lived with the consumer. Even among workers who did not live with the consumer, however, those who were related to the consumer provided many more hours of unpaid care (12) than those who were not related (2).[15]

DISCUSSION

1. Summary and Policy Implications

As expected, most directly hired workers were relatives or close friends of the consumer. The proportion of directly hired workers who were relatives varied from state to state. In each

[15] The hours of unpaid care include those provided for the consumer only and those provided for the whole household.

state, however, directly hired workers provided an average of about 26 hours of unpaid care per week. Thus, it was clear that these caregivers fulfilled the roles of both employee and informal caregiver. Directly hired workers also were more likely to help with a variety of health care tasks. They could do this because they were not bound by agency rules or other state regulations.

Directly hired workers did not fare as well as agency workers on some measures of well-being. In Arkansas and Florida, directly hired workers felt more emotional strain than agency workers. Similarly, directly hired workers were more likely than agency workers to desire more respect from the consumer's family and friends in Arkansas, New Jersey, and among those who served the elderly and children in Florida. The reason that directly hired workers did not fare particularly well on these measures of well-being was not that consumers make poor employers, but rather that directly hired workers typically were 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 *nonrelated* directly hired workers in the levels of emotional strain and lack of family respect.

Why do related workers seem to fare worse than nonrelated workers on these measures of 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. Relatives involved in caring for other family members may take each other's efforts for granted. In addition, family members who provide only unpaid care may resent the fact that another family member is being paid for some of the help he or she provides, leading to resentment expressed as lack of respect for the efforts of the paid worker. Finally, the

well-being of related live-in workers may have suffered in part 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.

The greater strain felt by family members who became paid workers was not necessarily *caused* by their becoming a paid worker. From research presented in a companion report (Foster et al. 2005), we know that, in all three states, primary informal caregivers at baseline who subsequently became paid workers suffered significantly *less* emotional strain than did those who remained unpaid .

Notably, in all three states, workers (both related and nonrelated directly hired workers, as well as agency workers) reported favorable perceptions of their working conditions. Most were very satisfied with both their overall working conditions and the supervision they received. Nearly all reported getting along very well with their client. These findings were remarkably consistent across all three states and for those serving children in Florida (see Appendix B), even though the states served different target populations and had different restrictions concerning whom consumers could hire.

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 (Benjamin and Matthias 2004). These findings also are consistent with the reports of workers hired under Arkansas's Cash and Counseling program 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 that their jobs were quite gratifying (Zacharias 2002).

In all three states, directly hired workers were satisfied with their wages and fringe benefits, especially compared to agency workers. This result might not be surprising in Florida or New

Jersey, where the wages of directly hired workers averaged about $10 per hour and were more than $1 per hour higher than those of agency workers. However, directly hired workers' high level of satisfaction with their compensation was similar in Arkansas, where directly hired workers' average hourly wage was modest (about $6 per hour) and somewhat less than that of agency workers. Directly hired workers' satisfaction with their compensation may be due to the fact that many had cared for their client without pay before the demonstration. For those workers providing many hours of unpaid care, 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. In addition, because caregiving is a second job for many directly hired workers, 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 modest levels of compensation or poor working conditions. The finding that IndependentChoices lowered nursing home costs in Arkansas (Dale et al. 2003b) suggests that caregiver burnout may be reduced under consumer direction.

Some aspects of the working environment under consumer direction may be cause for concern. Many directly hired workers—especially those who were related to the consumer—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, nearly all of the consumers' directly hired workers had been caring for the consumer before the demonstration, and most reported that they were well prepared to help 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. (The lack of training is less of an issue for nonrelated workers, nearly all of whom did receive training for the care they provided.)

The lack of formal training does not appear to have affected worker safety, as, after controlling for the total number of hours of care that they provided, directly hired workers were no more likely than agency workers to suffer physical strain or injuries related to caregiving. In fact, in New Jersey, directly hired workers suffered less physical strain and reported fewer injuries than their agency counterparts. Directly hired workers in Florida serving those with developmental disabilities (children and the nonelderly) also suffered less physical strain than their agency counterparts. Moreover, it does not appear that *consumer* safety was jeopardized by the absence of formal training, as Carlson et al. (2005) found that Cash and Counseling 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 back-up care but had difficulty doing so. Agency workers presumably would not face this problem. However, some agencies (particularly in Arkansas) were having difficulty providing back-up care during the study period, so it is unclear whether the consumer would be more or less likely to receive back-up care if an agency employed the worker.

In general, our findings echo those for the IHSS program reported in Benjamin and Matthias (2004), though it is difficult to make exact comparisons due to differences in the scales used. In both programs, compared to agency workers, workers under consumer direction:

- Were less likely to receive formal training but were more likely to feel they were well informed about their client's needs.
- Were more likely to feel close to the consumer but fared less well on measures of emotional well-being.
- Reported similar, high levels of satisfaction with their working conditions.

The major difference between the IHSS results and those of Cash and Counseling is that workers hired by consumers under Cash and Counseling were more satisfied than agency workers with their compensation, while those hired by consumers in the IHSS program were less satisfied than agency workers with pay and career opportunities. Part of the reason for this difference is that directly hired workers in the IHSS program received wages that were about 30 percent lower than those of their agency counterparts, while workers hired under Cash and Counseling received wages that were much closer to those of their agency counterparts (ranging from 4 percent lower in Arkansas to about 15 percent higher in Florida and New Jersey). Dissatisfaction with the low wages in the IHSS program may have been exacerbated by the fact that workers hired by consumers in that program worked more hours and were less likely to have another job than workers hired by consumers under Cash and Counseling.

