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**Consumer and Counselor
Experiences in the
Arkansas
Independent Choices
Program**

Final Report

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EXECUTIVE SUMMARY

Roughly 1.2 million people receive Medicaid-funded, noninstitutional supportive services. Traditionally, many of these services are provided by home care agencies under nurse supervision and help recipients with such activities as bathing, using the toilet, meal preparation, and light housework. Consumer-directed personal assistance is an alternative to agency care. It offers a care model over which recipients have more control: deciding the types of assistance needed and, if human help is desired, hiring, training, supervising, and paying workers and defining workers' duties and schedules. Inherent in this model is increased flexibility and control for consumers, but also increased responsibility for decision making and the consequences of those decisions.

Cash and Counseling is a model of consumer direction that gives Medicaid beneficiaries with disabilities a monthly allowance in place of agency services to purchase personal assistance and related goods, as well as support to help direct care and manage the allowance. Arkansas is one of three states (along with Florida and New Jersey) that have implemented a Cash and Counseling demonstration. Its demonstration, IndependentChoices, was open to elderly and nonelderly adults eligible for Medicaid personal assistance services (PAS). Mathematica Policy Research, Inc. (MPR) is evaluating the three demonstration programs.

This report describes the implementation of IndependentChoices by synthesizing information from in-person interviews with program staff, a mail survey of program counselors, and telephone interviews with consumers who had the opportunity to receive the program allowance. It discusses the program's goals and features, how consumers managed their responsibilities under it and made use of its flexibility, and levels of consumer satisfaction with the program. Other reports present estimates of demonstration impacts on beneficiaries, their caregivers, and public costs; describe the types of beneficiaries who chose to participate; describe the features and procedures adopted by IndependentChoices in greater detail; and draw implementation lessons from all three demonstration states.

IndependentChoices Intervention. IndependentChoices provided a monthly allowance based on the hours in the consumer's PAS care plan. Consumers were required to develop a spending plan for the allowance to cover purchases that promoted independence or increased mobility. When consumers enrolled, the average monthly allowance was roughly \$320. IndependentChoices provided counseling and bookkeeping services at no direct cost to consumers. Counselors were required to review spending plans and monitor consumer well-being and the use of the allowance. They were available to train consumers about program rules and employer responsibilities. A bookkeeper was available to write checks for goods and services purchased with the allowance and to manage payroll taxes and unemployment insurance for consumers who hired workers. Almost all consumers chose to use the bookkeeper. In addition, consumers could select representatives to assist them in directing care or to make decisions about whom to hire or how much to pay. Just over 40 percent of consumers chose representatives when they enrolled, usually family members who assisted them previously.

Outreach and Enrollment. IndependentChoices hired nurses living in different regions of the state to conduct a community information campaign and enroll beneficiaries. It also sent a series of letters signed by the governor to PAS users, which were particularly effective in generating interest in the program. IndependentChoices did not screen applicants for appropriateness, in part because such screening was inconsistent with the philosophy of consumer direction. The program enrolled 2,008 beneficiaries between December 1998 and April 2001. MPR then interviewed them and randomly assigned half to receive the IndependentChoices intervention and half to the control group, eligible for agency-delivered PAS as usual. Enrollment represented about 11 percent of PAS users in the state in a given year.

The typical consumer was an elderly white female, living with someone other than a spouse. Just over a third of consumers reported living in a rural part of the state. Nearly all consumers had paid or unpaid help with personal care and household activities when they enrolled in the program; however, about two-thirds reported they needed more help. Nearly a third of the consumers were dissatisfied with the paid help they had been receiving.

Use of the Allowance. Just under 85 percent of consumers assigned to receive the IndependentChoices intervention had received the monthly allowance for at least one month by the time the evaluation conducted its nine-month follow-up survey. (Almost all of the other 15 percent had died or had disenrolled from the program.) Just under 80 percent hired a worker with the allowance during that time—in almost all cases, someone previously known to them. (Consumers could hire anyone except spouses and representatives or could meet their care needs without hiring, by purchasing care-related goods and services.) A third hired more than one worker. Most workers helped with housework and personal care, but many helped with routine health care or provided transportation (for example, for shopping, a service which Arkansas Medicaid did not permit agency workers to provide). Most received between one and three hours of paid care per day; three-fourths of paid workers also provided unpaid assistance. Many workers helped when it was difficult to get help from an agency: weekends, weekday evenings, and early on weekday mornings. A tenth of consumers, however, tried to hire a worker but were unable to do so. Program staff reported that consumers who had not identified a family member or friend as a potential worker at enrollment were likely to have trouble hiring a worker.

Nearly half of all consumers also used part of their allowance to purchase personal care supplies, although such purchases used only about a tenth of the monthly allowance, on average. About a third took advantage of the option of receiving up to 10 percent of the allowance in cash to use at their discretion.

There was no evidence that consumers or their representatives materially misused the program allowance. Almost all consumers chose to use the bookkeeping service rather than receive the allowance directly. To ensure that the program allowance was not misused, counselors compared worker timesheets and check requests to spending plans before checks were issued. Counselors also reviewed receipts for all consumer purchases (other than those made with the discretionary cash) for consistency with spending plans. On the other hand, just over a tenth of consumers reported that program spending rules kept them from getting things that would have enhanced their independence. Counselors reported having to deny the use of the allowance to purchase furniture and appliances or make home or vehicle modifications unrelated to disability.

Satisfaction with IndependentChoices and Overall Care. Ninety-six percent of consumers (including those who disenrolled) said they would “recommend the program to others who wanted more control over personal care services.” Among respondents who received the allowance, more than half (56 percent) said the allowance improved the quality of their lives a great deal, and another 25 percent said it improved their lives somewhat. Ninety-four percent said they were satisfied with their overall care arrangements, and 69 percent said they were very satisfied. Nearly all consumers who hired a worker with the allowance were satisfied with their relationship with the worker and how and when the worker performed tasks.

Despite these high levels of satisfaction, 189 consumers (19 percent) disenrolled from the program voluntarily within a year, which underscores the fact that consumer direction is not for everyone. The most commonly cited reasons were that the allowance was too low, they changed their minds about traditional services, or they had difficulty with employer responsibilities such as initially hiring or replacing workers.

Summary and Implications. The Arkansas IndependentChoices program is one of three Cash and Counseling demonstrations testing a model of consumer direction that provides a monthly allowance to consumers (or their representatives) to purchase personal assistance-related goods and services and provides the support of counselors and bookkeepers. Consumers included in its evaluation were highly satisfied with the program and their care. Program staff were pleased that IndependentChoices increased the availability of personal assistance for consumers affected by the state’s chronic worker shortage and for the minority of consumers who were dissatisfied with agency-provided assistance.

Consumer-directed personal assistance in a publicly funded program like Medicaid raises concerns among policymakers, however. These concerns include (1) whether consumer direction should be available to all PAS users, (2) whether to allow family members who might otherwise help without pay to be hired as workers, (3) how to ensure care quality for consumers, (4) how to ensure that workers are trained adequately and treated fairly, and (5) how to avoid fraudulent use of a cash benefit. The structure of IndependentChoices and its procedures addressed each of these concerns to a greater or lesser degree.

Appropriateness screening did not appear to have been necessary for IndependentChoices, although use of representatives was common.

Any beneficiary of any age who was eligible for the Arkansas Medicaid PAS benefit, including those with cognitive or behavioral problems, could enroll in IndependentChoices. Program staff believed that individuals would self-select for the program once they understood the responsibilities and risks involved. Moreover, consumers could identify representatives to help them manage the benefit or to manage it on their behalf. (Counselors reported that more than three-quarters of representatives acted in consumers’ best interest and according to their wishes, while only about 1 percent had a serious divergence of wishes or interests from consumers.) The program also reserved the right to terminate a consumer from IndependentChoices and return him or her to agency services if the program seemed unsuitable. That IndependentChoices terminated only 3 of the 1,004 mostly elderly consumers who enrolled and that reports of abuse of consumers or of the allowance were negligible, supports the idea that appropriateness screening was not necessary for this program.

Allowing consumers to hire relatives appeared to have been critical to program success.

Although IndependentChoices consumers were not allowed to hire spouses as personal assistance workers, more than three-quarters hired other family members, and a fifth hired acquaintances. Family and friends represented a labor pool unavailable to agencies, many of which experienced severe worker shortages during the demonstration. Outreach staff reported, however, that some beneficiaries—particularly nonelderly ones—did not apply to the program because they could not hire their spouses.

Regular counselor monitoring and followup identified and resolved potential consumer safety and care quality issues.

There was no evidence from consumers, counselors, or state program staff that participation in IndependentChoices led to any adverse effects on consumers' health and safety. IndependentChoices oversaw safety and care quality primarily through regular counselor contacts with consumers by telephone and in person. Subtle behavior changes or other cues in telephone contact sometimes prompted a home visit by a counselor, occasionally unannounced. Reports of consumer abuse were rare, and consumers overwhelmingly were satisfied with the program and care arrangements. Furthermore, a companion analysis found that IndependentChoices had no deleterious effect on objective, care-related outcomes like falling or developing decubiti.

Although few workers were offered fringe benefits, reports of worker abuse were rare in IndependentChoices.

Critics of consumer direction are concerned about the welfare of workers in the absence of collective bargaining and agency protection from abusive caregiving situations. Reports by IndependentChoices counselors of worker abuse were rare. However, the program did not have procedures to receive and address worker complaints against consumers or their representatives. Thus, some worker complaints may have gone unreported. Nevertheless, a companion analysis of a worker survey found reports of workers hired with the IndependentChoices allowance concerning wages, physical caregiving strain, and satisfaction with working conditions to be similar to reports of workers for evaluation control group members.

Counseling and bookkeeping procedures helped make abuse of the allowance rare.

There was no evidence that consumers or their representatives materially misused the allowance. Although consumers could receive the monthly allowance directly, almost all chose to use the program's optional bookkeeping service to pay workers and other providers. The program monitored allowance use by having IndependentChoices counselors compare each consumer check request with the consumer's spending plan. Counselors also reviewed the receipts consumers were required to keep for purchases other than those made with the relatively small discretionary cash disbursement consumers could take from the allowance.

In Conclusion. IndependentChoices successfully addressed many important concerns about consumer direction. The program successfully implemented a consumer-directed program using the Cash and Counseling model without major operational difficulties or adverse outcomes for consumers, their families, or their caregivers. It provided a benefit that allowed consumers with

a range of disabilities to meet their personal assistance needs with a high level of flexibility. Agency reports of worker shortages during the demonstration suggest that some consumers who hired family and acquaintances would not have been able to obtain care from agencies had they been in the traditional program. For all these reasons, most consumers were extremely satisfied with the program and care arrangements.

Background and Introduction

About 1.2 million individuals receive noninstitutional supportive services through state Medicaid plans or home- and community-based waiver programs (LeBlanc et al. 2001; Kitchener and Harrington 2001).¹ Under state plans, services are largely restricted to human assistance with personal care and homemaking and must be provided by licensed home care agencies. These agencies recruit, train, schedule, and supervise the staff who assist beneficiaries. Waiver programs may also offer other disability-related goods and services, but their coverage is often limited and someone other than the beneficiary (namely, a case manager) decides whether they are needed. This system of care, while adequate for many recipients, has been criticized for over-medicalizing services and not being flexible enough to meet recipient needs effectively. Moreover, a perennial shortage of workers providing this help, stemming from its low pay, poor benefits, and physically and emotionally demanding nature, worsens when the economy is strong and is likely to deepen as the U.S. population ages and demand for workers increases.

In contrast to these traditional service models, states are increasingly offering Medicaid beneficiaries the opportunity to obtain personal care from individual providers (Velgouse and Dize 2000). This alternative has come to be known as “consumer-directed” care, since beneficiaries who use individual providers assume the employer’s role of hiring, managing, and possibly terminating their workers (Eustis 2000). An expanded model of consumer direction would allow beneficiaries to manage not only their human assistance but also other covered supportive goods and services. Consumer direction is based on the premise that personal care does not require the intervention of medical professionals because it is “low tech” and

¹Includes 467,487 users of states’ optional personal care benefits in 1998 and 1999 (LeBlanc et al. 2001) and 688,152 users of home and community-based waiver program services in 1999 (Kitchener and Harrington 2001). Because some people receive services from more than one program, the total number of users (1.2 million) may be overestimated.

nonmedical. Rather, consumers should be empowered to make informed choices about their assistance and provided with supports to take control of it (Benjamin 2001; Stone 2001; Eustis 2000; Stone 2000; and Doty et al. 1996).

For people with disabilities, supporting choice and control over personal assistance has the potential to better meet individual needs and resonates strongly with basic American values, as re-affirmed in the current administration's New Freedom Initiative. Moreover, consumer direction could enlarge the pool of personal care workers if consumers can hire family or friends to help them. Finally, consumer-directed care might be less costly because agencies would no longer be responsible for hiring, training, and supervising workers (Stone 2000; and Eustis 2000).

Nevertheless, consumer-directed personal assistance in a publicly funded program, like Medicaid, raises many concerns. These include (1) how to ensure care quality and establish accountability for adverse consumer outcomes; (2) how to ensure the benefit is used appropriately; (3) how to ensure workers are trained adequately and treated fairly; (4) whether family members who might otherwise help without pay may be hired as workers; and (5) whether consumer direction should be available to individuals with cognitive deficits (Benjamin 2001; Kane and Kane 2001; Kapp 2000; and Doty et al. 1996). Despite these concerns, in 1999, there were an estimated 139 publicly funded consumer-directed personal assistance programs in the United States (Flanagan 2001).

Cash and Counseling is an expanded model of consumer-directed supportive services in that it provides a flexible monthly allowance that beneficiaries—as consumers—may use to hire their choice of workers, including family members, and to purchase other goods and services (as their state permits). Cash and Counseling requires consumers to develop plans showing how they would use the allowance to meet their personal care needs and provides counseling and

fiscal assistance to help them plan and manage their responsibilities. Consumers who are unable or unwilling to plan and manage their care themselves may designate a representative, such as a family member, to help them or to do it for them. These features are meant to make Cash and Counseling adaptable to consumers of all ages and with all types of disabilities.

With funding from The Robert Wood Johnson Foundation and the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services, the Cash and Counseling Demonstration and Evaluation was implemented as a voluntary demonstration in three states—Arkansas, Florida, and New Jersey.² Because the Medicaid programs and political environments differed considerably across the demonstration states, they were not required to implement a standard intervention, but had to adhere to basic Cash and Counseling tenets, as summarized above. Because of such differences, Mathematica Policy Research, Inc. (MPR) is evaluating each program separately.

Cash and Counseling Evaluation. MPR's evaluation of the three Cash and Counseling demonstration programs addresses four broad questions: (1) Who participated in Cash and Counseling? (2) How was it implemented? (3) How did it affect consumers and their caregivers? (4) How did it affect public costs? To estimate impacts on consumers and their caregivers and on public costs, the evaluation randomly assigned interested, eligible Medicaid beneficiaries to receive either Cash and Counseling benefits (the treatment group) or personal assistance services (PAS) as usual from Medicaid-certified agencies (the control group). It then is comparing the groups' outcomes, based on responses to telephone interviews and Medicaid

²The demonstration operates under waivers provided by the Centers for Medicare & Medicaid Services (CMS). The National Program Office for Cash and Counseling is the Center on Aging at the University of Maryland. The University of Maryland Baltimore County is conducting an ethnographic evaluation of the demonstration (Eckert et al. 2001).

and Medicare claims data. In addition, the evaluation will look at beneficiaries' reasons for participating or declining to participate in Cash and Counseling, based on questionnaires filled out when the beneficiary made this decision. It will also use beneficiary-level Medicaid PAS data to investigate trends in state PAS use for indirect evidence of demonstration-induced demand for PAS.³

This report, which addresses the second broad evaluation question, describes the implementation of the Arkansas demonstration, IndependentChoices, by considering:

- What were the major goals and features of IndependentChoices?
- How well did consumers manage the responsibilities of the program?
- How did consumers take advantage of the increased flexibility the program offered?
- How did consumers like the program? For what types of consumers did it appear to work best, and for whom did it work less well?
- What lessons does IndependentChoices offer policymakers and program developers about consumer direction?

Sources and Methodology. Data and information for this report come from (1) on-site discussions with program staff conducted in March 2000;⁴ (2) a mail survey of program counselors conducted in May and June 2000; (3) telephone interviews with consumers when they enrolled in the demonstration, and four months and nine months later; and (4) data the

³This report focuses on the experiences of the IndependentChoices treatment group. Companion reports present estimates of IndependentChoices' impacts based on treatment-control group outcome comparisons. (See the List of Companion Reports following the References.)

⁴The description of IndependentChoices structure and procedures presented in this report summarizes that presented in greater detail in the program's site visit report (Phillips and Schneider 2002). Readers interested in implementation lessons drawn from the experiences of *all three* Cash and Counseling programs are referred to Phillips et al. 2003.

IndependentChoices program supplied. The report also incorporates the insights of National Program Office staff.

In addition to describing the implementation of IndependentChoices from the perspective of state program staff, this report includes a primarily descriptive examination of consumer and counselor interview responses and program data. We used regression analysis, however, to assess whether certain consumer characteristics affected their experiences and satisfaction with the program, by controlling for other factors on which consumer groups might differ. The regressions included a set of explanatory variables drawn largely from baseline interview data. The report presents selected statistics but references additional tables in the appendix.

Characteristics of IndependentChoices Consumers. Arkansas's Cash and Counseling demonstration program was open to elderly and nonelderly adults eligible for Medicaid PAS and enrolled beneficiaries for its evaluation from December 1998 to April 2001. (Beneficiaries continued to enroll in the demonstration after April 2001, but were not part of the evaluation.) The program provided treatment group members, referred to in the remainder of this report as consumers, a monthly allowance based on the number of hours of PAS for which they had been assessed. It also provided, at no direct cost to consumers, supportive services: counseling (for example, to help consumers develop an allowance spending plan) and optional bookkeeping services (for example, to pay and withhold taxes for workers hired with the allowance). The IndependentChoices allowance and support services were offered to 1,004 consumers who had been randomly assigned to the evaluation treatment group. The typical consumer was elderly (age 65 or older), white, female, and living with someone other than a spouse. Just over a third of consumers reported living in a rural part of the state. Nearly all had paid or unpaid help with personal care and household activities when they enrolled in the program; however, about two-thirds reported they needed more help. Slightly less than half had been receiving publicly funded

home care for more than a year when they enrolled in IndependentChoices. Many consumers were generally satisfied with the paid help they had been receiving; however, nearly a third were not (Table 1).

Table 1: Consumer Characteristics at Enrollment

Age 18 to 64	27.8%	Lived In Rural Area	38.2%
Age 65 to 79	36.4%		
Age 80 or Older	35.9%	Had Paid or Unpaid Help With Personal Care ^a	88.1%
		Had Paid or Unpaid Help With Household Activities ^b	95.7%
Female	77.7%		
		Needed More Help With Personal Care ^a	62.5%
Race Self-Identified as White Only	61.2%	Needed More Help With Household Activities ^b	66.6%
Race Self-Identified as Black	32.9%		
Self-Identified as Some Other Race ^c	5.9%	Had Been Receiving Public Home Care For 1 Year or More ^d	43.7%
Lived Alone	32.1%		
Lived With Spouse Only	8.4%	Was Satisfied Overall With Paid Help and Related Goods	71.1%
Lived With Others	59.6%		

SOURCE: Age and sex come from IndependentChoices program records. All other data come from MPR baseline interviews conducted with IndependentChoices participants between December 1998 and April 2001.

NOTE: Table includes responses for 1,004 consumers in evaluation treatment group.

^aPersonal care includes bathing, transferring from bed, eating, and using the toilet. Questions refer to week before baseline.

^bHousehold activities include light housework, yard work, meal preparation, and shopping. Questions refer to week before baseline.

^cOnly 13 of the 1,004 consumers considered themselves of Hispanic (or Latino) origin when asked in the baseline interview.

^dPublic home care includes help at home from someone who was paid by Medicaid or some other public program.

