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Cash & Counseling: Improving the Lives of Medicaid Beneficiaries Who Need Personal Care or Home and Community-Based Services

Final Report

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DISCLAIMER

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EXECUTIVE SUMMARY

Medicaid beneficiaries who are elderly or have disabilities and who qualify for home- and community-based assistance with personal care typically have had to rely on Medicaid-certified home care agencies for the paid assistance they need to perform the normal daily activities associated with living in the community. The assistance that beneficiaries receive from agencies, under the Medicaid State Plan optional personal care benefit, Section 1115 demonstration programs, or section 1915 (c) waiver programs, is a huge benefit to recipients and their families. However, for many years, advocates for people with disabilities have raised awareness about some shortcomings of the system from their perspective. Agency services fail to reflect some beneficiaries' needs and preferences for particular types and amounts of care, the timing and methods of delivery of the care, and the individuals or agencies delivering it. This mismatch between preferences and services also can adversely affect the beneficiaries' unpaid caregivers, who may have difficulty working for pay and meeting other family obligations because of the time required to provide caregiving. The inflexibility in and limitations of the paid services might lead to physical or emotional burnout in the unpaid caregivers, which may, in turn, require beneficiaries to move into nursing homes.

To address consumers' desire for greater control over their care, the federal government has encouraged states to offer consumer-directed options for personal care. States have responded by offering a range such options for beneficiaries who are eligible for home- and community-based services (HCBS). These options typically include allowing consumers to hire and direct their own workers, but some states allow consumers to manage an individual budget for their self-directed services and supports. Except in California, where consumer direction is the norm rather than the exception, nearly all of these programs are small.

One of the most innovative and flexible consumer-directed-care models is Cash and Counseling, recently tested in a demonstration program that was co-funded by The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services. This report summarizes the findings from five years of research by Mathematica Policy Research, Inc. (MPR) on how each of the three demonstration states implemented its program, and on how the programs have affected the consumers who participated, the consumers' paid and unpaid caregivers, and the costs to Medicaid. The analysis is based on an experimental design to ensure that the estimates of program effects are unbiased, and has sample sizes that are adequate to detect program effects of policy-relevant magnitudes.[1]

[1] 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 demonstration, provided technical assistance to the states, and oversaw the evaluation by MPR. This report draws on the many detailed MPR reports and journal articles that have been prepared over the course of the study.

THE CASH AND COUNSELING MODEL AND DEMONSTRATION

Cash and Counseling gives consumers a monthly allowance that they may use to hire workers, and to purchase care-related services and goods. Consumers can get help managing their care by designating representatives, such as relatives or friends, to help make decisions. It also offers counseling and bookkeeping services to help consumers and representatives to handle their program responsibilities. These tenets of Cash and Counseling—allowing flexible use of an allowance, use of representatives, and availability of counseling and fiscal services—are meant to make the model a viable option for consumers of all ages and abilities. Allowing consumers to hire family members, even legally responsible ones (in some states), without requiring these workers to contract with the state or work for an agency, further increases consumers' freedom of choice relative to other consumer-directed options.

Arkansas, Florida, and New Jersey participated in a three-state demonstration to test the Cash and Counseling model in their respective Medicaid programs. The three states adhered to the basic principles in establishing their cash and counseling programs but implemented their programs in different ways.

- Arkansas and New Jersey "cashed out" (that is provided cash allowances in lieu of) personal care services (PCS) provided under their respective Medicaid State Plans. Florida cashed out services covered under three Medicaid HCBS waiver programs.

- Florida offered its program to children and adults with developmental disabilities, as well as to frail elderly beneficiaries (age 60 and over) and nonelderly adults with physical disabilities, whereas the two other states both restricted their programs to adults (age 18 and older) with physical (and perhaps cognitive) disabilities.

- Arkansas sought to expand access to paid care for consumers in rural or other hard-to-serve areas, whereas Florida and New Jersey restricted their programs to consumers already receiving (or assessed for) covered services.

- The programs differed widely in the size of the monthly allowance, and in the methods used to determine the allowance amounts. Although all three based the allowance amounts on the consumers' care plans, only Arkansas and Florida scaled down the amounts (by 10 to 20 percent) to account for historic differences between the hours of care recommended and approved in the care plans and the hours that consumers actually received under the agency-delivered service model.

- The states also differed in the types of people who conducted the counseling, the mechanisms used to pay for the counseling, and the methods used to train the counselors.

- The states differed on many nonprogrammatic dimensions as well, including labor market conditions and relationships with agencies and unions.

All of these differences contributed to differences in the effects of the program across the three states.

HYPOTHESES, DATA, AND METHODOLOGY

The evaluation was designed to investigate questions about how the Cash and Counseling program operated, and questions about the program's effects on participating beneficiaries, on the beneficiaries' paid and unpaid caregivers, and on costs to Medicaid and Medicare. Both the implementation analysis and the impact analysis conducted to answer those questions required multiple data sources.

The impact analysis used an experimental design to assess the effects of Cash and Counseling on the well-being of consumers, and on the consumers' unpaid caregivers. After completing a baseline interview, half of the demonstration enrollees were randomly assigned to the treatment group, whose members were eligible to receive a monthly allowance that they could use to hire workers and to purchase care-related goods and services. The other half were assigned to the control group, whose members had to obtain their personal care services through the traditional agency-based model. In addition, the experiences of the workers hired by consumers were examined and compared with those of agency workers. Separate analyses were conducted for each state, using the same regression models and methodology for each one to ensure comparability.

To test the concern expressed by agencies and some policymakers that consumer direction is not appropriate for elderly people, MPR evaluated program effects separately for elderly consumers (aged 65 or older in Arkansas and New Jersey, aged 60 or older in Florida) and for nonelderly adult consumers, in each state. Effects on children also were evaluated separately. The three age groups were expected to have different needs, and (perhaps) to hire different types of workers. These differences were especially noteworthy in Florida, due to the fact the great majority of nonelderly adults there had developmental disabilities.

Program effects on consumers were measured by comparing the postenrollment outcomes for the full treatment and control groups, regardless of whether a particular treatment group member actually received the monthly allowance. The estimated treatment-control differences therefore reflect the effects on interested beneficiaries of being offered the opportunity to manage an allowance. Some consumers never received their allowances, so this "intent-to-treat" approach understates the impacts of actual participation in the program. Regression models and logit models were used to estimate these treatment-control differences. Only differences that were statistically significant at the .05 level were considered to be evidence of program effects. Patterns of results across measures and subgroups also were used to assess whether statistically significant differences were likely to reflect true program effects or chance differences.

Data on measures of consumer well-being were collected during 30-minute telephone surveys conducted nine months after the consumers had enrolled in the program. Data on Medicaid and Medicare costs and service use were drawn from claims data for the two years after enrollment. MPR also surveyed the individuals who had been the consumers' primary informal (unpaid) caregivers at the time of enrollment, to estimate program impacts on these

caregivers' well-being 10 months after enrollment. Finally, MPR interviewed the individuals who were the consumers' primary paid workers at the time of the consumers' nine-month interviews.

CONSUMERS' DEMAND FOR AND EXPERIENCES WITH THE PROGRAM

Enrollment periods differed among the three states according to each state's readiness to conduct outreach and enrollment activities, and to implement its consumer-directed program. Arkansas started in December 1998 and enrolled 2,008 adult consumers; New Jersey began intake in November 1999 and enrolled 1,755 adult consumers in the demonstration; and Florida enrolled 1,818 adult and 1,002 child consumers beginning in June 2000. Half the enrollees in each state were randomly assigned to the treatment group. Programs stopped enrolling into the demonstration either when they reached their enrollment targets or in July 2002, whichever came first, to allow the evaluation to proceed.

A modest proportion (6 to 10 percent) of eligible adults enrolled, but the program attracted 16 percent of Florida's Medicaid children with developmental disabilities before enrollment was terminated. Across all three states, enrollees generally were eligible individuals qualifying for somewhat larger allowances, those who already were receiving the personal care or waiver services before program enrollment began, and those who survived the entire enrollment period.

Although every treatment group member had the opportunity to receive an allowance, the proportion that actually received one during the first year after enrollment ranged from only 42 percent of the elderly sample members in Florida to 89 percent of the nonelderly in Arkansas. The great majority of those who received allowances began receiving them by the sixth month after enrollment. In Arkansas, however, most cash recipients received their allowances by Month 3, as the state required counselors to have their consumers develop the required spending plans within 45 days after enrolling. In Florida, on the other hand, counselors were uncertain how much help they should give consumers who were trying to develop spending plans because of the program's emphasis on consumer control and empowerment. Because they felt that consumers needing extensive help to develop a care plan were not likely to be able to manage their own care, they did not attempt to provide all of the help such consumers needed.

The allowance amounts varied widely among and within states. The median allowance offered in Arkansas was $313, compared with $829 for adults in Florida ($831 for children), and $1,097 in New Jersey. Consumers used their allowances mainly to hire workers; few used them to modify homes or cars. Consumers used the counseling and fiscal intermediary services widely and were very satisfied with them.

Program counselors reported very few cases of abuse or neglect of the consumer, or fraudulent use of the allowance. The requirement that only expenditures consistent with the approved spending plan would be allowed by the fiscal agent writing the checks, unless authorized by the counselor, helped ensure that the allowance would not be misused. Most consumers were very pleased with the program, --more than 85 percent of consumers in any age group in any state would recommend the program to others who needed personal care or waiver services. However, more than 30 percent of adults in all three states had disenrolled by the 12th

month after enrollment. Voluntary disenrollment tended to occur within a few months after enrollment, due to difficulties finding or replacing a worker, rather than to dissatisfaction with the program.

EFFECTS ON CONSUMERS' USE OF PERSONAL CARE AND WELL-BEING

For six of the seven state-age groups we examined, the treatment group was significantly more likely than the control group to be receiving paid personal assistance during a two-week reference period preceding the nine-month interview. The difference was largest in Arkansas, where many beneficiaries faced limited access to services due to worker shortages, but it also was sizable in New Jersey and in Florida (except in the case of elderly consumers). However, although treatment group members generally received more paid hours of care, they received less unpaid care than control group members on average, resulting in slightly to moderately lower total hours of care for elderly and nonelderly adults in all states and for children in Florida.

Treatment group members were much more likely than control group members to have their needs met, and to be very satisfied with their care. With one exception, treatment group members in every age group in every state were much more satisfied with virtually every aspect of their care. On the 18 measures examined, which included such indicators as satisfaction with caregivers' reliability, attentiveness, and behavior and consumers' satisfaction with the quality of care, treatment group members consistently gave much higher ratings than control group members to the care they received. Elderly consumers in Florida were the sole subgroup for which there were no favorable effects on satisfaction, as only 42 percent of the treatment group members received their allowances (continuing to rely instead on agency-supplied services).

Despite concerns about consumers' safety under Cash and Counseling, for every age group in every state, treatment group members were no more likely than control group members to suffer care-related health problems on any of the 11 measures examined. Furthermore, for about one-third of the 77 estimates obtained, the treatment group had a significantly *lower* rate of adverse events. Thus, care appears to be at least as good, if not better, under Cash and Counseling than under agency care.

Most important, treatment group members were far more satisfied than control group members with how they were spending their lives. More than one-half of the participants in each of the seven state-age groups reported that the program had improved their lives a great deal.

EFFECTS ON USE AND COST OF MEDICAID- AND MEDICARE-COVERED SERVICES

The Cash and Counseling program was not designed to save money, but rather, to give consumers much greater control and flexibility over their care without costing Medicaid any more per month of benefits received than that care would have cost under the traditional agency-based model. In addition, states are likely to want to understand how the introduction of Cash

and Counseling will affect their *total* Medicaid costs for cashed out services, and whether the program leads to higher or lower costs for other Medicaid services.[2]

Medicaid personal care/waiver costs were significantly and substantially higher for the treatment group than for the control group, both per sample member and per month of benefits received, for most of the state-age group subgroups examined. The treatment group's costs for cashed out services during the first year after enrollment ranged from essentially the same as the control group's (for Florida's elderly consumers) to double the control group's costs (for elderly and nonelderly adults in Arkansas). The costs were higher for the treatment group in Arkansas and in New Jersey in part because many control group consumers in those *states did not receive any paid services for which they were authorized.* However, the treatment group's personal care costs per month of benefits received also was higher than those of the control group in the two states. This unexpected result arose solely because control group care recipients received substantially less care than was authorized in their care plans (even in Arkansas, after the state's pre-demonstration ratio of actual to expected costs was applied to the care plan amount). The treatment group members in both states received, on average, roughly the allowance amounts that their (discounted) baseline care plan called for. In Florida, conversely, costs per recipient month among children and nonelderly adults (nearly all of whom had developmental disabilities) were higher for the treatment group because the group's members received 20 to 30 percent more than was authorized in their baseline care support plans on average. At the time consumers spending plans were developed, counselors revised upward the care/support plans of many consumers, adding additional resources. No analogous opportunity existed for the control group.

Other Medicaid costs were lower for the treatment group in each age group in all three states, but by modest (and statistically insignificant) amounts in most cases (four to seven percent). However, Arkansas's nonelderly treatment group had other Medicaid costs that were 17 percent lower than those of the nonelderly control group, mainly due to lower use of long-term care services, including nursing homes and home health care. Similarly, among Florida children, treatment group members had significantly lower costs than control group members (by 15 percent) for other Medicaid costs.

As a result of these lower costs for other Medicaid services partially offsetting the higher personal care costs, total Medicaid costs were higher for the treatment group than for the control

[2] The analyses of program effects on costs presented here differ substantially from the budget neutrality calculations performed by the states for CMS. Under the terms of the Medicaid Section 1115 waiver authority for the demonstration, each of the three program states was required to demonstrate that federal Medicaid expenditures with the program are no higher than expenditures without the program, over the life of the program. This test was implemented by comparing the treatment group's average Medicaid cost for a set of "core" services *per month the allowance was received* to the control group's analogous average cost per month that agency-based PCS/waiver services were received. These core services included the allowance and PCS/waiver services plus related services that might be affected by the program, such as home health, targeted case management, hospice, durable medical equipment, and transportation (although the exact definition varies by state). Our calculations in this report differ in that they are limited to the first two years after demonstration enrollment for all consumers, do not examine the "core" services as a group, and are not typically restricted to only months when consumers are receiving the allowance or agency services. CMS has determined that all three states have satisfied the budget neutrality requirements over the life of the demonstration.

group for every state and age group during the first year, but not significantly so in most cases. Only for younger adults in Florida and older adults in Arkansas were the treatment group's total Medicaid costs significantly higher than the control group's.

During the second year after enrollment, the patterns shifted, but in different ways across the three states. In Arkansas, the treatment-control difference in personal care expenditures fell and the savings in other Medicaid costs grew such that the total Medicaid cost differential decreased to a statistically insignificant five percent of the control's average cost. By contrast, in Florida and in New Jersey, the gap in total Medicaid costs for all adults grew to about 12 percent of the control group mean, a statistically significant difference in both states.

EFFECTS ON PAID AND UNPAID CAREGIVERS

Consumers' well-being depends largely on the individuals who are their primary caregivers, regardless of whether the caregivers are paid for any or all of that care. The evaluation therefore examined differences between the experiences of the primary unpaid (at enrollment) caregivers of the treatment and control groups, and the differences between the two groups' primary paid workers. These two groups of caregivers overlapped considerably for the treatment group, because many who were the consumers' primary unpaid caregivers at enrollment (29 percent for adults in Florida, 42 percent in New Jersey, and 56 percent in Arkansas) began receiving pay from consumers.

In all three states, among primary caregivers who were unpaid at enrollment, those caring for the treatment group were much more satisfied than those caring for the control group with the overall care that consumers received (and they worried less), and they were less likely to report emotional, physical, or financial strain. Although high proportions of caregivers for both treatment and control group members reported that caregiving had serious adverse effects on their social lives, work lives, and physical and emotional health, the rates were significantly lower for the treatment group's caregivers. As a consequence, the treatment group's caregivers reported much greater satisfaction with life. The only exception to this pattern across states and across age groups within states was for the caregivers for nonelderly adults in New Jersey, where the level of emotional, physical, and financial strain reported by caregivers for the treatment group was not significantly different than that reported by caregivers for the control group. This difference appeared to be due to differences across states in the program's effect on overall care burden. Whereas the treatment group's primary unpaid caregivers provided about seven to nine percent fewer total hours of care than control group caregivers for adults in Arkansas and Florida, the treatment group's caregivers for the non-elderly in New Jersey provided *more* total hours of care than the control group's. (Among the elderly in New Jersey, the total hours of care provided by caregivers for the treatment group was similar to the total hours of care provided by caregivers for the control group.) The favorable effects on caregivers were not due solely to the fact that some caregivers began receiving pay for some of the care provided—those who did not become paid workers also had significantly better outcomes than control group caregivers.

More than two-thirds of workers hired directly by treatment group consumers were previously unpaid caregivers—mostly family members-- and these workers continued to provide many hours of unpaid care. Directly hired workers received wages roughly similar to agency

workers in each of the three states, but the directly hired group was much more satisfied with the pay. Directly hired workers and agency workers experienced similar levels of physical strain and job-related injuries. In each state, however, the directly hired workers had *higher* levels of emotional strain and of feelings of being unappreciated by the care recipients' families and friends. These differences were due to the fact that many directly hired workers were related to their care recipients. Directly hired workers who were not related to the care recipient reported rates of emotional strain and feelings of being unappreciated that were very similar to those of agency workers. The difference between agency workers and directly hired relatives reflects family dynamics and the hired relatives' feeling of being constantly "on-call."

CONCLUSIONS AND POLICY IMPLICATIONS

Cash and Counseling was implemented successfully in three different states, with three different benefit levels, types of services covered, target populations, program rules, and structures for providing counseling and bookkeeping services. Consumers, often with the help of self-appointed representatives, successfully managed their allowances, hired workers they liked, and terminated the employment of relatives and friends when they had to. The flexibility of the allowance enabled consumers not only to hire whomever they wanted, define the tasks they wanted performed, and specify how and when the tasks would be accomplished, but to meet their needs through the purchase of goods and services not available in the traditional system. These goods and services included special communication devices, transportation, personal care supplies, kitchen appliances, security systems, home and vehicle modifications, and many other items. The counselors'/consultants' reviews of spending plans and monitoring of check requests and time sheets limited incidences of fraud, abuse of the funds, and abuse of consumers to a handful of cases.

The program had overwhelming positive effects on consumers of all ages, and their caregivers. Consumers who managed their own care were far happier with their care and their lives in general, and experienced no more—and in some cases significantly fewer—adverse events than those receiving agency care. Caregivers experienced much less physical, emotional, and financial stress.

The treatment group's higher satisfaction and lower unmet needs occurred in spite of the fact that its total hours of care was lower. Furthermore, the treatment group had more favorable outcomes even when the ratio of actual to expected benefit amounts was controlled for. Thus, the greater amount of benefits received was not the sole source of the treatment group's greater satisfaction. Interviews with consumers suggested that the difference was due to the assistance received being of higher quality and greater efficiency than agency care.

Despite its overwhelmingly positive effects, some potential cost-related and operational drawbacks to the program remain. Among the potential cost-related problems are the following:

- Total costs to Medicaid were consistently higher with Cash and Counseling than without it, a worrisome concern in times of tightening Medicaid budgets, even if the higher costs were due mostly to correction of failings of the traditional system.

- Using a "discount factor" to scale down care plan amounts by the share that consumers actually receive on average may be needed to keep costs the same under Cash and Counseling, but could leave some consumers with too little money to meet their needs. In practice, none of the three states actually restricted cash allowances to less than the expected cost of the approved care, even though both Arkansas and Florida did use a discount factor. In Florida, consumers actually received substantially more than their care plan amounts due to generous reassessments when spending plans were being developed. In Arkansas, the amount allocated for counseling services was reduced over time, through more aggressive negotiating, and the surplus was used to augment the amount paid per hour of care in the care plan. Thus, the demonstration provides no evidence on what would happen if the allowance were actually discounted. Failure of the traditional program to provide the number of authorized hours because of agencies' inability to find enough workers (as occurred in Arkansas) should not be compounded by scaling down allowances by a comparable percentage for those who self-direct.

- Costs could increase if the existence of the program were to lead some eligible Medicaid beneficiaries who would not have applied for the PCS or HCBS benefit under the agency model to do so under Cash and Counseling. The fact that only one-third of Arkansas's control group consumers who were not receiving agency services before enrollment received them after enrolling suggests that at least some of these consumers were not interested in receiving agency-based services; many non-recipients in the control group said they did not seek agency services. Other evidence, however, suggests that an inadequate supply of workers is probably the reason why most of the members of that group of consumers did not receive services. Florida and New Jersey limited their programs to consumers who had been receiving (or, in New Jersey, those who already had been assessed for) the benefit in the traditional program, and they advertised the programs only to those consumers. However, limiting enrollment to current recipients of services prevents people who have access problems under the traditional program from resolving these problems through participation in Cash and Counseling.

- Except in Arkansas, the cost savings in other Medicaid costs for adults, most notably the adults' long-term care costs, did not persist into the second year. This suggests that substantially increasing the number of eligible beneficiaries receiving services and filling major gaps between actual and authorized levels of services may be the only way to generate savings in other long term care costs.

The demonstration states each learned a number of important lessons about how costs can be controlled. Attention to these lessons by other states adopting Cash and Counseling or similar programs may lead to better lives for consumers at little or no additional costs to the states:

- The assessments and reassessments used to determine consumers' PCS/waiver benefits on which the allowance is based should be prepared by trained independent state staff, rather than counselors, who may act more as advocates for

the consumer than as objective assessors of need. The assessments and reassessments should be done without regard to whether the consumers will be directing their own care. New Jersey did this successfully, using Medicaid nurses to conduct the assessment and avoided the problem experienced by Florida of consumers receiving far more resources on average than were authorized in their *initial* care plan.

- Contracting for counseling services should be done in a manner that provides incentives for cost efficiency. For example, Arkansas found that the length of time until consumers' required spending plans were completed, and the corresponding cost to the program, decreased substantially when the state shifted from paying counselors a fixed monthly fee per consumer to paying a one-time lump sum for each consumer until the consumer began receiving his/her cash allowance.

- Unused allowance amounts should be recovered by the state at regular scheduled intervals made known to consumers.

- Costs for Cash and Counseling and the traditional PCS/waiver program should be monitored on a regular and frequent basis against authorized care plan amounts. This monitoring will help to ensure that consumers receiving agency care and those who self-direct both receive the care that has been authorized, and that cost disparities between the two systems do not develop.

Other problems experienced by the programs also merit attention:

- Unless counselors aggressively seek to help consumers to establish their spending plans within a short period after enrollment, many consumers who want to direct their own care might not ever do so. The very low proportion of Florida's elderly beneficiaries who participated suggests that states may have to develop incentives for counselors and may have to train counselors to encourage and help consumers to develop their spending plans within a few months of enrollment. Arkansas's method of requiring counselors to get consumers started on the cash allowances within 45 days was particularly effective.

- The program's favorable effects on consumers may not be realized or, if realized, may not be sustained if many consumers are unable to hire workers, or if stress leads hired family workers to quit. States should consider establishing worker registries or offering consumers lists of current or former hired workers who would like to work for additional consumers to help consumers with the critical task of obtaining or replacing hired workers. States should also consider providing resources, such as information brochures and referrals, to help consumers' relatives to cope with the emotional stress of caregiving, and with the lack of respect they perceive from other family members.

The early evidence from the demonstration has convinced many states to implement their own Cash and Counseling programs, or to adopt principles from Cash and Counseling, to

improve the lives of consumers who are receiving PCS or HCBS. The three demonstration states have renewed their 1115 waivers and have ongoing Cash and Counseling programs. Eleven new states have been selected to participate in the next round of Cash and Counseling, and each one has received start-up grants from RWJF. A twelfth state program (in Illinois) is being funded by the Retirement Research Foundation. By taking advantage of the lessons learned from the demonstration, these states may be able to achieve for their beneficiaries the same type of gains in well-being as demonstration participants and caregivers experienced, while controlling their costs and, perhaps, reducing beneficiaries' dependence on other long-term care services.

CASH AND COUNSELING: IMPROVING THE LIVES OF MEDICAID BENEFICIARIES WHO NEED PERSONAL CARE OR HOME- AND COMMUNITY-BASED SERVICES

Medicaid beneficiaries who qualify for home- and community-based assistance with personal care typically have had to rely on Medicaid-certified home care agencies to provide it. The assistance that beneficiaries receive from these agencies, under State Plan personal care services or a 1915(c) waiver program, often fails to reflect the beneficiaries' needs and preferences for particular types and amounts of care, the timing and methods of care delivery, and the individuals or agencies delivering it. This mismatch also adversely affects the beneficiaries' unpaid caregivers. The demands of caregiving may lead to physical or emotional burnout in unpaid caregivers, which may, in turn, force beneficiaries to move into nursing homes.

Advocates for people with disabilities have worked for decades to raise awareness about the shortcomings of the agency-based system, and states are gradually responding with "consumer-directed" alternatives that offer consumers more control over the care they receive. Existing consumer-directed options range from allowing consumers to choose the agencies and workers who will provide their care, and the schedule for receipt of their care services, to allowing them to hire whomever they choose to do whatever tasks they need to have done.[1]

One of the most innovative and flexible consumer-directed-care options currently in operation is the Cash and Counseling demonstration program, co-funded by The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation (ASPE), U.S. Department of Health and Human Services (DHHS). Three states—

[1] See Flanagan (2001) for a description of the various consumer directed programs and options for states.

Arkansas, Florida, and New Jersey—received funding in 1996 to develop their programs. Arkansas began enrolling beneficiaries in December 1998, New Jersey began doing so in November 1999, and Florida began its enrollment in June 2000.[2]

This report summarizes the findings from data collected and reports prepared since the program's inception by Mathematica Policy Research, Inc. (MPR). These analyses have examined how each of the three demonstration states implemented its program, and on how the programs have affected the consumers who participated, the consumers' paid and unpaid caregivers, and the costs to Medicaid. Although no study is perfect, the findings from this one are highly robust and defensible, as they are drawn from a randomized experimental design with adequate sample sizes in three different settings. The report draws on the many detailed reports and journal articles that have been prepared over the course of the study (see Appendix C).

We begin by describing the demonstration parameters, rules, and time frame, then provide a brief description of the data and the evaluation methodology in Chapter II. Chapter III presents data on the number and characteristics of program participants and on these participants' satisfaction with the program. The impacts of the program on the amount of care received by consumers and on their unmet needs and well-being are examined in Chapter IV. Chapter V shows program effects on Medicaid and Medicare costs. We then turn to program effects on unpaid caregivers and describe the experiences of directly hired workers in Chapter VI. The final chapter discusses the implications of the study for states and consumers.

[2] CMS collaborated with the National Program Office and ASPE in the development of the model, approved the demonstration programs under Section 1115 authority of the Social Security Act, and monitors and oversees the implementation of these Medicaid programs. The National Program Office for the demonstration, at Boston College and the University of Maryland, coordinated the demonstration, provided technical assistance to the states, and oversaw the evaluation. MPR evaluated the demonstration.

I. THE DEMONSTRATION

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

Cash and Counseling allows consumers to control care, and to use their allowance flexibly.

Cash and Counseling gives consumers a monthly allowance that they may use to hire workers of their own choosing, and to purchase care-related services and goods (within state guidelines). It allows consumers to designate representatives, such as relatives or friends, to help them to make decisions about managing their care. It also offers counseling and fiscal services (such as issuing paychecks to workers hired with the allowance, writing checks for other services, handling payroll taxes, and maintaining the consumer's program-related accounts) to help consumers and representatives to handle their program responsibilities. These tenets of Cash and Counseling—a flexible allowance, use of representatives, little or no restrictions on who the consumer can hire, and availability of counseling and fiscal services—are meant to make the model a viable option for consumers of all ages and abilities.

The three demonstration states implemented their programs in different ways.

All three demonstration states wished to assess the political and economic feasibility of offering consumers greater choice and control over their publicly funded care through a consumer-directed option. In addition, Arkansas (more so than either Florida or New Jersey) hoped to increase access to services in parts of the state in which agency workers were in short

supply. All three states had to meet federal budget neutrality requirements over the life of the demonstration, but none had the goal of *saving* public funds during the demonstration.

Because the Medicaid programs and political environments of the demonstration states differed considerably, the states were not required to implement a standardized Cash and Counseling program. However, they did have to adhere to the model's basic tenets. The key features of each state's program are described in the remainder of this section and are summarized in Table I.1.[3]

Services on Which Allowance Was Based. The demonstration programs in Arkansas and New Jersey provided participants with an allowance in lieu of the personal care services benefit in their respective Medicaid State Plans, which covered services such as help with eating, bathing, housekeeping, and shopping. Florida's program offered an allowance instead of the benefits usually provided through a Medicaid HCBS waiver program, such as in-home nursing, professional therapies, care-related supplies and equipment, caregiver respite, and help performing daily living activities.

Target Populations and Eligibility. Differences between the states in eligibility criteria have important implications for the results discussed in this report. Arkansas's demonstration was open to Medicaid beneficiaries age 18 or older who were *eligible for* but not necessarily receiving Medicaid State Plan personal care services. Eligible beneficiaries who were also participating in either of two HCBS waiver programs—ElderChoices and Alternatives—were not prohibited from participating in the Arkansas demonstration. These waiver benefits were delivered as usual during the demonstration; they were not "cashed out" as part of the Cash and Counseling allowance. ElderChoices provides nurse-supervised homemaker, chore, and respite

[3] For additional information about demonstration implementation in the three states, see Phillips and Schneider (2002, 2003, and 2004.)

