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How Cash and Counseling Affects Informal Caregivers: Findings from Arkansas, Florida, and New Jersey

Final Report

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EXECUTIVE SUMMARY

Cash and Counseling Is a Promising Way to Deliver Medicaid Supportive Services.

Adult Medicaid beneficiaries who have disabilities and live at home rely mostly on unpaid family members and other informal caregivers for personal care. States supplement beneficiaries' informal assistance with disability-related supportive services. These are usually delivered through a Medicaid state plan as personal care services (PCS) or through a Medicaid waiver program as home- and community-based services (HCBS). If beneficiaries find their services unsatisfactory or too inflexible to meet their needs, the burden to compensate for those shortcomings often falls on informal caregivers, potentially causing them emotional, physical, and financial strain.

The Cash and Counseling Demonstration and Evaluation, implemented in Arkansas, Florida, and New Jersey, gave eligible Medicaid beneficiaries the opportunity to receive a monthly allowance to purchase supportive services of their choosing. By helping beneficiaries avoid the potential drawbacks of traditional PCS and HCBS, Cash and Counseling programs could also be expected to improve the well-being of beneficiaries' informal caregivers.

This report estimates the effects of Cash and Counseling on the caregivers who were providing the most unpaid assistance to adult beneficiaries when those beneficiaries volunteered to participate in the demonstration and completed a baseline interview. The caregivers in this analysis—identified by beneficiaries as their *primary informal caregiver* at baseline—were interviewed about 10 months later.

A Rigorous Design Provided Definitive Evidence of Program Effects on Caregivers.

The demonstration and evaluation used a randomized design. After a completing their baseline telephone interview, participating beneficiaries were randomly assigned to direct their own Medicaid supportive services as Cash and Counseling consumers (the treatment group) or to rely on PCS or HCBS as usual (the control group). The primary informal caregivers of treatment group consumers could be affected by Cash and Counseling if those consumers (1) hired the primary informal caregiver as a worker or named him or her as their representative decision maker; (2) adjusted the amount, timing, and types of services used; or (3) purchased assistive devices or home modifications.

Data on caregiver outcomes were collected through telephone interviews. These were conducted between February 2000 and May 2003, depending on the state, and were completed by 1,433 caregivers in Arkansas, 1,193 in Florida, and 1,042 in New Jersey. Caregivers, who typically were related to their care recipients, were asked factual questions about the frequency, amounts, timing, and types of assistance they provided and about their labor force participation and income. They were asked for their opinions on the quality of their relationships with care recipients; their satisfaction with care recipients' care; and their own emotional, financial, and physical well-being, and satisfaction with life. Program effects were estimated by comparing outcomes for the caregivers of treatment group members with those for the caregivers of control group members. Regression models controlled for the baseline characteristics of care recipients and the demographic characteristics of caregivers.

Treatment Group Caregivers Reported Greater Well-Being in All Three States.

Despite variations in design and implementation across states, all three demonstration programs positively affected the well-being of caregivers. On average, the caregivers of treatment group members were less likely than their control group counterparts to report high levels of physical and financial strain. Treatment group caregivers worried less about insufficient care and safety and were more likely to be very satisfied with their care recipient's overall care arrangements. They were also less likely to say caregiving impinged on their privacy, social lives, and job performance. On average, treatment group caregivers were much more likely than their control group counterparts to be very satisfied with their own lives.

For some outcomes, the estimated effects were proportionally largest, relative to control group means, in Arkansas. Arkansas also had the largest proportion of treatment group members receiving the Cash and Counseling allowance when we interviewed caregivers.

As expected, some treatment group caregivers were paid for caregiving during the follow-up period (56 percent in Arkansas, 29 percent in Florida, and 42 percent in New Jersey). To explore whether Cash and Counseling affected paid and unpaid treatment group caregivers differently, we estimated program effects separately for each of these subsets. The results suggested that getting paid for caregiving was not the sole determinant of improved well-being but that it did contribute to magnitude of many treatment-control differences.

An analysis of program effects by care recipients' age group suggested that Cash and Counseling can positively affect the well-being of caregivers for elderly and nonelderly adults (as evidenced in Arkansas and Florida). The same analysis suggested that benefits to well-being may diminish if caregivers provided more hours of assistance under Cash and Counseling than they would have provided otherwise (as evidenced in New Jersey among caregivers for nonelderly care recipients).

The Implications for Medicaid Policy Are Encouraging.

The three-state findings were robust and encouraging. Viewed with earlier evaluation results, they illustrate that when Medicaid beneficiaries wish to direct their own supportive services and do so, both they and their primary informal caregivers benefit. Improvements seemed to come about because some informal caregivers became paid workers and some care recipients made service arrangements that lightened their caregiver's burden. The three demonstration states continue to operate their Cash and Counseling programs under Section 1115 authority of the Social Security Act (without random assignment). Other states have good reason to consider offering consumer-directed options as part of their Medicaid systems.

INTRODUCTION

Medicaid beneficiaries who have disabilities and live at home receive much more personal care from unpaid family members and other informal caregivers than they do from paid sources (U.S. Department of Health and Human Services 2002). Providing informal care often is rewarding, but it also can be emotionally, physically, and financially taxing. If the strain of caregiving becomes debilitating, it could imperil the health of caregivers and hasten Medicaid beneficiaries' entry into nursing homes or other institutions, thereby increasing public costs (Doty 1997).

States help beneficiaries live at home by supplementing their informal care with disability-related supportive services. These are usually delivered through a Medicaid state plan as personal care services (PCS) or through a Medicaid waiver program as home- and community-based services (HCBS). However, states often limit the amounts, types, and providers of the PCS or HCBS they cover (Doty 2004). If beneficiaries find the services unsatisfactory or too inflexible to meet their needs, the burden to compensate for those shortcomings often falls on informal caregivers.

The Cash and Counseling Demonstration and Evaluation, implemented in Arkansas, Florida, and New Jersey, gave eligible Medicaid beneficiaries the opportunity to receive a monthly allowance to purchase disability-related supportive services of their choosing. By increasing beneficiaries' autonomy and control over their care, Cash and Counseling programs are meant to help them avoid the potential drawbacks of PCS or HCBS from personal care agencies and other providers. In turn, the programs could also be expected to improve the well-being of beneficiaries' informal caregivers.

This report describes the effects of Cash and Counseling on the caregivers who were providing the most unpaid assistance to adult beneficiaries when those beneficiaries volunteered to participate in the demonstration and completed a baseline telephone interview. The caregivers in this analysis—identified by beneficiaries as their *primary informal caregiver* at baseline—were interviewed about 10 months later. This report follows earlier findings that beneficiaries who were randomly assigned to participate in a Cash and Counseling program (the treatment group) were more satisfied with their supportive services than were beneficiaries who were assigned to rely on PCS or HCBS as usual (the control group) (Carlson et al. 2005).

The report begins with a brief overview of the Cash and Counseling model and its implementation by the demonstration states. It sets forth research hypotheses about caregiver outcomes and briefly describes the methods used to estimate program effects. (Readers familiar with the demonstration and evaluation may wish to skip these introductory sections.) The report then presents findings for each state and concludes with a discussion of findings, limitations, implementation lessons, and policy implications. Appendices contain additional detail about analytic methods and tables of results that are noted, but not shown, in the body of the report.

A NEW MODEL OF MEDICAID SUPPORTIVE SERVICES

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

Cash and Counseling, which is a fairly expansive model of consumer-directed care, provides a monthly allowance that consumers may use to hire workers, including relatives, and to purchase other services and goods related to their need for personal care (within state guidelines). Cash and Counseling allows consumers to designate a representative, such as a relative or friend, to help them make decisions about managing their care. It also offers counseling and fiscal services to help consumers and representatives handle their program responsibilities. These tenets of Cash and Counseling—a flexible allowance, use of representatives, and availability of counseling and fiscal services—are meant to make consumer direction adaptable to consumers of all ages and abilities.

As noted, Cash and Counseling was tested in Arkansas, Florida, and New Jersey as a three-state demonstration. The Robert Wood Johnson Foundation (RWJF) and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services funded the demonstration. The Centers for Medicare & Medicaid Services approved the demonstration programs under Section 1115 authority of the Social Security Act. The National Program Office for the demonstration, at Boston College and the University of Maryland, coordinated the overall demonstration, provided technical assistance to the states, and oversaw the evaluation. Mathematica Policy Research, Inc. (MPR) is the demonstration evaluator.

GOALS AND FEATURES OF THE DEMONSTRATION

With the principles of consumer autonomy, choice, and control foremost in mind, each demonstration state had the practical goal of assessing the political and economic feasibility of publicly funded consumer-directed care. In addition, Arkansas (more so than Florida and New Jersey) hoped to increase access to services in parts of the state where 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.

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. They did have to adhere to the model's basic tenets, however. The key features of each state's program are described below and summarized in Table 1.[1]

Covered Services

The demonstration programs in Arkansas and New Jersey offered an allowance instead of the supportive services, such as help with eating, bathing, housekeeping, and shopping, that beneficiaries otherwise would have received as Medicaid state plan PCS. Florida's program offered an allowance instead of the benefits usually provided through an HCBS waiver program, such as in-home nursing, professional therapies, care-related supplies and equipment, caregiver respite, and help with personal care.

Target Populations and Eligibility

Each state's target population included adult Medicaid beneficiaries with primarily physical disabilities. In addition, Florida targeted beneficiaries with primarily developmental disabilities.

In Arkansas the demonstration was open to adult Medicaid beneficiaries who were eligible for, but not necessarily receiving, state plan PCS. Beneficiaries who were participating in either of two HCBS waiver programs—ElderChoices or Alternatives—could also participate in the Arkansas demonstration. (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 service to nursing-home-qualified elderly adults. Alternatives provides attendant care and environmental modifications for nonelderly adults and lets them choose and supervise paid caregivers.)

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

TABLE 1

KEY FEATURES OF CASH AND COUNSELING PROGRAMS, BY STATE

	Arkansas	Florida	New Jersey
Program Name	IndependentChoices	Consumer Directed Care	Personal Preference
Evaluation Intake Period	December 1998-April 2001	June 2000-July 2002 (adults); June 2000-August 2001 (children)	November 1999-July 2002
Eligible Medicaid Beneficiaries	Adults 18 or older with primarily physical disabilities who were eligible for Medicaid state plan PCS	Adults with primarily physical disabilities, and children and adults with primarily developmental disabilities, who were receiving HCBS	Adults 18 or older with primarily physical disabilities who were receiving or had been assessed for Medicaid state plan PCS
Benefits Included in the Calculation of the Program Allowance	Medicaid state plan PCS	Medicaid HCBS, except for case management/support coordination services	Medicaid state plan PCS
Hiring Restrictions	Could not hire legally responsible relatives (that is, spouses), and representative decision makers could not also be paid workers.	None during the evaluation period. If a representative was also a paid worker, someone else from the care recipient's "circle of support" was asked to verify the completion of agreed-upon work.	Representative decision makers could not also be paid workers.
Method for Calculating the Program Allowance	$8 per hour in care plan multiplied by a provider-specific adjustment factor. (Adjustment factors were used to help the state meet federal budget neutrality requirements.)	Value of recent claims or care plan multiplied by an adjustment factor. (Care plans were used for beneficiaries with developmental disabilities, if claims history was not stable, or care plan value exceeded recent claims by $50 or more per month.)	Value of care plan minus 10 percent set-aside for fiscal agent and counseling services.
Median Monthly Allowance at Baseline	$313	$829 (adults) and $831 (children)	$1,097
Participation in Other Consumer-Directed or Home Care Programs	Demonstration enrollees could also participate in the HCBS waiver programs ElderChoices and Alternatives.[a]	For adults with developmental disabilities, the demonstration excluded several 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.

Source: Program records and in-person and telephone discussions with state officials and demonstration program staff members. Discussions were conducted about 18 months after each state began random assignment (see Phillips and Schneider, 2002, 2003, and 2004).

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

HCBS = Home- and Community-Based Services; PCS = Personal Care Services

In Florida the demonstration was open to Medicaid beneficiaries who were receiving HCBS under the state's Developmental Disabilities (DD) Waiver or Aged/Disabled Adult (ADA) Waiver and living in selected areas of the state.[2] Together, these waivers serve adults and children with developmental disabilities, frail elderly adults, and adults with physical disabilities.[3] For adults with developmental disabilities, the demonstration catchment area was the entire state except several northern counties where a state-funded consumer-directed program was being piloted. For elderly adults and those with physical disabilities, the catchment area consisted of 19 counties, including most of the state's major metropolitan areas.

In New Jersey the demonstration was open to adult Medicaid beneficiaries who (1) were using PCS or had been assessed as eligible for it, (2) were not also participating in an HCBS waiver program or state-funded consumer-directed program, and (3) were expected to require PCS for at least six months. Recipients of both PCS and HCBS were excluded because authorization procedures for those services differed and beneficiaries would have received assistance from Cash and Counseling consultants *and* HCBS case managers, which the state program office feared would cause confusion. Beneficiaries who were expected to require PCS for less than six months were excluded because Cash and Counseling consumers were expected to require several months to develop and implement a plan for spending the monthly allowance.

Except for applying these eligibility criteria, the three demonstration states relied on beneficiaries and their families to decide whether they wanted to take on the responsibilities of consumer direction. Beneficiaries could disenroll from consumer direction at any time.

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[2] Florida's initial demonstration design included beneficiaries in the state's Brain and Spinal Cord Injury Program (BSCIP). The participation of BSCIP was delayed, however, so BSCIP beneficiaries were excluded from the MPR evaluation.

[3] The experiences of Florida children and their primary informal caregivers are described in companion reports (Foster et al. 2004 and 2005).

Enrollment and Random Assignment

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

Enrollment and random assignment periods differed by state, depending on when each was ready to conduct outreach and enrollment activities and implement its consumer-directed program. Arkansas enrolled 2,008 beneficiaries between December 1998 and April 2001; Florida enrolled 1,816 adult beneficiaries between June 2000 and July 2002; and New Jersey enrolled 1,755 beneficiaries between November 1999 and July 2002. Half the enrollees in each state were randomly assigned to the treatment group.

Calculation of Program Allowances

Arkansas and New Jersey based program allowances on the number of hours in consumers' Medicaid PCS plans and the average rates the state would otherwise pay for agency services. Plan hours were capped at 16 per week in Arkansas and 25 per week in New Jersey absent special authorization for more hours. Florida based allowances on all the benefits in consumers' HCBS care plans or recent Medicaid waiver claims, except those for case management/support coordination.[4] To meet federal budget neutrality standards, Arkansas and Florida applied adjustment factors to consumers' allowances. The states had determined that beneficiaries in the predemonstration period had not, on average, received all the services authorized in their plans (for example, because in-home services were suspended during hospitalizations or agency workers failed to arrive as scheduled). 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 the demonstration budget neutral. Median monthly allowances calculated for adult demonstration participants varied considerably by state. They were $313 in Arkansas, $829 in Florida, and $1,097 in New Jersey.

