



U.S. Department of Health and Human Services  
Assistant Secretary for Planning and Evaluation  
Office of Disability, Aging and Long-Term Care Policy



# **CONSUMER AND CONSULTANT EXPERIENCES IN THE FLORIDA CONSUMER DIRECTED CARE PROGRAM**

June 2005

## **Office of the Assistant Secretary for Planning and Evaluation**

The Office of the Assistant Secretary for Planning and Evaluation (ASPE) is the principal advisor to the Secretary of the Department of Health and Human Services (HHS) on policy development issues, and is responsible for major activities in the areas of legislative and budget development, strategic planning, policy research and evaluation, and economic analysis.

ASPE develops or reviews issues from the viewpoint of the Secretary, providing a perspective that is broader in scope than the specific focus of the various operating agencies. ASPE also works closely with the HHS operating divisions. It assists these agencies in developing policies, and planning policy research, evaluation and data collection within broad HHS and administration initiatives. ASPE often serves a coordinating role for crosscutting policy and administrative activities.

ASPE plans and conducts evaluations and research--both in-house and through support of projects by external researchers--of current and proposed programs and topics of particular interest to the Secretary, the Administration and the Congress.

## **Office of Disability, Aging and Long-Term Care Policy**

The Office of Disability, Aging and Long-Term Care Policy (DALTCP), within ASPE, is responsible for the development, coordination, analysis, research and evaluation of HHS policies and programs which support the independence, health and long-term care of persons with disabilities--children, working aging adults, and older persons. DALTCP is also responsible for policy coordination and research to promote the economic and social well-being of the elderly.

In particular, DALTCP addresses policies concerning: nursing home and community-based services, informal caregiving, the integration of acute and long-term care, Medicare post-acute services and home care, managed care for people with disabilities, long-term rehabilitation services, children's disability, and linkages between employment and health policies. These activities are carried out through policy planning, policy and program analysis, regulatory reviews, formulation of legislative proposals, policy research, evaluation and data planning.

This report was prepared under contract #HHS-100-95-0046 between HHS's ASPE/DALTCP and the University of Maryland. Additional funding for this project was provided by the Robert Wood Johnson Foundation. For additional information about this subject, you can visit the DALTCP home page at [http://aspe.hhs.gov/\\_/office\\_specific/daltcp.cfm](http://aspe.hhs.gov/_/office_specific/daltcp.cfm) or contact the ASPE Project Officer, Pamela Doty, at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. Her e-mail address is: [Pamela.Doty@hhs.gov](mailto:Pamela.Doty@hhs.gov).

# **CONSUMER AND CONSULTANT EXPERIENCES IN THE FLORIDA CONSUMER DIRECTED CARE PROGRAM**

Leslie Foster  
Barbara Phillips  
Jennifer Schore

Mathematica Policy Research, Inc.

June 2005

Prepared for  
Office of Disability, Aging and Long-Term Care Policy  
Office of the Assistant Secretary for Planning and Evaluation  
U.S. Department of Health and Human Services  
Contract #HHS-100-95-0046

The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of the Department of Health and Human Services, the contractor or any other funding organization.

# TABLE OF CONTENTS

<b>ACKNOWLEDGMENTS</b> .....	v
<b>EXECUTIVE SUMMARY</b> .....	vi
<b>INTRODUCTION</b> .....	1
Consumer Direction of Medicaid Supportive Services .....	1
The Cash and Counseling Model.....	2
The Cash and Counseling Evaluation.....	2
Guide to This Report.....	3
<b>KEY FEATURES OF CASH AND COUNSELING IN FLORIDA</b> .....	6
Goals .....	6
Target Population.....	6
Government Stakeholders .....	7
Outreach and Enrollment .....	7
The CDC Allowance.....	9
Organization of Consulting and Fiscal Services.....	10
<b>FINDINGS</b> .....	12
Consumer Characteristics.....	12
Consumer-Consultant Interactions.....	13
Starting on the Allowance .....	14
Consumer-Fiscal Agent Interactions .....	16
Consumer Management of Program Responsibilities .....	17
How Consumers Took Advantage of Increased Flexibility .....	21
Consumer Satisfaction .....	23
Disenrollment .....	25
Experiences of Different Types of Consumers.....	25
Consultant Assessment of CDC.....	28
<b>SUMMARY, LESSONS, AND POLICY IMPLICATIONS</b> .....	30
Summary .....	30
Implementation Lessons from CDC .....	30
How CDC Addressed Policy Concerns .....	33
Conclusion .....	36
<b>REFERENCES</b> .....	37
<b>COMPANION REPORTS</b> .....	40
<b>APPENDIX A. ADDITIONAL TABLES</b>	

# LIST OF TABLES

TABLE 1:	Topics Covered in MPR Consumer Surveys .....	5
TABLE 2:	Consumer Characteristics at Random Assignment, by Age Group .....	13
TABLE 3:	Time from Random Assignment to Start of Monthly Allowance, by Age Group .....	15
TABLE 4:	Use of and Satisfaction with CDC Services .....	18
TABLE 5:	Recruiting and Hiring Workers.....	19
TABLE 6:	Assistance from Paid Workers Among Consumers Who Hired with the Allowance, by Age Group .....	22
TABLE 7:	Satisfaction with CDC, by Age Group.....	24
TABLE A.1:	Enrollment Flow and Length of Stay, All Consumers .....	A-1
TABLE A.1a:	Enrollment Flow and Length of Stay, by Age Group and Waiver Tenure.....	A-2
TABLE A.2:	Waiver Participation, CDC Allowance, and Use of Representatives, at the Time of Random Assignment, by Age Group.....	A-2
TABLE A.3:	Consumer Characteristics at the Time of Random Assignment, by Age Group.....	A-3
TABLE A.4:	Program Features Important to Consumers at the Time of Random Assignment, by Age Group.....	A-6
TABLE A.5:	Consultant Characteristics and Experience with CDC .....	A-7
TABLE A.6:	Activities Conducted by Consultants .....	A-8
TABLE A.7:	Consumer Monitoring.....	A-9
TABLE A.8:	Time Between Random Assignment and Monthly Allowance Start, Disenrollment, or Death, All Consumers.....	A-10
TABLE A.8a:	Time Between Random Assignment and Monthly Allowance Start, by Age Group and Waiver Tenure .....	A-11

TABLE A.9:	Use of Representatives .....	A-12
TABLE A.10:	Use of, and Satisfaction With, Program Services, All Consumers.....	A-12
TABLE A.10a:	Use of, and Satisfaction With, Program Services, Children’s Parents.....	A-13
TABLE A.10b:	Use of, and Satisfaction With, Program Services, Nonelderly Adults .....	A-14
TABLE A.10c:	Use of, and Satisfaction With, Program Services, Elderly Adults .....	A-15
TABLE A.11:	Aspects of Program Services Found Useful, by Age Group.....	A-16
TABLE A.12:	Difficulties Assuming the Role of Employer, by Age Group.....	A-17
TABLE A.13:	Recruiting Methods, by Age Group .....	A-18
TABLE A.14:	Satisfaction with Workers as Reported by Consultants.....	A-18
TABLE A.15:	Consultant Reports of Abuse of Consumers and Workers.....	A-19
TABLE A.16:	Consultant Reports of Misuse of the Monthly Allowance .....	A-20
TABLE A.17:	Assistance from Paid Workers, by Age Group .....	A-21
TABLE A.18:	Uses of the Monthly Allowance, All Consumers.....	A-22
TABLE A.18a:	Uses of the Monthly Allowance, Children’s Parents .....	A-23
TABLE A.18b:	Uses of the Monthly Allowance, Nonelderly Adults .....	A-24
TABLE A.18c:	Uses of the Monthly Allowance, Elderly Adults .....	A-25
TABLE A.19:	Specific Types of Consumer Purchases Reported by Consultants .....	A-26
TABLE A.20:	Flexibility and Constraints of the Monthly Allowance.....	A-27
TABLE A.21:	Satisfaction with CDC, by Age Group .....	A-28
TABLE A.22a:	Satisfaction with and Unmet Need for Personal Assistance, by Age Group.....	A-29

TABLE A.22b: Satisfaction with CDC and Personal Assistance, by Type of Respondent.....	A-30
TABLE A.23: Disenrollment and Death During Follow-up Year, by Age Group.....	A-31
TABLE A.24: Effect of Consumer Characteristics on Whether Started on Allowance Within 9 Months of Random Assignment.....	A-32
TABLE A.25: Effect of Consumer Characteristics on Whether Found Hiring Difficult.....	A-34
TABLE A.26: Effect of Consumer Characteristics on Whether Consumer Found CDC Spending Rules Restrictive.....	A-36
TABLE A.27: Effect of Consumer Characteristics on Satisfaction and Unmet Need.....	A-38
TABLE A.28: Effect of Consumer Characteristics on Voluntary Disenrollment.....	A-41
TABLE A.29: Consultant Assessment of Consumers' Overall Experiences with CDC.....	A-43
TABLE A.30: Consumer Difficulties with Program Responsibilities.....	A-44
TABLE A.31: Consultant Opinions of, and Recommendations for, CDC.....	A-44

# ACKNOWLEDGMENTS

This report has benefited greatly from the thought-provoking comments of several people. In particular, we thank external reviewers Richard Browdie (Benjamin Rose), James Firman (National Council on the Aging), and Robyn Stone (Institute for the Future of Aging Services). Several members of the Cash and Counseling Demonstration and Evaluation management team--Kevin Mahoney, Lori Simon-Rusinowitz, Sue Flanagan, Barbara Schneider, Marie Squillace, Nancy Wieler Fishman, and members of the staff of the Centers for Medicare & Medicaid Services (CMS)--provided useful and insightful comments. We also appreciate comments and suggestions from the Florida Consumer Directed Care Plus program in the Department of Elder Affairs, the Agency for Persons with Disabilities, and the Agency for Health Care Administration.

The report would not have been possible without the contributions of several colleagues at Mathematica Policy Research, Inc. Nora Paxton, Licia Gaber, Amy Zambrowski, and Peter Crosta programmed the analysis, and Henry Ireys provided thoughtful comments on an earlier draft. Patricia Ciaccio edited the report, and Jill Miller produced it.

The opinions presented here are those of the authors and do not necessarily reflect those of the funders (the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation), the Cash and Counseling National Program Office, CMS, or the demonstration states.

# EXECUTIVE SUMMARY

## Background

Roughly 1.4 million people with physical or developmental disabilities receive Medicaid-funded supportive services at home or in the community each year. Home care agencies provide many of these services: under professional supervision, agency workers help beneficiaries with bathing, preparing meals, light housework, and other basic activities. “Consumer-directed care,” wherein Medicaid beneficiaries hire, train, supervise, and pay workers of their choice, is an alternative to the professional service model. Consumer direction increases beneficiaries’ autonomy and control, but it also increases their responsibilities.

Cash and Counseling is a model of consumer-directed care that offers eligible Medicaid beneficiaries the opportunity to receive a monthly allowance to hire workers, including family members, and purchase other disability-related services and goods. Parents manage the allowance for consumers younger than 18, and adult consumers can designate a representative, such as a family member or friend, to help them manage their care. Cash and Counseling also offers counseling and fiscal services to consumers and representatives. Florida, along with Arkansas and New Jersey, has tested the Cash and Counseling model as part of a three-state demonstration. Mathematica Policy Research, Inc. is the demonstration evaluator.

In Florida, the demonstration was open to children and adults with developmental disabilities, frail elderly adults, and adults with physical disabilities who were receiving Medicaid home and community-based services (HCBS) through the state’s Developmental Disabilities (DD) or Aged/Disabled Adult (ADA) waiver programs. The evaluation randomly assigned demonstration enrollees to participate in Florida’s Consumer Directed Care (CDC) program (the treatment group) or to receive HCBS as usual (the control group).

**Goals of the Report.** This report describes the implementation of CDC by synthesizing information from in-person discussions with program staff, a mail survey of program consultants, telephone interviews with consumers in the treatment group, and program records. It discusses the program’s goals and features, the ways beneficiaries managed their program responsibilities and took advantage of increased flexibility, and the degree to which beneficiaries were satisfied with the program. (Other reports from the evaluation estimate the program’s impacts on beneficiaries, their caregivers, and public costs; describe the types of beneficiaries and workers who chose to participate in the demonstrations; and explain demonstration implementation and program operations in greater detail.)

**The CDC Intervention.** The CDC program allowance was based on the value of consumers’ waiver care plans or claims histories. At enrollment, consumers were eligible for monthly allowances of \$1,186, on average (\$1,108 for children, \$1,641 for

nonelderly adults, and \$818 for elderly adults). To receive the allowance, consumers or their representatives had to develop a written purchasing plan that met the approval of the CDC program. Consultants helped consumers develop their purchasing plans and monitored their well-being. They were also available to train consumers on program rules and employer responsibilities. The fiscal agent was available to write checks for goods and services purchased with the allowance and to process payroll taxes and employment forms for consumers who hired workers. The program did not charge consumers directly for consulting services, but consumers did pay for the fiscal services they used, up to a maximum of \$25 a month.

## Major Findings

**Outreach and Enrollment.** Florida began enrolling consumers in the demonstration and evaluation in June 2000. Initially, case managers from the ADA waiver program and support coordinators from the DD waiver program were responsible for outreach and enrollment activities. However, some did not support the concept of consumer direction--particularly for elderly adults--or were occupied with other responsibilities, and enrollment lagged far behind evaluation targets. About six months into the enrollment period, CDC hired 20 temporary state employees to work as enrollment specialists and build demonstration caseload. It also arranged to send a letter describing the demonstration from the governor's office to eligible participants. The pace of enrollment then increased considerably, especially among children and nonelderly adults with developmental disabilities.

Florida enrolled 1,002 children in the demonstration and evaluation by August 2001 (15 months), 914 nonelderly adults by November 2001 (18 months), and 904 elderly adults by July 2002 (26 months). The evaluation randomly assigned 501 children, 456 nonelderly adults, and 453 elderly adults to the treatment group. All children in the treatment group, 90 percent of nonelderly adults, and 2 percent of elderly adults joined the demonstration through the DD waiver. Ninety-eight percent of elderly adults and the remaining 10 percent of nonelderly adults joined through the ADA waiver.

**Consumer Characteristics.** Despite differences in age and disability, consumers who enrolled in the demonstration had some characteristics in common. Most were White, and either they or their representative were high school graduates. Nearly all consumers were receiving help with household and community activities and personal care when they enrolled in the demonstration, but many said they needed more help. A larger proportion of nonelderly than elderly consumers had representatives (84 versus 70 percent), which reflects the prevalence of developmental disabilities in the younger group.

**Planning for, and Using, the Allowance.** It took many consumers a long time to develop purchasing plans and begin receiving their monthly allowance, if they did so at all. Twelve months after being assigned to CDC, only 57 percent of all consumers had received the allowance--71 percent of children, 58 percent of nonelderly adults, and

only 41 percent of elderly adults. Allowance delays stemmed from consumers' individual circumstances (such as illness or not having family or friends to hire), staff workloads and procedural delays (such as the purchasing plan review and approval process), and an initial uncertainty about whether consumers were suitable for CDC if they could not develop a purchasing plan mostly independently. The program eventually began offering consumers more help with their purchasing plans if they had not started on the allowance within 90 days of enrollment.

Consumers who received the allowance used it to meet a variety of care-related needs. Among consumers receiving the allowance around the time of a nine-month follow-up survey, 78 percent (82 percent of children, 71 percent of nonelderly adults, and 81 percent of elderly adults) said they used it to hire one or more workers. Nearly 60 percent of these consumers hired family members, but the proportion was smaller for children (52 percent) than for elderly adults (64 percent). Most workers helped consumers with household and community activities and personal care, and many provided assistance with routine health care and transportation. According to program records, consumers used at least half their monthly allowance to pay workers. Four in ten consumers opted to receive some of the allowance (up to 20 percent) as cash for incidental purchases identified in the purchasing plan. Some also used the allowance to buy personal care supplies (16 percent) or community services (15 percent).

Hiring workers was difficult for some consumers. Nineteen percent of all consumers (15 percent of children and approximately 21 percent of nonelderly and elderly adults) tried to hire but were not able to. Two-fifths of those who did hire said it was difficult, often because of a lack of interested or qualified candidates. Parents who hired for minor children were more likely than adult consumers to report difficulty (46 percent versus roughly 37 percent).

**Consulting and Fiscal Services.** Consultants reported that they spent most of their time helping consumers develop purchasing plans, performing administrative tasks, and encouraging or listening to consumers. Most consultants believed their services were of value to consumers. Likewise, most consumers said they received useful help from their consultants. According to program staff and consultants who took part in site visit discussions, however, consultants' initial reluctance to provide hands-on assistance while consumers were developing their purchasing plans might have led some consumers to drop out of the program without completing a plan or receiving the program allowance.

Nearly all allowance recipients used the program's fiscal services; the availability of these services undoubtedly contributed to consumers' success in the program. The fiscal agent's performance of some of its CDC responsibilities was hampered, however, by slow cash flow, higher-than-expected costs, and inadequate reimbursement from the program. For example, about 18 months elapsed before the fiscal agent was able to produce timely, easily understood financial statements, which consumers and consultants needed to monitor spending.

**Consumer Satisfaction.** Nine months after being assigned to CDC, 88 percent of consumers said they would “recommend the program to others who wanted more control over their personal care services.” Among consumers who received the allowance, roughly 60 percent said the allowance had “greatly improved” their life, and another quarter said it improved life “somewhat.” Satisfaction with the program was fairly uniform across age groups. In addition, 56 percent of children’s parents, 67 percent of nonelderly adults, and 50 percent of elderly adults were very satisfied with their overall care arrangements nine months after enrollment. Among consumers who hired workers with the CDC allowance, 25 percent of children’s parents, 29 percent of nonelderly adults, and 37 percent of elderly adults reported unmet needs for personal care. Thirty-two percent of all consumers said program rules kept them from purchasing things that would have enhanced their independence or that of their child. Parents of minor children were most likely to report this constraint (38 percent).

**Disenrollment.** As in the other demonstration states, about one-quarter of consumers chose to leave the CDC program within a year of enrolling. Elderly consumers were most likely to disenroll (38 percent), and children were least likely (16 percent). Consumers most commonly said they disenrolled because they changed their minds or were satisfied with their usual waiver services. Elderly adults were more likely than younger consumers to say they disenrolled because they had problems with their responsibilities as employers or with fiscal tasks.

**Experiences of Different Types of Consumers.** Multivariate models used to assess the experiences of different types of consumers suggested that, all else being equal, consumers eligible for fairly generous allowances and those who enrolled during the first 12 months of demonstration intake--presumably the most eager and self-motivated consumers--were more likely than others to receive the allowance and remain in the program for their follow-up year. Consumers who were interested in paying family and friends for caregiving, those who had informal caregivers, and those with prior hiring experience or a representative with such experience also were especially likely to fare well in CDC.

## **Policy Implications**

Of the Cash and Counseling demonstration states, only Florida targeted the demonstration to people with primarily developmental disabilities, and only Florida enrolled children. Moreover, whereas Arkansas and New Jersey based the consumer-directed allowance only on Medicaid state plan personal care services, Florida based it on a wide range of Medicaid HCBS benefits, including professional therapies. Our analysis of data from discussions with program staff, consultant questionnaires, and consumer surveys shows that Florida’s CDC program is worthwhile from a consumer perspective and feasible from an administrative one. In terms of enrollment, retention, and satisfaction, the program was most attractive to the families of children with developmental disabilities and least attractive to frail elderly adults.

Consumer direction of public funds raises concerns among policymakers, however. These concerns include: (1) whether all Medicaid beneficiaries should be able to direct their own supportive services if they want to; (2) whether it is appropriate for consumers to pay family members for caregiving; (3) how to ensure the quality of consumer-directed services; (4) how to ensure that workers are trained and fairly treated; and (5) how to avoid fraudulent use of the allowance. CDC procedures addressed each of these concerns to at least some extent.

**Assessing Suitability for Consumer Direction.** Florida's policy was to *not* screen prospective enrollees for their suitability for consumer direction, but rather to inform them of their responsibilities and rights under the program and let them decide whether to enroll and whether to select a representative. In practice, however, some case managers appear to have discouraged the enrollment of elderly adults. Likewise, some consultants were reluctant to help consumers develop their purchasing plans, believing that consumers needing extensive help were not fit for the program. Florida addressed these issues by hiring temporary state employees to conduct outreach and enrollment activities, and by instructing consultants to give consumers more assistance in developing their purchasing plans if they needed it. It also allowed consumers to receive HCBS as usual until the CDC allowance started and to disenroll from the program and revert to traditional HCBS on the first day of the following month. Thus, Florida made procedural adjustments and learned about consumers' suitability for consumer direction without undue risk to the consumers.

**Paying Family Members.** While policymakers debate the use of public funds to pay family members for caregiving, Florida allowed CDC consumers to hire family members, including (legally responsible) spouses and parents of minors. The option to hire relatives probably was critical to the program's success. Nearly 60 percent of all consumers who hired workers hired family members. Although 38 percent of consumers who hired workers hired at least one person unrelated to them, the proportion that successfully hired nonrelatives was considerably smaller than the proportion that tried to do so.

**Exploitation of Workers.** Although CDC had no formal mechanism for workers to report grievances, worker abuse does not seem to have been a serious problem in the program. Furthermore, although few CDC consumers provided fringe benefits to their workers, nearly all workers were paid on a part-time basis, and fringe benefits are rare in most part-time jobs.

**Ensuring Consumer Safety.** Data for this analysis yielded no evidence that participation in CDC led to adverse effects on consumers' health and safety. CDC monitored consumer safety and care quality primarily through consultants' contacts with consumers and representatives, which occurred through telephone calls and home visits. Moreover, while there was very little evidence of consumer neglect or exploitation in CDC, program staff developed formal arrangements for consultants to refer suspicious cases to protective-services agencies.

**Preventing Fraud.** The CDC program developed several policies to prevent misuse of the allowance: (1) consultants were to review monthly financial statements with the consumer or representative each month; (2) consumers were to retain receipts for incidental purchases made with cash; and (3) the fiscal agent was to pay only for purchases listed in consumers' purchasing plans. It took time to implement these policies, especially the provision concerning financial statements. Any misuse of the allowance seemed to result from honest error on the part of consumers.

## **Conclusion**

Despite challenges Florida faced in implementing the CDC program, many consumers successfully arranged supportive services that met their individual needs and enhanced their sense of self-sufficiency. Program staff adhered to the tenets of the relatively expansive Cash and Counseling model of service delivery and made operational adjustments in areas where practice fell short of policy. Florida continues to offer the CDC program as an option to eligible HCBS recipients. In summer 2002 the state legislature passed the Florida Consumer-Directed Care Act, which directed several state agencies to develop and seek Medicaid waivers for consumer-directed programs like CDC.

# INTRODUCTION

## **Consumer Direction of Medicaid Supportive Services**

Each year in the United States, about 1.4 million people with disabilities receive Medicaid supportive services benefits to help them live at home or in other community settings, instead of in institutions (Harrington and Kitchener 2003). Whether states offer such benefits as Medicaid home and community-based services (HCBS) or state plan personal care services (PCS), they cover them in limited amounts and select the providers or vendors who can supply them. Often, case managers decide which benefits people need, and nurses supervise home care workers. This system of service delivery has been criticized for over-medicalizing supportive services and for being too inflexible to meet individual needs. Moreover, home care workers are perennially in short supply. Shortages worsen when the economy is strong, and they will likely deepen as the United States population ages and demands more supportive services.

As an alternative to traditional models of service delivery, states are increasingly offering Medicaid beneficiaries and their families opportunities to obtain supportive services directly from individual providers (O'Brien and Elias 2004; Velgouse and Dize 2000). This alternative has become known as "consumer-directed" care, because beneficiaries who use individual providers assume the employer's role of hiring, managing, and, possibly, terminating their paid caregivers (Eustis 2000). Consumer-directed care is based on the premise that, because supportive services are "low tech" and nonmedical, they do not require the intervention of medical professionals. Rather, beneficiaries should be empowered to direct their own benefits, as service consumers (Benjamin and Matthias 2001; Stone 2001; Eustis 2000; Doty et al. 1996). In 1999, an estimated 139 publicly-funded consumer-directed programs served adults or children with physical or developmental disabilities in the United States (Flanagan 2001).

From the perspective of many people affected by disabilities, consumer direction has the potential to meet individual needs better than traditional HCBS or PCS and to promote autonomy and independence. These two basic American values have recently been affirmed in policies such as President George W. Bush's New Freedom Initiative. Consumer direction also could help address the shortage of home care workers by allowing people to pay family and friends for caregiving, thereby expanding the pool of potential workers. Finally, consumer direction has the potential to lower public costs by eliminating home care agency involvement in hiring, training, and supervising workers (Stone 2000; Eustis 2000).

Publicly-funded consumer-directed programs do raise some concerns. These include: (1) whether consumer direction should be available to all users of supportive services; (2) whether to allow family members to be paid for caregiving; (3) how to ensure care quality; (4) how to ensure that workers are trained adequately and treated fairly; and (5) how to avoid fraudulent use of the cash benefit (Simon-Rusinowitz et al.

forthcoming; Benjamin 2001; Feinberg and Whitlach 2001; Kane and Kane 2001; Kapp 2000; Tilly et al. 2000; Doty et al. 1996).