2. Possible Improvements

Despite the satisfaction that workers hired under Cash and Counseling expressed with their work arrangements, compensation, and relationship with the care recipient, there remain some concerns about workers' well-being and willingness to continue in their role over a longer period. Because the consumer was the official employer, states took a fairly hands-off position regarding paid workers hired under the program. The program's emphasis on consumer empowerment led states to avoid taking a more paternalistic approach toward consumers or the workers they hired. States also may have felt they did not have the resources to provide assistance to caregivers as well as care recipients. Nonetheless, a few modest, proactive efforts could be made at little cost to improve worker well-being. The importance of taking such proactive efforts to improve the well-being of caregivers has been recognized by Congress through the National Family Caregiving Support Program (NFCSP). Established in 2000, the NFCSP calls for states to provide a continuum of caregiver services, including information,

assistance, individual counseling, support groups and training, respite, and supplemental services (Squillace and Jackson 2004).

Having counselors/consultants give educational materials to hired workers could lessen one such concern—that consumers or workers could be injured because few workers receive training in how to do their jobs. While the incidence of such injuries is no greater for directly hired workers than for agency workers (and no greater for treatment than control group consumers), the number of injuries might be reduced inexpensively with this type of intervention. Such materials could describe how to safely perform some common assistance tasks, such as helping care recipients into or out of a bed or chair or helping them bathe. Consumers also could use a portion of their allowance to pay for their worker to attend classes in caregiving offered by local community colleges. Such information might be particularly helpful if the hired worker begins providing types of assistance different from what that worker had been providing free before becoming a paid caregiver.

A second concern—the high levels of emotional stress reported by workers (although similar to those reported by unpaid family caregivers)—also might be lessened at little cost to the state. Counselors could be made aware of local caregiver support groups and sources of information (such as books, websites, or informational brochures) on how to deal with this stress, and then trained to refer caregivers to them. Counselors could also let hired workers know of possible sources of respite care and could explain to consumers that their workers might need some such care. They could then help interested consumers revise their spending plan to incorporate such opportunities.

Education also might help address a third concern—that hired workers often feel that family members and friends of the consumer do not show enough respect for the work they do. The state could prepare materials (printed or videotaped) for consumers and their families, alerting

them to this fact and suggesting ways to minimize such tensions. Providing such information to consumers and their families when a spending plan is being developed may make it possible to avoid this potentially divisive situation, which could affect the consumer's entire caregiving network. These guidelines could include common areas of contention or conflict, as well as suggestions on how the entire family can address these issues constructively.

Finally, our findings suggest that Cash and Counseling participants tend to hire family members or friends as their main workers, and that both related and unrelated hirees have high levels of satisfaction under the program. While this bodes well for consumers who expect to be in the program for several years, it begs the following question: Could this highly successful program benefit far more consumers if it provided those who are unable to hire family or friends with a list of people who want to become workers? Furthermore, such a listing could help program participants find suitable replacements if their current hired workers were unable or unwilling to continue in the positions. In opposition, it is possible that offering such a list could be opposed by the state's home care industry and could put the state at risk of lawsuits if a worker hired from the state's list abused the consumer in some way.

3. Limitations

This study is limited in that we have no way of knowing how these hired workers would have fared without 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 only describe the experiences of directly hired workers in this sample and compare them to those of agency workers as a benchmark. Furthermore, in Arkansas, the sample overrepresents those who worked for consumers who enrolled later in the demonstration and, therefore, 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. While most of our findings were similar across all three of the Cash and Counseling states, the results may not be generalizable to other programs that have different features. For example, other programs might not provide fiscal agent and counseling services. In addition, our results may not pertain to programs where consumers primarily hire workers who are *not* their relatives or friends. We also note that our results describe the experiences only of those workers who were providing paid care to consumers when the consumer was interviewed—nine months after enrolling in Cash and Counseling. Thus, the findings may not be representative of all workers *ever* hired by consumers in Cash and Counseling and do not necessarily reflect the satisfaction and strain levels that these workers would report if interviewed after more than six to nine months in their paid caregiving role.

Despite these limitations, our results do suggest that workers hired under consumer direction tend to be very satisfied with their experiences and do not suffer physical or emotional hardship beyond what might be expected for people providing care to a relative. Although consumer direction cannot eliminate the emotional strain on these hired workers, paying them for at least some of the care they are providing does not seem to exacerbate the tensions they face and perhaps alleviates it somewhat. These findings are bolstered by the fact that the experiences of workers hired under consumer direction in the IHSS program in California are largely consistent with the experiences of workers hired under Cash and Counseling in Arkansas, Florida, and New Jersey, even though the two programs are different.

4. Other Research

In this report, we examine only a single dimension of consumer-directed care. Other MPR evaluation reports (some of which we have cited) are available or will be available soon to provide a fuller picture of Cash and Counseling. Some of these reports 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 reports use claims-based data to assess how Cash and Counseling affected the cost of personal assistance (in Arkansas and New Jersey) or waiver services (in Florida), as well as the use and cost of services covered by Medicaid and Medicare. In general, other research by the evaluation team has shown that Cash and Counseling brings sizable benefits to consumers (Carlson et al. 2005) and caregivers (Foster et al. 2005) at a cost that is similar (in most cases) to what agencies would have incurred in supplying the care authorized in consumers' care plans (Dale et al. 2005b). This report suggests that the workers hired under consumer direction are quite satisfied as well, even though they may continue to suffer the types of emotional strain that they had experienced as unpaid caregivers, due to their close relationship with consumers. Taken together, these results suggest that states can adopt consumer-directed programs with the assurance that the program will be well received by workers, consumers, and caregivers.

COMPANION REPORTS

Impacts on Quality of Care and Use of Personal Care

These reports compare treatment and control group members, using data from telephone interviews describing, among other outcomes measured nine months after random assignment: satisfaction, unmet need, disability-related health, and hours and types of personal care received.