Permitted Uses of the Allowances

Consumers (or their representatives) in all three programs were required to develop a written spending plan that specified the goods and services they wished to purchase with the allowance. States permitted purchases of services and goods that were related to consumers' care needs and ability to exercise independence. For example, they might permit microwave ovens and washing machines, but not televisions. Consumers could elect to receive small portions of their allowance (10 to 20 percent) as cash for incidental expenses, such as taxi fare, that were not readily purchased through an invoicing process. They could also save portions of the allowance for larger, one-time purchases, such as home modifications.

Although consumers were permitted to use their allowances to hire relatives, some restrictions applied. Arkansas did not allow consumers to hire spouses, despite a federal waiver

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[4] Claims were used to calculate the allowance if they were historically stable and consistent with the consumer's care plan. In practice, claims were not used to calculate the allowances of consumers with developmental disabilities, because their care plans were being systematically revised when the demonstration began. (The revisions resulted from a substantial increase in state funding for the HCBS waiver programs serving people with developmental disabilities.) Claims were used to calculate the allowances of consumers with primarily physical disabilities, however.

that permitted states to let consumers pay legally responsible relatives (spouses, parents of minors, and other legal guardians). Neither Arkansas nor New Jersey allowed the same person to serve as both a representative and paid worker. Florida had no such restriction during the evaluation period, because it recognized that parents typically represent *and* care for children with developmental disabilities. To protect consumers in cases where the representative and the worker were the same person, however, Florida required that someone else from the consumer's "circle of support" verify that the representative/worker performed the agreed-upon 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 a 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) monitor consumers' well-being; and (4) monitor use of the allowance. Florida and New Jersey required that state- or district-level staff review all spending plans. Arkansas required such review only if a plan included goods and services not on a preapproved list; otherwise, counselor review sufficed. Interaction between counselors and consumers occurred during 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 these services were included in federal budget neutrality calculations.

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

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[5] After the evaluation period, Florida modified its operational protocol so that that no one could serve as both a representative and paid worker. This restriction is currently enforced in Florida's CDC+ program, which operates under a Section 1115 waiver.

check writing. Florida and New Jersey charged consumers modest fees for fiscal services, while Arkansas did not charge them directly. Although consumers who demonstrated ability to handle fiscal tasks themselves were allowed to do so—and thus receive the allowance as cash each month—all but a handful of consumers chose to have the fiscal agent maintain a program account on their behalf.

The demonstration programs prevented misuse of the allowance by comparing check requests and worker time sheets with consumers' spending plans before they disbursed funds. In Florida and New Jersey, the fiscal agent was responsible for performing this verification; in Arkansas, counselors were responsible for performing it. Arkansas and Florida required consumers to keep receipts for purchases made with the allowance, and receipts were subject to review by counselors. New Jersey did not require that consumers keep receipts.

CONSUMER DIRECTION AND INFORMAL CAREGIVERS

Previous Research

This report provides rigorous, empirical evidence on how an innovative model of paid supportive services affects the well-being of unpaid caregivers. It helps bridge an extensive literature on informal caregiving and a more nascent one on consumer-directed care.

The emotional, physical, and financial tolls of informal caregiving are well documented (Rabow et al. 2004; Zarit 2004; Schulz and Beach 1999). According to a recent national survey, for example, one-third of caregivers for elderly adults describe caregiving as emotionally stressful, 15 percent suffer physical or mental health problems as a result of caregiving, and half report that caregiving detracts from time spent with other family members (National Alliance for Caregiving and AARP 2004).

The literature also identifies a reciprocal relationship between the health status and quality of life of informal caregivers and care recipients. Caregivers of depressed elderly people report a poorer quality of life than do caregivers of elderly people who are not depressed (Sewitch et al. 2004). Caregivers of elderly people with dementia are more likely to institutionalize their care recipient if they rate their own burden as great and their own health as poor (Gaugler et al. 2003). Whether caregivers feel they provide good care and whether care recipients had problems with household tasks and/or woke the caregiver or other family members during the night have been identified as predictors of nursing home placements for elderly adults (Schur and Whitlatch 2003).

Because of the relationships between the well-being of care recipients and informal caregivers and between caregiver burden and care recipients' institutionalization, the effects of consumer direction on caregivers merit attention. Evidence is mounting that consumer direction benefits consumers (see, for example, Carlson et al. 2005 and Benjamin et al. 2000). By contrast, this and other recent studies (see, for example, Benjamin and Matthias 2004) examine whether consumer benefits translate into caregiver benefits or into caregiver strain, and identify mechanisms leading to these outcomes.

Hypotheses About Caregiver Outcomes

Under Cash and Counseling, consumers could change their use of Medicaid supportive services in many ways. They could choose their workers and designate a representative to help them manage their care. They could adjust the amount and timing of assistance they received from paid workers and informal caregivers, and they could buy assistive devices and home modifications. They could also use the program's counseling and fiscal services. These changes, in turn, could affect:

- The frequency, amounts, timing, and types of assistance that primary informal caregivers provided
- The quality of relationships between caregivers and care recipients

- Caregivers’ satisfaction with care recipients’ supportive services
- Caregivers’ emotional, physical, and financial well-being
- Caregivers’ satisfaction with life

The amount, types, and timing of assistance the caregivers in this analysis provided could increase or decrease under Cash and Counseling. This would depend on whether they were hired to perform additional tasks (beyond those they performed without pay) or whether other workers were hired to relieve some of their burden.

Similarly, outcomes measuring quality of life could be favorably affected if Cash and Counseling consumers replaced unsatisfactory agency workers with workers they and their caregiver liked and trusted; began paying others to perform tasks the primary informal caregiver found especially difficult, unpleasant, time-consuming, or hard to schedule; purchased assistive devices to increase their own independence and ease the caregiver’s physical strain; or began paying the primary informal caregiver, thereby acknowledging the value of his or her assistance and reducing financial strain. Cash and Counseling could also improve caregivers’ financial well-being by affording them enough flexibility in meeting their caregiving responsibilities to enter the labor force or change jobs.

Conversely, Cash and Counseling could make matters worse for primary informal caregivers. Assuming the responsibilities of an agency worker or other paid provider could create emotional and physical stress. Becoming the paid employee of a relative could strain familial relationships, as could continuing to provide unpaid assistance while other family members start to receive pay. Serving as a consumer’s program representative could be burdensome, especially if the program’s counseling or fiscal services were inadequate or if other workers were hired and did not meet the consumer’s or caregiver’s expectations.

METHODS[6]

Data Collection and Samples

Data on the types of caregiver outcomes discussed in the previous section were collected through computer-assisted telephone interviews with caregivers. (Table A.1 lists specific outcome measures.) As noted, the caregivers in this analysis were identified by beneficiaries as their *primary informal caregiver* during each beneficiary's baseline interview. Specifically, beneficiaries were asked for the name and telephone number of the person (if any) who had given them the most unpaid assistance during the previous week with personal care, household and community tasks, routine health care, and transportation. Interviews with caregivers were conducted 10 months after the baseline beneficiary interview, between February 2000 and June 2003, depending on the state.[7] The number of caregivers completing interviews were 1,433 caregivers in Arkansas, 1,193 in Florida, and 1,042 in New Jersey. Overall response rates were 84 percent for caregivers associated with treatment group members and 78 percent for those associated with control group members. Proxy respondents were not allowed

To preserve the benefits of random assignment and obtain a complete picture of caregivers' experiences, caregiver interviews were conducted even with caregivers whose care recipient had disenrolled from the demonstration program (25 to 29 percent across states) or died (3 to 7 percent) (not shown). Caregivers who had not helped their care recipients shortly before the caregiver interview (six to nine percent) were included in the sample. For most measures, interviewers asked these caregivers to recall the period when they were last helping care

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[6] Appendix A includes additional detail on analytic methods.

[7] Unlike beneficiaries who participated in the demonstration, caregivers were interviewed only once; thus, we do not have analogous baseline measures of the caregiver outcomes measured at 10 months.

recipients. However, if recall error seemed likely (in questions measuring hours of assistance, for example), interview questions were skipped.

Estimation of Program Effects

Program effects on caregivers were measured by comparing the outcomes of all caregivers in the treatment group with those of all caregivers in the control group, regardless of whether a particular care recipient in the treatment group actually received the monthly allowance. Because some care recipients had not received the monthly allowance by the time their caregiver was interviewed (for reasons described in the Results section of this report), this "intent-to-treat" analysis understates program impacts on caregivers whose care recipients participated fully in a consumer-directed program.[8]

Models. For each state, the analysis used logit models to estimate program effects on categorical outcomes, an ordered logit to estimate effects on caregivers' level of household income, and ordinary least squares models to estimate effects on the frequency and amount of assistance.

Many outcome measures were constructed by converting responses to survey questions with four-point scales (for example, degree of satisfaction) into two alternative binary measures. One measure represented the most favorable rating (very satisfied), the other an unfavorable rating (somewhat or very dissatisfied).[9] We used this approach so readers could easily see the basis on

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[8] Assuming the demonstration affected only caregivers of allowance recipients, the effects on those caregivers could be estimated by dividing the overall program effects reported in our tables by the proportion of treatment group members receiving the allowance in each state (0.88 in Arkansas, 0.55 in Florida, and 0.75 in New Jersey). For example, whereas the overall effects on whether caregiving limited privacy were -14.0, -4.8, and -9.4 percentage points in Arkansas, Florida, and New Jersey (Table 8), the respective effects on caregivers of allowance recipients would be -16.0, -8.7, and -12.5.

[9] The caregiver survey also included several questions with five-point scales. In these cases, respondents rated the level of strain they experienced, with 1 representing little or no strain and 5 representing a great deal of strain.

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

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

Control Variables. The models controlled for care recipient and caregiver characteristics. Most of these characteristics were measured during baseline interviews with care recipients or their proxy respondents, and a few were drawn from baseline program records or the caregiver interview. As specified by state in Tables A.2a through A.2c, the models controlled for care recipients' demographic characteristics, health and functioning, use of unpaid and paid supportive services, satisfaction with care and life, work and community activities, unmet needs, reasons for and month of enrollment, use (if any) of a proxy respondent for all or most of the baseline interview, and whether named a representative to manage the monthly allowance by the time of the baseline interview (applicable only in Arkansas and Florida).

The models also controlled for the amount or value of benefits in the care recipient's baseline Medicaid care plan (expressed as hours of authorized PCS in the Arkansas models, and

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(continued)
We converted each scale into two binary measures. The first was set equal to 1 if the respondent gave a rating of 1; the other was set equal to 1 for ratings of 4 or 5.

as a categorical measure of the prospective weekly allowance amount in the Florida and New Jersey models). These variables were drawn from each state's program records.

The models controlled for the familial relationship between care recipients and primary informal caregivers and whether the caregiver was employed, interested in being paid for caregiving, and living with the care recipient, as reported by care recipients at baseline. Finally, the models controlled for caregiver age, sex, race, education, marital status, and whether has dependent children. These variables were measured during the caregiver interview.

Appendix Tables A.2a through A.2c present the mean baseline characteristics of the care recipients and caregivers in this analysis, by state and treatment status. Although nearly all the characteristics were distributed similarly across the treatment and control groups (as expected with random assignment), a few treatment-control differences emerged within the subset of sample members whose primary informal caregivers responded to our survey, whether by chance or differential attrition. As noted, the regression models controlled for these differences.

Statistical Power. Given the number of caregivers in each state's sample, the analysis had 80 percent power to detect treatment-control differences of 7 to 8 percentage points for binary variables with means of 0.5, assuming two-tailed tests at the .05 significance level (Appendix Table A.3). For a key continuous outcome—the hours of assistance provided by live-in caregivers during two weeks—the analysis could detect differences of 14 to 17 hours (about 8 to 11 percent of the sample means).

Baseline Characteristics of Care Recipients and Primary Informal Caregivers

The care recipients associated with the caregivers in our analysis samples differed considerably by state. In Arkansas, care recipients typically were elderly (75 percent) and female (78 percent) (Table 2). Sixty-one percent were white, 34 percent were black, and 1 percent was Hispanic (regardless of race). About 4 in 10 Arkansas care recipients said they lived in rural

TABLE 2

BASELINE CHARACTERISTICS OF CARE RECIPIENTS, BY STATE
(Percentages)

Characteristic	Arkansas	Florida	New Jersey
Age in Years			
18 to 39	8.3	47.8	18.4
40 to 64	17.2	17.1	26.7
65 to 79	35.5	15.3	28.2
80 or older	39.0	19.8	26.7
Eligible for Demonstration Because of Developmental Disability	n.a.	61.5	n.a.
Hispanic	1.2	25.7	35.2
Race			
White	60.6	73.5	55.1
Black	34.3	22.8	35.2
Other	5.1	3.7	9.7
Female	77.5	58.8	72.6
Graduated from High School[a]	23.8	76.0	38.4
Lives Alone	23.3	9.0	21.0
Area of Residence			
Rural	40.6	15.3	12.2
Nonrural but high-crime or with poor public transportation	27.6	39.9	40.8
In Poor Health Relative to Peers	48.1	23.3	41.6
Needed Help Using Toilet in Past Week	70.2	68.7	75.9
Number of Informal Caregivers in Past Week			
1	32.1	26.5	29.7
2	31.0	26.7	26.7
3 or more	36.9	46.8	43.7
Receiving Publicly Funded Home Care (at All or for at Least Six Months)[b]	73.4	66.8	44.6
Dissatisfied with Overall Care Arrangements[c]	18.6	18.0	27.7
Appointed a Representative	47.0	85.8	NA
Number of Respondents	**1,433**	**1,193**	**1,042**

Source: Program records from each of the demonstration states and MPR's baseline interview. Interviews were conducted in Arkansas between December 1998 and April 2001; in Florida between June 2000 and July 2002; and in New Jersey between November 1999 and July 2002.

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[a] For Arkansas and New Jersey, the percentages reflect the care recipient's education. For Florida, the percentage reflects the education of the person (that is, the care recipient or a representative if the representative responded to the baseline interview) who would make care-related decisions in the demonstration program.

