

**Medicaid Costs  
Under Consumer  
Direction for Florida  
Children with  
Developmental  
Disabilities**

***Final Report***

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# **MEDICAID COSTS UNDER CONSUMER DIRECTION FOR FLORIDA CHILDREN WITH DEVELOPMENTAL DISABILITIES**

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## **EXECUTIVE SUMMARY**

When the parents of children with developmental disabilities rely on Medicaid waiver services for home- and community-based services (HCBS), they may not have as much control over their child's benefits as they would like. If parents, rather than case managers, could allocate the resources for their child's assistance, supplies, and equipment, they might be both better able to obtain the care their child needs and better satisfied with that care. This study of Consumer Directed Care, Florida's Cash and Counseling Demonstration program for children, examines the ways in which consumer direction affects the cost of Medicaid personal care services, as well as the cost and use of other Medicaid services.

Demonstration enrollment, which occurred between June 2000 and August 2001, was open to children age 3-17 who were receiving HCBS through Florida's Developmental Services Waiver program. After their parents completed a baseline survey, enrollees were randomly assigned to participate in Consumer Directed Care (the treatment group) or to continue receiving traditional waiver services (the control group). Parents of treatment group members were given the opportunity to receive a monthly allowance they could use to hire their choice of caregivers or to buy other services or goods to meet their child's care needs. Program consultants and fiscal agents were available to help them manage these responsibilities. The cost of Consumer Directed Care was expected to be similar to that of the traditional waiver program.

Outcome measures were drawn from Medicaid claims data for 1,002 children for the first two years post-enrollment. We used regression models to estimate program effects, while controlling for a comprehensive set of baseline characteristics.

Waiver expenditures per treatment group member were more than \$3,000 (about 25 percent) higher than waiver expenditures per control group member during the first post-enrollment year, and nearly \$5,000 higher during the second. The treatment-control difference in waiver expenditures was due to two factors. First, control group members incurred waiver costs that were 18 percent lower than expected in the first year and 9 percent lower than expected in the second year according to their discounted baseline support plans; and second, treatment group members' allowances were, on average, about 30 percent higher than expected in both years.

The treatment group's higher waiver expenditures were partially offset in both years by lower expenditures for Medicaid home health services. This difference in home health expenditures was due primarily to an increase in the proportion of control group members with high spending on Medicaid private-duty nursing after the demonstration began, whereas no such difference was observed for the treatment group. No other Medicaid costs were affected. Total Medicaid costs for treatment group children averaged nearly \$30,000, about 3 percent (\$880) higher than the control group's cost. The difference was statistically insignificant. In year 2, the difference grew to \$2,581 per child ( $p=0.081$ ), about 8 percent higher than the control group's cost.



To control costs in the future, Florida may need to review its process for revising its support plans to ensure that allowances are not increased by counselors beyond those called for by a reasonable care plan. Conversely, Florida staff need to ensure that those in the traditional program (who had lower-than-expected costs) are able to receive the services they need.

Consumer Directed Care increased access to paid personal care and the quality of care received. Only individual states can decide whether they are willing to risk incurring somewhat higher total Medicaid costs in order to reap these sizable benefits. Ideally, states might be able to draw on Florida's experience to find ways to keep costs at the level incurred under the traditional system while preserving the highly favorable effects on children's well-being.

# INTRODUCTION

Although the parents of children with developmental disabilities have the primary responsibility for their child's health and welfare, some of them must rely on government programs for supplemental support or for the special resources parents need in order to manage their child's condition. Medicaid home- and community-based services (HCBS) waiver programs can offer such support; however, because state or agency staff decide the types and amounts of assistance families need, these programs leave some parents desiring greater control over their child's benefits. The Cash and Counseling model of consumer directed care, which gives parents more control over the funds for their child's care, is designed to improve the well-being of these families without increasing public costs.

While such programs as Cash and Counseling may appeal to consumers, in the current environment of tight state Medicaid budgets, costs are a crucial determinant of whether states can take on these programs. Recent research suggests that Florida's Cash and Counseling model--Consumer Directed Care--significantly increased the well-being of children with disabilities and their parents in Florida (Foster et al. 2004). Similarly, the Arkansas Cash and Counseling program increased the well-being of both non-elderly and elderly adults (Foster et al. 2003). The results on costs to date are less clear-cut. Arkansas' Cash and Counseling program increased personal care costs for adults, because many control group members received no personal care services (PCS) and those who did receive these services received only two-thirds of the care recommended in their care plan. However, because of savings on other Medicaid services, the higher costs were partially offset during the first post-enrollment year, and almost fully offset during the second (Dale et al. 2003).

Florida's program for children, which cashes out numerous HCBS waivers, has features different from those of Arkansas' program for adults, which cashes out only personal care. Thus, the cost findings for adults in Arkansas may not be generalizable to the Cash and Counseling program for children in Florida.

Florida's Consumer Directed Care could affect public costs in several ways. Costs under consumer direction could increase (or decrease) if a state sets a monthly allowance for self-directing consumers that is higher (or lower) than the amount it would have paid for authorized services under the waiver program. Medicaid reimbursements for other services could increase or decrease if changes in the way that parents manage their children's care under consumer direction lead to changes in the child's need for the services of hospitals, home health care providers, nursing facilities, and other Medicaid service providers.

The randomized design of the evaluation of the national Cash and Counseling Demonstration enables researchers to rigorously analyze costs under traditional and consumer-directed approaches. In this report, we use results from Florida's Consumer Directed Care for children to investigate the program's effect on Medicaid waiver costs,

other Medicaid costs, and Medicaid service use under consumer directed and traditional programs for the two-year period after demonstration enrollment.

## **BACKGROUND**

### **A New Model of Medicaid Supportive Services**

About 1.2 million people receive supportive services in their homes through state Medicaid plans or through HCBS waiver programs (Kitchener and Harrington 2003). These programs typically offer eligible children a wide range of supportive services, such as personal care, consumable supplies, professional therapies, and caregiver respite. Case managers, however, decide which services a particular child needs, while the states usually select the providers or vendors who supply them. This system leaves some parents desiring greater control over their child's supportive services.

As an alternative to these traditional service models, states are increasingly offering Medicaid beneficiaries and their families opportunities to obtain supportive services directly from individual providers (Velgouse and Dize 2000). This alternative has come to be known as "consumer directed care," because beneficiaries decide what services they need and who to get them from; those who need personal care may hire, manage, and possibly terminate their paid caregivers (Eustis 2000). In 1999, there were an estimated 139 publicly funded, consumer directed care programs in the United States, about a third of which served children with physical or developmental disabilities (Flanagan 2001).

Cash and Counseling expands upon more common models of consumer directed care by allowing consumers to do more than merely choose their paid providers. It provides a flexible monthly allowance that consumers--or the parents of consumers younger than age 18--may use to hire their choice of caregivers and purchase other services and goods, as states permit. Cash and Counseling requires that consumers, or parents, develop plans showing how they would use the allowance to meet their needs or those of their child. Instead of the case management or support coordination that traditional programs provide, Cash and Counseling offers counseling and fiscal services to help consumers, or parents, plan for and manage their responsibilities. These tenets of Cash and Counseling--flexible use of the allowance, availability of counseling and fiscal services, and use of representative decision-makers (such as parents, adult caregivers, or other designees)--are meant to make Cash and Counseling adaptable to consumers of all ages and with all types of impairments.

With funding from the Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, waivers from the Centers for Medicare & Medicaid Services, guidance and technical assistance from the National Program Office, Cash and Counseling was implemented as a voluntary demonstration in Arkansas, Florida, and New Jersey. Because the Medicaid programs and political environments differed considerably across

the demonstration states, the states were not required to implement a standardized intervention; although the programs did have to adhere to the basic Cash and Counseling tenets summarized above. Arkansas and New Jersey designed their demonstration programs for adults and gave participants an allowance for their Medicaid PCS. In contrast, Florida designed its demonstration program for both adults and children, and based allowances on a variety of HCBS waiver benefits (not just PCS). Florida and New Jersey allowed legally liable relatives (that is, parents and spouses) to become workers, whereas Arkansas did not. Because of such differences, we are evaluating the programs separately. Moreover, we examine the experiences of Florida children--the subject of this paper--separately from those of Florida adults.