In addition to presenting data for all IndependentChoices consumers, we also compare the program experiences of elderly and nonelderly consumers. We hypothesized that elderly and nonelderly consumers might differ in their ability to manage the allowance, informal care resources, attitudes toward personal assistance, or desire to control that assistance.

As a basis for understanding differences (if any) in program experiences between elderly and nonelderly consumers, we examined differences in the two groups at enrollment. While elderly and nonelderly consumers were similar on most dimensions at enrollment, they did differ in a few. Elderly consumers had less formal education, were less likely to be new to publicly funded home care, and were more likely to be satisfied with current PAS (Appendix Tables A.1 and A.2). In addition, proxy respondents to the baseline interview were much more common for elderly consumers than nonelderly consumers (57 versus 25 percent).

Of the 1,004 consumers, 924 responded to the evaluation's four-month interview and 885 to the nine-month interview. The baseline characteristics of the responding consumers were nearly identical to those of the original 1,004 enrollees. As for the baseline interview, proxy respondents for the follow-up interviews were much more common for elderly than nonelderly consumers.⁵

Characteristics of IndependentChoices Counselors. IndependentChoices' counselors were surveyed about a year and a half after the program started operating. Five had backgrounds in social work, one was a nurse, and one was a speech pathologist. Five were college educated. All had worked for the program for between 8 and 21 months at the time of they were surveyed (Appendix Table A.3).

Key Goals and Features of IndependentChoices

In February 1996, the Arkansas Department of Human Services, Division of Aging and Adult Services responded to a solicitation from RWJF for proposals to conduct "Cash and Counseling Demonstrations." The solicitation stipulated only that demonstration programs provide an allowance, instead of the optional Medicaid PAS benefit or home- and community-based waiver program services, covering goods and services to promote independence. Arkansas hoped that its program would (1) provide an indication of the demand for a consumer-directed PAS option in Arkansas; (2) test whether consumer direction could operate efficiently in the state's service environment; and (3) increase access to care for consumers whom the agencies did not have enough staff to serve, especially in rural areas. While Arkansas did not hope to

⁵The proxy response rates for the four-month follow-up interview were 67 percent for elderly consumers and 28 percent for nonelderly. Proxy rates for the nine-month follow-up interview were 71 and 29 percent, respectively.

generate savings through implementing Cash and Counseling, budget neutrality was a condition of the CMS waiver under which the demonstration operated.

IndependentChoices provided a monthly allowance in lieu of the Arkansas Medicaid PAS benefit that permitted consumers to hire personal assistance workers (including friends or family, but not spouses or those also named as IndependentChoices' representatives) and to purchase equipment, personal care supplies, and home or vehicle modifications. For many years, eight Area Agencies on Aging (AAAs) and the state Department of Health have provided most Medicaid PAS in Arkansas. At the outset of the demonstration, most of these organizations resisted consumer direction because they were concerned about consumers' health, safety, and vulnerability to exploitation, as well as their own potential loss of revenue. Therefore, Arkansas designed IndependentChoices in ways that would not exacerbate this antagonism (for example, by *not* also cashing out ElderChoices, a Medicaid waiver program for nursing-home-eligible elderly beneficiaries, in which many elderly PAS users also participated).

Outreach and Enrollment. IndependentChoices was open to all adults eligible for the PAS benefit (that is, those categorically eligible for Medicaid, residing in the community, impaired in at least two daily living activities, and having a physician's prescription for PAS).^{6,7}

⁶The terms and conditions for demonstration waivers required the ratio of new-to-ongoing PAS users enrolling in IndependentChoices to remain within the state's historic ratio (0.41) to control induced demand (that is, the flow of individuals coming forward for a consumer-directed benefit who would not have come forward for agency-provided services).

⁷Beneficiaries participating in the state's home and community-based waiver programs were *not* precluded from also participating in IndependentChoices. An analysis of Medicaid enrollment data indicated that among nonelderly IndependentChoices consumers, 2 percent were also in Alternatives and 1 percent were in the state's developmental disability waiver program; among elderly consumers, 58 percent were also in ElderChoices (not shown). Alternatives is a small home- and community-based waiver program for nonelderly adults with disabilities that permits family and friends to become Medicaid providers and thus receive payment for caregiving. ElderChoices is for elderly beneficiaries who require nursing-home level care and

IndependentChoices did not screen applicants for appropriateness for consumer direction, partly because such screening seemed inconsistent with the philosophy of consumer direction and partly out of concern over possible legal challenges from those deemed inappropriate.

IndependentChoices hired nurses living in different regions of the state, who worked mainly full-time for the program, to conduct a community information campaign and enroll beneficiaries. State program staff also developed public service announcements and newspaper articles about IndependentChoices and sent direct mailings to beneficiaries already receiving PAS. Letters to PAS users signed by the governor were effective in generating responses from individuals eligible for the program. The more general publicity attracted many individuals ineligible for Medicaid PAS but required staff resources (which were scarce) to address their inquiries. IndependentChoices also set up a toll-free telephone number for interested beneficiaries to call and a central database to verify their eligibility. Contact information for eligible applicants was electronically forwarded from the database to the enrollment nurses.

The nurses visited interested, eligible beneficiaries at home to explain the details of the program, complete enrollment, and, if necessary, help identify a representative to plan and manage the use of the allowance if the beneficiary were randomly assigned to receive it. To reduce the likelihood that the monthly allowance would induce demand for PAS, beneficiaries were required to promise during these visits that they would accept agency services if they were randomly assigned to the control group.

The pace of enrollment was insufficient to meet the initial sample size target for the evaluation (3,100) and it was reduced to 2,000. The program enrolled 2,008 beneficiaries

(continued)

provides agency services to augment the state's Medicaid PAS benefit to further prevent nursing home placement.

between December 1998 and April 2001, half of whom were randomly assigned to receive the allowance. Several factors seemed to contribute to the slower-than-expected pace. First, expectations regarding the level of interest in consumer direction among Arkansas PAS users may have been too optimistic. A 1996 study of roughly 400 Arkansas PAS users suggested between 30 and 40 percent (regardless of age) would be interested in consumer-directed PAS (Simon-Rusinowitz et al. 1997). However, the 2,008 enrollees who came forward represented just 11 percent of an estimated 18,000 Arkansas PAS users annually (Nawrocki and Gregory 2000)⁸. Second, IndependentChoices did not have the ongoing, enthusiastic support of disability advocates, who might have promoted the program more aggressively among their nonelderly constituents.⁹ Third, program staff reported that some PAS users declined to participate in IndependentChoices because they could not hire their spouses to provide care. Fourth, because of their opposition to consumer direction, agency staff may have been discouraging some beneficiaries from enrolling in IndependentChoices. Fifth, IndependentChoices might have been less attractive to those also receiving ElderChoices because services from that program continued to be provided by agencies. Sixth, the relatively small state staff implementing the program had difficulty finding time for outreach and promotional activities in addition to their other duties.

⁸The estimate of 11 percent may overstate the actual participation rate of eligible beneficiaries in IndependentChoices because program enrollment took place over nearly two and a half years, not one. So the number of eligible beneficiaries during the full enrollment period was likely larger than 18,000.

⁹IndependentChoices staff noted three likely explanations for the waning of support from these advocates, who were enthusiastic about the program prior to its implementation: (1) disappointment over the decision not to allow consumers to hire spouses, (2) one of the most vocal supporters leaving Arkansas for a job in another state, and (3) implementation of another consumer-directed program—Alternatives, described earlier.

Finally, some beneficiaries may not have come forward for the program because of its experimental nature (its relatively short duration and use of random assignment).¹⁰

Beneficiaries randomly assigned to receive the allowance reported finding many program features attractive at the time they enrolled in IndependentChoices. More than three-quarters reported that the opportunity to pay family members to help with their care and to have a say about when and what types of help they received were very important to them. Sixty percent reported having the opportunity to pay friends to help was very important, although this feature was more important to nonelderly than to elderly consumers (Appendix Table A.4). Program staff also noted the importance consumers ascribed to having a family member or friend provide care, asserting that many found personal care provided by strangers demeaning. Program staff also indicated that some consumers found agency work schedules inflexible and agency workers unreliable.

Just over 60 percent of consumers assigned to receive the allowance were still enrolled in IndependentChoices at the end of the evaluation follow-up year, although the percentage was greater among nonelderly consumers (70 percent). Of the consumers who were not enrolled at the end of the year, 22 percent had died and 28 percent had lost eligibility for Medicaid PAS. (Also, the participation of three *individuals* was terminated by program staff.) The remaining 50 percent disenrolled voluntarily; we discuss reasons for this later (Appendix Tables A.5, A.5a, and A.6).

¹⁰Among 584 beneficiaries who inquired about the program but later decided not to participate, only 7 percent reported the experimental nature of the program kept them from joining (not shown). It is likely, however, that some beneficiaries put off by the program's experimental status did not inquire at all.

Counseling and Fiscal Services. IndependentChoices counseling and fiscal services were offered at no direct charge to consumers and provided them with support to self-direct their PAS. Counselors helped most consumers develop mandatory spending plans for the allowance and then were required to review those plans. IndependentChoices permitted counselors to authorize the inclusion of a pre-approved list of goods and services in the plan. State IndependentChoices staff reviewed all requests for goods and services not on the list to determine their relevance to promoting the consumer's independence. Counselors also monitored whether the allowance was used appropriately. They did this by comparing worker timesheets and requests for other purchases against the spending plan, as well as by reviewing receipts for all purchases except those made with funds for incidental expenses (which were intended for purchases that could not be readily invoiced and which could not exceed 10 percent of the monthly allowance).

Counselors provided different types of advice and support to consumers. They were available to explain program rules to consumers and their families, help with program paperwork, and provide information about other public programs for which the consumer might be eligible. For consumers who decided to hire workers, counselors were available to train them on employer responsibilities such as how to hire, train, assess, and potentially fire workers; how to set an hourly wage, taking into account the cost of state and federal taxes and unemployment insurance; and how to keep and submit worker timesheets. Counselors occasionally helped consumers recruit workers or find emergency back-up workers and generally provided encouragement and support to consumers.

Counselors also monitored consumer well-being through monthly telephone calls and quarterly (later, semiannual) in-person visits. Program staff reported that information or impressions gathered during telephone calls sometimes prompted home visits, occasionally unannounced, to investigate potential problems in the home environment or with the use of the

allowance. The regular quarterly home visits were reduced to semiannual ones when staff learned that most consumers did not need regular visits that frequently.

An optional fiscal service, or bookkeeper, was available, at no direct charge to the consumer, to write checks for goods and services included in the spending plan, provide monthly statements to consumers, and, for those who hired workers, manage payroll taxes and unemployment insurance and file documents required of the consumer as the “employer of record.” When the consumer wished to make a purchase, he or she requested a check be made out in the needed amount payable to a specific vendor. The bookkeeper cut the checks and sent them to the consumer, who, in turn, paid the worker or vendor.

Arkansas issued a formal solicitation to select organizations that could provide *both* counseling and bookkeeping, recognizing the need for staff providing these services to communicate frequently with each other. The state made awards to three organizations each covering a different region: a rehabilitation services agency, a provider of education and support services to children and adults, and an AAA that provided Medicare home health and Medicaid home care. The AAA withdrew from IndependentChoices a few months after enrollment began, citing cash flow difficulties. It was replaced by the already selected rehabilitation agency, which then served consumers in three-fourths of the state, with the other agency serving the largely rural, northeast quarter of the state. Counselors and bookkeepers were trained by IndependentChoices state program staff and received technical assistance from two consultants. Technical assistance with fiscal matters was particularly important, as neither agency had extensive experience in providing accounting or tax preparation services to the public. IndependentChoices hired a local certified public accountant to provide technical assistance, and

the National Program Office also provided a consultant to audit accounting and tax preparation procedures in all three demonstration programs.¹¹

Counseling/fiscal agencies received a monthly payment for each consumer. The payment for both counseling and fiscal services began at \$115 per month for the first six months after enrollment, when consumer planning and training were expected to be most intense. It then fell at 6-month intervals until the 18th month after enrollment. Thereafter, the monthly payment per consumer was \$75 per month. This monthly payment was meant to cover all the counseling/fiscal agencies' IndependentChoices administrative and consumer-specific costs. In the early months, when the caseload of consumers was small, agencies reported cash flow problems. However, IndependentChoices staff concluded that in the long run this monthly per-consumer payment overpaid agencies.¹²

Counselors, most of whom worked full-time on IndependentChoices, had many responsibilities, as already noted.¹³ They reported that they spent most of their time (20 percent

¹¹The audit for IndependentChoices discovered that bookkeepers were not limiting disbursements for incidental expenses to 10 percent nor refunding excess withholding to consumers and workers. These problems were remedied immediately after they were discovered.

¹²In July 2001, when the counseling/fiscal agency contracts were renewed, the payment structure was revised to provide for each consumer a one-time payment of \$50 for enrollment and a one-time payment of \$150 for training consumers and helping them with the allowance spending plan, followed by a monthly payment of \$75. Payments were made after the consumer started receiving the allowance. The changes were meant to avoid counseling/ fiscal agencies receiving payment for consumers who had not yet started receiving the allowance and to more accurately reflect the agencies' program costs.

¹³Arkansas' initial contract with the counseling/fiscal agencies required one counselor for every 70 consumers, later increased to 90 consumers. In response to the MPR survey, three counselors reported that their caseloads included between 75 and 90 consumers, while four each reported 405 (not shown). One of the two agencies designated some of the counselors as "generalists," who responded to the questions from all consumers on the caseload and made monthly monitoring calls to all of them. These generalists, and, perhaps other counselors, may have viewed the entire agency caseload of 405 as their caseload, albeit shared with other

or more in a typical week) on relatively few tasks, however: helping with spending plans, providing advice about worker payroll issues (like setting wages), and conducting administrative activities such as record keeping and contacting other program staff. Nevertheless, counselors felt that consumers valued a range of counseling services, including help with program paperwork, encouragement and support, and help with emergency back-up arrangements (Appendix Table A.7). Counselors reported that relatively few consumers (about 20, on average, in each caseload) required extensive monitoring due to concerns about their safety or ability to manage the allowance (Appendix Table A.8).¹⁴

A key concern about consumer direction is that, without home care agency supervision, consumers may be exploited or abused or their safety compromised—however, almost no such instances were identified among IndependentChoices consumers.¹⁵ Four counselors reported having about three consumers for whom they had evidence of self-neglect or for whom they had evidence of neglect by representatives or workers (Appendix Table A.9). That evidence prompted counselors to first consult with the state program staff, then conduct home visits (sometimes unannounced) and increase telephone monitoring until the problem was resolved.

(continued)

counselors. (To promote confidentiality, the counselor survey did not ask respondents to identify the agencies for which they worked.)

¹⁴When the “generalist” counselors were reporting on the number of consumers with a particular trait (for example, those requiring extensive monitoring), they may have been talking about the same consumers. (See earlier discussion on generalist counselors.)

¹⁵In addition to a lack of counselor reports of consumer abuse or neglect, the evaluation’s impact analysis found no difference between treatment and control group members (according to self-reports) in: the likelihood of adverse care-related health outcomes (such as falling, injury while receiving care, or worsening decubiti) or the quality of relationships with workers (for example, workers taking things without permission, leaving early or arriving late for work, being rude, or neglecting consumers) (Foster et al. 2002b).

The program could also have required a consumer in this situation to take on a representative (or to change an existing one) or could return the consumer to agency services.

Monthly Allowance. The IndependentChoices allowance was based on the number of hours in the Medicaid PAS benefit care plan (which was capped at 16 hours per week, unless Medicaid approved more for that beneficiary). Care plans were meant to meet consumers' care needs over and above those met with existing unpaid (or other paid) help. Beneficiaries already receiving the PAS benefit when they enrolled in IndependentChoices used existing benefit care plans that had been developed by home care agencies. IndependentChoices outreach nurses developed them for those new to the benefit. Before IndependentChoices began enrolling consumers, staff compared the number of hours of planned care with hours received for random samples of PAS users. They determined that, on average, planned hours were higher, and differences between planned and received hours of care varied across the agencies developing the plans. As a result, to maintain budget neutrality, IndependentChoices developed agency-specific discount rates: the average ratio of the cost of care received to the cost of care planned for a sample of clients of a given agency. These rates varied from 70 to 91 percent; IndependentChoices also applied a discount rate of 91 percent to plans that program outreach nurses developed. The monthly allowance was the discounted number of hours in the care plan multiplied by \$8 per hour, the rate used in Alternatives.¹⁶ IndependentChoices paid for counseling and fiscal services with the savings generated by cashing out PAS care plans at \$8 per hour, rather than the \$12.36 per hour the Medicaid program paid agencies for PAS. The state retained the remainder (\$4.36 per discounted hour) to pay the counseling/fiscal agencies.

¹⁶If a consumer went into a nursing home or was hospitalized for more than five days, the state requested that the bookkeeper recover the allowance for the time the consumer was not living in the community.

The allowance was not large: \$319 per month (or about \$74 per week) on average at enrollment. Of the 1,004 consumers in the evaluation, a quarter received an allowance of \$50 per week or less, and a quarter received \$101 per week or more (not shown). Nonelderly adults received a somewhat higher allowance on average (\$84 per week) than elderly adults (\$70), perhaps reflecting the fact that many elderly consumers received some services through ElderChoices (Appendix Table A.2). Baseline measures of independence in activities of daily living and the likelihood of having an unpaid caregiver were roughly equivalent for nonelderly and elderly consumers, suggesting they had similar levels of need for PAS assistance.

The allowance could be used only to purchase items included in the spending plan. The consumer could request up to 10 percent of the allowance for incidental expenses that could not readily be invoiced, but the nature of these expenses were specified in the plan (for example, taxi fare). Allowable purchases generally had to promote independence or increase mobility.

More than 80 percent of consumers developed a spending plan and started receiving the allowance within three months of enrolling in IndependentChoices; this percentage was somewhat higher for nonelderly consumers (86 percent, compared with 79 percent for elders) (Appendix Tables A.10 and A.10a, top panel).¹⁷

¹⁷Consumers did not begin receiving the allowance immediately after enrollment for a number of reasons. First, the consumer and counselor talked by telephone at least once to discuss program details and to set up a home training visit. The visit covered developing a spending plan, training the consumer (or representative) on employer responsibilities, and completing hiring paperwork. Occasionally, follow-up telephone calls were required to finish the training. If the consumer wanted to spend the allowance for a purpose not on the state's pre-approved list, the plan also had to be approved by state program staff. If the consumer was hiring a worker, the allowance could not start until the worker was actually ready to begin. If the consumer had been receiving agency services, the agency had to be given notice that those services were to end. Finally, the Medicaid information system needed to be updated so that the allowance would be paid to the program bookkeeper and payment to home care agencies terminated.

Consumer Management of Program Responsibilities

IndependentChoices allowed consumers to designate representatives to help them: decide how to spend the allowance (for example, whether to hire a worker, who to hire, and how much to pay); supervise workers, monitor care provided, sign worker timesheets; and handle program paperwork. Program staff reported that when consumers were not able to make decisions, representatives generally sought to learn consumers' preferences. When consumers could make decisions, the consumer and the representative shared benefit-management tasks. IndependentChoices counselors reported that, when a consumer named a representative, they nevertheless worked with both the consumer and the representative and stressed that the consumer was "the boss."

When they enrolled, 41 percent of consumers (26 percent of nonelderly and 47 percent of elderly consumers) had designated a representative to help them manage the IndependentChoices allowance (Appendix Table A.2). Most consumers who required representatives identified that need themselves when enrollment nurses asked them about help they were already getting. Counselors occasionally first brought up the subject of a representative after the consumer was assigned to the treatment group, if work with the consumer was progressing poorly (for example, was having difficulty developing an allowance spending plan). Representatives tended to be relatives who had already been helping consumers (for example, with financial matters). In a few cases, a consumer's need for a representative decreased over time. As the consumer became more secure in the employer role, he or she then took over benefit management from the representative.

Counselors reported that, for about three-fourths of consumers using representatives, the representatives followed consumers' wishes and acted in their best interest. Only for a fraction of consumers (about one percent) did counselors believe that the representative might have been

unsuitable or that the representative's interests or wishes diverged substantially from those of the consumer (Appendix Table A.11). In that case, the counselor asked the consumer to name another representative.