TABLE I.1

KEY FEATURES OF CASH AND COUNSELING PROGRAMS, BY STATE

Feature	Arkansas—IndependentChoices	Florida—CDC	New Jersey—Personal Preference Program
Demonstration enrollment period	December 1998 to April 2001	June 2000 to July 2002 (adults, age 60 or older), June 2000 to November 2001 (adults aged 18 to 59), and June 2000 to August 2001 (children)	November 1999 to July 2002
Eligible population	Adults (elderly and nonelderly) with physical disabilities (may also have cognitive disabilities) who were eligible for the state plan Medicaid personal care program	Elderly adults and nonelderly adults with physical disabilities, and children and adults with developmental disabilities who were receiving services under the HCBS waiver	Adults (elderly and nonelderly) with physical disabilities (and perhaps cognitive disabilities) who were already enrolled in the state plan Medicaid personal care program
Services included in calculating the allowance amount	Personal care with activities of daily living, such as eating, bathing, dressing, toileting, and transfer, and with instrumental activities such as housework and meal preparation	HCBS waiver services, except case management/support coordination[a]	Personal care with activities of daily living
Hiring restrictions	Could not hire legally responsible relatives (such as spouses or parents) or representative	None	Could not hire representative
Care plan adjustment factor used in setting allowance	Provider-specific for those previously receiving agency services, ranging from 70 to 91 percent and averaging 86 percent across all enrollees; set at 91 percent for new applicants for PCS	89 percent for elderly adults, 83 percent for adults with physical disabilities, 92 percent for children and adults with developmental disabilities	None

TABLE I.1 *(continued)*

Feature	Arkansas—IndependentChoices	Florida—CDC	New Jersey—Personal Preference Program
Method for calculating allowance	$8 per hour in care plan multiplied by provider-specific adjustment factor	Claims history or adjustment factor multiplied by value of care plan. (Care plan always used for those with developmental disabilities. For others, used care plan if claims history was not stable or if care plan value was at least $50 per month more than claims history.)	Value of care plan minus 10 percent set-aside for fiscal agent and counseling services
Median monthly prospective allowance of all demonstration enrollees	$313	$829 (adults) and $831 (children)	$1,097
Funding for fiscal agent and counseling services	Paid for through pool of money generated from difference between $12.36 per hour paid to agencies and $8.00 per hour rate at which allowance was cashed out. Originally, agencies were paid a per-client per-month rate for counseling and fiscal services, which was reduced at six-month intervals. Later in the demonstration, agencies were paid a fixed rate for developing a spending plan and then paid per client per month for counseling and fiscal services.	Counseling paid for through existing Medicaid funding stream for case management and support coordination in traditional program. Fiscal agent fees paid for by schedule of fees charged to consumers (for example, $5 per check)	Set aside 10 percent of care plan value to cover counseling services and some fiscal agent costs. From this pool of money, the state paid human services agencies a lump sum per consumer to complete a cash management plan and an hourly fee thereafter for consulting; state also paid fiscal agent for some tasks, such as the processing of employment-related forms. Consumers paid some fiscal agent fees (such as for cutting and stopping checks)
Entity conducting reassessment	Provider agencies (for traditional program) and counselors (for allowance recipients)	Support coordinators or case managers (for traditional program) and counselors (for allowance recipients)	Provider agencies (for traditional program) and Medicaid nurses (for allowance recipients)
Participation in other consumer-directed or home care programs	Demonstration enrollees could also participate in the HCBS waiver programs ElderChoices or Alternatives[b]	For adults with developmental disabilities, the demonstration excluded some northern counties with a state-funded consumer-directed program.	Demonstration enrollees could not participate in HCBS waiver programs or a state-funded consumer-directed program.

[a]HCBS services covered under Florida's waiver included a wide variety of services, including behavioral therapy and personal care supplies, as well as personal care.

TABLE I.1 *(continued)*

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

HCBS = home- and community-based services.

service to nursing-home-qualified elderly adults. Alternatives provides attendant care and environmental modifications for nonelderly adults, who also are permitted to choose and supervise their own paid caregivers, including family members.

Florida's demonstration was open to Medicaid beneficiaries who were *receiving* HCBS under either the state's Developmental Disabilities 1915(c) Waiver or its Aged and Disabled Adults 1915 (c) Waiver, and were living in selected areas of the state.[4] Together, these waivers serve children and adults with developmental disabilities, frail elderly adults, and adults with physical disabilities. For children, the catchment area for the demonstration was the entire state. For adults with developmental disabilities, it was the entire state with the exception of several northern counties in which a pilot of a state-funded consumer-directed program was under way. The catchment area for elderly adults and for adults with physical disabilities consisted of 19 counties, including most of Florida's major metropolitan areas.

New Jersey's demonstration was designed for adult Medicaid beneficiaries who were *enrolled in* the Medicaid State plan (that is, they were receiving agency services or had been assessed by an agency). Beneficiaries who also were participating in HCBS waiver programs or in any of New Jersey's state-funded consumer-directed programs could *not* take part in the demonstration. New Jersey's demonstration also excluded beneficiaries who were not expected to continue living in the community for at least six months, as developing and implementing plans for the Cash and Counseling allowance was expected to take several months.

None of the demonstration states screened eligible beneficiaries for ability to self-direct. Beneficiaries were allowed to enroll if they and their representatives believed that they could

[4] Florida's initial demonstration design called for the inclusion of beneficiaries in the state's Brain and Spinal Cord Injury Program (BSCIP). However, the Cash and Counseling option was not offered by BSCIP until many months after intake began for beneficiaries from the two other waiver programs, so BSCIP participants were excluded from MPR's evaluation.

manage their program responsibilities. Treatment group consumers already receiving PCS or HCBS at enrollment continued to receive them as usual until their allowances began; others (such as new consumers in Arkansas), could get agency services until they could develop an approved spending plan and hire a worker. Consumer could disenroll from Cash and Counseling at any time.

Enrollment and Random Assignment. The demonstration states were responsible for outreach and enrollment activities, including the collection of informed consent and the collection of basic intake data (such as contact information). In general, the states used a combination of direct mailings, telephone calls, and home visits to inform all eligible beneficiaries about the opportunity to participate in the demonstration. Generally, within about one week of each beneficiary's enrollment, MPR conducted a baseline telephone interview with the beneficiary (or with a knowledgeable proxy respondent) and then randomly assigned the beneficiary to the treatment group (with the opportunity to participate in Cash and Counseling) or to the control group (to rely on PCS or HCBS as usual).

Demonstration enrollment periods differed among the three states according to each state's readiness to conduct outreach and enrollment activities, and to implement its consumer-directed program. Arkansas started in December 1998 and enrolled 2,008 adult consumers in the demonstration; New Jersey began intake in November 1999 and enrolled 1,755 adult consumers and Florida enrolled 1,818 adult and 1,002 child consumers beginning in June 2000. Half the enrollees in each state were randomly assigned to the treatment group. Programs stopped enrolling into the demonstration either when they reached their enrollment targets or in July 2002, whichever came first, to allow the evaluation to proceed.

Calculation of Program Allowances. Arkansas and New Jersey calculated program cash allowances by multiplying the number of hours in consumers' Medicaid PCS plans by an hourly

rate that was set below the average rates paid to agencies. (The difference was used to pay for counseling services and for the fiscal agent in the demonstration programs.) Plan hours were capped at 16 per week in Arkansas, and at 25 per week in New Jersey, absent special authorization for additional hours. Florida based its allowances on all the benefits in consumers' HCBS care plans or recent Medicaid waiver claims with the exception of those for case management/support coordination. Claims were to be used to calculate allowances if they were historically stable and consistent with the consumers' current care plans. Claims were used to calculate the allowances of consumers who were eligible because of their physical disabilities. In practice, however, claims were *not* used to calculate the allowances of consumers with developmental disabilities, because those consumers' care plans were being systematically revised at the time that the demonstration began. (The revisions resulted from a substantial increase in state funding for the HCBS waiver programs serving people with developmental disabilities.)

To keep expected program costs comparable to what costs would have been under agency-based care, Arkansas and Florida applied adjustment factors to consumers' allowances. Both states had determined that, during the pre-demonstration period, recipients of covered services had not, on average, received all the services in their plans (for example, because in-home services were suspended during hospitalizations). In contrast, New Jersey determined that consumers' actual and planned costs had been roughly equal historically, indicating that adjustment factors were not necessary to keep costs comparable to anticipated costs for agency care. Median monthly allowances calculated for adult demonstration participants varied considerably by state. They ranged from $313 in Arkansas, to $829 in Florida, to $1,097 in New Jersey. The median for Florida children was $831.

Permitted Uses of the Allowances. All three programs required consumers (or their representatives) to develop written spending plans that specified the goods and services that the consumers wished to purchase with their allowances. Only goods and services related to a consumer's disability were permitted; however, the states usually took a broad view of allowable purchases. (For example, they permitted the use of the allowance to purchase transportation, laundry services, insurance, and kitchen appliance.) Consumers could elect to receive small portions (10 to 20 percent) of their allowances as cash for incidental expenses, such as taxi fares, that could not readily be purchased through an invoicing process. They also could save portions of their allowances for larger, one-time purchases, such as home modifications.

Although consumers were permitted to use their allowances to hire relatives, some restrictions applied. A federal waiver permitted states to let consumers pay their legally responsible relatives (spouses, parents of minors, and other legal guardians) for providing care, but Arkansas chose not to allow this. Neither Arkansas nor New Jersey allowed the same person to serve as both a representative and a paid worker, to avoid potential conflicts of interest. Florida had no such restriction during the evaluation period because it recognized that parents typically represent *and* care for their children with developmental disabilities. However, to protect consumers in cases in which the representative and the worker were the same person, Florida required that someone else from the consumer's "circle of support" verify that the representative/worker had performed the agreed-on services.[5]

Counseling and Fiscal Services. In all three demonstration programs, consumers were offered the assistance of counselors (called "consultants" in Florida and New Jersey) and of a

[5] While not encountering any major problems with this approach, Florida subsequently modified its operational protocol so that that no one could serve as both a representative and a paid worker. This restriction currently is enforced in Florida's ongoing Consumer Directed Care Plus (CDC+) program, which operates under a Section 1115 waiver.

fiscal agent (called a "bookkeeper" in Arkansas). Counselors interacted with consumers to (1) develop, review, and revise written plans for spending the monthly allowance in permissible ways; (2) offer advice about recruiting, hiring, and training workers; (3) offer advice about other services available in the community, among other issues; (4) monitor consumers' well-being; and (5) monitor use of the allowance. Florida and New Jersey also required that state- or district-level staff review all spending plans. Arkansas required this type of review only if a plan included goods and services that were not on the state's preapproved list; otherwise, counselor review sufficed. Interactions between counselors and consumers took the form of telephone calls and home visits, the frequency of which varied by state. Counselor services were provided at no direct charge to consumers, but the costs of providing these services are included in all measures of program costs.

Consumers in the three programs were offered assistance with fiscal tasks, including the payroll functions of an employer (such as preparing and submitting payroll tax returns) and check writing. Florida and New Jersey charged consumers modest fees for fiscal services; Arkansas covered these costs globally through the amount set aside for counseling and fiscal services costs. Although consumers who demonstrated their ability to handle fiscal tasks themselves were allowed to do so—and thus receive their entire allowances as cash each month—with only a few exceptions, consumers chose to have their fiscal agents maintain program accounts on their behalf.

To prevent misuse of the allowances, the demonstration programs compared check requests and workers' time sheets with consumers' spending plans before disbursing funds. Arkansas and Florida also required consumers to save receipts for all purchases (except incidental ones) made with the allowance, for subsequent review by program staff.

II. THE EVALUATION DESIGN, DATA, AND METHODOLOGY

The key questions that the evaluation was designed to investigate included questions about how the Cash and Counseling program operated, and questions about the program's effects on participating beneficiaries, on the beneficiaries' paid and unpaid caregivers, and on costs to Medicaid. Both the implementation analysis and the impact analysis conducted to answer those questions required multiple data sources. Table II.1 displays the key hypotheses, data sources, and methodologies used.

The implementation analysis drew on site visits, program data, and surveys to provide critical information on operational issues and performance measures.

The implementation analysis was critical for documenting key decisions that the states made about their programs, and for identifying lessons learned by the demonstration states that can be used by other states that wish to adopt Cash and Counseling or a similar type of consumer-directed program. As we show in subsequent sections of this report, differences in implementation explain some of the key differences in program impacts observed across the states. Thus, these differences are important for fully understanding the impact analysis, and for assessing the likelihood of replicating or improving on the outcomes examined.

The key implementation questions in the evaluation related to targeting of the program, operational aspects, and performance measures. Targeting issues included determining which beneficiaries would be offered the program, how the states determined program eligibility, and how the states promoted it. Operational aspects included how the states defined and implemented the counseling component of the program, how they set allowances, what restrictions they placed on uses of the allowance, how allowance use was monitored, and how they provided the fiscal services that helped consumers to meet their obligations as employers. Performance measures included the programs' level of success in enrolling and starting

consumers on allowances, the frequency of fraud or abuse, the extent to which consumers liked the program, and identification of program features that counselors and consumers found to be particularly attractive or unattractive.

As noted, the implementation analysis relied on numerous sources of data. Information about program operations was obtained through in-person discussions with program staff, state officials, and representatives from the personal care industry (such as leaders of agency associations or trade groups in the state). Mail surveys of counselors provided information about the counselors' perceptions of the effectiveness of and problems with the program. A telephone survey of treatment group members, conducted four or six months after enrollment, yielded analogous data from the participants' perspective. The states provided administrative data on allowance amounts, start dates, reassessments, disenrollments, and uses of the allowance at eight months after enrollment.

Program effects on consumers and caregivers were estimated using a rigorous experimental design.

The impact analysis used an experimental design to assess the effects of Cash and Counseling on the well-being of consumers, and on the consumers' unpaid caregivers. In addition, the experiences of the workers hired by consumers were examined and were compared with those of agency workers serving the control group. Separate analyses were conducted for each state, using the same models and methodology for each one to ensure comparability. We also estimated program effects separately for elderly and nonelderly consumers, for two reasons. One reason was to evaluate concerns about whether consumer direction would work for aged beneficiaries, who may have more cognitive problems than younger beneficiaries with physical disabilities. The other was to distinguish between adults aged 18 to 59 in Florida's program, 90 percent of whom had developmental disabilities and were covered under Florida's

Developmental Services waiver program, and those aged 60 or older, almost all of whom were adults with physical disabilities (and often cognitive impairments as well) covered under its Department of Elder Affairs waiver program. Thus, we define "elderly" as being older than age 60 in Florida, whereas in Arkansas and New Jersey we use the Medicaid definition of "aged," that is, age 65 and older.

Program effects on consumers were measured by comparing the subsequent outcomes for the full treatment and control groups, *regardless of whether a particular treatment group member actually received the monthly allowance*. The estimated treatment-control differences therefore reflect the effects on interested beneficiaries of being offered the opportunity to manage an allowance. Some beneficiaries never received an allowance (for various reasons, as we discuss in Section IV), so this "intent-to-treat" approach understates the impacts of actual participation in the program.

Program impacts on consumers' well-being were estimated using survey data gathered 9 months after enrollment.

The key hypotheses tested concerning consumers' well-being were whether the program affected the types and amounts of care received, the consumers' unmet needs for care, their satisfaction with their care, their health and functioning, their quality of life, and the incidence of adverse outcomes, such as falls or pressure sores. The expectation was that the flexibility and increased choice offered by the program would enable consumers to arrange for the type of help they wanted, the times during which they wanted it, the manner in which it was delivered, and the people who provided it. These choices, in turn, were expected to lead to fewer unmet needs than the control group experienced, and to greater satisfaction with care and with life overall. The program was not expected to increase or decrease the number of adverse health outcomes that could arise from care of inadequate quality.

Data on all of the *outcomes* above were collected in a 30-minute telephone survey conducted nine months after the consumer enrolled in the program. Table II.1 provides the sample sizes, by state and by age group. Response rates to the survey were very high; roughly 85 percent of sample members in each state responded. Due to the high proportion of elderly sample members who had difficulty speaking, hearing, or understanding, over 60 percent of the elderly in each state had proxies respond for them at the nine-month followup.[6] Use of proxies was much lower among non-elderly adults, except in Florida, where nearly 90 percent of the sample had developmental disabilities.

Because virtually all of the outcome measures were binary (or four-point scales collapsed into binary measures), treatment-control differences in outcomes were estimated using multivariate logistic regression models. The use of multivariate models enabled us to control for any baseline differences between the treatment and control groups that occurred by chance or by differential nonresponse, or because some observations had to be excluded from the analysis of certain outcomes (for example, satisfaction with paid care was measured only for people receiving paid care). Appendix A contains a list of the control variables used in the model. The statistical significance of the coefficient on the binary indicator for treatment group was used to determine whether the treatment-control difference on any given outcome was greater than might be expected to occur by chance. We calculated the magnitude of the treatment-control difference by using the estimated model to predict the average probability of the outcome occurring across all sample members under the assumption that every sample member was in the treatment group, and then repeating the calculation under the assumption that every member was in the control group. The difference between the two mean probabilities is the estimated impact on the probability of the outcome occurring.

[6] Proxy response rates were generally 5 to 10 percentage points lower at baseline than at follow-up.

TABLE II.1

SAMPLE SIZES AND RESPONSE RATES FOR NINE-MONTH CONSUMER SURVEY

	Arkansas		Florida			New Jersey	
	Age 18 to 64	Age 65+	Age 3 to 17	Age 18 to 59	Age 60+	Age 18 to 64	Age 65+
Baseline Interviews							
Treatment	279	725	501	456	453	404	467
Control	277	727	501	458	451	413	471
Total	556	1,452	1,002	914	904	817	938
Nine-Month Interviews							
Treatment	243	642	441	419	373	345	402
Control	230	624	418	392	363	337	381
Total	473	1,266	859	811	736	682	783
Response Rates							
Treatment	87.1	88.6	88.0	91.9	82.3	85.4	86.1
Control	83.0	85.8	83.4	85.6	80.5	81.6	80.9
Total	85.1	87.2	85.7	88.7	81.4	83.5	83.5
Percentage of Nine-Month Surveys Completed by Proxy Respondents							
Treatment	30.0	71.7	–	82.6	65.7	35.7	61.9
Control	27.4	70.5	–	82.4	65.6	38.0	59.8
Total	28.8	71.1	–	82.5	65.6	36.8	60.9

Only outcomes for which the treatment-control difference was significantly different from zero at the .05 level, using two-tailed tests, are considered to have been affected by the Cash and Counseling program. This conservative approach may have resulted in our failure to detect small program effects on some outcomes. However, the sample sizes are sufficiently large, by design, that we can be 80 percent certain of correctly concluding from our tests that the program had an impact if the true effect of the program is about 10 percentage points or greater for binary outcomes with means of .4 to .6. The only state-age group with lower precision is the smallest group—adults in Arkansas aged 18 to 64—for whom the detectable effect is about 13 percentage points).

Program impacts on Medicaid and Medicare costs and service use were estimated from Medicaid claims data for the two years after enrollment.

Another core set of research questions is whether Cash and Counseling affected costs to Medicaid for services covered under the allowance ("cashed out" services), and whether it affected costs to Medicaid for all Medicaid services. Cash and Counseling was designed to be budget neutral, meaning that over the full five-year period covered by the waivers, the cost to Medicaid per Cash and Counseling recipient per month for the allowance, counseling, and fiscal services (and some related "core home and community-based services) was not to exceed the monthly cost per recipient of the cashed-out and related core services under the traditional program by the control group. We did not test precisely this hypothesis, given the need to focus on the evaluation period. However, we did test for whether the cost of cashed-out services per month received differed for the treatment and control groups during the year after enrollment. We also tested whether the average annual cost of these benefits per person for the entire treatment and control groups differed over the first year after enrollment, and (for an early cohort of enrollees) over the second year after enrollment. Even if costs per month of benefit received

were equivalent for the two groups, costs for cashed out services *per consumer enrolled* would be higher for the treatment group if treatment group members were more likely than control group members to actually receive the PCS/HCBS benefit for which they were eligible. Costs per consumer would be lower (or higher) for the treatment group if the adjustment factor used to set consumers' allowances was set lower (or higher) than the average of actual costs to expected costs for the control group based on the care plans.

We also tested for whether the treatment and control groups differed on the use and cost of other Medicaid-covered services, especially for nursing home and other long-term care. Costs for those services could be lower for the treatment group if consumers managing their own care were less likely to enter nursing homes or require other types of long-term care services. Alternatively, these costs could be higher if treatment group consumers were more likely to fall, become ill, or experience other health problems, perhaps as a result of the workers whom they hired having less training and supervision than agency workers. We also examined treatment-control differences on the use and cost of Medicare-covered services for the subset of sample members enrolled in Medicare.

The data for these analyses were obtained from Medicaid and Medicare claims for the two-year period after the consumer enrolled in the demonstration. We used multivariate regression analysis to test our hypotheses. The variances of cost measures are substantially greater than the variance of binary indicators of consumer outcomes; however, we have about a 90 percent or greater power to detect true program effects of 10 percent or greater on total Medicaid expenditures for each age group in each state, except for younger adults in Arkansas and New Jersey (where the power is 44 and 54 percent, respectively).

Survey data on primary informal (unpaid) caregivers collected 10 months after consumers' enrollment were used to estimate impacts on their well-being.

An extremely important potential benefit of the Cash and Counseling program was to lighten the burden on the person who had been providing the most unpaid care to the consumer before the beneficiary enrolled in the demonstration. This benefit could be very important because the ability of the primary unpaid caregiver to continue providing many hours of care often is the factor that enables a consumer to remain in the community, rather than having to enter a nursing home. Consumers' participation in Cash and Counseling could improve the unpaid caregiver's well-being if the consumer pays the caregiver to assume some of the caregiving duties that an agency would have provided, hires a worker to provide care at times that are particularly difficult for the caregiver or for tasks that the unpaid caregiver considered most stressful, or purchases equipment that makes it easier for the caregiver to provide care. Purchasing respite care to give unpaid caregivers an occasional break may also reduce caregivers' stress. Conversely, primary unpaid caregivers could be adversely affected by the program if the consumer pays some family members for services but expects the primary caregiver (or other unpaid caregivers) to continue providing care without pay, or if the unpaid caregiver feels compelled to take on additional physically or emotionally difficult tasks, even if for pay. Finally, becoming a paid worker could affect the caregiver's relationship with the consumer, for better or for worse.

To assess whether Cash and Counseling had any of these effects, we used survey data collected on individuals whom the consumer had identified during the baseline interview as the people providing the most unpaid care during the week preceding the interview. Data from these unpaid caregivers about their experiences were collected in a telephone survey conducted about 10 months after the baseline interview with demonstration enrollees. Approximately 84 percent of the adult treatment group members' caregivers and 78 percent of the control group members'

caregivers, completed the survey, yielding the sample sizes given in Table II.2. These sample sizes provided 80 percent power to detect effects as small as seven to eight percentage points for binary outcomes, for each state (with caregivers for younger and older adults combined). Among children's caregivers response rates were slightly higher, but precision was lower (detectable effects of eight to nine percentage points), due to the smaller sample sizes.

Using data collected in the telephone survey, we tested for differences between the caregivers of the treatment and control members on (1) the types and amounts of care provided; (2) the extent to which the caregivers worried about the beneficiaries' care and safety; and (3) measures of the caregivers' physical, emotional, and financial well-being. The methods and models were similar to those used to estimate impacts on consumers. Appendix B contains a list of the control variables used in the models. We also estimated a model showing which caregiver characteristics were most strongly related to caregivers' becoming paid workers.

Consumers' directly hired workers were compared with agency workers on working conditions, stress levels, and satisfaction.

The well-being of the individuals hired under Cash and Counseling, who could also be the primary unpaid caregiver, is critical to the model's success. Consumers who are unable to find, and keep, workers are likely to be forced to return to agency services. Furthermore, representatives of unions and others expressed concern that directly hired workers could be exploited by the consumers who employed them, or could sustain injuries because of inadequate training. Thus, we studied the wages and benefits of these hired workers, their training, and their reported levels of physical and emotional stress and injuries on the job. To assess whether the benefits and stresses that the hired workers reported were unusually high or unusually low for someone performing caregiving duties for pay, we compared their experiences with the

TABLE II.2

SAMPLE SIZES AND RESPONSE RATES FOR INFORMAL CAREGIVER SURVEY

	Arkansas		Florida			New Jersey	
	Age 18 to 64	Age 65+	Age 3 to 17	Age 18 to 59	Age 60+	Age 18 to 64	Age 65+
Completed Interviews							
Treatment	190	531	429	376	241	246	300
Control	175	537	400	344	232	224	272
Total	365	1,068	829	720	473	470	572
Response Rates							
Treatment	77.1	86.2	86.8	90.4	81.7	75.9	81.3
Control	76.0	83.3	81.5	81.4	76.4	69.4	72.2
Total	76.6	84.8	84.2	85.8	79.0	72.7	76.7

experiences of agency workers providing services to control group members. Differences between the two groups reflect not only the effect of being employed directly by the care recipient instead of by an agency, but also (typically) the effects of being a family member or friend of the care recipient, as opposed to being someone without a personal attachment to the care recipient.

The data for this analysis were obtained from telephone surveys of the individuals identified by consumers at their nine-month follow-up survey as the one who provided the most paid care during the two weeks preceding the survey. Treatment group workers were interviewed within one month after the nine-month survey, using contact information provided by the consumers. We attempted to interview the hired worker for each treatment group member who had hired a worker at nine months.[7] For agency workers identified by control group members, we sought target sample sizes of 300 completed interviews in Arkansas and New Jersey, and 400 in Florida; we stopped interviewing after our targets had been reached. Table II.3 provides the sample sizes. The mean values and distributions of outcomes are presented for directly hired workers and are compared those for agency workers, using t-tests and chi-squared tests to identify all differences greater than might be expected to occur by chance. We did not use regression analysis for these comparisons because we were not trying to adjust for the differences between the two groups arising from differences in their characteristics. Rather, the differences between the groups' characteristics and outcomes were what we wished to observe. For example if directly hired workers reported being in poor health, and they were older, we did not want to eliminate the difference in health status by controlling for the age difference.

[7] Funding for this survey was not secured until August 2000, well after the nine-month consumers interviews had begun in Arkansas. To reach the target sample size in Arkansas, we called back some treatment group members who had already completed their nine-month followup before August 2000 to obtain the names and contact information for their primary paid workers.

TABLE II.3

SAMPLE SIZES AND RESPONSE RATES FOR PAID WORKER SURVEY

		Florida		
	Arkansas	Children	Adults	New Jersey
Completed Interviews				
Directly hired workers	391	222	298	382
Agency workers	281	164	255	308
Response Rates				
Directly hired workers	92.1	91.6	91.6	94.7
Agency workers	77.9	83.6	78.1	79.7

Note: The response rates in this table are for the subset of individuals who were not also the primary unpaid caregiver.

III. CONSUMER DEMAND FOR AND EXPERIENCES WITH THE PROGRAM

Although no firm information was available in the planning stages of the demonstration on the number of eligible beneficiaries who would be interested in Cash and Counseling, a preference study conducted by the Cash and Counseling National Program Office at that time suggested that as many as one-third of eligible beneficiaries at that time were potentially interested (Mahoney et al. 2004). After initially setting fairly large enrollment targets (3, 100 adults per state; 1,550 children in Florida; for a 12-month intake period and discovering that it was more difficult than anticipated to recruit enrollees, the program extended the intake period in each state, and the evaluation reduced the target sample sizes to 2,000 adults in each state, plus 1,000 children in Florida. Arkansas, which started enrolling nearly one year before New Jersey and 18 months before Florida, reached its enrollment target in April 2001. Intake into the evaluation sample for Florida and New Jersey was terminated in July 2002 to allow the evaluation to proceed, with both states falling about 10 percent short of the target enrollment levels for adults. Figure III.1 shows the enrollment flows.[1]

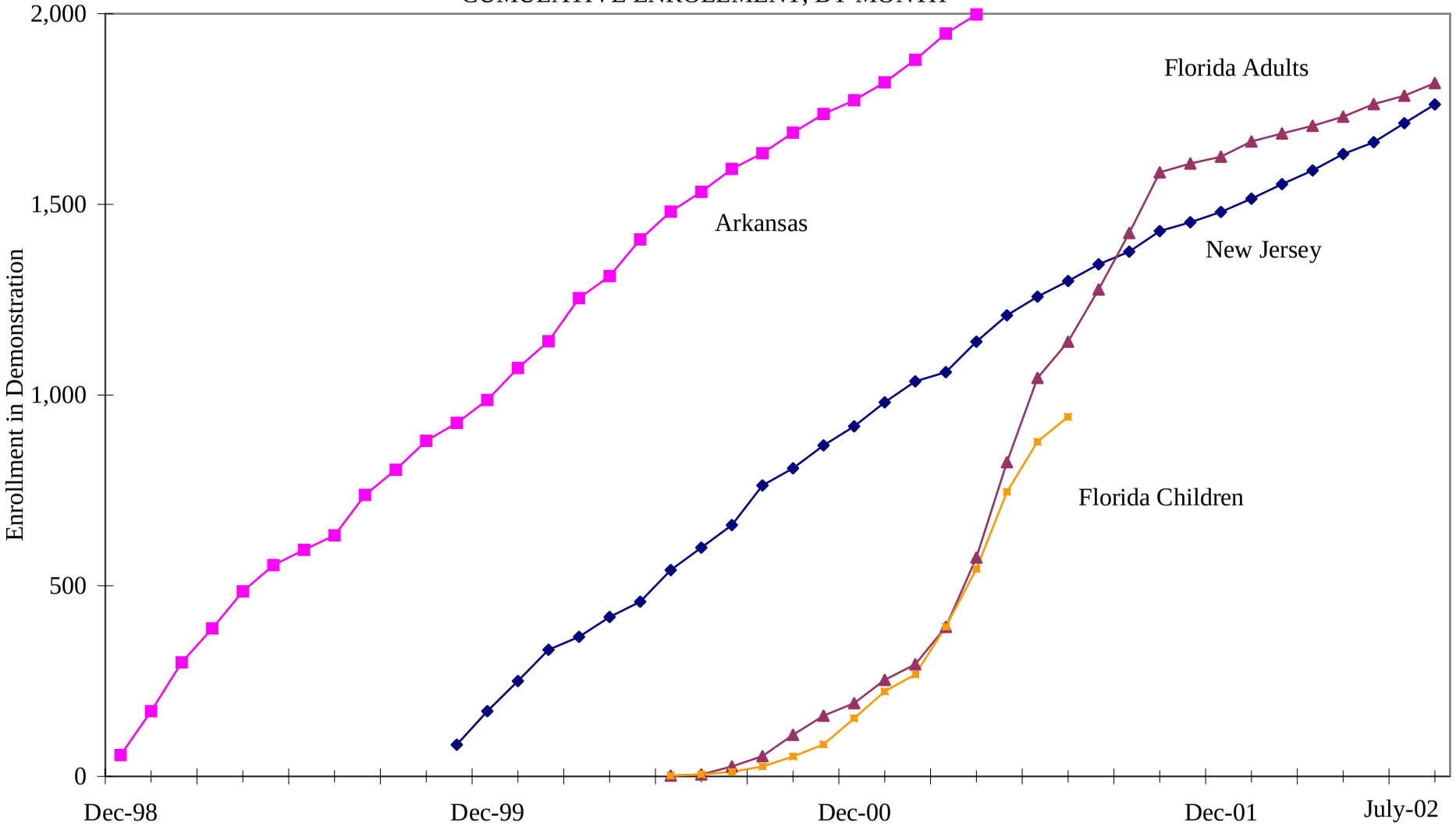
Modest proportions of eligible beneficiaries enrolled during the allowed intake periods.