[b] For Arkansas, the percentage represents care recipients who were receiving publicly funded home care at baseline, regardless of how long they had been receiving it. For Florida and New Jersey, the percentages represent care recipients who had been receiving publicly funded home care for six months or longer at baseline. The measures differ because care recipients in Florida and New Jersey typically received traditional home care services before they enrolled in the demonstration; in Arkansas, this was not necessarily the case.

[c] Calculations of the percent dissatisfied excludes beneficiaries who said they used no paid services or goods during the week before the baseline interview (see Appendix Tables A.2a through A.2c).

n.a. = not applicable; NA = data not available.

areas of the state, and about one-quarter lived alone. Nearly half of Arkansas care recipients said they were in poor health compared to other people their age, and nearly half named a representative who would help them manage Cash and Counseling responsibilities. In addition, 61 percent of elderly care recipients were enrolled in the HCBS waiver program ElderChoices at baseline, and 3 percent of the nonelderly were enrolled in Alternatives (not shown).

In Florida, where the demonstration was targeted in part to adults with developmental disabilities, a larger proportion of care recipients were nonelderly than elderly (65 versus 35 percent) (Table 2). Most care recipients were white (74 percent) or black (23 percent), and one-quarter were Hispanic (regardless of race). Relatively few Florida care recipients (15 percent) said they lived in a rural area, but 40 percent said their neighborhood had high crime or poor public transportation. Because a large proportion of Florida care recipients had developmental disabilities, more than 8 in 10 said they would use a representative in the consumer-directed program, and few (nine percent) lived alone. About one-quarter said their health was poor.

Care recipients in New Jersey were, as a group, more demographically diverse than those in Arkansas and Florida (Table 2). About 55 percent were elderly. Fifty-five percent were white, 35 percent were black, 10 percent reported another race, and 35 percent were Hispanic. In addition, 21 percent of New Jersey care recipients lived alone, and 41 percent said their neighborhood had high crime or poor public transportation. Slightly more than 4 in 10 care recipients said their health was poor.[10] New Jersey care recipients were somewhat more likely than their counterparts in the other states to be dissatisfied with their overall care arrangements at baseline (28 percent in New Jersey, 19 percent in Arkansas, and 18 percent in Florida).

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[10] In New Jersey, data on representatives were not collected during baseline interviews, because care recipients were not asked to name them until after they were randomly assigned to the treatment group. Program staff estimated that up to two-thirds of elderly New Jersey treatment group members, and a somewhat smaller proportion of nonelderly ones, named representatives.

The caregivers in our analysis samples had many characteristics in common, regardless of state. Roughly 8 in 10 caregivers were female, a majority had graduated from high school, and between 52 and 58 percent were married (Table 3). Many caregivers were employed at baseline (38 to 49 percent), and many were interested in getting paid for caregiving (31 to 38 percent). The most notable difference across states was that Florida caregivers were more likely to be the care recipient’s parent (48 percent versus 7 percent in Arkansas and 18 percent in New Jersey). Thus, Florida caregivers were also somewhat older, on average, than their counterparts in the other states. (Twenty-two percent of Florida caregivers were 65 or older, compared with 14 percent of Arkansas caregivers and 17 percent of New Jersey caregivers.)

RESULTS

Receipt and Use of the Allowance in the Treatment Group

As noted earlier, all beneficiaries randomly assigned to the Cash and Counseling treatment group could receive a monthly allowance if they developed an acceptable spending plan. In fact, the proportions of treatment group members who had received the program allowance for at least one month by the time caregivers were interviewed for this analysis (about 10 months after beneficiaries’ random assignment) varied considerably by state. The proportions were 88 percent in Arkansas, 55 percent in Florida, and 75 percent in New Jersey (Table 4). The variations stemmed, in part, from the complexity of states’ allowance-planning procedures, the number of people involved in allowance planning, and the degree to which program counselors were responsible for getting consumers started on the allowance.

Furthermore, although this analysis is of people who were providing unpaid care at baseline, some treatment group caregivers were paid for caregiving during the follow-up period. This was true for 56 percent of all treatment group caregivers in Arkansas, 29 percent of treatment group caregivers in Florida, and 42 percent of treatment group caregivers in New Jersey (Table 4).

TABLE 3

CHARACTERISTICS OF PRIMARY INFORMAL CAREGIVERS, BY STATE
(Percentages)

Characteristic	Arkansas	Florida	New Jersey
Age in Years			
39 or younger	22.4	8.1	19.7
40 to 64	64.1	70.4	63.5
65 or older	13.5	21.5	16.8
Hispanic	1.2	24.8	35.7
White	61.0	70.7	45.4
Female	86.0	83.9	79.4
Graduated from High School	69.0	81.1	70.7
Married	55.3	57.6	51.7
Has Child(ren) Younger than 18	29.3	18.6	29.9
Relationship to Care Recipient			
Spouse	5.5	6.1	8.3
Parent	7.0	48.3	17.9
Daughter or son	62.3	26.3	49.9
Other relative	17.7	12.6	15.4
Nonrelative	7.4	6.7	8.4
Lived with Care Recipient at Baseline	61.7	83.1	65.0
Employed at Baseline[a]	37.7	45.9	49.0
Interested in Being Paid for Caregiving[a]	35.8	31.1	38.2
Number of Respondents	**1,433**	**1,193**	**1,042**

Source: MPR's caregiver and baseline interviews. Caregiver interviews were conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003. Baseline interviews were conducted in Arkansas between December 1998 and April 2001; in Florida between June 2000 and July 2002; and in New Jersey between November 1999 and July 2002.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline.

[a] As reported by care recipients during the baseline interview.

TABLE 4

RECEIPT AND USE OF THE ALLOWANCE AMONG CARE RECIPIENTS IN THE TREATMENT GROUP, BY STATE

	Arkansas	Florida	New Jersey
Percentage of Care Recipients Who Received a Program Allowance[a]	87.7	55.4	74.7
Percentage of Caregivers Paid for Helping Care Recipient[b]	56.4	28.5	41.8
Percentage of Caregivers Paid for Helping Care Recipient, if Care Recipient Received a Program Allowance	62.6	45.9	55.6
Number of paid hours (if any) provided during two-week reference period (mean)[c]	12.5	19.6	20.6
Hourly wage (mean)[c]	\$6.07	\$10.26	\$9.84
Number of Care Recipients/Caregivers in the Treatment Group	**721**	**617**	**546**

Source: Program records from each of the demonstration states and MPR’s caregiver interview. Interviews were conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

[a] Measured 10 months after care recipients were randomly assigned to the treatment group and, thus, about the same time as caregivers were interviewed.

[b] The percentage of caregivers who were paid for any of the help they provided since care recipients’ random assignment, according to caregiver self-reports.

[c] Paid hours and hourly wages were measured for a subset of caregivers who were care recipients’ primary paid workers during the follow-up period. The mean paid hours provided by all caregivers is probably somewhat lower.

Among caregivers who became paid, those in Arkansas were paid for about 13 hours of care per week and earned $6 an hour; those in Florida and New Jersey were paid for about 20 hours of care per week and earned about $10 an hour.

Estimated Program Effects

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

Frequency, Amounts, and Timing of Assistance.[11] Regardless of treatment status, the caregivers in this analysis devoted substantial amounts of time to activities that benefited care recipients exclusively (such as help eating and bathing) and to activities that also may have benefited others in the household (such as preparing meals and doing laundry). Program effects on the amount of assistance provided by caregivers varied by state. The frequency of assistance was affected only in New Jersey, and the timing of assistance was affected only in Arkansas.

Caregivers in Arkansas provided assistance on 12 days during the two-week period they were asked about, regardless of treatment status (Table 5). During that time, treatment group caregivers provided about 107 hours of assistance and control group caregivers provided about 117 hours. The mean difference equaled one less hour of assistance per day (–10.4 hours/14.0

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[11] Appendix Table B.1 shows additional results on caregivers' living arrangements, provision of any assistance, and types of assistance provided.

TABLE 5

ESTIMATED EFFECTS ON FREQUENCY, AMOUNTS, AND TIMING OF ASSISTANCE PROVIDED BY PRIMARY INFORMAL CAREGIVERS, BY STATE

	Arkansas			Florida			New Jerseym		
	Predicted Means			Predicted Means			Predicted Means		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Frequency of Assistance Provided in Recent Two Weeks[a]									
Number of Days Helped Care Recipient	12.4	12.2	0.2 (.371)	12.7	12.7	0.0 (.844)	12.2	11.8	0.5** (.036)
Time Spent Meeting the Needs of Care Recipient and Other Household Members in Recent Two Weeks[a]									
Total Hours of Assistance[b]	106.6	117.0	–10.4* (.089)	123.7	132.7	–9.0 (.111)	123.2	113.3	9.9* (.057)
Among live-in caregivers	140.1	153.0	–12.9** (.035)	139.5	149.3	–9.8* (.069)	148.4	140.1	8.3 (.279)
Hours that benefited care recipient only[c]	64.8	68.2	–3.5 (.364)	72.0	77.7	–5.7 (.126)	77.0	74.7	2.3 (.652)
Hours that benefited entire household[d]	75.4	84.8	–9.4** (.012)	67.6	71.6	–4.1 (.190)	71.4	65.4	6.0 (.195)
Among visiting caregivers[e]	61.9	68.9	–7.0 (.164)	48.9	54.0	–5.1 (.676)	84.8	72.5	12.3* (.090)
Timing of Assistance Provided in Recent Two Weeks[a] (Percents)									
Assisted Care Recipient									
Before 8:00 A.M. weekdays	59.6	62.5	–3.0 (.264)	70.0	73.7	–3.8 (.121)	64.5	63.9	0.6 (.830)
After 6:00 P.M. weekdays	84.0	87.5	–3.5* (.081)	91.3	92.3	–0.9 (.533)	89.3	90.2	–0.1 (.650)

TABLE 5 (*continued*)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with ordinary-least-squares or logit models.

[a] The most recent two weeks during the two months before the interview in which the care recipient lived in the home or community.

[b] The estimates for total hours are constructed as weighted averages of the estimates for caregivers who are live-in and those who are visiting, with the weights being the proportion of all caregivers (treatment and control groups combined) who were live-in or visiting at followup. In Arkansas, these proportions were .571 (live-in) and .429 (visiting); in Florida, they were .826 and .174; and in New Jersey, they were .603 and .397. The variance of the estimated effect used to construct the t-statistic and corresponding p-value is $var = p_L^2 * \sigma_L^2 + (1\text{-}p_L)^2 * \sigma_V^2$, where σ_L^2 and σ_V^2 are the variances of the estimated coefficients on the treatment status indicator from the regressions on live-in and visiting caregivers, respectively. This approach ensures that the impact on total hours is a weighted average of the impacts on live-in and visiting caregivers.

[c] Includes routine health care, personal care, and transportation.

[d] Includes preparing meals and doing housework, laundry, shopping, and yard work to meet the needs of all household members.

[e] Includes time spent helping away from the care recipient's home, such as shopping for him or her or preparing meals to take to him or her. Excludes purely social visits and time traveling, doing paperwork, or not actively helping.

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

days = –0.7 hours) and was significant at the .10 level. This overall impact was driven by a 13-hour treatment-control difference in the amount of care provided by live-in caregivers (57 percent of the Arkansas sample), including a 9-hour difference in the time live-in caregivers spent on activities that benefited the entire household. In addition, Arkansas treatment group caregivers were slightly less likely than their control group counterparts to provide care after 6:00 P.M. on weekdays.

Florida caregivers provided assistance on nearly 13 days during the two-week period they were asked about, regardless of treatment status (Table 5). The treatment-control difference in the hours reported by all caregivers was not statistically significant. However, among caregivers who lived with their care recipient (83 percent of the Florida sample), those in the treatment group provided 140 hours of assistance during the two-week reference period, compared with 149 hours of assistance provided by control group caregivers. The mean difference of –0.7 hours per day was significant at the .10 level. The treatment-control difference was not significant for visiting caregivers.

In New Jersey, treatment group caregivers reported providing assistance on 12.2 days, somewhat more than the 11.8 days reported by control group caregivers (Table 5). During the two-week reference period, treatment group caregivers reported providing 10 more hours of assistance overall. Visiting caregivers (40 percent of the New Jersey sample) drove this difference. Visiting caregivers in the treatment group reported providing about 85 hours of assistance during the two-week reference period, compared with 73 hours reported by the control group (a difference of 0.9 hours per day).

Quality of Relationships with Care Recipients. All three Cash and Counseling programs seemed to positively affect some aspects of the relationships between caregivers and care recipients (Table 6). Caregivers were asked how well they got along with care recipients,

TABLE 6

ESTIMATED EFFECTS ON THE QUALITY OF RELATIONSHIPS BETWEEN PRIMARY INFORMAL CAREGIVERS AND CARE RECIPIENTS, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Caregiver and Care Recipient Get Along Very Well[a]	87.5	86.1	1.4 (.467)	88.7	84.9	3.8** (.047)	84.1	79.5	4.6* (.057)
Relationship Is Better Now than at Enrollment	27.9	26.7	1.2 (.619)	24.7	20.2	4.5* (.062)	30.8	25.6	5.2* (.064)
Caregiver Consults Care Recipient About Personal Care Questions[a,b]	21.9	13.7	8.2*** (.000)	9.7	12.3	–2.6 (.224)	23.0	23.0	0.0 (.993)
Caregiver Refuses to Cooperate When Caregiver Tries to Help[a]	28.6	34.5	–5.9** (.019)	28.5	34.0	–5.5** (.039)	28.1	29.6	–1.6 (.574)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models.

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

[b] Measured only for caregivers who provided assistance with personal care, such as eating, bathing, and using the toilet.

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

whether the relationship had improved since baseline, whether they consulted care recipients with questions about their personal care, and whether care recipients refused to cooperate when the caregiver offered help. Statistically significant effects were seen for three of the four measures in Florida, and for two of the four measures in Arkansas and New Jersey. All the treatment-control differences were modest (ranging from 4 to 8 percentage points). In no instances did treatment group caregivers report worse outcomes than control group caregivers.

Satisfaction with Quality of Care.[12] In all three states, treatment group caregivers were substantially more satisfied with care recipients' overall care arrangements and were less worried about insufficient care, safety, and theft when they were not with the care recipient (although many still worried) (Table 7).

Program effects on the proportions of caregivers that were very satisfied with care recipients' overall care arrangements were large in all states (Table 7). Specifically, the proportions of very satisfied treatment group caregivers were about 60 percent larger than the control group proportions of 30 percent in Florida and 32 percent in New Jersey, and 42 percent larger than the control group proportion of 43 percent in Arkansas. The proportions of dissatisfied treatment group caregivers were smaller than the control group proportions by similarly large amounts.