Carlson, Barbara Lepidus, Stacy Dale, Leslie Foster, Randall Brown, Barbara Phillips, and Jennifer Schore. "Effect of Consumer Direction on Personal Care and Well-Being in Arkansas, New Jersey, and Florida." Princeton, NJ: Mathematica Policy Research, Inc., May 2005.

Foster, Leslie, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Does Consumer Direction Affect the Quality of Medicaid Personal Assistance in Arkansas?" Princeton, NJ: Mathematica Policy Research, Inc., March 2003.

Also see published version of this report: Foster et al. "Improving the Quality of Medicaid Personal Care Through Consumer Direction." *Health Affairs* Web exclusive W3, March 26, 2003, pp. 162–175.

Dale, Stacy, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "The Effect of Consumer Direction on Personal Assistance Received in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., April 2003.

Also see published version of this report: Dale et al. "The Effects of Cash and Counseling on Personal Care Services and Medicaid Costs in Arkansas." *Health Affairs* Web exclusive W3, November 19, 2003, pp. 566–575.

Foster, Leslie, Stacy Dale, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Do Consumer-Directed Supportive Services Work for Children with Developmental Disabilities?" Princeton, NJ: Mathematica Policy Research, Inc., September 2004.

Impacts on the Cost of Medicaid and Medicare Services

These reports compare treatment and control group members, using Medicaid and Medicare data describing the cost of personal care and other covered services measured during the year after random assignment, as well as presenting information about Cash and Counseling program costs.

Dale, Stacy, Randall Brown, and Barbara Phillips. "Does Arkansas' Cash and Counseling Program Affect Service Use and Public Costs?" Princeton, NJ: Mathematica Policy Research, Inc., July 2004.

Dale, Stacy, Randall Brown, and Barbara Phillips. "Medicaid Costs Under Consumer Direction for Florida Children with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., December 2004.

Dale, Stacy, and Randall Brown. "The Effect of Cash and Counseling on Medicaid and Medicare Costs: Findings for Adults in Three States." Princeton, NJ: Mathematica Policy Research, Inc., 2005.

Impacts on Informal Caregiving

These reports compare the experiences of primary informal caregivers of treatment and control group members (identified at the time of random assignment), using data from telephone interviews describing caregiver burden and well-being nine months after random assignment.

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "Easing the Burden of Caregiving: The Impact of Consumer Direction on Primary Informal Caregivers in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., August 2003.

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "The Effects of Cash and Counseling on the Primary Informal Caregivers of Children with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., April 2005.

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "How Cash and Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., July 2005.

Experiences of Paid Workers

These reports compare the experiences of primary paid workers of treatment and control group members (identified nine months after random assignment), using data from telephone interviews describing working conditions, burden, and well-being 10 months after random assignment. This report describes outcomes for workers in all states. The Arkansas report is listed below.

Dale, Stacy, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "The Experiences of Workers Hired Under Consumer Direction in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., June 2003.

Program Implementation

These reports describe program goals, features, and procedures in detail based on in-person interviews with program staff. There is one report for each state program and a fourth report presenting implementation lessons drawn across the three programs.

Phillips, Barbara, and Barbara Schneider. "Moving to IndependentChoices: The Implementation of the Cash and Counseling Demonstration in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., May 2002.

Phillips, Barbara, and Barbara Schneider. "Enabling Personal Preference: The Implementation of the Cash and Counseling Demonstration in New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., March 2003.

Phillips, Barbara, and Barbara Schneider. "Changing to Consumer-Directed Care: The Implementation of the Cash and Counseling Demonstration in Florida." Princeton, NJ: Mathematica Policy Research, Inc., July 2004.

Phillips, Barbara, Kevin Mahoney, Lori Simon-Rusinowitz, Jennifer Schore, Sandra Barrett, William Ditto, Tom Reimers, and Pamela Doty. "Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey." Princeton, NJ: Mathematica Policy Research, Inc., June 2003.

These reports provide an overview of program implementation by distilling information from the site visit reports noted above and synthesizing this information with data from a mail survey of counselors and telephone interviews with consumers in the program treatment groups.

Schore, Jennifer, and Barbara Phillips. "Consumer and Counselor Experiences in the Arkansas IndependentChoices Program." Princeton, NJ: Mathematica Policy Research, Inc., January 2004.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the Florida Consumer Directed Care Program." Princeton, NJ: Mathematica Policy Research, Inc., June 2005.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the New Jersey Personal Preference Program." Princeton, NJ: Mathematica Policy Research, Inc., July 2005.

Program Demand and Participation

This report describes changes in enrollment in demonstration feeder programs before and after demonstration implementation, as well as compares program participants with eligible nonparticipants.

Foster, Leslie, Randall Brown, and Rachel Shapiro. "Assessing the Appeal of the Cash and Counseling Program in Arkansas, New Jersey, and Florida." Princeton, NJ: Mathematica Policy Research, Inc., July 2005.

Final Evaluation Report

This report summarizes the findings from five years of research by Mathematica Policy Research, Inc., on how each of the three demonstration states implemented its program, and on how the programs have affected the consumers who participated, as well as the consumers' paid and unpaid caregivers, and how the programs have affected the costs to Medicaid.

Brown, Randall, Barbara Lepidus Carlson, Stacy Dale, Leslie Foster, Barbara Phillips, and Jennifer Schore. "Cash and Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home- and Community-Based Services." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., July 2005.

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Dale, Stacy, Randall Brown, and Barbara Phillips. "Does Arkansas' Cash and Counseling Program Affect Service Use and Public Costs?" Princeton, NJ: Mathematica Policy Research, Inc., June 2003b.

