U.S. Department of Health and Human Services
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Office of Disability, Aging and Long-Term Care Policy

THE EFFECTS OF CASH AND COUNSELING ON THE PRIMARY INFORMAL CAREGIVERS OF CHILDREN WITH DEVELOPMENTAL DISABILITIES

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EXECUTIVE SUMMARY

Cash and Counseling Is a Promising Model of Medicaid Supportive Services

Because parents and other relatives provide vital, unpaid personal care to children with developmental disabilities, promoting the well-being of these informal caregivers is an important policy objective. The *paid* supportive services that children receive in addition to unpaid care could profoundly affect the informal caregivers who help them most. This study assesses the effects of consumer direction on the experiences and well-being of the primary informal caregivers of children who participated in Florida's Cash and Counseling demonstration. Instead of Medicaid home and community-based services (HCBS) waiver benefits, the demonstration program, Consumer Directed Care (CDC), provided a monthly allowance and let parents hire providers and manage the other services and goods their child needed.

A Rigorous Design and Comprehensive Survey Data Provided Definitive Evidence

Our analysis included the 829 caregivers--mostly mothers--who were providing the most unpaid assistance to children when the children were randomly assigned to participate in CDC (the treatment group) or to continue receiving HCBS waiver benefits as usual (the control group). We hypothesized that the amounts, types, and quality of services and goods that parents arranged for their children under CDC, with the support of the program's counseling and fiscal services, would affect caregivers' emotional, physical, and financial well-being. Becoming a child's paid worker or the "representative" responsible for managing a child's care also could affect these outcomes.

We constructed outcome variables from computer-assisted telephone interviews conducted with caregivers between April 2001 and June 2002, about 10 months after children's random assignment. We asked caregivers factual questions about the frequency, amounts, timing, and types of assistance they provided, as well as about their labor force participation and income. We asked their opinions on the quality of their relationship with the child they assisted, their satisfaction with the child's overall care arrangements, and their own health and emotional, physical, and financial well-being. To estimate program effects, we compared these outcomes for the caregivers of treatment group children with those for the caregivers of control group children. Regression models controlled for the baseline characteristics of children and the demographic characteristics of caregivers.

Caregivers Reported Greater Well-Being Under CDC

At the time of our interviews, treatment group caregivers still provided as much overall assistance as did control group caregivers, yet they reported greater satisfaction with the child's care and less physical strain on themselves. Treatment group caregivers were more likely than their control group counterparts to be in the labor force and less likely to say that caregiving caused them great financial strain. Treatment group caregivers also were more likely to be very satisfied with how they were spending their own lives. As expected, some treatment group caregivers (21 percent) were paid for caregiving during the follow-up period. The program's estimated impacts on some outcomes were especially large for these sample members.

These findings, coupled with earlier findings about the effects of the CDC program on children's service use and care quality, suggest that the program may be a desirable option to offer the parents of children receiving HCBS waiver benefits.

INTRODUCTION

Medicaid home and community-based services (HCBS) waiver programs provide vital supportive benefits to children with developmental disabilities. For some families, however, the programs have drawbacks. States limit the types, amounts, and providers of HCBS that they cover, and case managers or support coordinators often decide which of the covered benefits a child receives. If parents find HCBS benefits unsatisfactory or too inflexible to meet their child's needs, they may forgo benefits or try to compensate for their shortcomings by placing more burden on themselves or other unpaid caregivers.

In contrast to traditional HCBS waiver programs, Cash and Counseling programs provide parents with a monthly allowance to arrange and pay for their child's supportive service benefits as they see fit. Parents who control their child's benefits may be more satisfied with the benefits. In turn, parents' own well-being, or that of other caregivers, might improve.

This report describes the effects of Florida's Cash and Counseling demonstration program, Consumer Directed Care (CDC), on the caregivers who were providing the most unpaid assistance to children when their parents voluntarily enrolled those children in the demonstration. This report follows another one containing earlier findings, which showed that the parents of children randomly assigned to participate in the CDC program were more satisfied with the children's care than were the parents of children randomly assigned to receive traditional HCBS (Foster et al. 2004).

A NEW MODEL OF MEDICAID SUPPORTIVE SERVICES

About 1.4 million Medicaid beneficiaries receive disability-related supportive service benefits in their homes (Harrington and Kitchener 2003). Most receive traditional HCBS or state plan personal care services, but states increasingly are allowing beneficiaries or their parents to direct some aspects of their care, as service “consumers” (O’Brien and Elias 2004). In 1999, an estimated 139 publicly funded consumer-directed programs served adults or children with physical or developmental disabilities (Flanagan 2001).

Compared with programs that merely allow consumers to choose paid workers, Cash and Counseling programs represent a fairly expansive model of consumer-directed care. The programs give consumers the opportunity to receive a monthly allowance with which to hire workers and purchase services and goods related to their care (within state guidelines). Parents manage the allowance for children, and adult consumers can designate a representative decision maker (such as a family caregiver) to help them manage their care. The programs also offer counseling and fiscal services to help consumers and representatives handle their program responsibilities. These tenets of Cash and Counseling--a flexible allowance, freedom to use representatives, and availability of counseling and fiscal services--are meant to make the model adaptable to consumers of all ages and abilities.

As part of a three state demonstration, Arkansas, Florida, and New Jersey have each tested the Cash and Counseling model in their Medicaid programs. The Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, funded the demonstration. The Centers for Medicare and Medicaid Services issued the waivers required for states to implement it. The National Program Office for the demonstration, at Boston College and the University of Maryland, coordinated the overall demonstration, provided technical assistance to the states, and oversaw the evaluation. Mathematica Policy Research, Inc. (MPR) is the demonstration evaluator.

SUMMARY OF THE DEMONSTRATION IN FLORIDA[1]

Goals

By participating in the Cash and Counseling demonstration, Florida wished to promote the independence of people with disabilities, offer services that would better meet families' needs, and encourage the prudent use of public resources. Parents who participated in focus groups conducted to aid the design of the demonstration said they wanted a program that would give them decision-making power, flexibility, and privacy; allow them to choose caregivers whom they trusted and their children liked; and help them obtain respite for themselves without unduly infringing on others (Zacharias 1998; Simon-Rusinowitz et al. 1998).

Eligibility

Children 3-17 years of age who were receiving benefits under Florida's HCBS Developmental Disabilities (DD) waiver program were eligible to participate in the Cash and Counseling demonstration.[2,3] Children qualified for the DD program on the basis of level of need; intelligence quotient; a diagnosis of mental retardation, autism, spina bifida, cerebral palsy, or Prader-Willi syndrome; and limitations in self-care, understanding and use of language, learning, mobility, or self-direction or capacity for independent living (Florida Medicaid 2004).

Covered Benefits

The CDC program offered an allowance instead of the benefits the DD program usually provided. For example, in the DD program, children with spina bifida might have received supplies to care for incontinence and pressure sores. Children with autism might have received behavior therapy to address self-injurious tendencies. In general, according to Medicaid claims data, the benefits that had most commonly been provided to children who enrolled in the Cash and Counseling demonstration were supplies and equipment (provided to 71 of children in their preenrollment year), personal care services (provided to 53 percent), and therapy services, such as behavioral, mental health, and habilitation therapy (32 percent). Smaller proportions of children had received such benefits as environmental modifications (6 percent), professional services (3 percent), private-duty nursing (1 percent), and transportation (0.5 percent).[4]

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[1] See Phillips and Schneider (2004) for a detailed description of demonstration implementation in Florida.

[2] Adults also could participate. Their experiences, and those of their primary informal caregivers, are described in companion reports by Carlson et al. (2005) and Foster et al. (2005).

[3] The DD waiver was formerly known as the Developmental Services (DS) waiver.

[4] Appendix Table A.1 lists all benefits covered by the DD waiver.

Enrollment and Random Assignment

Florida, like the other demonstration states, was responsible for its own outreach and enrollment activities, including the collection of informed consent and basic intake data (such as contact information). Florida introduced the demonstration to all eligible families through a letter from the governor's office and during routine home visits conducted by support coordinators in the DD program. Later in the enrollment period, dedicated enrollment specialists conducted home visits. Within a week of each child's enrollment, MPR conducted a baseline telephone interview with one of the child's parents, then randomly assigned the child to the treatment group (to participate in CDC) or the control group (to receive DD benefits as usual). The enrollment and random assignment of Florida children began in June 2000 and continued until the evaluation target of 1,000 enrollees was met in August 2001.[5] Half the children were randomly assigned to the treatment group.