In all states, smaller proportions of treatment group caregivers than of control group caregivers said they worried quite a lot that care recipients would not get enough care in their absence, that care recipients' safety was at risk, or that someone would take care recipients' money or other belongings (Table 7). As a percentage of the control group means, differences for these measures were generally somewhat larger in Arkansas than they were in the other

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

TABLE 7

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' SATISFACTION WITH CARE QUALITY, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
How Satisfied with Care Recipient's Overall Care Arrangements									
Very satisfied	60.8	42.7	18.1*** (.000)	47.9	29.8	18.1*** (.000)	51.6	31.7	19.9*** (.000)
Dissatisfied	9.1	22.8	–13.7*** (.000)	15.7	27.5	–11.8*** (.000)	13.3	32.2	–18.8*** (.000)
When Not with Care Recipient, How Often Worries That:[a]									
Care Recipient Does Not Have Enough Help									
Quite a lot	35.8	53.5	–17.6*** (.000)	47.8	60.5	–12.7*** (.000)	52.2	70.2	–18.0*** (.000)
Rarely or not at all	35.6	20.2	15.4*** (.000)	27.3	13.4	13.8*** (.000)	23.9	12.7	11.2*** (.000)
Care Recipient's Safety Is at Risk									
Quite a lot	39.3	53.4	–14.1*** (.000)	43.1	52.3	–9.2*** (.001)	53.5	64.8	–11.3*** (.000)
Rarely or not at all	31.8	21.9	9.9*** (.000)	30.6	18.7	11.9*** (.000)	23.4	13.6	9.8*** (.000)
Someone Will Take Care Recipient's Money or Other Belongings									
Quite a lot	14.0	20.3	–6.3*** (.001)	22.2	29.2	–7.0*** (.005)	24.9	30.3	–5.5** (.041)
Rarely or not at all	69.4	62.7	6.8*** (.007)	61.5	49.9	11.6*** (.000)	62.0	53.4	8.7*** (.004)

TABLE 7 (*continued*)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models.

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

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

states. For example, in Arkansas, the proportion of treatment group caregivers who said they worried quite a lot about their care recipient's safety was 26 percent smaller than the control group proportion of 53 percent, while the treatment group proportions in Florida and New Jersey were about 17 percent smaller than the control group proportions of 52 percent and 65 percent, respectively.

A somewhat different pattern emerged for estimated effects on the proportion of caregivers that worried only rarely or not at all about sufficient care, safety, and theft. As a percentage of the control group means, impacts were somewhat smaller in Arkansas than they were in Florida or New Jersey, but they were still sizable and significant (Table 7).

Emotional Well-Being. Cash and Counseling seemed to favorably affect caregivers' emotional well-being by all of five measures in Arkansas and New Jersey, and by three of five measures in Florida (Table 8). First, although many caregivers in each state said care recipients required their almost constant attention, the treatment group proportions were 8 or 9 percent smaller than the control group proportions, which ranged from 57 percent in Arkansas to roughly 70 percent in Florida and New Jersey. Second, the proportions of treatment group caregivers who said caregiving impinged on their privacy were 27 percent smaller than the control group proportions in Arkansas, 19 percent smaller than in New Jersey, and only 8 percent smaller than in Florida, with slightly more than half the control group caregivers in each state reporting that caregiving affected their privacy. Third, treatment group caregivers were less likely to say caregiving limited their free time or social lives in each state, though as a percentage of the control group mean the effects were twice as large in Arkansas as they were elsewhere.

Finally, the proportions of treatment group caregivers saying caregiving caused them a great deal of emotional strain were substantially smaller than the control group proportions in

TABLE 8

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' EMOTIONAL WELL-BEING, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Care Recipient Requires Almost Constant Attention from Caregiver	52.6	57.2	–4.6* (.054)	63.7	68.9	–5.2** (.028)	64.0	70.5	–6.5** (.013)
Caregiving Limits:									
Privacy	38.7	52.7	–14.1*** (.000)	52.3	57.1	–4.8* (.084)	41.1	50.5	–9.4*** (.001)
Free time or social life	52.5	63.8	–11.3*** (.000)	66.9	73.3	–6.5*** (.008)	54.8	60.1	–5.3* (.061)
Level of Emotional Strain as a Result of Caregiving									
A great deal	26.8	34.3	–7.5*** (.002)	35.7	38.6	–2.9 (.286)	42.3	49.4	–7.1** (.017)
Little or none	41.0	35.0	6.0** (.015)	29.4	28.1	1.3 (.600)	28.3	23.1	5.2** (.049)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Outcomes were measured "at present" or "when you were last helping." Means were predicted with logit models.

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

Arkansas and New Jersey (Table 8). Likewise, the treatment group proportions reporting little or no emotional strain were substantially larger than the control group proportions in both states. In Florida, treatment and control group caregivers reported similar levels of emotional strain.

Job Performance and Financial Well-Being. In all three states, substantial proportions of caregivers said that caregiving adversely affected their choice and performance of jobs, but some problems were less prevalent in the treatment group (Table 9). For example, while at least 38 percent of control group caregivers in each state said they had not looked for a job, or another job, although they wanted to, since their care recipients' demonstration enrollment, the proportions of treatment group caregivers reporting this problem were 39 percent smaller than the control group proportions in Arkansas, 24 percent smaller than in New Jersey, and 16 percent smaller than in Florida. Among caregivers who were working for pay (other than for their care recipient) when interviewed, those in the treatment group were less likely than those in the control group to say they missed work or arrived late because of caregiving. Again, the estimated program effects were proportionally largest in Arkansas and smallest in Florida. Also in Arkansas, the proportion of treatment group caregivers that declined a better job or a promotion because of caregiving was significantly smaller than the control group proportion of 28 percent.

Although Cash and Counseling did not discernibly affect caregivers' household income, it seemed to alleviate their perception of financial strain in all three states (Table 9). In Arkansas, the proportion of treatment group caregivers reporting a great deal of financial strain as a result of caregiving was nearly 40 percent smaller than the control group proportion, while in Florida and New Jersey the treatment group proportions were about one-fourth smaller than the control group proportions. Similarly, treatment group caregivers were substantially more likely than control group caregivers to report little or no financial strain in each state.

TABLE 9

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' JOB PERFORMANCE AND FINANCIAL WELL-BEING, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Job Performance Since Care Recipient's Enrollment									
Worked for Pay, Other than for Care Recipient	48.4	49.2	–0.8 (.683)	50.6	49.7	0.9 (.613)	54.2	57.0	–2.9 (.171)
Did Not Look for a Job or Another Job but Wanted to	23.5	38.6	–15.1*** (.000)	35.1	41.8	–6.7** (.011)	33.9	44.1	–10.3*** (.000)
Among Those Who Worked for Pay, Other than for Care Recipient, Caregiving Caused Them to:									
Miss work or arrive late	48.6	60.6	–12.0*** (.001)	60.9	67.1	–6.2* (.095)	53.6	65.8	–12.2*** (.002)
Decline a better job or promotion	21.5	27.8	–6.3** (.046)	35.3	35.4	–0.1 (.975)	31.8	32.3	–0.4 (.906)
Quit job or reduce hours	29.2	31.5	–2.2 (.511)	29.3	34.0	–4.7 (.179)	34.3	37.1	–2.8 (.464)
Financial Well-Being									
Level of Financial Strain as a Result of Caregiving[a]									
A great deal	22.4	35.7	–13.3*** (.000)	29.9	38.9	–9.0*** (.001)	30.0	38.6	–8.6*** (.001)
Little or None	48.3	34.9	13.4*** (.000)	36.2	25.3	10.9*** (.000)	39.8	31.5	8.4*** (.005)
Household Income Last Month									
$1,000 or less	40.7	42.1	–1.4 (.504)	24.8	25.0	–0.2 (.903)	37.4	40.4	–3.0 (.175)
$1,001 to $2,000	41.5	41.1	0.4 (.504)	36.5	36.5	0.0 (.903)	31.0	30.7	0.3 (.175)
$2,001 to $3,000	10.6	10.2	0.5 (.504)	20.1	20.0	0.1 (.903)	15.6	14.7	0.9 (.175)
$3,001 or more	7.1	6.6	0.4 (.504)	18.6	18.4	0.2 (.903)	16.0	14.1	1.8 (.175)

Source: MPR’s caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit or orderered-logit models.

[a] Measured “at present” or “when you were last helping.”

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

Physical Well-Being and Health.[13] The physical burden so often associated with informal caregiving was markedly less prevalent under Cash and Counseling (Table 10). Across states, the proportions of treatment group caregivers reporting that caregiving caused them a great deal of physical strain were smaller than those of control group caregivers by about 24 to 28 percent, with control group proportions ranging from 32 to 42 percent. Smaller proportions of treatment group caregivers reported that their physical health suffered as a result of caregiving, and smaller proportions said their own health was fair or poor (as opposed to good or excellent) compared to the health of other people their age. For example, while 34 to 45 percent of control group caregivers in each state said their health had suffered, the proportions of treatment group caregivers saying the same were 23 to 31 percent smaller.

Satisfaction with Life. In all three states, treatment group caregivers were much more likely than control group caregivers to be very satisfied with their own lives and much less likely to be dissatisfied (Table 11). While 35 to 39 percent of control group caregivers in each state were very satisfied with their lives, the proportions of very satisfied treatment group caregivers were roughly one-third larger in each state. Moreover, while about a quarter of control group caregivers in each state was dissatisfied with life, the proportions of dissatisfied treatment group caregivers were smaller by nearly half in Arkansas and New Jersey, and by one-fourth in Florida.

Primary Informal Caregivers Who Became Paid Workers

Explanatory Variables. Under Cash and Counseling, the treatment group's caregivers continued to provide many hours of assistance to care recipients, but only some were paid. We used logistic regression to estimate the odds that caregivers became paid workers as a function of

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

TABLE 10

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS’ PHYSICAL WELL-BEING AND HEALTH, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Level of Physical Strain as a Result of Caregiving[a]									
A great deal	23.0	32.0	–9.0*** (.000)	28.4	38.8	–10.4*** (.000)	31.7	41.8	–10.1*** (.000)
Little or none	37.6	30.6	7.0*** (.004)	30.3	25.1	5.3** (.034)	33.3	24.3	9.0*** (.001)
Physical Health Has Suffered as a Result of Caregiving[a]	23.6	34.3	–10.7*** (.000)	32.7	44.9	–12.2*** (.000)	30.7	40.3	–9.6*** (.001)
Current Health Is Fair or Poor Relative to That of Peers	35.5	46.7	–11.2*** (.000)	31.8	39.6	–7.8*** (.004)	30.3	42.3	–12.0*** (.000)

Source: MPR’s caregiver interviews, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models.

[a] Measured “at present” or “when you were last helping.”

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

TABLE 11

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' SATISFACTION WITH LIFE, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Current Satisfaction with Life									
Very satisfied	51.3	39.9	11.4*** (.000)	47.0	35.2	11.8*** (.000)	51.6	37.5	14.1*** (.000)
Dissatisfied	13.1	23.2	–10.1*** (.000)	16.7	22.8	–6.1*** (.008)	15.2	27.3	–12.2*** (.000)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models.

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

their observable characteristics and those of care recipients.[14] (The dependent variable was a binary self-reported measure of whether the caregiver was paid for helping the care recipient at any time since enrollment.)

Across states, a few explanatory variables were consistently associated with whether primary informal caregivers became paid workers. These were (1) the sex of caregivers, (2) whether care recipients used a proxy respondent for the baseline interview, and (3) whether care recipients considered it very important to be able to pay family or friends for caregiving when they enrolled in the demonstration (Appendix Table B.4). All else equal, female caregivers were more than twice as likely as male caregivers to become paid in all three states. Care recipients who—because of physical or cognitive impairment—used a proxy respondent for the baseline interview were less likely than others to pay their primary informal caregiver (odds ratios ranged from 0.49 to 0.84). These caregivers may have preferred that the allowance be used to pay others to perform some stressful tasks, rather than be paid themselves.

No other strong patterns of association emerged across states. In Arkansas, caregivers' income level was most strongly associated with becoming paid (after being female). Primary informal caregivers who had monthly household incomes greater than $1,000 were less likely than other caregivers to become paid workers, presumably because they had less need of additional income. In Florida, if a representative managed or helped manage the care recipient's program responsibilities, the primary informal caregiver was more than twice as likely to become paid, relative to there being no representative. Representatives may have advocated paying the

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[14] In each state, we estimated the model for all treatment group caregivers (except spouses in Arkansas), and then for the subset of treatment group caregivers whose care recipients had received the program allowance within 10 months of random assignment. Results were similar for both samples; thus, we report results for the full samples. Results for the restricted samples could be confounded by the interdependence of allowance receipt and payment of caregivers. That is, although caregiver payment is conditional on allowance receipt, caregivers may also affect the likelihood of allowance receipt—by being willing or unwilling to be hired.

primary informal caregiver when developing the allowance-spending plan. Indeed, the representative may have *been* the primary informal caregiver and advocated self-payment. In New Jersey, care recipients who considered it very important, at baseline, to be able to pay family members or friends for caregiving were more than three times as likely as other care recipients to hire their primary informal caregiver. (Appendix Table B.4 gives the estimated odds ratios for all variables in the models.)

Reasons for Remaining Unpaid. Treatment group caregivers who were not paid for caregiving at the time of their interview were asked why not. (The survey question was open-ended, but interviewers recorded responses with the aid of a precoded list.) No single reason predominated in any state; however, caregivers in all three states most commonly said they helped out of love, devotion, or family tradition (cited by 26 to 28 percent of caregivers) (Appendix Table B.5). Across states, 11 to 16 percent of caregivers said they were not able to perform all the tasks care recipients required, lived too far from them, or had other obligations. Others (8 to 11 percent) said the allowance was not large enough to pay them and meet the other needs of the care recipient. Less than five percent of caregivers in each state said they were not paid because their care recipient had not yet received the program allowance. Finally, substantial proportions of caregivers said they did not know they could be paid—9 percent in Arkansas, 14 percent in Florida, and 15 percent New Jersey.

Estimated Effects of Payment. To explore whether Cash and Counseling affected paid and unpaid treatment group caregivers differently, we estimated separate programs effects for each of these subsets. For 15 key measures of caregiver well-being and satisfaction, similar patterns emerged in all three states: (1) paid and unpaid treatment group caregivers both fared significantly better than control group caregivers for at least half the outcomes; and (2) in most such instances, the estimated effects were substantially larger for paid caregivers than they were for unpaid caregivers. Thus, while the results suggest that getting paid for caregiving was not the sole factor that led treatment group caregivers to report better outcomes than control group caregivers, getting paid did seem to increase the magnitude of most treatment-control differences. We discuss specific findings below; however, differences between paid (or unpaid) caregivers in the treatment group and all caregivers in the control group must be interpreted with caution. Estimated effects may be driven more by unobserved differences between paid and unpaid caregivers in the treatment group than they were by payment. Such “self-selection bias” could arise, for example, if caregivers who became paid had had more responsibility, on average, for arranging care recipients’ personal care than caregivers who remained unpaid. Caregivers accustomed to responsibility and control may have benefited most from Cash and Counseling.