Doty, Pamela, A.E. Benjamin, Ruth E. Matthias, and Todd M. Franke. "In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery." Washington, D.C.: U.S. Department of Health and Human Services and the University of California. April, 1999. Available at: [http:aspe.hhs.gov/daltcp/reports/ihss.htm]. Accessed August 8, 2005.

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APPENDIX A: ADDITIONAL TABLES

TABLE A.1

CHARACTERISTICS OF CONSUMERS CARED FOR BY DIRECTLY HIRED AND AGENCY WORKERS
(Percent, Unless Noted Otherwise)

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Age						
18 to 39	7.2	5.3	47.0	40.8	16.8	13.3
40 to 64	21.7	16.0*	18.5	19.2	28.8	33.4
65 to 79	38.9	40.9	18.1	16.5	29.1	28.3
80 or older	32.2	37.7	16.4	23.5*	25.4	25.0
Female	78.0	80.4	59.7	62.8	72.8	73.4
Race						
Black	33.9	35.0	19.1	23.1	32.7	37.8
Other	5.7	4.3	4.5	1.7*	11.4	6.4**
Hispanic	1.5	1.1	23.2	32.7**	36.6	46.3**
Living Arrangement						
Lives alone	34.3	34.2	15.8	19.2	27.8	40.6***
Lives in rural area	37.3	39.9	16.9	13.1	13.3	10.3

TABLE A.1 (*continued*)

	Arkansas Adults		Florida Adults		New Jersey Adults	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Caregiver/Worker/Situation						
No paid workers week before baseline	37.8	20.6***	21.2	9.4***	17.3	6.5***
Informal caregiver currently employed	32.7	32.0	46.3	42.1	46.3	39.3*
Primary informal caregiver interested in being paid	31.2	32.5	36.0	25.1***	33.0	31.2
Among Those Receiving Personal Care:						
Very satisfied with personal care	26.2	30.3	35.4	41.5	29.9	32.7
Health and Functioning						
Is in fair health	31.4	32.5	29.3	31.5	34.5	39.2
Is in poor health	44.0	49.6	26.3	26.4	44.5	36.3**
Not independent in transferring	62.7	66.8	66.4	68.2	72.2	64.9**
Not independent in bathing	87.5	92.9**	87.6	89.0	91.1	87.0*
Not independent in using bathroom	65.2	65.5	70.8	71.8	74.6	68.8*
Cash and Counseling Enrollment						
Enrolled during latter half of demonstration	68.5	63.7	47.7	42.4	56.8	41.2***
Weekly Prospective Allowance (Dollars)	119	105***	381	324*	248	261
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

A.4

TABLE A.2

TIMING OF CARE PROVIDED

	Arkansas		Florida		New Jersey	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Provided Care (Percent)						
Before 8:00 A.M. weekdays	49.6	21.2***	55.7	30.2***	54.8	17.5***
After 6:00 P.M. weekdays	70.5	11.5***	75.1	32.4***	75.5	17.2***
On weekends	84.7	16.2***	82.7	44.8***	89.0	31.0***
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

TABLE A.3

OUTCOMES FOR WORKERS, BY CONSUMER-WORKER RELATIONSHIP, FOR ADULT SAMPLES IN ARKANSAS, FLORIDA, AND NEW JERSEY
(Percent, Unless Noted Otherwise)

Variable	Directly Hired Related Workers (n = 751)	Directly Hired Unrelated Workers (n = 320)	Agency Workers (n = 844)
Hours of Care Provided			
Paid hours provided per week (hours)	16.8	18.7**	15.7
Unpaid hours provided per week (hours)	34.1	7.4***	1.7
Compensation			
Hourly wage (dollars)	8.34	9.11***	7.93
Received some fringe benefits	2.9	4.0	20.6
Paid for travel time (percent of visiting workers only)	3.6	10.4***	30.9
Satisfaction with working conditions			
Very satisfied with wages and fringe benefits	46.3	42.5	21.3
Very satisfied with working conditions overall	82.1	83.3	82.4
Very satisfied with supervision of care	86.9	87.3	85.0
Very satisfied with amount of feedback on how care is provided	88.4	87.9	85.5
Asked to do things not agreed to	2.3	2.5	5.7
Close supervision interfered with work	2.8	3.5	3.4
Scheduling			
Has a lot of flexibility in scheduling care	78.3	81.5	76.2
Ever disagreed about schedule	2.3	2.2	4.2
Must hurry to meet all of consumer's needs	30.4	21.1***	24.2
Training Received			
Received any health care training	53.9	72.5***	96.7
Received any personal care training	45.9	71.9***	96.0
Preparedness for job			
Is well informed about consumer's condition and services	89.9	87.3	84.8
Feels fully prepared to meet expectations in helping consumer	95.5	96.2	96.1

TABLE A.3 (*continued*)

Variable	Directly Hired Related Workers (n = 751)	Directly Hired Unrelated Workers (n = 320)	Agency Workers (n = 844)
Physical strain and injuries			
Suffered any injury from caregiving	4.4	3.8	4.2
Reported little or no physical strain	38.8	45.0*	39.8
Reported much physical strain	23.7	26.4	30.5
Provided:			
Any routine health care	89.4	76.3***	72.6
Personal care	95.1	89.4**	92.7
Household care	99.3	96.4***	93.3
Company	96.6	83.1***	n.a.
Provided Assistance with			
Medicine	82.4	61.5***	35.1
Pressure sores	25.2	18.6**	10.7
Feeding tube	4.6	7.1	4.2
Urinary catheter	6.1	6.8	7.8
Colostomy	2.7	2.7	1.6
Range of motion	67.1	61.0*	54.0
Ventilator	12.8	11.5	10.1
Special care of the feet	40.1	34.5*	32.5
Relationship with Consumer			
Caregiver and consumer get along very well	90.4	90.0	88.9
Emotional Strain			
Little or none	46.5	56.8***	56.7
A great deal	25.7	18.7**	23.8
Consumer needs to be more respectful	19.0	13.0**	14.4
Consumer's family and friends need to be more respectful	34.6	18.9***	19.3

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for related directly hired workers different from that of unrelated directly hired workers at .10 level.