## **Cash and Counseling for Florida Children**

Florida implemented Consumer Directed Care to promote the independence of people with disabilities, to offer services that would better meet the needs of families, and to encourage the prudent use of public resources. Parents who participated in early focus groups conducted to aid in the design of Consumer Directed Care said they wanted to participate in a program that would give them decision-making power, flexibility, and privacy; allow them to choose caregivers whom they trusted and their child liked; and enable them to obtain respite for themselves without unduly impinging on others (Zacharias 1998; Simon-Rusinowitz et al. 1998).

The demonstration was open to children age 3-17 who were receiving any waiver services through the state's home- and community-based Developmental Services waiver program.<sup>1</sup> To be thus enrolled, these children required the level of care that is furnished in Florida's intermediate care facilities for people with developmental disabilities. Children who need this level of care have at least one of the following developmental disabilities: mental retardation, autism, spina bifida, cerebral palsy, or Prader-Willi syndrome (in descending order of prevalence in the United States population). They also have severe functional limitations in at least three of the following major life activities: self-care, understanding and use of language, learning, mobility or self-direction, and capacity for independent living (Florida Medicaid Program 2000).<sup>2</sup> Children covered under Florida's developmental services waiver require a level of care and additional health and developmental services that are well beyond those usually provided to children. For example, about 60 percent of children covered under the waiver need help getting into or out of bed. Overall, caring for these children requires substantial time and resources and must be integrated into the life of the family as a whole.

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<sup>1</sup> Florida allowed only those already receiving waiver services to participate in the consumer directed care program. This requirement prevented consumers who were solely interested in the cash allowance from signing up for the demonstration.

<sup>2</sup> Waiver program participants also met state-specified income and asset requirements, but they qualified for Medicaid on the basis of disability, not on the basis of financial means.

Before enrollment, the children in our sample were receiving a wide variety of benefits through the waiver program. For example, children with spina bifida may have received supplies to care for incontinence and pressure sores, whereas children with autism may have received behavior therapy to address self-injurious tendencies. According to Medicaid claims data, after support coordination (which was mandatory), the most commonly used benefits during the year prior to enrollment were supplies and equipment (71 percent); PCS (53 percent); and therapy services, including behavioral, mental health, and habilitation (32 percent). Children also received such benefits as environmental modifications (6 percent), professional services and therapies (3 percent), and transportation (0.5 percent). Because these children require frequent and multiple services, parents can experience frustration if the service system is inflexible. Consumer Directed Care was intended to support families in their caregiving role by enhancing flexibility and choice and allowing them to integrate caretaking more easily into family life.

Most parents of children receiving waiver services were notified about the Consumer Directed Care program through a letter from the governor. Program administrators told parents who applied for the program what the child's monthly allowance would be if the child were assigned to the treatment group.<sup>3</sup> As prepared by support coordinators under the traditional program, allowances were set equal to the expected costs of benefits in children's waiver support plans.<sup>4</sup> In addition to services and goods needed regularly, waiver support plans could include "one-time" expenditures (for example, for remodeling a bathroom to make it wheelchair-accessible). In calculating the allowance amount, the value of the support plan was multiplied by a discount rate of 0.92 to reflect historical differences between expected and actual costs, so that the costs of serving similar treatment and control group children under the demonstration would be on a par with each other. At enrollment, the average allowance was \$1,109 a month, or \$256 a week.<sup>5</sup>

Enrollment, which was voluntary, began in June 2000 and continued until August 2001, when the evaluation target of 1,000 enrollees was met.<sup>6</sup> MPR conducted a baseline telephone interview with parents who enrolled their child in the demonstration, then randomly assigned each child to the treatment or the control group. After random assignment, the experiences of the treatment and control groups diverged. While

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<sup>3</sup> We use "parents" to denote both parents and legal guardians.

<sup>4</sup> Table A.1 provides a complete list of benefits that Florida covers through its Developmental Services waiver program. With the exception of support coordination, any benefits that were in a child's support plan could be "cashed out" as part of treatment group members' allowances under Consumer Directed Care. This feature distinguishes Florida's program from those of Arkansas and New Jersey, which cashed out only PCS.

<sup>5</sup> See Phillips and Schneider (2004) for a detailed description of program operations.

<sup>6</sup> Florida enrolled into its Cash and Counseling demonstration 1,002 children, 34 percent of the 3,000 children it estimated were eligible to participate. Children continued to enroll and be randomly assigned after August 2001, but these children were not included in the evaluation. Instead, random assignment continued so that Florida could continue to compare costs of Consumer Directed Care participants to those participating in the traditional program in order to meet federal requirements that Consumer Directed Care be budget-neutral.

control group children and their parents were to continue to rely on traditional waiver program benefits and support coordination, the parents of treatment group children were contacted by Consumer Directed Care consultants about starting on the allowance.

With assistance from program consultants, a “representative” of the child (all representatives were parents) in each treatment group family developed and implemented a written plan for using the child’s monthly allowance. This plan did not have to conform to the waiver support plan, on which the allowance was based. The allowance could be used to purchase services or goods to meet the child’s needs for home or community support, and purchases did not have to be furnished by Medicaid-certified suppliers or be covered under the traditional waiver program, so long as they were directed toward the child’s disability. For example, parents could purchase experimental therapies not covered by Medicaid, and they could hire caregivers who were not certified by Medicaid, including themselves or other relatives. In many families, one parent served as the representative, the other as a paid caregiver.<sup>7</sup>

The responsibilities of consultants in Consumer Directed Care were similar in some ways to those of support coordinators in the traditional waiver program but different in others. Coordinators were responsible for reviewing the support plans of control group members and revising them as necessary to ensure that needs were met. Consultants had comparable responsibility for those receiving the allowance. The reviews were conducted annually or upon a change in the child’s circumstances. Thus, consultants could authorize changes to the amount of the allowance for the treatment group, and support coordinators could modify the value of the support plan for the control group. On the other hand, support coordinators in the traditional program were expected to access, coordinate, and troubleshoot goods and services on *behalf* of families, whereas consultants were not. Nonetheless, parents could call on program consultants for advice about recruiting caregivers, arranging backup assistance, and similar matters. In addition, consultants monitored satisfaction, safety, and the use of funds through monthly telephone calls and periodic home visits.

The payment for consulting services for the treatment group was identical to the payment for support coordination for the control group. Agencies or contractors who provided these services were paid \$148 per month for each beneficiary on their caseloads. (Both consulting services and support coordination services were paid directly by Medicaid, not by families.)

With few exceptions, treatment group parents chose to have the fiscal agents maintain their program-related accounts, withhold paid caregivers’ payroll taxes, file payroll tax returns, and write checks to cover caregivers’ wages and other goods and

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<sup>7</sup> In the few instances where the same parent was both the representative and a paid caregiver, Florida arranged for someone known to, but outside, the immediate family to check that the child was being well cared for. This practice helped to ensure quality of care despite the inherent conflict of interest that arises when a paid caregiver is, in effect, his or her own employer and supervisor.

services purchased with the allowance. Parents were charged \$5 per check for this service, up to a monthly maximum of \$25.<sup>8</sup>

## **EXPECTED PROGRAM EFFECTS ON USE AND COST OF MEDICAID SERVICES**

### **Hypotheses**

Although Consumer Directed Care was expected to increase consumer satisfaction and reduce unmet needs, its expected effects on the use and cost of Medicaid services were not as clear. The program was required to meet CMS's budget neutrality requirements, which meant that costs per recipient per month for Consumer Directed Care and other core Medicaid services<sup>9</sup> for which use was expected to be affected by Consumer Directed Care could be no greater than the comparable, traditional per-person cost for those receiving traditional waiver services. Accordingly, the value of the allowance was set to equal the expected cost of waiver services under the traditional program, and the cost of consultants was exactly equal to the cost of support coordinators. Thus, Florida's Consumer Directed Care program was designed to cost the same as the traditional program per recipient-month.<sup>10</sup> Nonetheless, the costs per month for the treatment group could still be higher (or lower) than those for the control group if the discount rate (which was based on the period before the demonstration) was not accurate for the demonstration period. In addition, compared to control group members, treatment group members could be more (or less) likely to receive authorizations for revising their support plans, and could have been more (or less) likely to incur one-time expenditures.