Calculation of the CDC Allowance

When parents expressed an interest in the demonstration, CDC program staff calculated a baseline program allowance for their child. The allowance amount was equal to the costs of the benefits in the child's existing DD support plan times a discount factor (0.92). The costs of support coordination services were excluded from the allowance, because the state would use equivalent funds to pay for the consulting services provided under CDC. (Florida used the term "consulting," rather than "counseling," in its demonstration program.) The discount factor was used to help Florida meet federal budget neutrality standards for the demonstration. At baseline, the median allowance for children who enrolled in the demonstration was $768 per month. (The mean was $1,109.)

Permitted Uses of the Allowance

After a child was assigned to participate in CDC, the parent (or guardian) serving as the child's representative in the program had to write a plan that specified the goods and services to be purchased with the monthly allowance. Although purchases had to be related to the child's needs for home and community support, the state viewed needs broadly. Parents could use the allowance to hire their choice of workers--including

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[5] Florida enrolled 1,002 children in the demonstration, 34 percent of the 3,000 children it estimated were eligible to participate. Florida continued to enroll and randomly assign children after August 2001, but they were not included in the evaluation. Random assignment continued in order to keep the demonstration budget neutral vis-à-vis the DD waiver for a five-year period.

themselves and other family members--to care for their child.[6] They could also use it, for example, to pay professional therapists and nurses, purchase experimental therapies, or buy bulk-rate care supplies. They could save a portion of the allowance for large purchases (such as home modifications) or receive up to 20 percent of it as cash each month for incidental expenditures specified in the spending plan (such as fare for public transportation). District-level staff reviewed all spending plans and approved or denied them.

Consulting and Fiscal Services

Parents were offered the assistance of a CDC consultant and fiscal agent. Consultants interacted with parents to: (1) develop, review, and revise the allowance spending plan; (2) offer advice about recruiting, hiring, and training workers; (3) monitor children's well-being; and (4) monitor use of the allowance. This interaction took place during monthly telephone calls and periodic home visits, including a mandatory initial home visit. During these interactions, consultants were to serve as advisers, not decision makers. Moreover, unlike support coordinators in the DD waiver program, consultants did not coordinate and access goods and services on behalf of families. Consultant services were offered at no direct charge to parents. Parents also were offered assistance with fiscal tasks. They could choose to have the CDC fiscal agent maintain their program-related accounts, withhold payroll taxes for paid workers, file payroll tax returns, and write checks against the allowance to pay wages and purchase other goods and services. Alternatively, parents who showed they could handle such tasks themselves, by passing a skills examination, could perform the tasks and submit to a monthly "desk review" of their program-related records. Nearly all parents chose the comprehensive fiscal services. They paid $5 per check, up to a $25 per month maximum. (The program charged $10 per month for desk reviews.)

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[6] During the demonstration, Florida allowed the same person to be a child's representative *and* paid worker, on the condition that someone else from the child's "circle of support" verified that the representative/worker had performed the agreed upon services. After the demonstration, Florida modified its operational protocol so that no one person could have both roles. The restriction is currently enforced in Florida's CDC+ program, which operates under a Section 1115 waiver.

CONSUMER DIRECTION AND CHILDREN'S INFORMAL CAREGIVERS

Previous Research

This report provides rigorous, empirical evidence on how an innovative model of paid supportive services affects the well-being of children's unpaid caregivers. It thus bridges an extensive literature on caring for children with developmental disabilities and a more nascent one on consumer-directed care.

In trying to obtain adequate services for a child with developmental disabilities, parents face many challenges. According to a recent national survey, 48 percent of parents with a child who was eligible for home health care services had difficulty finding skilled, experienced, or reliable workers or could not obtain enough services for the child (Wells et al. 2000). Moreover, substantial proportions of parents said the child had unmet needs for nutritional supplements (38 percent), durable medical equipment (31 percent), or disposable medical supplies (26 percent).

Parents also face obstacles as they attempt to preserve their own well-being and that of other family members while meeting the needs of a child with disabilities. According to the national survey just cited, 46 percent of parents were dissatisfied with respite services, or needed them but could not get them. According to another national survey, 53 percent of parents of children with developmental and intellectual disabilities reported that caring for such children caused a family member to make a major accommodation (such as not taking a job, working fewer hours, or changing sleep patterns) or caused severe financial problems (Anderson et al. 2002).

The literature also identifies a paradox in which supportive services designed for children with developmental disabilities at times conflict with the interests of parents and other family members (Rosenau 2000). Indeed, in 1997, when a representative sample of Florida parents were asked about their potential interest in Cash and Counseling, 55 percent thought consumer direction would make their job easier, but 37 percent were unsure, and 7 percent thought it would make their job harder (Loughlin et al. 2004). Since then, the Cash and Counseling evaluation has yielded ample evidence that the CDC program positively affected parents' satisfaction with children's care and quality of life (Foster et al. 2004). However, the effects of the program on the well-being of parents or other primary informal caregivers merit attention. Do children's benefits translate into caregiver benefits or greater caregiver strain? What mechanisms lead to gains or losses?

Hypotheses About Caregiver Outcomes

As noted earlier, parents in the CDC program could change their child's use of Medicaid supportive services in many ways. These changes, in turn, could affect:

- The amount of assistance that primary informal caregivers provided.
- The quality of relationships between caregivers and children.
- Caregivers' satisfaction with children's supportive services.
- Caregivers' emotional and physical well-being.
- Caregivers' job performance and financial well-being.
- Caregivers' satisfaction with life.

The amount of assistance that primary informal caregivers provided could increase or decrease, depending on whether they were hired to perform additional tasks for children (beyond those performed without pay) or whether other workers were hired to relieve them of some burden.

The quality of relationships between caregivers and children could improve if the arrangements made under CDC helped both parties feel more at ease. Similarly, caregivers' satisfaction and well-being could be favorably affected if the program allowance was used to: (1) relieve caregivers of some difficult, unpleasant, time-consuming, or inconvenient tasks; (2) replace unsatisfactory service providers with ones whom the caregivers or children preferred; or (3) purchase assistive devices that enhanced children's independence and lessened caregivers' physical strain. Caregivers' financial well-being could improve if they became paid workers in the CDC program or if children's participation in the program gave caregivers enough flexibility to enter the labor force or change jobs.

Conversely, children's participation in the CDC program could be detrimental to the caregivers who had helped them most. Caregivers could experience physical and emotional stress if they assumed responsibilities that agency workers had handled or if parents could not recruit qualified service providers. Serving as children's CDC representatives could be a burden for caregivers if they felt the program's consulting and fiscal services did not give them enough professional support.

METHODS[7]

Data Collection and Sample

Data on the types of outcomes listed in the previous section were collected through computer-assisted telephone interviews with the primary informal caregivers of children who participated in the Florida demonstration. (Appendix Table B.1 lists all the outcome measures examined.) The interviews were conducted about 10 months after children were randomly assigned to the treatment or control group. Parents had named their child's primary informal caregiver and provided the caregiver's telephone number during the baseline interview. To identify the primary informal caregiver, we asked the responding parent which person (if any) had provided the most unpaid assistance to their child during the previous week with personal care, doing things around the house and community, routine health care, and transportation. Between April 2001 and June 2002, interviews were completed with 829 caregivers. (Proxy respondents were not allowed.) The response rates were 87 percent for the caregivers of children in the treatment group and 82 percent for the caregivers of children in the control group.

To preserve the benefits of random assignment and obtain a complete picture of caregivers' experiences, interviews were conducted even if the child who was the care recipient had disenrolled from CDC (12 percent of children had disenrolled; not shown). The few caregivers (1.7 percent of the sample) who had not helped children during a two week reference period used throughout the interview also were included in the sample. Interviewers generally asked these caregivers to recall the period when they were last helping. However, questions were skipped if recall error seemed likely (for example, in questions measuring hours of assistance).