Relatively modest proportions (5 to 10 percent) of the eligible adult beneficiaries in the three states enrolled in the demonstration, but 16 percent of eligible children in Florida enrolled (see Table III.1, row 5), even though the intake period was substantially shorter for this group than for any of the adult groups. For example, 8.7 percent of the 16,523 eligible elderly adults in Arkansas enrolled. Given that half the enrollees were assigned to the control group, and that some treatment group members never received their allowances, the proportion of elderly

[1] Most of the results presented in this section were drawn from Foster et al. (2005a), Schore and Phillips (2004), and Foster et al. (2005c and 2005d). See those reports for more detailed results and discussion of methodology.

FIGURE III.1

CUMULATIVE ENROLLMENT, BY MONTH



Source: Mathematica Policy Research, Inc. enrollment files.

Note: Enrollment for Florida's younger adults ended in November 2001.

TABLE III.1

ENROLLMENT IN CASH AND COUNSELING AND TRADITIONAL PROGRAM

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Months Opened to Enrollment	29	29	15	18	26	33	33
(1) Number of demonstration enrollees[a]	556	1,452	1,002	914	904	817	938
(2) Number of treatment and control group members who did not receive *any* PCS or HCBS benefits during 12 months after random assignment	102	183	5	3	9	68	61
(3) Number of all Medicaid beneficiaries who received PCS or HCBS or the allowance during intake period[b]	5,368	16,523	6,237	16,160	11,722	8,880	15,856
(4) Percentage of known eligibles who enrolled in Cash and Counseling = (1)/[(3)+(2)][c]	10.2	8.7	16.1	5.7	7.7	9.1	5.9
(5) Expected percentage of known eligibles who would actually receive cash in ongoing program [c,d]	9.1	7.2	11.4	3.3	3.2	6.3	3.8

Source: Program records from each demonstration state and claims for PCS or HCBS. Claims were observed for 24 months after the first month of intake in each state: from December 1998 through December 2000 for Arkansas, from June 2000 through June 2002 for Florida, and from November 1999 through November 2001 for New Jersey.

[a]The number of people who enrolled in the demonstration during each state's evaluation intake period; includes all those randomly assigned to the treatment and control groups.

[b]For Arkansas and New Jersey and for elderly adults in Florida, this number is the number of people who had claims for Medicaid PCS or HCBS during the first 24 months of the state's intake period. For children in Florida and for nonelderly adults in Florida, it is the number who had claims for Medicaid HCBS during the first 15 months of intake and first 18 months of intake, respectively. Florida met its evaluation-related enrollment targets for those groups during those time periods; thereafter, children and nonelderly adults who enrolled in the demonstration were not part of the evaluation.

[c]Known eligibles are those who actually received the PCS/HCBS "cashed out" by the program from agencies or who received the allowance (row 4), plus those who enrolled in the study (and therefore were eligible for benefits) but never received these benefits for some reason (row 3).

[d]Based on actual experience of the treatment group, doubled to reflect the fact that half the program enrollees were in the control group.

HCBS = home- and community-based services; PCS = personal care services.

consumers actually receiving their personal care benefits through the Cash and Counseling program was substantially smaller than the proportion that enrolled (see later tables in this chapter). Based on the demonstration experience, we would expect 3 to 9 percent of eligible adults (and 11 percent of eligible children) to receive a Cash and Counseling allowance in an ongoing program. However, actual enrollment may well be substantially higher, as more consumers learn about the program and its benefits.

The characteristics of program enrollees differed substantially across the three states (Table III.2). Three-fourths of Arkansas's enrollees were aged 65 or older, compared with roughly half the adult enrollees in Florida and in New Jersey. However, enrollments are affected by the number of eligible consumers—in both Arkansas and New Jersey. The proportion of eligibles who enrolled was somewhat higher among non-elderly consumers than among elderly consumers.[1] Within the nonelderly adult group, enrollees in Florida were younger and more likely to be male than were enrollees in the other states, reflecting the differences between the Florida program's target population of individuals with developmental disabilities and Arkansas's and New Jersey's populations of frail elderly adults and adults with physical disabilities. Half or more of enrollees in all three states in all age groups were white, but the proportion that was Hispanic ranged from 1 percent in Arkansas to 40 percent among the elderly in New Jersey. More than one-third of Arkansas's enrollees lived in rural areas, versus 10 to 20 percent for the different age groups in the two other states. Models estimated to assess whether consumer characteristics available from Medicaid enrollment and service use files were associated with enrollment suggested that, across all three states, consumers who received higher

[1] Enrollment levels are also affected by the length of the intake period. Florida ended enrollment of younger adults in November 2001 because they had nearly reached their target for this age group (1,000), and wanted to concentrate on increasing enrollment of elderly consumers. Enrollment of older adults in Florida was slower and had to be continued until July 2002 to obtain a sufficiently large research sample.

TABLE III.2

SELECTED BASELINE CHARACTERISTICS OF DEMONSTRATION ENROLLEES
(In Percentages)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Age (Years)							
3 to 12	—	—	71.2	—	—	—	—
13 to 17	—	—	28.8	—	—	—	—
18 to 39	27.5	—	—	75.5	—	33.8	—
40 to 64 (40 to 59 in Florida)	72.5	—	—	24.5	—	66.2	—
65 to 79 (60 to 79 in Florida)	—	50.4	—	—	52.9	—	58.5
80+	—	49.6	—	—	47.1	—	41.5
Female	67.6	81.5	37.0	45.4	79.0	66.1	78.7
Self-Identified as:							
White	63.5	59.2	79.7	77.6	69.5	49.9	58.5
Hispanic (regardless of race)	0.9	1.3	18.6	21.2	34.6	29.8	40.4
Graduated High School[a]	44.6	16.5	89.7	81.8	68.6	51.8	30.6
Lived Alone	38.8	29.6	0.0	9.1	28.4	34.3	36.5
Had at Least One Informal Caregiver	89.6	91.5	99.7	94.1	84.9	84.6	84.2
Lived in Area that Was:							
Rural	36.5	39.7	18.2	14.6	10.7	9.5	10.6
Nonrural but with high crime or poor public transportation	35.3	26.7	34.6	39.6	41.3	50.0	38.9
Not Independent in:[b]							
Transferring	62.1	67.4	61.0	51.8	65.2	66.3	66.5
Using toilet	59.2	68.0	84.2	63.6	66.8	69.4	65.7
Bathing	86.3	91.9	91.4	77.8	88.4	85.7	86.9
Needed More Help with Personal Care[c]	69.3	61.9	66.0	53.7	64.2	74.1	73.6
Proxy Respondent Completed at Least Half of Baseline Interview	24.3	58.2	99.9	78.0	60.2	30.1	51.7

TABLE III.2 (*continued*)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Was Receiving Publicly Funded Home Care (at All or for at Least Six Months)[d]	60.6	79.1	59.1	65.2	70.2	43.7	46.4
Demonstration Feeder Program							
Developmental Disabilities Program	—	—	100.0	88.8	2.2	—	—
Department of Elder Affairs	—	—	—	—	97.8	—	—
Office of Adult Services	—	—	—	11.2	0.0	—	—
Sample Size	**556**	**1,452**	**1,002**	**914**	**904**	**817**	**938**

Source: Program records from each demonstration state and baseline telephone interviews by Mathematica Policy Research, Inc.

[a]For Arkansas and New Jersey, the percentages of high school graduates reflect the characteristics of demonstration enrollees. For Florida, the percentage reflects the characteristics of people who would make decisions in the Cash and Counseling program. These people were assumed to be the demonstration enrollees, if the enrollees completed the interview; their representative, if they had proxy respondents; or their parents, if they were minors.

[b]Received hands-on or stand-by help or did not perform activity at all.

[c]Personal care includes bathing, transferring, eating, and using the toilet.

[d]For Arkansas, the percentages reflect whether consumers were receiving publicly funded home care at baseline, regardless of how long they had been receiving it. For Florida and New Jersey, the percentages reflect whether consumers were receiving publicly funded home care for six months or longer at baseline. The measures differ because demonstration enrollees in Florida and New Jersey typically were already receiving traditional supportive services at the time they enrolled in the demonstration; in Arkansas, many were not receiving these services.

dollar amounts of PCS benefits, those who already were receiving PCS/HCBS benefits at the time that program enrollment began, and those who were alive for the entire intake period were significantly more likely to enroll in Cash and Counseling than were their counterparts (data not shown; see Foster et al. 2005).

Among all three states, the consumers who enrolled in the study were quite impaired. Across the seven state-age group categories, one-half to two-thirds of consumers needed help moving to or from a bed or chair, over 80 percent required help with bathing, and as many as three-fourths reported that they needed more help with personal care than they were receiving at baseline. Another indication of impairments is the high proportion of consumers for whom proxy respondents completed the baseline interviews for them. For elderly adults, the rate ranged from 50 to 60 percent across the three states. For younger adults, it was much lower in Arkansas and in New Jersey, but very high among Florida's younger adults, 89 percent of whom had developmental disabilities.

By design, nearly all consumers in Florida and New Jersey were receiving agency services at the time that they enrolled, and many had been receiving them for at least six months by the time of their enrollment. In Arkansas, which allowed people not already receiving services to enroll, 61 percent of nonelderly adults and 79 percent of elderly adults were receiving agency services at enrollment.

A substantial proportion of the treatment group never received an allowance.

Although all treatment group members were offered the opportunity to develop spending plans and to receive a monthly allowance, the proportion that did so during the first year after enrollment ranged from only 42 percent of elderly sample members in Florida to 89 percent of nonelderly adults in Arkansas (Table III.3). Most of those receiving the allowance had received it by Month 6, although consumers in Arkansas received theirs substantially more quickly than

consumers in Florida and New Jersey. In all three states, younger consumers were more likely than older ones to receive allowances, although the difference was sizeable only in Florida.

A variety of factors account for the differences across states and across age groups in the proportion of consumers who received the allowance. Arkansas took an aggressive approach by requiring the counselor to establish a spending plan within 45 days after the consumer had enrolled (unless the consumer disenrolled or had health problems preventing establishment of the plan). By contrast, a sizeable number of early enrollees in New Jersey never received a cash allowance because the state did not have all of the procedures for fiscal agents finalized when enrollment started. In addition, New Jersey's process for getting consumers started on an allowance was fairly complex initially, requiring multiple steps and approvals that led to long delays for many consumers, and that discouraged some from pursuing participation. The low rate of allowance receipt in Florida was due mainly to counselors' uncertainty about how much assistance to offer consumers, and to their belief that consumers who needed a lot of help were unfit for Cash and Counseling. By design, Florida's consumers already were receiving agency services at the time of their enrollment; consequently, unless they were quite unhappy with their care, they may have felt little urgency about having to develop spending plans. Thus, elderly Florida consumers, many of whom had a hard time with the math and paperwork necessary for developing spending plans (even with assistance from counselors), were especially unlikely to ever receive allowances.

TABLE III.3

MONTHS FROM RANDOM ASSIGNMENT TO START OF MONTHLY ALLOWANCE

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Percentage Receiving Allowance at Any Time in Year 1[a]	88.8	81.7	71.1	57.5	41.7	67.2	64.1
Receiving Allowance in Month 12[b]	71.0	60.0	68.3	54.8	31.8	59.4	54.6
Among Recipients, Started Allowance by End of[c]:							
Month 3	86.0	79.3	21.8	13.8	19.0	31.7	31.3
Month 6	87.5	81.5	53.9	42.8	35.5	58.7	55.0
Month 9	89.3	82.1	65.9	54.0	38.9	67.1	62.7
Month 12	89.3	83.2	71.1	57.9	40.8	69.6	64.0
Allowance Amount at Baseline (Dollars)[d]							
Mean	371	310	1,212	1,929	902	1,049	1,066
Minimum	67	29	50	93	142	226	181
Bottom quartile	291	216	418	753	509	604	608
Median	359	301	870	1,465	817	1,091	1,097
Top quartile	441	414	1,663	2,596	1,158	1,364	1,413
Maximum	1,775	2,017	5,600	28,298	5,655	2,436	2,354
Sample Size (Treatment Group Only)							
All	**279**	**725**	**501**	**456**	**453**	**404**	**467**
Recipients Only	**240**	**585**	**356**	**262**	**190**	**270**	**294**

Source: Medicaid claims for first row; program records from each demonstration state for all other entries.

Note: A few sample members were missing one of the components (such as the discount rate) used to calculate the monthly prospective allowance.

[a]See Dale and Brown (2005; Appendix Table C.2).

[b]Dale and Brown (2005).

[c]Schore and Phillips (2004) and Foster et al. (2005a and 2005b).

[d]Calculated over only treatment group members who actually *received* the allowance.

The monthly allowance amounts at enrollment varied widely among and within states. Median monthly allowances for those who actually received them ranged from $301 for elderly consumers in Arkansas to $1,465 for nonelderly consumers in Florida.[10] Furthermore, the mean monthly allowance for children and nonelderly adults in Florida (the two groups of consumers with developmental disabilities) substantially exceeded the median, reflecting the skewness of allowances there (maximum, $28,102). Allowances in Arkansas and New Jersey exhibited far less variation.

Consumers used the allowance mainly to hire workers.

For any state or age group except Florida's children and younger adults with developmental disabilities, about 80 to 90 percent of those receiving an allowance used part or all of it to hire workers (Table III.4). Only a few consumers in any state (2 to 10 percent) said they used their allowance in the first 9 months after enrollment to modify their homes, and only about one percent used it to modify a car (Carlson et al. 2005). These rates are considerably lower than would be expected based on the proportion of prospective enrollees who reported home or car modification as one of the reasons for their interest in Cash and Counseling (see Schore and Phillips 2004; and Foster et al. 2005a and 2005b).[11] The proportion using the allowance to purchase equipment or supplies varied widely across states and age groups, being especially high in Arkansas, and very low for elderly consumers in Florida and New Jersey. Sizeable proportions (30 to 60 percent) of each age group in each state opted to take some of their

[10] These medians differ from those in Table II.1, which are computed over *all* treatment group members and are for younger and older adults combined.

[11] Carlson et al. (2005) also shows no treatment-control differences in the proportion of consumers making such changes, regardless of the source of funds.

TABLE III.4

TREATMENT GROUP'S USES OF MONTHLY ALLOWANCE
(In Percentages)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Used Allowance to[a]:							
Pay worker(s)	88.6	87.7	62.4	63.4	78.9	86.7	85.8
Purchase equipment or supplies[b]	50.0	60.0	28.3	17.1	6.6	13.4	4.5
Modify home or vehicle	2.0	2.3	1.3	0.8	0.0	0.8	1.1
Received Cash for Incidental Purchases[c]	35.5	38.6	40.2	31.9	59.0	55.6	47.2
Among Those Using Allowance to Pay Worker(s), Had a Worker Who Was Their:							
Spouse	0.0	0.0	0.4	0.6	5.0	4.3	0.5
Child	28.9	52.9	0.0	1.9	47.1	24.3	59.4
Parent	13.9	0.2	28.6	36.3	0.0	22.2	0.5
Other relative	26.7	24.5	39.9	36.9	22.7	24.3	21.7
Had Only Unrelated Paid Workers	30.5	24.3	41.6	33.8	37.8	33.0	22.2
Sample Size	**220**	**498**	**311**	**235**	**166**	**239**	**267**

Source: Data on use of the allowance during Month 8 are from each program's fiscal agent or bookkeeper. Data on who the beneficiary hired are from telephone interviews with consumers conducted by Mathematica Policy Research, Inc. nine months after consumers' random assignment.

Note: All data are for use of monthly allowance during Month 8 after random assignment.

[a]Percentages exclude consumers who had disenrolled or died before Month 8 or who were still enrolled but had no record for Month 8 with the fiscal agent/bookkeeper.

[b]Equipment includes equipment to assist with mobility, transferring, bathing, communicating, personal safety, preparing meals, and housekeeping. Supplies include diapers or pads to protect bedding, ostomy supplies, and feeding equipment.

[c]In Arkansas and New Jersey, consumers could receive up to 10 percent of the monthly allowance as cash for incidental purchases. In Florida, consumers could receive up to 20 percent of the monthly allowance as cash.

allowance in cash for incidental expenses. (These amounts were limited by the states to 10 or 20 percent of the allowance.)[12]

Most consumers (58 to 78 percent) hired family members, although which family members were hired depended on the population served. Less than five percent of consumers in Florida and New Jersey hired their spouses (although many did not have spouses); Arkansas did not allow consumers to hire their spouses under Cash and Counseling. Elderly adults generally hired their adult children or daughters-in-law, whereas about one-fourth of younger adults in both Arkansas and New Jersey did so. The proportion of younger adults who hired their parents ranged from 14 percent in Arkansas to 36 percent in Florida, where nearly 90 percent of nonelderly adults had developmental disabilities. The parents of more than 40 percent of the children in the program hired only unrelated individuals, but nearly 30 percent paid themselves or the other parent, and 40 percent hired another relative. Despite this general tendency for hiring relatives, 22 to 42 percent of consumers who hired workers employed only workers who were unrelated to them. Most (over 90 percent) of these unrelated workers were friends or neighbors of the consumers.

Consumers used the counseling and fiscal intermediary services widely and were very satisfied with them.

Consumers used a range of program services, including counseling on how to set up their spending plans (a required service) and how to recruit and train workers (Table III.5). Over 93 percent of allowance recipients used the fiscal intermediary services to perform bookkeeping functions. In all states and all age groups, 85 to 95 percent of users of the various services found the services to be helpful (data not reported; see Foster et al. 2005c; Foster et al. 2005d; Foster et

[12] For a more extensive discussion of consumers' other uses of the monthly allowance, see Meiners et al. (2004).

al. 2004; and Schore and Phillips 2004). Consumers in Arkansas were especially likely to receive help from counselors as a result of Arkansas's requiring counselors to develop a spending plan within 45 days after enrollment. Younger and older consumers reported similar rates of use of counseling services.

Most consumers were pleased with the program, but 20 to 50 percent disenrolled in first year.

The great majority of consumers who established a spending plan and received the allowance were very pleased with the program (Table III.5). Across the seven state-age group categories, 85 to 98 percent of allowance recipients reported that they would recommend the program to others seeking more control over their care, and one-half to two-thirds of each group said that the program had "improved their lives a great deal." While the majority of those who received the allowance reported that the program had greatly improved their lives, a sizeable number of treatment group consumers disenrolled during the 12 months following their enrollment, most of whom never received the allowance (Table III.6). The proportion disenrolling overall ranged from a low of 20 percent for children in Florida to nearly half of the elderly consumers in Florida, with the rate for all other state-age groups clustering around 30 percent. Consumers initiated about half the disenrollments that were not due to death; the remainder was mostly due to loss of a representative or loss of eligibility for PCS.[13] At 12 months after enrollment, 15 percent of children in Florida and 15 to 25 percent of adults in all three states had disenrolled voluntarily (with the exception of older adults in Florida, 38 percent of whom voluntarily disenrolled). The majority of these voluntary disenrollees in all three states (61 percent in Arkansas, 81 percent in New Jersey, 92 percent in Florida) had never started

[13] Voluntary disenrollment rates (not shown) were obtained from Foster et al. (2005a, 2005b) and Schore and Phillips (2004).

TABLE III.5

USES OF AND SATISFACTION WITH PROGRAM SERVICES
(In Percentages)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Consumers Reporting that Program Counselors Had:							
Helped them develop allowance spending plan	87.4	81.7	74.7	65.6	62.1	72.9	70.7
Advised them about recruiting workers (among those who tried to hire)	57.0	49.4	43.4	35.3	42.2	39.4	44.6
Advised them about training workers (among those who hired)	55.7	53.6	28.3	36.6	42.3	32.2	35.4
Among Those Receiving Allowance:							
Consumers Reporting that They Used Fiscal Agency Services	93.6	95.1	98.4	96.2	94.4	95.7	98.1
Consumers Reporting that Program:							
Improved their lives a great deal	62.6	53.1	61.9	54.5	60.5	54.2	60.0
Improved their lives a little	21.5	26.8	22.5	27.0	21.7	26.7	22.9
Improved their lives not at all	15.5	19.9	14.7	18.0	15.8	17.8	17.1
Made their lives worse	0.5	0.2	1.0	0.5	2.0	1.3	0.0
Consumers Reporting that They Would Recommend Program to Others	95.7	97.5	89.0	88.2	85.3	90.9	91.2
Sample Size (Maximum)	**254**	**670**	**479**	**440**	**421**	**367**	**416**

Source: Telephone interviews with treatment group consumers conducted by Mathematica Policy Research, Inc. four and nine months after consumers' random assignment in Arkansas, and six and nine months after consumers' random assignment in Florida and in New Jersey.

TABLE III.6

PARTICIPATION IN CASH AND COUNSELING
(In Percentages)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Snapshot at End of 12 Months							
Enrolled and receiving allowance	71.0	60.0	68.3	54.8	31.8	59.4	54.6
Enrolled but allowance not received[a]	1.1	0.4	11.2	11.0	10.2	5.0	5.8
Disenrolled	21.2	30.8	19.6	33.6	48.3	31.8	32.3
Deceased	6.8	8.8	1.0	0.7	9.7	3.8	7.4
Was Receiving Allowance During[b]:							
Month 12 after random assignment	70.1	57.3	67.7	56.2	31.6	59.6	55.0
Month 18 after random assignment	60.8	47.0	70.9	55.0	27.9	57.8	50.4
Month 24 after random assignment	59.3	41.8	70.3	54.0	24.2	55.1	45.7
Sample Size (Treatment Group Only)							
Full Sample	**279**	**725**	**501**	**456**	**453**	**404**	**467**
Early Cohort	**194**	**464**	**501**	**413**	**297**	**332**	**387**

Source: Program records and Medicaid claims data from each demonstration state.

[a]Some consumers never started receiving an allowance, but never formally disenrolled. Because they were able to receive agency services if they chose, provided they were not currently receiving an allowance, there was no need or incentive for treatment group consumers to disenroll even if they did not intend or were not able to manage an allowance.

[b]Percentages based on the cohort of early treatment group enrollees. Early enrollees were those who enrolled in the demonstration before May 2000 in Arkansas, October 2001 in Florida, and January 2002 in New Jersey. This sample difference explains the slight discrepancies between the two 12-month snapshot measures.

receiving an allowance. They left the program for various reasons, with the most common being that they felt the allowance was too low, they were satisfied with the traditional agency services, or had problems with employer responsibilities.

However, in each subgroup, about one-third to one-half of those who did not hire a worker with their allowance had tried to, but could not, suggesting that difficulty finding a worker also contributed to disenrollment.

As shown earlier in Table III.3, as a result of the reasons given there and these various sources of disenrollment, only about 55 to 60 percent of consumers in most of the state-age groups were receiving an allowance 12 months after enrollment. The exceptions to this general pattern were that about 70 percent of younger adults in Arkansas and children in Florida were receiving an allowance at 12 months after enrollment, while only 32 percent of elderly beneficiaries in Florida were (Table III.6). However, once consumers began receiving an allowance, most continued to get it unless they died or entered a nursing home. The proportion of younger adults in Florida and New Jersey, and children in Florida, receiving an allowance at 12 months stayed fairly constant at 24 and 36 months. The proportion of younger adults receiving an allowance in Arkansas dropped from the high of 70 percent in year one to 61 percent in year 2, as more nonelderly adults there died or lost their caregiver and were not able to replace them, Elderly consumers experienced a somewhat greater year to year decline than younger adults in the percent receiving an allowance, due to their higher rates of death and entering a nursing home.

Program counselors reported very few cases of abuse, neglect, or fraud.

One of the major concerns expressed about consumer-directed programs, especially ones that impose relatively few constraints on how people use their allowances, is that consumers might be exploited or abused by family members or other hired workers. Other concerns have

centered on whether consumers would misuse the allowances, even though only expenditures consistent with their spending plans were allowed.

Counselors, whose job included checking on the consumer regularly for evidence of abuse or neglect, rarely observed, such problems. For example, only 1 of 37 counselors interviewed in New Jersey reported *any* incidents of financial exploitation of consumers, and that counselor reported only a single incident (see Foster et al. 2005d). One other counselor reported one case of self-neglect. All the interviewed counselors in New Jersey agreed that representatives selected by consumers clearly acted in the consumers' best interest in all but a handful of cases. Similar results were observed in Arkansas and Florida (see Schore and Phillips 2004; and Foster et al. 2005a). This evidence suggests that consumers and their families, with assistance and oversight from counselors and fiscal agents, were able to manage their own care responsibly and safely.

IV. EFFECTS ON CONSUMERS' USE OF PERSONAL CARE AND WELL-BEING

Treatment group members in Arkansas and New Jersey were substantially more likely than control group members in those two states to receive paid care. Treatment group members in all three states also were much more satisfied with the care they received. These results held for both elderly and nonelderly consumers, except in Florida, where there were no effects on satisfaction for the elderly group, the only subgroup in which fewer than half the treatment group members received their allowance (continuing to rely instead on agency-supplied services).[14]

[14] Results in this section are drawn from Carlson et al. (2005) and Foster et al. (2004).

The treatment group generally received more paid care than the control group but received comparable total hours of care.

Nine months after enrollment, for six of the seven state-age groups we examined, the treatment group was significantly more likely than the control group to be receiving paid personal assistance during a two-week reference period preceding the interview (Table IV.1). The difference was largest in Arkansas, where many beneficiaries faced limited access to agency services due to worker shortages, but it also was sizeable in New Jersey and in Florida (except in the case of elderly consumers). The difference in New Jersey, while smaller, was perhaps more surprising because sample members there had to be already receiving agency services or to have sought such services and been assessed and approved for them. It is unclear whether the control group members not receiving services could not get them from agencies, or did not seek them. In Florida, children and younger adults had to be already receiving HCBS in order to participate. However, sizeable minorities of these two groups were receiving only supplies or therapies, not personal assistance, through the waiver. Thus, about one-third of these consumers who were not receiving human assistance with personal care [.122/(1 – .642) = .34] hired someone to provide such care under the program. Ninety percent or more of both the treatment and control group members in every state and age group were receiving some *unpaid* assistance at nine months (not shown; see Carlson et al. 2005).

By contrast, the average number of hours of all care (paid plus unpaid) received was consistently *lower* for the treatment group than for the control group, although the differences were small for most groups and statistically significant only among younger adults in Arkansas and older adults in Florida. The treatment group received significantly more hours of paid care, with the exception of nonelderly adults in Arkansas (whose control group mean was distorted by

TABLE IV.1

PAID AND UNPAID CARE RECEIVED, BY AGE GROUP

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Percent Receiving Paid Assistance at 9-Months[a]							
Treatment	94.5	94.2	79.3	76.4	94.0	91.6	93.9
Control	67.8	78.8	65.1	64.2	91.2	78.7	81.9
Difference	26.7**	15.4**	14.2**	12.2**	2.8	12.9**	12.0**
p-Value	(<.001)	(<.001)	(<.001)	(<.001)	(.176)	(<.001)	(<.001)
Sample Size	**453**	**1,087**	**849**	**794**	**672**	**644**	**719**
Total Hours of Care[b]							
Treatment	96.7	124.0	237.2	187.5	139.9	145.2	133.2
Control	119.8	133.3	246.8	188.7	158.4	149.9	142.9
Difference	–23.1*	–9.4	–9.5	–1.2	–18.6*	–4.7	–9.7
p-Value	(.014)	(.185)	(.228)	(.878)	(.042)	(.612)	(.283)
Paid Hours of Care[b]							
Treatment	23.1	22.7	39.5	39.4	28.0	38.8	39.1
Control	23.0	18.2	29.6	28.9	32.9	33.2	31.2
Difference	0.2	4.5**	9.9**	10.5**	–4.9	5.6*	7.9**
p-Value	(.959)	(.001)	(<.001)	(<.001)	(.140)	(.023)	(<.001)
Unpaid Hours[b]							
Treatment	73.6	101.3	197.7	148.1	111.8	106.5	94.2
Control	96.8	115.1	217.1	159.8	125.6	116.7	111.7
Difference	–23.2**	–13.8*	–19.4**	–11.7	–13.7	–10.2	–17.6*
p-Value	(.008)	(.036)	(.009)	(.130)	(.109)	(.242)	(.034)
Sample Size	**428**	**1,111**	**819**	**726**	**619**	**616**	**680**

Source: Nine-month evaluation interview conducted by Mathematica Policy Research, Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

Note: Hours are measured over the two-week period preceding the interview.