In addition to affecting waiver costs, Consumer Directed Care could reduce the costs and use of other Medicaid services. Personal care or other goods and services purchased with the allowance might be substituted for services covered by Medicaid, such as home health services. The program also could affect the use and cost of Medicaid services that reflect the adequacy of waiver services, such as inpatient hospital use and physician visits. These costs could be higher (or lower) for the

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<sup>8</sup> Alternatively, parents who preferred to maintain their own accounts and handle payroll, taxes, and checking activities themselves could do so if they first passed a skills examination. In these cases, Consumer Directed Care fiscal agents performed monthly "desk reviews" of participating families' program-related records. Families paid \$10 a month for desk reviews.

<sup>9</sup> Core services were designated prior to the demonstration, and included services that seemed likely to be affected by the cashing out of waiver services. Core services included home health, targeted case management, hospice, durable medical equipment, and transportation.

<sup>10</sup> Because agency overhead is eliminated, policymakers often expect the costs of consumer direction to be cheaper than those of agency services. However, Consumer Directed Care program was designed to cost the same as (rather than less than) the traditional program, per month of service.

treatment group if workers hired under consumer direction provided higher (or lower) quality care. Self-reports in Foster et al. (2004) showed that Consumer Directed Care children were less likely than control group children to develop pressure sores, to have existing bed sores worsen, to experience shortness of breath, to have a urinary tract infection, or to fall--and were no more likely than control group children to suffer any of the other adverse events studied. Thus, if claims data are consistent with survey reports, we would expect the treatment group's expenditures for other Medicaid services for these problems to be similar to (or less than) those of the control group.

## **Hypotheses About Subgroup Effects**

It is possible that program effects will differ--in magnitude or direction for certain subgroups of children. In particular, we hypothesize that differences may arise, depending on whether children:

- were receiving PCS under the waiver at baseline;
- had an unmet need for PCS at baseline;
- had a relatively high allowance; and
- lived in a rural area.

Costs might increase more under Consumer Directed Care for subgroups of children whose parents are more likely to request (and receive) increases in their allowances. For example, a parent who reported an unmet need for PCS at baseline might request that the allowance be increased in order to cover the cost of both a newly hired worker and the other goods and services in the child's support plans. Likewise, a parent whose child was not receiving PCS at baseline might hire a worker and then request an allowance increase. Further, costs might increase more for those with relatively high allowances than for those with relatively low allowances if control group members with high allowances have greater difficulty obtaining all the services they are authorized to receive.

Finally, we examine whether there are greater treatment-control differences in costs in rural areas where control group members might face a scarcity of Medicaid-certified providers; if the program increases access to care in underserved rural areas, it might also increase costs because control group members would receive only some of the services authorized in their support plans.

## **METHODS**

### **Data Collection and Sample**

Data for this analysis were drawn primarily from Medicaid claims data and a computer-assisted telephone baseline survey was administered to parents of treatment and control group members (or to their proxy respondents) between June 2000 and



August 2001. We used Medicaid claims data for the first 24 months after enrollment to construct outcome measures for the full sample.<sup>11</sup> We constructed control variables from claims data for the year preceding enrollment and from the baseline survey. Control variables from the claims data included the sample members' pre-enrollment Medicaid expenditures, as well as a "predicted case mix value" based on the costs that each sample member would be likely to incur according to pre-enrollment diagnoses.<sup>12</sup> Control variables from the baseline survey include the consumers' demographic characteristics, measures of health and functioning, and measures of unmet need for personal care.

## Outcome Measures

Outcome measures included for the 24 months after enrollment were Medicaid waiver expenditures, Medicaid expenditures for other services, and selected measures of service use. We compiled these measures from Medicaid claims data supplied by Florida. Most of these measures are fairly straightforward and do not require further explanation. We must clarify, however, that the treatment group's waiver expenditures included costs for the allowance as well as payments for waiver services received after randomization but before receipt of the cash allowance, and for any waiver services disenrollees received after they left the Consumer Directed Care program.

For our key outcome measure--total Medicaid expenditures--we have 80 percent power to detect an impact of +/-11 percent of control group mean costs (or about \$3,600), assuming a two-tailed test at the 0.10 significance level.

## Estimation of Program Effects

Because treatment group members did not necessarily receive the allowance during the full post-enrollment period that we examined, our impact estimates measure the effects of having the *opportunity* to receive the monthly allowance (by virtue of being assigned to the treatment group), rather than actually *receiving* it. Likewise, some control group members did not necessarily receive waiver services in every post-enrollment month. To avoid introducing selection bias, we based most of our analyses on the expenditures of all treatment group and all control group members.

We estimated program impacts for most continuous outcome measures (including all our expenditure outcomes) using ordinary least squares regression models. For continuous outcome measures with a high proportion of zero values, such as the number of inpatient days, we used tobit models. For binary outcome measures (such

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<sup>11</sup> Three children in the sample had less than 24 months of follow-up data.

<sup>12</sup> We use Chronic Illness and Disability Payment System (CPDS) software to calculate the "predicted case mix value," an index intended to capture future Medicaid costs. The predicted case mix value is constructed from individuals' pre-enrollment diagnoses, according to Medicaid claims data. See Kronick et al. (2000) for a description of the CPDS.

as whether a sample member had any visits to the emergency room), we used logit models to estimate program impacts. For all outcome measures, we measured impacts by calculating the treatment-control difference in predicted means. We estimated the mean predicted values for the treatment and control groups for each outcome by computing the predicted value of the outcome from the regression (or logit or tobit) equation twice for each sample member, first assuming that they were in the treatment group, then assuming that they were in the control group and computing the mean over all sample members for both sets of predicted values. (For outcomes estimated with least squares regression models, this approach is exactly equivalent to computing the predicted outcome for treatments and controls at the point of means for the regressors, but such equivalence does not hold for outcomes estimated with logit or tobit models.)

For each type of model, we used the p-values of the estimated coefficients on the treatment status variable to assess the statistical significance of the impacts and report these values in the tables. The impact estimates are almost always very similar to the treatment-control raw (unadjusted) differences in means.

All the models controlled for the sample members' baseline measures of demographic characteristics, health and functioning, unmet needs for personal care, pre-enrollment Medicaid expenditures, and predicted case mix value based on the sample member's pre-enrollment diagnosis. Means of the control variables used in the model are shown on Table 1. These models increased the precision of the impact estimates and ensured that any differences between treatment and control groups in these pre-existing characteristics that may have arisen by chance did not distort our impact estimates.

As expected, the mean values of the control variables are generally similar for the treatment and control groups. While the treatment group had significantly higher expenditures for therapy services than the control group, none of the other differences in pre-enrollment characteristics were statistically significant. However, the treatment-control difference in average home health expenditures was large (-\$1,800), but not quite statistically significant ( $p = 0.12$ ). By chance, 12 control group members had home health expenditures that were over \$100,000 per year, while only six treatment group members had home health expenditures that were this high. Nevertheless, we should avoid any bias that would be introduced by this difference by controlling for pre-enrollment home health expenditures.

## **Sample Description**

Our sample includes the 1,002 children who enrolled in Consumer Directed Care and whose parents completed baseline surveys. Most of the children in this analysis were white, male, and younger than 12 (Table 1). Slightly more than half of the sample lived in parts of Florida that parents described as rural or as having a high rate of crime or poor public transportation. (These conditions could make it difficult for agencies to recruit paid workers or for treatment group families to hire workers other than nearby relatives and friends.) About 40 percent of parents said their child's health was fair or

poor (rather than excellent or good) compared with the health of the child's peers. Further, although 46 percent of the children were 12 or older, about 60 percent could not get out of bed without help or supervision. During the year prior to baseline, total Medicaid costs were high, averaging about \$20,000 per child, with more than one-third (about \$7,500) being for waiver services. About half of their waiver expenditures (an average of about \$3,400) was for personal care, about 20 percent (nearly \$1,500) was for supplies, 15 percent was for support coordination (nearly \$1200), and 13 percent (or \$1,000) was for therapy. At baseline, only about half of children received personal care under the waiver (Table 2).