## **The Cash and Counseling Model**

Cash and Counseling, which is a fairly expansive model of consumer-directed care, provides a flexible monthly allowance that consumers may use to hire providers, as well as to purchase the other services and goods they may need (within state guidelines). Parents manage the allowance for consumers under 18, and adult consumers can designate a representative (such as a family caregiver) to manage, or help them manage, their care. In addition, Cash and Counseling offers counseling and fiscal services to help consumers and representatives handle their program responsibilities. These tenets of Cash and Counseling--a flexible allowance, use of representatives, and availability of counseling and fiscal services--are meant to make consumer direction adaptable to consumers of all ages and abilities.

Arkansas, Florida, and New Jersey have each tested the Cash and Counseling model in their Medicaid systems as part of a three-state demonstration. The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services funded the demonstration. The Centers for Medicare & Medicaid Services approved the demonstration programs under Section 1115 authority of the Social Security Act. 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.

## **The Cash and Counseling Evaluation**

The evaluation addresses four broad questions: (1) Who participated in the Cash and Counseling demonstration? (2) How were the demonstration programs implemented? (3) How did the programs affect consumers and their caregivers? (4) How did they affect public costs? To estimate program impacts on consumers, caregivers, and costs, the evaluation randomly assigned demonstration enrollees either to participate in Cash and Counseling (the treatment group) or to rely on HCBS or PCS as usual (the control group). With data from telephone interviews and Medicaid and Medicare claims, the evaluation compares the groups' outcomes at designated follow-up intervals. The evaluation also is describing eligible beneficiaries' reasons for agreeing or declining to participate in Cash and Counseling, and it is examining trends in the use of HCBS and PCS for indirect evidence that the demonstration affected the number of beneficiaries who used such services.

## Guide to This Report

**Research Questions.** This report addresses the second broad evaluation question by describing the implementation of Florida's Cash and Counseling demonstration program, Consumer Directed Care (CDC). Unlike a companion report that describes demonstration design and program operations in greater detail (Phillips and Schneider 2004), this report focuses on program implementation as experienced by consumers and the program consultants who worked with them. The report considers:

- The major goals and features of CDC.
- The characteristics of treatment group consumers.
- How consumers handled their CDC responsibilities and how they availed themselves of the program's flexibility.
- Whether consumers were satisfied with CDC and their personal care.
- Reasons consumers left the program.
- Whether the program worked better for some types of consumers than for others.
- Consultants' assessment of the program's strengths and weaknesses.
- The lessons that CDC offers policymakers and program developers.

**Sources and Methods.** This report draws on information and data from several sources:

- **Florida Site Visit.** Researchers held discussions with Florida state officials, state employees at the regional level, CDC staff members, and staff members of organizations providing fiscal and consulting services under CDC. (Florida used the term "consulting" rather than "counseling" in its demonstration.) The discussions were conducted in January 2002, about 18 months after the demonstration began random assignment. The discussions were in person, except for three conducted by telephone.
- **Consultant Survey.** Also about 18 months into the demonstration, MPR administered a mail survey of CDC program consultants. The survey questionnaire contained sections on consultants' education and professional background, program caseload, uses and perceived misuse (if any) of the program allowance by consumers or representatives, and abuse of consumers by workers or representatives. It also contained sections on consultant activities, recommended changes to those activities, and consultants' overall assessment of the program. Questions eliciting consultants' recommendations and overall program assessment were open-ended. Questionnaires were sent to all 213 consultants who had active CDC caseloads when the survey was administered, and 195 consultants returned them.
- **Consumer Surveys.** MPR conducted telephone interviews with consumers or knowledgeable proxy respondents immediately before consumers were randomly assigned to participate in CDC, and six and nine months later. Each survey instrument covered a range of topics (listed in Table 1). Interviews were

completed by 1,410 treatment group respondents at baseline; 1,340 respondents at six months; and 1,213 respondents at nine months.<sup>1,2</sup> To obtain a complete picture of consumers' CDC experiences, we conducted follow-up interviews even if consumers had disenrolled from CDC, were not receiving the monthly allowance, or had died.

We interviewed a parent or guardian of consumers younger than 18; questions eliciting opinions referred to those of the respondent. When interviewing the proxy respondent of an adult consumer, however, we measured the consumer's opinion. Thus, questions eliciting opinions were skipped if the consumer was unable to form opinions (for example, because of a severe cognitive impairment) or the proxy was not comfortable assessing the consumer's opinion. During the six and nine-month interviews, questions about the consumer's satisfaction and unmet needs were skipped if the proxy respondent was also a paid caregiver, because the proxy may have been unable to answer objectively.

Many adult consumers used proxy respondents during the interviews. At baseline, for example, 60 percent of adults age 60 or older used proxy respondents, as did 77 percent of younger adults, nearly all of whom had developmental disabilities.

- **Program Records.** CDC program records were available for the 1,410 consumers who were randomly assigned to participate in the program. The records included data on receipt and use of the monthly allowance and reasons for disenrollment.

Survey and program data were analyzed primarily through an examination of frequency distributions, means, and cross-tabulations of constructed variables. Researchers also reviewed and coded open-ended responses to the consultant and consumer surveys. Logistic regression analysis was used to assess whether certain types of consumers fared better than others in the program (for example, by starting on the allowance and remaining in the program for at least a year). The regression models included a set of explanatory variables from baseline interviews and program records.

---

<sup>1</sup> This report focuses on the experiences of Florida treatment group members. Companion reports present estimates of program impacts based on comparisons of the treatment and control groups. (See the List of Companion Reports following the References.)

<sup>2</sup> In preparing our analysis file for the nine-month survey data, we inadvertently excluded 20 18-year-olds from the sample. Because these consumers represent only 1.6 percent of the survey sample used in this analysis, their inclusion would not materially change the statistics we present. The 18-year-olds *are* included in statistics drawn from program records and from the baseline and six-month surveys.

<b>TABLE 1: Topics Covered in MPR Consumer Surveys</b>		
<b>Baseline Survey</b>	<b>Six-Month Follow-Up Survey</b>	<b>Nine-Month Follow-Up Survey</b>
Household composition and living arrangements Unpaid assistance Paid assistance, unmet needs, and satisfaction Use of HCBS Health and functioning Attitudes about consumer direction	Program participation and allowance receipt Allowance spending plan Use of the allowance Employer responsibilities Reasons for disenrollment	Program participation and allowance receipt Health and functioning Living arrangements Unpaid assistance Paid assistance Satisfaction with care and unmet needs Equipment, supplies, and modifications Use of allowance for equipment, supplies and modifications Receipt of community services and use of allowance Use of the allowance to hire workers Allowance spending plan and employer responsibilities Reasons for disenrollment

**Presentation and a Limitation.** The body of this report consists of a narrative text and tables of selected descriptive statistics. The report's appendix also contains many statistical tables, some of which are discussed in the report. Many of the tables in the report and the appendix present statistics by consumer age group (3-17 years, 18-59 years, and 60 or older) because we hypothesized that consumers in these groups may have experienced the CDC program differently from each other and because policymakers have long debated the suitability of elderly adults for consumer direction. In addition, key measures of satisfaction are presented by whether adult consumers responded to evaluation surveys themselves or through proxy respondents.

The report covers a period beginning in February 1996, when Florida submitted its demonstration proposal, and ending in July 2003, a year after the last demonstration enrollees were randomly assigned for the evaluation. Nonetheless, the report is limited in that we conducted site visit discussions and administered the consultant survey at one point in time (winter 2002), although the CDC program of course continued to evolve, learn from experience, and make improvements thereafter. The report notes some programmatic changes that occurred after the site visit, but it was not possible to document them all.

# KEY FEATURES OF CASH AND COUNSELING IN FLORIDA<sup>3</sup>

## Goals

In implementing the Cash and Counseling demonstration, Florida's main goals were to promote the independence of people with disabilities, offer services that would better meet the needs of individual families, and encourage the prudent use of public resources. The state viewed the demonstration as an opportunity to learn--to determine which policies and procedures worked well and which did not. Cost savings were not a goal for Florida, but the Federal Government required that the demonstration be budget-neutral.<sup>4</sup>

## Target Populations

The demonstration was open to Florida Medicaid beneficiaries who were receiving HCBS under the state's Developmental Disabilities (DD) waiver or Aged/Disabled Adult (ADA) waiver and living in selected areas of the state.<sup>5</sup> Together, these waivers serve children and adults with developmental disabilities, frail elderly adults, and adults with physical disabilities. For children, the demonstration catchment area was the entire state. For adults with developmental disabilities, it was the entire state, except several northern counties where a state-funded consumer-directed program was being piloted. For elderly adults and those with physical disabilities, the catchment area consisted of 19 counties, including most of the state's major metropolitan areas.

Florida did not screen prospective enrollees or any person who might be their representative in the program for their suitability for consumer direction. In keeping with the Cash and Counseling credo of autonomy, as well as its own wish to learn from the demonstration, the state relied on prospective enrollees and their families to decide whether to enroll. Consumers would receive HCBS as usual until they began receiving their program allowance, and they could disenroll from CDC at any time and revert to their usual services on the first day of the following month.

---

<sup>3</sup> This section of the report draws mostly on information collected during the Florida site visit.

<sup>4</sup> In a budget-neutral demonstration, the average monthly costs of serving recipients of CDC services would not exceed those of serving recipients of traditional HCBS. That is, costs per recipient per month would be equal for the treatment and control groups over the life of the five-year demonstration.

<sup>5</sup> Florida's initial demonstration design called for the inclusion of beneficiaries in the state's Brain and Spinal Cord Injury Program (BSCIP). The participation of BSCIP was delayed, however, so BSCIP beneficiaries were excluded from the MPR evaluation.

## Government Stakeholders

A number of government entities were involved in the design and implementation of CDC. Florida's Department of Elder Affairs (DOEA), which serves the elderly adults who were eligible for the demonstration, drafted much of the state's demonstration proposal and was the official demonstration grantee and host agency. Two programs in the Department of Children & Families (DCF) also were involved, to different extents. The Developmental Disabilities Program (DDP), which serves children and adults with developmental disabilities, devoted substantial resources to demonstration design and implementation, including the time of four staff members.<sup>6</sup> The Adult Services (AS) program, which serves nonelderly adults with physical disabilities, played a limited role in design and implementation. In fact, although nonelderly adults could enroll in the demonstration through DDP or AS, nearly all (90 percent) were DDP clients and only 10 percent were AS clients. Finally, the Florida Agency for Health Care Administration prepared the application for the federal Section 1115 waiver needed to run the demonstration and ensured that the state met the waiver's terms and conditions.

DOEA formed an interdepartmental work group to coordinate the activities of the relevant government entities. Nonetheless, it was not always possible to have a single set of procedures for some important aspects of the CDC program. As described in the following sections of this report, procedures for determining the amount of program allowances, training and paying consultants, and approving consumers' purchasing plans varied by target population.

## Outreach and Enrollment

For the evaluation, Florida initially set out to enroll 1,550 beneficiaries in each of three age groups in about 12 months, beginning in June 2000. Generating enrollment for the demonstration proved demanding, however. Sample size targets eventually were reduced, to 1,000 beneficiaries in each age group, and evaluation enrollment remained open until the targets were met (or nearly met). By the time evaluation enrollment closed for all age groups, in July 2002, Florida had approached outreach and enrollment in two distinct ways.

In the first approach, CDC program staff made presentations to advocacy organizations and conducted other community outreach, but case managers from the ADA waiver program and support coordinators from the DD waiver program were responsible for reaching consumers directly. (Case managers and support coordinators have different titles but similar functions in their respective programs.) During routine visits with the waiver beneficiaries in their caseloads, case managers and support coordinators were to introduce the demonstration to beneficiaries and their families, give them informational brochures, and invite them to complete a reply card to request more information. If beneficiaries expressed interest in the demonstration, their case

---

<sup>6</sup> DDP later become a separate state agency, the Agency for Persons with Disabilities.

manager or support coordinator was supposed to follow up with them or arrange for a CDC consultant to do so. If beneficiaries decided to enroll in the demonstration, a support coordinator, case manager, or CDC consultant was to collect their informed written consent and basic intake data, such as contact information. Cases were then forwarded to MPR for interviewing and randomization.

Florida used this approach for about six months. According to people who took part in site visit discussions, however, many case managers were skeptical about consumer direction, particularly for elderly beneficiaries. For their part, many support coordinators were overwhelmed with other responsibilities. Florida had recently been compelled by a court order to serve thousands of people who had been on a waiting list for HCBS and reassess the needs of existing HCBS users. For these reasons, outreach was not as successful as anticipated. During this period, few consumers expressed interest in the program, and those who did often had to wait to receive additional information. Enrollment lagged well behind monthly targets.

Remedial efforts were implemented. CDC staff and senior state officials began meeting frequently with the executives of case management agencies to boost enrollment among eligible elderly beneficiaries. The meetings were meant to make case managers more comfortable with the concept of consumer direction for elderly beneficiaries, but they were largely unsuccessful, according to people who took part in site visit discussions.<sup>7</sup> For its part, the DDP began including district-level enrollment statistics in monthly reports to the governor's office hoping that the reports would motivate district offices to pay more attention to enrolling beneficiaries with developmental disabilities. This tactic seemed somewhat effective, but it did not increase enrollment enough to meet evaluation targets.

Florida implemented its second approach to outreach and enrollment in fall 2000. It hired about 20 temporary employees, split between DOEA and DCF, to build demonstration caseload. It was hoped not only that these enrollment specialists would devote more time to the CDC project, but also that they would not have preconceived notions about which types of beneficiaries were suitable for consumer direction. After the enrollment specialists had been hired, the CDC program arranged to send an informational letter from the governor's office to eligible demonstration participants.

The governor's letter generated a lot of interest in the demonstration. In response, enrollment specialists were expected to visit five or six prospective enrollees a day. Neither the DOEA nor the DDP set enrollment quotas, however, lest the specialists resort to "selling" the program. Like the case managers and support coordinators who preceded them, enrollment specialists were to explain CDC to beneficiaries and their

---

<sup>7</sup> To understand the sluggish enrollment of elderly beneficiaries, RWJF funded four focus group discussions in October 2000 with Florida case managers who were trained as CDC outreach workers and consultants. The focus group moderator observed that the case managers were "very skeptical of the ability of their elderly clients to participate in CDC. They believe the clients are too frail, too sick, and with a much too limited support system to be able to participate. The belief [is that] the program is too complex, too confusing, and too burdensome for these frail elders." (Zacharias 2001)

families, tell them what their CDC allowance would be if they were randomly assigned to the treatment group, and help them complete enrollment and consent forms. (MPR continued to handle baseline interviewing and randomization.) The enrollment specialists, enthusiastic about CDC and not distracted by other duties, did increase the pace of enrollment into the demonstration (Appendix Table A.1 and Table A.1a).

Having begun outreach and enrollment activities in June 2000, Florida enrolled 1,002 children into the demonstration and evaluation by August 2001 (15 months), 914 nonelderly adults by November 2001 (18 months), and 904 elderly adults by July 2002 (26 months).<sup>8</sup> After these dates, eligible beneficiaries continued to enroll into the demonstration but were not part of the evaluation.

## The CDC Allowance

**Cashed Out Services.** A monthly CDC allowance was offered instead of the benefits in beneficiaries' usual HCBS care plans or support plans, as they are known in the DD waiver. "Cashed out" services might include help with personal care, in-home nursing, professional therapies, care-related supplies and equipment, or caregiver respite, among other benefits.<sup>9</sup> Only case management or support coordination services were not cashed out as part of the CDC allowance; funds for those services would be used to pay CDC consultants.

**Allowance Calculations.** Allowance amounts were based on the beneficiary's HCBS claims history or care/support plan and multiplied by a discount factor. If past claims data were available for at least six months, the allowance was set equal to the monthly average of Medicaid expenditures. If claims were available for fewer than six months, or if the beneficiary's condition or situation recently had changed, the allowance was based on the care/support plan.<sup>10</sup> Using care plans to calculate allowances was more arduous than using claims, because staff had to look up the rates that would be paid to all vendors specified in the plans. Discount factors were applied to help keep the program budget-neutral: Florida had determined that planned costs for waiver services consistently exceeded actual costs (for example, because services were suspended during hospitalizations). The discount factors were 0.89 for elderly adults, 0.83 for nonelderly adults with physical disabilities, and 0.92 for adults and children with developmental disabilities.

---

<sup>8</sup> Half the demonstration enrollees were randomly assigned to the control group and thus were not included in the analyses conducted for this report. Overall, demonstration participants represented 8.2 percent of eligible HCBS recipients--16.0 percent of children known to be eligible, 5.6 percent of nonelderly adults, and 7.6 percent of elderly adults (Foster et al. 2005).

<sup>9</sup> In cashing out a full range of HCBS benefits, Florida differed from the other demonstration states, which cashed out only state plan PCS. All treatment and control group members in Florida received HCBS before enrolling in the demonstration--as the state required--but not all received PCS, per se. Some HCBS care/support plans include benefits such as therapy or supplies, but not personal care, according to individual needs.

<sup>10</sup> In fact, all consumers with developmental disabilities had experienced a recent change in the care plans because of the aforementioned court order. Therefore, for this segment of the demonstration population, Florida was not able to implement its initial plan to determine the monthly budget from claims history.

At enrollment, the average monthly allowance after discounting was \$1,108 for children, \$1,641 for nonelderly adults, and \$818 for elderly adults. Consumers with primarily developmental disabilities--children and nearly all nonelderly adults--had relatively generous allowances, on average, because they tended to have relatively high needs for care.

**Flexibility in Purchasing.** The CDC allowance, like the program allowances in the other demonstration states, could be used to purchase a range of goods and services that would help consumers function more independently. Consumers could use the allowance to pay workers, including legally responsible family members (spouses and parents of minors) and, in some cases, a consumer's CDC representative.<sup>11</sup> The program generally did not pay for workers, services, and goods unless they were specified in consumers' purchasing plans. However, CDC allowed some leeway if purchases that had not been specified in advance met needs the plan identified. For example, in a given month, consumers could purchase extra care supplies to take advantage of sales without preapproval from the program. Florida also allowed consumers to receive up to 20 percent of the monthly allowance as cash for incidental expenditures that could not be readily invoiced, such as taxi fare or paying a neighbor for yard work.<sup>12</sup> To receive cash, consumers could specify such purchases in their purchasing plan or request an ad hoc payment from the fiscal agent up to twice monthly.

## **Organization of Consulting and Fiscal Services**

Florida asked existing providers of case management or support coordination services to provide consulting services to CDC consumers. This choice was practical--state funds to pay these providers had already been committed--but Florida also believed that consumers would benefit from the continuity of the arrangement. All consultants completed a day and a half of training before they began working with CDC consumers.

CDC adopted different payment structures for consulting by case managers than for consulting by support coordinators. Under the ADA waiver, one "lead agency" provides case management services to all beneficiaries in a given county. Under the DD waiver, multiple agencies and independent contractors provide support coordination services to children and adults in groups of contiguous counties, or districts. Under the CDC program, consultants who were also case managers conducted up to two home

---

<sup>11</sup> During the evaluation period, Florida sometimes allowed the same person to be a consumer's representative and paid worker if: (1) two people were not available, as in a single-parent family, for example; and (2) someone else from the consumer's "circle of support" verified that the representative/worker had performed the agreed-upon services. The state later modified its operational protocol so that no one could serve as both a representative and paid worker. This restriction is currently enforced in Florida's CDC+ program, which operates under a Section 1115 waiver.

<sup>12</sup> Payments for incidental expenditures were later limited to \$250 per month.

visits to help consumers (frail elderly adults and younger adults with physical disabilities) develop purchasing plans. The state paid the lead agencies \$125 for the first visit and \$75 for the second. The state paid lead agencies an hourly rate for other consultant services, such as advising consumers about hiring workers.<sup>13</sup> In contrast, the state paid consultants who were also support coordinators a flat monthly fee of \$148 for each consumer in their CDC caseloads, the rate paid under the usual waiver program.<sup>14</sup> Monthly payments began as soon as cases were assigned to consultants.

Although CDC consulting services were decentralized, Florida selected one organization, a human services firm in another eastern state, to provide fiscal services to all consumers. The state did not charge consumers directly for consulting services, but consumers did pay for the fiscal services they used. Under a comprehensive fiscal services plan, consumers paid the fiscal agent \$5 to cut a check, up to a \$25 monthly maximum.<sup>15</sup> Alternatively, consumers could manage the allowance themselves and pay the fiscal agent \$10 a month to audit their CDC account and records.

Over time it would become clear that providing fiscal services for the CDC project was a financial drain on the selected agency. There were three main causes of financial drain. First, the fiscal agent received no payments, apart from an upfront payment for design tasks, until consumers developed approved purchasing plans. Second, the monthly costs incurred by the fiscal agent per consumer far exceeded the maximum fee (\$25) each consumer might pay (for example, because many consumers hired more workers than expected). Third, the unexpectedly slow buildup of caseload made it difficult for the fiscal agent to realize economies of scale. Although the fiscal agent persevered through these difficulties, and contract amendments were being considered at the time of our site visit, the fiscal agent's performance of its CDC responsibilities was sometimes hampered.

---

<sup>13</sup> Hourly rates differed by agency, but they were the same as those paid for case management under the usual waiver program. Quarterly average payments per CDC consumer, including training visits, were capped at the historical average of quarterly payments per client for case management services at that agency.

<sup>14</sup> Rates for consultants serving consumers with developmental disabilities varied over time; \$148 per month was in effect at the time of our site visit.

<sup>15</sup> Per-check fees increased slightly during the second year of the demonstration, but the monthly maximum charge remained \$25.

# FINDINGS

## Consumer Characteristics

The evaluation randomly assigned 1,410 beneficiaries to the CDC program--501 children, 456 nonelderly adults, and 453 elderly adults (Appendix Table A.2). All of the children, 90 percent of nonelderly adults, and 2 percent of elderly adults joined the demonstration through the DD waiver program. Ninety-eight percent of elderly adults and the rest of the nonelderly adults joined through the ADA waiver program.

Despite differences in age and type of disability, consumers had some characteristics in common. Most were White, and either they or their representatives were high school graduates (Table 2 and Appendix Table A.3). Nearly all consumers were receiving help with personal care and household activities when they enrolled in the demonstration, but many said they needed more help with each of these activities. In addition, roughly half of consumers said they lived in areas of Florida that were rural or had high levels of crime or poor public transportation--places where obtaining services from home care workers might be difficult.

Consumers in the three age groups also differed from each other in important ways. For example, 80 percent of elderly adults were female, compared with 38 percent of children (Table 2 and Appendix Table A.3).<sup>16</sup> Across the two adult age groups, elderly consumers were more likely than nonelderly consumers to live alone (27 percent versus 9 percent) and to be in poor health relative to their peers (39 percent versus 14 percent). Elderly consumers were less likely than other adult consumers to have no paid caregivers at the time of random assignment (12 percent versus 40 percent), but notably more likely to have no unpaid caregivers (18 percent versus 7 percent). Children's parents were more likely to be dissatisfied with their child's overall care arrangements than were adult consumers to be dissatisfied with their own care arrangements. Finally, while a majority of consumers had participated in HCBS waiver programs for at least six months at the time of random assignment, the proportion was higher for elderly consumers than for children (71 percent versus 59 percent) (Appendix Table A.2).

---

<sup>16</sup> The predominance of women among the elderly may reflect the fact that women tend to live longer than men, while the predominance of boys among the children may reflect correlations between sex and certain types of developmental disabilities. Autism, in particular, is more commonly diagnosed in boys than in girls. Florida's DD waiver program serves children with autism (as well as cerebral palsy, mental retardation, Prader-Willi syndrome, and spina bifida).

<b>TABLE 2: Consumer Characteristics at Random Assignment, by Age Group</b>			
	<b>Percentage</b>		
	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
Female	38.1	42.1	80.4
Self-Identified as:			
White	78.4	77.3	69.1
Hispanic (regardless of race)	17.8	18.9	33.1
Area of Residence Is:			
Rural	16.8	16.0	10.5
Nonrural but has high crime or poor public transportation	31.4	36.4	40.1
Consumer or Representative Graduated from High School <sup>a</sup>	88.6	81.0	69.5
Receiving Any Help with:			
Personal care <sup>b</sup>	97.4	77.2	87.0
Household and community activities <sup>c</sup>	100.0	95.4	95.8
Needs More Help with:			
Personal care <sup>b</sup>	66.4	53.6	64.6
Household and community activities <sup>c</sup>	75.9	69.0	74.0
Demonstration Feeder Program			
Developmental Disabilities	100.0	89.5	2.0
Department of Elder Affairs	0.0	0.0	98.0
Adult Services	0.0	10.5	0.0
<p><b>SOURCE:</b> CDC program records and MPR consumer interviews conducted by telephone immediately before consumers' random assignment. The table summarizes the characteristics of the 1,410 consumers randomly assigned to participate in CDC.</p> <p>a. Education was measured for consumers or representatives, depending on the interview respondent. Parents' education was measured if consumers were younger than 18.</p> <p>b. Personal care includes bathing, transferring, eating, and using the toilet during the week before baseline.</p> <p>c. Household and community activities include light housework, yard work, meal preparation, shopping, and help with homework during the week before baseline.</p>			

At baseline, consumers also were asked about program features that may have been important to them. More than nine in ten said having a choice about the type of help they received was very important (Appendix Table A.4). More than eight in ten said having a choice about when caregivers came was very important. More than half said the ability to pay family members was very important, and a similar proportion said the same about paying friends.