Nearly all consumers took advantage of IndependentChoices support services and nearly all doing so found these services to be helpful. About 95 percent reported using the optional bookkeeping services.¹⁸ Most consumers reported receiving assistance from counselors with developing spending plans and with hiring and training workers, primarily during the first few months after enrollment, when consumers were not yet familiar with the program. During the first four months after enrollment, more than 80 percent reported getting help from counselors developing spending plans, more than 80 percent reported receiving written materials or advice about recruiting workers, and just over half reported that they got advice about how to train workers. Counselor assistance was also available as consumers continued in IndependentChoices. Nonelderly consumers were somewhat more likely than their elderly counterparts to report getting help revising spending plans or with recruiting during months 5 through 9.¹⁹ Nearly all those getting these types of help reported that it was useful. Consumers found counselors' explanations of program rules and help clarifying spending plan priorities particularly useful (Table 2, Appendix Tables A.12, A.12a, A.12b, and A.13).

¹⁸Counselors and bookkeepers trained all consumers who did not wish to use the bookkeeping service to conduct bookkeeping tasks, after which consumers had to demonstrate their ability to conduct those tasks, and were monitored closely until program staff were sure they were doing the tasks properly. Program staff reported that fewer than five consumers *who hired workers* acted as their own bookkeepers.

¹⁹Data were not available to differentiate between reports of getting help revising spending plans and actual spending plan revisions.

Table 2: Use of, and Satisfaction with, IndependentChoices Services

	Percentage Reporting	Of Users, Percentage Finding It Useful
Used Fiscal Services During First 9 Months	94.7	98.0
Had Help Developing Spending Plan During First 4 Months	83.3	96.3
Received Written Materials or Advice About Recruiting Workers During First 4 Months	80.9	96.2
Received Advice About Training Workers During First 4 Months	54.2	80.0

SOURCE: MPR four-month interview conducted in Arkansas between March 1999 and August 2001 and nine-month interview conducted between August 1999 and January 2002.

NOTE: Table includes responses to four-month interview for 924 consumers in the evaluation treatment group and responses to nine-month interview for 885 consumers in the evaluation treatment group. "First 9" and "first 4" months refer to the months following random assignment to the treatment group.

About 85 percent of consumers assigned to receive the IndependentChoices allowance had received it for at least one month by the time of the evaluation's nine-month follow-up interview.²⁰ Nearly 80 percent of consumers reported that they hired at least one worker with the allowance within the first nine months of enrolling in IndependentChoices; most had hired a worker in the first four months. A tenth, however, tried to hire a worker but were not able to. Program staff reported that consumers who had not identified a family member or friend as a potential worker at the time of enrollment had difficulty hiring a worker. Indeed, 80 percent of consumers tried to hire family members as workers, and most were successful; more than three-quarters of all consumers who hired a worker hired a family member. By comparison, only 20 percent hired acquaintances (friends, neighbors, or fellow church members), while 7 percent hired home care agency workers.²¹ Nonelderly consumers were much more likely to hire an acquaintance: 30 percent, versus 16 percent of elderly consumers. Another tenth of consumers reported that they did not try to hire a worker, perhaps because they chose to meet their personal

²⁰Almost all of the other 15 percent had died or disenrolled from the program.

²¹In addition, just under 85 percent of workers who helped consumers the most at the time of the nine-month interview reported that they had also helped consumers *before* they were hired (Dale et al. 2003a).

assistance needs in other ways or disenrolled from IndependentChoices before attempting to recruit one (Table 3, Appendix Tables A.14 and A.15).

Table 3: Recruiting and Training Workers During the First Nine Months After Random Assignment to the Treatment Group

	Percentage
Recruiting Workers to Be Paid With Allowance	
Hired a worker	79.3
Tried to hire a worker, but did not	10.9
Did not try to hire a worker	9.7
Recruiting Methods Attempted, Among Those Who Hired or Tried to Hire	
Tried to hire	
Family member	80.5
Friend, neighbor, or church member	30.1
Home care agency worker	14.8
Asked family or friend to recommend worker	19.4
Posted or consulted advertisements	5.1
Contacted employment agency	3.3
Recruiting Methods Resulting In Hires, Among Those Who Hired	
Hired family member	77.2
Hired friend, neighbor, or church member	20.1
Hired former home care agency worker	7.2
Hired worker recommended by family or friend	6.1
Posted or consulted advertisement	3.2
Contacted employment agency	0.4

SOURCE: MPR four-month interview conducted in Arkansas between March 1999 and August 2001 and nine-month interview conducted between August 1999 and January 2002.

NOTE: Table includes responses for 914 consumers in the evaluation treatment group who responded to either the four-month or the nine-month interview and answered questions about hiring with the allowance.

Even among those who hired a worker, 20 percent reported that the task was hard and that the biggest difficulties were finding interested, qualified applicants and offering a high enough wage with the allowance (Appendix Table A.14). Consumers whose hires did *not* include any family members were more likely to have found hiring hard: 29 percent, compared with 17 percent of those who did hire family (not shown). Counselors reported that 11 percent of consumers also had serious problems with worker turnover (workers resigning or being fired) (Appendix Table A.16). Just five percent of consumers reported firing a worker hired with the allowance (not shown).

Although nearly 70 percent of consumers gave their workers written contracts or agreements to sign delineating worker responsibilities, few consumers (six percent) offered workers fringe benefits, most commonly free room or food. Health insurance was never offered (not shown). The paucity of fringe benefits was likely a result of the low level of the monthly allowance, the fact that most workers were family members, and the fact that fringe benefits are rare in part-time jobs. (A companion analysis based on a survey of workers indicates that only roughly 20 percent of workers for control group members, almost all of whom were employed by agencies, received fringe benefits. See Dale et al. 2003a.)

A third of consumers who hired a worker provided training for them, almost all by showing the worker how to carry out tasks. A small number arranged for training outside the home. Few consumers who provided training (under 10 percent) found the task difficult (Appendix Table A.14).

How Consumers Took Advantage of Increased Flexibility

Most consumers used the allowance to hire personal assistance workers. As noted, nearly 80 percent of consumers responding to the evaluation's follow-up interview hired a worker with the allowance during the nine months following enrollment. According to program records, consumers used most of the allowance (three-fourths) to pay workers. Of those who had paid personal assistance at home in the most recent two weeks they were at home before the evaluation's nine-month follow-up interview (simply referred to below as "the past two weeks") and who had used the allowance to hire a worker (just under 600 consumers), a third had hired more than one worker, although nonelderly consumers were more likely to have hired just one (Table 4, Appendix Table A.17, A.18).

Table 4: Assistance from Paid Workers Nine Months After Enrollment
Among Those Who Used the Allowance to Hire a Worker

	Percentage		
	All Consumers	Under Age 65	Age 65 or Older
Had 1 Worker	67.8	81.8	61.4
Had 2 or More Workers	32.2	18.2	38.6
Helped With Housework ^a	97.8	98.4	97.6
Helped With Personal Care ^b	94.8	95.2	94.7
Helped With Routine Health Care ^c	78.3	78.5	78.4
Provided Transportation ^d	58.7	75.8	51.0
At Least 1 Worker Lived With Consumer	39.1	28.9	43.7
At Least 1 Worker Did Not Live with Consumer	72.5	75.9	70.9
Helped on Weekends	77.0	74.3	78.2
Helped After 8:00 P.M. on Weekdays	64.2	61.0	65.7
Helped Before 8:00 A.M. on Weekdays	49.1	43.9	51.5

SOURCE: MPR nine-month interview conducted in Arkansas between August 1999 and January 2002.

NOTE: Table includes responses for 599 consumers (187 nonelderly and 412 elderly) in the evaluation treatment group who hired a worker with the monthly allowance during the nine months following random assignment and who had paid personal assistance in the most recent two weeks before the evaluation's nine-month follow-up interview during which the consumer was at home. Roughly five percent of consumers in this table had disenrolled from IndependentChoices and were likely reporting about PAS received from agency workers.

^aHousework includes light housework, yard work, meal preparation, and shopping.

^bPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^dTransportation includes both medical and nonmedical transportation.

Most consumers received between one and three hours of paid care per day, on average; their workers helped with a variety of tasks. Most frequently, workers helped with housework and personal care. However, many helped with routine health care (such as taking medications or checking blood pressure) or provided transportation (for example, for shopping, a service that Arkansas Medicaid did not permit agency workers to provide). Nonelderly consumers were markedly more likely than elderly ones to have help with transportation from a worker (Table 4, Appendix Table A.17). A substantial proportion of consumers (particularly elderly ones) hired someone who lived in their households, but the majority did not. As already noted however, most consumers made use of the flexibility of the allowance by hiring someone already known to them--a relative, former agency worker, or other acquaintance--rather than a stranger. A

companion analysis found that three-quarters of workers hired by consumers also provided unpaid care. (See Dale et al. 2003b.)

Many consumers received help from paid workers at times when it is often difficult to get help from an agency. More than three-quarters had help on weekends, nearly two-thirds had help weekday evenings, and half had help early on weekday mornings (Table 4; Appendix Table A.17).

The flexibility of the IndependentChoices allowance permitted consumers to meet care needs in other ways as well. According to records the IndependentChoices bookkeepers kept for the eighth month after random assignment, nearly half of all consumers used a portion of their allowance to purchase personal care supplies, although such purchases used only about a tenth of the monthly allowance, on average. Roughly a third took advantage of the ability to get up to 10 percent of the allowance in cash for incidental expenses (just over \$30 per month, on average). Anecdotally, the allowance was also used to purchase prescription and over-the-counter medications that the Medicaid pharmacy benefit did not cover. (Arkansas Medicaid covers only three prescriptions per month. If beneficiaries apply for an exception to this cap, they can receive six per month.) Few used the allowance to purchase assistive equipment or to make home or vehicle modifications, perhaps because these were costly and the benefit level was relatively low. However, nonelderly consumers were more likely than elderly consumers to modify their homes or purchase equipment. None used the allowance to purchase services from home care agencies (Table 5, Appendix Tables A.18, A.18a, and A.18b).

Table 5: Uses of the Allowance During Month 8

	Percentage Consumers with Type of Use		
	All Consumers	Under Age 65	Age 65 or Older
Paid A Worker Hired Directly By Consumer	88.3	87.7	88.6
Purchased Personal Care Supplies ^a	48.7	51.8	47.4
Received Petty Cash Disbursement ^b	36.5	38.6	35.5
Purchased Community Services ^c	15.0	18.6	13.5
Purchased Equipment ^d	4.3	8.2	2.6
Received Cash for Emergency Expenses ^e	2.1	2.3	2.0
Purchased Home Modification	1.5	2.3	1.2
Purchased Vehicle Modification	0.6	0.0	0.8
Purchased Home Care Agency Services	0.0	0.0	0.0
Purchased Other Goods or Services	1.0	0.9	1.0

SOURCE: Arkansas IndependentChoices bookkeeper records for month 8 after random assignment.

NOTE: Table includes records for 718 consumers (220 nonelderly and 498 elderly) in the evaluation treatment group. Records include 32 for consumers who were still enrolled in IndependentChoices but who had no spending during the month.

^a Supplies include diapers or pads to protect bedding, ostomy supplies, and feeding equipment.

^b Consumers could request a check, limited to 10 percent of the allowance each month, for petty cash to pay for goods and services directly. Petty cash may have been used to purchase personal care supplies.

^c Community services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, and laundry services.

^d Equipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping.

^e Emergency funds were used to pay for clothing, pest control, and utilities.

Counselor reports about the content of most consumer spending plans were largely consistent with bookkeeper records of spending in month 8. In addition, counselors were asked to describe particularly creative consumer purchases. Few such purchases were noted, but counselors did mention consumers using the allowance to pay for an Internet account to join an on-line support group and paying for professional housecleaning services (Appendix Tables A.19 and A.20).

Although IndependentChoices spending rules were fairly flexible, consumers sometimes requested goods or services that were not permitted. Counselors reported having to deny the use of the allowance to purchase furniture and appliances or make home or vehicle modifications not

related to disability, to pay utility bills, and to purchase recreational goods, services, cigarettes, and alcohol. For their part, 12 percent of consumers reported that program spending rules kept them from getting things that would have enhanced their independence, although only a handful of consumers actually disenrolled for that reason (Appendix Tables A.6 and A.20).

As noted, counselors compared all check requests with spending plans and reviewed receipts for all consumer purchases (other than those incidental expenses) to ensure the program allowance was not misused. There was no evidence that consumers or their representatives materially misused the allowance. Five of seven counselors, however, reported that a small number of their consumers did purchase nonpermissible goods or services or had a worker do so for them. Three of seven counselors reported that a small number of consumers did not keep adequate spending records; the same three counselors also noted that a few consumers did not report worker hours in a timely way (Appendix Table A.21).²²

Satisfaction with and Personal Assistance

Consumers were highly satisfied with IndependentChoices and their care arrangements. This is not surprising, given that most consumers were able to start receiving the monthly IndependentChoices allowance within a few months of enrollment and were generally successful in managing it and capitalizing on the increased flexibility it offered.

Consumer Satisfaction with IndependentChoices. Ninety-six percent of respondents to the evaluation’s nine-month follow-up interview (including disenrollees) said they would “recommend the [IndependentChoices] program to others who wanted more control over personal care services.” Among respondents who received the allowance, more than half

²²When consumers did not keep adequate spending records, counselors provided additional training to the consumer. If those efforts failed to remedy the problem, the counselor would have suggested that the consumer take on (or change) a representative or return to agency care.

(56 percent) said the allowance improved the quality of their lives a great deal, and another 25 percent said it improved their lives somewhat. (Nineteen percent reported it made no difference, and only two *individuals* reported the program made their lives worse.) Nonelderly consumers were more likely to say it improved their lives a great deal (63 percent, versus 53 percent of elderly consumers) (Appendix Table A.22).

Respondents primarily cited IndependentChoices as improving the quality of their lives by enabling them to (1) purchase or repair equipment or modify homes (18 percent); (2) purchase personal care supplies, nutritional supplements, and other care-related supplies (16 percent); (3) purchase medications that Medicaid did not cover (14 percent); and (4) choose their caregivers (14 percent). Elderly consumers were also somewhat more likely to cite getting enough care or care at the right time as the ways the allowance improved their lives (11 percent, versus 6 percent for nonelderly consumers), but elderly and nonelderly consumers cited similar improvements otherwise (Appendix Tables A.22a and A.22b).

Consumer Satisfaction with Personal Assistance. Nine months after enrollment, consumers were generally satisfied with their care arrangements and relationships with workers hired with the allowance, but substantial proportions still had unmet needs for personal assistance.²³ Ninety-four percent said they were satisfied with their overall arrangement for care, and 69 percent said they were very satisfied, regardless of age or whether the consumer or a

²³To avoid bias, questions about consumer satisfaction with paid care were not asked of proxy respondents who were also paid workers, or proxy respondents who were not paid workers but who felt they could not report the consumer's opinion (30 percent of the 885 respondents to the nine-month interview). Questions about unmet need for care were not asked of proxies who were paid workers (24 percent of respondents). All questions were asked of respondents who were no longer enrolled in IndependentChoices, as well as those who were enrolled. Among consumers who hired workers with the allowance, five percent responding to the nine-month interview had disenrolled. Responses for these disenrollees likely reflected opinions about care delivered by agency workers.

proxy responded. Nearly all consumers who hired a worker with the allowance and had paid help during the two weeks before the interview were satisfied with their relationship with the worker and how and when the worker performed tasks (Table 6, Appendix Tables A.23a and A.23b).²⁴

Table 6: Satisfaction with, and Unmet Need for, Personal Assistance

	Percentage
Current Satisfaction With Overall Care Arrangements	
Very satisfied	68.6
Satisfied	25.4
Dissatisfied	6.0
Among Those Who Hired With Allowance and Had Paid Help In Past Two Weeks (Before Interview), Satisfied With:	
Relationship with paid caregiver	99.8
How paid caregiver helps with personal care ^a	99.5
How paid caregiver helps with routine health care ^b	99.0
How paid caregiver helps with housework or community chores ^c	99.0
Times of day help provided	96.9
Among Those Who Hired With Allowance, Paid Caregiver	
Always or almost always completed all tasks	87.1
Never neglected consumer	92.0
Never left early or arrived late (among those with regular schedule)	60.5
Never was rude or disrespectful	90.6
Never helped when help was not wanted	63.7
Never took belongings without asking	96.6
Had Unmet Need For Help With:	
Housework or community chores ^c	40.1
Personal care ^a	32.6
Routine health care ^b	28.1
Transportation ^d	29.0

SOURCE: MPR nine-month interview conducted in Arkansas between August 1999 and January 2002.

NOTE: Satisfaction with overall care includes responses for 621 consumers in the evaluation treatment group who responded for themselves or who had a proxy respondent who was not also their paid worker but who thought they could provide the consumer's opinion. Satisfaction with paid caregivers includes responses for 440 consumers who hired a worker with the monthly allowance during the nine months following random assignment, who had paid personal assistance in the most recent two weeks before the evaluation's nine-month follow-up interview during which the consumer was at home, and who responded for themselves or who had a proxy respondent who was not also their paid worker. Unmet need includes responses for 671 consumers in the evaluation treatment group who responded for themselves or who had a proxy respondent who was not also their paid worker. Roughly five percent of consumers who hired workers with the allowance had disenrolled from IndependentChoices and were likely reporting about PAS received from agency workers.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^cHousework includes light housework, yard work, meal preparation, and shopping.

^dTransportation includes both medical and nonmedical transportation.

²⁴The satisfaction outcomes presented in Table 6 were also measured for control group members and were used to estimate program impacts. (See Foster et al. 2003b.)

Consumers also scored workers well on particular aspects of caregiving. Most consumers reported that their workers completed all tasks, never neglected them, were never rude or disrespectful, and did not take belongings without asking. However, about 40 percent of consumers reported that workers sometimes arrived late or left early, or provided help when it was not wanted.²⁵ These proportions were similar for proxy and self-respondents, and most were similar for elderly and nonelderly consumers. The sole exception was that nonelderly consumers were somewhat more likely to report workers providing unwanted help (42 percent, versus 33 percent for elderly consumers) (Table 6, Appendix Tables A.23a and A.23b).

A substantial proportion of consumers reported that they needed more help with housework (40 percent), personal care (33 percent), transportation (29 percent), and routine health care (28 percent).²⁶ These proportions were similar for elderly and nonelderly consumers, except that a lower proportion of nonelderly consumers reported an unmet need for personal care (27 percent, versus 35 percent for elderly consumers). Proxy respondents, however, were consistently more likely than self-reporting consumers to report unmet need for assistance with different types of care: housework (43 percent among consumers with proxy respondents versus 38 for self-responding consumers), personal care (44 versus 25 percent), transportation (32 versus 27 percent), and routine health care (38 versus 22 percent). The differences between self-responding consumers and proxies may have resulted from differences in perception about

²⁵Rates of workers arriving late or leaving early were higher among workers for control group members, while rates of workers providing unwanted help were roughly the same among workers for control group members (Foster et al. 2003b). Thus, the seemingly high rates among consumers in the treatment group do not result from the program increasing the occurrence of these events.

²⁶The percentages of control-group members reporting unmet needs for help with personal care, housework, and transportation were larger than for (treatment group) consumers, while the percentages reporting unmet need for help with routine health care were about the same (Foster et al. 2002b). Thus, as above, the high rates of unmet need are not program effects.

the consumers' need for care. Or, consumers who used proxy respondents may have been more impaired than self-responders, which, in turn, may have led to a difference in unmet needs (Table 6, Appendix Tables A.23a and A.23b).

Disenrollment. Consumer direction was not intended for all PAS users. Despite consumers reporting high levels of satisfaction with the program and their care during evaluation interviews, program records show that, of the 1,004 consumers who enrolled in IndependentChoices, 189 (19 percent) had disenrolled *voluntarily* within a year of enrolling (Appendix Table A.6). Of those 189, roughly two-thirds disenrolled before they started on the allowance (not shown). The evaluation's nine-month follow-up interview asked consumers who reported disenrolling voluntarily about their reasons for doing so. Reasons most commonly cited were (1) the allowance was too low, (2) they changed their minds about traditional services, or (3) they had difficulty with employer responsibilities such as recruiting or training (Appendix Table A.6).