Most treatment group members (68 percent) received allowances at the end of Month 12 after demonstration enrollment. However, because of delays in getting started on the allowance, only 22 percent of treatment group members received an allowance during Month 3, and only 52 percent did so during Month 6. (Allowances were sometimes delayed because Consumer Directed Care consultants and district or state staff both had to approve spending plans before families could begin receiving their allowance.) On average, treatment group members received allowances for 5.4 months during the first post-enrollment year and for 8.5 months during the second (Table 2).<sup>13</sup> Most treatment group members received traditional waiver services during months in which they did not receive allowances; in fact, nearly all treatment group members and nearly all control group members received at least some waiver services during each month of the post-enrollment period.

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<sup>13</sup> About 63 percent of treatment group members received an allowance during each month of the second post-enrollment year; however, due to disenrollment from the program, a quarter did not receive the allowance during either the first or the second year. In most cases (88 percent), disenrollment was initiated by parents who changed their minds about the program or found that some aspect of it was not working well for them, according to records from the program's first year. Other children disenrolled because they were no longer eligible for Medicaid or HCBS waiver benefits. The program did not identify any instances of abuse or mismanagement of the allowance that would warrant disenrollment. Allowance delays and disenrollment are further discussed in a companion analysis (Foster et al. 2004).

<b>TABLE 1. Baseline Characteristics of Samples Members, by Evaluation Status (Percentages, unless otherwise noted)</b>		
<b>Characteristic</b>	<b>Treatment Group</b>	<b>Control Group</b>
<b>Demographics</b>		
Younger than 12 Years	63.5	64.1
Female	38.1	35.9
Of Hispanic Origin	17.8	19.4
Race		
White	78.4	81.0
Black	16.8	14.6
Other	4.7	4.5
Area of Residence Is:		
Rural	16.8	19.5
<b>Pre-enrollment Medicaid Expenditures</b>		
Medicaid Expenditures for (in Dollars):		
Inpatient services	824	1,239
Home health services	4,583	6,401
Waiver services	7,319	7,849
Total Medicaid services	18,838	21,437
Waiver Expenditures, by Type of Service (in Dollars):		
Personal care	3,412	3,450
Support coordination	1,178	1,172
Supplies	1,470	1,492
Therapy	739	1,143**
Professional services	157	68
Environmental modifications	351	420
Transportation	1	3
Other services	12	28
Predicted Case Mix Value <sup>a</sup>	0.75	0.74
<b>Health and Functioning</b>		
Relative Health Status		
Excellent or good	59.3	58.7
Fair	28.5	26.0
Poor	12.2	15.4
Compared to Last Year:		
Health is worse	9.8	10.0
Not Independent in Past Week in <sup>b</sup> :		
Getting into or out of bed	60.3	61.7
<b>Use of Personal Assistance at Baseline</b>		
Mean Weekly Benefit (in Dollars)	256	267
Received Medicaid PCS Under Waiver (Percent)	53.3	53.1
Months on Medicaid Prior to Enrollment	11.6	11.5
<b>Unmet Needs for Personal Assistance</b>		
Not Getting Enough Help with:		
Personal care	66.4	65.6
<b>Sample Size</b>	<b>501</b>	<b>501</b>
<p><b>SOURCE:</b> MPR's baseline evaluation interview, conducted between June 2000 and August 2001, Medicaid claims data from June 1999 through July 2001, and the Consumer Directed Care program.</p> <p><b>NOTES:</b> Waiver expenditures by type of service are shown here for descriptive purposes, but were not used as control variables in the regression models</p> <p>**Treatment group mean different from control group mean at 0.05 level.</p> <p>a. The predicted case mix value (which ranged from 0.1 to 14.4) was calculated from CDPS software based on the sample member's diagnoses according to Medicaid claims data in the year prior to enrollment in the demonstration.</p> <p>b. Needed hands-on or standby help or performed no activity at all.</p>		

<b>TABLE 2. Receipt of Waiver Services, Personal Care, and Allowances</b>		
<b>Measure</b>	<b>Treatment Group</b>	<b>Control Group</b>
Received Personal Care Under Waiver in Year Prior to Baseline (%)	52.3	53.1
Received Paid Personal Care at Follow-up (Nine-Month Survey, %)	79.8	65.3
Received Paid Personal Care in 1st Post-enrollment Year (Medicaid Claims Data, %)	NA	65.7
Average Number of Months Receiving Waiver Services in 1 <sup>st</sup> Post-enrollment Year	11.6	11.5
Average Number of Months Receiving Waiver Services in 2 <sup>nd</sup> Post-enrollment Year	11.4	11.2
Average Number of Months Receiving Allowance in 1 <sup>st</sup> Post-enrollment Year	5.4	NA
Average Number of Months Receiving Allowance in 2 <sup>nd</sup> Post-enrollment Year	8.5	NA
Percentage Receiving Allowance During Month:		
1	0.0	NA
2	4.6	NA
3	22.4	NA
4	34.7	NA
5	43.5	NA
6	52.1	NA
7	57.7	NA
8	61.7	NA
9	63.7	NA
10	64.7	NA
11	67.9	NA
12	67.7	NA
13	68.7	NA
14	68.3	NA
15	70.3	NA
16	69.5	NA
17	70.1	NA
18	70.9	NA
19	71.1	NA
20	70.7	NA
21	71.1	NA
22	69.7	NA
23	71.1	NA
24	70.3	NA
<b>SOURCE:</b> Medicaid claims data, June 1999 through September 2003. NA = not applicable because the Medicaid claims data do not show whether treatment group members purchased personal care with their allowances.		

# **RESULTS**

## **Effect of Consumer Directed Care on Waiver Expenditures**

During the first year post-enrollment, waiver expenditures for the treatment group were sizable (\$15,966, Table 3), \$3,319 (more than one-fourth) higher than those of the control group (\$12,647). The expenditures rose for both groups in the second year post-enrollment, and the treatment-control difference (\$4,812) was even greater. This difference in waiver expenditures occurred even though treatment and control group members had similar average support plan values at baseline. Their average annual “baseline waiver costs” (defined as the child’s expected baseline costs according to the discounted value of their support plan at enrollment plus \$148 per month for consulting or support coordination) was \$15,060 for the treatment group and \$15,672 for the control group (not shown). We first discuss the reasons for this discrepancy and then return to a discussion of the other estimates in Table 3.

## **Reasons for Treatment-Control Difference in Waiver Expenditures**

The treatment-control difference in waiver expenditures was due to two factors: (1) the control group incurring costs that were lower than their average baseline waiver costs, and (2) allowance recipients in the treatment group incurring costs that were higher than their average baseline waiver costs. The first explanation accounts for most (about three-fourths) of the treatment-control difference in Year 1. The second explanation accounts for most (about two-thirds) of the difference in Year 2. The treatment-control difference in waiver expenditures increased over time as more treatment group members received allowances, and the problem of allowances exceeding what was initially authorized continued.

During Year 1, the treatment group incurred costs that were 5 percent higher than their baseline waiver costs (Table 4). This was due entirely to the fact that during months in which individuals actually received allowances, their expenditures were 30 percent greater than their average baseline waiver costs. During Year 2, the entire treatment group’s actual costs were 24 percent higher than their average baseline waiver costs, due to allowance recipients’ costs being 32 percent higher than their average baseline waiver costs. The average waiver expenditures for allowance recipients (nearly \$1,800 during both years) did not appreciably increase over time, but the average number of children receiving an allowance during a given month increased from 226 to 351.

In contrast, the control group’s average monthly waiver expenditure was \$1,071, only 82 percent of the group’s average baseline waiver costs (\$1,306). During the second year, control group expenditures were higher but still only 91 percent of their average baseline waiver costs.