## Consumer-Consultant Interactions

Consumers could begin using CDC consulting services as soon as they were assigned to the program. Of the 195 consultants who completed the MPR questionnaire, nine in ten had been working for the CDC program for six months or less when surveyed (Appendix Table A.5). Each had an average of three consumers in their caseloads at that time. (The median was two consumers.)

Consultants potentially had many responsibilities. During initial visits to consumers' homes, they helped consumers or representatives write purchasing plans for the monthly allowance. Consultants reviewed these plans, signed them, and sent them to the appropriate agency for final approval. (The state CDC office granted final approval for elderly consumers and those with physical disabilities. Medicaid specialists in DCF district offices did so for consumers with developmental disabilities. Allowances were not disbursed until purchasing plans were approved.) The program required consultants to speak with consumers by telephone each month and visit them at home two and 12 months after their enrollment. Consultants also were expected to review receipts for incidental cash purchases, compare purchasing plans to monthly financial statements from the fiscal agent, and help consumers revise their purchasing plans as needed.

Unlike case managers and support coordinators in the usual waiver programs, CDC consultants were to serve as advisers, not decision makers. Thus, if consumers wished, consultants could advise them about recruiting and hiring workers or about choosing community programs and vendors, but they were not to access goods and services on consumers' behalf. Consultants could contact the fiscal agent or the CDC program office for consumers, but consumers were expected to make most such contacts themselves.

According to questionnaire data, consultants spent most of their time on a few tasks and devoted four hours per week, on average, to CDC duties (Appendix Table A.6). The most time-consuming tasks were: (1) helping consumers develop purchasing plans; (2) performing administrative activities such as record keeping, updating case notes, and contacting other program staff; and (3) listening to or encouraging consumers. Most consultants believed that these services were of value to consumers. Forty-four of 195 consultants (23 percent) reported that at least one consumer required extensive monitoring (Appendix Table A.7). The most common reasons for this were that consumers had difficulty completing paperwork or staying on budget (reported by 29 and 20 consultants, respectively).

## **Starting on the Allowance**

It took many consumers a long time to develop purchasing plans and begin receiving their monthly allowance, if they did so at all. Three months after being assigned to CDC, only 18 percent of consumers had begun receiving the allowance (Table 3 and Appendix Table A.8 and Table A.8a). By month six, the percentage had risen to 44 percent, though it was higher for children (54 percent) and lower for elderly adults (36 percent). By month 12, only 57 percent of all consumers, and only 41 percent of elderly consumers, had begun to receive the allowance.

<b>TABLE 3: Time from Random Assignment to Start of Monthly Allowance, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
Started Monthly Allowance by End of Month:				
3	18.3	21.8	13.8	19.0
6	44.4	53.9	42.8	35.5
9	53.3	65.9	54.0	38.9
12	57.1	71.1	57.9	40.8
<b>SOURCE:</b> CDC program records. This table represents the 1,410 consumers randomly assigned to participate in CDC.				
<b>NOTE:</b> Percentages are cumulative and include consumers who started on the allowance before the referenced month but subsequently died or disenrolled.				

Many factors contributed to the delays. Some consumers became ill or did not have family members to hire as workers. However, program procedures, staff workloads, and uncertainty about how much hands-on assistance consultants should provide to consumers also delayed allowances.

During site visit discussions, program staff described two types of procedural delay. The first concerned allowance-planning. Consultants were supposed to schedule consumer training visits after consumers had received and read a training and reference manual--the CDC notebook. Because the state program office did not always distribute notebooks promptly, however, training visits and, thus, allowance-planning could both be delayed. The second type of procedural delay concerned the first allowance disbursement. Once consumers wrote purchasing plans, their allowance could start as early as the first day of the following month, but only if all paperwork, employment forms, and approvals were complete by the 20th day of the prior month. Otherwise, the allowance was held up until the first day of the month *after* the following month.

Large workloads for consultants, CDC state office staff, and district staff also contributed to allowance delays. The especially long delays elderly consumers experienced may have stemmed in part from state regulations allowing case managers to have caseloads of up to 80 clients, including CDC consumers. In contrast, the maximum caseload for support coordinators is 38 clients, including CDC consumers. Large workloads resulting from a court order unrelated to the demonstration may also have kept state and district staff from reviewing and approving consumers' purchasing plans quickly, as some consultants suggested during site visit discussions.

Finally, consultants were generally uncertain about how much assistance to provide to consumers, and this confusion contributed to allowance delays. According to people who took part in site visit discussions, many in the CDC project expected that consumers and representatives would quickly grasp the requirements of the program and develop their purchasing plans with little difficulty. When this was not the case, some consultants questioned consumers' suitability for consumer direction. Doing the paperwork and arithmetic for the purchasing plan was difficult for many consumers and could require several sessions with consultants. Some consumers who did not get the help they needed dropped out of the program. During site visit discussions, some

consultants reported that many consumers enrolled in CDC without a clear understanding of it, a problem that consultants attributed to the explanations, or lack thereof, provided by enrollment specialists.

With experience, CDC program staff realized that, although arithmetic and paperwork were difficult for many consumers, most were able to make decisions about the services and goods they wished to include in their plans. Moreover, once the purchasing plan was completed, most consumers and representatives could manage other program responsibilities independently. Thus, in early 2002, the program began instructing consultants to provide more help with the purchasing plan if consumers needed it. The program also began sending letters to consumers who had not begun receiving the allowance within 90 days of their random assignment to ask if they needed more help with their purchasing plan. At the same time, the program contacted consultants about consumers who had fallen behind and offered to help the consultants expedite completion of purchasing plans. Nonetheless, after a year in the program, less than 60 percent of all consumers were receiving a program allowance.

## **Consumer-Fiscal Agent Interactions**

Once consumers were receiving the monthly allowance, as noted, they chose between two levels of fiscal services. Under the more comprehensive level, chosen by nearly all consumers, the fiscal agent processed employment forms, payroll taxes, worker time sheets, and vendor invoices, and disbursed funds for any incidental expenditures included in the consumer's purchasing plan. Alternatively, consumers who took and passed a skills examination could manage the allowance on their own, but the fiscal agent would still conduct a monthly audit of their CDC accounts. The fiscal agent was required to send monthly financial statements to all consumers and their consultants.

According to people who took part in site visit discussions, the fiscal agent handled many tasks very well but had difficulty producing timely, easily understood financial statements. There were two periods of several months in which the fiscal agent did not produce any statements, once because of the financial difficulties described earlier, and once because the statements had to be adapted for new accounting software. Other times, the statements were prepared on schedule but mailed late, because the fiscal agent did not have up-to-date contact information for consumers or, more often, for consultants, who exhibited fairly high turnover. When statements were distributed, many consultants and consumers found them lacking in detail and difficult to understand. The fiscal agent twice redesigned the statements in response to such feedback.

## Consumer Management of Program Responsibilities

Consumers themselves bore important responsibilities in the CDC program. They decided whether to use a representative, what that representative would do, and which of the optional consultant and fiscal services they would use. Most important, consumers were responsible for recruiting and hiring workers if they chose to, and for otherwise using the allowance responsibly.

**Use of Representatives.** As noted, CDC let adult consumers designate a representative to manage or help them manage their program responsibilities, and it required that children be represented by a parent or guardian. Representatives could help consumers decide how to spend the allowance (for example, whether to hire a worker, whom to hire, and how much to pay), supervise workers and monitor care, sign worker time sheets, and handle other program paperwork.

When they enrolled in the demonstration, 84 percent of all consumers, including children, had designated a representative to help them manage their CDC responsibilities (Appendix Table A.2). As noted, a larger proportion of nonelderly than elderly consumers had representatives (84 percent versus 70 percent), which probably reflects the prevalence of developmental disabilities in the younger group. Program staff reported that the need for representatives usually was obvious to consumers and consultants. Consumers with severe developmental disabilities or dementia were generally not able to manage the allowance themselves. In addition, consultants who participated in site visit discussions said they usually suggested that visually impaired consumers use a representative because program paperwork could be difficult without one.

According to program staff, representatives were usually family members who were already helping consumers with personal care or household tasks. Adults with developmental disabilities who were living with their families usually selected a parent as a representative. Many elderly consumers named their daughters as representatives.

Nearly all the consultants who completed the MPR questionnaire (96 percent) said they worked with at least one consumer who used a representative (Appendix Table A.9). Although 19 percent of those consultants indicated they “questioned the suitability” of at least one representative, 94 percent said every representative they worked with did “his or her best to act according to the wishes or best interests of the consumer.” (Quotes indicate the wording of closed-ended questions, not responses. The questionnaire did not ask consultants to elaborate about any unsuitability they perceived in representatives.) During site visit discussions, two consultants said they occasionally visited consumers who used representatives because they thought telephone calls with the representative were insufficient for monitoring consumer well-being.

**Use of, and Satisfaction with, Consulting and Fiscal Services.** Like representatives, program consultants and fiscal agent staff helped consumers manage their program responsibilities. Despite allowance delays, many consumers were pleased with the consulting and fiscal services they received. During six-month follow-up interviews, roughly two-thirds of consumers said a CDC consultant helped them or their representative develop a purchasing plan (Table 4).<sup>17</sup> The proportion was higher for children (75 percent) and lower for elderly consumers (62 percent) (Appendix Tables A.10 to A10c). Nine in ten consumers who received help found it useful. These consumers most commonly said consultants' explanations of program rules were useful (Appendix Table A.11). A substantial minority of consumers (10 percent) said consultants helped them get approval for special uses of the allowance. In addition, some nonelderly adults and children's parents (9 percent and 15 percent, respectively) used peer support before their six-month interviews (Appendix Table A.10a and Table A.10b). All found it useful to speak with others in the program. No elderly consumers reported using peer support. Of consumers who started receiving the cash allowance within nine months of their random assignment, 97 percent said they used the program's fiscal services, and 87 percent of them said the services were useful. These proportions varied little by age group.

<b>TABLE 4: Use of and Satisfaction with CDC Services</b>		
	<b>Percentage Reporting</b>	<b>Of Users, Percentage Finding It Useful</b>
Used Fiscal Services During First 9 Months	96.9	87.0
Had Help with Purchasing Plan During First 6 Months	67.8	92.6
Received Advice or Materials About Recruiting During First 6 Months	40.4	94.0
Received Advice About Training Workers During First 6 Months	34.3	84.2
<b>SOURCE:</b> MPR consumer interviews, conducted by telephone six and nine months after consumers' random assignment. The table summarizes responses of 1,340 consumers who completed 6-month interviews and of 1,213 consumers who completed nine month interviews.		

**Recruiting and Hiring Workers.** Forty-six percent of all consumers reported that they had hired at least one worker with the allowance by the time of the nine-month follow-up interview, 19 percent had tried to hire but did not, and 35 percent had not tried (Table 5 and Appendix Table A.12). Fully 40 percent of those who hired workers said they had difficulty doing so, and most of them said the difficulty lay in finding interested or qualified candidates. At the same time, most consumers who tried to hire family members were able to. Across age groups, smaller proportions of workers hired for children than for adults were family members (52 percent versus 64 percent, respectively) (Appendix Table A.13). Consumers who hired from beyond their circle of immediate acquaintances sought recommendations from family and friends, placed or consulted advertisements, or used contacts at schools, support groups, or provider agencies. One-fourth of consumers said they hired home care agency workers.

<sup>17</sup> Although consultants were required to help consumers develop their purchasing plans, some consumers disenrolled from CDC without ever getting to that stage of program participation.

TABLE 5: Recruiting and Hiring Workers	
	Percentage
Hiring Workers with Allowance During First 9 Months	
Hired a worker	46.2
Tried to hire a worker, but did not	19.2
Did not try to hire a worker	34.7
Attempted Recruiting Methods, if Hired or Tried to Hire Workers	
Tried to hire:	
Family member	62.1
Friend, neighbor, or church member	45.5
Home care agency worker	38.1
Asked family or friends to recommend worker	40.0
Posted or consulted advertisements	10.8
Contacted employment agency	6.7
Successful Recruiting Methods, if Hired Workers Hired:	
Family member	58.3
Friend, neighbor, or church member	31.5
Home care agency worker	24.5
Through a recommendation	18.4
Through an advertisement	10.3
Through an employment agency	1.6
Through other means	10.7
<b>SOURCE:</b> MPR consumer interviews, conducted by telephone six and nine months after consumers' random assignment. The table summarizes responses of 1,363 consumers who responded to either or both interviews.	

Consultants confirmed that hiring or retaining workers was difficult for some consumers. One-fourth of consultants said they worked with consumers who had serious turnover problems because their workers quit or were fired (Appendix Table A.14). Still, some consumers did find success with inventive recruitment strategies. One consultant reported that a consumer used newspaper ads to attract “young, energetic” students of speech, occupational, and physical therapy who provided services that were “outlined by licensed professionals.”

In addition to recruiting and hiring workers, consumers had to decide whether and how to train them, how much to pay, whether to offer fringe benefits, and whether to describe such arrangements in a contract or written agreement. About 61 percent of consumers who hired workers by the time of their nine-month interviews had trained them in some way (Appendix Table A.12). Fifty-three percent said they showed their worker how to perform tasks, and the other 8 percent arranged for outside training. Only 15 percent of these consumers said that training workers was difficult, and about half of those (ten consumers) said workers' inexperience made it so. Adult consumers paid workers \$10.26 an hour, on average, and parents paid \$11.81 an hour, on average, for children's workers. Eight percent of consumers (overall and by age group) provided fringe benefits, such as paid sick time, to their workers. Finally, 50 percent of consumers who used their allowance to pay workers, including family members, signed contracts or work agreements with them. (Data on wages, benefits, and work agreements are not shown in tables.)

**Neglect, Exploitation, and Abuse.** The possibility that consumers could be exploited by workers or representatives, or vice versa, and the possibility that the CDC allowance would be misused or squandered were major concerns for all involved in the program, as they were for the demonstration programs in Arkansas and New Jersey. At the same time, everyone directly involved in the demonstration realized that extensive control and oversight of consumers and their families were incompatible with the philosophy of consumer direction. Consumers had to be free to make their own choices, even if others disagreed with them. At the time of the Florida site visit and the consultant survey, neither neglect or exploitation, nor abuse of the allowance, seemed to be serious problems.

Consultants' interactions with consumers and representatives were the CDC program's key means of monitoring for possible physical or verbal abuse or financial exploitation of consumers. Consultants used their monthly telephone calls and home visits to monitor consumers' well-being. For example, one consultant listened for subtle clues during the monthly calls, such as hesitant responses to questions, and probed for more information if in doubt. Another consultant reported that she made unannounced home visits if something seemed amiss over the telephone. To assess a child's well-being, one consultant made a point of speaking with the child and watching for changes in the child's appearance. Florida directed consultants to refer cases of possible neglect or exploitation to the state's protective-services agencies.

In responding to the consultant questionnaire, no consultants reported verbal or physical abuse of consumers by representatives or workers, but two indicated they had seen evidence of consumer self-neglect. Four consultants (of 195 who responded to the survey) indicated they had seen evidence that one of the consumers in their caseloads was being financially exploited by a representative or worker (Appendix Table A.15). Financial abuse may be a matter of opinion, however. For example, one questionnaire respondent considered it financially exploitative for the mothers of young consumers to pay themselves for caregiving while forfeiting other paid services the consultant believed were needed.

CDC used three methods to prevent abuse of the monthly allowance. First, consultants were to review the consumer's monthly financial statement (to be prepared and distributed by the fiscal agent) with the consumer or representative during the monthly call. Second, consumers were to maintain a record of purchases they made with any portion of the allowance they received as cash and keep receipts for those purchases. Third, in most cases, the fiscal agent was to pay only for purchases specifically identified in the purchasing plan.

In responding to the consultant questionnaire, less than 10 percent of consultants reported seeing evidence of allowance misuse (Appendix Table A.16). Of 17 consultants who did report misuse, 12 said consumers overspent their allowances, which was possible because allowances were prospectively credited to consumers' accounts. During site visit discussions, we heard of several cases of overpayment stemming from consumers not being aware of laws governing overtime rates. These

appeared to be honest errors, not deliberate misuse of the allowance. In addition, according to questionnaire data, seven consultants said some consumers failed to document incidental cash purchases as they were supposed to.

## **How Consumers Took Advantage of Increased Flexibility**

Consumers who used their allowance to hire workers determined how many to hire, what tasks they would perform, and when they would help. Most consumers with primarily developmental disabilities (children and nonelderly adults), and thus a variety of professional and personal care needs, used the allowance to pay more than one worker. In comparison, elderly adults were as likely to hire one worker as they were to hire more than one (Table 6 and Appendix Table A.17). About 45 percent of consumers had paid caregivers who lived with them at the time the nine-month interviews.

Roughly nine in ten consumers received paid help with household tasks and with personal care, and roughly seven in ten received paid help with routine health care tasks. Compared with elderly adults, larger proportions of children and nonelderly adults received paid transportation assistance. More than 80 percent of consumers paid someone to help them on weekends. Consumers who used the allowance to pay workers typically received at least two hours of paid care a day during a two-week period shortly before the nine-month interviews (Appendix Table A.17). Children and nonelderly adults were especially likely to receive more than five hours of paid care per day.

According to program records, nonelderly adults and children used about half their allowances to pay home care workers or therapists whom they did not hire through home care agencies. Elderly adults, whose allowances tended to be smaller, used about 64 percent to pay workers. A substantial fraction of all consumers (11 percent) also hired workers and therapists through home care agencies (Appendix Tables A.18 to A.18c).<sup>18</sup>

Consumers also used the allowance in ways other than to pay caregivers. Substantial proportions of consumers in all three groups received cash for incidental expenditures during the observed month, and these payments represented the biggest portion of allowance spending after workers were paid. Forty-two percent of children's parents received cash, at an average of \$90 a month. Thirty-five percent of nonelderly adults did so, at an average of \$51 a month. Sixty-three percent of elderly adults received cash, at a monthly average of \$115. In addition, one-third of nonelderly consumers used the allowance to pay for community services, such as adult day care, transportation, and meal delivery. One-quarter of children's parents and 16 percent of nonelderly adults used the allowance to pay for personal care supplies. According to

---

<sup>18</sup> Our analysis of how consumers used their cash is limited in that the data do not differentiate the purchase of professional services, such as behavior therapy and nursing, from the purchase of personal care. In a companion analysis, we will examine consumers' preenrollment Medicaid claims for use of professional services to assess the magnitude of this limitation.

program staff who participated in site visit discussions, consumers were often able to purchase supplies from commercial establishments for less than Medicaid typically paid vendors.

<b>TABLE 6: Assistance from Paid Workers Among Consumers Who Hired with the Allowance, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>In Two-Week Period Shortly Before Interview:</b>				
Had 1 worker	40.7	34.0	43.3	50.4
Had 2 or more workers	59.4	66.0	56.7	49.6
Had visiting worker(s)	78.8	84.9	73.9	73.1
Had live-in worker(s)	45.3	40.8	49.7	48.7
<b>Worker Helped with:</b>				
Household and community activities <sup>a</sup>	96.7	97.1	94.3	99.2
Personal care <sup>b</sup>	94.0	97.9	88.6	95.8
Routine health care <sup>c</sup>	76.9	77.7	72.6	80.7
Transportation <sup>d</sup>	66.7	70.6	76.4	46.2
<b>Worker Helped:</b>				
Before 8 A.M. weekdays	48.5	48.7	50.3	45.8
After 8 P.M. weekdays	80.5	89.5	75.2	69.5
On weekends	83.9	86.1	82.8	80.7
<b>SOURCE:</b> MPR consumer interviews, conducted by telephone nine months after consumers' random assignment. The table summarizes the responses of 514 consumers who hired with the allowance by the time of their interview and received paid assistance during a two-week period shortly before the interview. Of these consumers, nine had disenrolled from CDC and were likely reporting on help from agency workers.				
<p>a. Household and community activities include light housework, yard work, meal preparation, shopping, and help with homework.</p> <p>b. Personal care includes bathing, transferring, eating, and using the toilet.</p> <p>c. Routine health care includes taking medications, checking vital signs, and doing exercises.</p> <p>d. Transportation includes trips for medical and nonmedical reasons.</p>				

Consultant questionnaire data provide detailed examples of the types of goods and services consumers included in their purchasing plans. For example, 72 percent of consultants worked with a consumer whose purchasing plan included incontinence supplies (Appendix Table A.19). Other items and services--each reported by roughly 20 percent of consultants--included devices to aid mobility, dietary supplements, transportation by taxi or van, training or education for the consumer, and over-the-counter medications.

Few consultants mentioned particularly creative uses of the allowances in their questionnaire responses, but some did. Among a handful of consultants reporting that a consumer used the allowance to hire workers with special skills, for example, one noted that a consumer purchased services from a psychiatrist who was able to communicate with the consumer in sign language (Appendix Table A.20). Several consultants also mentioned that parents used the allowance for special summer camps or extracurricular activities. One consultant worked with a child with autism whose

behavior suffered during interruptions to daily routines. The parents used the child's CDC allowance to pay for recreational programs during school vacations, which made breaks from school less disruptive. Finally, a consultant described a wheelchair-bound consumer who used the allowance to dine outside the home twice a month with a friend. Before enrolling in CDC, the consumer had not been on social outings in "several years."

Although spending rules were quite flexible under CDC, consumers were not entirely unfettered in using the allowance. The CDC notebook listed gifts, loans, rent or mortgage payments, clothing groceries, and entertainment as examples of prohibited purchases. According to questionnaire data, about one-fourth of consultants denied consumers' requests to use the allowance for certain purchases (Appendix Table A.20). One questionnaire respondent did not approve use of the CDC allowance for a swimming pool alarm, which parents requested after the child learned to open the latch of the fence around the pool. Another respondent, apparently helping a family conserve scarce allowance dollars, did not approve a plan to spend the allowance on dietary supplements that Medicaid ordinarily covers. Still another respondent reported that a CDC district office denied a family's request to pay for services provided by a school for the deaf, although the consultant thought the request was allowable. For their part, 32 percent of consumers said during interviews that CDC spending rules preventing them from obtaining goods or services that would have enhanced their independence. (They were not asked to provide examples.)

## **Consumer Satisfaction**

**Satisfaction with CDC.** Consumers were largely satisfied with the CDC program. Eighty-eight percent of respondents to the nine-month evaluation interview said they would recommend CDC to "others who wanted more control over their personal care services" (Table 7 and Appendix Table A.21). Among allowance recipients, roughly 60 percent said the allowance had greatly improved their lives, and another quarter said life improved somewhat. Satisfaction was fairly uniform across age groups.

Asked about the most important way the allowance improved their lives, consumers most often cited having the ability to choose their own caregivers (cited by 25 percent of all consumers) (Appendix Table A.21). Many consumers (20 percent) said managing the allowance contributed to their sense of independence or control, or that the care they purchased with the allowance contributed to their child's emotional well-being. Another common improvement, cited by 14 percent of consumers, was the ability to obtain higher-quality services than they were used to in the usual waiver program.

TABLE 7: Satisfaction with CDC, by Age Group				
	Percentage			
	Overall	3 to 17	18 to 59	60 or Older
Would Recommend CDC to Others Wanting More Control Over Their Personal Care Services	87.6	89.0	88.2	85.3
Effect of Monthly Allowance on Quality of Life, Among Recipients				
Improved a great deal	59.2	61.9	54.5	60.5
Improved somewhat	23.8	22.5	27.0	21.7
Stayed the same	16.0	14.7	18.0	15.8
Reduced somewhat	0.4	0.3	0.5	0.7
Reduced a great deal	0.6	0.7	0.0	1.3
<b>SOURCE:</b> MPR consumer interviews, administered by telephone nine months after consumers' random assignment. The table summarizes the responses of 1,213 consumers.				

**Satisfaction with Personal Assistance Services.** Nine months after enrollment, most consumers reported they were somewhat or very satisfied with their overall care arrangements and with specific aspects of their paid care. Nonetheless, sizable proportions of consumers needed help or more help with various activities or needed more personal care supplies. Across age groups, the proportions of consumers who were very satisfied with their overall care arrangements were 56 percent of children's parents, 67 percent of nonelderly adults, and 50 percent of elderly adults (Appendix Table A.22a). Not only were nonelderly adults most likely to be very satisfied, they were least likely to be dissatisfied (at 6 percent).<sup>19</sup> Regardless of age group, consumers who used their allowance to hire workers were uniformly satisfied with the way workers performed their tasks and with their relationships with workers. Asked about aspects of paid workers' reliability, promptness, and disposition, children's parents were somewhat more satisfied than were other consumers. For example, 92 percent of parents said paid workers always or almost always completed their tasks, compared with 83 percent and 74 percent of nonelderly and elderly consumers, respectively. Likewise, 94 percent of children's parents said paid workers were never rude or disrespectful, compared with an average of 85 percent of consumers in the adult age groups. In an exception to this pattern, elderly consumers were more likely than others to say their paid workers never tried to help them when they did not want help. This may be because elderly consumers, who had physical rather than developmental disabilities, may have been more able than other consumers to express their preferences.