Elderly consumers were more likely than nonelderly consumers to disenroll *for any reason* in the year following enrollment (41 versus 30 percent). Among those who reported disenrolling within nine months, nonelderly consumers were somewhat more likely to say that the disenrollment was voluntary (50 percent, compared with 42 percent for elderly consumers). Elderly consumers who disenrolled voluntarily were more likely to say it was because they changed their mind or that they had difficulty with employer responsibilities. Nonelderly consumers were more likely to say they disenrolled due to conflict with program staff or because the program had too many rules about the use of the allowance (Appendix Table A.6).

Experiences of Different Types of Consumers. It is not difficult to imagine that certain groups of consumers might adapt to consumer direction more quickly or be more satisfied with it than others, although there is little theory or empirical evidence upon which to base such predictions. For example, consumer direction might be too burdensome for beneficiaries (or

their representatives) if the beneficiary is very ill or has severe cognitive or functional limitations. On the other hand, those with an ample network of unpaid helpers might find it easier to hire workers. It is also possible that consumers getting a relatively more generous allowance would be more satisfied with the program. In addition, as program staff gain more experience and the program matures, it may run more efficiently or its rules may change, thus affecting consumers' satisfaction with the program and care arrangements.

To explore possible differences in the way groups of consumers experienced IndependentChoices, we conducted regression analysis on a few key outcomes: (1) whether the consumer started receiving the allowance within three months of enrolling,²⁷ (2) whether the consumer found it difficult to hire a worker, (3) whether the consumer found program spending rules restrictive, (4) how satisfied the consumer was with the program, (5) how satisfied the consumer was with overall care arrangements, (6) whether the consumer had an unmet need for personal care, and (7) whether the consumer disenrolled voluntarily from the program (Appendix Tables A.24, A.25, A.26, A.27, and A.28).

Only a few consistent patterns emerged. Consumers with one or more unpaid caregivers at enrollment tended to be more satisfied with IndependentChoices and with their overall care after nine months and were less likely to disenroll voluntarily after a year, perhaps because it was easier for them to hire workers. Such consumers were also less likely to report that the program spending rules were restrictive. Consumers with more than six hours of planned care each week at enrollment, and thus, relatively larger allowances, were more likely to start receiving the allowance within three months, were more satisfied with IndependentChoices, were less likely to

²⁷Almost all consumers who were to receive the allowance started within three months of enrollment (81 percent of 1,004 consumers). Only another 4 percent started between the fourth and twelfth months after enrollment.

report an unmet need for personal care nine months after enrollment, and were less likely to disenroll from IndependentChoices voluntarily. (The more generous allowance may have made it easier to attract and hire a worker and thus start receiving the allowance relatively quickly.) On the other hand, consumers for whom a proxy respondent answered most questions in the baseline interview, and who thus might have been in poorer health or might have had more cognitive limitations, were less likely to start receiving the allowance within three months, more likely to report unmet need for personal care at nine months, and more likely to disenroll voluntarily. Finally, consumers who enrolled later in the demonstration (in 2000 or 2001) were more likely to start receiving the allowance within three months of enrolling. However, the later enrollees were also less likely to be highly satisfied with IndependentChoices. Those who came forward for the program in its earlier days may have been more dissatisfied with agency care and may have been in situations that better supported consumer-directed care than those who came forward later.

A few characteristics also seemed to be strongly related to starting on the allowance quickly and remaining in the program, perhaps suggesting a strong interest in consumer direction on the part of consumers and caregivers. Consumers who did not have publicly funded home care at enrollment were more likely to start receiving the allowance within three months and were less likely to disenroll. Consumers dissatisfied with their paid care at enrollment were also less likely to disenroll. Those consumers who had an informal caregiver at baseline who was interested in becoming a paid worker were more likely to start receiving the allowance within three months and were less likely to disenroll voluntarily.

We also used regression analysis to investigate the independent effect of hiring a family member on the seven key outcomes described above. For five outcomes hiring a family member had no effect; however, those who hired family were less likely to have found hiring hard and

more likely to be very satisfied with overall care arrangements (not shown). The lack of effect for most of the outcomes analyzed may reflect the fact that of consumers who did not hire family, most hired acquaintances, many of whom had been providing care before they were hired.

Counselor assessment of IndependentChoices. Counselors were also asked to assess the experiences of consumers in IndependentChoices. On average, IndependentChoices counselors reported about a fifth of consumers in their caseloads required extensive amounts of counselor assistance. Those who required the most help were consumers who were ill or who had not identified a family member or friend to be a paid worker, and consumers (or representatives) who had little experience as employers. Six of seven counselors also reported having a handful of consumers (five or fewer) who made unreasonable demands, such as wanting checks for workers before they had done the work or wanting to make purchases not permitted under program rules (Appendix Table A.29). In addition, several counselors noted that the program worked best for consumers considering nursing home placement, those who had had a family member or friend in mind to hire as a worker, and those who wanted to purchase care-related equipment or services that Medicaid did not cover. In summary, one counselor noted that she heard more than once from consumers: “This is the best program I have ever received. I can finally get some help with my bath and meals. Without this program I would have no one.” On the other hand, counselors reported the program did not work particularly well for consumers who could not hire or retain a suitable worker (Appendix Table A.30).

Counselors were also asked to assess the program more generally. Only one counselor recommended changes to counseling activities or counselor training: using more peer counseling in training. At least one counselor recommended each of the following: increasing pay for workers, providing worker training, and simplifying the allowance spending plan. One reported

that the provision of “cash” created the incentive for financial exploitation and that just giving consumers control over who works for them and what tasks are carried out would be better. Another recommended expanding the current program to children with disabilities (Appendix Table A.31).

Discussion

The Arkansas IndependentChoices program is one of three Cash and Counseling demonstration programs testing a model of consumer direction that provides a monthly allowance to consumers (or their representatives) to purchase personal assistance and related goods and services, and provides the support of counselors and bookkeepers to assist in managing the allowance. Consumers included in its evaluation were highly satisfied with the program and care arrangements developed with the allowance. Program staff were pleased that the program appeared to increase the availability of personal assistance for consumers affected by the state’s chronic worker shortage and for the minority of consumers who were dissatisfied with agency-provided assistance. Nevertheless, the program may not have been suitable for everyone. Roughly only a tenth of eligible beneficiaries came forward for the program and among those randomly assigned to receive the allowance, consumers who did not have a relative or acquaintance to hire as a worker, tended to have difficulty hiring and were more likely to disenroll from the program.

Specific Implementation Lessons from IndependentChoices

IndependentChoices is only one of three Cash and Counseling demonstrations, so it would be premature to draw conclusions about what a consumer-directed PAS benefit should look like based on its implementation alone. Nevertheless, IndependentChoices does offer some specific lessons for consumer-directed PAS programs.

Outreach and Enrollment. Staff found direct mailings to PAS users (such as letters signed by the governor) to be the most efficient means of disseminating information about the program. Broader types of outreach, such as public service announcements, led to many calls from individuals not eligible for Medicaid PAS and took a great deal of staff time. Enrollment required more resources than originally anticipated. Staff streamlined some procedures around these activities (for example, by making sure all family members who were involved in care decisions were present at introductory home visits with consumers). Staff also made sure that outreach and other program materials were written at an appropriate reading level and that consumers also had many chances for verbal communication since written materials alone were seldom adequate for explaining the complexities of the program. (Over half of consumers had eight or fewer years of formal education (Appendix Table A.1).)

Counselors, Bookkeepers, and Representatives. The combined efforts of counselors, bookkeepers, and representatives enabled consumers with different types of disabilities to participate successfully in consumer direction. Several lessons emerge about the structure of the organizations that employ counselors and bookkeepers and about the services they provide. IndependentChoices originally awarded contracts to three organizations, each of which provided both counseling and bookkeeping services. It proved important that IndependentChoices contracted with more than one organization, because when one of them withdrew early in the demonstration, another was able to fill the void quickly.

Realizing that counselors and bookkeepers would need to communicate frequently with each other, IndependentChoices required that each organization provide both counseling and bookkeeping services. Few organizations had the needed staff to provide both types of services, however, and those that did were somewhat stronger in counseling activities. Although the organizations could conduct major bookkeeping tasks well—processing timesheets efficiently

and paying workers promptly—bookkeeping staff were relatively inexperienced in some of the details of their fiscal responsibilities (for example, those pertaining to payroll taxes) and required technical assistance, including from an independent auditor hired by the National Program Office.

Ensuring consumer well-being and avoiding misuse of the monthly allowance are key concerns for consumer-directed models. In response, IndependentChoices initially may have overestimated the need to monitor consumers, having counselors contact them monthly by telephone and quarterly in person. In-person visits were later reduced to every six months, as it became clear that few consumers required a regular quarterly visit. On the other hand, a small number of consumers needed frequent visits to resolve specific problems or to ensure their well-being or appropriate use of the allowance.

Representatives were key to many consumers' success with IndependentChoices. Forty-one percent named representatives at enrollment to help them manage the monthly budget or to manage it for them, although elderly consumers were much more likely than younger ones to do so. Counselors believed representatives largely acted according to consumer wishes and in their best interest.

Use of the Monthly Allowance. IndependentChoices provided a relatively flexible benefit that could be used to hire a personal care worker, including family members or friends. Consumers who could not hire family or friends had difficulty identifying workers, leading some to disenroll. In fact, some counselors thought the program may have been unsuitable for consumers who could not hire workers on their own. A formal worker registry, additional training about how to canvas a widening circle of acquaintances to identify potential workers, or the opportunity to hire spouses might have alleviated the burden of hiring for some. In addition, introductory program materials could highlight the complexities of hiring a worker so that

consumers and their families took that into consideration when deciding whether to go forward with consumer direction.

Although consumers used most of the monthly allowance to pay worker salaries, counselors and consumers noted the importance of being able to use the allowance to purchase care-related goods and services such as personal care supplies, medications, and community services, including transportation. Some consumers, primarily nonelderly ones, used the allowance to pay for home modifications and purchase assistive equipment.

How IndependentChoices addressed policy concerns about consumer direction

Consumer-directed personal assistance in a publicly funded program like Medicaid raises many concerns among policymakers, as discussed at the start of this report. These concerns include (1) whether consumer direction should be available to all PAS users, (2) whether to allow family members who might otherwise help without pay to be hired as workers, (3) how to ensure care quality for consumers, (4) how to ensure workers are trained adequately and treated fairly, and (5) how to avoid fraudulent use of a cash benefit. We conclude by discussing how the structure of IndependentChoices and its procedures addressed each of these concerns to a greater or lesser degree.

Appropriateness screening did not appear to have been necessary for IndependentChoices, although use of representatives was common.

IndependentChoices did not screen beneficiaries for their appropriateness to participate in a consumer-directed program. Any beneficiary eligible for the Arkansas Medicaid PAS benefit could apply, including those with cognitive deficits or behavioral problems, such as substance abuse or serious mental illness. The program was also open to eligible adults of any age despite some policymaker skepticism that consumer direction would be of interest to or appropriate for elders. Screening was avoided to be consistent with the philosophy of consumer direction and

out of concern that beneficiaries deemed inappropriate might bring legal challenges. Program staff believed that individuals would self-select for the program once they understood the responsibilities and risks involved. Moreover, consumers could identify representatives at enrollment (almost always family or friends) to help them manage the benefit or to manage it on their behalf. Use of representatives or surrogate decision makers is common in public consumer-directed programs (Tilly and Wiener 2001; and Flanagan 2001). A notable exception is the California In-Home Supportive Services program, which excludes consumers with cognitive impairments (Doty et al. 1999). IndependentChoices counselors encouraged consumers who had not initially chosen representatives to select one if the consumer was having difficulty developing the spending plan or recruiting workers. The program also reserved the right to terminate a consumer from IndependentChoices and return him or her to the traditional PAS benefit if the program seemed unsuitable. That IndependentChoices terminated only 3 of the 1,004 of the mostly elderly consumers who enrolled and that reports of abuse of consumers or of the allowance were negligible (as discussed further below) supports the idea that appropriateness screening was not necessary for this program.

Allowing consumers to hire relatives was critical to the success of the program, although consumers could not hire their spouses.

There is a long-standing debate in the history of community-based long-term care about whether it is appropriate to use public funds to pay family members and others who would provide all or some care without pay (Benjamin and Matthias 2001; Benjamin et al. 2000; Tilly et al. 2000; Doty et al. 1999; Simon-Rusinowitz et al. 1998). Those who consider it appropriate point to unpaid caregiver burnout and their foregone wages, while those who consider it inappropriate point to increased costs and loss of traditional familial caregiving values. Current federal law allows relatives who are not legally liable to be paid as caregivers. (Legally liable

relatives include spouses and parents of dependent children.) In 1999, more than 80 percent of the 139 publicly funded consumer-directed personal assistance programs in the United States allowed consumers to hire nonlegally liable relatives (Flanagan 2001).

Even though demonstration waivers permitted hiring spouses, IndependentChoices allowed consumers to hire any relatives *except* spouses as personal assistance workers. IndependentChoices designers decided not to allow consumers to hire spouses partly because it seemed too politically sensitive for Arkansas at the time. In addition, the design decision was made before demonstration waiver terms and conditions were finalized, and the designers feared allowing consumers to hire legally liable relatives might be an obstacle to waiver approval. Outreach staff, however, reported that some beneficiaries did not apply to the program because they could not hire their spouses with the allowance. IndependentChoices also appeared to have lost some support from disability advocates due to this restriction. Although consumers could not hire their spouses, more than three-quarters did hire other family members. Family and friends represented a labor pool unavailable to agencies, many of which experienced severe worker shortages during the demonstration. Moreover, consumers who did not hire relatives or acquaintances were more likely to report having a difficulty hiring a worker. (See Foster et al. 2003a for an analysis of IndependentChoices effects on informal caregivers and Dale et al. 2003b for a discussion of the substitution of paid for informal care.)

Regular counselor monitoring and follow up identified and resolved potential consumer safety and care quality issues.

Ensuring the health and safety of vulnerable consumers and the quality of their personal assistance without agency oversight is a major concern for consumer direction. For many years, regulations for agency-delivered home care have been in place to try to ensure care quality through requirements concerning agency structure and worker training and supervision (Kapp

2000; and Doty et al. 1996). However, researchers and policy makers disagree about the fundamental definition of care quality in consumer-directed models and how to assess it. Should the uniform professional standards of agency-based care apply? Or are the consumer's opinions of how well care is provided more germane and appropriate to the nontechnical nature of personal assistance (Benjamin 2001)? In 1999, most U.S. consumer-directed personal assistance programs (74 percent) required that workers have specific qualifications; nearly half (45 percent) required some type of worker training; and most (88 percent) conducted quality monitoring activities such as case management, consumer satisfaction reviews, and program evaluations (Flanagan 2001).

There was no evidence from consumers, counselors, or state program staff that participation in IndependentChoices led to any adverse effects on consumers' health and safety. (This is consistent with the evaluation of the California In-Home Supportive Services program, which also found that consumer direction had no deleterious effect on care quality or consumer safety (Doty et al. 1999).) IndependentChoices oversaw consumer safety and care quality primarily through regular counselor contacts with consumers by telephone and in person. Subtle behavior changes or other cues in telephone contact sometimes prompted a home visit by a counselor, occasionally unannounced. As noted, reports of consumer abuse were rare, and consumers were overwhelmingly satisfied with the program and their care arrangements. A companion analysis found IndependentChoices had no deleterious effect on objective, care-related outcomes for consumers. Relative to the randomly assigned control group, consumers in IndependentChoices had no more falls, decubiti, or injuries incurred while receiving paid care, and, for some of these outcomes, they had fewer such problems (Foster et al. 2003b).

Although few workers were offered fringe benefits, reports of worker abuse were rare in IndependentChoices.

Critics of consumer direction are also concerned about the welfare of workers in the absence of collective bargaining and agency protection from abusive caregiving situations. Reports by IndependentChoices counselors of worker abuse were rare. (The program did not, however, have formal procedures to receive and address worker complaints against consumers or their representatives, so if workers did have complaints, they may have gone unreported.) More than two-thirds of workers were given written contracts or agreements to sign delineating their responsibilities. Few were offered fringe benefits other than free room or food, and health insurance was never offered. The paucity of fringe benefits was likely a result of the low level of the monthly allowance, the fact that most workers were family members, and the fact that fringe benefits are rare in any low-paying part-time job.

A companion report (Dale et al. 2003a) compared responses to interviews with workers hired with the IndependentChoices allowance to responses given by workers for control group members. It found workers hired with the allowance, relative to those for the control group: received roughly equivalent wages (although they were much less likely to receive fringe benefits), were no more likely to suffer physical injury from caregiving (despite receiving less formal training), and were equally satisfied with working conditions.

Counseling and bookkeeping procedures helped make abuse of the allowance rare.

Providing a “cash benefit” instead of services in a public program always raises concerns about fraudulent use of the benefit. Roughly half of consumer-directed programs in 1999 addressed concerns about benefit fraud by directly paying worker salaries (Velgouse and Dize 2000; and Simon-Rusinowitz et al. 2000). IndependentChoices prevented abuse by ensuring that each spending plan contained only permissible goods and services and by comparing each

timesheet and consumer check request with the spending plan (except for the few consumers who did not use the bookkeeping service). Counselors also reviewed the receipts consumers were required to keep for purchases other than those made with the relatively small cash disbursement consumers could take from the allowance for incidental expenses. Only a third took advantage of the opportunity to receive even part of the allowance in cash (up to 10 percent of the allowance or about \$32 per month, on average). Moreover, although consumers could receive the monthly allowance directly, almost all chose to use the program's bookkeeping service to pay workers and other service providers. There was no evidence that consumers or their representatives materially misused the allowance.

In Conclusion. IndependentChoices successfully addressed many important concerns about consumer direction. It successfully implemented a consumer-directed program using the Cash and Counseling model without major operational difficulties or adverse outcomes for consumers, their families, or their caregivers. It provided a benefit that allowed consumers with a range of disabilities to meet their personal assistance needs with a high level of flexibility. Agency reports of worker shortages during the demonstration and results of a companion analysis (Dale et al. 2003b) suggest that some consumers who hired family and acquaintances would not have been able to obtain care from agencies had they been in the traditional program. For all of these reasons, most consumers were extremely satisfied with the program and care arrangements.

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COMPANION REPORTS

Impacts on Quality of Care and Use of Personal Care

These reports compare treatment and control group members, using data from telephone interviews describing, among other outcomes measured nine months after random assignment: satisfaction, unmet need, disability-related health, and hours and types of personal care received. Reports on the Arkansas program are listed below; a report on children participating in the Florida program and a report on adults from all three programs are forthcoming.

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

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

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

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

Impacts on the Cost of Medicaid and Medicare Services

These reports compare treatment and control group members, using Medicaid and Medicare data describing the cost of personal care and other covered services measured during the year after random assignment, as well as presenting information about Cash and Counseling program costs. Three reports are forthcoming: the first describes the Arkansas program, the second children in the Florida program, and the third adults in all three programs.

Impacts on Informal Caregiving

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

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

Experiences of Paid Workers

These reports compare the experiences of primary paid workers of treatment and control group members (identified nine months after random assignment), using data from telephone interviews describing working conditions, burden, and well-being 10 months after random assignment. The Arkansas report is listed below; a report on workers for the Florida and New Jersey programs is forthcoming.

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

Program Implementation

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

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

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. "Changing to Consumer-Directed Care: The Implementation of the Cash and Counseling Demonstration in Florida." (Draft) Princeton, NJ: Mathematica Policy Research, Inc., January 2004.

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

The current report is the first of a set of three. These reports will provide an overview of program implementation by distilling information from the site visit reports noted above and synthesizing this information with data from a mail survey of counselors and telephone interviews with consumers in the program treatment groups. This Arkansas report is noted

below; reports describing the implementation of the Florida and New Jersey programs are forthcoming.