[a]Effects were estimated for each state by pooling the two adult age groups and including an age*treatment status interaction term in the model. Means were predicted using logit models. Only consumers residing in the community were included in the analysis of this outcome.

TABLE IV.1 (*continued*)

[b]Means were predicted using ordinary least squares regression models. The analysis includes only those with complete data for every component of total hours (about 90 percent of the sample in each state). The sample was **not** restricted to consumers in the community, because the program may have had effects on nursing home admissions.

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

three large outliers) and elderly adults in Florida. For every state and age group, the control group had a very large number of unpaid hours of care, accounting for 80 to 85 percent of their total hours of care. The treatment group also reported high levels of unpaid hours, but consistently less than the control group for consumers of all ages in all three states. The treatment group's decrease in unpaid hours (compared to the control group) more than offset its increase in paid hours in each state-age group. The lower total hours of care for the treatment group may be due to increased use of equipment that can substitute for human assistance or to greater efficiency of the care provided.

The treatment group was much more likely to have its needs met, and to be very satisfied with its care.

With the exception of elderly consumers in Florida, treatment group members were much less likely than control group members to report unmet needs, more likely to state that their caregivers performed reliably and appropriately, and more satisfied with the help they received. Table IV.2 summarizes the findings from the many measures that we examined. Relative to control group members, treatment group members were much less likely to have remaining unmet needs for help with daily living activities, help around the house, and routine health care, and they reported much higher satisfaction with the way that paid caregivers helped with those services. These differences reflect the treatment groups' higher reported rates of paid caregivers' arriving on time and completing their work, and (in some state-age groups; see Table IV.2) lower rates of being neglected, treated disrespectfully, or having things stolen from them.

Elderly Florida consumers' lack of improvement (relative to the control group) in unmet needs and dissatisfaction with their care appears to be due to the low proportion of treatment group members who received an allowance. As the bottom row of Table IV.2 indicates, among all treatment group recipients of paid care at nine months after enrollment, two-thirds or more of

TABLE IV.2

SUMMARY OF TREATMENT-CONTROL IMPACTS ON SATISFACTION WITH AND QUALITY OF PAID CARE

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Unmet Needs for Help with:							
Daily living[a]	++		++	+		+	++
Household activities[b]	++	+	++	+			++
Transportation[c]	++	+	+			+	++
Routine health care[d]			++	+		++	++
Caregiver Reliability							
Always completed tasks[e]	++	++	++			++	++
Never arrived late	++	++	++			++	
Very satisfied with schedule[f]	++	++	++	++		++	++
Easy to change schedule	++		+	++			++
Paid Caregiver Behavior							
Neglected consumer	++	++	++			++	+
Was rude or disrespectful	++					++	
Took something without asking[f]	++	+				+	
Gave unwanted help[f]							
Consumer very satisfied with relationship[f]	++	++	++	++	+	++	++
Very Satisfied with Assistance:							
Help with daily living tasks[a,f]	++	+	++	++		++	++
Help around house/community[b]	++	++	++	++		++	++
Routine health care[d,f]	++	++	++	++			++
Transportation aid[c]	++	++	++	++		++	++
Overall care arrangements[g]	++	++	++	++		++	++
Percentage of Paid Care Recipients in Treatment Group Who Were Receiving Allowance at Nine Months	81	74	76	68	41	67	65
Sample Size (Maximum)	**439**	**1,048**	**796**	**746**	**625**	**637**	**680**

TABLE IV.2 (*continued*)

Source: Nine-month evaluation interview conducted by Mathematica Policy Research, Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

[a]Daily living activities include eating, dressing, toileting, transferring, and bathing.

[b]Household activities include preparing meals, doing laundry, doing housework, and doing yard work. Help doing things around the house and community does not include help with transportation.

[c]Transportation includes transportation to and from a physician's office, shopping, school, work, and social and recreational activities.

[d]Routine health care includes help with medications, checking blood pressure, and doing exercises.

[e]This measure was derived from a survey question with a five-point scale. The binary variable shown here represents the most favorable rating (always).

[f]Effects were estimated by pooling the two adult age groups and including an age*treatment status interaction term in the model.

[g]Includes arrangements for unpaid and paid help with personal care, activities around the house and community, routine health care, community services, transportation, and for use of care-related equipment.

+Signifies statistically significant treatment-control difference ($p < .05$) that favors the treatment group and is modest (less than 10 percentage points and less than half the size of the control group proportion or its complement).

++Signifies statistically significant treatment-control difference ($p < .05$) that favors the treatment group and is large (at least 10 percentage points or at least half the size of the control group proportion [pc] or its complement [1–pc]).

those in the other state and age groups were purchasing that assistance with their allowances, but only 4 in 10 elderly Florida consumers were doing so.[15] As a result, any favorable program effects on elderly consumers in Florida who were receiving the allowance were not large enough to produce a statistically significant treatment-control group difference in the full sample of randomized consumers.

Impacts on unmet needs and satisfaction with care are signified by the double + signs in Table IV.2 indicating treatment-control differences that are large (for example, greater than 10 percentage points), favor the treatment group, and are significantly different from zero. Table IV.3 provides some illustrative estimates for representative outcomes in each of the four categories of indicators of consumers' satisfaction with services received. Despite the services and sizeable amounts of unpaid care received, one-third to one-half or more of treatment and control group members reported unmet needs for help with personal care, help around the house, help with routine health care, and help with transportation. For most measures, Cash and Counseling enabled the treatment group to reduce those unmet needs by 10 to 40 percent below the incidence for the control group. The treatment-control differences in the proportion reporting that their caregivers were rude or disrespectful were less dramatic, but still significantly lower for the treatment group among younger adults in Arkansas and New Jersey, and of a sizeable magnitude (about one-fourth of the control group mean) in all three states for elderly consumers. The proportion reporting that they were very satisfied with the different types of care received, such as help around the house or help traveling around the community, and with their care

[15] The low proportion of elderly Florida consumers receiving an allowance was due to counselors' uncertainty over how much assistance they should provide in a consumer-directed program. Because they felt that consumers who could not develop a spending plan largely on their own would not be able to manage their own care effectively, they did not provide consumers with extensive assistance on this required step.

TABLE IV.3

UNMET NEEDS AND SATISFACTION WITH PAID CARE RECEIVED

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Has Unmet Needs for Help with Daily Living Activity[a]							
Treatment	25.8	35.9	32.8	26.7	42.8	46.1	44.1
Control	41.0	36.5	44.6	33.8	46.5	54.5	57.7
Difference	–15.2**	–0.7	–11.8**	–7.1*	–3.7	–8.4*	–13.7**
p-Value	(.001)	(.823)	(<.001)	(.014)	(.336)	(.028)	(<.001)
Paid Caregiver Was Rude or Disrespectful							
Treatment	10.5	11.8	10.8	16.5	15.6	18.7	15.4
Control	29.5	16.4	15.1	18.0	19.7	30.1	20.0
Difference	–18.9**	–4.7	–4.3	–1.4	–4.1	–11.4**	–4.6
p-Value	(<.001)	(.051)	(.097)	(.671)	(.228)	(.002)	(.130)
Very Satisfied with Way Caregiver Helped Around House/Community[b]							
Treatment	90.4	87.3	85.3	85.4	70.4	84.4	78.9
Control	64.0	68.3	73.1	70.9	66.1	66.0	58.8
Difference	26.4**	19.0**	12.3**	14.5**	4.3	18.4**	20.1**
p-Value	(<.001)	(<.001)	(.001)	(.001)	(.351)	(<.001)	(<.001)
Very Satisfied with Overall Care Arrangements[c]							
Treatment	71.0	68.3	56.4	68.2	50.0	51.9	56.5
Control	41.9	54.0	26.8	48.0	46.9	35.0	36.6
Difference	29.2**	14.3**	29.7**	20.2**	3.1	16.9**	19.9**
p-Value	(<.001)	(<.001)	(<.001)	(<.001)	(.463)	(<.001)	(<.001)

TABLE IV.3 (*continued*)

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Very Satisfied with Way Spending Life							
Treatment	43.4	55.5	51.9	63.5	35.9	37.5	47.1
Control	22.9	37.0	28.7	50.2	27.9	21.0	25.3
Difference	20.5**	18.5**	23.2**	13.3**	8.0*	16.5**	21.9**
p-Value	(<.001)	(<.001)	(<.001)	(.001)	(.049)	(<.001)	(<.001)
Sample Size	**439**	**1,048**	**796**	**746**	**625**	**637**	**680**

Source: Nine-month evaluation interview conducted by Mathematica Policy Research, Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

Note: Means were predicted using logit models. Sample sizes for some variables in this table were smaller because of differences in item nonresponse and skip patterns.

[a]Daily living activities include eating, dressing, toileting, transferring, and bathing.

[b]Help doing things around the house/community does not include help with transportation.

[c]Includes arrangements for unpaid and paid help with personal care, activities around the house and community, routine health care, community services, transportation, and for use of care-related equipment.

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

overall was much higher for the treatment group in every state and age group with the exception of older adults in Florida.

Many of the treatment-control differences in Table IV.2 were statistically significant for all three age groups, but differences generally were larger for nonelderly adults and children than for older adults. As Table IV.3 illustrates, the treatment-control difference in the proportion of nonelderly adults in Arkansas and in Florida that was very satisfied with their care overall exceeded 20 percentage points, but this difference was half that size or less among elderly adults in those states. (The estimated differences for the two age groups in New Jersey were comparable to each other.) Differences in the proportion who were *dis*satisfied with their care also favored treatment group members; thus, the explanation for the differences is not simply that treatment group members received better care, but that, compared with control group members, treatment group members were far less likely to consider the quality of their care to be unsatisfactory.

The treatment group was no more likely to suffer care-related health problems.

None of the 11 measures of health problems or adverse events examined showed worse outcomes for the treatment group than the control group, for any state or age group.[16] Furthermore, for nearly one-third of the 77 comparisons, the treatment group was significantly *less* likely to experience health problems. The significant differences were scattered across measures, age groups, and states, revealing no consistent pattern. For example, among the four representative measures presented in Table IV.4, we find the treatment group to be significantly

[16] Measures examined, in addition to the four shown in Table IV.4, included whether saw a physician due to a fall; whether saw a doctor because of a cut, burn, or scald; whether injured while receiving paid help; whether shortness of breath developed or worsened; whether had a respiratory infection; whether current health was poor; and whether hospitalized or in a nursing home during the past two months (see Carlson et al. 2005 and Foster et al. 2003 for all results).

TABLE IV.4

CARE-RELATED HEALTH PROBLEMS AND EVENTS

	Arkansas		Florida			New Jersey	
	18 to 64	65+	3 to 17	18 to 59	60+	18 to 64	65+
Had a Fall							
Treatment	28.4	19.0	27.3	14.5	17.5	18.7	13.2
Control	28.7	18.6	36.2	17.5	19.7	28.0	20.4
Difference	–0.4	0.4	–8.9**	–3.0	–2.2	–9.3**	–7.2**
p-Value	(.931)	(.869)	(.004)	(.235)	(.468)	(.004)	(.009)
Contractures Developed/Worsened							
Treatment	26.0	15.9	9.4	9.0	20.0	24.5	17.5
Control	25.2	19.7	13.4	14.0	21.9	28.1	27.1
Difference	0.8	–3.9	–4.0*	–5.0*	–2.0	–3.7	–9.6**
p-Value	(.826)	(.089)	(.049)	(.021)	(.534)	(.269)	(.002)
Bedsores Developed/Worsened[a,b]							
Treatment	5.9	7.5	3.0	4.1	7.9	9.0	7.2
Control	12.6	6.8	6.0	5.9	9.3	13.0	7.1
Difference	–6.7*	0.7	–3.0*	–1.8	–1.4	–4.1	0.1
p-Value	(.012)	(.640)	(.033)	(.252)	(.511)	(.094)	(.970)
Had a Urinary Tract Infection[b]							
Treatment	19.4	18.2	2.5	7.7	19.5	16.6	15.7
Control	21.6	21.0	6.0	11.7	21.5	19.4	15.8
Difference	–2.2	–2.8	–3.5*	–4.0*	–2.0	–2.8	–0.1
p-Value	(.560)	(.230)	(.011)	(.043)	(.516)	(.329)	(.966)
Sample Size	**462**	**1,164**	**857**	**808**	**696**	**668**	**742**

Source: Nine-month evaluation interview, conducted by Mathematica Policy Research, Inc. between September 1999 and March 2002 for Arkansas, March 2001 and May 2003 for Florida, and August 2000 and June 2003 for New Jersey.

Note: Means were predicted using logit models. Sample sizes for some variables in this table were smaller because of differences in item nonresponse and skip patterns.

[a]Effects were estimated by pooling the two adult age groups and including an age*treatment status interaction term in the model.

[b]For Florida children, impact could not be estimated from the logit model. Results presented are the unadjusted means and treatment-control differences.

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

less likely than the control group to have fallen (in New Jersey, for both age groups), to have contractures develop or worsen (for older beneficiaries in Arkansas and Florida), to have urinary tract infections (nonelderly in Florida), or to have bedsores develop or worsen (younger adults in Arkansas and New Jersey). The significant differences are sizeable, ranging from 20 to 50 percent of the control group means. Thus, concerns that consumer direction would place care recipients at greater risk of injury or illness related to the quality of their care are unwarranted in the Cash and Counseling model as implemented by the three demonstration states; consumer direction may actually have reduced consumers' risk of such problems in some instances.

The treatment group was far more satisfied with life.

On what is perhaps the most important measure of the value of Cash and Counseling, we see that treatment group members were 25 to 90 percent (8 to 23 percentage points) more likely than control group members to report that they were very satisfied with how they were leading their lives, and generally half as likely to report that they were dissatisfied with their lives. The smallest of these overwhelmingly positive and statistically significant effects on consumers' self-reported quality of life was reported by older adults in Florida, the state in which only 40 percent of treatment group members received their Cash and Counseling allowance. Even among this group, however, the treatment group was significantly more likely (by nearly 30 percent of the control group mean) to report that it was "very satisfied." These estimates are buttressed by the findings reported in Table III.5 that one-half to two-thirds of allowance recipients in every age group in every state reported that the program "improved [their] lives a great deal," and that more than 85 percent in any state or age group would recommend the program to others wanting

more control over their personal care services (Schore and Phillips 2004; and Foster et al. 2005a and 2005b). Thus, the message from the consumers' perspective is clear—Cash and Counseling led to a major improvement in their care and overall well-being, in every state and age group.

V. EFFECTS ON USE AND COST OF MEDICAID- AND MEDICARE-COVERED SERVICES

The Cash and Counseling program was not designed to save money, but rather, to give consumers greater control and flexibility over their care without costing Medicaid any more per month of allowance received than the authorized care would have cost under the traditional agency-based model.[17] In addition, states are likely to want to know how introduction of Cash and Counseling is likely to affect their total Medicaid costs for cashed out services, and whether the program leads to higher or lower costs for other Medicaid services. Finally, the sources of cost increases or savings are important, as higher treatment group costs resulting from the failure of the traditional program to serve the control group adequately have different policy implications than higher costs resulting from program design issues.

We found that Medicaid care costs for the costed-out services (personal care in Arkansas and New Jersey, and waiver services in Florida) were significantly and substantially higher for the treatment group than for the control group in each state for each age group (with the exception of elderly consumers in Florida), but that other Medicaid costs typically were at least somewhat lower for the treatment group. The treatment group's personal care/waiver costs remained higher into the second year after enrollment, but the effects on other Medicaid costs

[17] CMS's actual budget neutrality conditions involved the inclusion of some additional "core" services costs in the calculation, such as home health care, durable medical equipment, and targeted case management. Here we examine just the cost of the "cashed out" services—finally, we examine the effects on program costs over the two years after those on which the allowance was based—and on total Medicaid costs. Furthermore, our results are based solely on the consumers' first two years after enrollment, whereas CMS's budget neutrality conditions were for the entire five-year calendar period covered by the waivers.

were less consistent. Furthermore, the *reasons* why the treatment group's personal care/waiver costs were higher differed among the three states. Each of the states has instituted important changes in its ongoing program that are expected to reduce or eliminate the cost disparities between Cash and Counseling and agency-provided care.[18]

Nearly all of the elderly and about half of the nonelderly sample members were also enrolled in Medicare, which is first payor for most of their acute care costs, but covers very few long term care services. The treatment and control groups had very similar Medicare costs, in each state for each group. They also exhibited similar rates of hospitalization and other service use, supporting the earlier findings of no adverse effects on health outcomes.

Medicaid personal care/waiver costs were significantly higher for the treatment group than for the control group, both overall and among recipients.[19]

On average, Medicaid personal care/waiver costs were substantially higher for the treatment group than for the control group, in six of the seven state-age group combinations, and for both the first and second years after enrollment (Table V.1). However, the magnitudes of the cost differences varied widely across the three states. In Arkansas, average personal care/waiver costs per treatment group member for all adults were double the average care costs per control group member in both years, compared with a difference of only about 15 percent in Florida in both years (and limited to nonelderly consumers). In New Jersey, average treatment-control personal care/waiver costs differed by 16 percent in Year 1, but by 29 percent in Year 2. The treatment-control cost differences were somewhat smaller for older adults than for younger

[18] Results in this section are drawn from Dale and Brown (2005) for adults, and from Dale et al. (2004) for children in Florida.

[19] Medicaid costs reported here are net of the unspent allowance amounts that were recouped by Florida and New Jersey. No such adjustments were made for Arkansas; however, the amount recouped there was small ($600,000) and would reduce the treatment group's mean personal care expenditures per year by only about $150 (about three percent; see Dale and Brown [2005] and Dale et al. [2003]).

TABLE V.1

MEDICAID COSTS FOR PERSONAL CARE AND OTHER SERVICES

	Personal Care/HCBS Costs			Other Medicaid Costs			Total Medicaid Costs		
	Arkansas	Florida	New Jersey	Arkansas	Florida	New Jersey	Arkansas	Florida	New Jersey
Treatment-Control Differences as a Percentage of Control Group Mean									
Adults									
Year 1									
Ages 18 to 64	123.7**	20.2**	21.1**	–16.7*	–6.4	–6.7	9.8	13.8**	3.1
Ages 65+	88.2**	4.3	11.7**	–4.2	–5.1	–4.7	17.3**	0.9	4.3
All adults	96.0**	14.9**	15.9**	–8.7*	–5.8	–5.8	14.3**	8.9**	3.8
Year 2									
All adults (early cohort only)[a]	109.5**	14.9**	28.9**	–17.3**	6.0	–1.5	4.7	12.5**	12.1**
Children									
Year 1	—	26.2**	—	—	–14.8**	—	—	3.0	—
Year 2	—	34.3**	—	—	–13.3**	—	—	8.4	—
Control Group Means (Dollars)									
Adults									
Year 1									
Ages 18 to 64	2,430	18,321	9,220	10,432	5,785	16,829	12,862	24,106	26,049
Ages 65+	2,292	10,063	10,650	7,530	5,771	8,757	9,822	15,833	19,407
All adults	2,349	14,193	9,970	8,339	5,780	12,540	10,688	19,973	22,509
Year 2									
All adults (early cohort only)[a]	1,839	15,978	8,792	8,743	5,698	10,861	10,582	21,676	19,653
Children									
Year 1	—	12,647	—	—	16,448	—	—	29,095	—
Year 2	—	14,046	—	—	16,830	—	—	30,877	—

Source: Medicaid claims data. See Dale and Brown (2005).

[a]Year 2 results were calculated for only those early enrollees for whom complete Medicaid claims data for their second year were available at the time the claims data were provided by the state. Early enrollees were those who enrolled in the demonstration before May 2000 in Arkansas, January 2002 in New Jersey, and October 2001 in Florida.

*Treatment-control difference is significantly different from zero at the .05 level.
**Treatment-control difference is significantly different from zero at the .01 level.

adults in each state in Year 1. The absolute amounts of average personal care/waiver expenditures varied widely across the states, ranging during the first year from about $2,300 for all adult control group members in Arkansas, to $10,000 in New Jersey, and to $14,000 in Florida. Personal care/waiver costs were especially high in Florida for both children ($12,600) and for nonelderly adults, 90 percent of whom had developmental disabilities ($18,300).[20]

The treatment group's personal care/waiver costs were higher both because treatment group members were more likely than control group members to receive any paid care (in Arkansas and New Jersey, as shown in Table IV.1) and because average Medicaid payments per month of benefits received were higher for the treatment group (in some cases). For nonelderly adults in all three states and for children in Florida, the treatment group had significantly higher costs per recipient month than the corresponding control group in Year 1. For elderly consumers, by contrast, Medicaid cost per recipient month was significantly higher for the treatment group only in Arkansas. The significant differences ranged from 4 to 22 percent of the control group mean Year 1 (Table V.2). The Year 2 treatment-control differences for all adults and for children were somewhat larger than those observed in Year 1.

For policymakers, the more important factor is perhaps how actual costs compare with the costs that would be expected, had consumers received the services to which they were entitled through the traditional system. To assess this issue, we calculated the ratio of the actual average Medicaid cost for the allowance (plus counseling and fiscal agent costs incurred by the state) for treatment group members who received allowances to their average expected cost, computed from the number of hours or amounts in their care plans at enrollment. (In Arkansas and Florida,

[20] Year 2 results could be estimated only on the earlier enrollees for whom claims data were available at the time the analysis was conducted. Sensitivity tests showed that the Year 1 results for the early cohort were similar to those for the full sample. Thus, differences in results between Year 1 and Year 2 after enrollment are not due to the differences in the samples for the two periods (see Dale and Brown 2005).

TABLE V.2

COST PER RECIPIENT PER MONTH FOR PCS/WAIVER SERVICES

	Year 1				Year 2[a]	
	Nonelderly	Elderly	All Adults	Children	All Adults	Children
Arkansas						
Treatment	513	420	445	—	467	—
Control	422	336	359	—	369	—
Difference	91**	84**	86**	—	98**	—
p-Value	<.001	<.001	<.001	—	<.001	—
Florida						
Treatment	1,884	983	1,460	1,378	1,814	1,660
Control	1,593	967	1,292	1,099	1,630	1,251
Difference	291**	16	168**	279**	184**	409**
p-Value	<.001	.509	<.001	<.001	<.001	<.001
New Jersey						
Treatment	1,153	1,170	1,164	—	1,264	—
Control	1,106	1,172	1,140	—	1,219	—
Difference	47*	-2	25	—	45	—
p-Value	.043	.926	.112	—	.051	—
Sample Sizes						
Arkansas	**454**	**1,269**	**1,723**	—	**879**	—
Florida	**910**	**894**	**1,804**	**997**	**1,275**	**996**
New Jersey	**745**	**855**	**1,600**	—	**1,121**	—

Source: Medicaid claims data. See Dale and Brown (2005) for adults and Dale et al. (2004) for children.

[a]Year 2 results were calculated only for those early enrollees for whom complete Medicaid claims data for their second year were available at the time the claims data were provided by the state. Early enrollees were those who enrolled in the demonstration before May 2000 in Arkansas, January 2002 in New Jersey, and October 2001 in Florida.

PCS = personal care services.

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

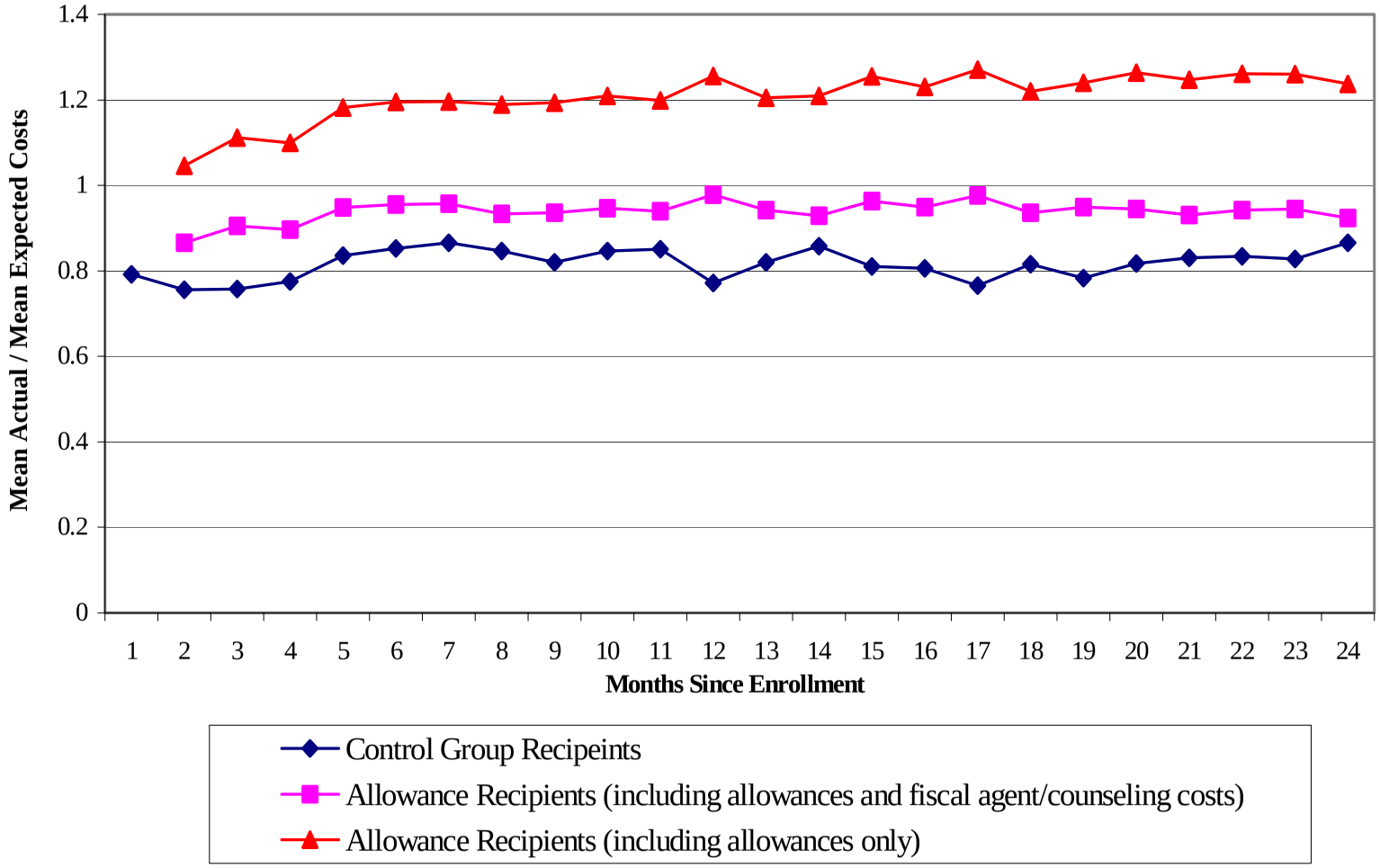
this calculation included multiplying the dollar value of the services authorized in the care plan services by the discount factor applicable to that individual. New Jersey did not discount the allowance.) We performed the same calculations for the control group and plotted the ratios of actual to expected costs for each of the first 24 months after enrollment (Figures V.1a through V.3c).

In Arkansas and New Jersey, the agency system's failure to deliver the authorized amounts of care to control group members was primarily responsible for the costs per recipient month being higher for the treatment group. For both adult age groups in both Arkansas and New Jersey, the plotted ratios show that the costs per month for allowance recipients in the treatment group were about what they were expected to be (ratios of about 1.0), but, with the exception of elderly beneficiaries in New Jersey, *control* group personal care/waiver recipients received *less* than the expected amounts. This finding was unexpected, especially in Arkansas, where the care plans had been adjusted when determining the allowance amounts to account for historic gaps between care plan recommendations and the amount of care actually received. The shortfall was sizeable in Arkansas, with control group recipients receiving only about 80 percent of the (already discounted) expected amounts.[21]

The pattern in Florida was quite different from the ones in both the other states, and it differed across age group as well. As shown in Figure V.3a – V.3c, in each age group, the treatment group members who received allowances received more than had been expected based on their care plans (30 percent more for children, 20 percent more for adults younger than age 60, and 10 percent more for adults aged 60 or older). Among control group members, nonelderly

[21] Note that the Arkansas graphs include separate lines for the allowance alone and for the combined cost of the allowance and counseling/fiscal intermediary costs. This distinction shows that consumers actually received higher allowances than initially planned, as the state was able to hold counseling costs below expectations after some early problems.