Estimation of Program Effects

Models. The analysis used logit models to estimate program effects on categorical outcomes, an ordered logit to estimate effects on caregivers' level of household income, and ordinary least squares (OLS) models to estimate effects on the amount of assistance caregivers provided.

Many outcome measures were constructed by converting responses to survey questions with four-point scales (for example, degree of satisfaction) into two alternative binary measures. One measure represented the most favorable rating (very satisfied), the other an unfavorable rating (somewhat or very dissatisfied).[8] We used this

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[7] Appendix B includes additional detail on analytic methods.

[8] The caregiver survey also included several questions with five-point scales. For these questions, respondents rated the level of strain they experienced, with 1 representing little or no strain and 5 representing a great deal of strain. We converted each scale into two binary measures. The first was set equal to 1 only if the respondent gave a rating of 1; the other was set equal to 1 only for ratings of 4 or 5.

approach so readers could easily see the basis on which we drew inferences about the key questions for each outcome: Did consumer direction increase the proportion of highly satisfied caregivers, reduce the proportion of dissatisfied ones, or have both (or neither) effects?

Except for treatment-control differences in the amount of care provided (which were estimated with OLS regression), we measured program impacts by using the estimated coefficients from the logit models to calculate the treatment-control difference in average predicted probabilities that the binary dependent variable took a value of 1. The p-values of the estimated coefficients on the treatment status variable are reported in our tables and were used to test whether treatment-control differences were significantly different from zero.

Control Variables. The models controlled for many characteristics measured during baseline interviews. (Appendix Table B.2 lists all the control variables.) These included children's demographic characteristics, health and functioning, use of paid and unpaid supportive services, and month of enrollment in the demonstration. They also included the responding parent's hiring and supervisory experience, satisfaction with the child's overall care arrangements, perception of the child's unmet needs, and attitudes about consumer direction. The models controlled for the familial relationship between children and the primary informal caregiver, and whether caregivers were employed and interested in being paid for caregiving, as reported by parents at baseline. Finally, the models controlled for the basic demographic characteristics of the primary informal caregivers, which were collected during interviews with them.

Although nearly all the characteristics were distributed similarly across the treatment and control groups (as expected with random assignment), a few treatment-control differences emerged within the subset of children whose primary informal caregivers responded to our survey, whether by chance or differential attrition (Appendix Table B.2). As noted, the regression models controlled for these differences.[9]

Statistical Power. With 829 primary informal caregivers in the analysis sample, we had 80 percent power to detect impacts of 8.6 percentage points for binary outcome variables with means of .50, assuming two-tailed tests at the .05 significance level (Appendix Table B.3). For binary variables with a mean of .10 or .90, the detectable difference was 5.2 percentage points. For the 736 live-in caregivers who reported the number of hours of (paid and unpaid) care they provided to the child during a two-week reference period, a continuous variable, we had 80 percent power to detect impacts of 8.7 hours (10 percent of the unadjusted mean), again assuming a two-tailed test at the .05 level.

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[9] In particular, the treatment and control groups differed in area of residence, number of informal caregivers, and whether had privately funded care at baseline (Appendix Table B.2).

Baseline Characteristics of Children and Their Primary Informal Caregivers

Two-thirds of the children who received assistance from the caregivers in our sample were boys, 8 of 10 were White, and 7 of 10 were younger than age 13 (Table 1). Slightly more than half the children lived in parts of Florida that parents described as rural or as having high crime or poor public transportation--conditions that could make it difficult for home care agencies to recruit staff or for treatment group families to hire workers other than nearby family and friends. At baseline, about 13 percent of parents said their child's health was poor, and many said the child needed help with basic activities.

TABLE 1: Children's Baseline Characteristics

Characteristic	Percent
Male	63.4
Hispanic	19.0
Race	
White	81.3
Black	13.8
Other	5.0
Age in Years	
3 to 6	21.0
7 to 9	27.9
10 to 12	22.2
13 to 15	17.1
16 or 17	11.8
Parents Described Area of Residence as:	
Rural	19.0
Nonrural but high-crime or lacking adequate public transportation	35.1
In Poor Health Relative to Peers	13.4
In the Past Week, Needed Help:	
Bathing	92.4
Using the toilet (or wore diapers)	85.3
Getting in or out of bed	59.5
In the Past Week, Number of Informal Caregivers	
1	11.1
2	23.3
3 or more	65.6
In the Past Week, Received Privately Funded Assistance with Personal Care Services	26.4
Parents Dissatisfied with Overall Care Arrangements	38.0
Number of Respondents	**829**

SOURCE: MPR's baseline interview, conducted between June 2000 and August 2001, and the Consumer Directed Care program.

Some children had several sources of assistance at baseline. In addition to receiving Medicaid HCBS through Florida's DD program, two-thirds of the children were receiving assistance from three or more informal caregivers. About one-quarter also received help that was paid for privately (for example, through private insurance or out-of-pocket). Nonetheless, 38 percent of parents were dissatisfied with their child's overall care arrangements when they enrolled the child in the demonstration.

Nearly all the caregivers in our sample were related to the child who was the care recipient, with 84 percent being the child's mother, 6 percent the father, 8 percent a grandparent, and 2 percent some other relative (Table 2).[10] Nearly all caregivers were at least 30 years old, nearly one-fifth were 50 or older, and 70 percent were married at baseline. Ninety percent were high school graduates, and about two-thirds had attended at least some college. About half were employed at baseline. One-quarter of the caregivers in our sample were interested in being paid for caregiving, according to the baseline interview with parents.

TABLE 2: Characteristics of Primary Informal Caregivers

Characteristic	Percent
Relationship to Child	
Mother	83.6
Father	5.7
Grandparent	7.5
Other relative	2.3
Nonrelative	1.0
Female	93.5
White	82.9
Age in Years	
29 or younger	4.2
30 to 39	32.1
40 to 49	45.2
50 or older	18.5
Married	70.0
Education	
Did not graduate from high school	10.2
Graduate from high school or obtained GED	25.4
Attended some college	35.2
Graduated college	18.3
Pursued graduate work or professional degree	11.0
Employed at Baseline[a]	49.0
Ever Expressed Interest in Getting Paid for Caregiving[a]	24.8
Number of Respondents	**829**

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002, and baseline interview with care recipients' parents, conducted between June 2000 and August 2001.

NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group.

a. As reported by children's parents during baseline interviews.

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[10] Thirty-five caregivers (4 percent of the sample) did not live with the child who was the care recipient. Of these visiting caregivers, 18 were children's grandparents, six were parents, three were sibling, six were other relatives, and two were not family members. (Caregivers' living arrangements were measured at follow-up, not baseline.)

RESULTS

Receipt and Use of the Allowance in the Treatment Group

As noted earlier, the parents of children randomly assigned to the CDC program could receive their child's monthly allowance if they developed an acceptable spending plan. By the time caregivers were interviewed for this analysis, 72 percent of children had started on the allowance. Furthermore, although this analysis is of people who provided unpaid care at baseline, 21 percent of treatment group caregivers were paid for caregiving during the follow-up period. On average, these caregivers were paid for about 19 hours of care per week and earned $12 an hour.

Estimated Program Effects

As noted, program effects were estimated over all responding primary informal caregivers for treatment and control group children, whether or not the CDC allowance was received or used to hire workers. Because payment of caregivers was a program effect, however, it and its influence on other outcomes are important to measure. Thus, following the presentation of overall program effects, this report discusses the characteristics associated with becoming paid, describes caregivers' self-reported reasons for remaining unpaid, and examines the extent to which outcomes differed by whether caregivers became paid workers.

Amounts of Assistance.[11] The caregivers in this analysis devoted substantial amounts of time to activities that exclusively benefited the child who was the care recipient (such as help eating and bathing) and to activities that may also have benefited others in the household (such as preparing meals and doing laundry). The CDC program did not seem to affect the amount of assistance caregivers provided (Table 3). During a two-week period shortly before we interviewed them, caregivers who lived with the care recipient (96 percent of the sample) provided roughly 157 hours of assistance to the child or to the child and other household members. Slightly more than half these hours were spent meeting the needs of the child exclusively (82 hours in two weeks--or 5.8 hours per day--among caregivers in the treatment group, and 86 hours in two weeks--or 6.2 hours per day--among caregivers in the control group).