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

Program Demand and Participation

This report will describe changes in enrollment in demonstration feeder programs before and after demonstration implementation, as well as compare program participants with eligible nonparticipants. The forthcoming report will include all three state programs.

APPENDIX A
ADDITIONAL TABLES

TABLE A.1
 CONSUMER CHARACTERISTICS AT BASELINE
 (Percent)

	Overall	Under 65	65 or older
Demographic Characteristics			
Age			
18 – 39	7.2	25.8	
40 – 64	20.6	74.2	
65 – 79	36.4		50.3
80 or older	35.9		49.7
Sex			
Female	77.7	67.4	81.7
Race			
Self-identified as white only	61.2	66.8	59.0
Self-identified as black only or black and some other race	32.9	26.0	35.6
Self-identified as some other race	5.9	7.2	5.4
Hispanic	1.3	1.1	1.4
Years of Education			
8 or fewer	53.7	24.4	65.1
9 to 12, non-graduate	22.1	30.5	18.9
12 (high school graduate)	16.4	25.4	12.9
More than 12 (some college)	7.8	19.7	3.2
Living Arrangement/Marital status			
Lives alone	32.1	37.3	30.1
Lives with spouse only	8.4	7.5	8.7
Lives with others/not married or married and living with 2 or more other people	59.6	55.2	61.2
Health and Functioning			
Health Status			
Excellent or good	21.5	20.1	22.1
Fair	30.9	29.9	31.3
Poor	47.5	50.0	46.5
Health Compared with Last Year			
Better or about the same	46.0	49.1	44.8
Worse	54.0	50.9	55.2
Expected Health Next Year			
Better	15.4	18.6	14.2
Worse	36.9	29.4	39.7
Same	29.9	38.0	26.8
Could not say	17.8	14.0	19.3
Last week, Not Independent In: ^e			
Transfer	65.1	63.1	65.9

TABLE A.1 (continued)

	Overall	Under 65	65 or older
Bathing	89.6	87.5	90.5
Using toilet	66.4	63.4	67.5
Functioning Compared with Last Year			
Better or about the same	35.3	40.5	33.3
Worse	64.7	59.5	66.7
Has Cognitive Impairment (Inferred) ^h	23.9	15.8	27.0
Unpaid and Paid PAS			
Had Unpaid or Paid Help at Home Last Week with:			
Personal care ^a	88.1	85.0	89.2
Transportation ^b	61.6	71.0	57.9
Routine health care ^c	74.7	68.5	77.1
Household activities ^d	95.7	93.9	96.4
Number of Unpaid Caregivers Last Week			
None	9.3	8.6	9.5
One	28.3	25.8	29.2
Two	28.8	27.2	29.4
Three or more	33.7	38.4	31.9
Primary Unpaid Caregiver Relationship to Consumer			
Spouse	5.7	7.2	5.1
Parent	5.2	18.6	0.0
Child	53.1	29.4	62.2
Other relative	17.6	20.8	16.4
Nonrelative	9.1	15.4	6.6
Had no primary informal caregiver	9.4	8.6	9.7
Primary Informal Caregiver Employed	32.7	32.9	32.7
Number of paid caregivers last week			
None	32.2	44.1	27.7
One	40.2	35.8	41.9
Two	18.6	13.6	20.5
Three or more	9.0	6.5	10.0
Had Paid Live-in Caregiver Last Week	1.5	1.4	1.5
Received Help at Home Paid by Privately Paid Source Last Week	13.6	11.1	14.5
Goods and Services Purchased Last Year			
Social/recreational programs	9.4	11.9	8.4
Adult day care	6.2	5.0	6.7
Transportation	27.8	35.8	24.7
Home or van modification	37.9	34.1	39.4
Equipment purchase	30.8	29.9	31.2

TABLE A.1 (continued)

	Overall	Under 65	65 or older
Unmet Need for and Access to PAS			
Last Week, Needed Help (or More Help) with:			
Personal care ^a	62.5	69.3	59.9
Transportation ^b	46.2	60.5	40.6
Household activities ^d	66.6	76.9	62.7
Potential Difficulty Hiring Due to Location			
Lives in a rural area	38.2	37.5	38.4
Live in a nonrural area but transportation difficult or high crime	30.7	35.7	28.8
Lives in a nonrural area, but transportation not difficult and not high crime	31.1	26.8	32.8
Satisfaction with Paid PAS			
Satisfaction with How Paid Help Provided ^f			
Very satisfied	29.6	24.4	31.6
Satisfied	21.7	14.3	24.5
Dissatisfied	14.5	14.7	14.5
No paid help with personal care, routine health care, housework	34.2	46.6	29.4
Satisfied with When Paid Help Provided Among Those Receiving Personal Care ^f			
Very satisfied	19.4	13.7	21.7
Satisfied	17.1	9.7	20.0
Dissatisfied	16.0	18.0	15.3
No paid help with personal care	47.4	58.6	43.1
Satisfied with Paid Services and Goods Overall			
Very satisfied	38.1	27.5	42.2
Satisfied	33.0	26.4	35.5
Dissatisfied	19.9	31.2	15.7
No paid services or goods ^g	8.9	14.9	6.6
Quality of Life			
Satisfied with Life Overall			
Very satisfied	13.1	10.6	14.0
Satisfied	18.4	25.9	15.6
Dissatisfied	19.1	38.0	11.8
Proxy respondent not asked	49.4	25.6	58.6
Employment Experience			
Ever employed	84.3	82.1	85.2
Ever supervised someone	29.5	42.9	24.3
Ever hired someone privately	32.3	42.4	28.4

TABLE A.1 (continued)

	Overall	Under 65	65 or older
Type of Respondent			
Majority of Baseline Questions Answered by Proxy Respondent	48.3	24.7	57.4
Number of Consumers Responding to Survey	1,004	279	725

SOURCE: Age and sex come from IndependentChoices program records. All other data come from MPR baseline survey conducted in Arkansas between December 1998 and April 2001.

NOTE: "Last week" refers to the week before the baseline survey.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fFor 48 cases, proxy respondent is providing own level of satisfaction because sample member reportedly not capable of forming opinion.

^gSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

^hConsumer could not respond to interview due to physical or mental limitation and used a representative to manage allowance.

TABLE A.2

HOME CARE AT ENROLLMENT AND USE OF REPRESENTATIVE FOR INDEPENDENTCHOICES
(Percent)

	Overall	Under 65	65 or Older
Length of Time With Publicly Funded Home Care			
Participant says no care last week and program says not a current Medicaid PAS user	26.1	39.4	20.9
Participant says no care last week, but program says current Medicaid PAS user	9.4	9.3	9.4
Participant says getting care less than a year	20.9	16.9	22.4
Participant says getting care 1 to 3 years	22.4	17.2	24.4
Participant says getting care more than 3 years	21.3	17.2	22.9
Number of Hours Per Week of Planned PAS			
Less than or equal to 6	22.6	16.8	24.8
More than 6, but less than or equal to 11	37.5	32.6	39.3
More than 11, but less than or equal to 15	37.6	45.9	34.5
More than 15	2.3	4.7	1.4
Mean Monthly Allowance ^a	\$319	\$362	\$302
Had an IndependentChoices Representative at Enrollment	40.8	26.2	46.5
Number of Consumers Responding to Survey	1,004	279	725

SOURCE: MPR baseline survey conducted in Arkansas between December 1998 and April 2001 and IndependentChoices program records.

NOTE: "Last week" refers to the week before the baseline survey. PAS is personal assistance services.

^aIndependentChoices calculated the monthly allowance by multiplying the planned weekly PAS hours of care by 4.33 (weeks per month), \$8 (dollars per hour), and an agency-specific discount rate. The discount rate, which ranged from 70 to 91 percent and was meant to promote budget neutrality, took into account the fact that agencies usually delivered fewer hours of care than appeared in care plans.

TABLE A.3

COUNSELOR CHARACTERISTICS AND EXPERIENCE WITH INDEPENDENTCHOICES

Number of Counselors by Characteristic	
Professional Background	
Social work/ social services	5
Nursing	1
Other (speech pathologist)	1
Highest Educational Degree	
Less than high school	0
High school graduate or GED	2
Associate	0
Baccalaureate	3
Master's or doctorate	2
Sex	
Female	4
Hispanic or Latino	
	0
Race	
White	4
African American/ black	2
White and American Indian/Alaska Native	1
Country of Birth	
United States	7
Time Working for IndependentChoices	
A year or less	4
More than a year	3
Number of Consumers with Whom Counselor Has Worked Since Started with IndependentChoices	
Mean	284
Median	405
Minimum	95
Maximum	405
Number of Consumers with Whom Counselor Working at Present	
Mean	268
Median	405
Minimum	75
Maximum	405
Number of Counselors Responding to Survey	
	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

TABLE A.4
PROGRAM FEATURES IMPORTANT TO CONSUMERS AT ENROLLMENT
(Percent)

	Age		
	Overall	Less than 65	65 or Older
Paying Family Members to Help			
Very important	78.3	79.9	77.7
Important or somewhat important	12.5	11.8	12.8
Not important	9.1	8.2	9.5
Paying Friends to Help			
Very important	60.3	67.0	57.7
Important or somewhat important	18.5	18.3	18.6
Not important	21.2	14.7	23.7
Primary Informal Caregiver Expressed Interest in Being Paid	29.6	33.5	28.1
Having a Choice About When Helpers Come			
Very important	82.0	82.1	82.0
Important or somewhat important	13.8	13.6	13.8
Not important	4.2	4.3	4.2
Having a Choice About the Type of Help Services Received			
Very important	85.9	87.8	85.1
Important or somewhat important	11.9	10.8	12.4
Not important	2.2	1.4	2.5
Number of Respondents to Baseline	1,004	279	725

SOURCE: MPR baseline survey conducted in Arkansas between December 1998 and April 2001.

TABLE A.5

ENROLLMENT FLOW AND LENGTH OF STAY, ALL CONSUMERS

	Percentage of Consumers Enrolled
Enrollment Month^a	
December 1998 – June 1999	29.6
July 1999 – December 1999	19.6
January 2000 – June 2000	24.5
July 2000 – December 2000	14.6
January 2001 – April 2001	11.7
Length of Enrollment During Followup Year	
Less than 2 months	11.7
2 months or more, but less than 6 months	13.8
6 months or more, but less than 12 months	12.6
12 months	62.0
Length of Allowance Receipt During Followup Year	
Never received	15.1
6 months or less	16.2
7 to 10 months	9.7
11 months	33.6
12 months	25.4
Number of Consumers Enrolled	1,004

SOURCE: IndependentChoices program records.

^a IndependentChoices enrolled consumers for the evaluation between December 1998 and April 2001.

TABLE A.5a

ENROLLMENT FLOW AND LENGTH OF STAY, BY CONSUMER AGE
AND PUBLIC HOME CARE TENURE

	Percentage of Consumers Enrolled			
	Age		Length of Time with Public Home Care	
	Less than 65	65 or Older	Less Than 1 Year or Not at Enrollment	1 Year or Longer
Enrollment Month^a				
December 1998 – June 1999	28.7	29.9	23.1	38.2
July 1999 – December 1999	25.1	17.5	20.6	18.5
January 2000 – June 2000	24.4	24.6	26.4	22.2
July 2000 – December 2000	10.4	16.3	14.4	14.9
January 2001 – April 2001	11.5	11.7	15.6	6.2
Length of Enrollment During Followup Year				
Less than 2 months	7.5	13.2	9.4	14.7
2 months or more, but less than 6 months	10.4	15.2	10.8	17.9
6 months or more, but less than 12 months	12.2	12.7	12.9	11.9
12 months	69.9	58.9	66.8	55.6
Length of Allowance Receipt During Followup Year				
Never received allowance	10.8	16.8	11.4	20.1
6 months or less	13.6	17.2	14.9	18.1
7 to 10 months	11.1	9.1	9.0	10.3
11 months	33.7	33.5	34.4	32.7
12 months	30.8	23.3	30.3	18.8
Number of Consumers Enrolled	279	725	564	437

SOURCE: IndependentChoices program records.

^a IndependentChoices enrolled consumers for the evaluation between December 1998 and April 2001.

TABLE A.6

DISENROLLMENT DURING FOLLOWUP YEAR AND REASONS FOR DISENROLLMENT
(Percent)

	Overall	Under 65	65 or Older
Disenrolled (or Died) at Any Time During Followup Year According To Program Records	38.1	30.1	41.1
Among Those Who Disenrolled (or Died) According To Records, Did So During Months			
1 to 3	48.7	44.1	50.0
4 to 6	22.5	21.4	22.8
7 to 9	16.8	20.2	15.8
10 to 12	12.0	14.3	11.4
Among Those Who Disenrolled (or Died) According To Records			
Disenrolled (or died) before started receiving allowance	44.0	39.3	45.3
Disenrolled after started receiving allowance	38.7	42.9	37.6
Died after started receiving allowance	17.3	17.9	17.1
Disenrolled (or Died) At Any Time During 9-Month Survey Followup Period According to Self-Reports	33.1	25.3	36.0
Among Those Who Disenrolled (Or Died) During The 9-Month Survey Followup Period According to Self-Reports, Did So			
Between baseline and 4- month interview	61.3	63.6	60.6
Between the 4- and 9- month interview	38.7	36.4	39.4
Reasons for Disenrollment			
Among Those Who Disenrolled (or Died) According to Records, Reason			
Death	21.7	22.6	21.5
No longer eligible for Medicaid	9.7	8.3	10.1
No longer eligible for PAS	18.3	15.5	19.1
Abuse or mismanagement of allowance	0.0	0.0	0.0
Program initiated disenrollment for some other reason	0.8	1.2	0.7
Consumer initiated disenrollment	49.5	52.4	48.7
Among Those Who Disenrolled (or Died) According to Self-Reports, Reason			
Death	22.7	17.4	24.0
Left the state	0.0	0.0	0.0
Entered hospital or nursing home	6.3	0.0	7.8
Lost or needed representative	4.2	0.0	5.2
No longer eligible for PAS	21.0	21.7	20.8
Program initiated disenrollment	2.5	10.9	0.5
Not able to hire in allowed time	0.0	0.0	0.0
Consumer-initiated disenrollment	43.3	50.0	41.7
Among Those with Consumer-Initiated Disenrollment According to Self-Reports, Reason:			
Allowance Not Enough	28.6	27.3	29.0
Other problems with allowance	1.0	4.6	0.0
Conflict with program staff/too many rules about use of allowance	6.1	9.1	5.3

TABLE A.6 (continued)

	Overall	Under 65	65 or Older
Changed mind/satisfied with traditional services/did not understand program	28.6	22.7	30.3
Program never contacted consumer	4.1	4.6	4.0
Problem with employer responsibilities	26.5	18.2	29.0
Consumer/worker/helper health worsened	8.2	9.1	7.9
Problem with fiscal responsibilities	8.2	9.1	7.9
Other reasons	4.1	4.6	4.0
Number of Consumers Enrolled (and Thus with Program Records)	1,004	279	725
Number of Consumers Responding to 4-Month or 9-Month Survey	952	261	691

SOURCE: IndependentChoices program records; MPR telephone surveys with consumers 4 and 9 months after random assignment.

TABLE A.7

ACTIVITIES CONDUCTED BY COUNSELORS

Average Number of Hours Counselors Worked per Week for IndependentChoices	44
Number of Counselors Spending at Least 20 Percent of Consulting Time on the Following Activities with Consumers:	
Reinforcing decision to participate	0
Assisting with spending plan or advising about purchases	3
Advising about payroll activities for workers ^a	2
Advising about worker training	1
Assisting in disputes with workers or advising about firing	0
Linking to peer counseling or other local services	0
Monitoring or investigating misuse of allowance or abuse/neglect/exploitation	0
Assisting with emergency backup arrangements	0
Listening or providing encouragement or support	1
Administrative activities ^b	3
Reassess Medicaid plans or investigate Medicaid problems	1
Number Of Counselors Reporting The Following As Valuable To Consumers	
Assistance with spending plan or advising about purchases	7
Advising about payroll activities for workers	2
Advising about worker training	5
Assisting in disputes with workers or advising about firing	4
Linking to peer counseling or other local services	4
Assisting with emergency backup arrangements	6
Listening or providing encouragement or support	7
Assisting with paperwork	7
Average Number Of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding To Survey	7

SOURCE: MPR mail survey of IndependentChoices counselors conducted between May and June 2000.

^a“Payroll activities” refer to activities such as setting wages, including estimating payroll taxes.

^b“Administrative activities” include record keeping, updating case notes, or making contacts with other program staff.

TABLE A.8
CONSUMER MONITORING

Number of Counselors Reporting That Some Consumers Needed Extensive Monitoring	6
Average Number of Consumers on Caseload Who Needed Extensive Monitoring	20
Number Of Counselors Reporting the Following Reasons for Monitoring	
Consumer or representative appeared to be abused, neglected, or financially exploited	4
Consumer or representative appeared to be abusing or financially exploiting worker	1
Consumer's living environment was unsafe	5
Consumer or representative was having difficulty staying on budget	2
Representative changed	3
Consumer or representative was ill	4
Consumer or representative had no experience as employer	2
Consumer or representative had difficulty completing paperwork	3
Workers changed frequently	5
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: MPR mail survey of IndependentChoices counselors conducted between May and June 2000.

NOTE: Counselors were asked about consumers or representatives who required extensive monitoring due to concerns about their ability to manage the cash benefit or about their safety.

TABLE A.9

COUNSELOR REPORTS OF ABUSE OF CONSUMERS AND WORKERS

Financial Exploitation of Consumers	
Number of Counselors Reporting Evidence of Financial Exploitation ^a	3
Average Number of Consumers for Whom There Was Evidence of Financial Exploitation	1
Number of Counselors Reporting Financial Exploitation of Consumers by:	
Representatives	1
Workers	2
Physical or Verbal Abuse or Neglect of Consumers	
Number of Counselors Reporting Evidence of Abuse or Neglect	4
Number of Counselors Reporting Abuse or Neglect by Type	
Physical or sexual abuse	0
Neglect of physical needs or abandonment	3
Self-neglect	4
Verbal, emotional, or psychological abuse	0
Average Number of Consumers for Whom There Was Evidence of Abuse or Neglect	3
Number of Counselors Reporting Abuse or Neglect of Consumers by:	
Representatives	3
Workers	3
Physical or Verbal Abuse of Workers	
Number of Counselors Reporting Evidence of Abuse of Workers by Consumers, Their Representatives, or Families	3
Number of Counselors Reporting Worker Abuse or Neglect by Type	
Physical or sexual abuse	0
Verbal, emotional, or psychological abuse	3
Average Number of Consumers for Whom There Was Evidence of Abuse of Workers	2
Number of Counselors Reporting Abuse of Workers by:	
Representatives	0
Consumers	2
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: MPR mail survey of IndependentChoices counselors conducted between May and June 2000.

^aFinancial exploitation includes stealing money or possessions from consumers, intentional overbilling, coercing to sign over assets.

TABLE A.10

TIME BETWEEN RANDOM ASSIGNMENT AND MONTHLY ALLOWANCE START,
DISENROLLMENT, OR DEATH, ALL CONSUMERS

	Percentage of Consumers
Started Monthly Allowance by End of: ^a	
1 month	23.5
2 months	76.1
3 months	81.2
4 months	82.6
5 months	82.8
6 months	83.2
7 months	83.6
8 months	83.9
9 months	84.1
10 months	84.4
11 months	84.5
12 months	84.9
Snapshot at End of 3 Months	
Enrolled and started allowance	75.7
Enrolled and allowance not started	6.4
Disenrolled	14.9
Deceased	3.0
Snapshot at End of 6 Months	
Enrolled and started allowance	71.5
Enrolled and allowance not started	2.6
Disenrolled	20.8
Deceased	5.1
Snapshot at End of 9 Months	
Enrolled and started allowance	66.7
Enrolled and allowance not started	1.3
Disenrolled	25.0
Deceased	7.0
Snapshot at End of 12 Months	
Enrolled and started allowance	63.1
Enrolled and allowance not started	0.6
Disenrolled	28.1
Deceased	8.3
Number of Consumers Enrolled	1,004

SOURCE: IndependentChoices program records.