TABLE 3. Effect of Consumer Directed Care on Medicaid Expenditures for Children, By Type of Service								
Expenditure Type	First Post-enrollment Year				Second Post-enrollment Year			
	Treatment Group Predicted Mean	Control Group Predicted Mean	Estimated Effect	p-value	Treatment Group Predicted Mean	Control Group Predicted Mean	Estimated Effect	p-value
Waiver Services	15,966	12,647	3,319	0.000***	18,859	14,046	4,812	0.000***
Home Health	6,393	7,968	-1,574	0.055*	6,361	8,402	-2,041	0.050*
Physician	3,038	3,099	-61	0.799	2,656	2,899	-242	0.314
Prescription Drugs	1,718	1,911	-193	0.199	1,970	2,194	-223	0.236
Inpatient	777	1,186	-409	0.240	1,184	1,109	75	0.829
Transportation	134	159	-25	0.619	111	180	-69	0.147
Case Management	76	69	6	0.578	42	39	2	0.839
Payment to Managed Care Provider	178	192	-14	0.600	198	187	11	0.697
Other <sup>a</sup>	1,694	1,864	-169	0.443	2,076	1,820	256	0.440
Total Medicaid	29,974	29,095	880	0.476	33,458	30,877	2,581	0.082*
<b>Sample Size</b>	<b>501</b>	<b>501</b>			<b>501</b>	<b>501</b>		
<b>SOURCE:</b> Medicaid Claims Data, June 1999 through September 2003. <b>NOTES:</b> Means predicted using ordinary least squares regressions controlling for person's baseline characteristics and pre-enrollment Medicaid expenditures. *Significantly different from zero at the 0.10 level, two-tailed test. **Significantly different from zero at the 0.05 level, two-tailed test. ***Significantly different from zero at the 0.01 level, two-tailed test. a. Includes mainly nursing facility, hospice, x-ray, and laboratory costs.								

<b>TABLE 4. Comparison of Actual to Baseline Monthly Waiver Costs</b>						
	<b>Months 1 - 6</b>	<b>Months 7 - 12</b>	<b>Months 13 - 18</b>	<b>Months 19 - 24</b>	<b>First Post- enrollment Year (Months 1 - 12)</b>	<b>Second Post- enrollment Year (Months 13 - 24)</b>
<b>All Control Group Members</b>						
Sample Size	501	501	501	501	501	501
Average Monthly Actual Waiver Costs	1,070	1,072	1,158	1,218	1,071	1,188
Average Monthly Baseline Waiver Costs	1,306	1,306	1,306	1,306	1,306	1,306
Difference Between Average Actual and Average Baseline Waiver Costs	-236	-234	-148	-128	-235	-118
Ratio of Average Actual Costs to Average Baseline Costs	0.82	0.82	0.89	0.93	0.82	0.91
Median Ratio of Actual to Baseline Waiver Costs	0.67	0.71	0.76	0.76	0.69	0.76
Mean Ratio of Actual to Baseline Waiver Costs <sup>a</sup>	0.96	1.01	1.14	1.22	0.99	1.18
<b>All Treatment Group Members</b>						
Sample Size	501	501	501	501	501	501
Average Monthly Actual Waiver Costs	1,171	1,456	1,515	1,593	1,313	1,554
Average Monthly Baseline Waiver Costs	1,255	1,255	1,255	1,255	1,255	1,255
Difference Between Average Actual and Average Baseline Waiver Costs	-84	201	259	338	59	299
Ratio of Average Actual Costs to Average Baseline Costs	0.93	1.16	1.21	1.27	1.05	1.24
Median Ratio of Actual to Baseline Waiver Costs	0.85	1.00	1.00	1.03	0.99	1.00
Mean Ratio of Actual to Baseline Waiver Costs <sup>a</sup>	1.12	1.48	1.58	1.72	1.30	1.65
<b>Allowance Recipients Only</b>						
Average Number of Allowance Recipients Each Month	131	320	349	354	226	351
Average Monthly Actual Waiver Costs	1,831	1,751	1,758	1,833	1,774	1,796
Average Monthly Baseline Waiver Costs	1,320	1,390	1,360	1,362	1,369	1,361
Difference Between Average Actual and Average Baseline Waiver Costs	511	361	398	471	405	435
Ratio of Average Actual Costs to Average Baseline Costs	1.39	1.26	1.29	1.35	1.30	1.32
Median Ratio of Actual to Baseline Waiver Costs	1.04	1.02	1.04	1.11	1.03	1.09
Mean Ratio of Actual to Baseline Waiver Costs <sup>a</sup>	1.66	1.67	1.76	1.91	1.67	1.84
<b>SOURCE:</b> Medicaid claims data, June 1999 through September 2003.						
<b>NOTE:</b> Baseline waiver costs include the discounted value of the baseline care plan plus \$148 per month for support coordination or counseling. Actual waiver costs include Medicaid waiver expenditures for allowances, support coordination/counseling, and other waiver services.						
a. Ratio computed for each individual, then averaged.						

The fact that the control group incurred waiver costs that were lower than expected at baseline suggests that the discount rate used was inaccurate for the study period. Florida set its discount rate by calculating the ratio of actual expenditures to authorized support plan expenditures for a sample of several hundred people. It is possible,



however, that those who actually volunteered for the demonstration were different from the typical waiver recipient in the sample.<sup>14</sup> For example, the Consumer Directed Care program might appeal especially to those in rural areas who have difficulty finding Medicaid-certified providers and would like to hire their own worker. Because of difficulties in obtaining authorized services, those in rural areas might also receive less of their planned services than consumers in urban areas. However, we found that control group members in rural areas were not more likely to be underserved than those in non-rural areas. (We tested this finding by regressing the ratio of actual to baseline costs on whether a person lived in a rural area.) There was considerable variation in actual-to-baseline waiver cost ratios by district (see Table A.2), which suggests that people may have experienced greater difficulty than others in locating providers in some areas, but the ratio of actual to baseline waiver costs was higher for the treatment group than the control group in every area (except in the smallest district, which had only six sample members in each group). Thus, this finding is not due to consultants in a few areas being overly generous in revising the support plans for children in Consumer Directed Care.

The control group's apparent underutilization of services could also be an artifact of the way the discount rate was calculated. One method that could be used is to compute the ratio of actual to expected costs (according to the support plan) for each person, and then take the average ("average ratio").<sup>15</sup> Over the first year in Florida, the average ratio was 0.98. Although information is not available on how Florida computed its discount rate, it is possible that the discount rate was calculated by using the average ratio in the pre-enrollment period. If this is the case, then its rate was consistent with the experiences of control group members during the demonstration period, since the average ratio (0.98) was very close to 1. However, from a budgetary standpoint, in order for the average actual expenditures for the entire control group to equal the average expected expenditures, the discount rate should have been calculated as the ratio of the average actual expenditures for the sample to the average expected expenditures for the sample ("ratio of averages"), which was 0.82 ( $\$1,071 \div \$1,306$ ).

## **Effect of Consumer Directed Care on Other Medicaid and Total Medicaid Services**

During the first year post-enrollment, the difference in total annual average Medicaid expenditures for the treatment group (\$29,974) and the control group

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<sup>14</sup> Future research will compare the characteristics of those who volunteered for the demonstration with all those eligible to participate in the demonstration to rigorously assess whether those who volunteered for the demonstration were different from the typical waiver recipient in the traditional program.

<sup>15</sup> The average ratio is more sensitive to outliers than the ratio of averages, as illustrated by the following example. Suppose someone has a very low support plan value at baseline of \$100 but, because of revisions in the support plan, receives \$400 of care in a particular month. From a budget perspective, the extra \$300 in actual costs in this example would not contribute much to the overall mean actual expenditures (which are expected to be \$1,306), but the ratio of 4 ( $\$400 \div \$100$ ) would drive up the average ratio considerably (which is expected to be 1).

(\$29,095) was small and not statistically significant (Table 3). About half the \$3,319 difference in waiver expenditures was offset by the treatment group's lower expenditures for home health services (\$1,574 less than those of the control group). For all the other non-waiver services, the treatment group's expenditures were not significantly different from the control group's during the first post-enrollment year.

During the second year post-enrollment, the treatment-control difference in average total Medicaid expenditures grew to \$2,581 ( $p = 0.082$ ). Again, the treatment group had significantly lower home health expenditures than the control group, by a somewhat greater margin than in Year 1. However, the treatment group's savings in home health expenditures (\$2,041) offset less than half the treatment-control difference in waiver expenditures, which grew to \$4,812.