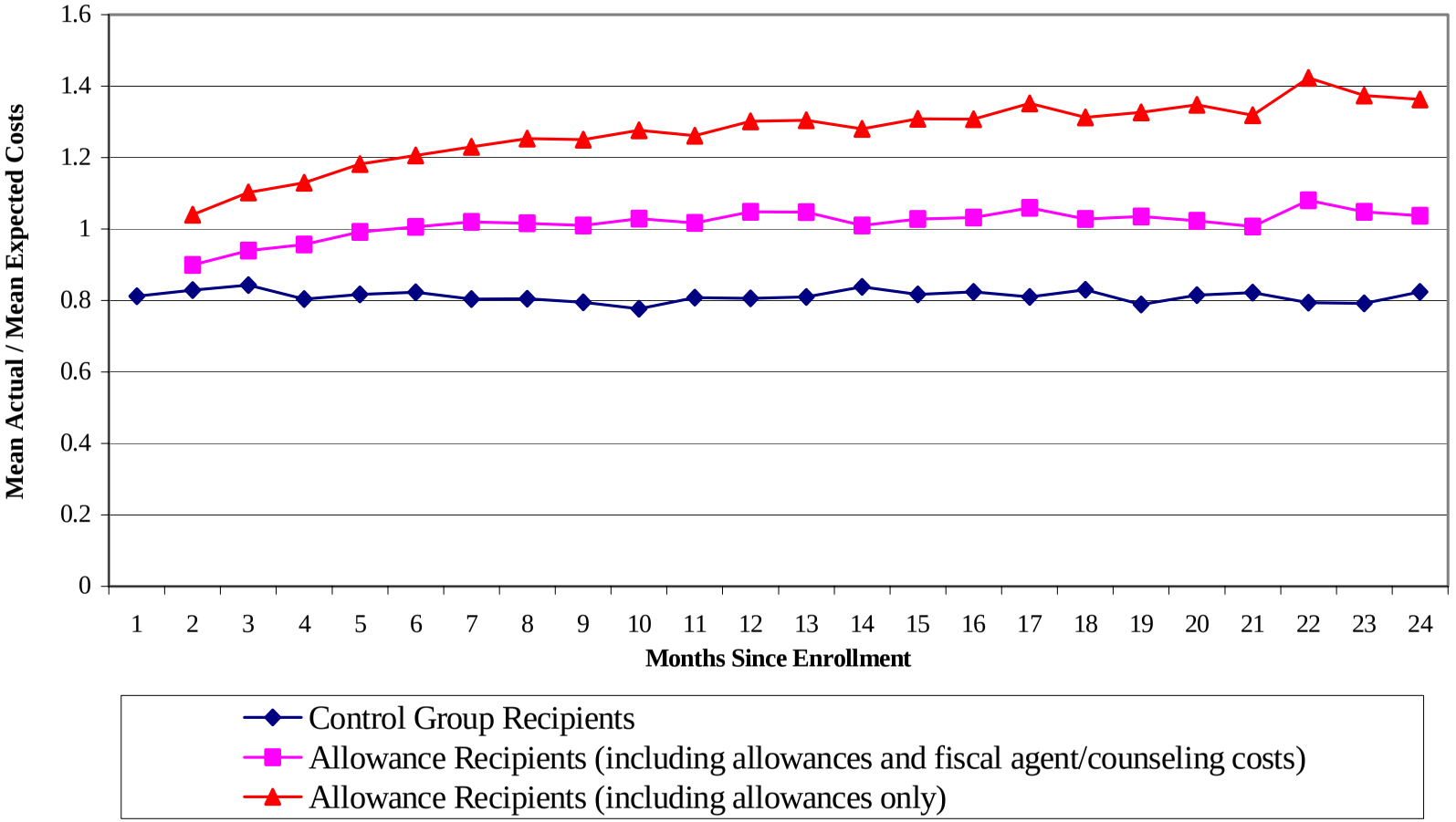
Figure V.1a
Arkansas's Ratios of Mean Actual to Mean Expected Costs for the Nonelderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: The first month is excluded for allowance recipients, since the first allowance often was prorated. The care plan is discounted in calculating expected costs.

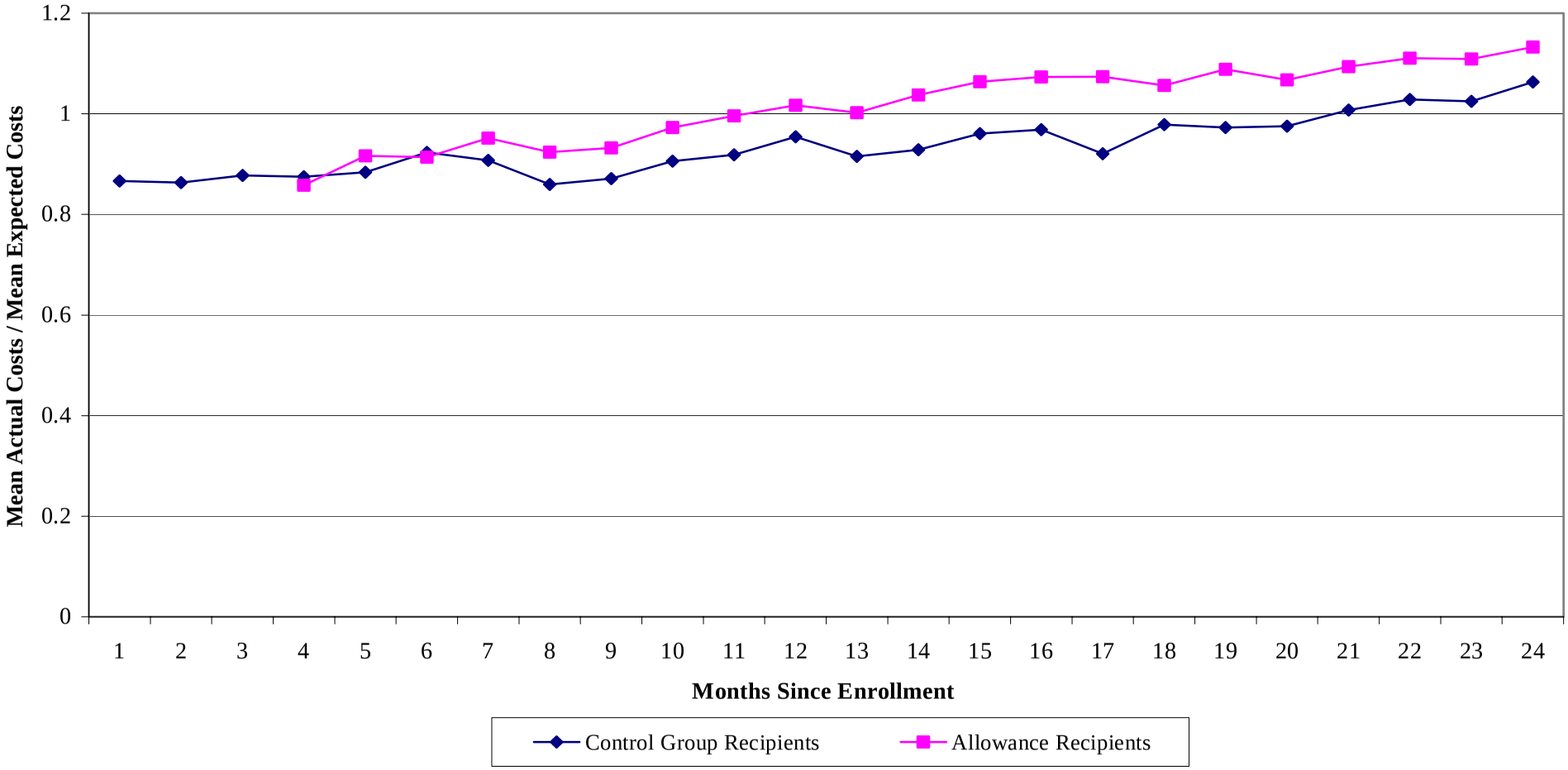
Figure V.1b
Arkansas's Ratios of Mean Actual to Mean Expected Costs for the Elderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: The first month is excluded for allowance recipients, since the first allowance often was prorated. The care plan is discounted in calculating expected costs.

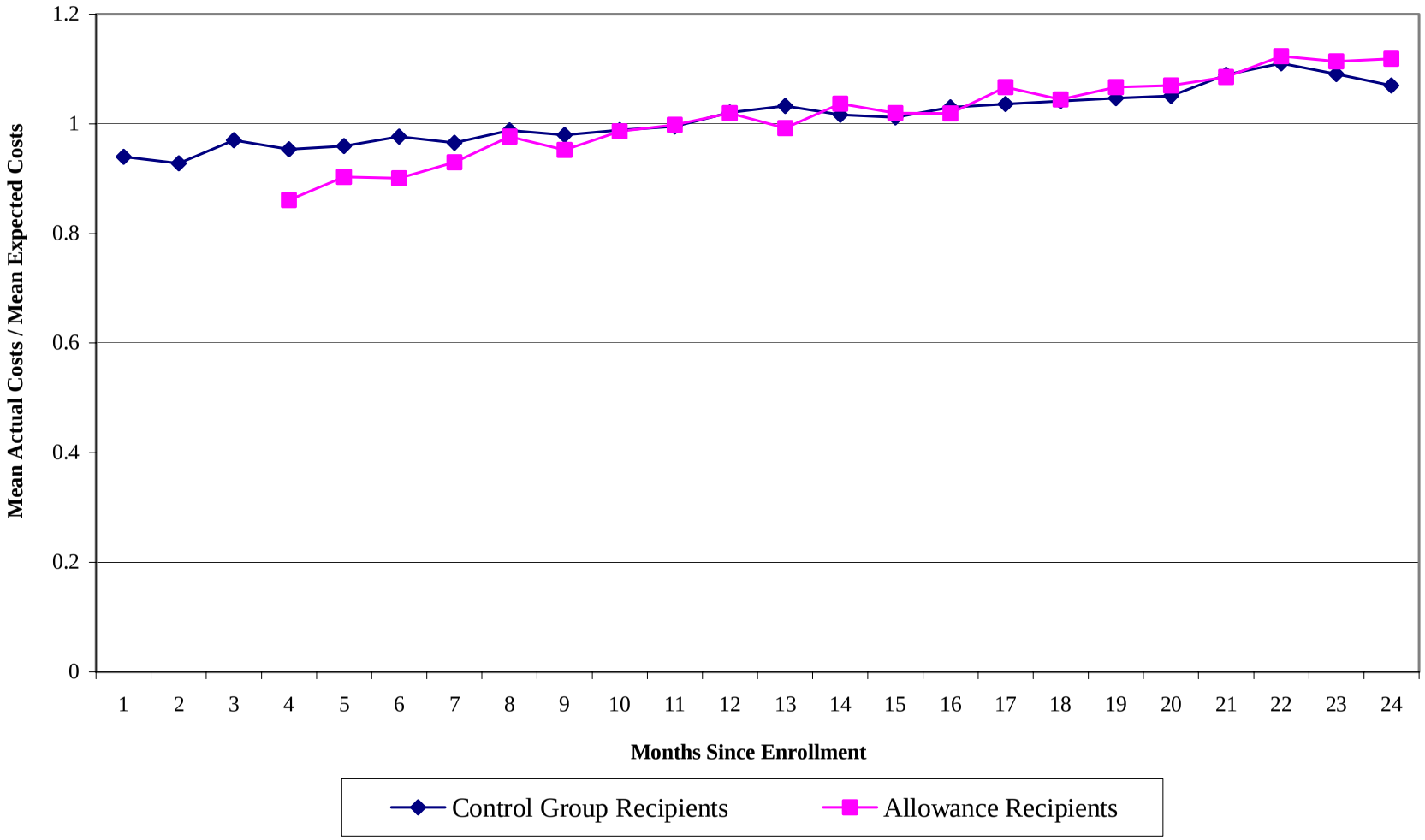
FigureV.2a
New Jersey's Ratios of Mean Actual to Mean Expected Costs for the Nonelderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: Early months are excluded for allowance recipients since few (less than 100) individuals had received full allowances.

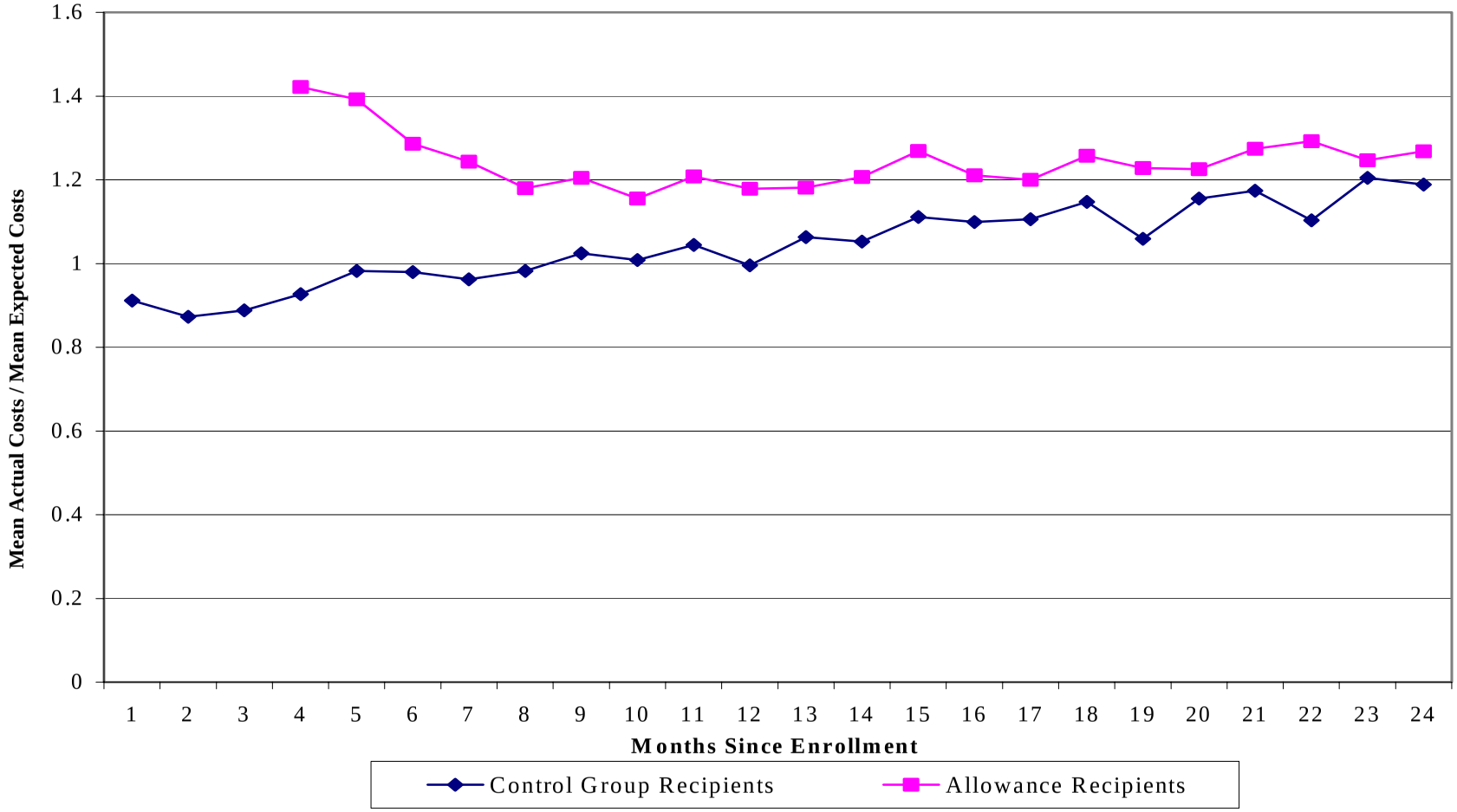
Figure V.2b
New Jersey's Ratios of Mean Actual to Mean Expected Costs for the Elderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: Early months are excluded for allowance recipients since few (less than 100) individuals had received full allowances.

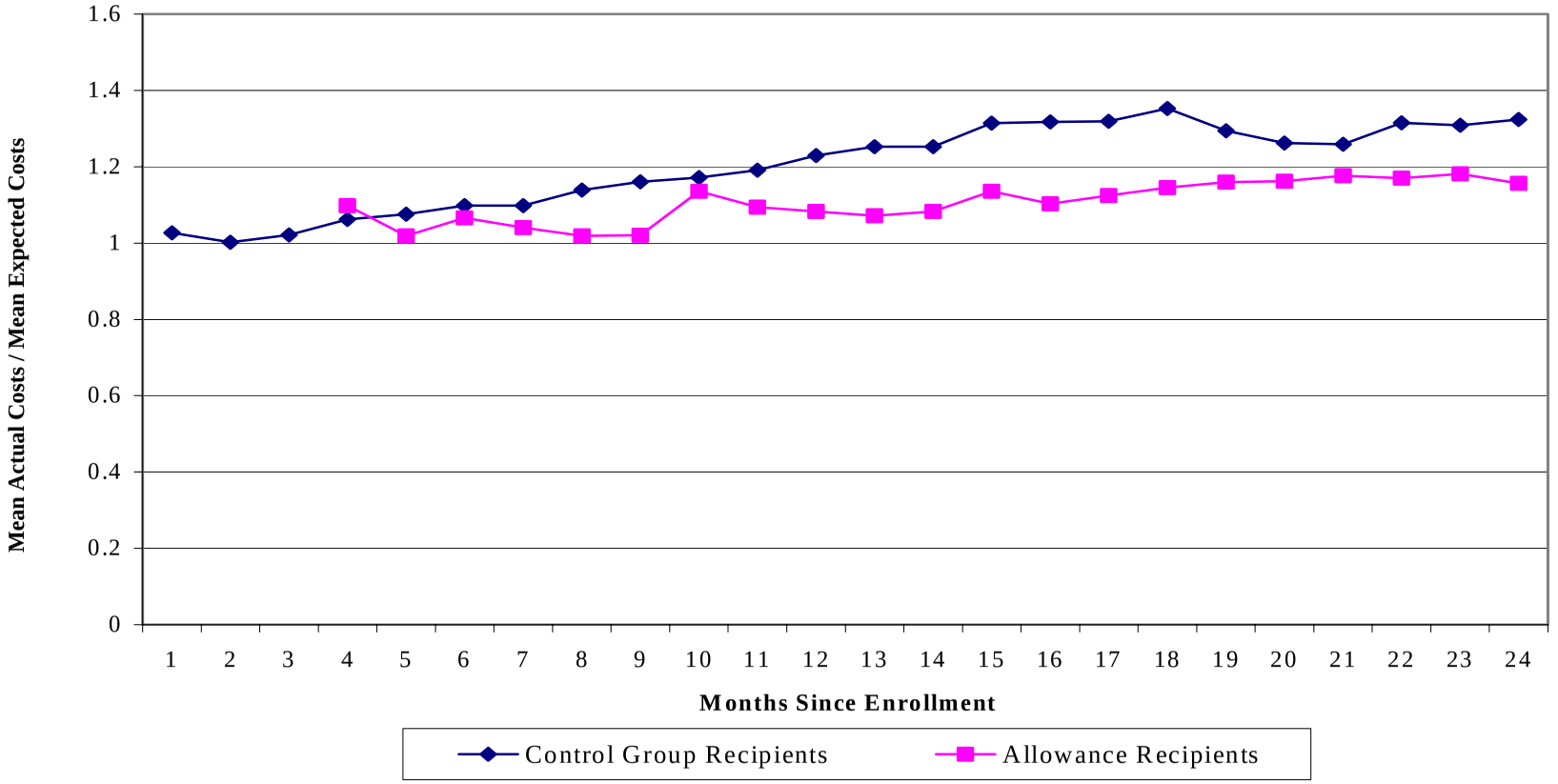
Figure V.3a
Florida's Ratios of Mean Actual to Mean Expected Costs for the Nonelderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: Early months are excluded for allowance recipients since few (less than 100) individuals had received full allowances.

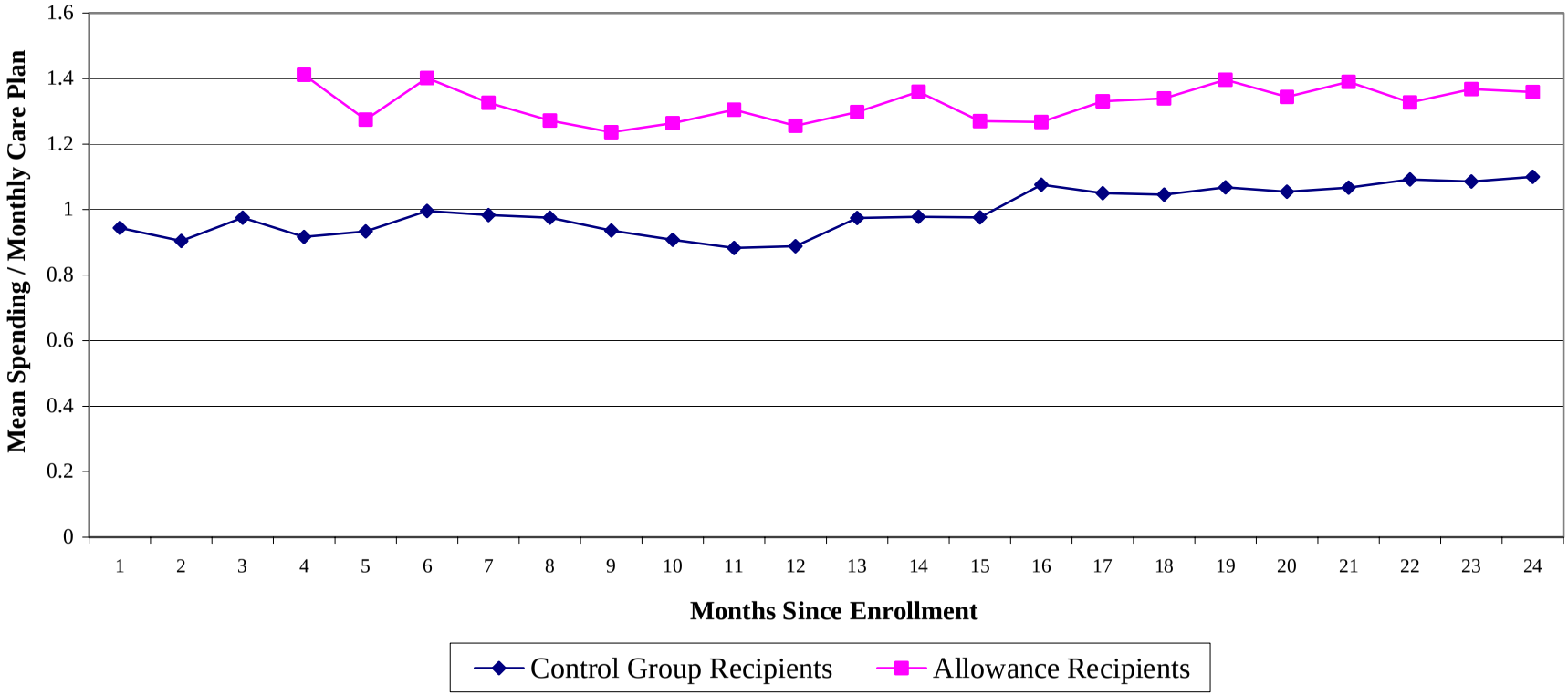
Figure V.3b
Florida's Ratios of Mean Actual to Mean Expected Costs for the Elderly



Source: Medicaid claims data and care plan data. See Dale and Brown (2005).

Notes: Early months are excluded for allowance recipients since few (less than 100) individuals had received full allowances.

Figure V.3.c
Florida's Ratios of Mean Actual to Mean Expected Costs for Children



Source: Medicaid claims data and care plan data. See Dale et al. (2004).

Notes: Data for early months are excluded for allowance recipients, as fewer than 115 (or one-third of allowance recipients) received full allowances. The care plan is discounted in calculating expected costs.

waiver recipients received about what was expected, but older ones received more than expected. Thus, cost per recipient month was actually about the same for treatment group and control group members among Florida's elderly care recipients, but substantially higher for the treatment group among younger care recipients. The treatment-control difference was even more striking for children. Whereas the treatment group's average waiver costs in month 12 were about 26 percent *more* than the average discounted amount in the baseline care plan, the control group had average waiver costs per month of benefits that were about 12 percent *less* than the average discounted care plan amount.[22]

This differential pattern across states and age groups in the ratio of actual to expected costs per month of benefits received for both treatment and control groups appears to be due to a number of factors. Based on conversations with agencies, it appears that the failure of the traditional system to provide the benefit recipients with care hours even close to the discounted care plan amounts in Arkansas was probably due largely to worker shortages faced by agencies. Agencies seeking to maximize either profits or consumer satisfaction would be expected to provide all of the care for which a consumer has been authorized, if they could do so. While no firm evidence is available on the reasons that the ratio of actual to expected costs for nonelderly control group care recipients in New Jersey is less than 1.0 (about .95), it could be due to a combination of factors, including workers occasionally not showing up as scheduled, consumers being hospitalized, or other reasons.

The very high ratios of actual to expected costs for Florida's Cash and Counseling participants who were are under the developmental disabilities waiver (children and nonelderly

[22] These estimates differ somewhat from those presented in Dale et al. (2004), because those estimates include months during which the only service received was case management, and the results presented are the weighted average over months 1 through 12 after enrollment.

adults) appear to be due in part to a coincidental increase in the availability of funds for this population.[23] As a result of a substantial increase in state funding for the HCBS waiver programs serving people with developmental disabilities, all care plans were being systematically reviewed (and frequently increased) during much of the demonstration period. Thus, baseline care plan amounts for both the treatment and control group members were affected. However, when representatives for treatment group members in the developmental disabilities population met with state counselors to develop spending plans (usually two to six months after enrollment), many sought to have their allowance increased beyond the amount in the consumer's care plan. Due to the general climate of increasing the amount of services to this group and the availability of funds, coupled with the program's focus on consumer control, these requests often had a favorable reception from both the counselors and the state, which approved all care plans. Counselors, following the state mandate to increase spending for this population's waiver services, may themselves have suggested sizeable increases. Although control group members also had their care plans reexamined initially, they would not have had the added opportunity that treatment group members had of developing their own spending plan, and of seeking further increases at that point.

Other Medicaid costs were lower for the treatment group in all three states and age groups, but by modest amounts in most cases.

Costs for Medicaid services other than the personal care or waiver services that the allowance was intended to replace were lower for the treatment group than for the control group in every state-age group category during the first year after enrollment (Table V.1). However, the differences were large and statistically significant only for younger adults in Arkansas and

[23] The explanation given in this paragraph is based on information obtained in discussions with the director of Florida's Cash and Counseling Program.

for children in Florida. For those two groups, other Medicaid costs were about 15 and 17 percent lower, respectively, for the treatment group. For the five other state-age groups, the treatment groups' costs were only about four to seven percent below the corresponding control group costs.

The particular types of services for which costs were lower were primarily costs related to long-term care (not shown; see Dale and Brown 2005, Tables 4a to 7c), although this differed somewhat across states and age groups. The main cost reductions in Arkansas were for nursing facility, hospital, home health care, and ElderChoices (the supplementary waiver program covering additional personal care hours for older Medicaid beneficiaries beyond what was offered under the state's personal care benefit). Medicaid costs for several other services (laboratory services, physician visits, and durable medical equipment) also were somewhat lower for the treatment group (for the nonelderly). In New Jersey, the treatment group had significantly lower nursing home expenditures and home health expenditures. However, when these expenditures are combined with hospital, physician, and other costs, the resulting treatment group total for all non-PCS Medicaid expenditures is not significantly lower than the control group amounts. For adults in Florida, the treatment group had slightly lower costs than the control group for nursing home and inpatient care, but these differences were not statistically significant. For children, the major source of the difference in non-waiver Medicaid costs was the treatment group's nearly 30 percent lower cost for private duty nursing ($4,773, versus $6,639 for the control group).

The second postenrollment year's results followed a pattern similar to those of the first year; treatment-control differences in other Medicaid costs were statistically significant only for

children in Florida and for adults in Arkansas.[24] However, the magnitudes of some of the differences changed substantially; in Arkansas in Year 2, other Medicaid costs for the treatment group were 17 percent below those for the control group, twice the difference observed during Year 1. The treatment-control difference for Florida adults, which was statistically insignificant in Year 1, was insignificant in Year 2 as well, but it changed substantially; the treatment group's mean was six percent lower than the control group's in Year 1, whereas in Year 2, it was six percent *higher* than the control group's. For adults in New Jersey and for children in Florida, the treatment-control differences in Year 2 were similar to those observed in Year 1.

Total Medicaid costs were higher for the treatment group for every state and age group, but not significantly so in most cases.

The treatment group's lower cost for long-term care and other services partially offset its higher personal care/waiver costs, resulting in differences in total Medicaid costs that were statistically significant only for elderly consumers in Arkansas (17 percent) and for younger adults in Florida (14 percent) in the first year after enrollment. For four of the five other state-age group categories, treatment group costs exceeded those of the control group by less than five percent (not shown).

The results for most groups for the second postenrollment year show treatment group costs exceeding control group costs by a larger proportion than in year 1. In both Florida and New Jersey, total Medicaid costs for all adults were significantly higher for treatment group members than for control group members, by about 12 percent. For children, the treatment-control difference grew from only three percent of the control group mean in Year 1 to eight percent (p =

[24] In Year 2, the treatment-control differences in other Medicaid costs were statistically significant for both the elderly group and the nonelderly group in Arkansas (not shown; see Dale and Brown 2005, Table A.2a). In Year 1, the treatment-control difference for elderly consumers was not statistically significant.

.082 in Year 2). Only in Arkansas does the trend suggest that the treatment-control difference in total cost was shrinking over time—the significant 14 percent Year 1 difference decreased to an insignificant 4.7 percent in Year 2.