^aPercentages in this panel are cumulative and include consumers who started on cash prior to the referenced month, but subsequently disenrolled or died.

TABLE A.10a

TIME BETWEEN RANDOM ASSIGNMENT AND MONTHLY ALLOWANCE START,
BY CONSUMER AGE AND PUBLIC HOME CARE TENURE

	Percentage of Consumers			
	Age		Length of Time with Public Home Care	
	Less than 65	65 or Older	Less Than 1 year or Not at Enrollment	1 Year of Longer
Started Monthly Allowance by End of:^a				
1 month	26.9	22.2	27.1	18.5
2 months	80.3	74.5	80.5	70.3
3 months	86.0	79.3	84.9	76.2
4 months	87.5	80.7	86.4	77.6
5 months	87.5	81.0	86.7	77.6
6 months	87.5	81.5	87.1	78.0
7 months	88.5	81.7	87.6	78.3
8 months	88.9	81.9	87.8	78.7
9 months	89.3	82.1	87.8	79.2
10 months	89.3	82.5	88.1	79.4
11 months	89.3	82.6	88.1	79.6
12 months	89.3	83.2	88.7	79.9
Snapshot at End of 3 Months				
Enrolled and started allowance	80.7	73.8	80.1	69.8
Enrolled and allowance not started	7.2	6.1	6.6	6.2
Disenrolled	9.7	17.0	9.9	21.5
Deceased	2.5	3.2	3.4	2.5
Snapshot at End of 6 Months				
Enrolled and started allowance	78.9	68.7	76.2	65.2
Enrolled and allowance not started	2.9	2.5	3.2	1.8
Disenrolled	15.1	23.0	15.3	28.2
Deceased	3.2	5.8	5.3	4.8
Snapshot at End of 9 Months				
Enrolled and started allowance	74.6	63.7	71.5	60.4
Enrolled and allowance not started	1.8	1.1	2.0	0.5
Disenrolled	17.9	27.7	19.3	32.5
Deceased	5.7	7.5	7.3	6.6
Snapshot at End of 12 Months				
Enrolled and started allowance	71.0	60.0	67.9	56.8
Enrolled and allowance not started	1.1	0.4	1.1	0.0
Disenrolled	21.2	30.8	23.1	34.6
Deceased	6.8	8.8	8.0	8.7
Number of Consumers Enrolled	279	725	564	437

SOURCE: IndependentChoices program records.

TABLE A.10a (*continued*)

^aPercentages in this panel are cumulative and include consumers who started on cash prior to the referenced month but subsequently disenrolled or died.

TABLE A.11

USE OF REPRESENTATIVES

Percentage Of Consumers with Whom Counselor Worked Who Used Representatives	46.4
Of Those Using Representatives:	
Percentage of consumers for whom counselor questioned suitability of representative	3.0
Percentage of consumers who disenrolled because representative was unsuitable	1.9
Percentage of representatives who acted according to the wishes and best interest of consumers	76.6
Percentage of representatives who had a serious divergence of wishes or interests from consumers	1.0
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

TABLE A.12

USE OF AND SATISFACTION WITH PROGRAM SERVICES

	Percentage of Consumers Reporting	Percentage Of Users Reporting Service Useful/ Satisfied With Service
Help Developing Allowance Spending Plan Between Baseline and 4-Month Interviews	83.3	96.3
Help Revising Allowance Spending Plan Between 4-Month and 9-Month Interviews	30.5	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 4-Month Interviews	50.0	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 4-Month Interviews (Among Those Who Tried to Hire)	74.8	81.5
Advice About How to Recruit Workers Between Baseline And 4-Month Interviews (Among Those Who Tried To Hire)	51.6	91.3
Advice or Materials About How to Recruit Workers Between 4-Month And 9-Month Interviews (Among Those Who Tried to Hire)	37.1	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	94.7	98.0
Advice About How to Train Workers Between Baseline and 4-Month Interviews (Among Those Who Hired)	54.2	80.0
Advice About How to Train Workers Between 4-Month and 9-Month Interviews (Among Those Who Hired)	28.8	n.a.
Use of Peer Counseling Services Between Baseline and 4-Month Interviews (Among Those Receiving Allowance)	1.3	100.0
Use of Peer Counseling Services Between 4-Month and 9-Month Interviews (Among Those Receiving Allowance)	1.0	n.a.
Number of Respondents to 4-Month Interview	924	
Number of Respondents to the 9-Month Interview	885	

SOURCE: MPR telephone interviews with consumers 4 and 9 months after random assignment.

n.a. = means not applicable.

TABLE A.12a

USE OF AND SATISFACTION WITH PROGRAM SERVICES, ELDERLY ADULTS

	Percentage of Consumers Reporting	Percentage of Users Reporting Service Useful/Satisfied with Service
Help Developing Allowance Spending Plan Between Baseline and 4-Month Interviews	81.7	95.2
Help Revising Allowance Spending Plan Between 4-Month and 9-Month Interviews	27.9	n.a.
Help Identifying Programs or Services with Little or No Cost to Consumer Between Baseline and 4-Month Interviews	52.5	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 4-Month Interviews (Among Those Who Tried to Hire)	73.6	81.4
Advice About How to Recruit Workers Between Baseline and 4-Month Interviews (Among Those Who Tried to Hire)	49.4	91.1
Advice or Materials About How to Recruit Workers Between 4-Month and 9-Month Interviews (Among Those Who Tried to Hire)	34.5	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	95.1	98.0
Advice About How to Train Workers Between Baseline and 4-Month Interviews (Among Those Who Hired)	53.6	78.2
Advice About How to Train Workers Between 4-Month and 9-Month Interviews (Among Those Who Hired)	31.9	n.a.
Use of Peer Counseling Services Between Baseline and 4-Month Interviews (Among Those Receiving Allowance)	0.8	100.0
Use of Peer Counseling Services Between 4-Month and 9-Month Interviews (Among Those Receiving Allowance)	0.8	n.a.
Number of Respondents to 4-Month Interview	670	
Number of Respondents to 9-Month Interview	642	

SOURCE: MPR telephone interviews with consumers 4 and 9 months after random assignment.

n.a. = means not applicable.

TABLE A.12b

USE OF AND SATISFACTION WITH PROGRAM SERVICES, NONELDERLY ADULTS

	Percentage of Consumers Reporting	Percentage of Users Reporting Service Useful/Satisfied with Service
Help Developing Allowance Spending Plan Between Baseline and 4-Month Interviews	87.4	99.1
Help Revising Allowance Spending Plan Between 4-Month and 9-Month Interviews	37.1	n.a.
Help Identifying Programs or Services with Little or No Cost To Consumer Between Baseline and 4-Month Interviews	44.6	n.a.
Materials with Information About How to Recruit Workers Received Between Baseline and 4-Month Interviews (Among Those Who Tried to Hire)	77.8	81.6
Advice About How to Recruit Workers Between Baseline and 4-Month Interviews (Among Those Who Tried to Hire)	57.0	91.6
Advice or Materials About How to Recruit Workers Between 4-Month and 9-Month Interviews (Among Those Who Tried to Hire)	40.7	n.a.
Use of Program Bookkeeping Services Between Baseline and 9-Month Interviews (Among Those Receiving Allowance)	93.6	98.0
Advice About How to Train Workers Between Baseline and 4-Month Interviews (Among Those Who Hired)	55.7	83.9
Advice About How to Train Workers Between 4-Month and 9-Month Interviews (Among Those Who Hired)	24.5	n.a.
Use of Peer Counseling Services Between Baseline and 4-Month Interviews (Among Those Receiving Allowance)	2.7	100.0
Use of Peer Counseling Services Between 4-Month and 9-Month Interviews (Among Those Receiving Allowance)	1.4	n.a.
Number of Respondents to 4-Month Interview	254	
Number of Respondents to 9-Month Interview	243	

SOURCE: MPR telephone interview with consumers 4 and 9 months after random assignment.

n.a. = means not applicable.

TABLE A.13

ASPECTS OF PROGRAM SERVICES FOUND USEFUL

	Percentage		
	Overall	Under 65	65 or Over
Among Those Receiving Help with Allowance Spending Plan,			
What Aspect of Help Found Useful:			
Explaining program rules	79.3	78.7	79.6
Clarifying goals, options, and priorities	47.4	53.2	44.9
Handling paperwork	9.5	6.5	10.8
Determining service costs	5.6	10.2	3.6
Getting approval for special uses of allowance	6.6	6.5	6.6
Among Those Receiving Advice About How to Recruit			
Workers, What Aspects of Advice Found Useful:			
Locating potential workers	24.6	27.9	22.9
Setting wage or benefit levels	16.2	17.1	15.7
Screening or interviewing potential workers	36.5	41.4	34.1
Arranging for background check	5.1	5.4	4.9
Provided training or advice of unspecified nature	40.7	34.6	43.7
Number of Respondents to 4-Month Interview	924	254	670

SOURCE: MPR telephone interview of consumers 4 months after random assignment.

TABLE A.14

DIFFICULTIES ASSUMING THE ROLE OF EMPLOYER

	Percentage		
	Overall	Under 65	65 or Over
Hiring Workers			
Hiring Workers with Allowance Between Baseline and 9-Month Interviews			
Hired a worker	79.3	85.4	77.0
Tried to hire a worker, but did not	10.9	9.5	11.5
Did not try to hire a worker	9.7	5.1	11.5
Among Those Who Hired with Allowance Between Baseline and 9-Month Interviews, Found Hiring Hard			
	19.6	20.7	19.1
Among Those Who Found Hiring Hard Between Baseline and 4-Month Interviews, Aspect That Was Hardest			
Could not find interested/ qualified workers	40.3	36.8	41.9
Wages offered were too low	18.6	15.8	19.8
Applicants disliked hours or tasks	19.4	23.7	17.4
Getting references/judging qualifications	7.3	2.6	9.3
Did not trust applicants	7.3	7.9	7.0
Training Workers			
Among Those Who Hired with Allowance, Provided Training for Workers Hired with Allowance Between Baseline and 9-Month Interviews			
Showed worker how to carry our tasks	31.3	37.0	28.8
Arranged for training outside the home	2.4	1.4	2.8
Among Those Who Trained Workers Between Baseline and 9-Month Interviews, Found Training Hard			
	9.3	7.8	10.1
Among Those Who Found Training Hard Between Baseline and 4-Month Interviews, Aspect That Was Hardest			
Worker did not seem to understand/worker had no previous experience/difficult to communicate what was wanted	15.4	0.0	18.2
Worker wanted to do task some other way	0.0	0.0	0.0
Consumer or family unable to demonstrate task/answer questions about task	23.1	50.0	18.2
Difficult to find training programs	7.7	0.0	9.1
Worker had no experience	15.4	0.0	18.2
Difficult to train and also get work done	15.4	50.0	9.1
Difficult for consumer and worker to get used to each other	23.1	0.0	27.3
Number of Respondents to the 4-Month or 9-Month Interview	952	261	691

SOURCE: MPR telephone interviews with consumers 4 and 9 months after random assignment.

TABLE A.15
RECRUITING METHODS

	Percentage		
	Overall	Under 65	65 or Older
Recruiting Methods Attempted, Among Those Who Hired or Tried to Hire Worker			
Tried To Hire			
Family member	80.5	76.4	82.2
Friend, neighbor, or church member	30.1	41.1	25.6
Home care agency worker	14.8	17.4	13.7
Asked Family or Friend To Recommend Worker	19.4	23.2	17.8
Posted or Consulted Advertisements	5.1	8.3	3.8
Contacted Employment Agency	3.3	2.1	3.8
Recruiting Methods Resulting in Hires, Among Those Who Hired			
Hired family member	77.2	72.4	79.3
Hired friend, neighbor, or church member	20.1	30.4	15.8
Hired former agency worker	7.2	9.7	6.1
Hired worker recommended by family or friend	6.1	7.8	5.3
Posted or consulted advertisement	3.2	6.0	2.0
Contacted employment agency	0.4	0.0	0.6
Number of Respondents to Either the 4-Month or 9-Month Interview	952	261	691

SOURCE: MPR telephone interviews with consumers 4 and 9 months after random assignment.

TABLE A.16

SATISFACTION WITH WORKERS AS REPORTED BY COUNSELORS

Of Consumers with Whom Counselor Has Worked, Percent of Consumers Who Included a Paid Worker in Allowance Spending Plan	85.0
Of Consumers Who Planned to Hire a Paid Worker, Percent Who Had Serious Problem with Turnover Due to Workers Resigning or Being Fired	11.1
Of Consumers Who Planned to Hire a Paid Worker, Percent Who Hired a Relative	72.1
Of Consumers Who Hired a Relative as a Paid Worker, Percent Who Were Very Satisfied with Worker	88.3
Of Consumers Who Hired a Relative as a Paid Worker, Percent Who Were Very Dissatisfied with Worker	1.4
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

TABLE A.17
PAID HUMAN ASSISTANCE

	Percentage		
	Overall	Under 65	65 or Over
Hired a Worker With Monthly Allowance Between Baseline and 9-Month Interview	77.2	83.5	74.8
Had Paid Worker in 2 Weeks Prior to 9-Month Interview	82.8	88.9	80.5
Hired Worker Paid with Monthly Allowance Between Baseline and 9-Month Interview and Had Paid Worker in 2 Weeks Prior to Interview	68.2	77.0	64.8
Among Those Who Hired Worker with Monthly Allowance and Had Worker in During 2 Weeks Prior to 9-Month Interview ^a			
Had 1 worker	67.8	81.8	61.4
Had 2 workers	22.0	11.8	26.7
Had 3 or more workers	10.2	6.4	11.9
Had a visiting worker(s)	72.5	75.9	70.9
Had live-in worker(s)	39.1	28.9	43.7
At least one worker was consumer's:			
Spouse	0.0	0	0
Parent	4.5	13.9	0.2
Child	45.4	28.9	52.9
Other relative	25.2	26.7	24.5
Not related	26.2	30.5	24.3
Hours of paid care			
14 or fewer	15.0	18.4	13.5
15 to 42	71.9	71.8	71.9
43 to 70	8.6	4.9	10.3
71 or more	4.5	4.9	4.3
Worker helped with routine health care ^b	78.3	78.5	78.4
Worker helped with personal care ^c	94.8	95.2	94.7
Worker helped with housework or community chores ^d	97.8	98.4	97.6
Worker helped with transportation ^e	58.7	75.8	51.0
Worker helped before 8 am on weekdays	49.1	43.9	51.5
Worker helped after 8 pm on weekdays	64.2	61.0	65.7
Worker helped on weekends	77.0	74.3	78.2
Number of Respondents to the 9-Month Interview	885	243	642

SOURCE: MPR telephone interviews with consumers 9 months after random assignment.

^aDescription is of all paid workers for treatment group members who hired with the allowance, which includes workers for 5 percent of the sample who had disenrolled from IndependentChoices and were likely reporting on help received from agency workers.

TABLE A.17 (continued)

^bRoutine health care includes taking medications, checking blood pressure, and doing exercises. Among those receiving paid help with routine health care and who had hired with allowance (n=445), 8 percent said all help was provided by person hired with the allowance.

^cPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eTransportation includes both medical and nonmedical transportation.

TABLE A.18

USES OF THE MONTHLY ALLOWANCE, ALL CONSUMERS

During Month 8 After Random Assignment	Percent with Cash Use	Mean Expenditure (\$)	Mean Percent Spent
Hired a Worker	88.3	249	74.6
Purchased Home Care Agency Services	0.0	0	0.0
Purchased Home Modifications	1.5	2	0.6
Purchased Vehicle Modifications	0.6	<1	0.1
Purchased Equipment ^a	4.3	3	1.1
Purchased Personal Care Supplies ^b	48.7	37	11.1
Purchased Community Services ^c	15.0	13	3.5
Received Petty Cash ^d	36.5	14	3.7
Received Cash for Emergency Expenses ^e	2.1	3	0.8
Other Expenses	1.0	<1	0.2
Total Expenses Paid During Month 8	95.5	324	na
Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8		718	

SOURCE: IndependentChoices program bookkeeper records.

NOTE: Of the 1,004 treatment group members, 274 had disenrolled or died before month 8, and 12 were still enrolled but had no record for month 8 with the bookkeeper. In addition, 32 were still enrolled and had a record for month 8, but the record showed no spending for goods or services during that month; these cases are included in the means as zeros.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping, for example.

^bSupplies for personal care include diapers or pads to protect bedding, ostomy supplies, or feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, laundry services.

^dTreatment group members may request a check for petty cash each month to pay for goods and services directly. In Arkansas this is limited to 10 percent of the allowance each month. Petty cash may have been used to purchase personal care supplies.

^eClothing, pest control, utilities.

n.a. = not applicable.

TABLE A.18a

USES OF THE MONTHLY ALLOWANCE, ELDERLY ADULTS

During Month 8 After Random Assignment	Percent with Cash Use	Mean Expenditure (\$)	Mean Percent Spent
Hired a Worker	88.6	243	76.0
Purchased Home Care Agency Services	0.0	0	0.0
Purchased Home Modifications	1.2	2	0.5
Purchased Vehicle Modifications	0.8	<1	0.1
Purchased Equipment ^a	2.6	1	0.3
Purchased Personal Care Supplies ^b	47.4	37	11.1
Purchased Community Services ^c	13.5	11	3.2
Received Petty Cash ^d	35.5	13	3.5
Received Cash for Emergency Expenses ^e	2.0	3	0.8
Other Expenses	1.0	<1	0.1
Total Expenses Paid During Month 8	95.6	311	n.a.
Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8		498	

SOURCE: IndependentChoices program bookkeeper records.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping, for example.

^bSupplies for personal care include diapers or pads to protect bedding, ostomy supplies, or feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, laundry services.

^dTreatment group members may request a check for petty cash each month to pay for goods and services directly. In Arkansas this is limited to 10 percent of the allowance each month. Petty cash may have been used to purchase personal care supplies.

^eClothing, pest control, utilities.

n.a. = not applicable.

TABLE A.18b

USES OF THE MONTHLY ALLOWANCE, NONELDERLY ADULTS

During Month 8 After Random Assignment	Percent with Cash Use	Mean Expenditure (\$)	Mean Percent Spent
Hired a Worker	87.7	264	71.6
Purchased Home Care Agency Services	0.0	0	0.0
Purchased Home Modifications	2.3	3	1.1
Purchased Vehicle Modifications	0.0	0	0.0
Purchased Equipment ^a	8.2	8	2.8
Purchased Personal Care Supplies ^b	51.8	37	11.0
Purchased Community Services ^c	18.6	19	4.0
Received Petty Cash ^d	38.6	17	4.1
Received Cash for Emergency Expenses ^e	2.3	3	0.7
Other Expenses	0.9	1	0.3
Total Expenses Paid During Month 8	95.5	354	n.a.
Number of Consumers Who Used Bookkeeping Service and Had Spending Record for Month 8		220	

SOURCE: IndependentChoices program bookkeeper records.

^aEquipment includes that to assist with mobility, transfer, bathing, communication, personal safety, meal preparation, or housekeeping, for example.

^bSupplies for personal care include diapers or pads to protect bedding, ostomy supplies, or feeding equipment.

^cCommunity services include day care, day programs, medical and nonmedical transportation, home-delivered meals, food from commercial establishments, congregate meals, chore services, grocery delivery, laundry services.

^dTreatment group members may request a check for petty cash each month to pay for goods and services directly. In Arkansas this is limited to 10 percent of the allowance each month. Petty cash may have been used to purchase personal care supplies.

^eClothing, pest control, utilities.

n.a. = not applicable.