In all three states, both subsets of treatment group caregivers (paid and unpaid) fared better than control group caregivers with respect to satisfaction with overall care arrangements, worries about insufficient care, pursuit of desired jobs, and level of financial strain (Appendix Table B.6). In Arkansas, both paid and unpaid treatment group caregivers were also less likely than control group caregivers to report limitations on privacy and free time. In Florida and New Jersey, both paid and unpaid treatment group caregivers had greater satisfaction with life than control group caregivers. In all three states, the estimated program effects on whether caregivers did not pursue desired jobs were similar for paid and unpaid treatment group caregivers, relative to control group caregivers.

For other key satisfaction and well-being outcomes, paid treatment group caregivers had significantly better outcomes than control group caregivers, but unpaid treatment group caregivers and control group caregivers had similar ones (Appendix Table B.6). For example, in all three states, only paid treatment group caregivers fared better than control group caregivers with respect to the important measures of emotional strain and physical health. In addition, in

Arkansas, only paid treatment group caregivers fared better than control group caregivers with respect to a high level of satisfaction with life and whether care recipients cooperated when caregivers tried to help. In Florida and New Jersey, only paid treatment group caregivers were less likely than control group caregivers to report limitations on privacy and free time.

We also examined whether estimated program effects on the amount of care provided may have stemmed from caregiver payment. The results differed by state. In Arkansas, live-in treatment group caregivers provided fewer hours of care than their control group counterparts, whether or not they became paid workers. Among visiting caregivers, however, those in the treatment group provided fewer hours of assistance than did those in the control group only if they remained unpaid. In Florida, unpaid treatment group caregivers provided substantially less care (about 17 fewer hours per two weeks) than control group caregivers. The mean number of hours for paid treatment group caregivers *exceeded* that of the control group by about 10 hours, but the difference was not statistically significant. In contrast, in New Jersey, no program effects were seen on the amount of care provided by unpaid treatment group caregivers, but those who became paid provided about 21 *more* hours of care per two weeks, relative to the control group, and they helped more often. This was true for both live-in and visiting caregivers.

Caregiver Effects, by Care Recipients' Age Group

Because providing personal assistance to an elderly care recipient may be very different from caring for a nonelderly one, we conducted a subgroup analysis to assess whether key caregiver outcomes differed by care recipients' age group. Because some of the subgroups were quite small, only very large differences within and between groups were statistically significant; however, the size and direction of the differences revealed interesting patterns.

First, regardless of care recipients' age group, treatment group caregivers in all three states were much more likely than their control group counterparts to be very satisfied with their care recipient's overall care arrangements (Appendix Tables B.7a through B.7c). For key measures of caregivers' emotional, physical, and financial well-being, however, the results differed by state. In Arkansas, treatment group caregivers fared better than their control group counterparts regardless of care recipients' age group. In New Jersey, program effects were large and positive for treatment group caregivers who assisted elderly care recipients, but they were smaller and not significant for treatment group caregivers who assisted nonelderly adults. In Florida, treatment group caregivers who assisted elderly adults reported less physical strain than their control group counterparts, while treatment group caregivers who assisted nonelderly adults reported less physical and financial strain. Cash and Counseling did not affect emotional well-being in either Florida subgroup.

The subgroup results for Arkansas and New Jersey suggest that the amount of assistance caregivers provided may have been related to their levels of emotional, physical, and financial strain. In Arkansas, treatment group caregivers in both subgroups provided fewer (or similar) hours of assistance to care recipients as control group caregivers provided (Appendix Table B.7a). As noted, treatment group caregivers in both subgroups were less likely than their control group counterparts to report a great deal of emotional, physical, and financial strain, on average. In contrast, in New Jersey, treatment group caregivers for nonelderly adults provided substantially *more* hours of assistance than their control group counterparts, and their levels of emotional, physical, and financial strain were *similar* to those of control group caregivers (Appendix Table B.7c). (Although the estimated effects favored the treatment group, they were not statistically significant.) Within the subgroup of caregivers for elderly adults in New Jersey, treatment and control group caregivers provided about the *same* hours of assistance, and treatment group caregivers reported *less* strain.

The Florida results for physical and financial strain follow a similar pattern. In both age groups, live-in treatment group caregivers (who comprised 83 percent of the analysis sample) provided similar or fewer hours of assistance and were less likely to report a great deal of at least one type of strain (Appendix Table B.7b). The relationships were not entirely consistent across subgroups, however. For example, while the emotional strain for caregivers of nonelderly care recipients was not significantly different from zero, it was close in magnitude to, and not significantly different from, the estimate for caregivers for elders, despite the large difference in the effects on hours of care.

Overall, the estimates did follow a general pattern that is consistent with expectations, given the burden that caregivers face. If caregivers provide more hours of assistance to care recipients under consumer direction than they would provide otherwise, their emotional, physical, and financial well-being may not improve. In contrast, if caregivers provide approximately the same amount of care or less than they would otherwise, they may be more likely to benefit emotionally, physically, and financially.

DISCUSSION

Summary and Interpretation

The demonstration programs implemented in Arkansas, Florida, and New Jersey all tested the Cash and Counseling model of delivering Medicaid supportive services. The programs had the goal of improving consumer satisfaction and quality of life and were expected, in turn, to improve the well-being of consumers' primary informal caregivers.

Regardless of treatment status, the caregivers who responded to our interview devoted a great deal of time to caregiving and reported considerable emotional, physical, and financial strain, on average. Cash and Counseling did not eradicate caregiver strain, but it appeared to alleviate it. Compared with the informal caregivers in the randomly assigned control group, those in the treatment group had better outcomes with respect to:

- Feeling very satisfied with the care recipient's overall care arrangements
- Worrying about insufficient care, safety, and theft
- Having privacy and free time
- Getting along with the care recipient
- Experiencing financial strain as a result of caregiving
- Being able to pursue desired jobs and getting to work on time
- Experiencing physical strain, or physical health problems, as a result of caregiving
- Feeling very satisfied with their own lives

Of course, results were not entirely uniform. Although positive program effects were seen for these key outcomes in all three states, the size of the effects relative to the control group means often differed. For some outcomes, the estimated effects were proportionally largest in Arkansas, where care recipients were more likely to receive an allowance (87 percent) and the proportion of primary informal caregivers hired by care recipients was largest (56 percent). In addition, the direction of estimated program effects on the amounts of assistance provided by caregivers differed by state. Although Cash and Counseling seemed to somewhat reduce the amount of assistance caregivers provided in Arkansas and Florida, it seemed to increase the amount provided by the caregivers of nonelderly care recipients in New Jersey, perhaps diminishing gains for some other outcomes. Finally, the Arkansas and New Jersey programs seemed to have large, positive effects on the level of emotional strain reported by caregivers overall. In contrast, there were no apparent effects on emotional strain in Florida, where slightly more than half the care recipients were receiving the allowance, and only about one-fourth hired their primary informal caregiver.

Several mechanisms probably contributed to the positive effects we observed. For example, reductions in caregivers' financial strain may have stemmed from being hired as workers, from having more flexibility to do other paid work, or from consumers using their program allowance to buy care-related items that caregivers might have paid for otherwise. Caregivers may have been more likely to get to work on time because consumers hired workers who were more reliable than those sent by agencies. Likewise, caregivers may have worried less about safety and theft because consumers hired workers whom they, and their caregivers, knew personally and trusted. Apparent reductions in caregivers' physical strain may have resulted from consumers hiring other workers to perform the physically demanding tasks (especially if caregivers themselves were frail) or from consumers' using the program allowance to buy assistive devices to help them transfer or increase mobility. For example, a companion report for the evaluation found that nonelderly treatment group members in Arkansas were more likely than control group members to have modified their homes or purchased assistive equipment (Carlson et al. 2005).

Our assessment of the effects of payment on caregiver outcomes suggests that primary informal caregivers who became paid workers derived substantial benefit from their change in status, even though they were paid for only a fraction (12 to 17 percent) of the hours they worked. Most notably, paid treatment group caregivers in all three states were about 20 percentage points more likely than control group caregivers to be very satisfied with their own lives at the time they were interviewed. Although estimated program effects on caregiver satisfaction and well-being often were smaller for unpaid caregivers than they were for paid caregivers, unpaid caregivers fared better than control group caregivers on many measures of satisfaction and well-being. In addition, compared with control group caregivers in Arkansas and Florida, unpaid treatment group caregivers in those states provided substantially fewer hours of assistance to care recipients, which could be seen as an important caregiver benefit.

Across states, some of the differences in the relative magnitude of overall program effects may have stemmed from differences in program implementation and design. As noted, it is not surprising to see some of the largest program effects in Arkansas, because its treatment group had the largest proportion of active care recipients—those who developed an allowance-spending plan and used the allowance to meet their needs for supportive services. Moreover, the demonstration states enrolled markedly different consumer populations in terms of age and disability. If Florida's demonstration program did not affect caregivers' emotional strain, it may have been because the emotional strain experienced by the caregivers of younger adults with primarily developmental disabilities (such as Florida enrolled) was different from that experienced by the caregivers of elderly adults with primarily physical disabilities (such as Arkansas and New Jersey enrolled) in ways consumer direction could not address. For example, compared with caregivers in Arkansas and New Jersey, those in Florida may have worried more about consumers' future care arrangements if the consumers outlived them. Consumer direction, despite being attractive in the near term, might not allay the emotional strain experienced by aging parents of adult children with developmental disabilities.

Limitations

Each state's analysis was based on a randomized design and yielded estimated program effects that were quite large and consistent across many types of measures. Despite the robustness of our findings, a few caveats are warranted about study duration, possible reporting bias, and the desirability of additional data. In Arkansas, our analysis also may have been affected by consumers' participation in an HCBS waiver program.

First, given the relatively short duration of our follow-up period, we do not know whether the positive effects observed for treatment group caregivers would persist. Improvements in the satisfaction and well-being of caregivers might not last, for example, if changes in the amount of assistance caregivers provided were not sustainable, the gratification derived from getting paid for caregiving were to diminish, or consumers made short-term or unstable care arrangements (such as by hiring young relatives who later went away to school).

Second, we cannot rule out the possibility that some caregivers for treatment group members might have inflated reports on some outcomes, such as their own health status, because Cash and Counseling brought them other benefits and they wanted the program to continue. Conversely, some caregivers for control group members may have overstated their dissatisfaction or burden because they were disappointed that their care recipient was not randomly assigned to the treatment group.

Third, having data on additional caregiver characteristics would have enriched our analysis in two ways. First, having data on caregivers' baseline health status and levels of strain would have enabled us to determine how Cash and Counseling affected subgroups of caregivers defined by those characteristics. Second, if the models used to estimate payment effects had controlled for such variables, we would be more confident in concluding that observed differences in the outcomes between paid and unpaid caregivers actually resulted from their payment status and not from unobserved differences between the groups.

As noted, the estimated program effects for Arkansas must be considered in light of the fact that 45 percent of the caregivers in the analysis were helping care recipients who participated in ElderChoices, an HCBS waiver program, during the evaluation followup. Because ElderChoices provides nurse supervision, the treatment group caregivers in this analysis may have felt more secure about their care recipients' foray into consumer direction than they would have otherwise.

If this were true, our analysis would overstate the favorable effects of Cash and Counseling on caregivers. To the contrary, our tests of this hypothesis showed that, for all but three key outcomes, the estimated effects of Cash and Counseling were significantly larger for treatment group caregivers whose care recipients did *not* participate in ElderChoices than they were for treatment group caregivers whose care recipients did participate (Appendix Table B.8). Perhaps as long as workers from the ElderChoices program—as opposed to workers consumers had chosen and hired themselves—were still visiting the homes of treatment group consumers, their caregivers were more likely to worry about safety and theft.[15] All else equal, if Arkansas's Cash and Counseling program were replicated in states without programs like ElderChoices, even larger caregiver impacts might be expected.

Implementation Lessons and Policy Implications

Implementation Lessons. The findings from this three-state analysis suggest two lessons for state program administrators. Clearly, the sooner interested consumers begin receiving the allowance and implementing decisions about their care, the sooner their caregivers benefit. Thus, one lesson is that programs should give consumers whatever assistance they might need to develop their allowance spending plans, possibly holding program counselors responsible for starting most consumers on the allowance within a certain time frame. Arkansas contractually obligated its fiscal/counseling agency to start consumers on the allowance within 45 days of random assignment and developed a database program that reminded counselors about consumers who were not yet allowance recipients. Neither Florida nor New Jersey held counselors responsible in this way. Second, because some caregivers benefited from becoming

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[15] The subgroup analysis controlled for the care recipient and caregiver characteristics listed in Table A.2a; thus, it accounted for some important differences between ElderChoices participants and nonparticipants, such as self-reported health status and the number of hours authorized in consumers' Medicaid personal care plans.

paid workers, programs should give consumers and caregivers clear and accurate information about their hiring policies. Presumably, at least some of the caregivers in Arkansas, Florida, and New Jersey who remained unpaid during the evaluation period because they did not know they could be paid would have benefited from payment.

Policy Implications. Findings from this study may enlighten policy debates about whether consumer direction threatens care quality and whether to allow consumers to pay family members for caregiving. The demonstration states addressed concerns about care quality procedurally (for example, by mandating contact between consumers and program counselors). Although not in any official capacity, the caregivers in our sample also monitored care quality; their survey responses may be viewed as testimony to the programs' success. The caregivers in this study were less likely to report worrying about insufficient care, safety, and theft by paid workers. Moreover, treatment group caregivers, like treatment group consumers (see Carlson et al. 2005), were significantly more likely than their control group counterparts to be very satisfied with consumers' overall care arrangements.

Policymakers who are concerned about paying family caregivers may worry that the practice will erode traditional values about familial responsibility and induce demand for caregiver payment. The programs in this study had positive effects, or no effects, on the quality of relationships between caregivers and care recipients and, thus, do not add to concerns about the erosion of family values. Moreover, Cash and Counseling did not appear to induce widespread demand for caregiver payment. Although many caregivers in our samples became paid workers under Cash and Counseling, 44 percent or more in each state remained unpaid and even those who were paid continued to provide many hours of *unpaid* assistance.