As noted, sizable proportions of consumers who used the allowance to pay workers reported having unmet needs for personal care supplies and for help with tasks around the house, personal care, routine health care, and transportation. Overall, the proportions reporting unmet needs ranged from 20 percent (for help with routine health care) to 33 percent (for help with tasks around the house and community) (Appendix

<sup>19</sup> Where sample sizes permitted, we also examined satisfaction by whether adult consumers responded to the nine month interview themselves or through a proxy (Appendix Table A.22b). Among nonelderly adults, self-respondents were somewhat less likely than proxy respondents to say they would recommend the program, and they were substantially less likely to be very satisfied with their overall care arrangements. Among elderly adults, self-respondents also were substantially less likely than proxy respondents to be very satisfied with their care arrangements; however, they were slightly more likely than proxies to say they would recommend the program.

Table A.22a). In each instance, elderly consumers were more likely than others to report unmet needs. Like the other demonstration states, however, Florida did not expect that consumer direction would eradicate all unmet needs, which may be impossible at any cost.

## **Disenrollment**

As in the other demonstration states, a substantial proportion of Florida consumers--35 percent--disenrolled from the CDC program within a year of enrollment (Appendix Table A.23). Most did so voluntarily, according to program records, but others were disenrolled because the program could not locate them through available contact information, or because they lost Medicaid or HCBS eligibility. In addition, 4 percent of all consumers died. Both disenrollment and death were much more common in the elderly age group than in the other two. Nearly half of all elderly consumers disenrolled from the program during the follow-up year, compared with 34 percent of younger adults and 20 percent of children. Ten percent of elderly consumers died during the follow-up year, compared with about 1 percent of other consumers.

During six or nine-month interviews, consumers who disenrolled voluntarily were asked why they had done so. Overall, consumers most commonly said they disenrolled because they changed their mind or were satisfied with their usual waiver benefits (reported by 35 percent of voluntary disenrollees) (Appendix Table A.23). Others said the allowance was not enough (21 percent), that they had a conflict with program staff or found program rules too restrictive (13 percent), or that they had difficulty with their responsibilities as employers under the program (13 percent). Across age groups, elderly consumers were considerably more likely than consumers in the other age groups to disenroll because they had problems with their responsibilities as employers or with their fiscal responsibilities. Nonelderly consumers were more likely than the others to disenroll because of a conflict with program staff or because of program rules.

It is notable that two-thirds of consumers who disenrolled from the program did so within six months of enrolling, and 88 percent did so without receiving the allowance. This suggests that these consumers quickly determined that consumer direction was not for them and chose to continue with their usual HCBS. In contrast, consumers who succeeded in starting on the allowance tended to stay with the program.

## **Experiences of Different Types of Consumers**

Because demonstration enrollment was voluntary, CDC presumably attracted beneficiaries who wished to direct their own supportive services or those of their child. Nonetheless, participating in the program--developing a purchasing plan, hiring workers, and buying others services and goods--may have required more effort than some consumers and representatives were willing to expend. Satisfaction with the program was high, but not universal. What types of consumers found CDC worthwhile and

satisfying? One could speculate that consumers who felt ill served by Florida's usual HCBS programs would be more willing than others to undertake the responsibilities of consumer direction. This group might include consumers who found agency workers or other providers unreliable or too unlike them ethnically or culturally. Consumers with a strong desire to pay family or friends for caregiving might also be more motivated than others to fully participate in the program once enrolled. Conversely, one could speculate that consumer direction might be difficult for consumers with poor health or functioning, for those without hiring or supervisory experience, or for those without someone in mind to hire. Understanding the relationship between the characteristics, circumstances, and motivation of consumers and their probability of success at consumer direction could help program administrators hone their outreach efforts, identify possible shortcomings in program services, and dispel any prejudices about beneficiaries' suitability for consumer direction.

In this analysis, key indicators of consumers' experiences with CDC were regressed against a fairly comprehensive, but selected, set of characteristics measured during consumers' baseline interviews. The outcomes were whether consumers:

- Started receiving the allowance within nine months of enrollment.
- Voluntarily left the program within nine months or one year of enrolling.
- Found it difficult to hire a worker or tried to hire but failed.
- Said the program's spending rules kept them from buying things that would have increased their independence.
- Said the allowance had greatly improved their life (if they received the allowance).
- Were very satisfied with overall care arrangements at the nine-month interview.
- Had an unmet need for personal care at the nine-month interview.

The following discussion considers characteristics that were associated with outcomes at the 0.05 significance level. Coefficient estimates and p-values are found throughout Appendix Tables A.24 to A.28, as noted.

Several characteristics were positively associated with consumers starting on the CDC allowance and remaining in the program (Appendix Table A.24 and Table A.28). These were allowance amount at baseline, early enrollment, and considering it very important to be able to pay family or friends for caregiving. Compared with consumers eligible for the smallest allowances (less than \$150 per week), consumers eligible for larger ones were more likely to actually receive the allowance within nine months of enrolling. Furthermore, consumers eligible for allowances of \$500 a week or more were less likely than consumers with the smallest allowances to disenroll within nine months

or a year. Some consumers eligible for smaller allowances, and presumably with lesser needs, may have decided that program responsibilities were not worth the bother once they received their CDC notebooks or met with consultants. All else being equal, consumers who joined the demonstration during the first half of the evaluation enrollment period, June 2000 to June 2001, were more likely to receive the allowance and remain in the program than consumers who enrolled later. CDC employed both of its outreach strategies during this early period, relying first on case managers and support coordinators and then on enrollment specialists. Thus, the association between early enrollment and success in the program may be more a function of the self-motivation of early enrollees than of the outreach strategy employed by the program. Finally, consumers who considered it very important to be able to hire family and friends when they enrolled in the demonstration were more likely than others to receive the allowance and remain in the program. Again, success in the program appears to be linked to one's motivation for joining in the first place.

Two demographic characteristics were associated with success in the program or lack thereof. All else being equal, Black consumers were less likely than White consumers to receive the allowance and remain in the program for a year (Appendix Table A.24 and Table A.28). Compared with adults ages 18-59, adults ages 60 or older were more likely to disenroll from the program within nine months. However, it is noteworthy that, among consumers who received the CDC allowance, elderly adults were more likely than younger adults to say it had greatly improved their lives (Appendix Table A.27).

Allowance amount and early enrollment were associated with positive outcomes in addition to starting on the allowance and remaining in the program. Consumers eligible for allowances of more than \$150 a week were less likely than others to find hiring difficult and more likely than the others to say that the allowance had greatly improved their life or their child's life (Appendix Table A.25 and Table A.27). Similarly, consumers eligible for allowances between \$300 and \$499 a week were more likely than consumers eligible for the smallest allowances to say they were very satisfied with their overall care arrangements at follow-up (Appendix Table A.27). Early enrollees were also less likely than later ones to find hiring difficult or program rules restrictive (Appendix Table A.25 and Table A.26).

Consumers' caregiver networks and having past hiring experience were also associated with success in the program. Not surprisingly, consumers with informal caregivers at baseline were less likely than those with none to say hiring was difficult (Appendix Table A.25). In addition, compared with allowance recipients who had no informal caregivers at baseline, those with one informal caregiver were more likely to say the allowance greatly improved life and less likely to say CDC program rules were too restrictive (Appendix Table A.26 and Table A.27). In contrast, consumers who received help from paid caregivers during the week before the baseline interview were more likely than consumers without paid caregivers to disenroll from the program (Appendix Table A.28). It could be that consumers with paid caregivers felt well served by their HCBS waiver program and ultimately decided not to stay in consumer direction.

Finally, consumers or representatives who had hired someone on a private basis, such as a housekeeper or babysitter, were more likely than other consumers to start on the allowance within nine months of enrolling in CDC, presumably because they were undaunted by the idea of recruiting workers and, perhaps, already had workers in mind (Appendix Table A.24). Among allowance recipients, consumers with hiring experience were more likely than others to say the allowance greatly improved their lives, perhaps because they made successful hires (Appendix Table A.27).

Few other patterns emerged; however, characteristics that were *not* associated with program outcomes bear mentioning. All else being equal, the outcomes we examined were not related to whether consumers or their representatives had graduated from high school, or whether consumers lived alone. There also was no evidence to suggest that poor health or functional impairments interfered with consumer direction. In fact, among allowance recipients, consumers in poor health at baseline were more likely than consumers in good or excellent health to say the allowance greatly improved life (Appendix Table A.27).

In summary, the analysis suggests that no segment of the CDC consumer population had consistently negative experiences in the program. Those who with consistently positive experiences were early enrollees--presumably the most eager and self-motivated consumers--and those with fairly generous allowances. Consumers who were very interested in paying family or friends for caregiving, who had informal caregivers when they enrolled in the program, and who had prior hiring experience also had positive experiences in the program. This pattern suggests that consumers who enroll in CDC without a hiring strategy in mind may need additional advice about hiring from program consultants.

## **Consultant Assessment of CDC**

Consultants also were asked to assess the experiences of different types of consumers. In questionnaire responses, consultants said CDC worked best for consumers who were dissatisfied with their usual HCBS (reported by 33 percent of consultants), wished to purchase services or goods not covered by Medicaid (24 percent), or had a relative or friend in mind to hire as a worker (15 percent) (Appendix Table A.29). Thirteen percent of consultants said the program did not work well for consumers who needed more care than they could obtain with the allowance. In addition, 47 percent of consultants said they worked with at least one consumer or representative who required extensive assistance from them (Appendix Table A.30). Consumers who required the most help had little experience in preparing budgets and solving problems, or in recruiting, hiring, and training workers. Unfortunately, it is impossible to know how consultants defined “extensive assistance” when responding to the survey, in light of expectations that appropriate consumers should need limited assistance to succeed in the program.

In assessing the program more generally during site visit discussions and in response to the questionnaire, consultants identified three main weaknesses in program implementation. First, some consultants reported that many consumers enrolled in the demonstration without clearly understanding the CDC program. According to the consultants, this problem may have stemmed from enrollment specialists not having enough time to thoroughly explain the program to the consumers they visited or from efforts to boost enrollment. As a result, the consultants had to explain CDC in detail to newly enrolled consumers, some of whom quickly disenrolled. Second, consultants reported that fiscal agent staff were unresponsive to them or to consumers who called the fiscal agent directly. This problem seems to have stemmed partly from staffing levels. The fiscal agent reduced its staff size while enrollment lagged only to find it inadequate when enrollment surged in response to letters from the governor's office. At the time our site visit, the CDC program, unsure whether consumer complaints originated with a vocal minority or represented widespread dissatisfaction, was preparing to conduct a postcard survey of consumer satisfaction with the fiscal agent. Third, some consultants reported that consumers were unhappy with the timeliness of worker payment, especially for the first paycheck. For procedural reasons, payroll-processing normally took at least three weeks, and the initial processing took somewhat longer. The fiscal agent reduced payroll-processing time by instituting a direct-deposit service for workers paid with the CDC allowance.

As for their own CDC responsibilities, one-quarter of consultants indicated in questionnaires that they would change those responsibilities in some way, but few offered specific recommendations. Ten consultants said they should do more for consumers--for example, by behaving more like social workers or spending more time with the consumers (Appendix Table A.31). In contrast, seven consultants thought they should do less for consumers, by behaving more like advisers or not explaining the program to them in great detail.

Only 39 percent of consultants thought they were adequately trained for their CDC responsibilities. Of those who made suggestions about program training, 53 consultants would change its content. Some wanted less emphasis on training philosophy and more on the practicalities of helping consumers develop purchasing plans and do paperwork. Some consultants said they wished to be better informed about changes in program policies. Twenty-five consultants suggested either that Florida reduce the time between training and actually working with consumers or that the state provide refresher training during lengthy delays. (This comment in particular may reflect that program implementation was unexpectedly delayed by protracted contract negotiations between the state and the organization chosen as the CDC fiscal agent. Some consultants had been trained well before those negotiations began and had to be retrained later, when it was time to actually work with consumers.) During site visit discussions, we learned that, after the initial consultant training session, CDC program staff developed separate training curricula for consultants who were to work with consumers who had developmental disabilities and those who were to work with elderly adults or adults with physical disabilities.

# SUMMARY, LESSONS, AND POLICY IMPLICATIONS

## Summary

Florida's CDC program tested the Cash and Counseling model of consumer-directed Medicaid supportive services. Like the two other demonstration programs, in Arkansas and New Jersey, CDC offered consumers a monthly allowance and counseling and fiscal services, and let them designate a representative decision maker if they wished. Of the three demonstration states, however, only Florida targeted the demonstration to people with primarily developmental disabilities, and only Florida enrolled children. Whereas Arkansas and New Jersey based the consumer-directed allowance only on state plan PCS, Florida cashed out a full range of HCBS benefits, including some specialized professional services. Moreover, the portion of the allowance that consumers could receive as cash for incidental expenditures was larger in Florida than in the other states (20 percent versus 10 percent). For these reasons, it could be argued that Florida granted consumers and representatives more responsibility than did the other two demonstration states. In addition, unlike the other states, Florida relied on case managers and support coordinators from the traditional HCBS programs to provide consulting services to CDC consumers. It also initially relied on them to conduct outreach and enrollment.

In implementing CDC, Florida was challenged by sluggish enrollment and delays in starting consumers on the program allowance. The state addressed both problems, but they did not disappear altogether.

Despite the challenges the program encountered, most consumers said they would recommend it to other people wanting more control over their personal care. Consumers who developed purchasing plans said they received helpful guidance from program consultants, and consumers who received the allowance took advantage of the ability to use it flexibly. Allowance recipients successfully hired workers and were very satisfied with them, and some used the allowance to purchase supplies and community services. Consultants generally reported that CDC was well received by consumers, despite room for administrative improvement.

## Implementation Lessons from CDC

**Outreach and Enrollment.** During the first six months of the demonstration, when Florida relied on case managers and support coordinators to enroll eligible HCBS recipients into the demonstration, enrollment lagged far behind evaluation targets. Many case managers did not support the concept of consumer-directed care, particularly for elderly beneficiaries, and many support coordinators were distracted from the demonstration by other duties. Enrollment increased somewhat when program

staff began reporting monthly enrollment statistics to the governor's office. It increased even more when the governor's office sent an introductory letter to eligible beneficiaries and temporary state employees were hired as enrollment specialists. Children and young adults with developmental disabilities enrolled in the demonstration rather quickly, possibly because their parents were experienced advocates and thus undaunted by the prospect of consumer direction. In contrast, elderly adults enrolled much more slowly, at least in part because many case managers disparaged the demonstration during visits with them.

**Consultants, Fiscal Agents, and Representatives.** Consultants, fiscal agents, and consumer-designated representatives all contributed to consumers' participation in CDC. Florida's decision to recruit CDC consultants from the ranks of case managers and support coordinators was fiscally practical, and it was thought that consumers would benefit from the continuity of the arrangement. However, the decision also had a serious downside. Some consultants were the very case managers who had been reluctant to enroll beneficiaries in CDC in the first place. Now they were expected to help beneficiaries on their way to consumer direction, and their reluctance did seem to delay the allowance for some consumers, particularly elderly ones.<sup>20</sup> Moreover, most consultants thought they were not adequately trained for their CDC roles. Some recommended longer training, refresher training, or training that emphasized the practical aspect of their jobs rather than the philosophy of consumer direction. For the most part, however, consumers were satisfied with the consultant services they received, and many consultants reported positively about consumers' experiences in the program.

The organization that Florida retained to provide consumers with fiscal services had some trouble meeting its CDC responsibilities. Most important, CDC had been operating for many months before the fiscal agent was able to supply consumers and their consultants with timely, understandable, and detailed financial statements. The trouble seemed to stem partly from slow cash flow, higher-than-expected costs, and inadequate reimbursement from the program. Most of the fiscal agent's compensation for CDC was in the form of consumer fees; program enrollment lags translated into revenue lags for the fiscal agent and, in turn, affected its ability to serve a small caseload efficiently. Even after caseloads grew, however, the fiscal agent's costs far exceeded what it earned in consumer fees.<sup>21</sup>

Representatives were key to many adult consumers' success with CDC. Children, of course, could not have participated without one. Consultants believed that nearly all representatives acted in consumers' best interests. Florida's decision to allow (unpaid) representatives to also serve as consumers' paid workers raised questions about conflicts of interest. During the evaluation period, Florida permitted such arrangements

---

<sup>20</sup> This problem was eventually mitigated by Florida's decision to have CDC caseloads shared by a limited number of consultants per agency. The consultants who applied for the job tended to be those who supported consumer direction.

<sup>21</sup> Florida capped consumer fees at \$25 per month, as noted, but experience showed that the fiscal agent would need to earn \$70 per consumer per month to break even.

if they could not be readily avoided (as might be the case in a single-parent family of a minor consumer). In addition, it asked someone identified by the consumer's family to check on the consumer's well-being, and the consultant telephoned that person and the representative for monitoring purposes.

**Starting on the Monthly Allowance.** For many consumers, getting started on the monthly allowance was not easy or quick. Personal circumstances, such as declining health and lack of family caregivers, undoubtedly prevented some consumers from developing a purchasing plan. More commonly, however, consultants and program staff attributed allowance delays to the slow processing of paperwork by program staff and the fiscal agent and to consumers needing more help in developing purchasing plans than consultants or the program initially expected.

We considered other possible reasons that so few consumers received the allowance during the follow-up year. For example, because consumers received HCBS as usual during the allowance-planning process, they might not have been motivated to work on their purchasing plans. Service continuity was an important, perhaps indispensable, consumer protection; however, it may have contributed to the finding that, across age groups, being satisfied with traditional services and changing one's mind about CDC were the most common reasons for voluntary disenrollment. It might also be argued that more consumers would have been able to develop and implement a purchasing plan if PCS alone had been cashed out as the program allowance, leaving consumers to receive any specialized professional services, such as occupational therapy, through the usual system of service delivery.<sup>22</sup> Although assuming responsibility for the full range of HCBS might have deterred some people from enrolling in the demonstration, it is also true that the group of consumers who enrolled most quickly were those with developmental disabilities and, thus, those most likely to have services other than personal care in their waiver support plans. Moreover, the multivariate models we used to identify factors associated with allowance receipt and staying in the program suggested that having a relatively large allowance--and hence relatively high service needs--was strongly associated with success in the program. Being eligible for a generous allowance does not necessarily mean consumers' care plans included services other than personal care, but our findings do not cast doubts on Florida's decision to cash out the full range of HCBS benefits.

Over time, the CDC program office realized that once consumers cleared the allowance-planning hurdle, they managed other CDC responsibilities ably. The program instructed consultants to provide more hands-on assistance to consumers who needed it and it offered more help to consumers who had not started on the allowance within 90 days of enrollment. Even after this change, consultants in Florida had much less responsibility than their counterparts in Arkansas for helping consumers with allowance-planning. The Arkansas fiscal/counseling agency was contractually obligated

---

<sup>22</sup> This hypothesis arose during focus group discussions about why eligible HCBS recipients chose not to enroll in the Cash and Counseling Demonstration. Focus group participants were nonelderly adults with developmental disabilities or their surrogates. The Herron Group, Inc., Tampa, Florida, conducted the discussions, in October 2003.

to start consumers on the allowance within 45 days (originally 60) of random assignment, and a program database generated periodic reminders to counselors about consumers who were not yet allowance recipients. The strategy seemed effective; 80 percent of Arkansas consumers received the program allowance within three months of random assignment, compared with 18 percent of Florida consumers. The lesson for other states is to expect that many consumers will need considerable hands-on assistance in developing purchasing plans and that needing help should not preclude program participation.

## How CDC Addressed Policy Concerns

As noted in the introduction, consumer direction in a publicly-funded program like Medicaid raises certain concerns among policymakers, including: (1) whether consumer direction should be available to all users of supportive services; (2) whether to allow family members to be paid for caregiving; (3) how to ensure care quality; (4) how to ensure that workers are trained adequately and treated fairly; and (5) how to avoid fraudulent use of the cash benefit. We conclude this report by discussing how the structure and procedures of Florida's CDC program addressed each of these concerns.

**Assessing Suitability for Consumer Direction.** Like the other two Cash and Counseling states, Florida had a policy to *not* screen prospective enrollees on their suitability for consumer direction. The state instead decided it would inform prospects of the rights and responsibilities of CDC consumers and let them decide for themselves whether to enroll. Importantly, Florida granted consumers the right: (1) to disenroll from CDC and return to their HCBS waiver program by the first day of the following month, without risk of being placed on a waiting list; and (2) to receive HCBS waiver benefits until the CDC allowance started.

In practice, at least initially, the judgments of case managers and program staff may have discouraged the enrollment and active participation of some consumers more than the state's take-all-comers policy would suggest. As noted earlier, some case managers appear to have discouraged elderly adults from enrolling in the program because they did not think consumer direction was suitable for them. Likewise, some consultants were reluctant to help consumers develop their purchasing plans believing that consumers who needed extensive help were not fit for the program.

Once it recognized these tendencies, CDC made two important changes: (1) it shifted outreach responsibilities from case managers and support coordinators to enrollment specialists who proved less likely to prejudice beneficiaries' fitness for consumer direction; and (2) it offered consumers more help in developing their purchasing plans, and instructed consultants to provide that additional help. Our analysis did not identify any subgroup of consumers with consistently negative program experiences. Despite some skepticism about the program's suitability for elderly consumers, elderly adults who received the CDC allowance were more likely than nonelderly adults to say the program greatly improved their quality of life.

**Paying Family Members.** There is a long-standing debate about the appropriateness of using public funds to pay family members (Simon-Rusinowitz et al. forthcoming; Doty 2004; Benjamin 2001; Benjamin et al. 2000; Tilly and Weiner 2001; Doty et al. 1999). Proponents of paying family members contend that the practice may help postpone caregiver burnout or compensate for constraints on labor force participation. Some opponents argue that payment may erode traditional values about familial responsibility, while others worry that consumers may feel obligated to hire family members and thus not exercise full autonomy. Other opponents worry about the effects of payment on public costs. Will consumer direction lead government to pay for services that family caregivers have long provided free? Will it induce caregivers to demand payment?

This report has shown that the ability to hire family members was an important aspect of consumers' success in CDC. Before random assignment, 83 percent of consumers said hiring family members was important to them; among consumers who hired workers, 58 percent hired family; and among allowance recipients, 30 percent said the ability to choose caregivers or compensate informal caregivers was the greatest benefit of program participation. Moreover, program consultants did not mention observing frayed family relationships as a result of consumers' paying relatives.

Current federal law allows relatives to be paid for caregiving only if they are not legally responsible for their care recipient. (Parents are legally responsible for minor children, as are spouses for adults.) In contrast, the federal waivers for the Cash and Counseling demonstration did allow consumers to hire legally responsible relatives. In Florida, less than 3 percent of adults who used the allowance to hire workers hired their spouse, and 29 percent of minor children had a parent for a paid worker. We conducted sensitivity tests to compare the experiences of children whose parents were paid with those of other children. (Paid spouses were too few to support such a comparison.) The tests suggested that children with paid parents were more likely than other children to receive their program allowance within nine months of random assignment (not shown). Parents of these children were more likely than other parents to say their child's life had been greatly improved by the allowance, and they were less likely to report that their child had unmet needs for personal care. That children with paid parents got started on the allowance promptly is not surprising. Parents who paid themselves did not have to spend time recruiting other caregivers (unless they also hired others), and the prospect of becoming paid may have induced them to develop a purchasing plan quickly. Consultants who took part in site visit discussions or responded to the questionnaire suggested that only rarely did parents even appear to take undue advantage of the opportunity to be paid.

**Ensuring Consumer Safety.** Ensuring the health and safety of vulnerable consumers without oversight from home care agencies and hands-on involvement from case managers is a major concern for consumer direction. For many years, regulations for agency delivered home care have existed to ensure care quality through requirements about agency structure and worker training and supervision (Kapp 2000;

Doty et al. 1996). Researchers and policymakers disagree, however, about how to define and assess care quality in consumer-directed models. Should the uniform professional standards of agency-based care apply? Or are consumers the more appropriate arbiters of quality? In 1999, most United States consumer-directed personal assistance programs (74 percent) required workers to have specific qualifications; nearly half (45 percent) required some type of worker training; and most (88 percent) conducted quality monitoring activities such as case management, consumer satisfaction reviews, and program evaluations (Flanagan 2001).

Consumers, consultants, and CDC program staff gave no evidence that participation in CDC led to any adverse effects on consumers' health and safety. CDC monitored consumer safety and care quality primarily through consultants' contacts with consumers and representatives, which occurred by telephone and in consumers' homes. The program found that the appropriate frequency of monitoring visits varied for different types of consumers. For those who could articulate their needs and concerns, telephone calls to the consumer and representative were usually enough to identify the rare cases of potential neglect. For adults with developmental disabilities and for children, visits helped ensure the safety of consumers who may have had difficulty communicating their needs. While there was little evidence of consumer neglect or exploitation in CDC, project staff did develop formal arrangements for consultants to refer suspicious cases to protective services agencies.