**Mean for related directly hired workers different from that of unrelated directly hired workers at .05 level.

***Mean for related directly hired workers different from that of unrelated directly hired workers at .01 level.

APPENDIX B: COMPARISON OF FINDINGS FOR SAMPLE OF FLORIDA ADULTS AND SAMPLE OF FLORIDA CHILDREN

In this appendix, we present results for the directly hired workers and agency workers who cared for children in Florida. Due to program eligibility requirements, all the children in Florida's program have developmental disabilities. While more than 90 percent of nonelderly adults in Florida have developmental disabilities, most of the elderly adults have physical disabilities. Thus, the workers in the children's sample were caring for a somewhat different population than the workers in the adult sample. Nonetheless, the outcomes of workers caring for the children's sample were generally similar to the outcomes of those caring for the adult sample. Here, we highlight results that were different for the two samples.

Consumer Characteristics. There were some differences (in addition to the age difference) in consumer characteristics between the children's and adult samples. First, only 41 percent of the children's sample was female, compared to 60 percent of the adult sample (Table B.1a).[1] Second, about 34 percent of the children that directly hired workers cared for did not have paid workers the week before baseline, compared to 21 percent of the adults cared for by directly hired workers. Third, children were somewhat healthier and had fewer functional impairments than adults. For example, children were less likely to be in poor health than adults and less likely to need help in transferring. Finally, only about 20 percent of the children's sample enrolled in the latter half of Florida's intake period, compared to about 45 percent of the adult sample.

Worker Characteristics. As in the adult sample, a minority of the directly hired workers who cared for children (about 21 percent) were strangers, and the majority (54 percent) were family members (Table B.1b). Not surprisingly, the type of consumer-worker relationship was somewhat different for the children's sample and the adult sample. Thirty-one percent of the

[1] The predominance of boys in the children's sample likely reflects the correlation between sex and certain types of developmental disabilities, particularly autism, which is more common in boys than in girls. (Florida's Developmental Disabilities waiver program serves children with autism, cerebral palsy, mental retardation, Prader-Willi syndrome, and spina bifida.)

TABLE B.1a

CHARACTERISTICS OF CONSUMERS CARED FOR BY DIRECTLY HIRED AND AGENCY WORKERS IN FLORIDA

	Florida Adult Sample		Florida Children's Sample	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Age (Percent)				
Younger than 12	n.a.	n.a.	67.6	66.5
12 to 17	n.a.	n.a.	32.5	33.5
18 to 39	47.0	40.8	n.a.	n.a.
40 to 64	18.5	19.2	n.a.	n.a.
65 to 79	18.1	16.5	n.a.	n.a.
80 or older	16.4	23.5	n.a.	n.a.
Female (percent)	59.7	62.8	41.0	36.0
Race (percent)				
Black	19.1	23.1	12.0	11.4
Other	4.5	1.7*	4.2	4.4
Hispanic	23.2	32.7**	18.9	25.0
Living Arrangement (percent)				
Lives alone	15.8	19.2	n.a.	n.a.
Lives in rural area	16.9	13.1	16.4	18.3

TABLE B.1a *(continued)*

	Florida Adult Sample		Florida Children's Sample	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Caregiver/Worker/Situation (percent)				
No paid workers week before baseline	21.2	9.4***	33.8	12.8***
Informal caregiver currently employed	46.3	42.1	49.1	55.5
Primary informal caregiver interested in being paid	36.0	25.1***	23.3	22.2
Among Those Receiving Personal Care (percent)				
Very satisfied with personal care	35.4	41.5	32.1	36.7
Health and Functioning (percent)				
Is in fair health	29.3	31.5	30.2	22.6*
Is in poor health	26.3	26.4	10.8	17.7*
Not independent in transferring	66.4	68.2	56.3	66.9**
Not independent in bathing	87.6	89.0	91.4	94.5
Not independent in using bathroom	70.8	71.8	83.3	92.0**
Cash and Counseling Enrollment (percent)				
Enrolled during latter half of demonstration	47.7	42.4	19.4	23.2
Weekly Prospective Allowance (dollars)	381	324*	334	347
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

TABLE B.1b

WORKER CHARACTERISTICS: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Worker Age		***		
18 to 39	25.2	33.3	44.1	40.9
40 to 64	62.4	62.0	47.8	55.5
65 to 79	11.7	4.3	7.2	3.1
80 or older	0.7	0.4	0.9	0.6
At least 10 years younger than consumer	42.0	47.1	n.a.	n.a.
High School Graduate	82.1	79.3	91.0	90.9
Female	81.2	92.2***	83.8	96.3***
Race	***	***		***
White	68.4	51.4	80.8	63.5
Black	22.9	36.0	15.9	33.3
Other	8.8	12.7	3.3	3.1
Same Race as Consumer	83.6	60.2***	86.7	72.1***
Family and Work Situation				
Married	50.2	52.6	50.9	51.2
Has children	29.9	41.6***	54.5	42.7**
Currently has job other than caregiving	40.3	21.2***	50.7	39.5**