Quality of Relationships with Children. Of three outcomes used to measure the quality of relationships between caregivers and children, the CDC program seemed to affect one (Table 4). It did *not* affect the proportion of caregivers reporting that the child sometimes refused to cooperate when they tried to help the child (as about half of both groups reported) or the proportion who said they got along very well with the child (as

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[11] Appendix B describes our approach to measuring hours of assistance. Appendix Table C.1 shows additional results on caregivers' living arrangements, provision of any assistance, and type, timing, and frequency of assistance provided.

roughly 9 of 10 in both groups reported). However, treatment group caregivers were significantly more likely than control group caregivers to say their relationship with the child had improved since the child's enrollment in the demonstration (39 versus 30 percent).

TABLE 3: Estimated Effects on Hours of Assistance That Primary Informal Caregivers Provided to Children

Outcome	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)
In Recent Two Weeks:[a]			
Total Hours of Assistance[b] (n = 766)	150.1	155.0	-4.9 (.353)
Among live-in caregivers (n = 736)			
Total hours	154.1	159.9	-5.8 (.277)
Hours that benefits child only[c]	81.5	86.4	-4.9 (.182)
Hours that also benefited others in the household[d]	72.6	73.5	-0.9 (.797)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with ordinary least squares models.

a. The most recent two weeks the child lived at home during the two months before the interview.
b. Includes hours of assistance provided by 30 visiting caregivers. Those in the treatment group reported providing 62.5 hours of assistance in two weeks. Those in the control group reported providing 40.9 hours of assistance in two weeks. The treatment-control difference (21.7 hours) was not statistically significant.
c. Includes routine health care, personal care, and transportation.
d. Includes hours spent on tasks that jointly benefited the entire household, such as preparing meals, housework, laundry, shopping and yard work.

TABLE 4: Estimated Effects on the Quality of Relationships Between Children and Primary Informal Caregivers

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Child Refuses to Cooperate When Caregiver Tries to Help[a]	48.2	51.1	-2.9 (.393)
Caregiver and Child Get Along Very Well	91.7	90.1	1.6 (.421)
Relationship Is Better Now than at Enrollment	38.8	29.6	9.2*** (.005)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with logit models.

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

a. Measured "at present" or "when you were last helping."

Satisfaction with Quality of Care.[12] The CDC program seemed to have large, positive effects on how caregivers perceived the quality of care children received (Table 5). When we interviewed them, nearly twice as many treatment group caregivers as control group caregivers (42 versus 22 percent) said they were very satisfied with the arrangements for children's paid and unpaid services and goods. Likewise, fewer than half as many treatment group caregivers were dissatisfied (15 versus 37 percent). Compared with caregivers in the control group, those in the treatment group worried less about insufficient care, safety, and theft (although many still worried). Smaller proportions of treatment group caregivers than of control group caregivers said they worried quite a lot that the child who was their care recipient would not get enough care in their absence (47 versus 65 percent), that the child's safety was at risk (44 versus 57 percent), or that someone would take money or other family belongings (25 versus 35 percent). Moreover, substantially larger proportions of treatment group caregivers than control group caregivers worried only "rarely" or "not at all" about each of these problems.

TABLE 5: Estimated Effects on Primary Informal Caregivers' Satisfaction with Care Quality

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
How Satisfied with Child's Overall Care Arrangements			
Very satisfied	42.3	22.0	20.3*** (.000)
Dissatisfied	14.6	36.9	-22.4*** (.000)
When Not with Child, How Often Worries That:[a]			
Child Does Not Have Enough Help			
Quite a lot	47.2	64.7	-17.6*** (.000)
Rarely or not at all	21.2	12.4	8.8*** (.001)
Child's Safety Is at Risk			
Quite a lot	43.5	57.3	-13.8*** (.000)
Rarely or not at all	25.4	15.7	9.7*** (.000)
Someone Will Take Money or Other Belongings from the Household			
Quite a lot	25.0	34.7	-9.7*** (.002)
Rarely or not at all	57.9	43.2	14.7*** (.000)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with logit models.

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

a. Measured "at present" or "when you were last helping."

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[12] Appendix Table C.2 shows additional results on whether caregivers considered themselves knowledgeable about, and prepared for, caregiving.

Emotional Well-Being. The CDC program seemed to have little or no effect on measures of emotional well-being (Table 6). Whether in the treatment or control group, about 8 of 10 caregivers said the child who was the care recipient required their constant attention, roughly 6 of 10 said caregiving limited their privacy, and 8 of 10 said it curtailed their free time or social life. Roughly 40 percent of caregivers in both groups said they experienced a great deal of emotional strain as a result of caregiving. The proportion of caregivers that experienced little or no strain was somewhat larger in the treatment group than in the control group (24 versus 19 percent), but the difference was significant at only the .10 level.

TABLE 6: Estimated Effects on Primary Informal Caregivers' Emotional Well-Being

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Child Requires Almost Constant Attention from Caregiver	81.1	82.3	-1.1 (.653)
Caregiving Limits:			
Privacy	61.0	65.9	-4.9 (.125)
Free time or social life	80.9	81.6	-0.7 (.778)
Level of Emotional Strain as a Result of Caregiving			
A great deal	39.4	41.6	-2.2 (.495)
Little or none	23.8	18.7	5.1* (.054)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Outcomes were measured "at present" or "when you were last helping." Means were predicted with logit models.

* Significantly different from zero at the .10 level, two-tailed test.

Job Performance and Financial Well-Being. Although many sample members said caregiving adversely affected their job performance and financial well-being, treatment group caregivers fared somewhat better than control group caregivers on three important measures (Table 7). Treatment group caregivers were somewhat more likely than control group caregivers to work for pay (other than through the CDC program) (62 versus 57 percent). They also reported higher household income and less financial strain, on average. Specifically, a somewhat larger proportion of treatment group caregivers than control group caregivers reported household income of more than $3,000 per month (34 versus 28 percent). Treatment group caregivers were about a fifth less likely than control group caregivers to experience a great deal of financial strain as a result of caregiving, and they were about two-thirds more likely to experience little or no strain (-11.9/55.6 = -.214; 8.0/12.0 = .666).

Within the subset of caregivers who worked for pay (other than through the CDC program), however, those in the treatment group were not significantly less likely than those in the control group to say they quit their job or reduced their hours, or declined a better job or promotion, because of caregiving (Table 7). Caregivers in both groups were equally likely to miss work or arrive late.

TABLE 7: Estimated Effects on Primary Informal Caregivers' Job Performance and Financial Well-Being

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Job Performance Since Child's Enrollment			
Worked for Pay, Other than for Child	62.2	56.9	5.3** (.024)
Did Not Look for a Job or Another Job Though Wanted to	52.7	57.0	-4.3 (.192)
Among Those Who Worked for Pay Other than for Child, Caregiving Caused Them to:			
Decline a better job or a promotion	44.4	51.4	-7.0 (.104)
Quit job or reduce hours	46.7	53.1	-6.4 (.141)
Miss work or arrive late	84.0	82.6	1.4 (.657)
Financial Well-Being			
Household Income Last Month			***
$1,000 or less	14.9	19.0	-4.1
$1,001 to $2,000	29.9	32.7	-2.8
$2,001 to $3,000	21.3	20.7	0.6
$3,001 or more	33.9	27.7	6.2 (.007)
Level of Financial Strain Felt as a Result of Caregiving[a]			
A great deal	43.7	55.6	-11.9*** (.000)
Little or none	20.0	12.0	8.0*** (.001)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with logit models.

** Significantly different from zero at the .05 level, two-tailed test.
*** Significantly different from zero at the .01 level, two-tailed test.

a. Measured "at present" or "when you were last helping."

Physical Well-Being and Health.[13] Caregivers in the treatment group fared better than caregivers in the control group on several measures of physical well-being and health (Table 8). They were less likely to say caregiving caused them a great deal of physical strain (35 versus 42 percent). They also were about 25 percent less likely to say: (1) their physical health suffered as a result of caregiving, and (2) their health was fair or poor (as opposed to good or excellent).

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[13] Appendix Table C.3 shows additional results on caregivers' physical functioning.