## **Effects of Consumer Directed Care on Other Measures of Service Use**

Because Consumer Directed Care reduced Medicaid home health expenditures, we examined the source of the reduction to assess whether quality of care may have been affected. Specifically, we estimated treatment-control differences in the percentage of sample members using any Medicaid home health services and in the percentage using selected types of Medicaid home health services, as well as average expenditures for selected types of Medicaid home health services. The percentage of treatment group members using any Medicaid home health services was similar to that of the control group (about 30 percent for both groups during both the first and second post-enrollment years; Table 5). Similarly, the percentage of sample members using specific types of home health services was similar for the treatment and control group for each type of home health (private-duty nursing, aide, and therapy) that we examined.

Compared to the expenditures of the control group, those of the treatment group for private-duty nursing were \$1,866 lower during the first post-enrollment year and \$2,090 lower during the second.<sup>16</sup> No meaningful differences were observed for any of the other home health expenditure measures we examined. Thus, it appears that the control group's greater spending on private-duty nursing is the sole reason for the treatment-control difference in total home health expenditures. The treatment-control difference in private-duty nursing is further illustrated by the distribution of expenditures: the number of control group members who spent more than \$100,000 a year on private-duty nursing increased from 12 during the pre-enrollment year (about 2 percent of the

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<sup>16</sup> The raw difference in private-duty nursing expenditures was even larger, but it was due partly to pre-enrollment treatment-control differences in private-duty nursing spending. The regression models estimating the program's effect on private duty nursing expenditures and service use controlled for these pre-enrollment differences. Among treatment group members who received private-duty nursing services at baseline, private-duty nursing expenditures were lower, on average, during the post-enrollment period than during the pre-enrollment period; conversely, private-duty nursing expenditures were higher, on average, during the post-enrollment period than during the pre-enrollment period among control group members who received private-duty nursing care at baseline.

sample) to 17 in the first post-enrollment year; conversely, the number of treatment group members spending more than \$100,000 fell from 6 to 4 (Table A.3).

<b>TABLE 5. Estimated Effect of Consumer Directed Care on Selected Medicaid Service Use and Expenditure Measures</b>						
	<b>First Year</b>			<b>Second Year</b>		
	<b>Predicted Treatment Group Mean</b>	<b>Predicted Control Group Mean</b>	<b>Estimated Effect (p-value)</b>	<b>Predicted Treatment Group Mean</b>	<b>Predicted Control Group Mean</b>	<b>Estimated Effect (p-value)</b>
<b>Home Health Measures</b>						
Any Private-Duty Nursing Visits <sup>a</sup>	8.2	8.6	-0.4 (0.696)	8.6	8.2	0.4 (0.757)
Private-Duty Nursing Expenditures <sup>b</sup>	4,773	6,639	-1,866** (0.025)	4,827	6,918	-2,090** (0.044)
Any Home Health Aide Visit <sup>a</sup>	4.2	2.6	1.6 (0.158)	3.5	2.9	0.5 (0.617)
Home Health Aide Expenditures <sup>b</sup>	482	310	172 (0.336)	453	292	160 (0.367)
Any Home Health General Therapy Visits <sup>a</sup>	14.0	13.2	0.8 (0.722)	14.6	14.6	0.0 (0.997)
Home Health General Therapy Expenditures <sup>b</sup>	1,052	1,013	39 (0.830)	1,034	1,183	-150 (0.426)
Any Home Health Visit (%) <sup>a</sup>	29.3	27.8	1.5 (0.541)	29.8	31.7	2.0 (0.445)
Total Home Health Expenditures (\$) <sup>b</sup>	6,393	7,968	-1,574* (0.055)	6,361	8,402	-2,041* (0.050)
<b>Inpatient Measures</b>						
Number Inpatient Days <sup>c</sup>	1.3	1.5	-0.2 (0.448)	1.4	1.2	0.1 (0.597)
Any Inpatient Admission (%) <sup>a</sup>	12.0	13.4	-1.4 (0.445)	12.4	12.1	0.3 (0.873)
Total Medicaid Inpatient Expenditures (\$) <sup>b</sup>	777	1,186	-409 (0.240)	1,184	1,109	75 (0.829)
Any Emergency Room Visits (%) <sup>a</sup>	5.9	5.3	0.6 (0.680)	6.2	7.0	-0.8 (0.599)
<b>Sample Size</b>	<b>501</b>	<b>501</b>		<b>501</b>	<b>501</b>	
<b>SOURCE:</b> Medicaid claims data for the period from June 1999 through September 2003. *Significantly different from zero at the 0.10 level, two-tailed test. **Significantly different from zero at the 0.05 level, two-tailed test. ***Significantly different from zero at the 0.01 level, two-tailed test.  a. Means predicted using logit models. b. Means predicted using ordinary-least-squares regression models. c. Means predicted using tobit models.						

If Consumer Directed Care affected the quality of care children received, we might expect children in the treatment group to experience more (or fewer) adverse events or health problems than those in the control group. This, in turn, might affect their use of inpatient services. Therefore, we examined whether the program affected children's use of any inpatient services, the number of inpatient days, inpatient expenditures, or the likelihood of having an emergency room visit. The program, however, did not affect any of these measures significantly. Only 5 or 6 percent of children used emergency room services in a given year.

## Subgroup Effects

There were consistent patterns across subgroups (Table A.4). Within each subgroup, the treatment group generally had higher waiver expenditures, but lower home health expenditures, than the control group. There was one notable difference across subgroups: the increase in waiver expenditures (and, consequently, in total Medicaid expenditures), which was significantly higher for those who had high initial monthly allowances than for those with low ones. This difference was due mainly to control group members with high monthly allowances incurring only 77 percent of their expected waiver costs compared to control group members with low monthly allowances receiving an average of 102 percent of their expected waiver costs (not shown). This finding suggests that those with the greatest needs in the control group have difficulty obtaining all the services they are authorized to receive.

Policymakers might be concerned that the relatively valuable waiver benefits treatment group children received (in the form of the CDC allowance) was the main reason that the program increased parents' satisfaction with their child's care. To test this hypothesis, we estimated regressions on key quality outcomes that included an indicator variable for whether a person incurred monthly costs that were higher than the baseline value of their monthly care plan. Our results suggested that parents in both groups were more satisfied with their child's overall care when their child received higher-than-expected benefits (according to the child's discounted baseline waiver support plan). However, none of the estimated program effects on key outcomes were appreciably changed. For example, when we do not control for any cost ratio indicators, treatment group parents are 29.7 percentage points more likely than control group parents to be very satisfied with their child's overall care arrangements. When we do control for whether a child incurred higher costs than expected, the estimated treatment-control difference is 28.3 percentage points (Table A.5).<sup>17</sup>

## DISCUSSION

Waiver expenditures (both per sample member and per month of service) were higher for the treatment group than for the control group during both the first and second years post-enrollment, and the difference grew over time. The treatment group's higher waiver expenditures were partially offset by their lower expenditures for Medicaid home health services. The treatment-control difference in waiver expenditures was due to two factors. First, control group members incurred lower waiver costs than expected according to the discounted values of their baseline support plan. Second, treatment group members had higher-than-expected allowances.

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<sup>17</sup> These results are based on a logit model that included a binary control variable indicating whether a child incurred higher costs during the first post-enrollment year than would have been expected according to the child's discounted baseline waiver support plan. The program's impacts on quality outcomes were not appreciably affected when we included a continuous cost-ratio measure rather than a binary measure.

Our results raise several policy questions and concerns. First, why were the allowances of treatment group members an average of 30 percent higher than expected? The Consumer Directed Care program, which was intended to be flexible, permitted consumers to use their allowance in a variety of ways. In the spirit of flexibility, consultants may have authorized requests from parents for support plan increases that would not have been authorized under the traditional waiver program. Also, training for consultants was limited, and each consultant served only a small number (an average of nine) consumers. Consultants, possibly uncertain of program rules, may have been overly permissive in granting parents' requests for increases in the allowance.

Another policy concern is the control group's receiving fewer waiver services than were authorized at baseline, similar to our findings in the Arkansas Cash and Counseling demonstration, which we attributed primarily to agency worker shortages (Dale et al. 2003). We do not have data on which waiver services control group children were authorized to receive, or why they did not get them. It could be that that control group children failed to receive authorized PCS; indeed, the control group was 14 percentage points less likely than the treatment group to receive paid personal care at nine months post-enrollment (Foster et al. 2004).<sup>18</sup> Parents of children in the control group may have been uncomfortable having a stranger care for their child, and thus chose to forego the Medicaid PCS to which they were entitled. Alternatively, worker shortages in some parts of the state may have made it difficult for parents to find Medicaid certified providers. Another reason for the control group's lower-than-expected costs might be due to demonstration participants being different from the pool of waiver recipients from which the discount rate was calculated, or due to the discount rate being miscalculated. Finally, it is possible that support coordinators over-estimated the amount of care children needed. If that is true, however, it suggests that the treatment group's higher-than-expected costs are an even bigger problem.