The change in results from Year 1 to Year 2 is due to different reasons in the three states. In Arkansas, the treatment-control gap in total Medicaid costs narrowed because the unfavorable treatment-control difference in personal care decreased by about $500 per consumer, while the favorable difference in other Medicaid costs (mostly for nursing home care) increased by $500. In New Jersey, the trend was exactly the opposite; the treatment group's 16 percent higher personal care costs nearly doubled in Year 2, to 29 percent, while the modest "savings" in other Medicaid services of about 6 percent in Year 1 essentially disappeared in Year 2. The somewhat less favorable Year 2 results for children in Florida are due to the increase in the treatment-control difference in costs for waiver services. These increases in the gap in personal care or waiver costs arise from treatment group consumers receiving their allowances for more months in Year 2.

Medicare costs were similar for treatment and control groups.

Finally, examination of *Medicare* costs and services showed no statistically significant treatment-control differences, for any state, in either year. This result was not surprising. Neither the states nor the National Program Office for the demonstration expected that offering consumers more flexibility in managing their personal care would lead to fewer hospitalizations or to fewer uses of the other acute care services covered under Medicare.

VI. EFFECTS ON PAID AND UNPAID CAREGIVERS

Consumers' well-being depends to a large degree on the individuals who are their primary caregivers, regardless of whether the caregivers are paid for some of the care they provide. The

evaluation therefore examined differences between the experiences of the primary informal (initially unpaid) caregivers of the treatment and control groups ("caregivers"), and the differences between the two groups' primary paid caregivers ("workers"). The primary caregiver was the individual identified by the consumer during the *baseline* interview as the person providing the most unpaid care during the week preceding that interview. The primary worker was the individual identified by the consumer during the nine-month *follow-up* interview as the person providing the most paid care during the two weeks preceding the followup.

Under Cash and Counseling, many of the treatment group's previously unpaid primary caregivers (29 percent for adults in Florida, 42 percent in New Jersey, and 56 percent in Arkansas) began receiving pay from consumers. This change in the consumer-caregiver relationship affects how we interpret findings for both the paid workers and the (initially) unpaid caregivers. The findings are quite consistent across adult age groups for nearly all of the outcomes examined. This consistency enables us to display results for the unpaid caregivers of younger and older adults combined for each state; however, we present results for children separately, as well as for younger and older adults when there are marked differences. The samples of paid workers were too small to yield reliable estimates separately for younger adults and for older adults, so those results too are shown for all adults combined. Separate estimates are presented for workers providing care to children.[25]

[25] Results in this section were drawn from reports on unpaid caregivers for adults (Foster et al. 2005a), unpaid caregivers for children (Foster et al. 2005b), and paid workers for all age groups (Dale et al. 2005).

Treatment group caregivers provided fewer total hours of care than control group caregivers for adults in Arkansas and Florida, but more hours in New Jersey.

As expected, nearly all sample members' primary caregivers were relatives (not shown). Children's caregivers usually were their mothers. For younger adults, caregivers usually were parents. For older adults, most caregivers were daughters.

In Arkansas and Florida, treatment group caregivers for adult consumers provided fewer total hours of care than did control group caregivers; in New Jersey, this pattern was reversed (Table VI.1). Although none of these estimates is significantly different from zero at the .05 level, all have *p*-values between .05 and .11, suggesting that the differences may be effects of the program, rather than chance. In all three states, both treatment and control group caregivers reported providing more than 100 hours of care (or about 7 hours per day) during the two most recent weeks at home before the survey, with live-in caregivers generally reporting twice as many hours as visiting caregivers. Compared with their respective control group caregivers, treatment group members in Arkansas reported nine percent fewer total hours of care, and those in Florida reported about seven percent fewer hours. In New Jersey, the treatment group's average reported care hours exceeded the control group's, by about nine percent.

Age group-specific analysis of hours of care showed that the atypical result for New Jersey was confined entirely to the caregivers (both visiting and live-in) of younger adults, who provided more than 20 hours more care than did corresponding control group caregivers during the reference period. Thus, although Cash and Counseling provided some relief for the caregivers in two states, the caregiving burden (as measured in hours) of caregivers for nonelderly adults in New Jersey increased, on average. In Florida, the total numbers of hours of care provided by the caregivers of children (usually the mothers) was similar for the treatment and control groups, as might be expected.

TABLE VI.1

HOURS OF CARE PROVIDED BY PRIMARY UNPAID CAREGIVERS
(Two-Week Reference Period)

	Adults			Children
Outcome	Arkansas	Florida	New Jersey	Florida
Total Hours of Assistance				
Treatment	106.6	123.7	123.2	150.1
Control	117.0	132.7	113.3	155.0
Difference	–10.4	–9.0	9.9	–4.9
p-Value	.089	.111	.057	.353
Among Live-in Caregivers				
Treatment	140.1	139.5	148.4	154.1
Control	153.0	149.3	140.1	159.9
Difference	–12.9*	–9.8	8.3	–5.8
p-Value	.035	.069	.279	.227
Among Visiting Caregivers				
Treatment	61.9	48.9	84.8	—[a]
Control	68.9	54.0	72.5	—
Difference	–7.0	–5.1	12.3	—
p-Value	.164	.676	.090	—
Number of Respondents	**1,433**	**1,193**	**1,042**	**829**

Source: Survey of primary unpaid caregivers conducted by Mathematica Policy Research, Inc. See Foster et al. (2005a and 2005b).

Note: Hours were measured over the most recent two-week period preceding the interview that the consumer was not in a hospital or nursing home.

[a]Only 30 of the primary unpaid caregivers for Florida children were visiting caregivers; hence, results are not presented for this small group.

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

In all three states, treatment group caregivers were much more satisfied with the care that consumers received, and they worried less about them.

Treatment group informal caregivers were 18 to 20 percentage points more likely than control group caregivers to say that they were "very satisfied" with their care recipients' overall (paid and unpaid) care arrangements (Table VI.2). These differences ranged from 40 to 90 percent of the control group means. Furthermore, they were only half as likely as the control group caregivers to report being dissatisfied. (One-fifth to one-third of control group caregivers were dissatisfied with the care recipient's care.)

Treatment group caregivers also were consistently less likely than control group caregivers to report worrying that (in their absence) care recipients had insufficient care, were not safe, or would have things stolen from them in their absence. The observed differences again were large and statistically significant in each state, ranging from about 20 to 30 percent of the control group mean, for caregivers of adults and caregivers of children. Both ends of the satisfaction spectrum were affected, with treatment group caregivers less likely to report that they "worried quite a lot" about these issues, and much more likely to report that they worried "rarely or not at all."

Treatment group caregivers were less likely to report emotional, physical, or financial strain, and they were much more satisfied with life.

In addition to being more satisfied than control group caregivers about the care that consumers were receiving, treatment group caregivers fared better personally. They were significantly less likely than control group caregivers to say that caregiving limited their privacy or impeded their social lives, and (except in Florida) significantly less likely to say that

TABLE VI.2

PRIMARY CAREGIVERS' SATISFACTION WITH RECIPIENTS' CARE

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
Level of Satisfaction with Care Recipient's Overall Care Arrangements				
Very Satisfied				
Treatment	60.8	47.9	51.6	42.3
Control	42.7	29.8	31.7	22.0
Difference	18.1**	18.1**	19.9**	20.3**
p-Value	<.001	<.001	<.001	<.001
Dissatisfied				
Treatment	9.1	15.7	13.3	14.6
Control	22.8	27.5	32.2	36.9
Difference	–13.7**	–11.8**	–18.8**	–22.4**
p-Value	<.001	<.001	<.001	<.001
When Not with Care Recipient, Worried Quite a Lot that:				
Recipient Did Not Have Enough Help				
Treatment	35.8	47.8	52.2	47.2
Control	53.5	60.5	70.2	64.7
Difference	–17.6**	–12.7**	–18.0**	–17.6**
p-Value	<.001	<.001	<.001	<.001
Recipient's Safety Was at Risk				
Treatment	39.3	43.1	53.5	43.5
Control	53.4	52.3	64.8	57.3
Difference	–14.1**	–9.2**	–11.3**	–13.8**
p-Value	<.001	.001	<.001	<.001
Someone Would Take Recipient's Belongings				
Treatment	14.0	22.2	24.9	25.0
Control	20.3	29.2	30.3	34.7
Difference	–6.3**	–7.0**	–5.5*	–9.7**
p-Value	.001	.005	.041	.002
Number of Respondents	**1,433**	**1,193**	**1,042**	**829**

Source: Survey of primary caregivers conducted by Mathematica Policy Research, Inc. See Foster et al. (2005a and 2005b).

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

caregiving caused severe emotional strain (Table VI.3). Again, these differences generally were large. The somewhat smaller differences in Florida may reflect the fact that almost all of Florida's children and younger adults had developmental disabilities, which could be more emotionally draining for caregivers to address than physical disabilities, especially if communication is more difficult or if behavior problems are more prevalent in such consumers. Another factor contributing to the smaller effects in Florida is the lower proportion of treatment group adults in Florida than in either Arkansas or New Jersey that ever received the allowance.

Cash and Counseling also appeared to cause fewer work-related and financial problems for caregivers, but the rates are strikingly high for both the treatment and the control groups. About half of both treatment and control group caregivers in each state had jobs (other than caregiving), and a remarkable one-third of each group (one-half, for children's caregivers) reported that caregiving caused them to quit their jobs or reduce their hours (not shown; see Foster et al. 2005a). Although the program had no effect on caregivers' hours worked at other (non-caregiving) jobs, in all three states, treatment group caregivers for adults were significantly less likely to report that they could not look for a job or another job because of caregiving responsibilities. They also were significantly less likely to say that caregiving caused them to miss or arrive late for work—a problem experienced by 61 to 83 percent of the control group's caregivers. Furthermore, treatment group caregivers for consumers in every state and every age group were significantly less likely than control group caregivers to report that they experienced a great deal of financial strain as a result of caregiving.

Treatment group caregivers were substantially less likely than control group caregivers to report experiencing a high level of physical strain, and to have suffered physical health problems as a result of caregiving. They also were much less likely to rate their health as only "fair" or

TABLE VI.3

EMOTIONAL, PHYSICAL, AND FINANCIAL STRESS ON PRIMARY CAREGIVERS

	Adults			Children
Outcome	Arkansas	Florida	New Jersey	Florida
Emotional Indicators				
Caregiving Limits Privacy				
Treatment	38.7	52.3	41.1	61.0
Control	52.7	57.1	50.5	65.9
Difference	–14.1 **	–4.8	–9.4 **	–4.9
p-Value	<.001	.084	.001	.125
Limited Free Time/Social Life				
Treatment	52.5	66.9	54.8	80.9
Control	63.8	73.3	60.1	81.6
Difference	–11.3 **	–6.5 **	–5.3	–0.7
p-Value	<.001	.008	.061	.778
Experienced Great Deal of Emotional Strain Due to Caregiving				
Treatment	26.8	35.7	42.3	39.4
Control	34.3	38.6	49.4	41.6
Difference	–7.5 **	–2.9	–7.1 *	–2.2
p-Value	.002	.286	.017	.495
Financial Indicators				
Wanted to Look for a Job but Did Not Due to Caregiving				
Treatment	23.5	35.1	33.9	52.7
Control	38.6	41.8	44.1	57.0
Difference	–15.1 **	–6.7 *	–10.3 **	–4.3
p-Value	<.001	.011	<.001	.192
Missed Work or Arrived Late Due to Caregiving				
Treatment	48.6	60.9	53.6	84.0
Control	60.6	67.1	65.8	82.6
Difference	–12.0 **	–6.2	–12.2 **	1.4
p-Value	.001	.095	.002	.657
Experienced Great Deal of Financial Strain Due to Caregiving				
Treatment	22.4	29.9	30.0	43.7
Control	35.7	38.9	38.6	55.6
Difference	–13.3 **	–9.0 **	–8.6 **	–11.9 **
p-Value	<.001	.001	.001	<.001

TABLE VI.3 (*continued*)

Outcome	Adults			Children
	Arkansas	Florida	New Jersey	Florida
Physical Well-Being Indicators				
Experienced Great Deal of Physical Strain Due to Caregiving				
Treatment	23.0	28.4	31.7	34.5
Control	32.0	38.8	41.8	42.1
Difference	–9.0**	–10.4**	–10.1**	–7.6*
p-Value	<.001	<.001	<.001	.020
Physical Health Has Suffered Due to Caregiving				
Treatment	23.6	32.7	30.7	41.8
Control	34.3	44.9	40.3	55.4
Difference	–10.7**	–12.2**	–9.6**	–13.6**
p-Value	<.001	<.001	.001	<.001
Current Health Was Fair/Poor Relative to Peers				
Treatment	35.5	31.8	30.3	27.4
Control	46.7	39.6	42.3	36.8
Difference	–11.2**	–7.8**	–12.0**	–9.4**
p-Value	<.001	.004	<.001	.003
Overall Satisfaction with Life				
Very Satisfied				
Treatment	51.3	47.0	51.6	36.9
Control	39.9	35.2	37.5	23.8
Difference	11.4**	11.8**	14.1**	13.2**
p-Value	<.001	<.001	<.001	<.001
Dissatisfied				
Treatment	13.1	16.7	15.2	16.7
Control	23.2	22.8	27.3	31.1
Difference	–10.1**	–6.1**	–12.2**	–14.4**
p-Value	<.001	.008	<.001	<.001
Number of Respondents	**1,433**	**1,193**	**1,042**	**829**

Source: Survey of primary caregivers conducted by Mathematica Policy Research, Inc. See Foster et al. (2005a and 2005b).

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

"poor." All of these differences in physical well-being measures were large (20 to 30 percent of the control group mean; not shown), and highly consistent across states and age groups.

These various differences favoring the Cash and Counseling group are reflected in the significantly greater proportion of treatment group caregivers reporting that they were "very satisfied" with their lives, and the significantly lower proportions reporting that they were dissatisfied. Whereas roughly one-fourth of all control group caregivers in each state were very or somewhat dissatisfied with their lives, the corresponding proportions for the treatment group caregivers ranged from 13 to 17 percent (not shown).

Treatment group caregivers fared far better than control group caregivers across most of the physical, financial, and emotional stress outcomes examined for beneficiaries of all age groups and in all states, with one exception—treatment group caregivers for nonelderly adults in New Jersey (not shown; see Foster et al. 2005e). This subgroup was the only one in which the treatment group caregivers provided more total hours of care than did control group caregivers, and the only one in which there were no significant and large favorable effects on caregivers' levels of physical, emotional, or financial strain. Thus, it appears that, if consumers' participation in Cash and Counseling leads to an increase in the total hours of care provided by the person who previously had provided the most unpaid care, the added burden of additional hours (whether paid or unpaid) may offset some of the advantages that generally accrue to the primary unpaid caregivers of care recipients who manage their own care through Cash and Counseling.

Caregivers who became paid workers had less physical, emotional, and financial strain than those who were not paid, but both groups had better outcomes than control group caregivers.

Across the many measures of caregiver well-being that we examined, treatment group caregivers who were hired by consumers had especially favorable outcomes (see Foster et al.

2005a). The typical finding was that even those who did not become paid had significantly better outcomes than the control group's caregivers, but the differences were substantially smaller than those for the treatment group caregivers who did become paid. Whether a caregiver became a paid worker involved decisions by both the consumer and the caregiver. Because of the selection bias inherent in these decisions, we are unable to determine whether the differences between caregivers who became paid and those who did not are due to the fact that caregivers were paid, or to other differences between those who became paid workers and those who did not. For example, those who became paid workers may have been in better health or may have been closer to the consumers prior to the consumers' entry into the program. In addition, some of the caregivers who did not become paid workers were providing care to treatment group consumers who never received allowances, whereas all caregivers who were hired by consumers were caring for consumers who had gotten allowances. Given that Cash and Counseling cannot affect outcomes for caregivers of treatment group consumers who do not receive an allowance, the greater satisfaction observed for caregivers who became paid workers than for those who did not overstates the effects of becoming paid. Among the group of caregivers who were not hired, those who cared for consumers who had a hired worker had outcomes generally similar to those of caregivers who were hired (not shown).

Over two-thirds of workers hired directly by treatment group consumers were previously unpaid caregivers, and these workers continued to provide many hours of unpaid care.

The great majority of the primary *directly hired workers* had provided unpaid care to the consumers before the consumers had enrolled in Cash and Counseling, with one-fourth to one-half having been the primary unpaid caregiver prior to enrollment, and about 40 percent living with the consumer (Table VI.4). About 30 to 40 percent of directly hired workers for adults in each state had children, and 40 percent had jobs other than caregiving, suggesting that many

TABLE VI.4

CHARACTERISTICS OF PRIMARY PAID WORKERS
(In Percentages)

	Arkansas Adults		Florida Adults		New Jersey Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Age (Years)				**				
18 to 39	37.1	34.2	25.2	33.3	35.9	34.7	44.1	40.9
40 to 64	54.5	57.7	62.4	62.0	58.9	61.7	47.8	55.5
65 to 79	8.2	7.5	11.7	4.3	5.0	2.3	7.2	3.1
≥80	0.3	0.7	0.7	0.4	0.3	1.3	0.9	0.6
Same Race as Consumer	90.7	79.6**	83.6	60.2**	84.4	54.5**	86.7	72.1**
Family and Work Situation								
Married	51.7	51.3	50.2	52.6	51.4	49.3	50.9	51.2
Has children	35.6	47.0**	29.9	41.6**	40.4	47.5	54.5	42.7**
Currently has job other than caregiving	39.7	20.1**	40.3	21.2**	42.1	22.6**	50.7	39.5**
Relationship to Consumer								
Related	78.3	n.a.	58.4	n.a.	70.9	n.a.	53.6	n.a.
Not related; knew consumer before demonstration	16.4	n.a.	25.8	n.a.	19.1	n.a.	25.7	n.a.
Did not know consumer before demonstration	5.4	n.a.	15.8	n.a.	10.0	n.a.	20.7	n.a.

TABLE VI.4 (*continued*)

	Arkansas Adults		Florida Adults		New Jersey Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Living/Caregiving Arrangements								
Lives with consumer	39.4	n.a.	46.3	n.a.	40.1	n.a.	39.2	n.a.
Is primary informal caregiver	44.5	n.a.	35.2	n.a.	46.1	n.a.	26.6	n.a.
Provided consumer with informal care before demonstration	84.4	n.a.	69.7	n.a.	79.6	n.a.	66.7	n.a.
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**	**222**	**164**

Source: Survey of primary paid workers conducted by Mathematica Policy Research, Inc. between September 2000 and May 2003. See Dale et al. (2005).

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

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

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

directly hired workers are vulnerable to stress caused major competing demands on their time. Among directly hired workers for Florida children, both these proportions were even higher (about 50 percent).

Hired workers generally were in the 40- to 64-year age range, like agency workers, but they were much more likely to be of the same race as their care recipients. Most of the workers were related to their care recipients; relatively few (5 to 20 percent) did not know the care recipients prior to the demonstration.

Directly hired workers received roughly similar wages as did agency workers, but they were much more satisfied with their pay.

In Florida and New Jersey, adult treatment group consumers paid their directly hired workers 10 to 15 percent (about $1.00) more per hour on average than agency workers serving the control group were paid, whereas consumers in Arkansas paid about four percent less per hour than agency wages (Table VI.5). Almost no directly hired workers received fringe benefits, but few agency workers did either. (Most directly hired workers were part-time workers and so would not have been eligible for benefits.) One-third of directly hired workers were occasionally paid late, but few were ever paid less than they were owed.

In all three states, directly hired workers were twice as likely as agency workers to report that they were very satisfied with their compensation (Table VI.6) despite the similarity in wages. On other dimensions of their jobs, the two groups of paid workers reported similar, high rates of satisfaction. Only 50 to 70 percent of directly hired workers said that they received formal training on how to perform their jobs, compared with 95 percent or more of agency workers (not shown); however, the groups were equally likely to feel prepared to handle their responsibilities.

TABLE VI.5

PRIMARY PAID WORKERS' HOURS OF CARE PROVIDED AND COMPENSATION RECEIVED

	Arkansas Adults		Florida Adults		New Jersey Adults		Florida Children	
	Directly Hired Workers	Agency Worker[a]	Directly Hired Workers	Agency Workers[a]	Directly Hired Workers	Agency Workers[a]	Directly Hired Workers	Agency Workers[a]
Hours of Care Provided per Week (Percent)								
Average paid hours	12.5	11.7	19.9	16.2**	20.3	18.9	18.6	22.8*
Average unpaid hours	25.7	n.a.	26.5	n.a.	26.5	n.a.	21.2	n.a.
Total hours	38.2	n.a.	46.4	n.a.	46.8	n.a.	39.7	n.a.
Compensation								
Hourly wage (dollars)	6.07	6.30**	10.26	9.03**	9.84	8.53**	11.81	11.33
Received fringe benefits (percent)	1.6	20.6**	3.5	16.5**	4.6	24.2**	1.0	8.6**
Paid for travel time[b] (percent)	5.8	57.8**	7.3	21.2**	6.9	15.1**	7.5	7.1
Ever paid late (percent)	35.1	n.a.	29.2	n.a.	30.8	n.a.	29.8	n.a.
Ever paid less than owed (percent)	6.7	n.a.	5.1	n.a.	6.8	n.a.	2.8	n.a.
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**	**222**	**164**

Source: Survey of primary paidworkers Mathematica Policy Research, Inc. between September 2000 and May 2003.

[a]Responses for agency workers pertain only to the care the workers provided to the consumers who identified them during the nine-month follow-up survey as their primary worker.

[b]Among those living apart from consumer.

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

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

TABLE VI.6

PAID WORKERS' STRESS AND SATISFACTION WITH WORKING CONDITIONS
(In Percentages)

	Arkansas Adults		Florida Adults		New Jersey Adults		Florida Children	
	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers	Directly Hired Workers	Agency Workers
Satisfaction with:								
Wages and Fringe Benefits								
Very satisfied	44.6	22.2**	50.7	22.9**	41.4	19.1**	61.6	23.0**
Not satisfied	15.6	37.5**	16.3	38.0**	16.9	41.8**	8.4	41.0**
Working Conditions Overall								
Very satisfied	83.4	81.8	85.3	82.6	79.3	69.9**	88.7	84.7
Not satisfied	1.0	2.1	1.0	2.4	1.3	3.3	1.4	2.5
Physical Well-Being								
Great Deal of Physician Strain	16.9	15.1	29.6	33.9	28.4	42..0**	21.2	32.5*
Suffered Any Injury	3.6	1.4	5.7	4.3	3.7	6.5	8.6	4.9
Emotional Well-Being								
Little or No Emotional Strain	60.2	70.1**	47.5	59.1**	40.2	42.0	44.0	51.2
Consumer's Family and Friends Needed to Be More Respectful	37.1	22.4**	21.4	16.5	29.2	18.9**	21.6	12.4*
Maximum Sample Size	**391**	**281**	**298**	**255**	**382**	**308**	**222**	**164**

Source: Survey of primary paid workers conducted by Mathematica Policy Research, Inc. between September 2000 and May 2003. See Dale et al. (2005).

n.a. = not applicable for agency workers.

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

Directly hired workers and agency workers experienced similar or lower levels of physical strain and job-related injuries.

Between 17 and 30 percent of directly hired workers reported "a great deal" of physical strain, although few (3 to 9 percent) reported being injured while providing care (Table VI.6). Their injury rates are generally similar to rates reported by agency workers, but directly hired workers in New Jersey and in Florida (for children only) were significantly *less* likely than agency workers in those states to report high levels of physical strain. Directly hired workers were generally somewhat more likely than agency workers to report being injured, although the proportions were small, and the differences were not statistically significant at the .05 level. Furthermore, the difference in caregiving-related injuries in Arkansas (which was significant at the .10 level) disappeared when we used a regression model to control for the much larger total number of hours of care provided by the directly hired workers. Thus, we find no evidence that directly hired workers suffered more physical problems than is normal for the tasks they were performing and the hours of care provided, even though directly hired workers were much less likely to have received formal training than were agency workers.

Directly hired workers' higher levels of emotional strain and feelings of being unappreciated were due to their close personal relationships with their care recipients.

Directly hired workers in Arkansas and Florida were significantly *more* likely than agency workers in those states to report emotional strain (Table VI.6). In Arkansas and New Jersey, they also were more likely to say that they received too little respect from the care recipients' families and friends. Across states, 40 to 60 percent of the directly hired workers reported "some" or "a great deal" of emotional strain. Agency workers in both Arkansas and Florida were about 10 percentage points less likely to report such levels of stress than the directly hired workers. More than three-fourths of the directly hired workers in all three states felt very

emotionally close to their care recipients (not shown), and they were no more likely than agency workers to say that the care recipient should have shown more respect.

These differences appear to be due entirely to the familial relationship that most of the directly hired workers had with the beneficiaries whom they cared for. After pooling the data across states to yield adequate sample sizes, we see that directly hired workers who were *not* related to their care recipients reported rates of emotional strain and lack of respect from the care recipients' families that are very similar to the rates reported by agency workers (Table VI.7). Their observed rates of these problems were significantly lower than those of directly hired workers who were related to the care recipients. Unrelated hired workers also received higher wages, were more likely to receive training, and provided far fewer unpaid hours of care than did related workers. Not surprisingly, it is the family dynamics and overall burden of care that appear to explain why hired workers had more emotional problems, rather than the fact that the worker was hired by a consumer instead of being employed by an agency.

VII. DISCUSSION

Cash and Counseling was implemented successfully in three different states, with three different benefit levels, types of services covered, target populations, program rules, and structures for providing counseling and bookkeeping services. Consumers, often with the help of self-appointed representatives, successfully managed their allowances, hired workers they liked, and terminated the employment of relatives and friends when they had to (which counselors said was rare). The flexibility of the allowance enabled consumers not only to hire whomever they wanted, specify the assistance they desired, and determine how and when the tasks would be accomplished, but to meet some of their needs through the purchase of goods and services not available in the traditional system. These goods and services included special communication devices, transportation, cooking aids (for example, microwave ovens), washing machines,

TABLE VI.7

SELECTED PAID WORKER OUTCOMES, BY CONSUMER-WORKER RELATIONSHIP

	Directly Hired Workers						
	Related			Unrelated			
	Live-In	Not Live-In	All Related	Live-In	Not Live-In	All Unrelated	Agency Workers
Working Conditions							
Hourly wage (dollars)	8.64	7.98	8.34**	7.63	9.29	9.11	7.93
Satisfied with wages (percent)	45.5	47.1	46.3	48.8	41.5	42.5	21.3
Satisfied with working conditions (percent)	80.0	84.4	82.1	85.4	83.0	83.3	82.4
Worker Well-Being (Percent)							
Little or no emotional strain	40.8	53.0	46.5**	41.5	59.1	56.8	56.7
Consumer needed to be more respectful	22.9	14.5	19.0**	19.5	12.0	13.0	14.4
Consumer's family and friends needed to be more respectful	40.9	27.4	34.6*	31.7	17.0	18.9	19.3
Hours of Care Provided (Number)							
Paid hours	19	14	17**	22	18	19	16
Unpaid hours	53	12	34**	48	2	7	2
Maximum Sample Size[a]	**404**	**347**	**751**	**41**	**279**	**320**	**844**

Source: Survey of primary paid workers conducted by Mathematica Policy Research, Inc. between September 2000 and May 2003.

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

[a]Data for adults from all three states are combined here to provide adequate sample sizes for comparisons across subgroups of directly hired workers defined by their relationship to the consumer.

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

security systems, home and vehicle modification, and many other items. The fiscal agents' or counselors' review of spending plans to ensure that all care plan items were covered and their monitoring to ensure that check requests were only for covered items limited incidences of fraud, abuse of the funds, and abuse of consumers to a handful of cases.

Although all three states' programs were successful, a number of important lessons were learned about how they could be improved, and how new states might be able to avoid or minimize some potential problems. Attention to these issues, especially those related to cost control, by the 12 additional states adopting Cash and Counseling programs may lead to better lives for consumers at little or no additional costs to the states.

Relatively few Medicaid beneficiaries enrolled.

The Cash and Counseling program is not for everyone. Among both the elderly and non-elderly subgroups of adult Medicaid beneficiaries who received personal care during the first 24 months of the intake period, 5 to10 percent in each state enrolled in Cash and Counseling. However, the program was quite popular with parents of children with developmental disabilities. The target enrollment of 1000 children—representing 16 percent of all children receiving waiver services during the intake period-- was reached in just 15 months.

The program worked well for consumers and caregivers.

The program benefited consumers tremendously, in several ways. In Arkansas and New Jersey, it increased consumers' likelihood of receiving the paid care for which they were eligible. Across all states, for children and adults of all ages, and for people with physical and developmental disabilities, the control and flexibility offered by the program greatly increased consumers' satisfaction with the help they received and with their overall quality of life. Consumers under Cash and Counseling received care at least as good as that provided by

agencies, in that they had the same or an even lower incidence of care-related health problems. Moreover, these large improvements were achieved despite the program participants' receiving fewer total (paid plus unpaid) hours of care, as participants were able to make more efficient use of whatever assistance they did receive (and perhaps substituted goods and other services for direct human assistance).

The program also greatly benefited the individuals who were the consumers' primary unpaid caregivers at the time of enrollment in Cash and Counseling. Although these caregivers continued to provide many hours of unpaid care, many of them were paid under the program for some of their work, and overall, they were able to reduce the total hours of care they provided below what it would have been in the absence of the program. Across all three states, they reported far lower rates of physical, emotional, and financial stress than did caregivers for the control group. They also reported lower rates of caregiving-related injury, better health, and lower rates of caregiving interfering with their regular jobs.