TABLE 8: Estimated Effects on Primary Informal Caregivers' Physical Well-Being and Health

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Level of Physical Strain as a Result of Caregiving[a]			
A great deal	34.5	42.1	-7.6** (.020)
Little or none	20.2	16.7	3.5 (.159)
Physical Health Has Suffered as a Result of Caregiving[a]	41.8	55.4	-13.6*** (.000)
Current Health Is Fair or Poor Relative to That of Peers	27.4	36.8	-9.4*** (.003)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with logit models.

** Significantly different from zero at the .05 level, two-tailed test.
*** Significantly different from zero at the .01 level, two-tailed test.

a. Measured "at present" or "when you were last helping."

Satisfaction with Life. Treatment group caregivers were much more likely than control group caregivers to be very satisfied with their own lives and much less likely to be dissatisfied (Table 9). Specifically, the proportion of very satisfied treatment group caregivers was 55 percent larger than the proportion of very satisfied control group caregivers (13.2/23.8 = .554). The proportion of dissatisfied treatment group caregivers was 46 percent smaller (-14.4/31.1 = -.463).

TABLE 9: Estimated Effects on Primary Informal Caregivers' Satisfaction with Life

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Current Satisfaction with Life			
Very satisfied	36.9	23.8	13.2*** (.000)
Dissatisfied	16.7	31.1	-14.4*** (.000)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with logit models.

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

Primary Informal Caregivers Who Became Paid Workers

Explanatory Variables. Under the CDC program, treatment group caregivers continued to provide many hours of assistance to children, but only about one-fifth were paid for some of those hours. We estimated the odds that caregivers became paid workers as a function of their observable characteristics and those of children. (The dependent variable was a binary self-reported measure of whether the caregiver had been paid for helping the child at any time since enrollment, even if he or she was not the *primary* paid worker.)

The amount of the CDC allowance and children's needs for personal care were strongly associated with primary informal caregivers becoming paid workers. The larger the allowance, the greater the likelihood of payment. Compared with caregivers for children in the lowest allowance category (less than $150 per week), caregivers had 1.8 times the odds of becoming paid if the allowance was between $150 and $299, 2.4 times the odds if the allowance was between $300 and $499 per week, and 3.4 times the odds if the allowance was $500 or more per week. Moreover, if children had unmet needs for personal care at baseline in their parent's opinion, their primary informal caregiver was 2.6 times more likely to get paid for caregiving than if there were no perceived unmet need.

All else equal, the primary caregivers *least* likely to become paid workers were children's parents (the odds ratio was 0.3) and those who were married (the odds ratio was 0.5). (Appendix Table C.4 shows the estimated odds ratios of all variables in the model.)

Reasons for Remaining Unpaid. Treatment group caregivers who were *not* paid for caregiving at the time of their interview were asked why not. (The survey question was openended, but interviewers used a precoded list to record responses.) Fully 38 percent of caregivers said they did not know they could be paid or believed it was against program rules (Appendix Table C.5). Helping the child out of love, devotion, or family tradition was the second most common reason caregivers remained unpaid (cited by 35 percent). Smaller proportions of caregivers said that someone else was available for hire or that they could not perform the required tasks, lived far away, or had other obligations (8 percent). Others said the monthly allowance was not large enough to pay them or was needed for other things (7 percent). Three percent of caregivers said they intended to become paid as soon as the plan for spending the child's allowance was approved.

Estimated Effects of Payment. To explore whether the CDC program affected paid and unpaid treatment group caregivers differently, we estimated separate program effects for each of these subsets. For 8 of 14 measures of well-being and satisfaction, paid and unpaid treatment group caregivers both fared significantly better than did control group caregivers. In most of these instances (six of the eight), however, the estimated program effects were substantially larger for paid caregivers than for unpaid ones. Thus, it seems that getting paid for caregiving was not the sole reason treatment group caregivers reported better outcomes than control group caregivers, but getting paid did seem to increase the magnitude of most treatment-control differences. We discuss specific findings below.[14]

Both subsets of treatment group caregivers (paid and unpaid) fared better than control group caregivers with respect to being very satisfied or dissatisfied with the child's care arrangements, being very satisfied or dissatisfied with their own lives, worrying quite a lot about insufficient care, and experiencing physical health problems as a result of caregiving (Appendix Table C.6). However, except for being dissatisfied with care arrangements and worrying a lot about insufficient care, the estimated effects were a good deal larger for paid than unpaid caregivers (relative to all caregivers in the control group).

For four of the remaining six satisfaction and well-being outcomes, paid treatment group caregivers fared significantly better than control group caregivers, but unpaid treatment group caregivers fared about the same as control group caregivers. Specifically, only paid treatment group caregivers fared better than control group caregivers with respect to privacy and free time, experiencing a great deal of emotional strain as a result of caregiving, and feeling well informed about the child's condition and service needs (Appendix Table C.6). For the other two variables--rarely worrying about insufficient help and feeling little or no emotional strain--unpaid treatment group caregivers fared better than control group caregivers, while paid treatment group caregivers fared no differently than control group caregivers.

Although the CDC program seemed not to affect the amount of assistance caregivers provided overall (Table 3), we examined whether this was true for both paid and unpaid treatment group caregivers. We found two effects of borderline significance. Paid treatment group caregivers provided assistance more frequently than did control group caregivers (on 0.4 more days of 14) (Appendix Table C.7). In addition, live-in unpaid treatment group caregivers provided seven fewer hours of assistance to the child who was the care recipient than control group caregivers provided during the two-week reference period.

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[14] Difference between paid (or unpaid) caregivers in the treatment group and all caregivers in the control group must be interpreted with caution. Estimated effects may be driven more by unobserved differences between paid and unpaid caregivers in the treatment group than they were by payment. Such "self-selection bias" could arise, for example, if caregivers who became paid had more responsibility, on average, for arranging children's care than caregivers who remained unpaid. Caregivers accustomed to responsibility and control may have benefited most from Cash and Counseling.

DISCUSSION

Summary and Interpretation

Florida's CDC program tested the Cash and Counseling model of delivering Medicaid HCBS to children with developmental disabilities. The program had the primary goal of improving care quality and satisfaction by increasing parental control over children's benefits. In turn, the program was expected to improve the well-being of each child's primary informal caregiver, who was typically (but not always) a parent. However, because program participation imparted considerable responsibility to parents, we speculated that caregiver well-being might not improve, even though the program met its primary goal.

Regardless of children's random assignment status, the informal caregivers who responded to our survey devoted many hours to caregiving and to meeting the needs of all household members. Many caregivers experienced emotional, physical, and financial strain. Although CDC did not eradicate strain, it appeared to alleviate it, according to most of the measures used. Overall, treatment group caregivers provided as much assistance as did control group caregivers, yet they reported better satisfaction and well-being. Treatment group caregivers were substantially less prone to worrying about insufficient care and safety, and they were much more likely to be very satisfied with the child's overall care arrangements. Treatment group caregivers were somewhat more likely than their control group counterparts to work for pay (other than through CDC itself), and they were considerably less likely to say caregiving caused them a great deal of financial strain. They were also less likely to say caregiving was physically harmful. Treatment group caregivers were more likely than control group caregivers to be very satisfied with their own lives.

These findings indicate that caregivers derived benefits from the control and flexibility that the CDC program gave parents. Viewed with findings from the nine-month follow-up survey of parents (see Foster et al. 2004), they suggest that caregiver well-being improved because parents successfully recruited qualified service providers, assigned tasks appropriate to the abilities and availability of those providing paid and unpaid assistance to the child, paid some of the caregivers in this sample, and freed some to pursue other paid work.

Although Florida did not impose hiring restrictions during the demonstration, only a minority of caregivers (21 percent of those in the treatment group) were paid during the follow-up period. Parents, in particular, were less likely than other caregivers to become paid. Interview responses suggest that not getting paid was a choice for some and a misunderstanding of program policies for others. The observed associations between caregiver payment and sample members' baseline characteristics suggest that caregivers were most likely to become paid if children had unmet needs for personal care or if the monthly allowance was sufficiently generous. The estimated effects of payment on caregiver outcomes suggest that caregivers fared better under the CDC program than they would have under Florida’s traditional DD program, whether or not they became paid workers. However, those who became paid seemed to fare especially well--differences between their outcomes and those of control group caregivers often were larger than differences between unpaid treatment group caregivers and control group caregivers.