TABLE B.1b *(continued)*

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Consumer-Worker Relationship				
Related to consumer	58.4	n.a.	53.6	n.a.
Not related, but knew consumer before demonstration	25.8	n.a.	25.7	n.a.
Did not know consumer before demonstration	15.8	n.a.	20.7	n.a.
Worker Is Consumer's:				
Spouse	2.0	n.a.	0.0	n.a.
Parent	18.8	n.a.	30.6	n.a.
Daughter or son	19.5	n.a.	0.0	n.a.
Sister or brother	7.4	n.a.	5.9	n.a.
Grandparent	2.0	n.a.	10.8	n.a.
Grandchild	1.7	n.a.	0.0	n.a.
Other relative	7.1	n.a.	6.3	n.a.
Living/Caregiving Arrangements				
Lives with consumer	46.3	n.a.	39.2	n.a.
Is primary informal caregiver	35.2	n.a.	26.6	n.a.
Provided consumer with informal care before demonstration	69.7	n.a.	66.7	n.a.
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

directly hired workers for the children's sample were parents and 11 percent were grandparents, both of which were less common in the adult sample. (Among *nonelderly* adults in Florida, however, the proportion of workers who were the consumer's parents was nearly identical to the proportion in the children's sample.) Thirty-nine percent of workers for children lived in the same household (somewhat fewer than the 46 percent of the adult sample). Fifty-five percent of the directly hired workers for children had children of their own, while only 30 percent of the workers in the adult sample had children. Finally, 51 percent of the directly hired workers for children had a job other than caregiving, compared to 40 percent of the adult sample.

Hours of Care. Slightly more than half of the directly hired workers for children provided at least some unpaid care (Table B.2). About 24 percent provided more than 41 hours of unpaid care per week. While the fraction of workers providing unpaid care and the amount of unpaid care provided was somewhat less in the children's sample than in the adult sample, this is probably because fewer workers were family members and/or live-in workers in the children's sample than in the adult sample.

Compensation. The average wage for workers caring for children was similar for directly hired workers and agency workers (about $11.50 per hour). These wages were higher than the $10.26 and $9.03 average wages received by directly hired workers and agency workers (respectively) in the Florida adult sample (Table B.2).[2] Sixty-two percent of directly hired workers in the children's sample were very satisfied with their wages and fringe benefits—much higher than the 23 percent reported by agency workers in the sample (Table B.3). This

[2] The average wage for those serving the nonelderly in Florida (a population that was similar to children in that most had developmental disabilities) was $11.40 for directly hired workers and $9.92 for agency workers (not shown).

TABLE B.2

HOURS OF CARE PROVIDED: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Hours of Care Provided				
Average paid hours	19.9	16.2***	18.6	22.8**
Average unpaid hours	26.5	n.a.	21.2	n.a.
Total hours	46.4	n.a.	39.7	n.a.
Distribution of Paid Hours		***		
0	1.9	0.0	1.1	0.6
1 to 7	23.1	36.3	19.0	17.3
8 to 20	37.2	38.3	46.3	37.0
21 to 30	18.6	11.3	15.3	19.8
31 or more	19.3	14.1	18.4	25.3
Distribution of Unpaid Hours				
0	40.9	n.a.	48.4	n.a.
1 to 7	7.4	n.a.	7.9	n.a.
8 to 20	11.2	n.a.	11.6	n.a.
21 to 40	13.0	n.a.	8.4	n.a.
41 or more	27.5	n.a.	23.7	n.a.

TABLE B.2 *(continued)*

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Hourly wage (dollars)	10.26	9.03***	11.81	11.33
Received fringe benefits	3.5	16.5***	1.0	8.6***
Paid for travel time	7.3	21.2***	7.5	7.1
Ever been paid less than owed	5.1	n.a.	2.8	n.a.
Ever paid late	29.2	n.a.	29.8	n.a.
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

*Mean or distribution or directly hired workers different from that of agency workers at .10 level.
**Mean or distribution for directly hired workers different from that of agency workers at .05 level.
***Mean or distribution for directly hired workers different from that of agency workers at .01 level.

TABLE B.3

SATISFACTION WITH WORKING CONDITIONS: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Satisfaction:				
With Wages and Fringe Benefits				
Very satisfied	50.7	22.9***	61.6	23.0***
Not satisfied	16.3	38.0***	8.4	41.0***
With Working Conditions Overall				
Very satisfied	85.3	82.6	88.7	84.7
Not satisfied	1.0	2.4	1.4	2.5
Is Satisfied with Supervision of Care				
Strongly agrees	87.9	88.0	87.3	91.5
Disagrees	1.6	4.6*	2.0	2.0
Is Satisfied with Amount of Feedback on How Care Is Provided				
Strongly agrees	86.4	86.2	93.0	89.6
Disagrees	1.7	2.8	1.4	1.2
Asked to Do Things Not Agreed to	2.7	3.2	0.5	4.9***
Close Supervision Interfered with Work	3.1	3.2	1.4	3.1*

TABLE B.3 *(continued)*

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Has a Lot of Flexibility in Scheduling Care				
Strongly agrees	81.2	79.9	82.6	75.6*
Disagrees	8.2	7.4	5.5	8.5***
Ever Had Disagreement Regarding Schedule	1.7	5.2**	1.8	9.2**
Must Hurry to Meet All Consumer's Needs				
Strongly agrees	25.9	23.4	24.3	16.8*
Disagrees	58.5	67.7**	61.0	69.6*
Worker Responsible for Providing Back-Up Care	41.3	n.a.	28.2	n.a.
Somewhat or Very Difficult to Arrange Back-Up Care	21.5	n.a.	17.6	n.a.
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

difference in satisfaction with compensation between directly hired workers and agency workers was even greater in the children's sample than in the adult sample.