TABLE A.19

SPECIFIC TYPES OF CONSUMER PURCHASES AS REPORTED BY COUNSELORS

Number of Counselors Reporting Assistive or Safety Devices, by Type of Device	
Talking computer	0
Other communications device	4
Device to aid with vision or hearing	5
Device to aid with mobility	6
Home security or personal emergency response system	6
Other assistive device or device related to safety	0
Average Number of Consumers Who Purchased Assistive or Safety Devices	87
Number of Counselors Reporting Personal Care Products and Appliances, by Type	
Supplies for urinary catheter or ostomy	4
Incontinence supplies	7
Enteral/parenteral feeding supplies	4
Special eating tools	1
Dietary supplements or products	7
Supplies related to use of home oxygen or ventilator	3
Electric toothbrush or shaver	3
Personal hygiene products	7
Other personal care products or appliances (e.g., talking thermometer)	2
Average Number of Consumers Who Purchased Personal Care Products and Appliances	254
Number of Counselors Reporting Home or Vehicle Modification, by Type of Modification	
Install interior or exterior ramp	6
Widen doorway	1
Change door handles or light switches	0
Lower counters or other kitchen remodeling	2
Install shower stall or other bathroom remodeling	7
Modify van or automobile	6
Other home or vehicle modifications	0
Average Number of Consumers Who Purchased Home or Vehicle Modifications	109
Number of Counselors Reporting Home or Yard Appliances, by Type of Appliance	
Clothes washer or dryer	0
Microwave oven	7
Other kitchen appliances	6
Lawn mower	0
Snow removal device	0
Other home or yard appliance	0
Average Number of Consumers Who Purchased Home or Yard Appliances	54

TABLE A.19 (continued)

Number of Counselors Reporting Commercial Services, by Type	
Chore or homemaker services	4
Delivery of prepared food from a restaurant or groceries from a retail store	4
Transportation from a taxi or other car or van service	5
Laundry service	2
Errand or shopping services	1
Commercial snow removal	0
Other commercial services	0
Average Number of Consumers Who Purchased Commercial Services	50
Number of Counselors Reporting Training or Educational Services, by Type of Service	
Training or education for consumer	3
Training or education for worker	0
Other training or education	0
Average Number of Consumers Who Purchased Training Or Educational Services	12
Number Of Counselors Reporting Other Or Atypical Purchases, by Type Of Purchase	
Service animal	0
Equipment repair or backup equipment rental or purchase to use during repair	4
Day care	1
Exercise equipment or other devices to aid in rehabilitation	0
Over-the-counter medications	7
Prescription medications in excess of Medicaid limits	7
Other Medicaid services in excess of coverage limits	4
Other purchases not listed elsewhere	0
Average Number of Consumers Who Made Other or Atypical Purchases	128
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

NOTE: Table contains responses to questions about specific types of consumer purchases (or approved plans to purchase) with the monthly allowance.

TABLE A.20

FLEXIBILITY AND CONSTRAINTS OF THE MONTHLY ALLOWANCE

Number of Counselors Reporting Particularly Creative Purchases, by Type of Purchase	
Combination of paid care with equipment purchases and modifications	1
Changed worker's hours, wages, or duties to stay in budget	2
Bought Internet account to join online support group	1
Paid for professional housecleaning	1
Number of Counselors Reporting Denied Purchases, by Type of Purchase	
Food, dietary supplements, cigarettes, alcohol	2
Home or vehicle modification not related disability or health	1
Furniture, appliances, and equipment not related to disability	4
Utility bills	1
Recreational goods and services	2
Percentage of Consumers Reporting Program's Spending Rules Kept Them from Getting Things That Would Have Enhanced Independence ^a	12.1
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7
Number of Respondents to the 4-Month Survey	924

SOURCE: MPR mail survey of IndependentChoices counselors conducted between May and June 2000 and telephone interviews with consumers 4 months after random assignment.

^aAmong 254 consumers under age 65, 13.7 percent reported program rules kept them from getting things that would have enhanced independence, as compared with 11.5 percent of 670 consumers age 65 and over.

TABLE A.21

COUNSELOR REPORTS OF MISUSE OF THE MONTHLY ALLOWANCE

Number of Counselors Reporting Evidence of Misuse of the Allowance	5
Number of Counselors Reporting Misuse, by Type	
Purchased nonpermissible goods or services	4
Had worker purchase nonpermissible goods or services	3
Overspent allowance	0
Did not keep adequate records	3
Did not report worker hours in timely way	3
Did not pay worker on time or correct amount	0
Number of Counselors Reporting Misuse More Likely Among Consumers Without Representative	0
Number of Counselors Reporting Misuse Less Likely Among Consumers Without Representative	0
Average Number of Consumers for Whom There Was Any Evidence of Allowance Misuse	5
Average Number of Consumers for Whom Counselors Had to Follow Up on Evidence of Allowance Misuse	4
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

TABLE A.22a

SATISFACTION WITH INDEPENDENT CHOICES, BY TYPE OF RESPONDENT

	Percentage		
	Overall	Consumer Respondents	Proxy Respondents
Would Recommend the Program to Others	96.2	97.3	94.9
Effect of Monthly Allowance on Quality of Life, Among Those Ever Receiving Allowance			
Improved a great deal	55.9	57.5	53.9
Improved somewhat	25.2	25.4	25.0
Stayed the same	18.6	16.5	21.1
Reduced somewhat	0.0	0.0	0.0
Reduced a great deal	0.3	0.5	0.0
Most Important Ways Monthly Allowance Improved Life, Among Those Who Reported the Program Improved Their Lives			
Benefit enables consumer to choose caregivers	13.7	12.7	15.1
Benefit enables consumer to get the right types of care	8.8	9.6	7.7
Benefit enables consumer to get enough care or care at the right time	9.6	7.8	12.0
Benefit enables consumer to purchase medications not covered by Medicaid	13.9	16.0	11.2
Benefit enables consumer to purchase other items related to personal care or health, food or nutritional supplements, or care-related supplies	16.1	13.6	19.3
Benefit enables consumer to purchase, modify, or repair equipment or home	17.6	17.5	17.8
Consumer feels more independent or in control of care	4.9	6.0	3.5
Number of Respondents to the 9-Month Interview	885	462	423

SOURCE: MPR telephone interview with consumers 9 months after random assignment.

TABLE A.22b

SATISFACTION WITH INDEPENDENT CHOICES, BY CONSUMER AGE

	Percentage		
	Overall	Under Age 65	65 or Older
Would Recommend the Program to Others	96.2	97.5	95.7
Effect of Monthly Allowance on Quality of Life, Among Those Ever Receiving Allowance			
Improved a great deal	55.9	62.6	53.1
Improved somewhat	25.2	21.5	26.8
Stayed the same	18.6	15.5	19.9
Reduced somewhat	0.0	0.0	0.0
Reduced a great deal	0.3	0.5	0.2
Most Important Ways Monthly Allowance Improved Life, Among Those Who Reported the Program Improved Their Lives			
Benefit enables consumer to choose caregivers	13.7	12.0	14.5
Benefit enables consumer to get the right types of care	8.8	8.7	8.9
Benefit enables consumer to get enough care or care at the right time	9.6	6.0	11.3
Benefit enables consumer to purchase medications not covered by Medicaid	13.9	14.1	13.8
Benefit enables consumer to purchase other items related to personal care or health, food or nutritional supplements, or care-related supplies	16.1	13.6	17.2
Benefit enables consumer to purchase, modify, or repair equipment or home	17.6	19.0	17.0
Consumer feels more independent or in control of care	4.9	6.5	4.2
Number of Respondents to the 9-Month Interview	885	243	642

SOURCE: MPR telephone interview with consumers 9 months after random assignment.

TABLE A.23a

SATISFACTION WITH AND UNMET NEED FOR PERSONAL ASSISTANCE, BY TYPE OF RESPONDENT

	Percentage		
	Overall	Consumer Respondent	Proxy Respondent
Current Satisfaction with:			
Overall care arrangements ^a			
Very satisfied	68.6	68.3	69.2
Satisfied	25.4	25.2	25.9
Dissatisfied	6.0	6.6	4.9
Ability to get transportation when needed ^{b,i}			
Very satisfied	72.1	68.3	79.1
Satisfied	18.4	19.9	15.5
Dissatisfied	9.5	11.8	5.3
Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Satisfied with: ^{c,j}			
Relationship with paid caregiver	99.8	99.7	100.0
How paid caregiver helps with personal care ^d	99.5	99.3	100.0
How paid caregiver helps with routine health care ^e	99.0	99.0	98.9
How paid caregiver helps with housework or community chores ^f	99.0	99.0	99.1
Times of day help provided	96.9	96.6	97.6
Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Would Not Have Been Difficult to Change the Times of Day Help Provided ^{c,j}			
	51.6	52.6	49.2
Among Those Who Hired with Allowance, Paid Caregiver: ^{g,j}			
Always or almost always completed all tasks	87.1	86.7	87.9
Never neglected consumer	92.0	90.9	94.3
Never left early or arrived late, among those with regular schedule	60.5	60.1	61.2
Never was rude or disrespectful	90.6	90.8	90.3
Never helped when help was not wanted	63.7	64.2	62.7
Did not steal	96.6	95.8	98.2
Needs Help or More Help with: ^h			
Housework or community chores	40.1	38.3	42.8
Personal care	32.6	25.0	44.1
Routine health care	28.1	21.6	37.9
Transportation ⁱ	29.0	26.9	32.2
Number of Respondents to the 9-Month Interview	885	462	423

SOURCE: MPR telephone interviews with consumers 9 months after random assignment.

TABLE A.23a (continued)

^aSatisfaction with overall care not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion.

^bSatisfaction with ability to get transportation not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if no transportation sought.

^cSatisfaction with paid caregiver relationship and performance, and ability to change paid caregiver schedule not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, if consumer did not hire a caregiver with allowance, or if consumer had no paid help during the 2 weeks before interview.

^dPersonal care includes bathing, transfer from bed, eating, and using the toilet. Not asked if consumer had no paid help with personal care.

^eRoutine health care includes taking medications, checking blood pressure, and doing exercises. Not asked if consumer had no paid help with routine health care.

^fHousework and community chores include light housework, yard work, meal preparation, and shopping. Not asked if consumer had no paid help with housework or community chores.

^gSatisfaction with paid caregiver attitude and respectfulness not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if consumer did not hire a caregiver with allowance.

^hUnmet need not asked if proxy respondent is also paid caregiver.

ⁱTransportation includes both medical and nonmedical transportation.

^jDescription is of all paid caregivers for consumers who hired with the allowance (with the exceptions noted) and includes paid caregivers for roughly 5 percent of consumers who had disenrolled from IndependentChoices and were likely reporting about satisfaction with agency workers.

TABLE A.23b

SATISFACTION WITH AND UNMET NEED FOR PERSONAL ASSISTANCE, BY CONSUMER AGE

	Percentage		
	Overall	Under 65	65 or over
Current Satisfaction with:			
Overall care arrangements ^a			
Very satisfied	68.6	70.7	67.6
Satisfied	25.4	22.9	26.7
Dissatisfied	6.0	6.3	5.8
Ability to get transportation when needed ^{b,i}			
Very satisfied	72.1	70.9	72.7
Satisfied	18.4	16.3	19.5
Dissatisfied	9.5	12.8	7.8
Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Satisfied with: ^{c,j}			
Relationship with paid caregiver	99.8	99.4	100.0
How paid caregiver helps with personal care ^d	99.5	100.0	99.2
How paid caregiver helps with routine health care ^e	99.0	98.4	99.4
How paid caregiver helps with housework or community chores ^f	99.0	99.4	98.8
Times of day help provided	96.9	97.5	96.5
Among Those Who Hired with Allowance and Had Paid Help in Two Weeks Before Interview, Would Not Have Been Difficult to Change the Times of Day Help Provided ^{c,j}			
	51.6	52.8	50.8
Among Those Who Hired with Allowance, Paid Caregiver: ^{g,j}			
Always or almost always completed all tasks	87.1	88.9	86.0
Never neglected consumer	92.0	90.6	92.8
Never left early or arrived late, among those with regular schedule	60.5	61.6	59.8
Never was rude or disrespectful	90.6	90.1	91.0
Never helped when help was not wanted	63.7	58.1	67.0
Did not steal	96.6	95.9	97.0
Needs Help or More Help with: ^h			
Housework or community chores	40.1	42.3	39.0
Personal care	32.6	26.8	35.4
Routine health care	28.1	26.1	29.1
Transportation ⁱ	29.0	27.9	29.5
Number of Respondents to the 9-Month Interview	885	243	642

SOURCE: MPR telephone interviews with consumers 9 months after random assignment.

^aSatisfaction with overall care not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion.

TABLE A.23b (continued)

^bSatisfaction with ability to get transportation not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if no transportation sought.

^cSatisfaction with paid caregiver relationship and performance, and ability to change paid caregiver schedule not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, if consumer did not hire a caregiver with allowance, or if consumer had no paid help during the 2 weeks before interview.

^dPersonal care includes bathing, transfer from bed, eating, and using the toilet. Not asked if consumer had no paid help with personal care.

^eRoutine health care includes taking medications, checking blood pressure, and doing exercises. Not asked if consumer had no paid help with routine health care.

^fHousework and community chores include light housework, yard work, meal preparation, and shopping. Not asked if consumer had no paid help with housework or community chores.

^gSatisfaction with paid caregiver attitude and respectfulness not asked if proxy respondent used and proxy is also paid caregiver or cannot give consumer opinion, or if consumer did not hire a caregiver with allowance.

^hUnmet need not asked if proxy respondent is also paid caregiver.

ⁱTransportation includes both medical and nonmedical transportation.

^jDescription is of all paid caregivers for consumers who hired with the allowance (with the exceptions noted) and includes paid caregivers for roughly 5 percent of consumers who had disenrolled from IndependentChoices and were likely reporting about satisfaction with agency workers.

TABLE A.24

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER STARTED ON ALLOWANCE WITHIN
THREE MONTHS OF RANDOM ASSIGNMENT

Characteristic	Estimated Coefficient	P-Value of Coefficient
Demographic Characteristics		
Age		
(18 to 39)		
40 to 64	-1.27**	0.05
65 to 79	-1.15*	0.08
80 or older	-1.30**	0.05
Female	-0.11	0.65
Race		
(Self-identified as white only)		
Self-identified as black only or black and some other race	0.12	0.56
Self-identified as some other race	0.43	0.29
Years of Education		
Did not graduate high school (High school graduate)	0.26	0.24
Living Arrangement/Marital Status		
Lives alone (Lives with others)	-0.16	0.50
Health and Functioning		
Health Status at Enrollment		
(Excellent or good)		
Fair	-0.34	0.20
Poor	-0.52**	0.04
Last Week, Not Independent in: ^e		
Transfer	-0.21	0.45
Bathing	-0.19	0.65
Using toilet	0.23	0.41
Unpaid and Paid PAS		
Had Unpaid or Paid Help at Home Last Week with:		
Personal care ^a	-0.01	0.97
Transportation ^b	0.15	0.44
Routine health care ^c	0.09	0.73
Household activities ^d	0.11	0.83

TABLE A.24 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
Number of Unpaid Caregivers Last Week		
(None)		
One	0.04	0.92
Two	0.14	0.71
Three or more	0.40	0.32
Primary Unpaid Caregiver Employed	-0.20	0.33
Number of Paid Caregivers Last Week		
(None)		
One	0.61	0.36
Two or more	0.64	0.35
Length of Time with Publicly Funded Home Care		
(Participant says no care last week and program says not a current Medicaid PAS user)		
Participant says no care last week, but program says current Medicaid PAS user	-0.92***	0.01
Participant says getting care less than a year	-1.39**	0.04
Participant says getting care 1 to 3 years	-1.06	0.12
Participant says getting care more than 3 years	-1.55**	0.03
Unmet Need for and Access to PAS		
Last Week, Needed Help (or More Help) With: Personal Care, Transportation, or Things Around the House and Community		
Personal care ^a	-0.36	0.11
Transportation ^b	0.00	0.99
Household activities ^d	-0.05	0.83
Potential Difficulty Hiring Due to Location		
Lives in a rural area	-0.14	0.53
Live in a nonrural area but transportation difficult or high crime	-0.43	0.06
(Lives in a nonrural area, but transportation not difficult and not high crime)		
Satisfaction with Paid PAS		
Satisfied with Paid Services and Goods		
Overall		
Very satisfied	-0.16	0.57
Satisfied	-0.40	0.13
(Dissatisfied)		
No paid services or goods ^f	0.47	0.38

TABLE A.24 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
Employment Experience		
Ever employed	-0.28	0.32
Ever supervised someone	-0.29	0.18
Ever hired someone privately	-0.21	0.30
Type of Respondent		
Majority of Baseline Questions Answered by Proxy Respondent	-0.81***	0.00
Enrollment in Independent Choices		
Number of Hours Per Week of Planned Care (Less than or equal to 6)		
More than 6, but less than or equal to 11	0.65***	0.00
More than 11	0.52**	0.03
Had a Representative at Enrollment	-0.23	0.33
Enrolled in 2000 or 2001	0.56***	0.00
Being Allowed to Pay Family or Friends Very Important	0.59**	0.02
Having a Choice About Worker Schedule Very Important	-0.16	0.52
Having a Choice About Types of Help Received Very Important	0.14	0.61
Primary Unpaid Caregiver Expressed Interest in Being Paid	0.54***	0.01
Number of Consumers	1,004	

SOURCE: MPR baseline survey conducted in Arkansas between December 1998 and April 2001 and Independent Choices program records for independent variables; program records for dependent variable (whether started allowance within 3 months of random assignment).

NOTE: The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey. PAS stands for personal assistance services.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

TABLE A.24 (continued)

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

TABLE A.25

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER FOUND HIRING DIFFICULT

Characteristic	Estimated Coefficient	P-Value of Coefficient
Demographic Characteristics		
Age		
(18 to 39)		
40 to 64	-1.27***	0.00
65 to 79	-1.25***	0.00
80 or older	-1.11***	0.01
Female	0.53*	0.06
Race		
(Self-identified as white only)		
Self-identified as black only or black and some other race	-0.26	0.29
Self-identified as some other race	1.28***	0.00
Years of Education		
Did not graduate high school (High school graduate)	-0.07	0.80
Living Arrangement/Marital Status		
Lives alone (Lives with others)	0.35	0.20
Health and Functioning		
Health Status at Enrollment		
(Excellent or good)		
Fair	0.10	0.75
Poor	0.12	0.67
Last Week, Not Independent in: ^e		
Transfer	0.10	0.73
Bathing	-0.65	0.15
Using toilet	0.24	0.46
Unpaid and Paid PAS		
Had Unpaid or Paid Help at Home Last Week with:		
Personal care ^a	0.67	0.12
Transportation ^b	0.05	0.83
Routine health care ^c	0.20	0.50
Household activities ^d	0.21	0.72

TABLE A.25 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
Number of Unpaid Caregivers Last Week		
(None)		
One	-0.46	0.33
Two	-0.45	0.35
Three or more	-0.79*	0.10
Primary Unpaid Caregiver Employed	0.06	0.79
Number of Paid Caregivers Last Week		
(None)		
One	-0.57	0.39
Two or more	-0.10	0.89
Length of Time with Publicly Funded Home Care		
(Participant says no care last week and program says not a current Medicaid PAS user)		
Participant says no care last week, but program says current Medicaid PAS user	0.46	0.26
Participant says getting care less than a year	0.71	0.31
Participant says getting care 1 to 3 years	0.87	0.21
Participant says getting care more than 3 years	0.22	0.76
Unmet Need for and Access to PAS		
Last Week, Needed Help (or More Help) With: Personal Care, Transportation, or Things Around the House and Community		
Personal care ^a	0.17	0.51
Transportation ^b	-0.01	0.96
Household activities ^d	0.67**	0.02
Potential Difficulty Hiring Due to Location		
Lives in a rural area	-0.28	0.28
Live in a nonrural area but transportation difficult or high crime	-0.05	0.86
(Lives in a nonrural area, but transportation not difficult and not high crime)		
Satisfaction with Paid PAS		
Satisfied with Paid Services and Goods		
Overall		
Very satisfied	-0.48	0.12
Satisfied	-0.21	0.46
(Dissatisfied)		
No paid services or goods ^f	-0.52	0.27

TABLE A.25 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
Employment Experience		
Ever Employed	0.73**	0.03
Ever Supervised Someone	0.18	0.48
Ever Hired Someone Privately	-0.05	0.85
Type of Respondent		
Majority of Baseline Questions Answered by Proxy Respondent	0.27	0.38
Enrollment in Independent Choices		
Number of Hours Per Week of Planned Care (Less than or equal to 6)		
More than 6, but less than or equal to 11	-0.11	0.72
More than 11	0.17	0.57
Had a Representative at Enrollment	0.47*	0.10
Enrolled in 2000 or 2001	0.05	0.82
Being Allowed to Pay Family or Friends Very Important	-0.25	0.43
Having a Choice About Worker Schedule Very Important	-0.65**	0.02
Having a Choice About Types of Help Received Very Important	0.57	0.12
Primary Unpaid Caregiver Expressed Interest in Being Paid	-0.38	0.12
Number of Consumers	725	

SOURCE: MPR baseline interview conducted in Arkansas between December 1998 and April 2001 and Independent Choices program records for independent variables; 4-month and 9-month interviews for dependent variable (whether found hiring difficult, among those who hired with the program allowance between baseline and 9-month interviews).