Limitations

This analysis was based on a randomized design and yielded estimated program effects that were quite large and consistent across many types of measures. Moreover, the effects were consistent with those for the primary informal caregivers of adult consumers in Arkansas, Florida, and New Jersey (Foster et al. 2005). Nonetheless, a few caveats are warranted about study duration, possible reporting bias, and the desirability of additional data.

First, because our follow-up period was short, we do not know whether the positive effects observed for treatment group caregivers would persist. For example, improvements in the satisfaction and well-being of caregivers might not last if the gratification derived from getting paid for caregiving were to diminish, or if parents made short-term or otherwise unstable care arrangements.

Second, some treatment group caregivers might have inflated reports on some outcomes, such as their own health status, because they believed CDC served the child’s (or their own) interests and wanted the program to continue or because they valued the income earned by household members who were paid as part of the program. Conversely, some caregivers for control group children might have overstated their dissatisfaction or burden because they were disappointed that the child had not been randomly assigned to the treatment group.

Third, having data on additional caregiver characteristics would enrich our analysis. For example, having data on caregivers’ baseline health status and levels of strain would have enabled us to determine how CDC affected subgroups of caregivers defined by those characteristics. In addition, if the models used to estimate program effects had controlled for such variables, we would be more confident in concluding that observed differences in the outcomes between paid and unpaid caregivers actually resulted from their payment status and not from unobserved differences between the groups.

Policy Implications

In providing children with Medicaid HCBS waiver benefits, policymakers need to know whether granting their parents more freedom--and more responsibility--to manage those benefits promotes or detracts from their well-being or that of another primary informal caregiver. The demonstration evaluation found strong evidence that the CDC program improved the quality of children’s care and parents’ satisfaction with that care, but accompanying benefits for primary informal caregivers were not guaranteed. The fact that benefits did accrue to both caregivers and children suggests that CDC is an option worth continuing and offering to families with children who may have joined the DD program after the demonstration period.

The findings also might quell possible concerns that allowing family members, especially parents, to become children’s paid workers erodes traditional values about familial responsibility and could lead some parents to seek waiver services in order to pay themselves for caregiving. The option to be paid did not seem to increase enrollment into the Florida demonstration. Parents were significantly less likely than other caregivers in this analysis to become paid workers, and less than a third of all children in the treatment group had a parent for a primary paid worker (Dale et al. 2005). Moreover, family members who were paid continued to provide many hours of unpaid assistance, and anecdotal evidence suggests that some parents used the wages they earned through the CDC program to buy care supplies or other items for their child. Overall, the results from this report and the companion piece on children’s care quality suggest not that Medicaid funds were used to pay parents merely for raising their children, but that the CDC program enabled parents to use those funds to effectively purchase the supportive benefits their child was authorized to receive. This greater control and flexibility substantially lessened the strain of the family members and friends these very dependent children relied on most.

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APPENDIX A: WAIVER BENEFITS

Florida's Developmental Disabilities (DD) waiver, which serves children and adults, covers the benefits listed in Table A.1. The allowance provided to treatment group children was set at the amount the state expected to spend for all the benefits, except support coordination, in children's DD support plans. To calculate the amount it expected to spend, the state multiplied the costs of benefits in the support plan by a discount factor that accounted for the fact that, on average, some benefits are not delivered as planned. Florida used the funds it would have spent on support coordination to pay for the consulting services it offered to help parents manage their child's monthly allowance in the CDC program. (The state paid consultants and support coordinators the same rates.)

TABLE A.1: Benefits Covered by Florida's Developmental Disabilities Waiver, by Type

Support Coordination **Personal Care** Chore services Companion services Homemaker Personal care assistance Respite **Transportation** **Supplies and Equipment** Personal emergency response systems Special medical equipment and supplies	**Environmental Modifications** **Professional Services** Adult dental Dietitian Occupational therapy Physical therapy Private-duty nursing Psychological services Residential nursing Respiratory therapy Skilled nursing services Special medical home care Speech therapy	**Behavior, Mental Health Therapy, Habilitation, Community Integration** Adult day training Behavioral services Nonresidential support services Residential habilitation Specialized mental health services Supported employment Supported living coaching **Other** In-home supports Therapeutic massage

SOURCE: Florida Medicaid Program, 2003.

APPENDIX B: ADDITIONAL INFORMATION ON METHODS

This appendix provides additional information on analytic methods. Table B.1 lists all the outcomes measured, Table B.2 shows the distribution of control variables for the treatment and control groups, and Table B.3 shows the minimum program effects we could confidently detect. Here, we describe in detail the approaches we used to estimate logit models, measure care hours, and impute missing values for control variables.

Methods

Use of Logit Models

As noted in the body of the report, we used the estimated coefficients from logit models to measure most program effects on primary informal caregivers. We calculated two predicted probabilities that Y = 1 (for example, whether very satisfied with life) for each primary informal caregiver in the sample--first assuming the case was in the treatment group, then assuming it was in the control group--then calculated the mean probability for these two series to get predicted treatment and control values, and the difference between these means. This approach provides a more intuitive measure of the size and importance of an impact than does the traditional odds ratio, which is obtained by exponentiating the logit coefficient on the treatment status variable.

Measuring Outcomes Derived from Scales

As noted in the body of the report, we converted outcome measures derived from survey questions with four- or five-point scales into two binary measures--one for the most favorable rating and one for an unfavorable rating. We then estimated impacts on each of these two measures. Although we could have measured both impacts with one multinomial logit model, the resulting estimates would be less precise because of the large number of parameters involved. Moreover, ordered logit models are designed for outcome measures derived from scales, but they can mask important nonlinear patterns of impacts. Therefore, after examining simple frequencies and determining that using two binary measures would not obscure important results, we proceeded with this approach.

Statistical Power

As noted in the body of the report, we had 80 percent power to detect impacts of the sizes listed in Table B.3, assuming a two-tailed test at the .05 significance level.

Measuring Hours of Assistance Provided

Data on hours of assistance were collected for live-in and visiting caregivers who provided any help with routine health care, personal care, or tasks around the house or community during a two-week reference period (the most recent two weeks in the month before the caregiver interview during which the child was at home).

For visiting caregivers (n = 30), we asked for the number of hours spent actively helping the child during the reference period, excluding purely social visits, or time spent on paperwork or travel to and from the child's home. For live-in caregivers (n = 736), we separately asked for: (1) the number of hours spent helping the child with personal care, routine health care, or transportation; and (2) the number of hours spent on other things around the house and community. We did this to distinguish hours that benefited the child exclusively from those that also may have benefited others in the household.

For live-in caregivers, we then calculated the total hours of assistance by adding these "care recipient hours" and "household hours." In 28 cases (nine in the treatment group and 18 in the control group) where total reported hours exceeded 336 (the total number of hours in a two-week period), we made the following adjustments, so that no case had more than 336 total:

- If the caregiver reported the same number of hours for time spent helping the child (the "care recipient") as for time spent on other tasks around the house and community, we divided both types of hours in half and summed the halved amounts (for example, see case 1, Table B.4).

- Otherwise, if the caregiver reported that care recipient hours equaled 336 and household hours were less than 336, we kept the household value, decreased the care recipient value by that amount, and summed those values (case 2).

- Otherwise, if the caregiver reported different totals for care recipient hours and household hours, we kept the lesser value, decreased the greater value by that amount, and summed those values (case 3).

Before these adjustments, the average total hours for the 18 control group caregivers reporting excessive hours was 486--150 hours more than the maximum possible of 336--while the nine treatment group caregivers averaged 159 hours more than the maximum possible. The adjustments reduced the mean hours for all live-in control group caregivers from 167 per two weeks to 159, and the mean unadjusted hours for live-in treatment group caregivers from 159 to 155. (The total hours presented in Table 3 were estimated with regression models that controlled for baseline characteristics; thus, they differ slightly from the numbers just presented.)

Missing Values for Control Variables

When children or caregivers were missing data on one or two control variables, the sample mean of the missing variable(s) was imputed to keep the case in the analysis.