Type of Care Provided. About 95 percent of directly hired workers provided personal care for the child, and 77 percent provided routine health care (Table B.4). Assistance with medicine and range of motion machines were the most common types of health care provided in both the children's and adult samples, with about two-thirds of directly hired workers providing such assistance. Other types of health care, however, such as caring for pressure sores or special care of the feet, were not as commonly provided by workers in the children's sample, probably due to children's different health care needs. Finally, in the adult sample, directly hired workers were as likely or more likely than agency workers to provide assistance with each type of health care we examined. This was not always true in the children's sample, however, as directly hired workers for the children's sample were significantly less likely than agency workers to provide assistance with feeding tubes.

Training. In both samples, directly hired workers were much less likely than agency workers to receive training in health care or personal care. In the adult sample, directly hired workers were more likely than agency workers to be well informed about the consumer's condition and services. While this difference was not observed in the children's sample, the percentage that reported being well informed about the consumer's condition and services was extremely high (93 percent) for both directly hired workers and agency workers (Table B.5).

Worker Well-Being. In terms of worker well-being, there were several differences for the children and adult samples. First, in the children's sample, directly hired workers were significantly less likely than agency workers to suffer physical strain, a difference not observed for the adult sample (Table B.6). Furthermore, directly hired workers for children did not experience a higher level of emotional strain than agency workers, as was observed in the adult

TABLE B.4

TYPE OF CARE PROVIDED: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Provided:				
Any routine health care	81.2	70.6***	77.0	70.7
Personal care	89.6	88.1	94.7	95.1
Household care	96.9	87.3***	94.2	87.7***
Company	91.7	n.a.	91.8	n.a.
Provided Assistance with:				
Medicine	70.1	25.5***	64.9	44.2**
Pressure sores	18.5	12.8*	10.7	4.9**
Feeding tube	7.5	7.6	9.3	18.4**
Urinary catheter	7.1	10.4	2.9	3.1
Colostomy	3.2	2.0	2.0	2.5
Range of motion	62.5	52.4**	64.9	54.0**
Ventilator	11.4	7.6	10.7	14.1
Special care of the feet	28.5	25.9	12.7	14.1
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

n.a. = not applicable.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

TABLE B.5

TRAINING AND PREPAREDNESS FOR WORK: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Training				
Received any health care training	69.2	95.6***	58.4	98.5***
Received any personal care training	54.7	95.5***	55.3	98.6***
Preparedness for Job				
Is well informed about consumer's condition and services				
Strongly agrees	87.4	82.2*	93.2	93.2
Disagrees	3.4	7.4**	1.8	2.5
Feels fully prepared to meet expectations in helping consumer				
Strongly agrees	95.6	96.0	95.9	96.3
Disagrees	1.3	2.4	0.9	0.0
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

TABLE B.6

WORKER WELL-BEING: COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Physical Strain				
Little or none	36.4	40.6	35.1	35.0
A great deal	29.6	33.9	21.2	32.5**
Suffered any injury	5.7	4.3	8.6	4.9
Suffered injury serious enough to see doctor	0.7	1.2	1.4	1.2
Emotional Strain				
Little or none	47.5	59.1***	44.0	51.2
A great deal	25.1	26.7	19.7	19.1
Caregiver and consumer get along very well	93.1	92.8	95.7	94.2
Consumer needs to be more respectful	16.1	13.0	17.0	11.1
Consumer's family and friends need to be more respectful	21.4	16.5	21.6	12.4**
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

sample. Finally, about 21 percent of directly hired workers in both the children's sample and adult sample reported that the consumer's family and friends needed to be more respectful. Only in the children's sample, however, was there a significant difference between directly hired workers and agency workers in the percentage that desired more respect from the consumer's family and friends. The lack of respect that directly hired workers in the children's sample reported was driven entirely by those who cared for a family member. Only 10 percent of directly hired workers in the children's sample who were not related to the consumer (compared to 32 percent of those who were related) felt that the consumer's family and friends should be more respectful (Table B.7).

Timing. Compared to agency workers, directly hired workers were much more likely to provide care during non-business hours in both the children's sample and in the adult's sample (Table B.8).

In summary, in Florida, when each age group's experience is contrasted with that of agency workers, the directly hired workers for children seemed to fare slightly better than the directly hired workers for adults. Directly hired workers for children were actually less likely than agency workers to experience physical strain and did not suffer greater emotional strain than agency workers, as directly hired workers for adult consumers did. The children's hired workers provided many hours of unpaid care and received modest wages for the work they were paid for (although their wages, on average, were higher than the average wage of those working for adults). They were quite satisfied with their working conditions and their wages and fringe benefits. Directly hired workers were more likely than agency workers to report that the child's family and friends needed to be more respectful, but this difference was driven by those workers who were related to the child they cared for.

TABLE B.7

COMPARISON OF RELATED AND NONRELATED DIRECTLY HIRED WORKERS FOR THOSE CARING FOR THE FLORIDA ADULT SAMPLE AND FLORIDA CHILDREN'S SAMPLE

	Florida Adult Sample		Florida Children's Sample	
	Related	Nonrelated	Related	Nonrelated
Working Conditions				
Hourly wage (dollars)	10.16	10.42	10.78	12.99***
Very satisfied with wages (percent)	56.1	43.2**	63.2	59.6
Very satisfied with working conditions (percent)	83.0	88.5	89.1	88.4
Training and Preparedness for Job (Percent)				
Received health care training	61.3	88.2***	66.7	87.3***
Received personal care training	43.1	71.4***	38.7	75.3***
Is well informed about consumer's condition	90.2	83.6*	93.3	93.2
Worker Well-Being (Percent)				
Little or no emotional strain	41.0	56.6***	35.7	53.4***
Much emotional strain	29.5	18.9**	23.5	15.5
Consumer needs to be more respectful	20.6	9.8**	21.6	11.8*
Consumer's family and friends need to be more respectful	26.7	13.9***	32.2	9.7***
Hours of Care Provided				
Paid hours	38	42	40	34
Unpaid hours	82	14***	73	7***
Maximum Sample Size	**174**	**124**	**119**	**103**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for related workers different from mean for nonrelated workers at .10 level.
**Mean for related workers different from mean for nonrelated workers at .05 level.
***Mean for related workers different from mean for nonrelated workers at .01 level.