The program also worked well for workers who were directly hired by beneficiaries. Directly hired workers (typically, the consumer's family or friends) received similar or slightly higher wages than did agency workers, and they were much more satisfied with their compensation. Although only about half of all directly hired workers received formal training, directly hired workers were no more likely than agency workers to report either being injured while caregiving or feeling high levels of physical strain. More directly hired workers than agency workers reported emotional strain and lack of sufficient respect from the care recipients' families, but these differences were confined to directly hired workers who were related to the care recipients. The closeness of the relationship between those directly hired workers and their care recipients and the many hours of unpaid care these workers provided (in addition to their caregiving) led to the greater emotional stress that they experienced relative to agency workers.

The perceived lack of respect that they reported appeared to be driven by the complex family dynamics generally involved in caregiving.

Medicaid costs were higher under Cash and Counseling, mainly due to failure of the traditional system.

The program's effects on Medicaid cost were much less favorable than its effects on consumers and their paid and unpaid workers, but even here there are some positive findings, and the higher costs in two of the states were due to failure of the traditional system. Personal care or HCBS waiver costs under Cash and Counseling per month of benefits received exceeded those for the control group in each state and age group. However, in Arkansas and New Jersey, that gap was due mainly to the fact that control group recipients of agency services received less care than was expected based on their care plans, even after Arkansas adjusted the plans for the historical ratio of actual to care plan amounts (and New Jersey found the historic ratio to be close to 1.0, implying no adjustment was needed). Allowance recipients received about what was projected from their care plans on average. In Florida, however, both nonelderly adults and children in Cash and Counseling, almost all of whom had developmental disabilities, received far more than the expected amounts. This difference appears to be due primarily to Florida's increase in funding for waiver services to consumers with disabilities. This increase was mandated at about the same time that Cash and Counseling began, and it led Florida to reassess consumers when reviewing the consumers' initial spending plan and often to increase the amount of their allowances above the amount they were quoted at the time of enrollment in Cash and Counseling. The availability of funds and directions to increase spending for the population enabled consumers to increase the allowance amounts.

The higher first-year cost per month of benefit received and (in Arkansas and New Jersey) the proportion receiving paid care led to higher annual costs for cashed-out services for the

treatment group than the control group overall, in all three states. Whereas in Florida the higher cost among children and adults with developmental disabilities was due to higher-than-projected allowances, in Arkansas and New Jersey, higher costs were due to the lower proportions of control group consumers receiving any paid care, and to control group care recipients' receiving a smaller-than-normal fraction of the amount of care called for in their care plans.

The higher costs for cashed-out services were offset somewhat in every state and in every age group by lower costs for other Medicaid services, mostly those related to long-term care, including nursing home care, home health, other state waiver programs, and (for children) private duty nursing. These reductions were sizeable and statistically significant for both nonelderly adults in Arkansas and children in Florida. However, even for those groups, the increases in costs for cashed-out services exceeded the reductions in other Medicaid costs, leading to an increase in total Medicaid costs for the states' Cash and Counseling participants. The total Medicaid cost difference for the second year after enrollment, while still higher for the treatment group than for the control group, shrank in Arkansas to a statistically insignificant 5 percent of the control group's average, but grew to more than 8 percent of the control group's cost for children in Florida, and to more than 12 percent for adults in Florida and New Jersey.

Although the higher cost under Cash and Counseling clearly might make states wary about adopting such a program, the costs in two of the three states were higher because the traditional agency-based approach program failed to deliver the care that had been authorized. Thus, some states are "saving" money by having a program that does not meet its obligations. Furthermore, the second-year results in Arkansas suggest that savings in other long-term care costs may be large enough to nearly offset even the large increases in personal care costs. It appears that the ability to access the paid services for which they are approved may enable some consumers to remain in the community, rather than having to enter a nursing home. Florida, the state in which

the younger adults and children received allowances well beyond the amounts specified in the original care plan recommendations, has since developed standardized assessment and reassessment methods (and training of staff on using them) to prevent this problem from recurring.[26] If states can limit their cost per month of benefits under Cash and Counseling to what the cost would be expected to be under a traditional system that is meeting its obligations, a Cash and Counseling program should be both affordable and justifiable to tax payers and legislators.

Despite the favorable impacts on consumers and caregivers, Cash and Counseling has some potential drawbacks.

Despite its overwhelmingly positive effects on the well-being of consumers and caregivers, some potential cost-related and operational drawbacks to the program remain unresolved. Among the potential cost-related issues are the following:

- The experience in the three demonstration states suggests that, unless states heed the lessons learned in the demonstration, total costs to Medicaid are likely to be higher with Cash and Counseling than without it. This is a worrisome concern in times of tightening Medicaid budgets, even if the higher costs are due to correction of failings of the traditional system.
- Using a "discount factor" to scale down care plan amounts by the share that consumers actually receive on average could leave some consumers with too little money to meet their needs. In practice, none of the three states actually restricted cash allowances to the levels originally intended, even though both Arkansas and Florida did use a discount factor. In Florida, consumers actually received substantially more than their care plan amounts due to generous reassessments when spending plans were being developed. Florida attributed these increases to inadequate training of counselors and the state's broader efforts at that time to

[26] However, Arkansas also reported experiencing increases in care plan amounts over time for those in Cash and Counseling, despite having a standardized process. Arkansas staff believe this was due to the close personal bond many counselors had formed with consumers, leading them to act more as an advocate than as a neutral assessor, and to be more likely to suggest increases in the allowance at the six-month reassessments. To prevent such disparities between benefits for those in Cash and Counseling and those receiving agency care, the standardized assessment tool may need to be administered by an independent assessor who does not have a close personal relationship with the consumer (or should be reviewed by an independent monitor).

increase HCBS benefits to Medicaid beneficiaries with disabilities. Arkansas negotiated a more favorable contract for counseling services, under which they pay nothing for a consumer until a spending plan is developed, and then $40 per recipient per month less than the amount originally negotiated. The savings in counseling costs enabled the state to increase allowance amounts without the combined costs exceeding the agency-based rate per hour of care authorized in the care plan (see Dale and Brown, 2005, p.81).

- Costs could increase if the existence of the program leads some eligible Medicaid beneficiaries who would not have applied for the PCS or HCBS benefit under the agency model to do so under Cash and Counseling. The fact that only one-third of Arkansas's control group consumers who were not receiving agency services before enrollment received them after enrolling suggest that this outcome may have occurred to some extent in that state. However, an inadequate supply of workers (according to interviews with some agencies in Arkansas) is probably the reason why many of these consumers did not receive services. The proportion of Arkansas' enrollees comprised of new applicants for PCS was less than the historic proportion of PCS recipients who were new applicants, further suggesting no large influx of consumers applying for benefits due solely to the cash allowance option. Florida and New Jersey limited their programs to consumers who had been receiving (or already been assessed for) the benefit in the traditional program, and they advertised the programs only to these consumers. However, limiting enrollment in this way prevents people who have access problems under the traditional program from resolving their problems through participation in Cash and Counseling.

- Except in Arkansas, the cost savings in other Medicaid costs for adults, most notably their long-term care costs, did not persist into the second year.

Finally, although the program has overwhelmingly favorable effects, interested consumers cannot reap these benefits if they are unable to hire workers. Substantial proportions of treatment group consumers (ranging from 11 to 58 percent, depending on the state and age group) never actually received an allowance, often because they could not find anyone to hire. Nor can such effects be sustained for participants if emotional stress leads hired family members to quit and replacements are not readily available.

Cash and Counseling is an excellent option for states seeking to increase access to care, but it must be designed carefully to avoid unnecessary cost increases.

Based on the favorable findings from this evaluation, all three Cash and Counseling states extended their 1115 waivers to allow their programs to continue, and have amended their

demonstrations to eliminate the randomization component. The states learned a number of valuable lessons that they and other states considering the adoption of Cash and Counseling or a similar program should take into account.

If one of the state's goals is to increase access to paid PCS or HCBS, Cash and Counseling is a very appealing option. However, because it would be serving more of the population of eligible beneficiaries (and/or providing a greater fraction of the authorized services), a state should logically expect its total Medicaid costs to increase, at least during the first few years after adopting the program. The increased access could have a positive effect as well, as it may enable the state to realize some savings on other long-term care costs that would partially offset the costs arising from serving more of the eligible beneficiaries.

Cash and Counseling is an excellent option for states seeking to improve consumer and caregiver well-being.

If the state's goal is to improve beneficiary and caregiver well-being, again, Cash and Counseling is an excellent option. Consumers in the program repeatedly cited the control they had over their care and the flexibility to use their allowances in creative ways to improve the quality of their lives as their reasons for their high levels of satisfaction with Cash and Counseling. Adopting a program in which one-half to two-thirds of its participants feel that the program "improved their lives a great deal" is likely to be attractive to states.

Similarly, Cash and Counseling enables states to lighten considerably the heavy burden borne by unpaid family caregivers, without adopting potentially expensive, new respite programs. The reduction in caregivers' physical, emotional, and financial stress when their care recipients participate in Cash and Counseling may enable the caregivers to avoid or delay the onset of "burn out," which, in turn, may enable the care recipients to remain in the community

longer. Monitoring by counselors appears to ensure that instances of abuse of the consumer or of misuse of the allowance are extremely rare.

Attention to lessons learned could enable states to keep costs from increasing under Cash and Counseling.

The states learned that, to reap the gains from Cash and Counseling without also increasing cost per month of benefits, they would have to (1) set the cash allowance judiciously, (2) manage counseling costs effectively, and (3) use a single, independent, objective system for assessment and reassessment. To keep the cost per benefit month from exceeding the cost per benefit month in the traditional program, states may have to discount the care plan hours by a modest amount based on past history to reflect the fact that, on average, consumers do not receive all of the hours in their care plans. Both Arkansas and Florida did so, discounting care plans by 10 to 15 percent, but both ended up providing allowances sufficient to purchase all of the hours in the care plan (or more). New Jersey did not discount care plan amounts at all.

All three states also learned important lessons about contracting and paying for counseling services, including the importance of setting a one-time payment for developing a consumer's spending plan, and not paying a monthly counseling fee for the consumer until he or she has an approved plan and has started receiving the allowance. By making this change and negotiating more favorable terms for counseling services, Arkansas was able to increase the amount paid out in allowances beyond what was planned while keeping total program costs per month within the limits it had set.

Finally, the finding that Florida paid allowances 20 to 30 percent higher than the baseline care plan amount for consumers with developmental disabilities highlights the importance of establishing a single, independent system for assessing consumers' needs and developing a care plan regardless of whether the consumer is in Cash and Counseling or is seeking agency services.

The assessors should not be the consumer consultant or advocate, and should make objective evaluations of consumers' needs, using a standardized assessment tool. Similarly, states may wish to have independent assessors perform all *reassessments*, using the same objective criteria and assessment tool for all consumers. Reassessments should be monitored to ensure that increases in care plan amounts are not granted more readily to consumer-directed participants than to comparable consumers in the traditional program.

Careful attention to the design of key operational features can help to ensure that a Cash and Counseling program runs effectively and efficiently.

In addition to controlling costs, states should be aware of a number of operational lessons raised by Phillips and Schneider (2003) as part of this evaluation. The lessons cover a wide range of issues, including outreach and enrollment, rules about representatives, counseling and the spending plan, hiring and firing workers, use of the allowance, fiscal services (including recoupment of unused allowance amounts), prevention of exploitation of consumers and abuse of the allowance, and definition of the structure and procedures for counseling and fiscal services.

- **Outreach and enrollment.** Outreach and enrollment through agencies that provide traditional home care services can create problems, since some agencies are not supportive of a cash program. Thus, trying to persuade agencies of the benefits of self-direction is probably not the best use of resources. Direct outreach, which targets eligible beneficiaries, works better than community education in generating enrollment. Family members of beneficiaries are often involved in the decision to participate, so outreach to them can also be useful. Easy-to-understand materials that address the language diversity of the Medicaid population are critical.
- **Representatives.** Many consumers, especially those with developmental disabilities and the elderly, need or want assistance with managing the allowance and name representatives, usually relatives already providing unpaid care, to help them. The same person should not serve as both a representative and a paid worker, to avoid possible conflicts of interest that could arise from being both the employer and the employee.
- **Spending plans and counseling.** Helping consumers develop spending plans can be time-consuming for counselors, and plans must be revised as consumer needs change. Sending consumers information and having telephone conversations before

the initial visit minimizes the number of counselor visits required for developing the initial spending plan; flexible plans reduce the need for revision; and the use of computer programs for budget preparation expedites paperwork, partly by minimizing errors in arithmetic.

- **Use of allowance and workers.** Consumers who lack a relative or friend to hire often have difficulty recruiting a worker. States may wish to emphasize training counselors to assist such consumers with recruiting or to develop referral mechanisms (such as registries or informal lists of potential workers). Consumers *will* terminate the employment of relatives and friends whose work is unsatisfactory. However, they may need support from counselors, especially when firing a worker who lives in the same household.

- **Fiscal services.** Nearly all consumers are likely to rely on the fiscal agent for check writing and payroll functions (such as preparing and submitting tax returns), if fiscal services are provided at little direct expense to them. States may wish to encourage or mandate use of the fiscal agent as a means of preventing abuse of the allowance. However, organizations that provide fiscal services might need assistance with cash flow until they reach a "break-even" caseload.

  States must, when selecting a fiscal agent, define the responsibilities of the agent and assess the ability of that agent to meet them. It may also be useful to develop quality standards and monitor outcomes for fiscal agents, and audit consumer accounts regularly. Procedures should be established to minimize overpayments and facilitate recouping of them.

- **Prevention of exploitation and abuse.** Consumer exploitation (as reported by program counselors in our interviews with them) occurred only a "handful" of times under Cash and Counseling in each of the states. Periodic telephone calls and visits appear to provide allowance recipients adequate protection from exploitation.

  Abuse of the allowance was nearly nonexistent in the three Cash and Counseling programs. Two reviews are critical to its prevention: (1) review of spending plans to ensure they contain only permissible goods and services, and (2) checking time sheets and check requests against these plans. The requirement that consumers retain receipts is not needed to prevent abuse of funds managed by the fiscal agent. States may want to require receipts for purchases made with any cash disbursements of the allowance.

- **Structure and procedures for counseling and fiscal services.** Provision of counseling by agencies that also provide traditional services is problematic, as such agencies may not be supportive of the program. However, case managers are more likely to support a cash program if they see that it benefits their clients. States interested in implementing Cash and Counseling programs through traditional networks may need to devote considerable effort to securing the cooperation of these networks. The organization providing the counseling services must staff this task appropriately: a counselor can function satisfactorily only so long as a sizeable proportion of his or her work week is dedicated to Cash and Counseling (that is, a counselor's Cash and Counseling caseload must be large enough to require at least

several hours per week of the counselor's time). Counselors who spend only a small proportion of their time on Cash and Counseling clients tend to monitor less closely and are more likely to misapply rules. Ongoing or renewed training may be needed, and the quality of counseling services should be monitored.

The time from enrollment to receipt of the allowance varies considerably; it can be reduced by developing mechanisms to help consumers identify workers (such as worker registries) and by efficient program structure and procedures. Arkansas had by far the shortest time to receipt of the allowance and the highest proportion receiving one because it told counselors they had only 45 days to develop a spending plan. An efficient approach to the review of spending plans entails (1) giving counselors full authority to approve plans that request only goods and services on a preapproved list, (2) requiring that counselors seek program office approval for items not on the list, and (3) conducting audits to ensure adherence to these procedures. To avoid excessive counseling costs when the completion of the spending plan is delayed, the payment to counselors to assist with the plan can be limited, for example, by stipulating a fixed payment for that assistance.

Cash and Counseling is expanding to 12 new states, and its principles are being applied in other states as well.

The evidence from the demonstration evaluation has convinced many states to implement a Cash and Counseling program of their own, or adopt principles from it, to improve the lives of consumers who are receiving PCS or HCBS. Eleven additional states have been selected to receive three-year start-up grants from RWJF, ASPE, and the Administration on Aging to develop their own Cash and Counseling programs, and Illinois's program is being funded by the Retirement Research Foundation.[27] By taking advantage of the lessons learned from the demonstration, these states may be able to achieve for their Medicaid beneficiaries the same gains in well-being as demonstration participants and their caregivers experienced, while keeping Medicaid costs in check, and, perhaps, reducing beneficiaries' use of other long-term care services.

[27] See the Cash and Counseling website at www.cashandcounseling.org for more information on the new programs.

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APPENDIX A

CONTROL VARIABLES USED IN ANALYSIS OF IMPACTS ON CONSUMERS' WELL-BEING

TABLE A.1

BASELINE CHARACTERISTICS OF NONELDERLY ADULTS RESPONDING TO THE NINE-MONTH INTERVIEW (CONTROL VARIABLES), BY EVALUATION STATUS

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Demographics						
Age (Years)						
18 to 39	24.3	30.0	75.6	74.2	34.2	35.6
40 to 64[a]	75.7	70.0	24.3	25.8	65.8	64.4
Female	67.9	67.4	41.3**	49.7	67.3	62.9
Race						
White	67.2	61.7	77.5	80.2	49.5	49.2
Black	26.1	33.0	18.6	15.8	42.7	44.1
Other	6.6	5.2	4.0	4.0	7.8	6.8
Of Hispanic Origin[b]	1.2	0.9	18.4*	23.8	30.1	28.4
Language Spoken						
English	n.a.	n.a.	n.a.	n.a.	64.9	63.5
Spanish	n.a.	n.a.	n.a.	n.a.	20.9	20.5
Russian	n.a.	n.a.	n.a.	n.a.	0.9	0.9
Other	n.a.	n.a.	n.a.	n.a.	2.3	3.0
Living Arrangement/Marital Status					*	
Lived alone	39.1	39.1	8.8	8.7	34.8	33.6
Lived with spouse only	8.2	7.4	1.0	1.0	8.4	4.5
Lived with others but not married or married and lived with two or more others	52.7	53.5	90.5	90.6	56.8	62.3
Education[c]						
Had 8 years or fewer	21.8	27.6	5.6	4.9	22.7	25.8
Had 9 to 12 years (no diploma)	30.9	27.6	13.6	12.0	22.4	23.3
High school diploma or GED	25.9	25.4	26.7	25.3	26.9	26.4
At least some college	21.4	19.3	54.1	57.8	28.1	24.5

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Described Area of Residence as:						
Rural	38.0	35.3	16.1	14.5	8.7	10.6
Not rural but high-crime or lacking in adequate public transportation	32.9	34.8	37.6	42.0	48.4	50.3
Not rural, not high-crime, having adequate public transportation	29.1	29.9	46.3	43.5	42.9	39.1
Health and Functioning						
Relative Health Status	*					
Excellent or good	20.6	19.1	62.0	60.2	22.9	30.2
Fair	31.4	23.3	23.7	23.9	30.2	30.8
Poor	47.9	57.5	14.4	15.9	46.9	38.9
Relative to Past Year:						
Health now better or about the same	49.4	49.6	84.2	80.0	62.5	61.5
Now more physically active or about the same	41.2	46.9	75.5	75.3	51.8	54.6
Next Year, Expects Health to:						
Improve	18.5	21.3	25.8	28.3	37.5	35.7
Stay the same	38.7	36.5	55.9	54.6	28.2	35.7
Decline	30.0	30.9	9.1	11.5	16.9	13.1
Doesn't know	12.8	11.3	9.3	5.6	17.1	15.4
Not Independent in Past Week in[d]:						
Getting in or out of bed	61.3	60.9	48.3	53.6	66.0	67.1
Bathing	86.4	84.4	77.3	78.6	86.7	86.4
Using toilet/diapers	61.7	55.2	61.8	64.3	68.1	71.2
Cognitively Impaired (Inferred)[e]	16.1	16.1	58.7	60.2	n.a.	n.a.

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Use of Personal Assistance						
Received Any Help in Past Week with:						
Household activities[b,f]	93.8	91.3	95.7*	98.0	95.7	96.7
Personal care[g]	84.0	83.5	77.8	79.1	88.1	88.1
Transportation[h]	70.0	68.3	83.3	85.2	68.0	72.1
Routine health care[i]	69.1	62.6	80.4	77.3	76.5	80.1
Used Special Transportation Services in Past Year	35.0	38.4	55.6	58.2	62.2	62.0
Modified Home or Vehicle in Past Year	35.0	35.2	35.6	37.0	27.8	23.7
Purchased Assistive Equipment in Past Year	30.2	27.0	35.8	36.2	29.9	31.6
Number of Unpaid Caregivers Who Provided Help in Past Week						
0	9.1	13.5	6.5	4.3	14.2	15.7
1	24.3	28.3	19.9	19.9	23.8	19.9
2	26.8	25.2	25.8	26.3	25.8	20.5
≥3	39.9	33.0	47.9	49.5	36.2	43.9
Relationship of Primary Informal Caregiver to Consumer						
Daughter or son	30.5	21.7	1.9	1.5	17.7	19.9
Parent	18.5	23.5	75.7	69.9	26.7	30.6
Spouse	6.2	6.5	1.2	3.1	8.1	6.5
Other relative	20.6	17.0	9.3	14.0	17.1	14.2
Nonrelative	15.2	17.0	5.5	6.1	15.4	12.2
No primary informal caregiver	9.1	14.4	6.4	5.4	15.1	16.6
Primary Unpaid Caregiver Is Employed	32.8	35.4	45.5	47.5	36.1	35.7
Length of Time in PCS or Waiver Program at Enrollment						
≥6 months	n.a.	n.a.	64.4	66.1	44.6	44.2
<6 months	n.a.	n.a.	35.6	33.9	55.4	55.8

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Length of Time with Publicly Funded Home Care						
≤1 year	14.0	14.4	n.a.	n.a.	n.a.	n.a.
1 to 3 years	18.9	14.4	n.a.	n.a.	n.a.	n.a.
>3 years	17.7	17.8	n.a.	n.a.	n.a.	n.a.
Respondent reported no care in past week, but program reported as current user	7.8	14.8	n.a.	n.a.	n.a.	n.a.
Not a current recipient	41.6	38.7	n.a.	n.a.	n.a.	n.a.
Number of Paid Caregivers in Past Week						
0	44.9	45.7	40.1	37.5	16.8	14.5
1	35.4	32.2	28.9	32.4	53.9	52.5
2	14.4	16.5	17.0	17.6	17.7	22.3
≥3	5.4	5.7	14.1	12.5	11.6	10.7
Comparison of Reported Hours of Paid Care and Hours in Care Plan						
Same	n.a.	n.a.	n.a.	n.a.	41.2	43.6
Less	n.a.	n.a.	n.a.	n.a.	19.1	17.5
More	n.a.	n.a.	n.a.	n.a.	22.9	24.0
Received Paid Help from Private Source in Past Week	11.5	13.5	14.4	17.4	13.6	16.6
Had Live-In Paid Caregiver[b]	1.2	2.2	4.3	4.6	1.7	2.1
Weekly Allowance						
≤$0-$149	n.a.	n.a.	27.5	28.1	24.1	21.4
≥$150 to $299	n.a.	n.a.	28.2	30.6	46.7	43.5
≥$300 to $499	n.a.	n.a.	18.9	18.1	23.5	27.4
≥$500	n.a.	n.a.	25.5	23.2	5.8	7.7
Weekly Hours						
≤6	16.8	15.5	n.a.	n.a.	n.a.	n.a.
>6 up to 11	32.6	35.0	n.a.	n.a.	n.a.	n.a.
>11 up to 15	45.9	44.8	n.a.	n.a.	n.a.	n.a.
>15	4.7	4.7	n.a.	n.a.	n.a.	n.a.

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Satisfaction with Paid Care						
Level of Satisfaction with the Way Paid Caregiver Helped with Personal Care, Household Activities, Routine Health Care[f,g,i]					*	
Very satisfied	25.1	23.3	25.7	33.6	31.7	38.9
Satisfied	14.0	13.6	13.9	12.3	25.2	27.1
Dissatisfied	14.0	14.9	8.2	8.2	24.9	18.7
No paid help with those activities in past week	46.9	48.3	52.2	45.9	18.2	15.4
Level of Satisfaction with Time of Day Paid Worker Helped						
Very satisfied	13.6	13.6	21.6	26.3	23.3	25.1
Satisfied	9.9	12.3	14.4	14.0	22.7	23.6
Dissatisfied	18.2	17.1	10.1	10.7	24.1	25.1
No paid help in past week	58.3	57.0	53.9	49.0	29.9	26.3
Level of Difficulty in Changing Caregiver's Schedule[b]						
Very difficult	n.a.	n.a.	19.5	20.0	30.8	36.8
Somewhat difficult	n.a.	n.a.	13.6	16.1	17.5	16.6
Not at all difficult	n.a.	n.a.	12.4	14.3	20.5	19.6
No paid caregiver	n.a.	n.a.	54.5	49.7	31.1	27.0
Level of Satisfaction with Overall Care						
Very satisfied	29.4	25.8	41.4	49.1	29.0	29.4
Satisfied	25.1	29.0	32.5	27.3	32.0	35.0
Dissatisfied	30.6	31.7	20.0	18.2	36.4	31.9
No paid services or goods in past week	14.9	13.6	6.0	5.5	2.7	3.7
Unmet Needs for Personal Assistance						
Insufficient Help with:						
Household activities[f]	75.9	76.4	69.6	66.9	81.9	79.2
Personal care[g]	67.2	68.7	53.8	52.4	76.2	71.0
Transportation[h]	58.1	57.8	55.0	55.0	72.7	67.6

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Quality of Life						
Level of Satisfaction with How Spending Life[b]						
Very satisfied	10.9	12.5	9.6	5.9	10.3	11.7
Satisfied	25.5	21.4	6.2	7.4	18.8	21.6
Dissatisfied	39.3	41.1	7.2	7.7	40.9	33.5
Question not asked of proxy	24.3	25.0	77.1	79.0	30.0	33.2
Attitude About Consumer-Directed Care						
Being Allowed to Pay Family Members or Friends Was Very Important	86.4	85.7	69.9	69.6	85.8	83.4
Having a Choice About Paid Workers' Schedules Was Very Important	80.7	86.1	82.8	85.2	92.2	89.9
Having a Choice About Types of Services Received Was Very Important	88.1	86.5	90.2	91.3	93.6	91.1
Primary Informal Caregiver Expressed Interest in Being Paid for Caregiving	33.9	40.4	30.0	25.8	32.4	31.1
Work Experience and Community Activities						
Ever Supervised Someone[c]	44.4	37.3	66.4	68.6	36.0	32.1
Ever Hired Someone Privately[c]	44.6	38.4	68.5	68.6	32.8	29.7
Ever Worked for Pay[c]	83.1	76.5	94.8	95.2	76.2	71.5
Currently Working for Pay[b,c]	4.7	6.1	44.9	45.8	2.9*	5.6
Attended Social/Recreational Programs in Past Year	11.6	7.9	42.3	43.9	17.4	19.0
Attended Adult Day Care in Past Year	4.5	4.8	41.9	40.4	16.4	20.2

TABLE A.1 (*continued*)

Characteristic	Arkansas		Florida		New Jersey	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Other						
Proxy Completed All or Most of Survey	23.5	23.9	77.6	79.3	29.3	32.6
Appointed a Representative at Enrollment	25.9	28.7	85.7	85.5	n.a.	n.a
Enrollment Month Was in:						
First half of period[j]	56.0	55.7	59.2	59.2	51.3	52.2
Second half of period[k]	44.0	44.4	40.8	40.8	48.7	47.8
Feeder Program						
Department of Elder Affairs	n.a.	n.a.	0.0	0.0	n.a.	n.a.
Developmental Services	n.a.	n.a.	89.5	87.8	n.a.	n.a.
Adult Services	n.a.	n.a.	10.5	12.2	n.a.	n.a.
Sample Size	**243**	**230**	**419**	**392**	**341**	**332**

Source: Baseline evaluation interview conducted by Mathematica Policy Research, Inc. between December 1998 and April 2001 in Arkansas, between November 1999 and July 2000 in New Jersey, and between June 2000 and July 2002 in Florida.

Note: Chi-square tests were used to test significances for categorical variables; t-tests were used to test significances for all other variables.

[a]The samples in Arkansas and New Jersey included individuals aged 18 to 64. The sample for Florida included individuals aged 18 to 59, about 90 percent of whom had developmental disabilities.

[b]Because this characteristic was rare or had a very high mean value for one or two of the states, we did not include it in our logit models for those states.

[c]For Florida, the percentages reflect the characteristics of those people who would make decisions under CDC, including demonstration enrollees or their representative (if the person responding to the interview was the representative, as was typically the case in Florida, where most consumers had developmental disabilities). For New Jersey and Arkansas, the percentages reflect the characteristics of demonstration enrollees, regardless of whether they would have used a representative in their states' consumer-directed programs.

[d]Needed hands-on or standby help or did not perform activity at all.

[e]We inferred the presence of a cognitive impairment if the sample member appointed a representative at enrollment and was physically or mentally unable to respond to the baseline survey.

[f]Household activities include preparing meals, doing laundry, doing housework, and doing yard work.

TABLE A.1 (*continued*)

[g]Personal care activities include eating and bathing.

[h]Transportation includes transportation to and from physician's office, shopping, school, work, and social and recreational activities.

[i]Routine health care includes helping with medications, checking blood pressure, and doing exercises.

[j]First-half enrollment was from 1998 or 1999 for Arkansas; June 1, 2000, to May 31, 2002, for Florida; and November 1, 1999, to December 31, 2000, for New Jersey.

[k]Second-half enrollment was from 2000 or 2001 for Arkansas; June 1, 2001, to May 31, 2002, for Florida; and January 1, 2001, to July 31, 2002, for New Jersey.

GED = General Educational Development; PCS = personal care services.