Whatever the reason, the findings from both Arkansas and Florida point to the difficulty in setting a discount rate that will be accurate in a future period of time. To ensure that treatment group allowances are on a par with the costs of serving similar waiver recipients in the traditional program, discount rates may have to be reviewed (and, if necessary, changed) periodically. On the other hand, the use of fewer services than were authorized under the traditional program raises concerns about whether children are receiving adequate care in that program. Few policymakers would want to hold costs down by depriving children of services that assessment staff authorize as necessary. Thus, the focus may need to be less on initial discount rates than on ensuring that allowance amounts do not creep up faster for those on Cash and Counseling than do costs for children receiving waiver services from traditional sources.

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<sup>18</sup> This treatment-control difference in the receipt of paid assistance could also be due to parents of treatment group members choosing to purchase personal care that was not in their baseline care plan. The proportion of children getting paid personal care increased from the time of enrollment for both groups, but by a much larger percentage for the treatment group.

The reduction in home health costs under Consumer Directed Care suggests that there are opportunities for offsetting savings. The difference was due primarily to an increase in the proportion of control group members with high spending on private-duty nursing after the demonstration began. In contrast, parents of treatment group members may have preferred to use the allowance to hire family members, friends, and other non-Medicaid providers to meet their child's additional needs rather than seek extra private-duty nursing, even though Medicaid would have paid for this nursing care. This reduction in private-duty nursing under Consumer Directed Care could be problematic if some children are not receiving as much skilled nursing care as they need. However, only a handful of children in the treatment group who received private-duty nursing prior to enrollment did not receive any such help after the demonstration began; moreover, the distribution of spending on private-duty nursing for the treatment group barely changed over the course of the demonstration. Thus, it appears that those who needed private-duty nursing in the treatment group continued to receive it--although those who needed more care than they had at enrollment likely obtained assistance from workers hired with the allowance. Anecdotal evidence suggests that some parents did not like the way the private-duty nurses performed their duties. The allowance offered these parents the opportunity to reduce their dependence on these nurses somewhat.

## **Limitations**

Because the randomized evaluation design ensures that the impact estimates are unbiased, the limitations of the study described below do not cast doubt on the basic findings. Our study pertained to only one program in one state, however; so our findings may not apply to all programs featuring Consumer Directed Care. Impacts may differ for programs with other features (for example, those that target adults instead of children or that prohibit the hiring of parents, have benefits that are more or less generous, or cash out different services). Program effects on costs also will depend on the extent to which those receiving services under the traditional program receive the authorized amounts. Finally, only those who were already participating in the traditional waiver program were allowed to enroll in Consumer Directed Care. Programs that do not impose a prior-participation requirement might experience higher costs if the prospect of receiving a cash allowance leads to a greater influx of new applicants.

## **Implications of the Findings**

Both past and ongoing research indicates that findings for Florida children were similar to those for adults in Arkansas, in several respects. Compared to the traditional program, parents reported greater access to paid care, higher levels of satisfaction, and fewer unmet needs under Cash and Counseling in Florida (Foster et al. 2004); likewise, adult consumers received similar benefits in Arkansas (Foster et al. 2003). In part because the control group received only some of the services they were expected to receive, Cash and Counseling cost more than the traditional program for both Arkansas adults (Dale et al. 2003) and Florida children. In both states, the higher costs for Cash

and Counseling were offset somewhat by savings on other Medicaid services. However, between the first and second post-enrollment years, the treatment-control difference in total Medicaid costs decreased in Arkansas but increased in Florida.

The higher costs of the Consumer Directed Care program might discourage some states from adopting a similar program. However, this evaluation was conducted over a two-year follow-up period that started immediately after enrollment began, before Florida was able to identify and remedy any problems that occurred in implementing this innovative program. Since this demonstration, Florida has adopted for its current Consumer Directed Care program (CDC-Plus) many changes that might help control costs.<sup>19</sup> Florida's Developmental Disabilities agency received a Real Systems Change Grant to develop better training for a smaller pool of consultants. Rules were also adopted to help control the costs of allowances and one-time purchases. For example, parents wishing to make one-time purchases must first use unspent funds in their child's account before consultants can authorize revisions to their support plans. Also, unspent balances that exceed 1.5 times the monthly allowance must be spent or be forfeited. Ongoing training is being implemented for district and regional staff, one goal of which is to make sure that there is a common understanding about program goals and policies regarding granting requests for additional funding for support plans. Florida is adopting a new assessment form, called an Individual Cost Guideline, which will standardize the method for determining the costs of services that a child needs. Finally, an audit is being conducted to explore recouping funds from those who died, disenrolled, or had significant unexpended funds in their accounts.

To control costs in the future, Florida should carefully monitor the ratios of actual to expected costs for those in the traditional program, as well as those in the CDC program. If these actual costs under Consumer Directed Care increase faster than those for comparable individuals in the traditional program, staff will need to review the process for making revisions to support plans, to ensure that allowances are not increased beyond what is necessary to meet beneficiaries' needs. Conversely, Florida agencies overseeing the waiver program may wish to investigate why those in the traditional program (who had lower-than-expected costs) receive such a low proportion of the services they are authorized for. If they find that care plans are routinely set at overly generous amounts or if children have other reasons for not getting all of the services authorized, setting the allowance at a smaller fraction of the care plan amount than was used in the demonstration based on more recent historical data may be appropriate.

Parents reported greater satisfaction and fewer unmet needs under Consumer Directed Care than under the traditional program, even after controlling for Consumer Directed Care's higher-than-expected costs (Foster et al. 2004). These findings suggest that the benefits of the program to children and their families would be sizable even if allowances were limited to expected amounts. If the savings on other Medicaid

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<sup>19</sup> Personal communication with Florida Consumer Directed Care staff.

expenditures persist over time, and spending on cash allowances are controlled, the program might even generate savings to Medicaid. Future research will assess the robustness and generalizability of these findings by examining the effect of Cash and Counseling on Medicaid and Medicare costs and service use on adults in Florida and New Jersey.



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## APPENDIX A. ADDITIONAL TABLES

TABLE A.1. Benefits Covered by Florida's Developmental Services Waiver, By Type		
<b>Support Coordination</b>  <b>Personal Care</b> Chore services Companion services Homemaker Personal care assistance Respite  <b>Transportation</b>  <b>Supplies and Equipment</b> Personal emergency response systems Special medical equipment and supplies	<b>Environmental Modifications</b>  <b>Professional Services</b> 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	<b>Behavior, Mental Health Therapy, Habilitation, Community Integration</b> Adult day training Behavioral services Non-residential support services Residential habilitation Specialized mental health services Supported employment Supported living coaching  <b>Other</b> In-home supports Therapeutic massage
<b>SOURCE:</b> Florida Medicaid Program, 2003.		