TABLE B.8

TIMING OF CARE PROVIDED, COMPARISON OF SAMPLES FOR ADULTS AND CHILDREN IN FLORIDA

	Florida Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Provided Care:				
Before 8:00 A.M. weekdays	55.7	30.2***	51.7	30.1***
After 6:00 P.M. weekdays	75.1	32.4***	81.6	72.2***
On weekends	82.7	44.8***	80.2	54.6***
Maximum Sample Size	**298**	**255**	**222**	**164**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

TABLE B.9

KEY MEASURES OF WORKER WELL-BEING FOR NONELDERLY AND ELDERLY SAMPLES IN FLORIDA

	Nonelderly Adult Sample		Elderly Adult Sample	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Physical Strain				
Little or none	37.4	39.7	38.4	41.7
A great deal	24.0	34.6**	38.1	33.0
Emotional Strain				
Little or none	47.8	55.6	47.0	63.4**
A great deal	21.9	26.7	29.9	26.0
Consumer-Worker Relationship				
Consumer needs to be more respectful	17.4	13.0	14.0	13.0
Consumer's family and friends need to be more respectful	18.5	19.6	25.9	13.0**
Maximum Sample Size	**180**	**137**	**118**	**118**

Source: MPR's Caregiver Survey conducted between September 2000 and May 2003.

Note: Nonelderly includes people ages 18 to 59. Elderly includes people ages 60 or older.

*Mean for directly hired workers different from that of agency workers at .10 level.
**Mean for directly hired workers different from that of agency workers at .05 level.
***Mean for directly hired workers different from that of agency workers at .01 level.

APPENDIX C: PROGRAM FEATURES

TABLE C.1

KEY FEATURES OF CASH AND COUNSELING PROGRAMS, BY STATE

	Arkansas's IndependentChoices	Florida's CDC	New Jersey's Personal Preference Program
Demonstration Enrollment Period	December 1998-April 2001	June 2000-July 2002 (Adults) and June 2000-August 2001 (Children)	November 1999-July 2002
Eligible Population	Adults (elderly and nonelderly) with physical disabilities (may also have cognitive disabilities) who were eligible for the state plan Medicaid personal care program	Those elderly adults and nonelderly adults with physical disabilities, and children and adults with developmental disabilities, who were receiving services under the HCBS waiver	Adults (elderly and nonelderly) with physical disabilities who were already enrolled in the state plan Medicaid personal care program
Services Included in Calculating the Allowance Amount	Personal care	HCBS waiver services, except case management/support coordination	Personal care
Hiring Restrictions	Could not hire legally responsible relatives (such as spouses or parents) or representative	None	Could not hire representative
Care Plan Adjustment Factor Used in Setting Allowance	Provider specific, ranging from 70 to 91 percent and averaging 86 percent across all enrollees	89 percent for elderly adults, 83 percent for adults with physical disabilities, 92 percent for children and adults with developmental disabilities	None
Method for Calculating Allowance	$8 per hour in care plan multiplied by provider-specific adjustment factor	Claims history or adjustment factor multiplied by value of care plan. (Care plan always used for those with developmental disabilities. Also used care plan if claims history was not stable or if care plan value was at least $50 per month more than claims history.)	Value of care plan minus 10 percent set-aside for fiscal agent and counseling services

TABLE C.1 (*continued)*

	Arkansas's IndependentChoices	Florida's CDC	New Jersey's Personal Preference Program
Median Monthly Prospective Allowance of All Demonstration Enrollees	$313	$829 (adults) and $831 (children)	$1,097
Funding for Fiscal Agent and Counseling Services	Paid for through pool of money generated from difference between $12.36 per hour paid to agencies and $8.00 per hour rate at which allowance was cashed out. Originally, agencies were paid a per-client, per-month rate for fiscal agent and counseling services, which was reduced at six-month intervals. Later in the demonstration, agencies were paid a fixed rate for developing a spending plan and then paid per client per month for fiscal agent and counseling services.	Counseling paid for through existing Medicaid funding stream for case management and support coordination in traditional program. Fiscal agent fees paid for by schedule of fees charged to consumers (for example, $5 per check).	Set aside 10 percent of care plan value to cover counseling services and some fiscal agent costs. From this pool of money, the state paid human services agencies a lump sum per consumer to complete a cash management plan and an hourly fee thereafter for consulting; state also paid fiscal agent for some tasks, such as the processing of employment-related forms. Consumers paid some fiscal agent fees (such as for cutting and stopping checks).
Who Conducted Reassessments?	Agencies (for traditional program) and counselors (for allowance recipients)	Support coordinators or case managers (for traditional program) and counselors (for allowance recipients)	Agencies (for traditional program) and Medicaid nurses (for allowance recipients)
Participation in Other Consumer-Directed or Home Care Programs	Demonstration enrollees could also participate in the HCBS waiver programs ElderChoices or Alternatives.[a]	For adults with developmental disabilities, the six northern counties with a state-funded consumer-directed program.	Demonstration enrollees could not participate in HCBS waiver programs or a state-funded consumer-directed program.

[a]ElderChoices provides nurse-supervised homemaker, chore, and respite services to nursing-home-qualified elderly adults. Alternatives provides attendant care and environmental modifications to nonelderly adults and lets them choose and supervise caregivers. Among demonstration enrollees, 62 percent of the elderly participated in ElderChoices, and 9 percent of the nonelderly participated in Alternatives.

CDC = Consumer Directed Care; HCBS = home- and community-based services.