As states and the federal government seek to increase Medicaid beneficiaries' ability to live at home, instead of in institutions, attention must be paid to the burden society places on informal caregivers. The expanding availability of Medicaid supportive services, made possible in recent years through the federal New Freedom Initiative and Systems Change grants and through state-funded efforts, helps the nation's growing population of informal caregivers. The Cash and Counseling Demonstration and Evaluation has shown that expanding the availability of consumer-directed supportive services could help these caregivers even more.

REFERENCES

Benjamin, A.E., and Ruth Matthias. "Work-Life Differences and Outcomes for Agency and Consumer-Directed Home-Care Workers." *The Gerontologist*, vol. 44, no. 4, August 2004, pp. 479–488.

Benjamin, A.E., Ruth Matthias, and Todd Franke. "Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home." *Health Services Research*, vol. 35, no. 1, part 2, April 2000, pp. 351–366.

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

Doty, Pamela. "Consumer-Directed Home Care: Effects on Family Caregivers." Policy Brief. San Francisco, CA: Family Caregiver Alliance, October 2004. Available at [www.caregiver.org]. Accessed July 1, 2005.

Doty, Pamela. "Informal Caregiver 'Burnout': Predictors and Prevention." *ASPE Research Notes.* Washington, DC: U.S. Department of Health and Human Services, April 22, 1997.

Flanagan, Susan. "An Inventory of Consumer-Directed Support Service Programs: Overview of Key Program Characteristics." Presented at the Annual Meeting of the Cash and Counseling Demonstration and Evaluation, Arlington, VA, October 24, 2001.

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

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

Gaugler, Joseph, Robert Kane, Rosalie Kane, Ted Clay, and Robert Newcomer. "Caregiving and Institutionalization of Cognitively Impaired Older People." *The Gerontologist*, vol. 43, no. 2, April 2003, pp. 219–229.

Harrington, Charlene, and Martin Kitchener. "Medicaid Long-Term Care: Changes, Innovations, and Cost Containment." San Francisco, CA: University of California, San Francisco, July 2003. Available at [www.ncsl.org/programs/health/harrington]. Accessed March 18, 2004.

National Alliance for Caregiving and AARP. *Caregiving in the U.S.* Bethesda, MD: NAC and AARP, 2004. Available at: [www.caregiving.org/04finalreport.pdf]. Accessed July 27, 2004.

O'Brien, Ellen, and Risa Elias. "Medicaid and Long-Term Care." Menlo Park, CA: Henry J. Kaiser Family Foundation, May 2004.

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

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., June 2002.

Rabow, Michael, Joshua Hauser, and Jocelia Adams. "Supporting Family Caregivers at the End of Life." *Journal of the American Medical Association*, vol. 291, no. 4, January 28, 2004, pp. 483–491.

Schulz, Richard, and Scott Beach. "Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study." *Journal of the American Medical Association*, vol. 282, no. 23, December 15, 1999, pp. 2215–2219.

Schur, Dorothy, and Carol Whitlatch. "Circumstances Leading to Placement: A Difficult Caregiving Decision." *Lippincott's Case Management*, vol. 8, no. 5, September/October 2003, pp. 187–195.

Sewitch, M.J., J. McCusker, N. Dendukuri, and M.J. Yaffe. "Depression in Frail Elders: Impact on Family Caregivers." *International Journal of Geriatric Psychiatry*, vol. 19, no. 7, 2004, pp. 655–665.

U.S. Department of Health and Human Services. "Delivering on the Promise: Preliminary Report on the New Freedom Initiative." Washington, DC: U.S. Department of Health and Human Services, April 2002. Available at [www.hhs.gov/newfreedom/prelim/cargive.html]. Accessed October 22, 2002.

Zarit, Steven H. "Family Care and Burden at the End of Life." Commentary, E-Journal of the Canadian Medical Association, vol. 170, no. 12, June 8, 2004. Available at [www.cmaj.ca/cgi/content/full/170/12/1811]. Accessed July 7, 2005.

APPENDIX A

ADDITIONAL INFORMATION ON METHODS

TABLE A.1

OUTCOME MEASURES FOR PRIMARY INFORMAL CAREGIVERS, BY TYPE

Living Arrangements and Types of Assistance Provided in Recent Two Weeks

Whether lived with care recipient

Whether lived within 10 minutes' travel time of care recipient

Whether provided assistance

Among those providing assistance:

- Helped with personal care
- Helped with household tasks
- Helped with routine health care
- Kept care recipient company

Frequency, Amount, and Timing of Care Provided in Recent Two Weeks

Mean number of days provided care

Among live-in caregivers:
- Mean hours of care that benefited care recipient only
- Mean hours of care that benefited entire household

Among visiting caregivers:
- Mean hours of care per day

Whether provided care:
- Before 8:00 A.M. weekdays
- After 6:00 P.M. weekdays

Knowledge, Preparedness, and Consulting Others

Whether feels well informed about care recipient's condition and services

Whether feels fully prepared to meet expectations in helping care recipient

Whether consults care recipient with personal care questions

Caregiver-Care Recipient Relationship

How well caregiver and care recipient get along

Whether relationship is better or worse than, or about the same as, it was at enrollment

Whether care recipient refuses to cooperate when caregiver tries to help

Perception of Care Quality

How satisfied with care recipient's overall care arrangements

When caregiver is not with care recipient, how often worries about:
- Care recipient not getting enough care
- Care recipient's safety
- Someone taking care recipient's money or other belongings

Caregiver's Quality of Life

Whether caregiving limits:
- Privacy
- Free time or social life

Whether care recipient requires almost constant attention from caregiver

Level of emotional strain as a result of caregiving

How satisfied with life in general

Job Choice and Performance Since Enrollment

Whether worked for pay, other than for care recipient

Among those who did, whether caregiving caused them to:
- Miss work or arrive late
- Turn down a better job or promotion
- Quit job or reduce hours

Whether did not look for a job, or another job, although wanted to

Financial Well-Being

Level of financial strain as a result of caregiving

Household income last month

Physical Well-Being

Whether physical health suffered as a result of caregiving

Level of physical strain as a result of caregiving

Health and Functioning

Current health status relative to that of peers

Whether illness or disability caused problems with:
- Preparing meals, doing housework, laundry, shopping, taking medicine, or managing money
- Eating, getting out of bed or a chair, dressing, bathing, or using the toilet

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

TABLE A.2a

BASELINE CHARACTERISTICS OF CARE RECIPIENTS AND PRIMARY INFORMAL CAREGIVERS, BY EVALUATION STATUS: ARKANSAS

(Percentages)

Characteristic	Treatment Group	Control Group
Care Recipients' Demographics		
Age in Years		
18 to 39	8.9	7.8
40 to 64	15.7	18.6
65 to 79	36.1	35.0
80 or older	39.3	38.7
Female	77.0	78.1
Hispanic[a]	1.4	1.0
Race		
White	60.1	61.0
Black	34.8	33.9
Other	5.1	5.2
Lives Alone	23.4	23.2
Graduated from High School	22.8	24.9
Described Area of Residence as:		
Rural	40.3	41.0
Not rural but high-crime or lacking adequate public transportation	26.5	28.6
Not rural, not high-crime, having adequate public transportation	33.2	30.4
Care Recipients' Health and Functioning		
Relative Health Status		
Excellent or good	19.7	23.5
Fair	30.3	30.3
Poor	50.0	46.2
Not Independent in Past Week in:[b]		
Getting in or out of bed	69.4	70.8
Bathing	93.3	92.8
Using toilet/diapers	71.7	68.7
Care Recipients' Use of Personal Assistance		
Received Any Help in Past Week with:		
Household activities[c]	98.3	97.8
Personal care[d]	91.1	91.3
Transportation[e]	65.2	67.5
Routine health care[f]	79.9	78.5
Number of Unpaid Caregivers Who Provided Help in Past Week		
1	33.8	30.4
2	30.4	31.6
3 or more	35.9	38.0

TABLE A.2a (*continued*)

Characteristic	Treatment Group	Control Group
Length of Time with Publicly Funded Home Care:		**
Less than 1 year	21.2	20.2
1 to 3 years	19.6	23.7
More than 3 years	21.1	19.9
Respondent said no care last week, but program says current user	12.8	8.5
Not a current recipient	25.3	27.7
Number of Paid Caregivers in Past Week		
0	34.1	33.1
1	38.2	39.2
2 or more	27.7	27.8
Number of Hours per Week in Medicaid Care Plan		
1 to 6	24.7	22.5
7 to 11	34.8	37.6
12 or more	40.5	39.9
Care Recipients' Satisfaction with Care and Unmet Needs		
How Satisfied with Overall Care Arrangements		**
Very satisfied	42.7	40.3
Satisfied	30.9	32.6
Dissatisfied	14.7	18.8
No paid services or goods in past week	11.7	8.3
Not Getting Enough Help with:		
Household activities[c]	65.0	65.4
Personal care[d]	61.0	65.7*
Transportation[e]	43.4	46.9
Care Recipients' Preferences About Consumer Direction		
Being Allowed to Pay Family Members or Friends Was Very Important	88.1	86.7
Having a Choice About Paid Workers' Schedule Was Very Important	81.7	82.1
Having a Choice About Types of Services Received Was Very Important	86.8	87.4
Care Recipients' Work Experience and Other Characteristics		
Ever Supervised Someone	27.8	27.4
Ever Hired Someone Privately	31.2	29.8
Ever Worked for Pay	83.5	83.3
Proxy Completed All or Most of Baseline Survey	52.7	53.0
Appointed a Representative at Enrollment	45.2	48.7
Enrollment Month Was Between:		
December 1998 and December 1999	51.0	51.7
January 2000 and April 2001	49.0	48.3

TABLE A.2a (*continued*)

Characteristic	Treatment Group	Control Group
Primary Informal Caregivers' Characteristics		
Age in Years		
39 or younger	21.9	22.9
40 to 64	66.0	62.3
65 or older	12.1	14.8
Female	85.1	87.7
Relationship to Care Recipient		
Spouse	5.1	6.0
Parent	7.6	6.5
Daughter or son	64.1	60.6
Other relative	17.1	18.3
Nonrelative	6.2	8.6
Hispanic[a]	1.4	1.0
White	61.3	60.7
Married	53.5	57.2
Has Child(ren) Younger than Age 18	28.4	30.2
Highest Level of Education		
8 years or less	11.1	12.4
9 to 12 years, but no high school diploma or GED	18.1	20.5
High school diploma or GED	39.8	40.5
At least some college	31.0	26.7
Employed[g]	36.5	38.9
Expressed Interest in Being Paid for Caregiving[g]	32.1	39.5***
Sample Size	**721**	**712**

Source: MPR's baseline evaluation interview, conducted between December 1998 and April 2001; caregiver interview, conducted between February 2000 and April 2002; and program records.

[a] Because this characteristic was rare, it was not controlled for in regression models.

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

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

[d] Personal care includes eating, dressing, and bathing.

[e] Transportation includes trips for medical and nonmedical reasons.

[f] Routine health care includes checking vital signs and help taking medicine or doing exercises.

[g] As reported by care recipients during the baseline interview.

*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.2b

BASELINE CHARACTERISTICS OF CARE RECIPIENTS AND PRIMARY INFORMAL CAREGIVERS, BY EVALUATION STATUS: FLORIDA

(Percentages)

Characteristic	Treatment Group	Control Group
Care Recipients' Demographics		
Age in Years		
18 to 39	48.1	47.4
40 to 64	17.2	17.0
65 to 79	15.4	15.3
80 or older	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
Lives 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
Care Recipients' 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
Care Recipients' 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 or more	45.1	48.6

TABLE A.2b (*continued*)

Characteristic	Treatment Group	Control Group
Receiving Waiver Services for 6 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 or more	35.7	35.6
Proposed Weekly Allowance		
Less than $150	33.2	36.6
$150 to $299	32.9	31.8
$300 to $499	17.0	15.6
$500 or more	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
Care Recipients' Satisfaction with Care and Unmet Needs		
How Satisfied 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
Not Getting Enough Help with:		
Household activities[b]	73.2	72.0
Personal care[c]	59.6	56.1
Transportation[d]	54.5	55.5
Care Recipients' Preferences About Consumer Direction		
Being Allowed to Pay Family Members or Friends Was Very Important	75.0	75.2
Having a Choice About Paid Workers' Schedule Was Very Important	84.3	85.6
Having a Choice About Types of Services Received Was Very Important	92.7	91.7
Education and Work Experience of Decision Maker[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 A.2b (*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 in Years		
39 or younger	7.9	8.3
40 to 64	70.7	70.1
65 or older	21.4	21.5
Female	83.8	84.2
Relationship to Care Recipient		**
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
Has Child(ren) Younger than Age 18	17.7	19.7
Highest Level of Education		
8 years or less	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: MPR's baseline evaluation interview, conducted between June 2000 and July 2002; caregiver interview, conducted 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 include meal preparation, laundry, housework, and yard work.

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

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[d] Transportation includes trips for medical and nonmedical reasons.

[e] Routine health care includes checking vital signs and help taking medicine or doing exercises.

[f] Reflects the characteristics of the person (the care recipient or a representative if the representative responded to the baseline interview) who would make care-related decisions in the demonstration program. See text for description of imputation procedures used when the characteristics of the decision maker were not observed.

[g] As reported by care recipients during the baseline interview.