For the most part, consumers were satisfied with their care arrangements and with the CDC program, as this report shows. Furthermore, they fared as well as, or better than, their counterparts in a randomly assigned control group on objective, care-related outcomes such as falls, bed sores, and injuries (Foster et al. 2004; Carlson et al. 2005).

**Preventing Exploitation of Workers.** Mistreatment of workers is a potential problem in consumer-directed programs. Although CDC workers had no formal mechanism for reporting grievances, exploitation does not seem to have been a serious problem in CDC. During our site visit, consultants mentioned two cases that involved seemingly insensitive or arbitrary behavior on the part of consumers as employers. In our survey of consultants, just two out of 195 reported evidence of possible worker abuse by consumers, representatives, or other family members.

In addition to concerns about worker abuse and exploitation, critics of consumer-directed care worry that workers hired directly by consumers will suffer from low pay and a lack of fringe benefits. It is true that few CDC consumers offered fringe benefits; however, nearly all worked for the consumer part-time, and fringe benefits are rare in most part-time jobs. Although consumers set workers' wages, the CDC fiscal agent helped protect workers by adhering to state labor laws regarding overtime pay that some consumers were unaware of.

**Preventing Misuse of Public Funds.** The CDC project developed three policies to prevent abuse of the allowance. First, consultants were to review the consumer's monthly financial statement with the consumer or representative during the monthly call

or visit. Second, consumers were to retain receipts and maintain records of incidental purchases made with cash. Third, in most cases, the fiscal agent was to pay only for purchases listed in consumers' purchasing plans.

Practice did not initially adhere to policy. The CDC fiscal agent's difficulty in producing timely, well-designed financial statements seriously impeded the ability of consultants and consumers to monitor use of funds and prevent overspending. This problem seems to have persisted for much of the first 18 months of the life of CDC. Consultants differed in their understanding of, and willingness to follow, the program's policy that they review consumers' receipts for cash purchases. However, since cash purchases could not exceed 20 percent of the monthly allowance, receipt review may not have been critical to preventing major abuses of the allowance. Overall, unintentional misuse of the allowance, such as overspending, did occasionally result from difficulties in program implementation.

## **Conclusion**

Florida's CDC program offered a diverse group of HCBS recipients the opportunity to control the who, what, how, and when of their disability-related supportive services. Our analysis suggested consumers most likely to find success in the program were early enrollees, those eligible for relatively generous allowances, those interested in paying family or friends, and those with informal caregivers. Having prior hiring experience, or having a representative with such experience, was also associated with positive outcomes. Information from several sources suggests that, had the program decided differently on a few design decisions and been less firm in initial expectations about how much assistance consumers might need to get started in the program, positive outcomes might have been more common within other subgroups, including elderly consumers.

Overall, however, the demonstration in Florida addressed many important concerns about publicly-funded consumer-directed care. Program staff developed policies that adhered to the tenets of the Cash and Counseling model of service delivery and made adjustments in those areas where practice fell short of those policies. Encouraged by evidence that consumer direction improves quality of life for many participants, Florida continues to offer the CDC program as an option to eligible HCBS recipients. Moreover, in summer 2002 the state legislature passed the Florida Consumer-Directed Care Act, which directed several state agencies to develop and seek Medicaid waivers for consumer-directed programs like CDC.

## REFERENCES

- Benjamin, A.E. "Consumer-Directed Services at Home: A New Model for Persons with Disabilities." *Health Affairs*, November/December 2001, vol. 20, no. 6, pp. 80-95.
- Benjamin, A.E., and Ruth Matthias. "Age, Consumer Direction, and Outcomes of Supportive Services at Home." *The Gerontologist*, October 2001, vol. 41, no. 5, pp. 632-642.
- Benjamin, A.E., Ruth Matthias, and Todd M. Franke. "Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home." *Health Services Research*, April 2000, vol. 35, no. 1, pp. 351-366.
- Carlson, Barbara Lepidus, Stacy Dale, Leslie Foster, Randall Brown, Barbara Phillips, and Jennifer Schore. "Effect of Consumer Direction on Adults' Personal Care and Well-Being in Arkansas, New Jersey, and Florida." Princeton, NJ: Mathematica Policy Research, Inc., May 2005. [<http://aspe.hhs.gov/daltcp/reports/adultpcw.htm>]
- Doty, Pamela. "Consumer-Directed Home Care: Effects on Family Caregivers." San Francisco, CA: Family Caregiver Alliance, October 2004.
- Doty, Pamela, A.E. Benjamin, Ruth Matthias, and Todd M. Franke. "In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery." Nontechnical summary report. Washington, DC: U.S. Department of Health and Human Services and University of California-Los Angeles, 1999. [<http://aspe.hhs.gov/daltcp/reports/ihss.htm>]
- Doty, Pamela, Judith Kasper, and Simi Litvak. "Consumer-Directed Models of Personal Care: Lessons from Medicaid." *Milbank Quarterly*, vol. 74, no. 3, 1996, pp. 377-409. [<http://aspe.hhs.gov/daltcp/reports/lessons.htm>]
- Eustis, Nancy N. "Consumer-Directed Long-Term Care Services: Evolving Perspectives and Alliances." *Generations*, vol. 20, no. 3, 2000, pp. 10-15.
- Feinberg, Lynn Friss, and Carol Whitlach. "Are Persons with Cognitive Impairment Able to State Consistent Choices?" *The Gerontologist*, vol. 41, no. 3, 2001, pp. 374-382.
- Flanagan, Susan. "An Inventory of Consumer-Directed Support Service Programs: Overview of Key Program Characteristics." Presented at the Annual Meeting of the Cash and Counseling Demonstration and Evaluation, Arlington, VA, October 24, 2001.

- Foster, Leslie, Randall Brown, and Rachel Shapiro. "Assessing the Appeal of the Cash and Counseling Demonstration in Arkansas, Florida, and New Jersey." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., May 2005.  
[\[http://aspe.hhs.gov/daltcp/reports/CCappeal.htm\]](http://aspe.hhs.gov/daltcp/reports/CCappeal.htm)
- Foster, Leslie, Stacy Dale, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Do Consumer-Directed Medicaid Supportive Services Work for Children with Developmental Disabilities?" Princeton, NJ: Mathematica Policy Research, Inc., September 2004.  
[\[http://aspe.hhs.gov/daltcp/reports/ddkidsMss.htm\]](http://aspe.hhs.gov/daltcp/reports/ddkidsMss.htm)
- Harrington, Charlene, and Martin Kitchener. "Medicaid Long-Term Care: Changes, Innovations, and Cost Containment." San Francisco, CA: University of California, San Francisco, July 2003. Available online at  
<http://www.ncsl.org/programs/health/harrington>. Accessed March 18, 2004.
- Kane, Robert, and Rosalie Kane. "What Older People Want from Long-Term Care, and How They Get It." *Health Affairs*, vol. 20, no. 6, 2001, pp. 114-127.
- Kapp, Marshall. "Consumer-Directed Long-Term Care: A Taxonomy of Legal Issues." *Generations*, vol. 20, no. 3, fall 2000, pp. 16-21.
- O'Brien, Ellen, and Risa Elias. "Medicaid and Long-Term Care." Menlo Park, CA: Henry J. Kaiser Family Foundation, May 2004.
- Phillips, Barbara, and Barbara Schneider. "Changing to Consumer-Directed Care: The Implementation of the Cash and Counseling Demonstration in Florida." Princeton, NJ: Mathematica Policy Research, Inc., February 2004.  
[\[http://aspe.hhs.gov/daltcp/reports/FLchange.htm\]](http://aspe.hhs.gov/daltcp/reports/FLchange.htm)
- Simon-Rusinowitz, Lori, Kevin J. Mahoney, Dawn Loughlin, and Michelle Sadler. "Paying Family Caregivers: An Effective Policy Option in the Arkansas Cash and Counseling Demonstration and Evaluation." *Marriage and Family Review*, forthcoming.
- Stone, Robyn. "Providing Long-Term Care Benefits in Cash: Moving to a Disability Model." *Health Affairs*, vol. 20, no. 6, 2001, pp. 96-108.
- Stone, Robyn. "Consumer Direction in Long-Term Care." *Generations*, vol. 20, no. 3, fall 2000, pp. 5-9.
- Tilly, Jane, and Joshua Wiener. "Consumer-Directed Home and Community Services: Policy Issues." Washington, DC: Urban Institute, January 2001.

Tilly, Jane, Joshua Wiener, and Alison Evans Cuellar. "Consumer-Directed Home- and Community-Based Services Programs in Five Countries: Policy Issues for Older People and Government." *Generations*, vol. 24, no. 3, fall 2000, pp.74-83.

Velgouse, Linda, and Virginia Dize. "A Review of State Initiatives in Consumer-Directed Long-Term Care." *Generations*, vol. 24, no. 3, fall 2000, pp. 28-33.

Zacharias, Lee. "Consumer Directed Care: Report on Florida Elder Affairs Focus Groups." College Park, MD: University of Maryland Center on Aging, May 2001.

# COMPANION REPORTS

## Impacts on Quality of Care and Use of Personal Care

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

Foster, Leslie, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Does Consumer Direction Affect the Quality of Medicaid Personal Assistance in Arkansas?" Princeton, NJ: Mathematica Policy Research, Inc., March 2003. [<http://aspe.hhs.gov/daltcp/reports/arqual.htm>]

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

Dale, Stacy, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "The Effect of Consumer Direction on Personal Assistance Received in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., April 2003. [<http://aspe.hhs.gov/daltcp/reports/Arkpa.htm>]

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

Foster, Leslie, Stacy Dale, Randall Brown, Barbara Phillips, Jennifer Schore, and Barbara Lepidus Carlson. "Do Consumer-Directed Supportive Services Work for Children with Developmental Disabilities?" Princeton, NJ: Mathematica Policy Research, Inc., September 2004. [<http://aspe.hhs.gov/daltcp/reports/ddkidsMss.htm>]

Carlson, Barbara Lepidus, Stacy Dale, Leslie Foster, Randall Brown, Barbara Phillips, Jennifer Schore. "Effect of Consumer Direction on Adults's Personal Care and Well-Being in Arkansas, New Jersey, and Florida." Princeton, NJ: Mathematica Policy Research, Inc., May 2005. [<http://aspe.hhs.gov/daltcp/reports/adultpcw.htm>]

## Impacts on the Cost of Medicaid and Medicare Services

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

*and on costs for children in the Florida program are listed below; a report on adults in all three program is forthcoming.*

Dale, Stacy, Randall Brown, and Barbara Phillips. "Does Arkansas' Cash and Counseling Program Affect Service Use and Public Costs?" Princeton, NJ: Mathematica Policy Research, Inc., July 2004.  
[\[http://aspe.hhs.gov/daltcp/reports/ARsupc.htm\]](http://aspe.hhs.gov/daltcp/reports/ARsupc.htm)

Dale, Stacy, Randall Brown, and Barbara Phillips. "Medicaid Costs Under Consumer Direction for Florida Children with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., December 2004.  
[\[http://aspe.hhs.gov/daltcp/reports/FLddkids.htm\]](http://aspe.hhs.gov/daltcp/reports/FLddkids.htm)

## **Impacts on Informal Caregiving**

*These reports compare the experiences of primary informal caregivers of treatment and control group members (identified at the time of random assignment), using data from telephone interviews describing caregiver burden and well-being nine months after random assignment. Reports on caregivers for Arkansas participants and Florida children are listed below; a report on caregivers for adults from all three programs is forthcoming.*

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "Easing the Burden of Caregiving: The Impact of Consumer Direction on Primary Informal Caregivers in Arkansas" Princeton, NJ: Mathematica Policy Research, Inc., August 2003. [\[http://aspe.hhs.gov/daltcp/reports/easing.htm\]](http://aspe.hhs.gov/daltcp/reports/easing.htm)

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "The Effects of Cash and Counseling on the Primary Informal Caregivers of Children with Developmental Disabilities." Princeton, NJ: Mathematica Policy Research, Inc., April 2005. [\[http://aspe.hhs.gov/daltcp/reports/ddkidpic.htm\]](http://aspe.hhs.gov/daltcp/reports/ddkidpic.htm)

## **Experiences of Paid Workers**

*These reports compare the experiences of primary paid workers of treatment and control group members (identified nine months after random assignment), using data from telephone interviews describing working conditions, burden, and well-being ten months after random assignment. The Arkansas report is listed below; a three-state report is forthcoming.*

Dale, Stacy, Randall Brown, Barbara Phillips, and Barbara Lepidus Carlson. "The Experiences of Workers Hired Under Consumer Direction in Arkansas." Princeton, NJ: Mathematica Policy Research, Inc., June 2003.  
[\[http://aspe.hhs.gov/daltcp/reports/ARhired.htm\]](http://aspe.hhs.gov/daltcp/reports/ARhired.htm)

## Program Implementation

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

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

[\[http://aspe.hhs.gov/daltcp/reports/movingic.htm\]](http://aspe.hhs.gov/daltcp/reports/movingic.htm)

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

[\[http://aspe.hhs.gov/daltcp/reports/enablepp.htm\]](http://aspe.hhs.gov/daltcp/reports/enablepp.htm)

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

[\[http://aspe.hhs.gov/daltcp/reports/FLchange.htm\]](http://aspe.hhs.gov/daltcp/reports/FLchange.htm)

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

[\[http://aspe.hhs.gov/daltcp/reports/cclesson.htm\]](http://aspe.hhs.gov/daltcp/reports/cclesson.htm)

*The current report is the second of a set of three. These reports provide an overview of program implementation by distilling information from the site visit reports noted above and synthesizing this information with data from a mail survey of counselors and telephone interviews with consumers in the program treatment groups. This report and its Arkansas counterpart are listed below; a report describing the implementation of the New Jersey program is forthcoming.*

Schore, Jennifer, and Barbara Phillips. "Consumer and Counselor Experiences in the Arkansas Independent Choices Program." Princeton, NJ: Mathematica Policy Research, Inc., January 2004. [\[http://aspe.hhs.gov/daltcp/reports/arkexp.htm\]](http://aspe.hhs.gov/daltcp/reports/arkexp.htm)

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

[\[http://aspe.hhs.gov/daltcp/reports/FLcdcp.htm\]](http://aspe.hhs.gov/daltcp/reports/FLcdcp.htm)

## APPENDIX A. ADDITIONAL TABLES

<b>TABLE A.1: Enrollment Flow and Length of Stay, All Consumers</b>	
	<b>Percentage of Consumers Enrolled</b>
<b>Enrollment Month<sup>a</sup></b>	
June 2000-December 2000	11.9
January 2001-June 2001	56.0
July 2001-December 2001	25.3
January 2002-July 2002	6.8
<b>Length of Enrollment During Year After Random Assignment</b>	
Less than 2 months	7.9
2 months or more, but less than 6 months	16.8
6 months or more, but less than 12 months	13.3
12 months	62.0
<b>Length of Allowance Receipt During Year After Random Assignment</b>	
Never received	43.3
6 months or less	14.8
7 to 10 months	35.7
11 months	6.0
12 months	0.2
<b>Number of Consumers Enrolled</b>	<b>1,410</b>
<b>SOURCE:</b> CDC program records.	
a. CDC enrolled consumers for the evaluation between June 2000 and July 2002.	

<b>TABLE A.1a: Enrollment Flow and Length of Stay, by Age Group and Waiver Tenure</b>					
	<b>Percentage of Consumers Enrolled</b>				
	<b>Age</b>			<b>Length of Time with Waiver Services</b>	
	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>	<b>Less than 6 Months</b>	<b>6 Months or Longer</b>
<b>Enrollment Month<sup>a</sup></b>					
June 2000-December 2000	14.8	13.6	7.1	9.8	13.1
January 2001-June 2001	72.7	60.1	33.6	58.1	54.9
July 2001-December 2001	12.6	26.3	38.2	22.2	26.9
January 2002-July 2002	0.0	0.0	21.2	9.8	5.2
<b>Length of Enrollment During Year After Random Assignment</b>					
Less than 2 months	2.4	5.3	16.6	8.2	7.7
2 months or more, but less than 6 months	7.8	16.7	26.9	14.2	18.2
6 months or more, but less than 12 months	11.2	13.6	15.5	14.2	12.8
12 months	78.6	64.5	41.1	63.3	61.3
<b>Length of Allowance Receipt During Year After Random Assignment</b>					
Never received allowance	29.1	42.7	60.0	41.9	44.1
6 months or less	18.6	15.3	9.8	15.9	14.1
7 to 10 months	45.9	38.2	21.7	37.1	34.9
11 months	6.2	3.3	8.5	4.8	6.7
12 months	0.2	0.4	0.0	0.2	0.2
<b>Number of Consumers Enrolled</b>	<b>501</b>	<b>456</b>	<b>453</b>	<b>499</b>	<b>911</b>
<b>SOURCE:</b> CDC program records.					
a. CDC enrolled consumers for the evaluation between June 2000 and July 2002.					

<b>TABLE A.2: Waiver Participation, CDC Allowance, and Use of Representatives, at the Time of Random Assignment, by Age Group (Percentages, Unless Otherwise Indicated)</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Demonstration Feeder Program</b>				
Developmental Disabilities	65.1	100.0	89.5	2.0
Department of Elder Affairs	31.5	0.0	0.0	98.0
Adult Services	3.4	0.0	10.5	0.0
<b>Length of Time in HCBS Waiver Program</b>				
Less than 6 months	35.4	40.9	35.3	29.4
6 months or longer	64.6	59.1	64.7	70.6
Mean Monthly Allowance	\$1,186	\$1,108	\$1,641	\$818
Named a CDC Representative	84.3	97.4 <sup>a</sup>	84.4	69.5
<b>Number of Consumers Responding to Survey</b>	<b>1,410</b>	<b>501</b>	<b>456</b>	<b>453</b>
<b>SOURCE:</b> CDC program records and MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002).				
a. Although minor children were required to have a representative, none had been designated for a small number of children at the time of random assignment.				

<b>TABLE A.3: Consumer Characteristics at the Time of Random Assignment, by Age Group</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or older</b>
<b>Demographic Characteristics</b>				
Age				
3 to 12	25.5	71.7	0.0	0.0
13 to 17	10.1	28.3	0.0	0.0
18 to 59	32.3	0.0	100.0	0.0
60 or older	32.1	0.0	0.0	100.0
Sex				
Female	53.0	38.1	42.1	80.4
Race				
Self-identified as White only	75.1	78.4	77.3	69.1
Self-identified as Black only or Black and some other race	20.9	16.9	18.6	27.8
Self-identified as some other race	4.0	4.7	4.1	3.0
Hispanic	23.1	17.8	18.9	33.1
Education of Consumer or Representative (in Years) <sup>a</sup>				
8 or fewer	6.6	2.6	5.4	12.4
9 to 12, nongraduate	13.3	8.8	13.6	18.1
12 (high school graduate)	23.7	21.9	27.8	21.4
More than 12 (some college)	56.4	66.7	53.2	48.1
Living Arrangement/Marital Status				
Lives alone	11.7	0.0	9.4	26.9
Lives with spouse only	4.3	0.0	0.9	12.4
Lives with others/not married or married and living with two or more other people	84.2	100.0	89.9	60.9
<b>Health and Functioning</b>				
Health Status				
Excellent or good	48.9	59.3	62.4	23.6
Fair	29.8	28.5	23.5	37.6
Poor	21.4	12.2	14.1	38.9
Health Compared with Last Year				
Better or about the same	75.2	90.2	83.5	50.2
Worse	24.8	9.8	16.5	49.8
Expected Health Next Year				
Better	24.8	31.7	26.1	20.1
Worse	26.2	56.5	54.6	32.5
Same	48.2	5.6	9.4	35.2
Could not say	9.3	6.2	9.9	12.2
Last Week, Not Independent In: <sup>b</sup>				
Transferring	57.8	60.3	48.1	64.8
Bathing	85.9	92.2	76.3	88.5
Using toilet	71.0	83.4	61.4	66.9
Functioning Compared with Last Year				
Better or about the same	66.5	85.2	75.1	36.9
Worse	33.5	14.8	24.9	63.1
Has Cognitive Impairment (Inferred) <sup>c</sup>	33.4	n.a.	58.1	45.5

<b>TABLE A.3 (continued)</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or older</b>
<b>Unpaid and Paid Personal Assistance</b>				
Had Unpaid or Paid Help at Home Last Week with:				
Personal care <sup>d</sup>	87.5	97.4	77.2	87.0
Transportation <sup>e</sup>	79.5	96.2	83.0	57.4
Routine health care <sup>f</sup>	82.2	91.0	79.8	74.8
Household and community activities <sup>g</sup>	97.2	100.0	95.4	95.8
Number of Unpaid Caregivers Last Week				
None	8.0	0.2	7.3	17.5
One	19.8	12.0	19.8	28.5
Two	25.1	26.0	25.3	23.9
Three or more	47.1	62.9	47.7	30.1
Primary Unpaid Caregiver Relationship to Consumer				
Spouse	4.0	0.2	1.3	10.8
Parent	55.9	89.2	74.1	0.7
Child	18.7	0.2	1.8	56.3
Other relative	9.5	9.2	10.1	9.3
Nonrelative	3.8	1.0	5.5	5.3
Had no primary informal caregiver	8.1	0.2	7.2	17.7
Primary Informal Caregiver Employed	42.8	48.5	46.6	32.6
Number of Paid Caregivers Last Week				
None	30.6	39.3	39.9	11.5
One	34.4	27.5	29.0	47.6
Two	19.5	16.2	17.3	25.4
Three or more	15.5	17.0	13.8	15.5
Had Paid Live-in Caregiver Last Week	3.5	2.4	4.2	4.0
Received Help at Home from Privately Paid Source Last Week	18.3	22.6	14.3	17.7
<b>Goods and Services Purchased Last Year</b>				
Social/Recreational Programs	34.9	48.1	43.1	12.0
Day Care	26.7	24.6	42.6	13.0
Transportation	54.8	65.0	56.8	41.6
Home or Vehicle Modification	46.2	59.5	35.8	42.0
Equipment Purchase	44.7	61.1	35.6	35.6
<b>Unmet Need for, and Access to, Personal Assistance</b>				
Last Week, Needed Help (or More Help) with:				
Personal care <sup>d</sup>	61.7	66.4	53.6	64.6
Transportation <sup>e</sup>	53.4	48.7	55.3	56.6
Household and community activities <sup>g</sup>	73.1	75.9	69.0	74.0
Potential Difficulty Hiring Due to Location				
Lives in a rural area	14.5	16.8	16.0	10.5
Live in a nonrural area but transportation difficult or high crime	35.8	31.4	36.4	40.1
Lives in a nonrural area, but transportation not difficult and not high crime	49.6	51.8	47.6	49.3
<b>Satisfaction with Paid Personal Assistance</b>				
Satisfaction with How Paid Help Provided				
Very satisfied	32.8	28.8	26.7	26.1
Satisfied	18.9	17.1	13.7	16.9
Dissatisfied	10.9	8.5	7.7	13.5
No paid help with personal care, routine health care, housework <sup>h</sup>	37.4	45.7	51.9	27.7

<b>TABLE A.3 (continued)</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or older</b>
<b>Satisfied with When Paid Help Provided Among Those Receiving Personal Care</b>				
Very satisfied	23.0	20.1	21.6	13.5
Satisfied	19.5	19.7	14.1	27.7
Dissatisfied	15.7	13.5	10.4	24.6
No paid help with personal care	41.8	46.8	53.9	23.7
<b>Satisfied with Paid Services and Goods Overall</b>				
Very satisfied	31.3	16.7	40.7	38.2
Satisfied	37.2	39.7	32.7	39.1
Dissatisfied	27.5	40.1	19.9	20.9
No paid services or goods	4.0	3.4	6.6	1.8
<b>Quality of Life</b>				
<b>Satisfied with the Way Spending Life<sup>1</sup></b>				
Very satisfied	12.4	17.3	9.9	9.5
Satisfied	22.3	43.8	6.6	14.2
Dissatisfied	21.1	38.8	7.5	15.4
Proxy respondent not asked	44.2	0.2	76.1	61.0
<b>Employment Experience<sup>a</sup></b>				
Ever Employed	96.7	98.6	94.7	96.7
Currently Employed (if Ever)	42.9	52.8	47.3	24.2
Ever Supervised Someone	96.7	76.6	66.3	61.8
Ever Hired Someone Privately	68.5	74.7	67.3	61.7
<b>Type of Respondent</b>				
Majority of Baseline Questions Answered by Proxy Respondent	79.4	99.8	76.5	59.6
<b>Number of Consumers Responding to Survey</b>	<b>1,410</b>	<b>501</b>	<b>456</b>	<b>453</b>
<p><b>SOURCE:</b> Age and sex come from CDC program records. All other data come from MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002).</p> <p><b>NOTE:</b> "Last week" refers to the week before the baseline survey.</p> <p>a. In the "3 to 17" age group, this item was measured for the parent who completed the interview. In the adult age groups, this item was measured for the consumer unless the consumer's representative completed the interview. In such cases, the item was measured for the representative.</p> <p>b. Received hands-on or standby help or did not perform activity at all.</p> <p>c. Consumer could not respond to interview due to physical or mental limitation and used a representative to manage allowance.</p> <p>d. Personal care includes bathing, transfer from bed, eating, and using the toilet.</p> <p>e. Transportation includes trips for medical and nonmedical reasons.</p> <p>f. Routine health care includes taking medications, checking vital signs, and doing exercises.</p> <p>g. Household and community activities include light housework, yard work, meal preparation, shopping, and homework help.</p> <p>h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.</p> <p>i. In the "3 to 17" age group, we assessed the parent's satisfaction with the child's quality of life.</p>				

<b>TABLE A.4: Program Features Important to Consumers at the Time of Random Assignment, by Age Group (Percentages)</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Having a Choice About the Type of Help Received</b>				
Very important	93.4	98.0	90.1	91.6
Important or somewhat important	5.1	1.8	6.8	7.1
Not important	1.5	0.2	3.1	1.3
<b>Having a Choice About When Helpers Come</b>				
Very important	86.0	92.0	81.6	83.7
Important or somewhat important	9.8	5.2	12.9	11.7
Not important	4.3	2.8	5.5	4.6
<b>Paying Family Members to Help</b>				
Very important	61.1	58.9	57.9	66.7
Important or somewhat important	21.6	23.9	23.3	17.4
Not important	17.3	17.2	18.9	15.9
<b>Paying Friends to Help</b>				
Very important	59.6	59.7	57.5	61.6
Important or somewhat important	24.4	25.4	25.7	22.1
Not important	16.0	15.0	16.9	16.3
Primary Informal Caregiver Expressed Interest in Being Paid	27.5	24.3	29.5	29.2
<b>Number of Consumers Responding to Survey</b>	<b>1,410</b>	<b>501</b>	<b>456</b>	<b>453</b>
<b>SOURCE:</b> MPR consumer interviews, conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002).				