TABLE B.1: Outcome Measures for Primary Informal Caregivers, by Type

Amount, Frequency, and Timing of Care Provided in Recent Two Weeks Among live-in caregivers: • Hours of care that benefited child only • Hours of care that benefits entire household • Total hours of care Among visiting caregivers: • Hours of care Number of days provided care Whether provided care: • Before 8:00 A.M. weekdays • After 6:00 P.M. weekdays **Caregiver-Child Relationship** How well caregiver and child get along Whether relationship is better, worse, or the same as it was at enrollment Whether child refuses to cooperate when caregiver tries to help **Satisfaction with Child's Care** How satisfied with child's overall care arrangements When caregiver is not with child, how often worries about: • Child not getting enough care • Child's safety • Someone taking money or other belongings from the household	**Emotional Well-Being** Whether caregiving limits: • Privacy • Free time or social life Whether child requires almost constant attention from caregiver Level of emotional strain as a result of caregiving How satisfied with life in general **Job Choice and Performance** Whether worked for pay, other than for child Among those who did, whether caregiving caused them to: • Miss work or arrive late • Quit job or reduce hours • Turn down a better job or promotion Whether did not look for a job, or another job, though wanted to **Financial Well-Being** Level of financial strain as a result of caregiving Household income last month **Physical Well-Being** Whether physical health suffered as a result of caregiving Level of physical strain as a result of caregiving	**Health and Functioning** Current health status relative to that of peers Whether illness or disability cause problems with: • Preparing meals, doing housework, laundry, shopping, taking medicine, or managing money • Eating, getting out of bed or a chair, dressing, bathing, or using the toilet **Knowledge and Preparedness** Whether feels well informed about child's condition and services Whether feels fully prepared to meet expectations in helping child **Living Arrangement and Types of Assistance Provided in Recent Two Weeks** Whether lived with child Whether lived within 10 minutes' travel time of child Whether provided assistance Among those providing assistance: • Helped with daily living activities • Helped with household tasks • Helped with routine health care • Kept child company

NOTE: Primary informal caregivers are those providing the most unpaid care to children at baseline. Outcomes were measured about 10 months after baseline.

TABLE B.2: Baseline Characteristics of Children and Primary Informal Caregivers
by Children's Random Assignment Status
(Percentages)

Characteristic	Treatment Group	Control Group
Children's Demographics		
Younger than 12 Years of Age	62.7	64.2
Male	62.2	64.5
Hispanic	18.2	19.7
White	80.8	81.8
Parents Described Area of Residence as:		**
Rural	16.5	21.7
Not rural, but high-crime or without adequate public transportation	33.7	36.6
Not rural or high-crime, with adequate public transportation	49.8	41.7
Children's Health and Functioning		
Relative Health Status		
Excellent or good	60.0	59.0
Fair	28.3	25.8
Poor	11.7	15.2
Not Independent in Past Week in:		
Bathing	92.8	92.0
Using toilet/diapers	84.6	86.0
Getting in or out of bed	58.7	60.4
Children's Use of Personal Assistance		
Number of Informal Caregivers in Past Week		*
1	11.9	10.2
2	26.1	20.3
3 or more	62.0	69.5
Number of Paid Caregivers in Past Week		
0	38.0	36.0
1	28.4	24.0
2 or more	33.6	40.1
Receiving Waiver Services for Six Months or Longer	59.7	58.8
Proposed Allowance (per Week)		
Less than $150	41.0	42.0
$150 to $299	24.9	24.2
$300 to $499	20.3	19.0
$500 or more	13.8	14.8
In Past Week, Received Personal Care Services from Caregivers(s) Who Was:		
Publicly funded[a]	52.8	53.2
Privately funded	23.3	29.8**
Parents' Satisfaction and Perception of Unmet Needs		
How Satisfied with Overall Care Arrangements		
Very satisfied	16.9	17.5
Satisfied	40.9	43.9
Dissatisfied	39.1	35.3
No paid services or goods in past week	3.1	3.3
Child Not Getting Enough Help with:		
Household activities[b]	77.3	73.6
Personal care	66.6	65.7
Transportation	48.6	46.0
Parents' Attitude Toward Consumer-Directed Care		
Being Able to Choose Services Was Very Important[c]	98.0	98.3
Having a Choice About Paid Worker's Schedule Was Very Important	92.5	92.3
Being Allowed to Pay Family or Friends Was Very Important	69.5	71.3
Primary Informal Caregiver Expressed Interest in Being Paid	24.9	24.6
Parents' Hiring and Supervisory Experience		
Ever Supervised Someone	77.6	76.8
Ever Hired Someone Privately	75.3	75.8

TABLE B.2 (*continued*)

Characteristic	Treatment Group	Control Group
Primary Informal Caregivers' Characteristics		
40 Years of Age or Older	63.6	63.8
Female	93.7	93.2
Is Care Recipient's Parent	89.7	89.0
Hispanic	15.4	16.9
White	82.0	83.8
Married	69.5	70.7
High School Graduate	89.3	90.4
Primary Informal Caregiver Is Employed	48.7	49.3
Other		
Child's Demonstration Enrollment Month Was Between:		
June 2000 and February 2001	74.4	73.2
March 2001 and July 2002	25.6	26.8
Sample Size	**429**	**400**

SOURCE: MPR's baseline interview, conducted between June 2000 and August 2001; caregiver interview, conducted between April 2001 and June 2002; and the Consumer Directed Care program.

* Significantly different from zero at the .10 level, two-tailed test.
** Significantly different from zero at the .05 level, two-tailed test.

a. All children in the demonstration were receiving publicly funded assistance (that is, Medicaid home and community-based services) at baseline. The survey question on which this variable was based referred specifically to assistance with personal care services, as opposed to other services and benefits such as supplies and professional therapy, that children may have received.
b. Includes activities such as preparing special meals and homework help.
c. Because this characteristic was very common, it was not included in logit models.

TABLE B.3: Minimum Detectable Effects

Binary Variable Mean	Detectable Effect (Percentage Points)
.50	8.6
.30 or .70	7.9
.10 or .90	5.2

TABLE B.4: Examples of Adjustments to Hours of Care Provided

Case	Reported			Adjusted		
	Care Recipient Hours	Household Hours	Total Hours	Care Recipient Hours	Household Hours	Total Hours
1	252	252	504	126	126	252
2	336	84	420	252	84	336
3	168	224	392	168	56	224

APPENDIX C: ADDITIONAL RESULTS

TABLE C.1: Estimated Effects on Living Arrangements of, and Assistance Provided by, Primary Informal Caregivers

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Living Arrangements in Recent Two Weeks[a]			
Lived with Child[b]	95.5	93.9	1.6 (.299)
Lived Within 10 Minutes' Travel Time of Child[b]	2.8	2.3	0.5 (.626)
Assistance Provided in Recent Two Weeks[a]			
Provided Any Assistance[b]	98.6	98.0	0.6 (.495)
Number of Days Provided Care	13.6	13.5	0.1 (.365)
Among Those Providing Assistance:			
Helped with personal care[b]	97.6	97.2	0.4 (.681)
Helped with household activities[b,c]	100.0	99.5	0.5 (.141)
Helped with routine health care	94.7	92.8	1.9 (.273)
Socialized with or kept child company[b]	98.6	100.0	-1.4** (.019)
Helped Before 8:00 A.M. weekdays	91.8	91.4	0.4 (.823)
Helped After 6:00 P.M. weekdays[b]	98.3	98.5	-0.2 (.896)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.

NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with ordinary least squares or logit models, unless noted.

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

a. The most recent two weeks the care recipient lived at home during the two months before the interview.
b. Impacts could not be estimated with the logit model. Results presented are the unadjusted control group means and treatment-control differences.
c. Includes such activities as preparing special meals and homework help.

TABLE C.2: Estimated Effects on Primary Informal Caregivers' Knowledge and Preparedness

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Feels Well Informed About Child's Condition and Services			
Strongly agrees	74.3	66.0	8.3*** (.008)
Disagrees	3.7	6.1	-2.4 (.117)
Feels Fully Prepared to Meet Expectations in Helping Child			
Strongly agrees	84.1	79.2	4.9* (.062)
Disagrees[a]	1.9	3.1	-1.2 (.277)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with ordinary least squares or logit models, unless noted.

* Significantly different from zero at the .10 level, two-tailed test.
*** Significantly different from zero at the .01 level, two-tailed test.

a. Impact could not be estimated with the logit model due to perfect classification of some observations. Results presented are the unadjusted means and the treatment-control difference.