*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.2c

BASELINE CHARACTERISTICS OF CARE RECIPIENTS AND PRIMARY INFORMAL CAREGIVERS, BY EVALUATION STATUS: NEW JERSEY

(Percentages)

Characteristic	Treatment Group	Control Group
Care Recipients' Demographics		
Age in Years		
18 to 39	19.4	17.6
40 to 64	25.8	27.5
65 to 79	26.8	29.5
80 or older	28.0	25.5
Female	73.3	71.8
Hispanic	34.0	36.6
Race		
White	57.2	53.3
Black	34.5	35.8
Other	8.3	10.9
Lives Alone	21.8	20.2
Graduated from High School	39.7	37.0
Described Area of Residence as:		
Rural	11.3	13.1
Not rural but high-crime or lacking adequate public transportation	40.3	41.3
Not rural, not high-crime, having adequate public transportation	48.4	45.6
Care Recipients' Health and Functioning		
Relative Health Status		
Excellent or good	22.1	21.7
Fair	39.4	33.9
Poor	38.5	44.4
Not Independent in Past Week in:[a]		
Getting in or out of bed	72.8	74.2
Bathing	90.8	92.1
Using toilet/diapers	74.9	77.0
Care Recipients' Use of Personal Assistance		
Received Any Help in Past Week with:		
Household activities[b]	98.4	99.0
Personal care[c]	91.8	92.7
Transportation[d]	68.8	68.6
Routine health care[e]	85.9	88.1
Number of Unpaid Caregivers Who Provided Help in Past Week		
1	29.2	30.0
2	26.2	27.1
3 or more	44.6	42.9

TABLE A.2c (*continued*)

Characteristic	Treatment Group	Control Group
Receiving Personal Care Services for 6 Months or Longer	43.4	46.0
Number of Paid Caregivers in Past Week		*
0	16.3	17.4
1	53.8	58.8
2 or more	29.8	23.8
Proposed Weekly Allowance		
Less than $150	24.2	19.8
$150 to $299	43.0	43.0
$300 to $499	27.7	30.9
$500 or more	5.1	6.3
Care Recipients' Satisfaction with Care and Unmet Needs		
How Satisfied with Overall Care Arrangements		
Very satisfied	34.5	31.3
Satisfied	35.6	36.0
Dissatisfied	24.1	28.3
No paid services or goods in past week	5.9	4.5
Not Getting Enough Help with:		
Household activities[b]	78.5	78.1
Personal care[c]	75.5	75.9
Transportation[d]	69.0	65.2
Care Recipients' Preference About Consumer Direction		
Being Allowed to Pay Family Members or Friends Was Very Important	88.4	86.1
Having a Choice About Paid Workers' Schedule Was Very Important	88.1	88.7
Having a Choice About Types of Services Received Was Very Important	92.5	92.5
Care Recipients' Work Experience and Other Characteristics		
Ever Supervised Someone	31.7	27.2
Ever Hired Someone Privately	28.8	24.4
Ever Worked for Pay	73.7	69.8
Proxy Completed All or Most of Baseline Survey	51.5	56.1
Appointed a Representative at Enrollment	NA	NA
Enrollment Month Was Between:		
November 1999 and December 2000	47.3	48.6
January 2001 and July 2002	52.7	51.4

TABLE A.2c (*continued*)

Characteristic	Treatment Group	Control Group
Primary Informal Caregivers' Characteristics		
Age in Years		**
39 or younger	21.3	18.1
40 to 64	64.8	61.9
65 or older	13.9	20.0
Female	78.7	80.2
Relationship to Care Recipient		
Spouse	7.7	9.1
Parent	15.8	20.4
Daughter or son	50.7	49.0
Other relative	16.5	14.1
Nonrelative	9.3	7.5
Hispanic	33.9	37.8
White	44.8	46.2
Married	52.6	50.6
Has Child(ren) Younger than Age 18	30.4	29.2
Highest Level of Education		
8 years or less	12.4	14.4
9 to 12 years, but no high school diploma or GED	13.9	18.3
High school diploma or GED	26.5	26.1
At least some college	47.1	41.3
Employed at Baseline[f]	50.8	47.0
Expressed Interest in Being Paid for Caregiving[f]	37.5	39.1
Sample Size	**546**	**496**

Source: MPR's baseline evaluation interview, conducted between December 1999 and July 2002; caregiver interview, conducted between September 2000 and June 2003; and program records.

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

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

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

[d] Transportation includes trips for medical and nonmedical reasons.

[e] Routine health care includes checking vital signs and help taking medicine or doing exercises.

[f] As reported by care recipients during the baseline interview.

*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.

NA = data not available.

APPENDIX B

ADDITIONAL RESULTS

TABLE B.1

ESTIMATED EFFECTS ON LIVING ARRANGEMENTS FOR, AND ASSISTANCE PROVIDED BY, PRIMARY INFORMAL CAREGIVERS, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Living Arrangements in Recent Two Weeks[a]									
Lived with Care Recipient	57.3	56.8	0.6 (.719)	83.1	82.1	1.0 (.417)	61.6	58.7	2.9* (.089)
Lived Within 10 Minutes' Travel Time of Care Recipient	32.0	31.9	0.1 (.969)	10.5	11.5	–1.0 (.488)	28.1	29.0	–0.9 (.664)
Assistance Provided in Recent Two Weeks[a]									
Provided Any Assistance	93.1	91.2	1.9 (.197)	94.7	94.2	0.5 (.698)	92.3	90.9	1.4 (.421)
Among Those Providing Assistance:									
Helped with personal care[b]	92.5	89.7	2.8* (.077)	85.7	86.7	–1.0 (.548)	90.0	87.6	2.4 (.206)
Helped with household activities[c,d]	98.1	99.1	–1.0 (.144)	99.5	99.0	0.5 (.414)	97.6	98.8	–1.2 (.199)
Helped with routine health care[e]	90.7	90.4	0.2 (.882)	88.6	88.4	0.1 (.942)	92.2	86.3	5.9*** (.003)
Socialized with or kept care recipient company	96.9	97.9	–1.0 (.309)	97.0	97.3	–0.3 (.743)	96.7	97.5	–0.8 (.479)

TABLE B.1 (*continued*)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models, unless noted.

[a] The most recent two weeks the care recipient lived in the home or community during the two months before the interview.

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

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

[d] Impacts could not be estimated with logit models. Results presented are the unadjusted means and treatment-control differences.

[e] Routine health care includes checking vital signs and help taking medicine or doing exercises.

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

TABLE B.2

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' KNOWLEDGE AND PREPAREDNESS, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Feels Well Informed About Care Recipient's Condition and Services									
Strongly agrees	84.9	76.5	8.4*** (.000)	74.3	70.2	4.1 (.117)	81.3	67.0	14.3*** (.001)
Disagrees	3.4	7.2	–3.8*** (.000)	5.4	6.2	–0.8 (.559)	3.2	7.2	–4.0*** (.006)
Feels Fully Prepared to Meet Expectations in Helping Care Recipient									
Strongly agrees	90.2	84.3	5.9*** (.001)	87.1	85.3	1.8 (.375)	86.3	79.9	6.4*** (.006)
Disagrees[a]	1.8	3.4	–1.6* (.061)	1.8	2.8	–1.0 (.244)	3.2	5.4	–2.2* (.082)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Outcomes were measured "at present" or "when you were last helping." Means were predicted with logit models, unless noted.

[a] Impacts could not be estimated with the logit model. Results presented are the unadjusted means and treatment-control differences.

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

TABLE B.3

ESTIMATED EFFECTS ON PRIMARY INFORMAL CAREGIVERS' PHYSICAL FUNCTIONING, BY STATE

	Arkansas			Florida			New Jersey		
	Predicted Means (Percents)			Predicted Means (Percents)			Predicted Means (Percents)		
Outcome	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)	Treatment Group	Control Group	Estimated Effect (p-Value)
Because of Illness or Disability, Has Problems with at Least One:									
Instrumental activity of daily living[a]	11.4	18.3	–6.9*** (.000)	15.3	20.1	–4.9** (.022)	12.9	16.8	–3.9* (.058)
Activity of daily living[b]	4.9	7.0	–2.2* (.091)	5.9	8.3	–2.4* (.100)	5.5	7.1	–1.6 (.279)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. Includes those who became paid workers for care recipients randomly assigned to the treatment group. Means were predicted with logit models.

[a] Includes meal preparation, housework, shopping, taking medicine, and managing money.

[b] Includes eating, getting in or out of bed or chairs, dressing, bathing, or using the toilet.

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

TABLE B.4

ESTIMATED EFFECTS OF CARE RECIPIENT AND CAREGIVER CHARACTERISTICS ON WHETHER PRIMARY INFORMAL CAREGIVERS BECAME PAID WORKERS, BY STATE

(Omitted Categories in Parentheses)

Characteristic	Arkansas (n = 671) Estimated Odds Ratio	Arkansas (n = 671) p-Value	Florida (n = 617) Estimated Odds Ratio	Florida (n = 617) p-Value	New Jersey (n = 546) Estimated Odds Ratio	New Jersey (n = 546) p-Value
Care Recipient Characteristics						
Demographics						
65 (or 60) or older[a]	0.69	.183	0.75	.825	1.06	.853
Female	1.47	.109	0.84	.441	1.00	.990
Hispanic	n.a.	n.a.	1.16	.767	2.22	.249
Racial minority	0.90	.758	0.79	.588	1.04	.902
Did not graduate from high school[b]	0.63*	.057	0.86	.577	1.10	.700
Living Arrangements						
Lived alone	0.53**	.046	0.86	.789	0.86	.661
Described area of residence as rural or high-crime or lacking public transportation	1.19	.388	1.24	.295	1.31	.212
Health and Functioning						
In poor health relative to peers	0.91	.641	1.14	.599	1.19	.420
Not independent in past week in:						
Getting in or out of bed	0.92	.767	1.23	.464	1.62	.097
Bathing	0.77	.532	1.76	.159	1.58	.272
Using toilet/diapers	1.18	.584	0.85	.621	0.73	.296
Unpaid and Paid Assistance						
Number of informal caregivers who helped last week:						
(One)						
Two	0.97	.891	1.20	.507	2.12***	.005
Three or more	1.03	.915	1.01	.960	0.93	.770
Receiving publicly funded home care (at all or for at least six months)[c]	0.81	.297	1.01	.944	0.88	.534
Satisfied with overall care arrangements	0.99	.969	0.69	.130	1.11	.640
Demonstration Feeder Program (Department of Elder Affairs)						
Developmental Services or Adult Services	n.a.	n.a.	0.78	.846	n.a.	n.a.

TABLE B.4 (*continued*)

	Arkansas (n = 671)		Florida (n = 617)		New Jersey (n = 546)	
Characteristic	Estimated Odds Ratio	p-Value	Estimated Odds Ratio	p-Value	Estimated Odds Ratio	p-Value
Assistance Needs and Preferences						
Medicaid personal care plan indicates high level of need (in hours or dollars)[d]	1.61**	.033	1.25	.338	1.00	.994
Not getting enough help with:						
Personal care	0.99	.995	1.19	.515	0.98	.945
Transportation	0.79	.246	0. 90	.657	0.68*	.099
Household activities	0.69	.101	1.38	.275	1.50	.176
Proxy completed most or all of baseline evaluation survey	0.56**	.018	0.84	.608	0.49***	.005
Representative would manage monthly allowance	0.61**	.030	2.28*	.067	n.a.	n.a.
Ability to pay family members or friends was very important	1.33	.326	1.75**	.037	3.46***	.001
Setting paid workers' schedule was very important	0.52**	.013	1.40	.307	1.33	.414
Choosing types of paid services was very important	1.63*	.085	0.62	.266	0.71	.410
Work and Supervisory Experience						
Ever supervised someone	0.85	.476	1.06	.816	0.96	.860
Ever hired someone privately	0.90	.636	1.31	.256	0.94	.804
Ever worked for pay	0.90	.685	0.97	.952	1.04	.870
Caregiver Characteristics						
Demographics						
Age (years)						
(39 or younger)						
40 to 64	0.60*	.055	0.97	.945	0.62	.103
65 or older	0.48**	.047	0.82	.675	0.29***	.004
Female	2.36***	.001	2.24**	.012	1.97***	.010
Hispanic	n.a.	n.a.	0.71	.504	0.42	.211
Racial minority	1.46	.285	0.53	.130	0.67	.206
Did not graduate from high school	1.03	.903	1.22	.517	0.55**	.027
Married	1.66**	.011	0.75	.198	1.24	.357
Has child(ren) 18 or younger	0.88	.589	1.49	.165	1.32	.263
Employed, other than by care recipient	0.99	.981	1.64**	.029	0.65*	.053
Household income in month before caregiver interview						
($1,000 or less)						
$1,001-3,000	0.66**	.043	0.79	.366	1.09	.740
$3,001 or more	0.17***	.000	0.74	.412	0.81	.560
Missing income data	0.15***	.000	0.86	.716	0.22***	.001
Relationship to Care Recipient and Living Arrangements						
Relationship to care recipient:						

TABLE B.4 (*continued*)

	Arkansas (n = 671)		Florida (n = 617)		New Jersey (n = 546)	
Characteristic	Estimated Odds Ratio	p-Value	Estimated Odds Ratio	p-Value	Estimated Odds Ratio	p-Value
(Not related)						
Daughter or son	1.32	.407	1.15	.802	1.31	.524
Parent	0.94	.903	0.26**	.025	1.27	.609
Spouse	n.a.	n.a.	1.17	.821	0.48	.213
Other relative	1.29	.501	0.63	.437	1.23	.788
Lived with care recipient at baseline	0.90	.709	1.43	.374	2.09**	.022

Source: Program records from each of the demonstration states and MPR's baseline and caregiver interviews. Baseline interviews were conducted in Arkansas between December 1998 and April 2001; in Florida between June 2000 and July 2002; and in New Jersey between November 1999 and July 2002. Caregiver interviews were conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Primary informal caregivers are those providing the most unpaid care to care recipients at baseline. The Arkansas analysis sample excludes 50 caregivers who could not become paid workers because they were married to their care recipient. Odds ratios were estimated with logit models.

[a] The Florida model controlled for whether care recipients were age 60 or older (instead of 65 or older) to parallel the age groups served by the HCBS waiver programs that fed into the demonstration.

[b] The Florida model controlled for the education of the person (that is, the care recipient or a representative if the representative responded to the baseline interview) who would make care-related decisions in the demonstration program. The Arkansas and New Jersey models controlled for the education of the care recipient, whether or not they would use a representative in the program.

[c] The Arkansas model controlled for whether recipients were receiving publicly funded home care at baseline, regardless of how long they had been receiving it. The Florida and New Jersey models controlled for whether care recipients had been receiving publicly funded home care for six months or longer at baseline. The measures differ because care recipients in Florida and New Jersey typically received traditional home care services before they enrolled in the demonstration; in Arkansas, this was not necessarily the case.

[d] The Arkansas model controlled for whether the care recipient's Medicaid personal care plan included seven or more hours of care per week. The Florida and New Jersey models controlled for whether the plan included benefits valued at $150 or more per week.

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

n.a. = not applicable.

TABLE B.5

REASONS TREATMENT GROUP CAREGIVERS DID NOT BECOME PAID WORKERS
(Percentages)

Reason	Arkansas	Florida	New Jersey
Helped out of love, devotion, or family tradition	28.4	26.3	27.8
Not allowed to be paid under the program[a]	22.2	15.9	13.9
Not able to perform all tasks, or lived far away/had other obligations, or care recipient had someone else in mind	15.0	10.7	16.2
Benefit not enough to pay me and others or was needed for other things	10.5	9.1	8.3
Did not know could get paid or program made an error	8.8	14.4	15.2
Care recipient disenrolled from the program	8.2	10.5	8.9
Intends to be paid after care recipient receives program allowance	0.0	4.7	2.3
Too much hassle or caregiver disagrees with program philosophy	0.0	4.4	2.0
Did not need or want the money	3.9	2.1	3.3
Other	2.9	1.9	2.0
Number of Respondents	**306**	**429**	**302**

Source: MPR’s caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: Treatment group caregivers are those identified at baseline as the primary informal caregivers of care recipients who were randomly assigned to participate in a Cash and Counseling program.