TABLE A.2. Actual and Baseline Waiver Costs During the First Post-Enrollment Year, By District									
District		Treatment Group				Control Group			
		Sample Size	Actual Annual Waiver Costs	Baseline Annual Waiver Costs	Ratio of Average Actual to Average Baseline Costs	Sample Size	Actual Annual Waiver Costs	Baseline Annual Waiver Costs	Ratio of Average Actual to Average Baseline Costs
1	Escambia, Santa Rosa, Okaloosa, Walton	31	15,603	17,675	0.88	46	13,357	19,950	0.67
2	Calhoun, Franklin, Gadsden, Gulf, Holmes, Jackson, Jefferson, Leon, Liberty, Madison, Taylor, Wakulla, Washington, Bay	46	9,923	10,680	0.93	46	8,048	9,632	0.84
3	Alachua, Bradford, Columbia, Dixie, Gilchrist, Hamilton, Lafayette, Levy, Putnam, Suwannee, Union	19	17,020	16,995	1.00	16	16,850	19,252	0.88
4	Duval, Nassau, Baker, Clay, Saint Johns	40	10,225	10,493	0.97	43	9,485	10,711	0.89
7	Orange, Seminole, Osceola, Brevard	36	10,104	9,637	1.05	34	9,118	12,261	0.74
8	Charlotte, Collier, Glades, Hendry, Lee	18	20,840	20,876	1.00	18	11,504	12,844	0.90
9	Palm Beach	45	15,470	11,147	1.39	38	10,247	10,787	0.95
10	Broward	58	16,657	12,924	1.29	66	13,135	13,212	0.99
11	Miami-Dade, Monroe	52	20,212	19,156	1.06	59	19,373	19,485	0.99
12	Flagler, Volusia	7	11,229	7,384	1.52	10	5,101	10,198	0.50
13	Citrus, Hernando, Lake, Marion, Sumter	34	15,576	15,263	1.02	24	13,800	18,419	0.75
14	Hardee, Highlands, Polk	6	10,833	10,385	1.04	6	6,212	5,288	1.17
15	Indian River, Martin, Okeechobee, Saint Lucie	15	21,278	14,807	1.44	20	16,847	22,633	0.74
100	Suncoast	94	18,929	20,688	0.91	75	14,722	21,608	0.68
<b>SOURCE:</b> Medicaid claims data, June 1999 through September 2003. <b>NOTE:</b> Actual waiver costs include expenditures for allowances, support coordination/consulting, and other waiver services. Expected waiver costs include the discounted value of the support plan plus \$148 per month for counseling or support coordination.									

TABLE A.3. Expenditures on Medicaid Private-Duty Nursing												
Expenditure Range	Pre-enrollment				Year 1				Year 2			
	Treatment Group		Control Group		Treatment Group		Control Group		Treatment Group		Control Group	
	#	%	#	%	#	%	#	%	#	%	#	%
\$0	463	92.4	459	91.6	462	92.2	456	91.0	460	91.8	458	91.4
\$1 - \$50,000	23	4.6	20	4.0	22	4.4	15	3.0	26	5.2	16	3.2
\$50,000 - \$100,000	9	1.8	10	2.0	13	2.6	13	2.6	9	1.8	9	1.8
>\$100,000	6	1.2	12	2.4	4	0.8	17	3.4	6	1.2	18	3.6
<b>SOURCE:</b> Medicaid claims data, June 1999 through September 2003.												

TABLE A.4. Effect of Consumer Directed Care on Medicaid Expenditures for Children, By Subgroup									
	Treatment Group Predicted Mean	Control Group Predicted Mean	Estimated Effect	p-value for Estimated Effect	Treatment Group Predicted Mean	Control Group Predicted Mean	Estimated Effect	p-value for Estimated Effect	p-value for Interaction Term
	Live in Rural Area (n = 180)				Live in Non-rural Area (n = 822)				
Year 1									
Total Medicaid Costs	26,987	23,702	3,284	0.261	30,760	30,190	569	0.677	0.400
Waiver Costs	16,389	12,592	3,797	0.003***	16,009	12,529	3,481	0.000***	0.823
Medicaid Home Health Costs	4,356	4,490	-134	0.945	6,843	8,756	-1,914	0.035**	0.406
Year 2									
Total Medicaid Costs	31,162	25,339	5,822	0.099*	34,096	32,018	2,078	0.209	0.337
Waiver Costs	20,393	13,433	6,961	0.000***	18,698	14,046	4,652	0.000***	0.216
Medicaid Home Health Costs	3,949	5,375	-1,426	0.562	6,863	9,106	-2,244	0.051*	0.763
	Receiving Medicaid PCS at Baseline (n = 533)				Did Not Receive Medicaid PCS at Baseline (n = 469)				
Year 1									
Total Medicaid Costs	31,911	28,845	3,066	0.074*	28,043	29,099	-1,057	0.563	0.101
Waiver Costs	21,315	17,152	4,163	0.000***	10,107	7,305	2,802	0.001***	0.214
Medicaid Home Health Costs	3,375	4,050	-675	0.551	9,867	12,372	-2,505	0.038**	0.269
Year 2									
Total Medicaid Costs	35,958	30,675	5,284	0.011**	30,843	30,868	-24	0.991	0.079*
Waiver Costs	24,165	18,858	5,307	0.000***	13,079	8,328	4,751	0.000***	0.698
Medicaid Home Health Costs	3,706	4,023	-317	0.825	9,403	13,347	-3,944	0.010***	0.084*
	Had Unmet Need for Personal Care (n = 660)				Did Not Have Unmet Need for Personal Care (n = 342)				
Year 1									
Total Medicaid Costs	32,060	31,874	186	0.903	26,223	23,486	2,737	0.197	0.331
Waiver Costs	17,742	14,165	3,577	0.000***	12,860	9,397	3,463	0.000***	0.921
Medicaid Home Health Costs	6,489	8,637	-2,148	0.034**	6,188	6,713	-525	0.709	0.350
Year 2									
Total Medicaid Costs	35,129	33,492	1,637	0.376	30,500	25,600	4,899	0.057*	0.303
Waiver Costs	21,050	15,821	5,228	0.000***	15,003	10,244	4,758	0.000***	0.756
Medicaid Home Health Costs	6,357	8,734	-2,377	0.065*	6,293	7,849	-1,556	0.384	0.710
	Prospective Allowance at Baseline Was Above Average (n = 489)				Prospective Allowance at Baseline Was Below Average (n = 513)				
Year 1									
Total Medicaid Costs	38,623	35,042	3,581	0.044**	22,034	23,361	-1,327	0.442	0.048**
Waiver Costs	23,679	18,661	5,018	0.000***	8,904	6,766	2,138	0.005***	0.008***
Medicaid Home Health Costs	6,784	7,732	-949	0.421	6,036	8,238	-2,203	0.055*	0.446
Year 2									
Total Medicaid Costs	41,938	36,071	5,866	0.006***	25,702	25,893	-191	0.927	0.044**
Waiver Costs	27,052	19,900	7,152	0.000***	11,406	8,308	3,098	0.002***	0.005***
Medicaid Home Health Costs	6,273	7,701	-1,428	0.340	6,426	9,154	-2,728	0.061*	0.534
SOURCE: Medicaid claims data, June 1999 through August 2003.									
NOTE: P-value for interaction term indicates whether estimated effects for two subgroups are significantly different from each other. Effects estimated with ordinary-least-squares models controlling for person's baseline characteristics and pre-enrollment Medicaid expenditures.									
*Significantly different from zero at the 0.10 level, two-tailed test.									
**Significantly different from zero at the 0.05 level, two-tailed test.									
***Significantly different from zero at the 0.01 level, two-tailed test.									

TABLE A.5. Estimated Effects of Consumer Directed Care on Key Quality Outcomes, By Whether Controlling for Ratios of Actual-to-Baseline Waiver Costs		
Outcome	Estimated Effect (p-Value)	
	Cost Ratio Not Controlled For	Cost Ratio Controlled For
Very Satisfied With Child's Overall Care Arrangement (n = 794)	29.7*** (0.000)	28.3*** (0.000)
Child Has an Unmet Need for: (n = 796)		
Help doing things around the house	-17.0*** (0.000)	-17.7*** (0.000)
Help with personal care	-11.8*** (0.000)	-12.4*** (0.000)
Help with transportation	-9.2*** (0.004)	-9.2*** (0.004)
Help with routine health care	-10.0*** (0.001)	-9.5*** (0.002)
Care supplies	-12.0*** (0.000)	-11.5*** (0.001)
Very Satisfied With Paid Caregivers' Schedule (n = 562)	21.4*** (0.000)	21.8*** (0.000)
Very Satisfied With Way Child is Spending Life These Days (n = 794)	23.2*** (0.000)	22.8*** (0.000)
<b>SOURCE:</b> MPR's nine-month interview, conducted between April 2001 and July 2002, and Medicaid claims data. <b>NOTE:</b> Means were predicted with logit models. Results in the right-hand column were estimated with a logit model that included a binary control variable indicating whether a child incurred higher waiver costs during the direct post-enrollment year than would have been expected according to the child's discounted baseline waiver support plan. *** Significantly different from zero at the 0.01 level, two-tailed test.		