<b>TABLE A.5: Consultant Characteristics and Experience with CDC</b>	
	<b>Percentage</b>
<b>Characteristic</b>	
<b>Highest Educational Degree</b>	
Less than high school	0.0
High school graduate or GED	0.5
Associate	0.0
Baccalaureate	65.6
Master's or doctorate	31.3
<b>Sex</b>	
Female	79.0
Hispanic or Latino	14.4
<b>Race</b>	
White	80.0
African American/Black	14.9
White and American Indian/Alaska Native	1.5
<b>Country of Birth</b>	
United States <sup>a</sup>	85.1
<b>Time Working for CDC</b>	
Six months or less	89.1
Longer than six months	10.9
<b>Number of Consumers, if Any, with Whom Consultant Has Worked Since Started with CDC<sup>b</sup></b>	
Mean	9.0
Median	3.0
Minimum	1.0
Maximum	125.0
<b>Number of Consumers with Whom Consultant Working at Present</b>	
Mean	3.2
Median	2.0
Minimum	0.0
Maximum	30.0
<b>Number of Consultants Responding to Survey</b>	
<b>195</b>	
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	
a. Among consultants who reported being born outside in United States, five reported being from Cuba, four from Colombia, three from Nicaragua, and two each from Haiti, Puerto Rico, Jamaica, and Canada. No other countries were reported by more than one consultant.	
b. Five consultants reported that they had not yet worked with a consumer.	

<b>TABLE A.6: Activities Conducted by Consultants</b>	
Mean Number of Hours Consultants Worked per Week for CDC	3.5
Percentage of Consultants Spending at Least 20 Percent of Consulting Time on the Following Activities with Consumers:	
Assisting with spending plan or advising about purchases	26.2
Performing administrative activities <sup>a</sup>	19.5
Listening or providing encouragement or support	16.4
Advising about payroll issues <sup>b</sup>	7.2
Reinforcing decision to participate	4.6
Linking to peer counseling or other local services	2.1
Assisting with emergency back-up arrangements	2.1
Monitoring or investigating misuse of allowance or abuse/neglect/exploitation	1.0
Reassessing Medicaid plans	1.0
Advising about worker training	0.5
Assisting in disputes with workers or advising about firing	0.0
Percentage of Consultants Reporting the Following as Valuable to Consumers:	
Assisting with spending plan or advising about purchases	79.0
Listening or providing encouragement or support	72.3
Assisting with paperwork	65.6
Advising about payroll activities for workers	40.5
Linking to peer counseling or other local services	19.0
Assisting with emergency back-up arrangements	13.9
Advising about worker training	13.3
Assisting in disputes with workers or advising about firing	6.7
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding To Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	
a. Such as record keeping, updating case notes, or contacting other program staff.	
b. Such as setting wages and estimating payroll taxes.	

<b>TABLE A.7: Consumer Monitoring</b>	
Number of Consultants Reporting That Some Consumers Needed Extensive Monitoring	44
Average number of consumers on caseload who needed extensive monitoring	1.7
<b>Number of Consultants Reporting the Following Reasons for Monitoring:</b>	
Consumer or representative had difficulty completing paperwork	29
Consumer or representative was having difficulty staying on budget	20
Consumer or representative had no experience as employer	17
Workers changed frequently	12
Consumer or representative appeared to be abused, neglected, or financially exploited	3
Consumer's living environment was unsafe	2
Representative changed	2
Consumer or representative was ill	1
Consumer or representative appeared to be abusing or financially exploiting worker	0
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<p><b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.</p> <p><b>NOTE:</b> Consultants were asked about consumers or representatives who required extensive monitoring due to concerns about their ability to manage the cash benefit or about their safety. Consumers who had difficulty completing paperwork probably needed extensive assistance, rather than extensive monitoring, so some consultants may have misconstrued our question.</p>	

<b>TABLE A.8: Time Between Random Assignment and Monthly Allowance Start, Disenrollment, or Death, All Consumers</b>	
	<b>Percentage of Consumers</b>
<b>Started Monthly Allowance by End of:<sup>a</sup></b>	
1 month	0.0
2 months	5.0
3 months	18.3
4 months	29.7
5 months	37.8
6 months	44.4
7 months	48.8
8 months	51.6
9 months	53.3
10 months	54.9
11 months	56.3
12 months	57.1
<b>Snapshot at End of 3 Months</b>	
Enrolled and started allowance	17.9
Enrolled and allowance not started	68.7
Disenrolled	12.3
Deceased	1.1
<b>Snapshot at End of 6 Months</b>	
Enrolled and started allowance	42.6
Enrolled and allowance not started	32.7
Disenrolled	23.1
Deceased	1.6
<b>Snapshot at End of 9 Months</b>	
Enrolled and started allowance	49.9
Enrolled and allowance not started	18.7
Disenrolled	28.9
Deceased	2.6
<b>Snapshot at End of 12 Months</b>	
Enrolled and started allowance	52.2
Enrolled and allowance not started	10.8
Disenrolled	33.3
Deceased	3.7
<b>Number of Consumers Enrolled</b>	<b>1,410</b>
<b>SOURCE:</b> CDC program records.	
a. Percentages in this panel are cumulative and include consumers who started on cash before the referenced month but subsequently disenrolled or died.	

<b>TABLE A.8a: Time Between Random Assignment and Monthly Allowance Start, by Age Group and Waiver Tenure</b>					
	<b>Percentage of Consumers</b>				
	<b>Age</b>			<b>Length of Time with Waiver Services</b>	
	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>	<b>Less than 6 Months</b>	<b>6 Months or Longer</b>
<b>Started Monthly Allowance by End of:<sup>a</sup></b>					
1 month	0.0	0.0	0.0	0.0	0.0
2 months	5.0	2.0	8.2	4.2	5.5
3 months	21.8	13.8	19.0	17.2	18.9
4 months	34.9	25.2	28.5	28.9	30.2
5 months	44.9	34.9	32.9	36.7	38.4
6 months	53.9	42.8	35.5	44.1	44.6
7 months	59.3	48.5	37.5	49.3	48.5
8 months	63.7	51.3	38.4	53.1	50.7
9 months	65.9	54.0	38.9	54.9	52.5
10 months	67.7	55.9	39.7	57.1	53.7
11 months	70.1	56.8	40.6	57.9	55.4
12 months	71.1	57.9	40.8	58.3	56.4
<b>Snapshot at End of 3 Months</b>					
Enrolled and started allowance	21.4	13.8	18.1	17.0	18.3
Enrolled and allowance not started	74.5	75.9	55.0	70.1	67.8
Disenrolled	4.0	10.1	23.8	11.2	13.0
Deceased	0.2	0.2	3.1	1.6	0.9
<b>Snapshot at End of 6 Months</b>					
Enrolled and started allowance	52.5	42.1	32.2	42.7	42.6
Enrolled and allowance not started	37.7	36.0	23.8	35.1	31.4
Disenrolled	9.6	21.7	39.5	20.0	24.8
Deceased	0.2	0.2	4.4	2.2	1.2
<b>Snapshot at End of 9 Months</b>					
Enrolled and started allowance	63.7	52.4	32.2	52.1	48.7
Enrolled and allowance not started	21.6	18.6	15.5	19.4	18.2
Disenrolled	14.4	28.7	45.0	25.1	31.0
Deceased	0.4	0.2	7.3	3.4	2.1
<b>Snapshot at End of 12 Months</b>					
Enrolled and started allowance	68.3	54.8	31.8	53.9	51.3
Enrolled and allowance not started	11.2	11.0	10.2	10.0	11.2
Disenrolled	19.6	33.6	48.3	31.7	34.3
Deceased	1.0	0.7	9.7	4.4	3.3
<b>Number of Consumers Enrolled</b>	<b>501</b>	<b>456</b>	<b>453</b>	<b>499</b>	<b>911</b>
<b>SOURCE:</b> CDC program records.					
a. Percentages in this panel are cumulative and include consumers who started on cash before the referenced month but subsequently disenrolled or died.					

<b>TABLE A.9: Use of Representatives</b>	
Percentage of Consultants Working with Consumers Who Used Representatives	95.7
Of Those Consultants, Percentage Reporting That at Least One:	
Representative's suitability was questionable	18.8
Consumer disenrolled because representative was unsuitable	5.7
Representative acted according to the wishes and best interest of consumers	93.6
Representative had a serious divergence of wishes or interests from consumer	6.4
Average Number of Consumers with Whom Consultants Worked	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	

<b>TABLE A.10: Use of, and Satisfaction With, Program Services, All Consumers</b>		
	<b>Percentage of Consumers Reporting</b>	<b>Percentage of Users Reporting Service Useful/Satisfied with Service</b>
Help Developing Allowance Spending Plan Between Baseline and 6-Month Interviews	67.8	92.6
Help Revising Allowance Spending Plan Between 6- and 9-Month Interviews	29.9	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews	49.1	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	77.2	80.6
Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	40.4	94.1
Advice or Materials About How to Recruit Workers Between 6- and 9-Month Interviews (Among Those Who Tried to Hire)	37.6	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	96.8	87.0
Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired)	34.3	84.2
Advice About How to Train Workers Between 6- and 9-Month Interviews (Among Those Who Hired)	17.8	n.a.
Use of Peer Support Between Baseline and 6-Month Interviews <sup>a</sup> (Among Those Receiving Allowance)	9.7	100.0
Use of Peer Support Between 6- and 9-Month Interviews (Among Those Receiving Allowance)	6.4	n.a.
<b>Number of Respondents to 6-Month Interview</b>	<b>1,340</b>	
<b>Number of Respondents to 9-Month Interview</b>	<b>1,213</b>	
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.		
a. Training or advice from other allowance recipients.		
n.a. = not asked.		

<b>TABLE A.10a: Use of, and Satisfaction With, Program Services, Children's Parents</b>		
	<b>Percentage of Consumers Reporting</b>	<b>Percentage of Users Reporting Service Useful/Satisfied with Service</b>
Help Developing Allowance Spending Plan Between Baseline and 6-Month Interviews	74.7	94.1
Help Revising Allowance Spending Plan Between 6- and 9-Month Interviews	35.3	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews	48.1	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	79.3	80.3
Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	43.4	90.2
Advice or Materials About How to Recruit Workers Between 6- and 9-Month Interviews (Among Those Who Tried to Hire)	43.7	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	98.4	85.5
Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired)	28.3	81.0
Advice About How to Train Workers Between 6- and 9-Month Interviews (Among Those Who Hired)	21.4	n.a.
Use of Peer Support Between Baseline and 6-Month Interviews <sup>a</sup> (Among Those Receiving Allowance)	15.4	100.0
Use of Peer Support Between 6- and 9-Month Interviews (Among Those Receiving Allowance)	11.1	n.a.
<b>Number of Respondents to 6-Month Interview</b>	<b>479</b>	
<b>Number of Respondents to 9-Month Interview</b>	<b>441</b>	
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.		
a. Training or advice from other allowance recipients.		
n.a. = not asked.		

<b>TABLE A.10b: Use of, and Satisfaction With, Program Services, Nonelderly Adults</b>		
	<b>Percentage of Consumers Reporting</b>	<b>Percentage of Users Reporting Service Useful/Satisfied with Service</b>
Help Developing Allowance Spending Plan Between Baseline and 6-Month Interviews	65.6	93.0
Help Revising Allowance Spending Plan Between 6- and 9-Month Interviews	28.3	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews	55.4	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	75.6	81.3
Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	35.3	97.7
Advice or Materials About How to Recruit Workers Between 6- and 9-Month Interviews (Among Those Who Tried to Hire)	26.2	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	96.2	86.7
Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired)	36.6	85.7
Advice About How to Train Workers Between 6- and 9-Month Interviews (Among Those Who Hired)	21.4	n.a.
Use of Peer Support Between Baseline and 6-Month Interviews <sup>a</sup> (Among Those Receiving Allowance)	9.0	100.0
Use of Peer Support Between 6- and 9-Month Interviews (Among Those Receiving Allowance)	11.0	n.a.
<b>Number of Respondents to 6-Month Interview</b>	<b>440</b>	
<b>Number of Respondents to 9-Month Interview</b>	<b>399</b>	
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.		
a. Training or advice from other allowance recipients.		
n.a. = not asked.		

<b>TABLE A.10c: Use of, and Satisfaction With, Program Services, Elderly Adults</b>		
	<b>Percentage of Consumers Reporting</b>	<b>Percentage of Users Reporting Service Useful/Satisfied with Service</b>
Help Developing Allowance Spending Plan Between Baseline and 6-Month Interviews	62.1	89.9
Help Revising Allowance Spending Plan Between 6- and 9-Month Interviews	22.8	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 6-Month Interviews	42.4	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	76.0	80.4
Advice About How to Recruit Workers Between Baseline and 6-Month Interviews (Among Those Who Tried to Hire)	42.2	96.5
Advice or Materials About How to Recruit Workers Between 6- and 9-Month Interviews (Among Those Who Tried to Hire)	40.0	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	94.4	90.6
Advice About How to Train Workers Between Baseline and 6-Month Interviews (Among Those Who Hired)	42.3	86.5
Advice About How to Train Workers Between 6- and 9-Month Interviews (Among Those Who Hired)	27.8	n.a.
Use of Peer Support Between Baseline and 6-Month Interviews <sup>a</sup> (Among Those Receiving Allowance)	0.0	n.a.
Use of Peer Support Between 6- and 9-Month Interviews (Among Those Receiving Allowance)	1.4	n.a.
<b>Number of Respondents to 6-Month Interview</b>	<b>421</b>	
<b>Number of Respondents to 9-Month Interview</b>	<b>373</b>	
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.		
a. Training or advice from other allowance recipients.		
n.a. = not asked.		

<b>TABLE A.11: Aspects of Program Services Found Useful, by Age Group (Percentages)</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Among Those Receiving Help with Allowance Spending Plan, What Aspect of Help Found Useful:</b>				
Explaining program rules	62.0	53.7	61.4	74.8
Clarifying goals, options, and priorities	44.9	48.1	42.1	43.4
Handling paperwork	26.1	25.1	25.2	28.8
Determining service costs	16.3	17.0	16.1	15.5
Getting approval for special uses of allowance	10.2	10.8	8.7	11.1
<b>Among Those Receiving Advice About How to Recruit Workers, What Aspects of Advice Found Useful:</b>				
Locating potential workers	37.0	40.7	42.0	26.8
Setting wage or benefit levels	17.4	15.3	17.3	20.7
Screening or interviewing potential workers	38.4	44.9	39.5	28.1
Arranging for background check	6.4	5.9	4.9	8.5
Provided training or advice of unspecified nature	27.1	24.6	14.8	42.7
<b>Number of Respondents to 6-Month Interview</b>	<b>1,340</b>	<b>479</b>	<b>440</b>	<b>421</b>
<b>SOURCE:</b> MPR consumer interviews conducted six months after consumers' random assignment.				

<b>TABLE A.12: Difficulties Assuming the Role of Employer, by Age Group</b>				
	<b>Percentage (Unless Noted Otherwise)</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Hiring Workers</b>				
Hiring Workers with Allowance Between Baseline and 9-Month Interviews				
Hired a worker	46.2	59.0	42.2	35.2
Tried to hire a worker, but did not	19.2	14.7	21.2	22.2
Did not try to hire a worker	34.7	26.3	36.6	42.6
Among Those Who Hired with Allowance Between Baseline and 9-Month Interviews, Found Hiring Hard	41.3	46.0	38.7	35.3
Among Those Who Found Hiring Hard Between Baseline and 6-Month Interviews, Aspect That Was Hardest				
Could not find interested/qualified workers	48.2	59.8	45.0	26.2
Wages offered were too low	14.6	4.1	15.0	38.1
Applicants disliked hours or tasks	15.6	14.4	21.7	9.5
Getting references/judging qualifications	7.5	8.3	5.0	9.5
Did not trust applicants	6.0	6.2	5.0	7.2
<b>Training Workers</b>				
Among Those Who Hired with Allowance, Provided Training for Workers Hired with Allowance Between Baseline and 9-Month Interviews				
Showed worker how to carry out tasks	53.6	61.9	46.8	45.9
Arranged for training outside the home	7.8	10.6	7.1	3.0
Among Those Who Trained Workers Between Baseline and 9-Month Interviews, Found Training Hard	15.1	17.6	13.7	10.4
Among Those Who Found Training Hard Between Baseline and 6-Month Interviews, Number Who Cited Aspect as Hardest				
	Numbers (overall n = 19)			
Worker had no experience	10	4	3	3
Consumer was unable to demonstrate or answer questions about tasks	6	2	3	0
It was difficult to find training programs	2	2	0	0
Representative found it difficult to train and get own work done	1	0	1	0
<b>Number of Respondents to the 6- or 9-Month Interview</b>	<b>1,363</b>	<b>486</b>	<b>447</b>	<b>430</b>
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.				

<b>TABLE A.13: Recruiting Methods, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Recruiting Methods Attempted, Among Those Who Hired or Tried to Hire Worker</b>				
Tried to Hire				
Family member	62.1	61.0	63.7	61.9
Friend, neighbor, or church member	45.5	49.2	49.4	34.9
Home care agency worker	38.1	38.1	40.9	34.9
Asked Family or Friend to Recommend Worker	40.0	43.2	38.5	37.0
Posted or Consulted Advertisements	10.8	10.6	8.8	13.4
Contacted Employment Agency	6.7	9.4	6.1	3.2
<b>Recruiting Methods Resulting in Hires, Among Those Who Hired</b>				
Hired Family Member	58.3	51.7	64.2	63.9
Hired Friend, Neighbor, or Church Member	31.5	34.7	34.7	21.1
Hired Former Agency Worker	24.5	26.4	26.0	18.8
Hired Worker Recommended by Family or Friend	18.4	24.9	11.6	14.3
Posted or Consulted Advertisement	10.3	9.4	9.8	12.8
Contacted Employment Agency	1.6	1.5	2.3	0.8
Hired Through Other Means <sup>a</sup>	10.7	14.0	8.7	6.8
<b>Number of Respondents to Either the 6- or the 9-Month Interview</b>	<b>1,363</b>	<b>486</b>	<b>447</b>	<b>430</b>
<b>SOURCE:</b> MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.				
a. For example, through schools, support groups, or provider agencies.				

<b>TABLE A.14: Satisfaction with Workers as Reported by Consultants</b>	
<b>Consultants Reporting That He or She Worked with Consumers Who:</b>	<b>Percentage</b>
Included a Paid Worker in Purchasing Plan	96.2
Had Serious Problem with Turnover Due to Workers Resigning or Being Fired	25.6
Hired a Relative	82.1
Were very satisfied with worker	98.6
Were very dissatisfied with worker	5.4
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	

<b>TABLE A.15: Consultant Reports of Abuse of Consumers and Workers</b>	
<b>Financial Exploitation of Consumers</b>	
Number of Consultants Reporting Evidence of Financial Exploitation <sup>a</sup>	4
Number of Consultants Reporting Financial Exploitation of Consumers by:	
Representatives	3
Workers	2
Number of Consumers per Consultant for Whom There Was Evidence of Financial Exploitation	Maximum of 1
<b>Physical or Verbal Abuse or Neglect of Consumers</b>	
Number of Consultants Reporting Evidence of Abuse or Neglect	2
Number of Consultants Reporting Abuse or Neglect, by Type	
Self-neglect	2
Physical or sexual abuse	0
Neglect of physical needs or abandonment	0
Verbal, emotional, or psychological abuse	0
Average Number of Consumers for Whom There Was Evidence of Abuse or Neglect	No responses
Number of Consultants Reporting Abuse or Neglect of Consumers by:	
Representatives	No responses
Workers	No responses
<b>Physical or Verbal Abuse of Workers</b>	
Number of Consultants Reporting Evidence of Abuse of Workers by Consumers, Their Representatives, or Families	2
Number of Consultants Reporting Worker Abuse or Neglect, by Type	
Physical or sexual abuse	1
Verbal, emotional, or psychological abuse	1
Number of Consumers per Consultant for Whom There Was Evidence of Abuse of Workers	Maximum of 1
Number of Consultants Reporting Abuse of Workers by:	
Representatives	1
Consumers	2
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	
a. Financial exploitation includes stealing money or possessions from consumers, intentional overbilling, and coercing to sign over assets.	

<b>TABLE A.16: Consultant Reports of Misuse of the Monthly Allowance</b>	
Number of Consultants Reporting Evidence of Misuse of the Allowance	17
Number of Consultants Reporting Misuse, by Type	
Purchased nonpermissible goods or services	1
Had worker purchase nonpermissible goods or services	1
Overspent allowance	12
Did not keep adequate records	7
Did not report worker hours in timely way	0
Did not pay worker on time or correct amount	1
Number of Consultants Reporting Misuse More Likely Among Consumers Without Representative	0
Number of Consultants Reporting Misuse Less Likely Among Consumers Without Representative	0
Average Number of Consumers for Whom There Was Any Evidence of Allowance Misuse	1.3
Average Number of Consumers for Whom Consultants Had to Follow Up on Evidence of Allowance Misuse	1.2
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	

<b>TABLE A.17: Assistance from Paid Workers, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
Hired a Worker with Monthly Allowance Between Baseline and 9-Month Interview	45.1	58.5	40.6	34.0
Had Paid Worker in Two Weeks Before 9-Month Interview	79.5	79.8	72.9	86.1
Hired Worker with Monthly Allowance Between Baseline and 9-Month Interview and Had Paid Worker in Two Weeks Before 9-Month Interview <sup>a</sup>	42.4	54.0	39.3	31.9
<b>Among Those Who Hired Worker with Monthly Allowance and Had Worker in During Two Weeks Before 9-Month Interview</b>				
Had 1 worker	40.7	34.0	43.3	50.4
Had 2 workers	30.2	29.4	30.6	31.1
Had 3 or more workers	29.2	36.6	26.1	18.5
Had a visiting worker(s)	78.8	84.9	73.9	73.1
Had live-in worker(s)	45.3	40.8	49.7	48.7
<b>At least one worker was consumer's:</b>				
Spouse	1.6	0.4	0.6	5.0
Parent	24.3	28.6	36.3	0.0
Child	11.5	0.0	1.9	47.1
Other relative	35.0	39.9	36.9	22.7
Not related	38.3	41.6	33.8	37.8
<b>Hours of paid care</b>				
14 or fewer	16.3	16.0	18.6	13.9
15 to 42	36.7	37.8	34.0	38.0
43 to 70	20.8	19.8	13.3	33.3
71 or more	26.2	26.5	34.0	14.8
<b>Worker helped with:</b>				
Routine health care <sup>b</sup>	76.9	77.7	72.6	80.7
Personal care <sup>c</sup>	94.0	97.9	88.6	95.8
Household or community activities <sup>d</sup>	96.7	97.1	94.3	99.2
Transportation <sup>e</sup>	66.7	70.6	76.4	46.2
<b>Worker helped:</b>				
Before 8 A.M. on weekdays	48.5	48.7	50.3	45.8
After 8 P.M. on weekdays	80.5	89.5	75.2	69.5
On weekends	83.9	86.1	82.8	80.7
<b>Number of Respondents to the 9-Month Interview</b>	<b>1,213</b>	<b>441</b>	<b>399</b>	<b>373</b>
<b>Number of Consumers Who Hired with the Monthly Allowance and Reported on Care Received During a Two-Week Period</b>	<b>514</b>	<b>238</b>	<b>157</b>	<b>119</b>
<b>SOURCE:</b> MPR consumer interviews administered by telephone nine months after consumers' random assignment.				
<p>a. Includes workers for nine consumers who had disenrolled from CDC and were likely reporting on help received from agency workers.</p> <p>b. Routine health care includes taking medications, checking vital signs, and doing exercises.</p> <p>c. Personal care includes bathing, transfer from bed, eating, and using the toilet.</p> <p>d. Household and community activities include light housework, yard work, meal preparation, shopping, and homework help.</p> <p>e. Transportation includes trips for medical and nonmedical reasons.</p>				

<b>TABLE A.18: Uses of the Monthly Allowance, All Consumers</b>			
<b>During Month 8 After Random Assignment</b>	<b>Percent with Cash Use</b>	<b>Mean Expenditure (in Dollars)</b>	<b>Mean Percent Spent</b>
Paid a Worker	66.6	732	50.9
Purchased Home Care or Professional Services from Agency	10.5	78	4.4
Purchased Home Modifications	0.7	22	0.4
Purchased Vehicle Modifications	0.1	2	0.0
Purchased Equipment <sup>a</sup>	3.1	27	1.1
Purchased Personal Care Supplies <sup>b</sup>	16.4	29	4.7
Purchased Community Services <sup>c</sup>	15.4	140	6.7
Received Cash <sup>d</sup>	41.9	78	11.3
Total Expenses Paid During Month 8	82.3	1,108	n.a.
<b>Number of Consumers Who Used Fiscal Services and Had Spending Record for Month 8</b>	<b>712</b>		
<p><b>SOURCE:</b> CDC fiscal agent records.</p> <p><b>NOTE:</b> Of the 1,410 treatment group members, 359 had disenrolled or died before month 8, and 339 were still enrolled but had not record with the fiscal agent. In addition, 126 were still enrolled and had a record for month 8, but the record showed no spending for goods or services during that month; these cases are included in the means as zeros.</p> <p>a. Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.</p> <p>b. Supplies for personal care include diapers or pads to protect bedding, ostomy supplies and feeding equipment.</p> <p>c. Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.</p> <p>d. Treatment group members may request a check for cash each month to pay for goods and services directly. In Florida, this is limited to 20 percent of the allowance each month.</p> <p>n.a. = not applicable.</p>			

<b>TABLE A.18a: Uses of the Monthly Allowance, Children's Parents</b>			
<b>During Month 8 After Random Assignment</b>	<b>Percent with Cash Use</b>	<b>Mean Expenditure (in Dollars)</b>	<b>Mean Percent Spent</b>
Paid a Worker	62.4	623	48.0
Purchased Home Care or Professional Services from Agency	10.6	55	4.1
Purchased Home Modifications	1.3	50	0.8
Purchased Vehicle Modifications	0.0	0	0.0
Purchased Equipment <sup>a</sup>	4.5	57	2.1
Purchased Personal Care Supplies <sup>b</sup>	23.8	46	8.1
Purchased Community Services <sup>c</sup>	10.0	70	3.6
Received Cash <sup>d</sup>	40.2	84	12.0
Total Expenses Paid During Month 8	82.0	985	n.a.
<b>Number of Consumers Who Used Fiscal Services and Had Spending Record for Month 8</b>	<b>311</b>		
<b>SOURCE:</b> CDC fiscal agent records.			
<p>a. Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.</p> <p>b. Supplies for personal care include diapers or pads to protect bedding, ostomy supplies and feeding equipment.</p> <p>c. Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.</p> <p>d. Treatment group members may request a check for cash each month to pay for goods and services directly. In Florida, this is limited to 20 percent of the allowance each month.</p>			
n.a. = not applicable.			