*Difference between treatment and control groups significantly different from zero at the .10 level, two-tailed test.
**Difference between treatment and control groups significantly different from zero at the .05 level, two-tailed test.
***Difference between treatment and control groups significantly different from zero at the .01 level, two-tailed test.

TABLE A.2

BASELINE CHARACTERISTICS OF RESPONDENTS TO THE NINE-MONTH INTERVIEW (CONTROL VARIABLES)
ELDERLY ADULTS BY EVALUATION STATUS

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Demographics						
Age in Years					**	
65 to 79[a]	49.1	50.8	59.7	56.2	56.8	49.0
80 or older	50.9	49.2	40.3	43.8	43.2	51.0
Female	81.9	82.5	81.6	78.2	80.4	76.9
Race			**			
White	59.5	60.8	54.6	63.8	69.0	71.6
Black	35.2	32.8	33.2	27.7	28.1	24.6
Other	5.3	6.4	12.1	8.5	2.8	3.8
Of Hispanic Origin[b]	1.4	0.8	38.2	43.6	33.0	36.6
Language Spoken						
English	n.a.	n.a.	36.6	34.1	n.a.	n.a.
Spanish	n.a.	n.a.	33.1	39.6	n.a.	n.a.
Russian	n.a.	n.a.	8.7	8.1	n.a.	n.a.
Other Language	n.a.	n.a.	9.0	6.0	n.a.	n.a.
Living Arrangement/Marital Status						
Lives alone	30.8	30.1	33.8	38.3	27.4	30.9
Lives with spouse only	9.0	9.1	11.2	13.1	12.9	12.7
Lives with others but not married or married and lives with two or more others	60.1	60.7	56.0	49.1	59.8	56.8
Education[c]						
8 years or fewer	66.0	66.2	54.2	55.3	12.3	14.5
9 to 12 years (no diploma)	18.8	16.7	15.7	13.1	18.4	17.6
High school diploma or GED	12.2	14.1	13.1	13.6	21.1	22.9
At least some college	3.0	3.0	17.0	18.0	48.2	45.0

TABLE A.2 (*continued*)

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Described Area of Residence as:						
Rural	40.3	40.6	13.5	10.1	10.8	11.1
Not rural but high-crime or lacking in adequate public transportation	28.1	24.8	40.0	36.2	42.0	43.5
Not rural, not high-crime, having adequate public transportation	31.7	34.6	46.5	53.7	47.2	45.5
Health and Functioning						
Relative Health Status						
Excellent or good	21.7	18.6	18.8	16.3	25.1	24.4
Fair	31.6	33.6	38.2	45.0	34.3	41.1
Poor	46.6	47.7	43.0	38.7	40.5	34.4
Compared to Past Year						
Health is now better or about the same	45.5	47.0	42.3**	50.7	49.9	53.6
Is now more physically active or about the same	33.2***	40.9	31.8	30.3	37.8	39.1
Next Year, Expects Health to:						
Improve	13.9	14.3	26.8	27.1	19.9	23.2
Stay the same	27.0	28.0	22.8	24.7	33.1	29.3
Decline	39.3	41.0	29.8	27.6	35.2	35.4
Doesn't know	19.9	16.7	20.7	20.5	11.8	12.2
Not Independent in Past Week in:[d]						
Getting in or out of bed	65.7	68.1	67.8	64.3	65.7	65.5
Bathing	90.3*	93.1	87.3	87.1	89.0	88.1
Using toilet/diapers	67.4	67.8	66.0	64.0	67.3	66.1
Cognitively Impaired (Inferred)[e]	27.1	31.1	n.a.	n.a.	44.0	45.2
Use of Personal Assistance						
Received Any Help in Past Week with:						
Household activities[b,f]	96.1	96.8	96.0	96.6	96.5	97.3
Personal care[g]	89.4	90.3	86.3	88.2	88.5	88.4
Transportation[h]	57.8	59.9	58.4	59.0	57.6	61.4
Routine health care[i]	77.4	77.2	80.8	82.9	74.3	78.0

TABLE A.2 (*continued*)

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Used Special Transportation Services in Past Year	24.3	23.6	47.0	51.1	44.1	41.9
Modified Home or Vehicle in Past Year	39.8	36.6	19.8	19.6	42.1	41.0
Purchased Assistive Equipment in Past Year	31.1	33.4	31.7**	24.5	35.8	36.3
Number of Unpaid Caregivers Who Provided Help in Past Week						
0	8.6	7.9	15.7	14.4	17.2	12.4
1	29.0	30.3	26.1	29.1	27.4	28.7
2	29.4	28.3	22.6	23.6	23.9	26.0
3 or more	33.0	33.6	35.6	32.8	31.5	32.9
Relationship of Primary Informal Caregiver to Client	*				*	
Daughter or son	64.0	68.6	60.5	60.4	55.5	54.3
Parent	0.0	0.0	0.0	0.5	0.5	0.8
Spouse	5.0	4.2	5.7	9.2	12.1	9.6
Other relative	15.7	15.5	11.9	11.0	8.9	11.9
Nonrelative	6.5	3.4	4.5	4.2	5.6	10.5
No primary informal caregiver	8.7	8.3	17.4	14.7	17.4	13.0
Primary Unpaid Caregiver Is Employed	32.7	32.5	44.9	41.5	31.2	34.4
Length of Time in PCS or Waiver Program at Enrollment:						
6 months or more	n.a.	n.a.	46.0	47.8	70.0	69.4
Less than 6 months	n.a.	n.a.	54.0	52.2	30.0	30.6
Length of Time with Publicly Funded Home Care:						
Less than 1 year	22.5	22.4	n.a.	n.a.	n.a.	n.a.
1 to 3 years	25.0	23.3	n.a.	n.a.	n.a.	n.a.
More than 3 years	22.5	22.8	n.a.	n.a.	n.a.	n.a.
Respondent said no care in past week, but program says current user	9.1	11.1	n.a.	n.a.	n.a.	n.a.
Not a current recipient	20.8	20.4	n.a.	n.a.	n.a.	n.a.
Number of Paid Caregivers in Past Week			**			
0	27.5	28.2	16.4	15.2	9.7	11.0

TABLE A.2 (*continued*)

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
1	42.2	41.8	63.7	59.3	47.9	47.9
2	20.6	19.7	11.9	19.2	27.2	27.6
3 or more	9.7	10.3	8.0	6.3	15.3	13.5
Comparison of Reported Hours of Paid Care to Hours in Care Plan						
Same	n.a.	n.a.	51.2	51.3	n.a.	n.a.
Less	n.a.	n.a.	14.9	14.7	n.a.	n.a.
More	n.a.	n.a.	17.4	18.7	n.a.	n.a.
Received Paid Help from Private Source in Past Week	14.4	11.9	15.7	11.8	18.2	14.6
Had Live-In Paid Caregiver[b]	1.7	1.1	2.0*	0.5	4.3	5.0
Weekly allowance					**	
$0-$149	n.a.	n.a.	27.6	23.1	46.4	53.1
$150-$299	n.a.	n.a.	40.8	43.3	38.6	32.0
$300-$499	n.a.	n.a.	27.6	29.7	13.4	10.7
$500 or more	n.a.	n.a.	4.0	3.9	1.6	4.1
Weekly hours						
6 or less	24.8	28.2	n.a.	n.a.	n.a.	n.a.
More than 6 up to 11	39.3	36.3	n.a.	n.a.	n.a.	n.a.
More than 11 up to 15	34.5	34.7	n.a.	n.a.	n.a.	n.a.
More than 15	1.4	0.8	n.a.	n.a.	n.a.	n.a.
Satisfaction with Paid Care						
How Satisfied with the Way Paid Caregiver Helped with Personal Care, Household Activities, Routine Health Care[f,g,I]						
Very satisfied	31.3	34.5	33.8	38.0	43.9	44.1
Satisfied	25.0	20.6	30.8	26.3	28.1	28.5
Dissatisfied	14.3	15.9	17.0	18.6	16.4	15.0
No Paid Help with These Activities in Past Week	29.3	29.1	18.3	17.0	11.7	12.4
How Satisfied with Time of Day Paid Worker Helped						
Very satisfied	22.1	23.5	24.3	21.2	27.5	29.2

TABLE A.2 (*continued*)

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Satisfied	19.6	17.2	24.8	25.9	26.4	24.7
Dissatisfied	15.5	16.7	21.6	21.7	23.4	20.8
No paid help in past week	42.7	42.6	29.3	31.2	22.6	25.3
How Difficult to Change Caregiver's Schedule[b]						
Very difficult	n.a.	n.a.	28.0	26.2	27.3	29.3
Somewhat difficult	n.a.	n.a.	17.5	19.7	22.6	21.6
Not at all difficult	n.a.	n.a.	23.5	21.9	27.0	23.3
No paid caregiver	n.a.	n.a.	31.0	32.2	23.1	25.9
How Satisfied with Overall Care	**					
Very satisfied	42.7	45.1	30.3	34.3	38.8	41.7
Satisfied	35.7	33.1	38.9	37.8	39.8	37.8
Dissatisfied	15.2	11.7	25.4	21.3	20.8	18.6
No paid services or goods in past week	6.3	10.2	5.3	6.6	1.1	2.0
Unmet Needs for Personal Assistance						
Not Getting Enough Help with:						
Household activities[f]	63.1	63.9	76.8	76.7	75.0	74.7
Personal care[g]	59.2*	64.3	72.6	74.4	64.3	63.0
Transportation[h]	40.9	45.0	67.0	66.8	57.0	57.7
Quality of Life						
How Satisfied with Way Spending Life[b]						
Very satisfied	14.0	14.0	12.2	13.4	10.2	10.6
Satisfied	16.4	13.1	17.7	14.2	14.6	14.8
Dissatisfied	11.4	14.2	19.0	15.5	15.4	13.1
Question not asked of proxy	58.3	58.7	50.9	56.7	59.9	61.6
Attitude Toward Consumer Directed Care						
Being Allowed to Pay Family Members or Friends Was Very Important	85.9	85.9	85.1	85.8	77.8	78.5
Having a Choice About Paid Worker's Schedules Was Very Important	81.1	79.8	85.1	86.4	82.6	83.5

TABLE A.2 (*continued*)

Characteristics	Arkansas		New Jersey		Florida	
	Treatment Group	Control Group	Treatment Group	Control Group	Treatment Group	Control Group
Having a Choice About Types of Services Received Was Very Important	84.9	86.9	89.8	89.5	90.9	90.9
Primary Informal Caregiver Expressed Interest in Being Paid	28.6*	33.1	27.6	32.9	30.0**	22.7
Work Experience and Community Activities						
Ever Supervised Someone[c]	24.0	25.1	32.2	29.6	61.7	57.5
Ever Hired Someone Privately[c]	28.7	28.7	30.4	26.1	63.0	62.4
Ever Worked for Pay[c]	84.1	85.6	80.8	79.8	96.5	94.8
Work for Pay Now[b,c]	8.1	8.9	0.3	0.3	24.1	25.1
Attended Social/Recreational Programs in Past Year	8.4	8.2	13.9	14.7	12.4	15.2
Attended Adult Day Care in Past Year	5.9	5.3	11.4	14.0	13.1	15.4
Other						
Proxy Completed All or Most of Survey	57.0	57.7	50.8	51.2	58.5	60.3
Appointed a Representative of Enrollment	46.4	50.8	n.a	n.a	70.5	71.1
Enrollment Month Was in:						
First half of period[j]	47.4	48.9	49.3	48.8	31.4	28.7
Second half of period[k]	52.7	51.1	49.5	55.4	68.6	71.4
Feeder Program						
Department of Elder Affairs	n.a.	n.a.	n.a.	n.a.	97.9	97.3
Developmental Services	n.a.	n.a.	n.a.	n.a.	2.1	2.8
Adult Services	n.a.	n.a.	n.a.	n.a.	0.0	0.0
Sample Size	**642**	**624**	**402**	**381**	**373**	**363**

TABLE A.2 (*continued*)

Source: MPR's baseline evaluation interview, conducted between December 1998 and April 2001 in Arkansas, between November 1999 and July 2000 in New Jersey, and between June 2000 and July 2002 in Florida.

Note: Chi-square tests were used to test significances for categorical variables and t-tests were used to test significances for all other variables.

[a]The samples in Arkansas and New Jersey included individuals age 65 and older. The sample used for Florida included individuals age 60 and older.

[b]Because this characteristic was rare or had a very high mean value for one or two of the states, we did not include it in our logit models for those states.

[c]For Florida, the percentages reflect the characteristics of those people who would make decisions under Consumer Directed Care, be they demonstration enrollees or their representative (if the person responding to the interview was the representative). For New Jersey and Arkansas, the percentages reflect the characteristics of demonstration enrollees, regardless of whether they would use a representative in their state's consumer-directed program. See Appendix for description of the imputation procedures used when the education and employment valuables of the decision maker were not observed.

[d]Needed hands-on or standby help or did not perform activity at all.

[e]We inferred the presence of a cognitive impairment if sample member appointed a representative upon enrollment and was physically or mentally unable to respond to the baseline survey.

[f]Household activities may include meal preparation, laundry, housework, and yard work.

[g]Personal care activities may include eating and bathing.

[h]Transportation may include transportation to a doctor's office, shopping, school, work, or social and recreational activities.

[i]Routine health care may include checking blood pressure or doing exercises.

[j]First Half Enrollment was from 1998 or 1999 for Arkansas, 6/1/00 to 5/31/01 for Florida and 11/1/99 to 12/31/00 for New Jersey.

[k]Second Half Enrollment was from 2000 or 2001 for Arkansas, 6/1/01 to 6/31/02 for Florida and 1/1/01 to 7/31/02 for New Jersey.

*Difference between treatment and control groups significantly different from 0 at the .10 level, two-tailed test.
**Difference between treatment and control groups significantly different from 0 at the .05 level, two-tailed test.
***Difference between treatment and control groups significantly different from 0 at the .01 level, two-tailed test.

TABLE A.3

BASELINE CHARACTERISTICS OF CHILDREN AND THEIR PARENTS, BY EVALUATION STATUS
(Percentages, Unless Otherwise Noted)

Characteristic	Treatment Group	Control Group
Children's Demographic Characteristics		
Younger than 12 Years Old	63.3	63.4
Male	61.5	64.8
Of Hispanic Ancestry	17.3	18.7
Race		
White	81.4	82.3
Black	13.7	13.5
Other	4.9	4.2
Parents Described Area of Residence As:		**
Rural	17.1	20.8
Not rural but high-crime or lacking adequate public transportation	32.9	37.7
Not rural, not high-crime, with adequate public transportation	50.0	41.5
Parent Attended At Least Some College	69.0	67.2
Children's Health and Functioning		
Relative Health Status		
Excellent or good	58.8	58.6
Fair	28.9	25.6
Poor	12.3	15.8
Compared to Last Year:		
Health is worse	10.0	9.4
Is less physically active	15.4	12.7
Next Year Parent Expects Child's Health to:		
Improve	32.2	34.2
Stay the same	56.0	55.7
Decline	5.9	3.8
Doesn't know	5.9	6.2
Not Independent in Past Week in: [a]		
Getting in or out of bed	59.2	62.5
Bathing	92.7	92.6
Using toilet (or uses diapers)	84.6	86.8

TABLE A.3 (*continued*)

Characteristic	Treatment Group	Control Group
Children's Use of Personal Care Services		
Used Special Transportation Services in Past Year	65.0	62.2
Modified Home or Vehicle in Past Year	60.3	60.2
Assistive or Security Equipment Was Purchased for Child in Past Year	63.5	56.5**
Number of Unpaid Caregivers Who Provided Help in Past Week		
1	11.3	11.0
2	26.5	20.3
3 or more	62.1	68.7
Primary Unpaid Caregiver Is a Parent	89.3	89.5
Primary Unpaid Caregiver Is Employed	48.8	49.0
Number of Paid Caregivers in Past Week		
0	37.6	35.2
1	27.4	25.4
2	17.2	19.6
3 or more	17.7	19.9
Allowance if Assigned to Treatment Group (mean dollars per week)	266	272
In Past Week, Received PCS from:		
Publicly Funded Caregivers	52.8	53.2
Privately Funded Caregivers	23.8	30.1**
Had Live-In Paid Caregiver[b]	2.7	3.6
Enrolled in Waiver Program for Fewer than 6 Months	39.9	39.5
Parents' Satisfaction with Paid Care		
How Satisfied with the Way Paid Caregiver Helped with Personal Care, Doing Things Around the House, Routine Health Care		
Very satisfied	29.3	34.4
Satisfied	17.6	14.8
Dissatisfied	9.2	8.9
No paid help with these activities in past week	43.9	41.9
How Satisfied with Time of Day Paid Worker Helped		
Very satisfied	21.0	22.8
Satisfied	19.8	21.8
Dissatisfied	14.1	12.7
No paid help in past week	45.1	42.7

TABLE A.3 (*continued*)

Characteristic	Treatment Group	Control Group
How Difficult to Change Paid Caregiver's Schedule		
Very difficult	22.1	24.9
Somewhat difficult	24.4	24.0
Not at all difficult	8.2	8.4
No paid help in past week	45.2	42.7
How Satisfied with Overall Care Arrangements		
Very satisfied	17.7	17.2
Satisfied	39.7	44.1
Dissatisfied	39.7	35.6
No paid services or goods in past week	3.0	3.1
Parents' Perception of Unmet Needs for Personal Assistance		
Child Is Not Getting Enough Help with:		
Doing things around the house	77.5	73.1
Personal care	66.6	66.3
Transportation	47.5	46.5
Parents' Satisfaction with Children's Quality of Life		
How Satisfied with Way Spending Life		
Very satisfied	17.6	19.7
Satisfied	43.4	47.1
Dissatisfied	38.8	33.2
Proxy respondent-question not asked	0.2	0.0
Parents' Attitude Toward Consumer Directed Care		
Being Allowed to Pay Family Members or Friends Was Very Important	69.2	71.8
Having a Choice About Paid Workers' Schedule Was Very Important	92.1	91.9
Having a Choice About Types of Services Received Was Very Important	97.7	98.3
Primary Informal Caregiver Expressed Interest in Being Paid	23.7	23.1
Work Experience and Community Activities		
Parent Ever Supervised Someone	76.8	77.5
Parent Ever Hired Someone Privately	75.1	76.8
Parent Ever Worked for Pay[b]	98.6	98.6
Child Attended Recreational Programs in Past Year	48.3	46.7
Child Attended Day Care in Past Year	24.9	20.1*

TABLE A.3 (*continued*)

Characteristic	Treatment Group	Control Group
Enrollment Month		
Enrolled Between:		
June 2000 and May 2001	74.4	75.1
June 2001 and July 2002	25.6	24.9
Sample Size	**441**	**418**

Source: MPR's baseline evaluation interview, conducted between June 2000 and August 2001, and the Consumer Directed Care Program.

[a]Needed hands-on or standby help or did not perform activity at all.

[b]Because this characteristic was very rare (or very common) we did not include it in our logit models.

[c]The evaluation's enrollment target for children was met in August 2001; the enrollment of adults continued until July 2002.

*Difference between treatment and control groups significantly different from 0 at the .10 level, two-tailed test.
**Difference between treatment and control groups significantly different from 0 at the .05 level, two-tailed test.

PCS = Personal care services; includes help with personal care, routine health care, doing things around the house, and transportation.

APPENDIX B

CONTROL VARIABLES USED IN ANALYSIS OF IMPACTS ON INFORMAL CAREGIVERS

TABLE B.1

BASELINE CHARACTERISTICS OF CHILDREN AND THEIR PRIMARY INFORMAL CAREGIVERS, BY RANDOM ASSIGNMENT STATUS
(In Percentages, Unless Noted)

Characteristic	Treatment Group	Control Group
Children's Demographics		
≤12 Years of Age	62.9	64.2
Male	62.2	64.7
White	80.8	81.3
Parents Described Area of Residence as:		**
Rural	16.5	21.5
Not rural, but high-crime or without adequate public transportation	33.7	36.7
Not rural or high-crime, with adequate public transportation	49.8	41.8
Children's Health and Functioning		
Relative Health Status		
Excellent or good	60.0	58.9
Fair	28.3	25.8
Poor	11.7	15.3
Not Independent in Past Week in:		
Getting in or out of bed	58.7	60.6
Bathing	93.0	92.0
Using toilet/diapers	84.9	86.0
Children's Use of Personal Assistance		
Number of Informal Caregivers in Past Week		*
1	11.7	10.2
2	26.3	20.1
≥3	62.0	69.7
Number of Paid Caregivers in Past Week		
0	38.0	35.8
1	28.4	24.1
≥2	33.6	40.1
Was Receiving Waiver Services for Six Months or Longer	40.1	41.1
Consumer-Directed Care Allowance, if Assigned to Treatment Group (Mean Dollars per Week)	265.0	273.0
In Past Week, Received PCS from Caregiver(s) Who Were:		
Publicly funded	52.8	53.2
Privately funded	23.3	29.8**

TABLE B.1 (*continued*)

Characteristic	Treatment Group	Control Group
Parents' Satisfaction and Perception of Unmet Needs for Personal Assistance		
Level of Satisfaction with Overall Care Arrangements		
Very satisfied	16.9	17.6
Satisfied	41.2	44.0
Dissatisfied	39.1	35.1
No paid services or goods in past week	2.8	3.3
Insufficient Help for Child with:		
Household activities[b]	77.1	73.6
Personal care	66.4	65.8
Transportation	48.4	46.1
Parents' Attitudes About Consumer-Directed Care		
Being Allowed to Choose Services Was Very Important[c]	98.0	98.3
Having a Choice About Paid Workers' Schedules Was Very Important	92.8	92.8
Being Allowed to Pay Family or Friends Was Very Important	69.5	71.2
Primary Informal Caregiver Expressed Interest in Being Paid for Caregiving	24.9	24.4
Parents' Hiring and Supervisory Experience		
Ever Supervised Someone	77.6	76.9
Ever Hired Someone Privately	75.5	75.9
Primary Informal Caregivers' Characteristics		
≥40 Years of Age	63.6	63.7
Female	93.7	93.2
Consumer's Parent	89.7	89.0
White	82.0	83.8
Married	69.7	70.6
High School Graduate	89.3	90.4
Employed	48.7	49.1
Other		
Child's Enrollment Month Was Between:		
June 2000 and February 2001	27.5	27.6
March 2001 and July 2002	72.5	72.4
Sample Size	**429**	**399**

TABLE B.1 (*continued*)

Source: Baseline interview conducted by Mathematica Policy Research, Inc. (MPR) between June 2000 and August 2001, caregiver interview conducted by MPR between April 2001 and June 2002, and the CDC program.

[a]Needed hands-on or standby help or did not perform activity at all.

[b]Household activities included preparing special meals and helping with homework.

[c]Because this characteristic was very common, it was not included in logit models.

PCS = personal care services.

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

TABLE B.2

BASELINE CHARACTERISTICS OF CONSUMERS AND THEIR PRIMARY INFORMAL CAREGIVERS, BY EVALUATION STATUS: FLORIDA
(In Percentages)

Characteristic	Treatment Group	Control Group
Consumers' Demographics		
Age (Years)		
18 to 39	48.1	47.4
40 to 64	17.2	17.0
65 to 79	15.4	15.3
≥80	19.3	20.3
Female	57.2	60.6
Hispanic	24.0	27.5
Race		
White	72.8	74.2
Black	23.9	21.6
Other	3.2	4.2
Lived Alone	8.3	9.7
Described Area of Residence as:		
Rural	15.5	15.0
Not rural but high-crime or lacking adequate public transportation	38.0	42.0
Not rural, not high-crime, having adequate public transportation	46.5	43.0
Consumers' Health and Functioning		
Relative Health Status		
Excellent or good	49.4	48.8
Fair	27.1	28.2
Poor	23.5	23.1
Not Independent in Past Week in[a]:		
Getting in or out of bed	58.8	62.5
Bathing	84.6	84.2
Using toilet/diapers	68.9	68.4
Consumers' Use of Personal Assistance		
Received Any Help in Past Week with:		
Household activities[b]	97.9	98.1
Personal care[c]	85.3	84.9
Transportation[d]	79.7	78.1
Routine health care[e]	83.8	81.3
Number of Unpaid Caregivers Who Provided Help in Past Week		
1	26.1	27.1
2	28.9	24.3
≥3	45.1	48.6

TABLE B.2 (*continued*)

Characteristic	Treatment Group	Control Group
Was Receiving Waiver Services for Six Months or Longer	66.1	67.5
Number of Paid Caregivers in Past Week		
0	28.3	29.5
1	36.0	34.9
≥2	35.7	35.6
Proposed Weekly Allowance		
<$150	33.2	36.6
$150 to $299	32.9	31.8
$300 to $499	17.0	15.6
≥$500	16.9	16.0
Demonstration Feeder Program		
Department of Elder Affairs	38.7	38.3
Developmental Services	56.6	57.5
Adult Services	4.7	4.2
Consumers' Satisfaction with Care and Unmet Needs for Personal Assistance		
Level of Satisfaction with Overall Care Arrangements		
Very satisfied	40.5	47.1
Satisfied	37.5	31.3
Dissatisfied	17.5	16.8
No paid services or goods in past week	4.5	4.8
Insuffient Help with:		
Household activities[b]	73.2	72.0
Personal care[c]	59.6	56.1
Transportation[d]	54.5	55.5
Consumers' Preferences About Consumer-Directed Care		
Being Allowed to Pay Family Members or Friends Was Very Important	75.0	75.2
Having a Choice About Paid Workers' Schedules Was Very Important	84.3	85.6
Having a Choice About Types of Services Received Was Very Important	92.7	91.7
Decisionmakers' Education and Work Experience[f]		
Graduated from High School	76.0	76.1
Ever Supervised Someone	66.1	64.6
Ever Hired Someone Privately	68.1	67.5
Ever Worked for Pay	96.0	95.0

TABLE B.2 (*continued*)

Characteristic	Treatment Group	Control Group
Other		
Proxy Completed All or Most of Baseline Survey	78.4	77.4
Appointed a Representative at Enrollment	86.1	85.4
Enrollment Month Was Between:		
June 2000 and May 2001	50.7	51.0
June 2001 and July 2002	49.3	49.0
Primary Informal Caregivers' Characteristics		
Age (Years)		
≤39	7.9	8.3
40 to 64	70.7	70.1
≥65	21.4	21.5
Female	83.8	84.2
Relationship to Consumer		**
Spouse	5.7	6.6
Parent	50.2	46.2
Daughter or son	28.0	24.5
Other relative	10.9	14.4
Nonrelative	5.2	8.3
Hispanic	23.0	26.7
White	70.2	71.2
Married	57.8	57.4
Had Child(ren) Younger than Age 18	17.7	19.7
Highest Level of Education		
≤8 years	6.7	6.6
9 to 12 years, but no high school diploma or GED	11.8	12.7
High school diploma or GED	30.8	32.9
At least some college	50.7	47.7
Employed[g]	45.9	45.9
Expressed Interest in Being Paid for Caregiving[g]	34.1	27.9**
Sample Size	**617**	**576**

Source: Baseline evaluation interview by Mathematica Policy Research, Inc. (MPR) conducted between June 2000 and July 2002, caregiver interview conducted by MPR between May 2001 and May 2003, and program records.

[a]Needed hands-on or standby help or did not perform activity at all.

[b]Household activities included preparing meals, doing laundry, doing housework, and doing yard work.

[c]Personal care included eating, dressing, and bathing.

[d]Transportation included transportation to and from a physician's office, shopping, school, work, and social and recreational activities.

[e]Routine health care included helping with medications, checking blood pressure, and doing exercises.

[f]Reflects the characteristics of the person (the consumer or a representative if the representative responded to the baseline interview) who would make care-related decisions in the demonstration program. See Foster et al. (2005a) for a description of imputation procedures used when the characteristics of the decisionmaker were not observed.

[g]As reported by consumers during the baseline interviews.

GED = General Educational Development.

*Difference between treatment and control groups significantly different from zero at the .10 level, two-tailed test.

**Difference between treatment and control groups significantly different from zero at the .05 level, two-tailed test.

APPENDIX C

COMPANION REPORTS

COMPANION REPORTS

Impacts on Quality of Care and Use of Personal Care

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

Carlson, Barbara, Barbara Phillips, Stacy Dale, Leslie Foster, Randy Brown, and Jennifer Schore. "The Effect of Cash and Counseling on Service Use and Care Quality in Three States." Princeton, NJ: Mathematica Policy Research, Inc., 2005.

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, September 2004.

See also 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.

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

See also 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.

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

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. They also present information about Cash and Counseling program costs. Reports on costs in the Arkansas program and on the Florida program for children are listed here as well as a report on all three states.

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

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

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.

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. The Arkansas report and a report on caregivers for children participating in the Florida program are listed here.

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

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

Foster, Leslie, Randall Brown, Barbara Phillips, and Barbara Carlson. "How Cash and Counseling Affects Informal Caregivers: Findings from All Three States." Princeton, NJ: Mathematica Policy Research, Inc., 2005.

Experiences of Paid Workers

The current report reflects the experiences of workers in each of the three demonstration states. The following report, first one on paid workers reflected the experiences of workers in Arkansas.

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

Program Implementation

These reports describe program goals, features, and procedures in detail based on in-person interviews with program staff.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the New Jersey Personal Preference Program." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., December 2004.

Foster, Leslie, Barbara Phillips, and Jennifer Schore. "Consumer and Consultant Experiences in the Florida Consumer Directed Care Program." Draft report. Princeton, NJ: Mathematica Policy Research, Inc., November 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., July 2004.

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

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

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

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

Program Demand and Participation

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

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