[a] In Arkansas, caregivers were not allowed to be paid if they were the care recipient’s spouse or representative. In New Jersey, caregivers were not allowed to be paid if they were the care recipient’s representative. Florida did not impose hiring restrictions during its evaluation period. However, if a representative was also a paid worker, someone else from the care recipient’s “circle of support” was asked to verify the completion of agreed-upon work.

TABLE B.6

ESTIMATED EFFECTS OF BECOMING A PAID WORKER ON KEY CAREGIVER OUTCOMES, BY STATE

	Arkansas		Florida		New Jersey	
	Estimated Effect of Being a Treatment Group Caregiver and:					
Outcome	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)
Well-Being and Satisfaction						
Care Recipient Refuses to Cooperate When Caregiver Tries to Help	–11.0*** (.000)	1.4 (.668)	–12.3*** (.002)	–2.7 (.343)	–3.4 (.348)	–0.2 (.945)
How Satisfied with Care Recipient's Overall Care Arrangements						
Very satisfied	23.5*** (.000)	9.8*** (.003)	32.4*** (.000)	12.5*** (.000)	28.6*** (.000)	13.5*** (.000)
Dissatisfied	–14.5*** (.000)	–9.0*** (.000)	–15.8*** (.000)	–8.4*** (.001)	–21.7*** (.000)	–12.0*** (.000)
How Often Worries That Care Recipient Does Not Have Enough Help in Caregiver's Absence						
Rarely or not at all	18.6*** (.000)	12.6*** (.000)	25.1*** (.000)	11.5*** (.000)	18.7*** (.000)	8.2*** (.006)
Quite a lot	–20.4*** (.000)	–12.2*** (.000)	–21.2*** (.000)	–9.2*** (.002)	–24.3*** (.000)	–13.5*** (.000)
Caregiving Limits:						
Privacy	–19.4*** (.000)	–6.5** (.040)	–15.0*** (.000)	–0.7 (.806)	–19.7*** (.000)	–1.7 (.610)
Free time or social life	–15.4*** (.000)	–5.4* (.090)	–19.5*** (.000)	–2.1 (.441)	–14.2*** (.000)	1.2 (.716)

TABLE B.6 (*continued*)

	Arkansas		Florida		New Jersey	
	Estimated Effect of Being a Treatment Group Caregiver and:					
Outcome	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)
Level of Emotional Strain as a Result of Caregiving						
Little or none	11.7***	–2.0	11.3***	–2.2	12.5***	0.0
	(.000)	(.555)	(.005)	(.415)	(.000)	(.987)
A great deal	–12.7***	–0.7	–9.3**	–0.0	–13.6***	–2.3
	(.000)	(.827)	(.017)	(.994)	(.000)	(.498)
How Satisfied with Life						
Very satisfied	19.2***	0.2	24.7***	6.7**	20.0***	9.7***
	(.000)	(.948)	(.000)	(.030)	(.000)	(.004)
Dissatisfied	–13.2***	–4.4*	–8.1***	–4.6*	–20.1***	–4.6*
	(.000)	(.063)	(.000)	(.057)	(.000)	(.073)
Did Not Look for a Job, or Another Job, but Wanted to	–14.3***	–14.0***	–9.0**	–5.5*	–10.2***	–14.0***
	(.000)	(.000)	(.019)	(.055)	(.005)	(.003)
Level of Financial Strain as a Result of Caregiving						
Little or none	15.2***	11.4***	20.6***	7.7***	14.7***	4.0
	(.000)	(.001)	(.000)	(.006)	(.000)	(.254)
A great deal	–16.8***	–7.4***	–18.3***	–4.4	–12.6***	–6.6**
	(.000)	(.009)	(.000)	(.121)	(.001)	(.047)
Physical Health Has Suffered as a Result of Caregiving	–19.7***	0.3	–22.7***	–6.7**	–15.9***	–4.8
	(.000)	(.918)	(.000)	(.016)	(.001)	(.120)

TABLE B.6 (*continued*)

	Arkansas		Florida		New Jersey	
	Estimated Effect of Being a Treatment Group Caregiver and:					
Outcome	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)	Becoming Paid (p-Value)	Remaining Unpaid (p-Value)
Amount of Assistance Provided in Recent Two Weeks						
Number of Days Provided Care	0.7*** (.001)	–0.7*** (.003)	0.4* (.089)	–0.2 (.211)	1.0*** (.000)	–0.2 (.933)
Hours of Assistance[a]	–7.5 (.152)	–15.8* (.075)	10.3 (.169)	–17.4* (.061)	21.1* (.067)	–0.5 (.464)
Among live-in caregivers	–12.9* (.069)	–12.7 (.127)	8.5 (.289)	–17.5*** (.003)	20.8** (.028)	–3.2 (.724)
Hours that benefited care recipient only	–5.8 (.196)	0.1 (.986)	7.0 (.211)	–11.0*** (.007)	8.4 (.178)	–3.3 (.581)
Hours that benefited entire household	–7.1 (.103)	–12.8** (.013)	1.5 (.737)	–6.5* (.061)	12.4** (.031)	0.1 (.984)
Among visiting caregivers	–0.2 (.977)	–19.9*** (.004)	18.6 (.313)	–17.0 (.225)	21.7** (.020)	3.6 (.690)

Source: MPR's caregiver interview, conducted in Arkansas between February 2000 and April 2002; in Florida between May 2001 and May 2003; and in New Jersey between September 2000 and June 2003.

Note: The estimated effects of becoming paid (remaining unpaid) are the differences between the predicted means for treatment group caregivers who became paid workers (remained unpaid) and those for control group caregivers. Means were predicted with logit or ordinary-least-squares models. Sample sizes varied from measure to measure. In Arkansas, the largest sample included 712 control group caregivers, 403 paid treatment group caregivers, and 310 unpaid treatment group caregivers. In Florida, the largest sample included 576 control group caregivers, 176 paid treatment group caregivers, and 441 unpaid treatment caregivers. In New Jersey, the largest sample included 508 control group caregivers, 168 paid treatment group caregivers, and 380 unpaid treatment group caregivers.

TABLE B.6 (*continued*)

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[a] The estimates for total hours are constructed as weighted averages of the estimates for caregivers who are live-in and those who are visiting, with the weights being the proportion of all caregivers (treatment and control groups combined) who were live-in or visiting at followup. In Arkansas, these proportions were .571 (live-in) and .429 (visiting); in Florida, they were .826 and .174; and in New Jersey, they were .603 and .397. The variance of the estimated effect used to construct the t-statistic and corresponding p-value is $var = p_L^2 * \sigma_L^2 + (1\text{-}p_L)^2 * \sigma_V^2$, where σ_L^2 and σ_V^2 are the variances of the estimated coefficients on the treatment status indicator from the regressions on live-in and visiting caregivers, respectively. This approach ensures that the impact on total hours is a weighted average of the impacts on live-in and visiting caregivers.

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

TABLE B.7a

ESTIMATED EFFECTS ON KEY CAREGIVER OUTCOMES, BY CARE RECIPIENTS' AGE GROUP: ARKANSAS

	Care Recipients' Age Group					
	18 to 64 (n = 365)			65 or Older (n = 1,068)		
Outcome	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)
Satisfaction						
Very Satisfied with Care Recipient's Overall Care Arrangements (Percent)	62.2	41.9	20.2*** (.000)	60.4	43.0	17.4*** (.000)
Amount of Assistance Provided During Recent Two Weeks						
Live-In Caregivers (Hours)	141.3	155.4	–14.1 (.243)	140.6	152.8	–12.2* (.081)
Visiting Caregivers (Hours)	49.5	49.6	–0.1 (.990)	49.4	58.1	–8.7 (.154)
Well-Being						
Caregiving Caused a Great Deal of: (Percents)						
Emotional strain	24.8	36.7	–11.9** (.016)	27.5	33.6	–6.1** (.026)
Financial strain	22.4	38.6	–16.1*** (.001)	22.7	34.8	–12.1*** (.000)
Physical strain	19.3	30.0	–10.7** (.020)	24.4	32.7	–8.4*** (.002)

Source: MPR's caregiver interview, conducted between February 2000 and April 2002.

Note: Means were predicted with ordinary least squares or logit models. Subgroup effects were estimated by pooling the two age groups and including an age*treatment status interaction term in the model. Sample sizes vary from measure to measure, because certain survey questions were asked only of sample members who met certain criteria and because of item nonresponse.

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

None of the subgroup effects were significantly different from each other.

TABLE B.7b

ESTIMATED EFFECTS ON KEY CAREGIVER OUTCOMES, BY CARE RECIPIENTS' AGE GROUP: FLORIDA

	Care Recipients' Age Group					
	18 to 59 (n = 720)			60 or Older (n = 473)		
Outcome	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)
Satisfaction						
Very Satisfied with Care Recipient's Overall Care Arrangements (Percent)	45.1	26.2	18.9*** (.000)	51.9	35.3	16.5*** (.000)
Amount of Assistance Provided During Recent Two Weeks						
Live-In Caregivers (Hours)	130.9	137.7	–6.9 (.285)	153.0	168.8	–15.8* (.100)
Visiting Caregivers (Hours)	27.8	14.9	12.9 (.505)	79.1	98.7	–19.6 (.230)
Well-Being						
Caregiving Caused a Great Deal of: (Percents)						
Emotional strain	29.5	32.4	–2.9 (.381)	45.9	48.5	–2.6 (.557)
Financial strain	33.1	44.6	–11.5*** (.001)	25.8	30.9	–5.1 (.173)
Physical strain	30.6	39.0	–8.4** (.016)	25.5	38.5	–12.9*** (.001)

Source: MPR's caregiver interview, conducted between May 2001 and May 2003.

Note: Means were predicted with ordinary least squares or logit models. Subgroup effects were estimated by pooling the two age groups and including an age*treatment status interaction term in the model. Sample sizes vary from measure to measure, because certain survey questions were asked only of sample members who met certain criteria and because of item nonresponse.

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

None of the subgroup effects were significantly different from each other.

TABLE B.7c

ESTIMATED EFFECTS ON KEY CAREGIVER OUTCOMES, BY CARE RECIPIENTS' AGE GROUP: NEW JERSEY

	Care Recipients' Age Group					
	18 to 64 (n = 470)			65 or Older (n = 572)		
Outcome	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)
Satisfaction						
Very Satisfied with Care Recipient's Overall Care Arrangements (Percent)	46.4	31.6	14.7*** (.001)	55.6	31.9	23.7*** (.000)
Amount of Assistance Provided During Recent Two Weeks						
Live-In Caregivers (Hours)†	154.7	133.9	20.8* (.058)	143.7	147.9	–4.2 (.684)
Visiting Caregivers (Hours)	75.1	48.6	26.5** (.020)	61.5	58.5	3.0 (.753)
Well-Being						
Caregiving Caused a Great Deal of: (Percents)						
Emotional strain	43.4	49.7	–6.3 (.157)	41.6	49.2	–7.7* (.051)
Financial strain††	36.4	40.1	–3.7 (.406)	23.5	37.8	–14.3*** (.000)
Physical strain	30.7	36.7	–6.0 (.157)	32.7	45.7	–13.1*** (.001)

Source: MPR's caregiver interview, conducted between September 2000 and June 2003.

Note: Means were predicted with ordinary least squares or logit models. Subgroup effects were estimated by pooling the two age groups and including an age*treatment status interaction term in the model. Sample sizes vary from measure to measure, because certain survey questions were asked only of sample members who met certain criteria and because of item nonresponse.

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

†Estimated effects for the two subgroups were significantly different from each other at the .10 level, two-tailed test.
††Estimated effects for the two subgroups were significantly different from each other at the .05 level, two-tailed test.

TABLE B.8

ESTIMATED EFFECTS OF THE ARKANSAS PROGRAM ON CAREGIVER SATISFACTION AND WELL-BEING FOR SUBGROUPS DEFINED BY WHETHER CARE RECIPIENTS PARTICIPATED IN ELDERCHOICES DURING FOLLOWUP

(Elderly Sample Members Only)

	Care Recipient Participated in ElderChoices			Care Recipient Did Not Participate in ElderChoices		
Caregiver Outcomes	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)	Predicted Treatment Group Mean	Predicted Control Group Mean	Estimated Effect (p-Value)
Very Satisfied with Overall Care Arrangements†††	58.1	45.7	12.4*** (.001)	67.7	39.5	28.2*** (.000)
Worries Quite a Lot That:						
Care recipient does not have enough help†	36.6	50.2	–13.6*** (.000)	30.3	54.1	–23.8*** (.000)
Care recipient’s safety is at risk††	41.3	50.0	–8.8*** (.021)	37.6	59.1	–21.5*** (.000)
Someone will take care recipient’s belongings†	13.5	15.3	–1.8 (.517)	11.3	21.9	–10.6*** (.005)
Caregiving Limits Privacy††	47.1	52.6	–5.5 (.137)	35.8	55.4	–19.7*** (.001)
Caregiving Causes a Great Deal of:						
Emotional strain	29.1	33.7	–4.6 (.182)	27.6	35.2	–7.7 (.111)
Financial strain	22.1	36.6	–14.4*** (.000)	25.6	34.9	–9.3** (.048)
Physical strain	27.3	34.7	–7.3** (.032)	20.9	32.5	–11.6** (.010)
Very Satisfied with Life	48.6	37.9	10.7*** (.005)	56.3	40.4	15.9*** (.002)

TABLE B.8 (*continued*)

Source: MPR’s caregiver interview, conducted between February 2000 and April 2002, and Arkansas Medicaid data.

Note: Means were predicted with logit models. Subgroups effects were estimated by interacting the treatment status indicator and an ElderChoices enrollment status indicator. Sample sizes vary from measure to measure (from 1,045 to 1,065) because of item nonresponse. In the largest sample used, 677 primary informal caregivers were assisting care recipients who participated in ElderChoices, and 388 were assisting care recipients who were not participating.

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

†Estimated effects for the two subgroups were significantly different from each other at the .10 level, two-tailed test.
††Estimated effects for the two subgroups were significantly different from each other at the .05 level, two-tailed test.
†††Estimated effects for the two subgroups were significantly different from each other at the .01 level, two-tailed test.