<b>TABLE A.18b: Uses of the Monthly Allowance, Nonelderly Adults</b>			
<b>During Month 8 After Random Assignment</b>	<b>Percent with Cash Use</b>	<b>Mean Expenditure (in Dollars)</b>	<b>Mean Percent Spent</b>
Paid a Worker	63.4	953	45.4
Purchased Home Care or Professional Services from Agency	14.5	149	6.2
Purchased Home Modifications	0.4	2	0.2
Purchased Vehicle Modifications	0.4	5	0.1
Purchased Equipment <sup>a</sup>	2.6	6	0.6
Purchased Personal Care Supplies <sup>b</sup>	14.5	20	3.0
Purchased Community Services <sup>c</sup>	31.5	317	14.5
Received Cash <sup>d</sup>	31.9	47	7.1
Total Expenses Paid During Month 8	79.1	1,499	n.a.
<b>Number of Consumers Who Used Fiscal Services and Had Spending Record for Month 8</b>	<b>235</b>		
<b>SOURCE:</b> CDC fiscal agent records.			
<p>a. Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.</p> <p>b. Supplies for personal care include diapers or pads to protect bedding, ostomy supplies and feeding equipment.</p> <p>c. Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.</p> <p>d. Treatment group members may request a check for cash each month to pay for goods and services directly. In Florida, this is limited to 20 percent of the allowance each month.</p>			
n.a. = not applicable.			

<b>TABLE A.18c: Uses of the Monthly Allowance, Elderly Adults</b>			
<b>During Month 8 After Random Assignment</b>	<b>Percent with Cash Use</b>	<b>Mean Expenditure (in Dollars)</b>	<b>Mean Percent Spent</b>
Paid a Worker	78.9	626	64.3
Purchased Home Care or Professional Services from Agency	4.8	22	2.2
Purchased Home Modifications	0.0	0	0.0
Purchased Vehicle Modifications	0.0	0	0.0
Purchased Equipment <sup>a</sup>	1.2	1	0.1
Purchased Personal Care Supplies <sup>b</sup>	5.4	7	0.9
Purchased Community Services <sup>c</sup>	3.0	22	1.4
Received Cash <sup>d</sup>	59.0	108	15.9
Total Expenses Paid During Month 8	87.3	786	n.a.
<b>Number of Consumers Who Used Fiscal Services and Had Spending Record for Month 8</b>	<b>166</b>		
<b>SOURCE:</b> CDC fiscal agent records.			
<p>a. Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.</p> <p>b. Supplies for personal care include diapers or pads to protect bedding, ostomy supplies and feeding equipment.</p> <p>c. Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.</p> <p>d. Treatment group members may request a check for cash each month to pay for goods and services directly. In Florida, this is limited to 20 percent of the allowance each month.</p>			
n.a. = not applicable.			

<b>TABLE A.19: Specific Types of Consumer Purchases Reported by Consultants</b>	
<b>Percentage of Consultants Reporting Consumer Purchases of:</b>	
<b>Assistive or Safety Devices</b>	
Device to aid with mobility	20.5
Other communications device	9.7
Home security or personal emergency response system	9.7
Device to aid with vision or hearing	4.6
Other assistive device or device related to safety	2.6
Talking computer	2.1
<b>Personal Care Products and Appliances</b>	
Incontinence supplies	72.3
Dietary supplements or products	22.6
Personal hygiene products	16.4
Supplies for urinary catheter or ostomy	10.3
Enteral/parenteral feeding supplies	5.6
Supplies related to use of home oxygen or ventilator	3.6
Electric toothbrush or shaver	2.6
Other personal care products or appliances	1.0
Special eating tools	0.0
<b>Home or Vehicle Modification</b>	
Install shower stall or other bathroom remodeling	14.4
Install interior or exterior ramp	11.8
Modify van or automobile	11.3
Widen doorway	10.3
Change door handles or light switches	3.6
Lower counters or other kitchen remodeling	2.1
Other home or vehicle modifications	0.0
<b>Home or Yard Appliances</b>	
Lawn mower	2.1
Clothes washer or dryer	1.5
Other kitchen appliances	1.0
Microwave oven	0.5
Other home or yard appliance	0.0
<b>Commercial Services</b>	
Transportation from a taxi or other car or van service	20.5
Chore or homemaker services	17.3
Delivery of prepared food from a restaurant or groceries from a retail store	5.6
Errand or shopping services	5.4
Laundry service	3.2
Other commercial services	0.5
<b>Training or Educational Services</b>	
Training or education for consumer	17.7
Training or education for worker	1.1
Other training or education	0.6

<b>TABLE A.19 (continued)</b>	
<b>Percentage of Consultants Reporting Consumer Purchases of:</b>	
Other or Atypical Purchases	
Over-the-counter medications	22.6
Equipment repair or back-up equipment rental or purchase to use during repair	14.5
Exercise equipment or other devices to aid in rehabilitation	11.8
Day care	6.7
Prescription medications in excess of Medicaid limits	4.1
Service animal	1.5
Other Medicaid services in excess of coverage limits	8.2
Other purchases not listed elsewhere	1.0
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	
<b>NOTE:</b> Table contains responses to questions about specific types of consumer purchases (or approved plans to purchase) with the monthly allowance.	

<b>TABLE A.20: Flexibility and Constraints of the Monthly Allowance</b>	
	<b>Number of Consultants</b>
Examples of Creative Purchases, as Reported by Consultants	
Saved a portion of allowance each month	7
Paid for child to attend special summer camp or other recreational activities	6
Purchased worker services, equipment purchases, and modifications	3
Hired workers with special qualifications	5
Hired a companion for consumer during vacation	3
Examples of Denied Purchases, as Reported by Consultants	
Cosmetics, food, dietary supplements, cigarettes, alcohol	3
Home or vehicle modification not related to disability or health	15
Furniture, appliances, and equipment not related to disability	13
Educational items or services	6
Recreational goods and services	12
Attorney fees	1
Percentage of Consumers Reporting Program's Spending Rules Kept Them from Getting Things That Would Have Enhanced Independence <sup>a</sup>	32.0
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>Number of Respondents to the 6-Month Survey</b>	<b>1,340</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002 and consumer interviews conducted by telephone six months after consumers' random assignment.	
a. By age group, the percentage reporting restrictive program rules were 38.4 percent, ages 3 to 7; 26.8 percent, ages 18 to 59; and 29.2, age 60 and older.	

<b>TABLE A.21: Satisfaction with CDC, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
Would Recommend CDC to Others Wanting More Control Over Their Personal Care Services	87.6	89.0	88.2	85.3
<b>Effect of Monthly Allowance on Quality of Life, Among Those Ever Receiving Allowance</b>				
Improved a great deal	59.2	61.9	54.5	60.5
Improved somewhat	23.8	22.5	27.0	21.7
Stayed the same	16.0	14.7	18.0	15.8
Reduced somewhat	0.4	0.3	0.5	0.7
Reduced a great deal	0.6	0.7	0.0	1.3
<b>Most Important Ways Monthly Allowance Improved Life, Among Those Who Reported the Program Improved Their Lives<sup>a</sup></b>				
<b>Benefit enables consumer to:</b>				
Choose caregivers	25.2	25.5	26.7	22.4
Feel more independent, in control, or emotionally healthier	20.4	20.9	21.1	18.4
Get care of higher quality	14.0	14.3	11.7	16.8
Get the right types of care	11.7	13.9	12.8	5.6
Get enough care or care at the right time	9.8	11.6	6.1	11.2
Compensate informal caregivers or lessen their burden	7.4	10.8	3.9	5.6
Pay nonmedical bills or feel financially secure	2.5	0.4	2.2	7.2
Purchase medications or services not covered by Medicaid	1.8	1.5	2.8	0.8
Purchase other items related to personal care or health, food or nutritional supplements, or care-related supplies	5.0	7.0	1.7	5.6
Purchase, modify, or repair equipment or home	4.1	5.4	2.8	3.2
Do more in the community	4.4	5.4	5.6	0.8
<b>Other improvements related to:</b>				
Caregiver	2.0	3.9	0.6	0.0
Quality of life	0.9	1.9	0.0	0.0
Not specified	1.2	0.0	2.2	2.4
<b>Number of Respondents to the 9-Month Interview</b>	<b>1,213</b>	<b>441</b>	<b>399</b>	<b>373</b>
<b>SOURCE:</b> MPR consumer interviews conducted by telephone nine months after consumers' random assignment.				
a. Some columns sum to more than 100 percent because some consumers named more than one improvement.				

<b>TABLE A.22a: Satisfaction with and Unmet Need for Personal Assistance, by Age Group</b>				
	<b>Percentage</b>			
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Current Satisfaction with:</b>				
Overall care arrangements <sup>a</sup>				
Very satisfied	57.4	55.9	66.7	49.8
Satisfied	30.8	28.2	27.2	38.4
Dissatisfied	11.9	15.9	6.1	11.8
Ability to get transportation when needed <sup>b</sup>				
Very satisfied	59.3	57.2	68.2	52.5
Satisfied	24.0	22.4	18.6	32.1
Dissatisfied	16.7	20.4	13.2	15.4
<b>Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Somewhat or Very Satisfied with:<sup>c,d</sup></b>				
Relationship with paid caregiver	99.0	99.3	98.5	99.1
How paid caregiver helps with personal care <sup>e</sup>	97.5	98.2	98.7	95.5
How paid caregiver helps with routine health care <sup>f</sup>	98.8	99.0	100.0	97.0
How paid caregiver helps with household or community activities <sup>g</sup>	97.7	100.0	97.7	94.7
Times of day help provided	96.3	96.5	98.5	94.0
Would Not Have Had Difficulty in Changing the Times of Day Received Help <sup>c,d</sup>	40.0	36.6	48.7	36.5
<b>Among Those Who Hired with Allowance, Paid Caregiver:<sup>d,h</sup></b>				
Always or almost always completed all tasks	86.5	91.9	82.5	74.1
Never neglected consumer	88.2	91.9	81.4	86.2
Never left early or arrived late, among those with regular schedule	53.9	58.4	48.5	46.4
Never was rude or disrespectful	90.1	94.2	82.8	87.7
Never helped when help was not wanted	55.8	47.3	62.5	74.1
Never took things without asking	97.5	99.0	93.2	100.0
<b>Needs Help or More Help with:<sup>i</sup></b>				
Household or community activities	32.9	32.1	32.2	36.6
Personal care	28.4	25.2	28.9	36.6
Routine health care	19.7	16.7	19.8	28.6
Transportation	24.2	22.4	25.0	28.2
Needs More Personal Care Supplies	19.6	17.7	16.7	30.0
<b>Number of Respondents to the 9-Month Interview</b>	<b>1,213</b>	<b>441</b>	<b>399</b>	<b>373</b>
<b>SOURCE:</b> MPR consumer interviews conducted by telephone nine months after consumers' random assignment.				
<p>a. Satisfaction with overall care not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion.</p> <p>b. Satisfaction with ability to get transportation not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if no transportation sought. Transportation includes trips for medical and nonmedical reasons.</p> <p>c. Satisfaction with paid caregiver relationship and performance, and ability to change paid caregiver schedule, not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, if consumer did not hire a caregiver with allowance, or if consumer had no paid help during the two weeks before interview.</p> <p>d. Description is of all paid caregivers for consumers who hired with the allowance (with the exceptions noted) and includes paid caregivers for nine consumers who had disenrolled from CDC and were likely reporting about satisfaction with agency workers.</p>				

<b>TABLE A.22a (continued)</b>	
e.	Personal care includes bathing, transfer from bed, eating, and using the toilet. Not asked if consumer had no paid help with personal care.
f.	Routine health care includes taking medications, checking vital signs, and doing exercises. Not asked if consumer had no paid help with routine health care.
g.	Household and community activities include light housework, yard work, meal preparation, shopping, and homework help. Not asked if consumer had no paid help with household or community tasks.
h.	Satisfaction with paid caregiver attitude and respectfulness not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if consumer did not hire a caregiver with allowance.
i.	Unmet need not asked if proxy respondent is also paid caregiver.

<b>TABLE A.22b: Satisfaction with CDC and Personal Assistance, by Type of Respondent</b>		
	<b>Percentage</b>	
	<b>Consumer Respondents</b>	<b>Proxy Respondents</b>
<b>Would Recommend CDC to Others Wanting More Control Over Their Personal Care Services</b>		
All adults	86.7	86.8
Nonelderly adults	83.8	89.6
Elderly adults	88.6	83.2
<b>Quality of Life Improved a Great Deal as Result of Program Allowance, Among Recipients</b>		
All adults	57.9	56.6
Nonelderly adults	56.3	54.0
Elderly adults	59.6	61.0
<b>Very Satisfied with Overall Care Arrangements</b>		
All adults	49.6	65.5
Nonelderly adults	57.1	71.2
Elderly adults	44.9	56.1
<b>Dissatisfied with Overall Care Arrangements</b>		
All adults	12.6	6.0
Nonelderly adults	11.9	3.4
Elderly adults	13.0	10.3
<b>Number of Adult Respondents to the 9-Month Interview</b>	<b>246</b>	<b>526</b>
<b>SOURCE:</b> MPR consumer interviews conducted by telephone nine months after consumers' random assignment.		

<b>TABLE A.23: Disenrollment and Death During Follow-up Year, by Age Group</b>				
	<b>Overall</b>	<b>3 to 17</b>	<b>18 to 59</b>	<b>60 or Older</b>
<b>Disenrollment and Death During Follow-Up Year, According to Program Records (n = 1,410)</b>				
Disenrolled for Any Reason Other than Death	34.5	20.4	34.2	49.2
Disenrolled Voluntarily	26.7	16.2	27.2	38.0
Died	3.7	1.0	1.8	9.7
<b>Reasons for Disenrollment</b>				
<b>According to Program Records (n = 538)</b>				
Consumer could not be located	9.9	7.5	11.6	9.7
Death	9.7	4.7	1.8	16.5
No longer eligible for HCBS	2.4	2.8	1.8	2.6
No longer eligible for Medicaid	1.7	1.9	0.6	2.3
Abuse or mismanagement of allowance	0.0	0.0	0.0	0.0
Program initiated disenrollment for some other reason	6.3	7.5	8.5	4.5
Consumer initiated disenrollment	70.1	75.7	75.6	64.4
<b>According to Consumer or Proxy Reports (n = 438)</b>				
No longer eligible for HCBS	21.5	26.6	35.9	10.3
Lost or needed representative	17.1	21.3	13.0	17.8
Death	4.6	1.1	0.8	8.5
Entered hospital or nursing home	1.8	1.1	1.5	2.4
Left the state	0.0	0.0	0.0	0.0
Program initiated disenrollment	2.7	1.1	3.1	3.3
Consumer initiated disenrollment	52.3	48.9	45.8	58.2
<b>Reasons for Consumer-Initiated Disenrollment, According to Consumer or Proxy Reports (n = 204).<sup>a</sup></b>				
Changed mind/satisfied with traditional services	34.8	47.4	43.4	26.6
Allowance not enough	20.6	21.1	11.3	24.8
Conflict with program staff/too many rules about use of allowance	13.2	10.5	28.3	7.1
Other problems with allowance	5.4	5.3	5.7	5.3
Problem with employer responsibilities	13.2	7.9	9.4	16.8
Consumer/worker/helper health worsened	12.8	5.3	15.1	14.2
Problem with fiscal responsibilities	10.8	5.3	3.8	15.9
Program never contacted consumer	1.0	0.0	1.9	0.9
Misunderstood program or heard negative things about it	2.5	5.3	3.8	0.9
Other reasons	3.4	5.3	1.9	3.5
<b>Timing of Disenrollment</b>				
<b>Among Those Who Disenrolled or Died According to Records, Did So During Months (n = 538)</b>				
1 to 3	36.6	20.6	29.9	47.2
4 to 6	30.9	28.0	36.0	28.8
7 to 9	17.8	23.4	19.5	14.6
10 to 12	14.7	28.0	14.6	9.4
<b>Among Those Who Disenrolled or Died According to Records</b>				
Disenrolled or died before started receiving allowance	88.3	87.9	90.9	86.9
Disenrolled after started receiving allowance	7.8	11.2	7.9	6.4
Died after started receiving allowance	3.9	0.9	1.2	6.7
<b>Among Those Who Disenrolled or Died According to Consumer or Proxy Reports (n = 459), Did So</b>				
Between baseline and 6-month interview	82.1	80.6	83.6	81.9
Between 6- and 9-month interview	17.9	19.4	16.4	18.1
<b>Number of Consumers with Program Records</b>	<b>1,410</b>	<b>501</b>	<b>456</b>	<b>453</b>
<b>Number of Respondents to 6- or 9-Month Interview</b>	<b>1,363</b>	<b>486</b>	<b>447</b>	<b>430</b>
<b>SOURCE:</b> CDC program records; MPR consumer interviews conducted by telephone six and nine months after consumers' random assignment.				
a. Percentages sum to more than 100 because some consumers gave more than one reason for disenrolling.				

<b>TABLE A.24: Effect of Consumer Characteristics on Whether Started on Allowance Within 9 Months of Random Assignment (Omitted Categories in Parentheses)</b>		
<b>Characteristic</b>	<b>Estimated Coefficient</b>	<b>p-Value of Coefficient</b>
<b>Demonstration Enrollment</b>		
Length of Time in HCBS Waiver Program Upon Enrollment		
Less than 6 months	-0.05	.717
(6 months or longer)		
Mean Weekly Allowance		
(Less than \$150)		
\$150 to \$299	0.38**	.011
\$300 to \$499	0.48***	.007
\$500 or more	0.95***	.000
Had a Representative at Enrollment <sup>a</sup>	0.30	.228
Being Allowed to Pay Family or Friends Very Important <sup>b</sup>	0.36**	.013
Having a Choice About Worker Schedule Very Important <sup>b</sup>	-0.03	.820
Having a Choice About Types of Help Received Very Important <sup>b</sup>	0.10	.590
Primary Unpaid Caregiver Expressed Interest in Being Paid	0.21	.154
Enrolled Between June 2000 and June 2001	0.38***	.009
<b>Demographic Characteristics</b>		
Age		
3 to 17	0.30	.272
(18 to 59)		
60 or older	-0.26	.179
Female	-0.01	.945
Hispanic	-0.10	.557
Race		
(Self-identified as White only)		
Self-identified as Black only or Black and some other race	-0.61***	.000
Self-identified as some other race	0.26	.414
Education of Consumer or Representative		
High school graduate	-0.01	.942
(Did not graduate from high school)		
Living Arrangement/Marital Status		
Lives alone	0.26	.319
(Lives with others)		
<b>Health and Functioning</b>		
Health Status at Enrollment		
(Excellent or good)		
Fair	-0.09	.539
Poor	-0.08	.657
Last Week, Not Independent in: <sup>c</sup>		
Transferring	-0.03	.854
Bathing	-0.37	.181
Using toilet	0.14	.471
<b>Use of Unpaid and Paid Assistance</b>		
Number of Unpaid Caregivers Last Week		
(None)		
One	0.33	.322
Two	0.37	.277
Three or more	0.20	.549

<b>TABLE A.24 (continued)</b>		
<b>Characteristic</b>	<b>Estimated Coefficient</b>	<b>p-Value of Coefficient</b>
Primary Unpaid Caregiver Employed	0.01	.939
Had Unpaid or Paid Help at Home Last Week with:		
Personal care <sup>d</sup>	0.92***	.001
Transportation <sup>e</sup>	0.11	.521
Routine health care <sup>f</sup>	-0.09	.654
Household activities <sup>g</sup>	0.29	.499
Number of Paid Caregivers Last Week		
(None)		
One	0.05	.745
Two or more	-0.03	.859
<b>Unmet Need for, and Access to, Personal Assistance</b>		
Last Week, Needed Help (or More Help) with:		
Personal care <sup>d</sup>	-0.09	.564
Transportation <sup>e</sup>	-0.03	.797
Household activities <sup>g</sup>	0.31*	.051
Potential Difficulty Hiring Due to Location		
Lives in a rural area	0.21	.254
Live in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime)	0.28**	.036
<b>Satisfaction with Paid Personal Assistance</b>		
Satisfied with Paid Services and Goods Overall <sup>p</sup>		
Very satisfied	-0.06	.733
Satisfied	-0.16	.295
(Dissatisfied)		
No paid services or goods <sup>h</sup>	-0.38	.290
<b>Employment Experience of Consumer or Representative</b>		
Ever Employed	-0.19	.573
Ever Supervised Someone	0.12	.416
Ever Hired Someone Privately	0.37**	.011
<b>Type of Respondent</b>		
Majority of Baseline Questions Answered by Proxy Respondent <sup>a</sup>	-0.04	.885
<b>Number of Consumers</b>	<b>1,347</b>	
<b>SOURCE:</b> For independent variables, data on age and sex come from CDC program records; other data come from MPR consumer interviews conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002). For the dependent variable, data come from CDC program records.		
<b>NOTES:</b> The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey.		
<ul style="list-style-type: none"> <li>a. This was true of all children in the sample.</li> <li>b. Measured for the parent respondent of children in the sample.</li> <li>c. Received hands-on or standby help or did not perform activity at all.</li> <li>d. Personal care includes bathing, transfer from bed, eating, and using the toilet.</li> <li>e. Transportation includes trips for medical and nonmedical reasons.</li> <li>f. Routine health care includes taking medications, checking vital signs, and doing exercises.</li> <li>g. Household activities include light housework, yard work, meal preparation, shopping, and homework help.</li> <li>h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.</li> </ul>		
*Significantly different from zero at the .10 level, two-tailed test.		
**Significantly different from zero at the .05 level, two-tailed test.		
***Significantly different from zero at the .01 level, two-tailed test.		