TABLE C.3: Estimated Effects on Primary Informal Caregivers' Physical Functioning

Outcome	Predicted Treatment Group Mean (Percent)	Predicted Control Group Mean (Percent)	Estimated Effect (p-Value)
Because of Illness or Disability, Has Problems with at Least One:			
Instrumental activity of daily living[a]	13.6	17.8	-4.2* (.088)
Activity of daily living[b]	4.4	5.6	-1.2 (.412)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid care to the child at baseline. Includes those who became paid workers for children in the treatment group. Means were predicted with ordinary least squares or logit models.

* Significantly different from zero at the .10 level, two-tailed test.

a. Includes meal preparation, housework, shopping, taking medicine, and managing money.
b. Includes eating, getting in and out of bed or chairs, dressing, bathing, or using the toilet.

TABLE C.4: Estimated Effects of Care Recipient and Caregiver Characteristics on Whether Primary Informal Caregivers Became Paid Workers
(Omitted Categories in Parentheses)

Characteristic (n = 429)	Estimated Odds Ratio	p-Value
Characteristics of Child or Parent		
Child's Demographics		
Younger than 12	1.22	.501
Male	0.79	.402
Hispanic	1.09	.869
Race		
• (White)		
• Minority	1.02	.977
• Missing	1.13	.901
Parent Described Area of Residence as Rural or High-Crime or Lacking Public Transportation	0.68	.174
Health and Functioning		
In poor health relative to peers	0.77	.556
Not independent in past week in:		
• Getting in or out of bed	1.15	.665
• Bathing	1.15	.841
• Using toilet/diapers	0.51	.188
Unpaid and Paid Assistance		
Number of Informal caregivers who helped last week:		
• (One)		
• Two	1.18	.728
• Three or more	1.23	.642
Number of paid workers who helped last week:		
• (None)		
• One	1.08	.841
• Two or more	1.29	.522
Received help from a privately paid source last week	1.39	.384
Receiving Medicaid HCBS for at least six months	0.96	.876
Satisfied with overall care arrangements	0.86	.619
Parent's Preferences and Assessment of Child's Needs		
Ability to pay family members or friends was very important	1.96**	.050
Setting paid workers' schedule was very important	0.65	.440
Child not getting enough help with:		
• Personal care	2.58***	.008
• Transportation	1.08	.794
• Household activities	0.94	.884
Parent's Supervisory and Hiring Experience		
Ever supervised someone	1.07	.861
Ever hired someone privately	0.83	.594
Child's Weekly Allowance at Baseline		
(Less than $150)		
$150 to $299	1.80	.101
$300 to $499	2.42**	.019
$500 or more	3.39***	.005

TABLE C.4 (*continued*)		
Characteristic (n = 429)	**Estimated Odds Ratio**	**p-Value**
Caregiver Characteristics		
Is Mother or Father of Enrolled Child	0.33***	.007
40 or Older	0.80	.467
Female	0.88	.805
Hispanic	1.08	.886
Race		
(White)		
Minority	0.84	.293
Missing	1.39**	.046
Graduated from high school	1.32	.545
Married	0.54**	.046
Employed at baseline	0.63	.116

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: A child's primary informal caregiver is the one who provided the most unpaid assistance to the child at baseline. Odds ratios were estimated with a logit model.

** Significantly different from zero at the .05 level, two-tailed test.
*** Significantly different from zero at the .01 level, two-tailed test.

TABLE C.5: Reasons Treatment Group Caregivers Did Not Become Paid Workers	
Reason	**Percentage**[a]
Believed getting paid was against program rules or did not know could get paid	38.2
Helped out of love, devotion, or family tradition	34.9
Someone else was available for hire, not able to perform all tasks, lived far away, or had other obligations	7.5
Benefit was not enough to pay me or was needed for other things	7.2
Child disenrolled from the program	5.1
Intends to become paid, but child is not yet receiving the monthly allowance	3.3
Becoming paid involves too much paperwork or other hassle	2.7
Other	2.1
Number of Respondents	**335**

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: Treatment group caregivers are those identified at baseline as the primary informal caregivers of children randomly assigned to participate in the Cash and Counseling program.

a. Each caregiver was asked to name the most important reason. Percentages sum to slightly more than 100 percent because of rounding.

TABLE C.6: Treatment-Control Differences for Well-Being and Satisfaction, by Whether Caregivers Became Paid Workers		
Outcome	Estimated Differences for Caregivers Who:	
	Became Paid (p-Value)	Remained Unpaid (p-Value)
How Satisfied with Care Recipient's Overall Care Arrangements		
Very satisfied	31.6*** (.000)	17.7*** (.000)
Dissatisfied	-22.0*** (.000)	-19.0*** (.000)
How Often Worries That Care Recipient Does Not Have Enough Help in Caregiver's Absence		
Quite a lot	-19.5*** (.001)	-16.9*** (.000)
Rarely or not at all	4.9 (.294)	10.4*** (.000)
Caregiving Limits:		
Privacy	-15.6*** (.005)	-2.0 (.557)
Free time	-13.5*** (.001)	3.1 (.232)
Level of Emotional Strain as a Result of Caregiving		
A great deal	-9.2* (.092)	-0.3 (.927)
Little or none	3.9 (.409)	5.6* (.051)
Level of Financial Strain as a Result of Caregiving		
A great deal	-19.0*** (.001)	-9.8*** (.004)
Little or none	19.8*** (.000)	5.7** (.026)
Physical Health Has Suffered as a Result of Caregiving	-27.4*** (.000)	-9.3*** (.006)
How Satisfied with Own Life		
Very satisfied	28.3*** (.000)	9.6*** (.004)
Dissatisfied	-18.5*** (.000)	-11.5*** (.000)
Feels Well Informed About Care Recipient's Condition and Services		
Disagrees	-2.8 (.206)	-2.0 (.208)
Strongly agrees	19.1*** (.000)	4.6 (.156)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.

NOTE: The estimates were derived from logit models in which the outcome was predicted as a function of a binary variable equal to 1 for treatment group caregivers who became paid, a binary equal to 1 for treatment group caregivers who remained unpaid, and the baseline characteristics of caregivers and children. The estimated effects of becoming paid (remaining unpaid) are the differences between the predicted means for treatment group caregivers who became paid workers (remained unpaid) and those for control group caregivers. The sample consisted of 400 control group caregivers, 91 treatment group caregivers who became paid, and 338 treatment group caregivers who remained unpaid. Sample sizes varied slightly from measure to measure because of item nonresponse.

* Significantly different from zero at the .10 level, two-tailed test.
** Significantly different from zero at the .05 level, two-tailed test.
*** Significantly difference from zero at the .01 level, two-tailed test.

TABLE C.7: Treatment-Control Differences for the Amount of Assistance Provided, by Whether Caregivers Became Paid Workers

Outcome	Estimated Differences for Caregivers Who:	
	Became Paid (p-Value)	Remained Unpaid (p-Value)
In Recent Two Weeks[a]		
Number of Days Provided Care	0.4* (.057)	0.0 (.797)
Hours of Care Provided by All Caregivers[b]	-3.8 (.676)	-5.2 (.355)
By live-in caregivers	0.4 (.967)	-7.3 (.196)
• Hours that benefited care recipient only	3.6 (.582)	-7.0* (.073)
• Hours that benefited entire household	-3.2 (.586)	-0.3 (.935)

SOURCE: MPR's caregiver interview, conducted between April 2001 and June 2002.
NOTE: The estimates were derived from logit models in which the outcome was predicted as a function of a binary variable equal to 1 for treatment group caregivers who became paid, a binary equal to 1 for treatment group caregivers who remained unpaid, and the baseline characteristics of caregivers and children. The estimated effects of becoming paid (remaining unpaid) are the differences between the predicted means for treatment group caregivers who became paid workers (remained unpaid) and those for control group caregivers. The sample consisted of 400 control group caregivers, 91 treatment group caregivers who became paid, and 338 treatment group caregivers who remained unpaid.

* Significantly different from zero at the .10 level, two-tailed test.

a. The most recent two weeks the child lived at home during the two months before the interview.
b. Includes 30 visiting caregivers (4 percent of caregivers with data for this outcome) whose mean hours are not shown separately.