<b>TABLE A.25: Effect of Consumer Characteristics on Whether Found Hiring Difficult (Omitted Categories in Parentheses)</b>		
<b>Characteristic</b>	<b>Estimated Coefficient</b>	<b>p-Value of Coefficient</b>
<b>Demonstration Enrollment</b>		
Length of Time in HCBS Waiver Program Upon Enrollment		
Less than 6 months	0.37**	.026
(6 months or longer)		
Mean Weekly Allowance		
(Less than \$150)		
\$150 to \$299	-0.44**	.030
\$300 to \$499	-0.44*	.060
\$500 or more	-0.49*	.055
Had a Representative at Enrollment <sup>a</sup>	0.20	.566
Being Allowed to Pay Family or Friends Very Important <sup>b</sup>	-0.22	.256
Having a Choice About Worker Schedule Very Important <sup>b</sup>	0.28	.139
Having a Choice About Types of Help Received Very Important <sup>b</sup>	-0.17	.530
Primary Unpaid Caregiver Expressed Interest in Being Paid	-0.30	.109
Enrolled Between June 2000 and June 2001	-0.48**	.017
<b>Demographic Characteristics</b>		
Age		
3 to 17	0.11	.759
(18 to 59)		
60 or older	-0.36	.181
Female	0.16	.343
Hispanic	-0.40*	.068
Race		
(Self-identified as White only)		
Self-identified as Black only or Black and some other race	-0.10	.656
Self-identified as some other race	-0.96**	.013
Education of Consumer or Representative		
High school graduate	-0.17	.479
(Did not graduate from high school)		
Living Arrangement/Marital Status		
Lives alone	0.15	.677
(Lives with others)		
<b>Health and Functioning</b>		
Health Status at Enrollment		
(Excellent or good)		
Fair	0.23	.230
Poor	-0.14	.541
Last Week, Not Independent in: <sup>c</sup>		
Transferring	-0.04	.836
Bathing	0.30	.414
Using toilet	0.26	.294
<b>Use of Unpaid and Paid Assistance</b>		
Number of Unpaid Caregivers Last Week		
(None)		
One	-0.96*	.051
Two	-0.72	.146
Three or more	-1.02**	.039
Primary Unpaid Caregiver Employed	0.13	.437

TABLE A.25 (continued)		
Characteristic	Estimated Coefficient	p-Value of Coefficient
Had Unpaid or Paid Help at Home Last Week with:		
Personal care <sup>d</sup>	-1.16***	.005
Transportation <sup>e</sup>	-0.39	.118
Routine health care <sup>f</sup>	-0.21	.422
Household activities <sup>g</sup>	0.81	.259
Number of Paid Caregivers Last Week		
(None)		
One	0.11	.606
Two or more	0.03	.883
<b>Unmet Need for, and Access to, Personal Assistance</b>		
Last Week, Needed Help (or More Help) with:		
Personal care <sup>d</sup>	0.16	.414
Transportation <sup>e</sup>	0.30*	.074
Household activities <sup>g</sup>	0.47**	.035
Potential Difficulty Hiring Due to Location		
Lives in a rural area	0.25	.290
Live in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime)	0.26	.130
<b>Satisfaction with Paid Personal Assistance</b>		
Satisfied with Paid Services and Goods Overall <sup>p</sup>		
Very satisfied	-0.19	.393
Satisfied	-0.11	.579
(Dissatisfied)		
No paid services or goods <sup>h</sup>	-0.31	.569
<b>Employment Experience of Consumer or Representative</b>		
Ever Employed	-0.08	.874
Ever Supervised Someone	0.09	.668
Ever Hired Someone Privately	0.10	.621
<b>Type of Respondent</b>		
Majority of Baseline Questions Answered by Proxy Respondent <sup>a</sup>	0.11	.739
<b>Number of Consumers</b>	<b>785</b>	
<p><b>SOURCE:</b> For independent variables, data on age and sex come from CDC program records; other data come from MPR consumer interviews conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002). For the dependent variable, data come from consumer interviews conducted by telephone six and nine months after consumer's random assignment.</p> <p><b>NOTES:</b> The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey.</p> <p>a. This was true of all children in the sample.  b. Measured for the parent respondent of children in the sample.  c. Received hands-on or standby help or did not perform activity at all.  d. Personal care includes bathing, transfer from bed, eating, and using the toilet.  e. Transportation includes trips for medical and nonmedical reasons.  f. Routine health care includes taking medications, checking vital signs, and doing exercises.  g. Household activities include light housework, yard work, meal preparation, shopping, and homework help.  h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.</p> <p>*Significantly different from zero at the .10 level, two-tailed test.  **Significantly different from zero at the .05 level, two-tailed test.  ***Significantly different from zero at the .01 level, two-tailed test.</p>		

<b>TABLE A.26: Effect of Consumer Characteristics on Whether Consumer Found CDC Spending Rules Restrictive (Omitted Categories in Parentheses)</b>		
<b>Characteristic</b>	<b>Estimated Coefficient</b>	<b>p-Value of Coefficient</b>
<b>Demonstration Enrollment</b>		
Length of Time in HCBS Waiver Program Upon Enrollment		
Less than 6 months	0.17	.249
(6 months or longer)		
Mean Weekly Allowance		
(Less than \$150)		
\$150 to \$299	-0.03	.851
\$300 to \$499	-0.40*	.059
\$500 or more	-0.01	.956
Had a Representative at Enrollment <sup>a</sup>	0.66**	.030
Being Allowed to Pay Family or Friends Very Important <sup>b</sup>	-0.07	.687
Having a Choice About Worker Schedule Very Important <sup>b</sup>	0.11	.530
Having a Choice About Types of Help Received Very Important <sup>b</sup>	0.12	.600
Primary Unpaid Caregiver Expressed Interest in Being Paid	0.04	.828
Enrolled Between June 2000 and June 2001	-0.43**	.015
<b>Demographic Characteristics</b>		
Age		
3 to 17	-0.15	.635
(18 to 59)		
60 or older	-0.07	.761
Female	0.04	.789
Hispanic	0.24	.229
Race		
(Self-identified as White only)		
Self-identified as Black only or Black and some other race	-0.03	.878
Self-identified as some other race	-0.36	.339
Education of Consumer or Representative		
High school graduate	0.08	.700
(Did not graduate from high school)		
Living Arrangement/Marital Status		
Lives alone	-0.60*	.070
(Lives with others)		
<b>Health and Functioning</b>		
Health Status at Enrollment		
(Excellent or good)		
Fair	0.32*	.063
Poor	0.27	.187
Last Week, Not Independent in: <sup>c</sup>		
Transferring	-0.26	.157
Bathing	-0.16	.630
Using toilet	0.19	.438
<b>Use of Unpaid and Paid Assistance</b>		
Number of Unpaid Caregivers Last Week		
(None)		
One	-0.85**	.034
Two	-0.76*	.060
Three or more	-0.37	.356

<b>TABLE A.26 (continued)</b>		
<b>Characteristic</b>	<b>Estimated Coefficient</b>	<b>p-Value of Coefficient</b>
Primary Unpaid Caregiver Employed	-0.09	.552
Had Unpaid or Paid Help at Home Last Week with:		
Personal care <sup>d</sup>	-0.13	.695
Transportation <sup>e</sup>	0.25	.259
Routine health care <sup>f</sup>	0.08	.736
Household activities <sup>g</sup>	0.12	.814
Number of Paid Caregivers Last Week		
(None)		
One	-0.03	.882
Two or more	0.33*	.090
<b>Unmet Need for, and Access to, Personal Assistance</b>		
Last Week, Needed Help (or More Help) with:		
Personal care <sup>d</sup>	0.26	.143
Transportation <sup>e</sup>	0.09	.576
Household activities <sup>g</sup>	0.26	.192
Potential Difficulty Hiring Due to Location		
Lives in a rural area	-0.38*	.079
Live in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime)	0.06	.720
<b>Satisfaction with Paid Personal Assistance</b>		
Satisfied with Paid Services and Goods Overall <sup>p</sup>		
Very satisfied	-0.45**	.028
Satisfied	-0.20	.249
(Dissatisfied)		
No paid services or goods <sup>h</sup>	-0.52	.264
<b>Employment Experience of Consumer or Representative</b>		
Ever Employed	-1.57***	.000
Ever Supervised Someone	0.06	.768
Ever Hired Someone Privately	0.20	.269
<b>Type of Respondent</b>		
Majority of Baseline Questions Answered by Proxy Respondent <sup>a</sup>	-0.62**	.035
<b>Number of Consumers</b>	<b>1,070</b>	
<p><b>SOURCE:</b> For independent variables, data on age and sex come from CDC program records; other data come from MPR consumer interviews conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002). For the dependent variable, data come from consumer interviews conducted by telephone six months after consumer's random assignment.</p> <p><b>NOTES:</b> The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey.</p> <p>a. This was true of all children in the sample.  b. Measured for the parent respondent of children in the sample.  c. Received hands-on or standby help or did not perform activity at all.  d. Personal care includes bathing, transfer from bed, eating, and using the toilet.  e. Transportation includes trips for medical and nonmedical reasons.  f. Routine health care includes taking medications, checking vital signs, and doing exercises.  g. Household activities include light housework, yard work, meal preparation, shopping, and homework help.  h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.</p> <p>*Significantly different from zero at the .10 level, two-tailed test.  **Significantly different from zero at the .05 level, two-tailed test.  ***Significantly different from zero at the .01 level, two-tailed test.</p>		

<b>TABLE A.27: Effect of Consumer Characteristics on Satisfaction and Unmet Need (Omitted Categories in Parentheses)</b>						
<b>Characteristics</b>	<b>CDC Improved Life a Great Deal</b>		<b>Very Satisfied with Overall Care</b>		<b>Has Unmet Need for Personal Care</b>	
	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>
<b>Demonstration Enrollment</b>						
Length of Time in HCBS Waiver Program Upon Enrollment						
Less than 6 months	0.03	.888	-0.11	.514	-0.01	.944
(6 months or longer)						
Mean Weekly Allowance						
(Less than \$150)						
\$150 to \$299	0.74***	.001	0.15	.423	0.04	.844
\$300 to \$499	0.91***	.001	0.45**	.048	-0.21	.352
\$500 or more	1.37***	.000	0.10	.730	-0.14	.604
Had a Representative at Enrollment <sup>a</sup>	-0.89*	.051	-0.14	.623	0.05	.858
Being Allowed to Pay Family or Friends Very Important <sup>b</sup>	0.32	.146	-0.05	.788	0.10	.581
Having a Choice About Worker Schedule Very Important <sup>b</sup>	0.28	.187	-0.02	.930	-0.13	.492
Having a Choice About Types of Help Received Very Important <sup>b</sup>	0.58**	.049	0.47**	.042	0.37	.150
Primary Unpaid Caregiver Expressed Interest in Being Paid	0.15	.483	0.04	.836	0.03	.882
Enrolled Between June 2000 and June 2001	0.20	.375	0.27	.166	-0.16	.399
<b>Demographic Characteristics</b>						
Age						
3 to 17	0.81*	.069	-0.08	.796	-0.26	.435
(18 to 59)						
60 or older	0.68**	.031	-0.41	.114	0.26	.295
Female	-0.40**	.032	-0.06	.718	-0.12	.466
Hispanic	0.47*	.068	0.12	.595	0.47**	.028
Race						
(Self-identified as White only)						
Self-identified as Black only or Black and some other race	0.34	.199	-0.24	.269	0.14	.504
Self-identified as some other race	0.02	.958	-0.36	.367	0.30	.443
Education of Consumer or Representative						
High school graduate	-0.53*	.062	0.04	.848	0.06	.776
(Did not graduate from high school)						
Living Arrangement/Marital Status						
Lives alone	0.24	.569	-0.40	.199	0.23	.474
(Lives with others)						
<b>Health and Functioning</b>						
Health Status at Enrollment						
(Excellent or good)						
Fair	0.07	.749	-0.09	.634	0.31*	.095
Poor	0.72***	.006	0.36*	.100	0.39*	.067

<b>TABLE A.27 (continued)</b>						
<b>Characteristics</b>	<b>CDC Improved Life a Great Deal</b>		<b>Very Satisfied with Overall Care</b>		<b>Has Unmet Need for Personal Care</b>	
	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>
<b>Last Week, Not Independent in:<sup>c</sup></b>						
Transferring	-0.09	.695	-0.32	.114	0.45**	.023
Bathing	-0.06	.885	0.17	.631	-0.20	.604
Using toilet	-0.10	.734	0.00	.995	0.58**	.028
<b>Use of Unpaid and Paid Assistance</b>						
<b>Number of Unpaid Caregivers Last Week</b>						
(None)						
One	1.25**	.033	0.07	.862	-0.02	.955
Two	0.98*	.093	0.55	.176	-0.22	.599
Three or more	1.04*	.074	0.17	.661	0.11	.801
Primary Unpaid Caregiver Employed	0.28	.134	0.11	.491	0.00	.979
<b>Had Unpaid or Paid Help at Home Last Week with:</b>						
Personal care <sup>d</sup>	-0.95*	.053	0.48	.163	0.69*	.094
Transportation <sup>e</sup>	-0.29	.353	0.00	.996	-0.22	.343
Routine health care <sup>f</sup>	-0.09	.776	-0.31	.199	0.16	.543
Household activities <sup>g</sup>	0.07	.932	-0.71	.184	0.01	.989
<b>Number of Paid Caregivers Last Week</b>						
(None)						
One	-0.09	.718	-0.32	.135	0.17	.421
Two or more	0.03	.905	0.07	.759	0.22	.305
<b>Unmet Need for, and Access, to Personal Assistance</b>						
<b>Last Week, Needed Help (or More Help) with:</b>						
Personal care <sup>d</sup>	0.20	.362	-0.22	.236	0.79***	.000
Transportation <sup>e</sup>	-0.27	.173	-0.19	.259	0.00	.993
Household activities <sup>g</sup>	0.26	.307	-0.12	.553	0.42*	.054
<b>Potential Difficulty Hiring Due to Location</b>						
Lives in a rural area	-0.09	.734	-0.20	.388	0.18	.422
Live in a nonrural area but transportation difficult or high crime	0.08	.706	0.04	.825	0.07	.661
(Lives in a nonrural area, but transportation not difficult and not high crime)						
<b>Satisfaction with Paid Personal Assistance</b>						
<b>Satisfied with Paid Services and Goods Overall<sup>b</sup></b>						
Very satisfied	0.11	.668	1.26***	.000	-0.18	.406
Satisfied	-0.08	.712	0.42**	.024	-0.25	.187
(Dissatisfied)						
No paid services or goods <sup>h</sup>	-0.14	.822	0.17	.738	-0.64	.289
<b>Employment Experience of Consumer or Representative</b>						
Ever Employed	0.10	.853	0.08	.865	-0.42	.306
Ever Supervised Someone	0.56**	.023	-0.01	.950	0.08	.679
Ever Hired Someone Privately	0.16	.481	-0.20	.297	0.00	.996
<b>Type of Respondent</b>						
Majority of Baseline Questions Answered by Proxy Respondent <sup>a</sup>	0.05	.910	0.34	.263	-0.28	.357
<b>Number of Consumers</b>	<b>662</b>		<b>842</b>		<b>970</b>	

**TABLE A.27 (continued)**

**SOURCE:** For independent variables, data on age and sex come from CDC program records; other data come from MPR consumer interviews conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002). For the dependent variable, data come from consumer interviews conducted by telephone nine months after consumer's random assignment.

**NOTES:** The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey.

- a. This was true of all children in the sample.
- b. Measured for the parent respondent of children in the sample.
- c. Received hands-on or standby help or did not perform activity at all.
- d. Personal care includes bathing, transfer from bed, eating, and using the toilet.
- e. Transportation includes trips for medical and nonmedical reasons.
- f. Routine health care includes taking medications, checking vital signs, and doing exercises.
- g. Household activities include light housework, yard work, meal preparation, shopping, and homework help.
- h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

<b>TABLE A.28: Effect of Consumer Characteristics on Voluntary Disenrollment (Omitted Categories in Parentheses)</b>				
<b>Characteristic</b>	<b>Whether Disenrolled, According to Program Records, Within 1 Year of Enrollment</b>		<b>Whether Disenrolled, According to Self-Reports, Within 9 Months of Enrollment</b>	
	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>
<b>Demonstration Enrollment</b>				
Length of Time in HCBS Waiver Program Upon Enrollment				
Less than 6 months	0.06	.683	-0.05	.776
(6 months or longer)				
Mean Weekly Allowance				
(Less than \$150)				
\$150 to \$299	-0.06	.711	-0.33*	.093
\$300 to \$499	-0.39*	.059	-0.13	.600
\$500 or more	-1.40***	.000	-0.67**	.048
Had a Representative at Enrollment <sup>a</sup>	-0.23	.381	-0.90***	.002
Being Allowed to Pay Family or Friends Very Important <sup>b</sup>	-0.21	.198	-0.46**	.019
Having a Choice About Worker Schedule Very Important <sup>b</sup>	0.10	.546	-0.11	.564
Having a Choice About Types of Help Received Very Important <sup>b</sup>	-0.30	.110	-0.19	.398
Primary Unpaid Caregiver Expressed Interest in Being Paid	-0.15	.389	-0.24	.258
Enrolled Between June 2000 and June 2001	-0.41***	.008	-0.35*	.061
<b>Demographic Characteristics</b>				
Age				
3 to 17	-0.52*	.078	-0.11	.764
(18 to 59)				
60 or older	-0.10	.616	0.55**	.026
Female	0.14	.332	0.02	.907
Hispanic	0.14	.483	0.07	.774
Race				
(Self-identified as White only)				
Self-identified as Black only or Black and some other race	0.45**	.011	0.34	.108
Self-identified as some other race	-0.62	.157	-0.56	.280
Education of Consumer or Representative				
High school graduate	-0.17	.334	-0.12	.570
(Did not graduate from high school)				
Living Arrangement/Marital Status				
Lives alone	0.30	.240	0.05	.868
(Lives with others)				
<b>Health and Functioning</b>				
Health Status at Enrollment				
(Excellent or good)				
Fair	0.08	.613	0.08	.677
Poor	0.27	.159	-0.21	.364
Last Week, Not Independent in: <sup>c</sup>				
Transferring	-0.10	.595	0.18	.424
Bathing	0.11	.713	-0.03	.933
Using toilet	-0.10	.657	-0.48*	.065

<b>TABLE A.28 (continued)</b>				
<b>Characteristic</b>	<b>Whether Disenrolled, According to Program Records, Within 1 Year of Enrollment</b>		<b>Whether Disenrolled, According to Self-Reports, Within 9 Months of Enrollment</b>	
	<b>Estimated Coefficient</b>	<b>p-Value</b>	<b>Estimated Coefficient</b>	<b>p-Value</b>
<b>Use of Unpaid and Paid Assistance</b>				
Number of Unpaid Caregivers Last Week				
(None)				
One	0.24	.487	-0.02	.964
Two	0.23	.525	0.11	.776
Three or more	0.21	.561	0.26	.516
Primary Unpaid Caregiver Employed	-0.05	.736	-0.08	.637
Had Unpaid or Paid Help at Home Last Week with:				
Personal care <sup>d</sup>	-0.08	.789	-0.14	.672
Transportation <sup>e</sup>	-0.05	.807	-0.02	.921
Routine health care <sup>f</sup>	0.14	.504	0.38	.135
Household activities <sup>g</sup>	-0.59	.129	0.34	.499
Number of Paid Caregivers Last Week				
(None)				
One	0.02	.906	0.51**	.034
Two or more	-0.08	.664	0.49*	.051
<b>Unmet Need for, and Access to, Personal Assistance</b>				
Last Week, Needed Help (or More Help) with:				
Personal care <sup>d</sup>	-0.13	.450	0.01	.958
Transportation <sup>e</sup>	-0.17	.237	-0.29*	.095
Household activities <sup>g</sup>	-0.09	.607	-0.02	.937
Potential Difficulty Hiring Due to Location				
Lives in a rural area	-0.30	.164	-0.13	.621
Live in a nonrural area but transportation difficult or high crime	0.11	.469	0.15	.404
(Lives in a nonrural area, but transportation not difficult and not high crime)				
<b>Satisfaction with Paid Personal Assistance</b>				
Satisfied with Paid Services and Goods Overall <sup>b</sup>				
Very satisfied	0.30	.128	0.23	.351
Satisfied	0.07	.723	0.28	.216
(Dissatisfied)				
No paid services or goods <sup>h</sup>	0.03	.946	0.13	.796
<b>Employment Experience of Consumer or Representative</b>				
Ever Employed	-0.25	.498	0.26	.574
Ever Supervised Someone	-0.06	.709	-0.11	.598
Ever Hired Someone Privately	-0.23	.136	-0.16	.402
<b>Type of Respondent</b>				
Majority of Baseline Questions Answered by Proxy Respondent <sup>a</sup>	-0.05	.850	0.08	.785
<b>Number of Consumers</b>	<b>1,347</b>		<b>1,303</b>	
<b>SOURCE:</b> For independent variables, data on age and sex come from CDC program records; other data come from MPR consumer interviews conducted by telephone immediately before consumers' random assignment (from June 2000 to July 2002). For the dependent variable, data come from CDC program records and consumer interviews conducted by telephone 6 and 9 months after consumer's random assignment.				
<b>NOTES:</b> The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey.				

<b>TABLE A.28 (continued)</b>	
<p>a. This was true of all children in the sample.</p> <p>b. Measured for the parent respondent of children in the sample.</p> <p>c. Received hands-on or standby help or did not perform activity at all.</p> <p>d. Personal care includes bathing, transfer from bed, eating, and using the toilet.</p> <p>e. Transportation includes trips for medical and nonmedical reasons.</p> <p>f. Routine health care includes taking medications, checking vital signs, and doing exercises.</p> <p>g. Household activities include light housework, yard work, meal preparation, shopping, and homework help.</p> <p>h. Skipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.</p>	
<p>*Significantly different from zero at the .10 level, two-tailed test.</p> <p>**Significantly different from zero at the .05 level, two-tailed test.</p> <p>***Significantly different from zero at the .01 level, two-tailed test.</p>	

<b>TABLE A.29: Consultant Assessment of Consumers' Overall Experiences with CDC</b>	
	<b>Percentage of Counselors Reporting</b>
<b>CDC Was Particularly Effective for Consumers Who</b>	
Were dissatisfied with traditional home care/wanted more control over care	33.0
Wished to purchase care-related equipment or services not covered by Medicaid	24.0
Had a family member or friend in mind to hire as worker	15.0
Needed a lot of home care	5.0
Were well organized and decisive	3.0
Risked nursing home placement	0.0
<b>Types of Consumers for Whom CDC Did Not Work Well</b>	
Needed more care than they could obtain with allowance	13.2
Unable to hire or retain suitable worker	9.2
Client unable to manage own care, no representative available	7.9
Had trouble communicating	2.6
Disliked program responsibilities	2.6
Needed very little care	1.3
Lived in a rural area	1.3
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<p><b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.</p> <p><b>NOTE:</b> Consultants were asked to describe consumers for whom the program was particularly effective and those for whom the program did not work well. Their open-ended responses were then categorized, as noted above.</p>	

<b>TABLE A.30: Consumer Difficulties with Program Responsibilities</b>	
Percentage of Consultants Reporting That Some Consumers Requested Extensive Amounts of Assistance	46.8
Percentage of Consultants Reporting the Following Types of Consumers Requested Extensive Assistance:	
Consumers or representatives with little experience budgeting	28.7
Consumers or representatives who have little experience recruiting, hiring, training, or supervising workers	22.1
Consumers or representatives with poor problem-solving skills	16.4
Consumers who are ill	3.6
Consumers who do not have family member or friend to be paid worker	2.6
Consumers not using the bookkeeping service	1.0
Percentage of Consultants Reporting That Some Consumers Made Unreasonable Demands	36.1
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	

<b>TABLE A.31: Consultant Opinions of, and Recommendations for, CDC</b>	
	<b>Percentage or Number Reporting</b>
Percentage Who Would Recommend Changes to Consulting Activities	25.1
Types of Changes Recommended to Consulting Activities	
Number who said consultants should do more for consumers (for example, direct consumers to services as a social worker would, generally increase time spent with consumers)	10
Number who said consultants should do less for consumers (for example, play only an advisory role, not have to explain the program to the consumer)	7
Percentage Who Thought They Were Trained Adequately for Their Roles	38.5
Types of Changes Recommended for Consultant Training	
Number who suggested:	
Changing content of training (for example, put more emphasis on the cash spending plan and program paperwork, put less emphasis on program philosophy, update training as program rules or policies change)	53
Reducing time between training and first consumer assignment, or providing training refreshers	25
Making training more practical (for example, use role playing, make training manual more user-friendly, use peer counseling and shadowing)	1
Longer training	6
Shorter training	0
Types of Changes Recommended for Program Features Other Than Consultant Role and Training	
Number who suggested changing:	
Uses of cash: make less restrictive	5
Cash and cash spending plan: reduce time to review changes to plan, simplify the plan, keep consumer direction but eliminate cash payment to consumers	2
Outreach: improve description of program to consumers before enrollment, invite home care agencies to refer clients, change eligibility criteria	0
Bookkeeping: make bookkeeping service more responsive	0
Representatives: encourage wider use, pay them	0
Workers: increase pay, provide training	0
Other: for example, provide services in languages other than English	10
Average Number of Consumers with Whom Consultants Work	3.2
<b>Number of Consultants Responding to Survey</b>	<b>195</b>
<b>SOURCE:</b> MPR consultant survey administered by mail in January 2002.	