NOTE: The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. "Last week" refers to the week before the baseline survey. PAS stands for personal assistance services.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

TABLE A.25 (continued)

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

TABLE A.26

EFFECT OF CONSUMER CHARACTERISTICS ON WHETHER CONSUMER FOUND PROGRAM
SPENDING RULES RESTRICTIVE

Characteristic	Estimated Coefficient	P-Value of Coefficient
Demographic Characteristics		
Age		
(18 to 39)		
40 to 64	-0.13	0.79
65 to 79	0.03	0.96
80 or older	0.00	0.99
Female	-0.17	0.54
Race		
(Self-identified as white only)		
Self-identified as black only or black and some other race	0.47*	0.07
Self-identified as some other race	0.92**	0.02
Years of Education		
Did not graduate high school (High school graduate)	-0.30	0.28
Living Arrangement/ Marital Status		
Lives alone (Lives with others)	0.27	0.33
Health and Functioning		
Health Status at Enrollment		
(Excellent or good)		
Fair	-0.32	0.35
Poor	-0.17	0.59
Last Week, Not Independent in: ^e		
Transfer	0.13	0.69
Bathing	0.67	0.20
Using toilet	0.02	0.96
Unpaid and Paid PAS		
Had Unpaid or Paid Help at Home Last Week with:		
Personal care ^a	-0.44	0.31
Transportation ^b	0.24	0.36
Routine health care ^c	0.09	0.78
Household activities ^d	0.07	0.91

TABLE A.26 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
Number of Unpaid Caregivers Last Week		
(None)		
One	-1.26**	0.02
Two	-0.50	0.33
Three or more	-1.07**	0.04
Primary Unpaid Caregiver Employed	0.23	0.35
Number of Paid Caregivers Last Week		
(None)		
One	-0.87	0.26
Two or more	-0.84	0.28
Length of Time with Publicly Funded Home Care		
(Participant says no care last week and program says not a current Medicaid PAS user)		
Participant says no care last week, but program says current Medicaid PAS user	-0.22	0.62
Participant says getting care less than a year	0.96	0.23
Participant says getting care 1 to 3 years	0.86	0.28
Participant says getting care more than 3 years	0.62	0.44
Unmet Need for and Access to PAS		
Last Week, Needed Help (or More Help) With: Personal Care, Transportation, or Things Around the House and Community		
Personal care ^a	0.41	0.17
Transportation ^b	0.73***	0.01
Household activities ^d	0.00	0.99
Potential Difficulty Hiring Due to Location		
Lives in a rural area	0.14	0.62
Live in a nonrural area but transportation difficult or high crime	-0.12	0.70
(Lives in a nonrural area, but transportation not difficult and not high crime)		
Satisfaction with Paid PAS		
Satisfied with Paid Services and Goods		
Overall		
Very satisfied	-0.64**	0.05
Satisfied	-0.41	0.18
(Dissatisfied)		

TABLE A.26 (continued)

Characteristic	Estimated Coefficient	P-Value of Coefficient
No paid services or goods ^f	-0.91	0.11
Employment Experience		
Ever employed	0.23	0.55
Ever supervised someone	-0.08	0.79
Ever hired someone privately	0.51**	0.05
Type of Respondent		
Majority of Baseline Questions Answered by Proxy Respondent	-0.10	0.77
Enrollment in Independent Choices		
Number of Hours per Week of Planned Care (Less than or equal to 6)		
More than 6, but less than or equal to 11	-0.45	0.15
More than 11	-0.22	0.50
Had a Representative at Enrollment	0.30	0.31
Enrolled in 2000 or 2001	0.41*	0.09
Being Allowed to Pay Family or Friends Very Important	-0.15	0.69
Having a Choice About Worker Schedule Very Important	-0.06	0.86
Have a Choice About Types of Help Received Very Important	0.46	0.26
Primary Unpaid Caregiver Expressed Interest in Being Paid	0.17	0.52
Number of Consumers	859	

SOURCE: MPR baseline survey conducted in Arkansas between December 1998 and April 2001 and Independent Choices program records for independent variables; 4-month interviews for dependent variable (consumer found program spending rules kept him/her from getting something that would have promoted independence).

NOTE: The relationship between consumer characteristics and dependent variables estimated with a binary logit models. "Last week" refers to the week before the baseline survey. PAS stands for personal assistance services.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

TABLE A.26 (continued)

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

TABLE A.27

EFFECT OF CONSUMER CHARACTERISTICS ON SATISFACTION AND UNMET NEED

Characteristic	Estimated Coefficient (P-Value of Coefficient)		
	Independent Choices Improved Life Quality a Great Deal	Very Satisfied with Overall Care	Has Unmet Need for Personal Care ^a
Demographic Characteristics			
Age			
(18 to 39)			
40 to 64	-0.46 (0.23)	0.04 (0.92)	-0.42 (0.31)
65 to 79	-0.51 (0.19)	-0.06 (0.90)	-0.39 (0.36)
80 or older	-0.43 (0.28)	-0.42 (0.36)	-0.03 (0.94)
Female	-0.13 (0.54)	0.12 (0.62)	0.14 (0.56)
Race			
(Self-identified as white only)			
Self-identified as black only or black and some other race	-0.35* (0.06)	-0.05 (0.82)	0.54** (0.02)
Self-identified as some other race	0.95** (0.02)	0.34 (0.44)	1.19*** (0.00)
Years of Education			
Did not graduate high school	0.16 (0.45)	0.07 (0.78)	-0.11 (0.65)
(High school graduate)			
Living Arrangement/Marital Status			
Lives alone	0.44** (0.03)	-0.21 (0.37)	0.24 (0.33)
(Lives with others)			
Health and Functioning			
Health Status at Enrollment			
(Excellent or good)			
Fair	0.14 (0.53)	-0.47* (0.10)	0.14 (0.61)
Poor	0.40* (0.08)	-0.28 (0.33)	0.38 (0.17)

TABLE A.27 *continued*)

Characteristic	Estimated Coefficient (P-Value of Coefficient)		
	Independent Choices Improved Life Quality a Great Deal	Very Satisfied with Overall Care	Has Unmet Need for Personal Care ^a
Last Week, Not Independent in: ^c			
Transfer	-0.04 (0.87)	-0.32 (0.26)	0.06 (0.83)
Bathing	-0.84** (0.02)	-1.07*** (0.01)	0.04 (0.92)
Using toilet	0.26 (0.30)	0.45 (0.11)	0.41 (0.16)
Unpaid and Paid PAS			
Had Unpaid or Paid Help at Home Last Week with:			
Personal care ^a	0.28 (0.38)	-0.15 (0.70)	0.45 (0.26)
Transportation ^b	0.36** (0.04)	0.52*** (0.01)	-0.45** (0.03)
Routine health care ^c	0.20 (0.37)	0.06 (0.80)	0.28 (0.28)
Household activities ^d	-0.71 (0.12)	-0.94* (0.06)	0.00 (0.99)
Number of Unpaid Caregivers Last Week			
(None)			
One	0.85** (0.03)	0.75* (0.07)	0.25 (0.56)
Two	0.74* (0.06)	1.37*** (0.00)	0.39 (0.38)
Three or more	0.83** (0.04)	0.84** (0.05)	0.41 (0.36)
Primary Unpaid Caregiver Employed	-0.04 (0.82)	0.42* (0.06)	0.18 (0.40)
Number of Paid Caregivers Last Week			
(None)			
One	0.12 (0.82)	0.07 (0.90)	0.41 (0.45)
Two or more	-0.02 (0.97)	0.66 (0.27)	0.32 (0.56)

TABLE A.27 *continued*)

Characteristic	Estimated Coefficient (P-Value of Coefficient)		
	Independent Choices Improved Life Quality a Great Deal	Very Satisfied with Overall Care	Has Unmet Need for Personal Care ^a
Length of Time with Publicly Funded Home Care			
(Participant says no care last week and program says not a current Medicaid PAS user)			
Participant says no care last week, but program says current Medicaid PAS user	-0.09 (0.79)	0.17 (0.67)	-0.04 (0.92)
Participant says getting care less than a year	-0.46 (0.40)	0.23 (0.71)	-0.40 (0.48)
Participant says getting care 1 to 3 years	-0.36 (0.51)	-0.48 (0.42)	-0.23 (0.67)
Participant says getting care more than 3 years	0.08 (0.88)	-0.18 (0.77)	-0.29 (0.60)
Unmet Need for and Access to PAS			
Last Week, Needed Help (or More Help) with: Personal Care, Transportation, or Things Around the House and Community			
Personal care ^a	-0.35* (0.08)	-0.66*** (0.01)	0.12 (0.61)
Transportation ^b	-0.07 (0.70)	-0.35* (0.10)	0.25 (0.22)
Household activities ^d	0.12 (0.60)	0.03 (0.90)	0.60** (0.02)
Potential Difficulty Hiring Due to Location			
Lives in a rural area	0.03 (0.89)	0.42* (0.09)	-0.23 (0.35)
Live in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime)	-0.08 (0.72)	0.33 (0.17)	0.09 (0.72)
Satisfaction with Paid PAS			
Satisfied with Paid Services and Goods Overall			
Very satisfied	-0.49** (0.05)	-0.20 (0.49)	-0.20 (0.48)
Satisfied	-0.32 (0.21)	0.03 (0.90)	-0.04 (0.89)
(Dissatisfied)			
No paid services or goods ^f	-0.59* (0.10)	-0.23 (0.61)	-0.47 (0.32)

TABLE A.27 *continued*)

Characteristic	Estimated Coefficient (P-Value of Coefficient)		
	IndependentChoices Improved Life Quality a Great Deal	Very Satisfied with Overall Care	Has Unmet Need for Personal Care ^a
Employment Experience			
Ever Employed	-0.24 (0.31)	0.15 (0.62)	0.19 (0.52)
Ever Supervised Someone	0.30 (0.14)	0.29 (0.21)	0.08 (0.72)
Ever Hired Someone Privately	0.18 (0.35)	-0.15 (0.52)	0.16 (0.46)
Type of Respondent			
Majority of Baseline Questions Answered by Proxy Respondent	0.12 (0.61)	0.06 (0.84)	0.75*** (0.01)
Enrollment in IndependentChoices			
Number of Hours per Week of Planned Care (Less than or equal to 6)			
More than 6, but less than or equal to 11	0.27 (0.23)	0.02 (0.94)	-0.57** (0.02)
More than 11	0.53** (0.03)	0.12 (0.64)	-0.57** (0.03)
Had a Representative at Enrollment			
	-0.03 (0.88)	0.07 (0.79)	0.19 (0.46)
Enrolled in 2000 or 2001	-0.55*** (0.00)	0.13 (0.52)	-0.06 (0.75)
Being Allowed to Pay Family or Friends Very Important	-0.24 (0.38)	0.56** (0.05)	0.13 (0.64)
Having a Choice About Worker Schedule Very Important	0.53** (0.02)	0.32 (0.23)	-0.74*** (0.01)
Having a Choice About Types of Help Received Very Important	0.21 (0.43)	0.25 (0.39)	-0.70*** (0.01)
Primary Unpaid Caregiver Expressed Interest in Being Paid	-0.04 (0.84)	-0.23 (0.31)	0.15 (0.50)
Number of Consumers	741	621	659

SOURCE: MPR baseline interview conducted in Arkansas between December 1998 and April 2001 and IndependentChoices program records for independent variables; 9-month interview for dependent variables (IndependentChoices improved life quality a great deal, very satisfied with overall care, and had unmet need for personal care as of 9-month interview).

TABLE A.27 *continued*)

NOTE: The relationship between consumer characteristics and the dependent variable estimated with a binary logit model. “Last week” refers to the week before the baseline survey. PAS stands for personal assistance services.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

TABLE A.28

EFFECT OF CONSUMER CHARACTERISTICS ON VOLUNTARY DISENROLLMENT

Characteristic	Estimated Coefficient (P-Value of Coefficient)	
	Whether Disenrolled According to Program Records Within 1 Year of Enrollment	Whether Disenrolled According to Self- Reports Within 9 Months of Enrollment
Demographic Characteristics		
Age		
(18 to 39)		
40 to 64	0.47 (0.38)	0.87 (0.29)
65 to 79	0.22 (0.68)	0.64 (0.44)
80 or older	0.47 (0.39)	0.84 (0.31)
Female	-0.01 (0.95)	-0.26 (0.37)
Race		
(Self-identified as white only)		
Self-identified as black only or black and some other race	-0.04 (0.86)	-0.68** (0.02)
Self-identified as some other race	-0.15 (0.70)	-0.74 (0.16)
Years of Education		
Did not graduate high school	-0.26 (0.23)	-0.23 (0.42)
(High school graduate)		
Living Arrangement/Marital Status		
Lives alone	0.19 (0.41)	0.20 (0.50)
(Lives with others)		
Health and Functioning		
Health Status at Enrollment		
(Excellent or good)		
Fair	0.04 (0.87)	0.29 (0.41)
Poor	0.27 (0.29)	0.33 (0.32)

TABLE A.28 (continued)

Characteristic	Estimated Coefficient (P-Value of Coefficient)	
	Whether Disenrolled According to Program Records Within 1 Year of Enrollment	Whether Disenrolled According to Self- Reports Within 9 Months of Enrollment
Last Week, Not Independent in: ^c		
Transfer	-0.18 (0.51)	-0.01 (0.97)
Bathing	1.13*** (0.01)	0.73 (0.23)
Using toilet	-0.25 (0.35)	-0.09 (0.80)
Unpaid and Paid PAS		
Had Unpaid or Paid Help at Home Last Week with:		
Personal care ^a	-0.30 (0.41)	0.47 (0.41)
Transportation ^b	-0.18 (0.35)	-0.41 (0.10)
Routine health care ^c	-0.16 (0.51)	0.33 (0.32)
Household activities ^d	0.58 (0.24)	0.29 (0.67)
Number of Unpaid Caregivers Last Week		
(None)		
One	-1.30*** (0.00)	-0.91** (0.05)
Two	-1.20*** (0.00)	-0.73 (0.11)
Three or more	-1.50*** (0.00)	-0.97** (0.05)
Primary Unpaid Caregiver Employed	0.26 (0.20)	-0.13 (0.64)
Number of Paid Caregivers Last Week		
(None)		
One	-0.28 (0.67)	0.50 (0.56)
Two or more	-0.35 (0.61)	0.10 (0.91)

TABLE A.28 (continued)

Characteristic	Estimated Coefficient (P-Value of Coefficient)	
	Whether Disenrolled According to Program Records Within 1 Year of Enrollment	Whether Disenrolled According to Self-Reports Within 9 Months of Enrollment
Length of Time with Publicly Funded Home Care		
(Participant says no care last week and program says not a current Medicaid PAS user)		
Participant says no care last week, but program says current Medicaid PAS user	0.62 (0.13)	1.16* (0.07)
Participant says getting care less than a year	1.08 (0.11)	1.08 (0.23)
Participant says getting care 1 to 3 years	1.03 (0.12)	1.02 (0.25)
Participant says getting care more than 3 years	1.41** (0.04)	1.29 (0.15)
Unmet Need for and Access to PAS		
Last Week, Needed Help (or More Help) with: Personal Care, Transportation, or Things Around the House and Community		
Personal care ^a	0.48** (0.04)	0.25 (0.39)
Transportation ^b	0.17 (0.39)	0.28 (0.26)
Household activities ^d	0.26 (0.28)	0.27 (0.39)
Potential Difficulty Hiring Due to Location		
Lives in a rural area	0.08 (0.71)	-0.15 (0.61)
Live in a nonrural area but transportation difficult or high crime (Lives in a nonrural area, but transportation not difficult and not high crime)	0.28 (0.22)	0.24 (0.41)
Satisfaction with Paid PAS		
Satisfied with Paid Services and Goods Overall		
Very satisfied	0.40 (0.14)	0.52 (0.16)
Satisfied	0.63** (0.02)	0.73** (0.04)
(Dissatisfied)		
No paid services or goods ^f	0.23 (0.66)	0.09 (0.92)

TABLE A.28 (continued)

Characteristic	Estimated Coefficient (P-Value of Coefficient)	
	Whether Disenrolled According to Program Records Within 1 Year of Enrollment	Whether Disenrolled According to Self-Reports Within 9 Months of Enrollment
Employment Experience		
Ever Employed	0.50* (0.09)	0.29 (0.43)
Ever Supervised Someone	0.25 (0.24)	-0.04 (0.88)
Ever Hired Someone Privately	0.12 (0.58)	0.02 (0.94)
Type of Respondent		
Majority of Baseline Questions Answered by Proxy Respondent	0.73*** (0.01)	0.41 (0.24)
Enrollment in Independent Choices		
Number of Hours Per Week of Planned Care (Less than or equal to 6)		
More than 6, but less than or equal to 11	-0.41* (0.07)	-0.62** (0.03)
More than 11	-0.57** (0.02)	-0.62** (0.04)
Had a Representative at Enrollment	-0.03 (0.89)	-0.12 (0.72)
Enrolled in 2000 or 2001	0.16 (0.41)	-0.24 (0.33)
Being Allowed to Pay Family or Friends Very Important	-0.34 (0.20)	-0.05 (0.88)
Having a Choice About Worker Schedule Very Important	0.21 (0.42)	0.24 (0.47)
Having a Choice About Types of Help Received Very Important	0.21 (0.48)	-0.14 (0.69)
Primary Unpaid Caregiver Expressed Interest in Being Paid	-0.68*** (0.00)	-0.76*** (0.01)
Number Of Consumers	1,004	952

TABLE A.28 (continued)

SOURCE: MPR baseline interview conducted in Arkansas between December 1998 and April 2001 and IndependentChoices program records for independent variables; program records for whether disenrolled voluntarily according to program records; and 4- and 9-month interviews for whether disenrolled voluntarily according to self-reports.

NOTE: The relationship between consumer characteristics and the dependent variable estimated with a binary logit model.
“Last week” refers to the week before the baseline survey. PAS stands for personal assistance services.

^aPersonal care includes bathing, transfer from bed, eating, and using the toilet.

^bTransportation includes both medical and nonmedical transportation.

^cRoutine health care includes taking medications, checking blood pressure, and doing exercises.

^dHousework and community chores include light housework, yard work, meal preparation, and shopping.

^eReceived hands-on or standby help or did not perform activity at all.

^fSkipped satisfaction question because no paid help, community services, home or vehicle modifications, or equipment purchased.

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

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

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

TABLE A.29

CONSUMER DIFFICULTIES WITH PROGRAM RESPONSIBILITIES

Number of Counselors Reporting That Some Consumers Requested Extensive Amounts of Assistance	7
Average Number of Consumers Who Requested Extensive Assistance	57
Number of Counselors Reporting The Following Types of Consumers Requested Extensive Assistance	
Consumers under age 65	7
Consumer age 65 or older	7
Consumers or representatives with little experiences budgeting	3
Consumers not using the bookkeeping service	3
Consumers who do not have family member or friend to be paid worker	7
Consumers or representative who have little experience recruiting, hiring, training or supervising workers	5
Consumers or representatives do have experience training or supervising workers	2
Consumer or representative with poor problem-solving skills	4
Consumer who is ill	5
Number of Counselors Reporting That Some Consumers Made Unreasonable Demands	6
Average Number of Consumers Who Made Unreasonable Demands	4
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

TABLE A.30

COUNSELOR ASSESSMENT OF CONSUMERS' OVERALL EXPERIENCES
WITH INDEPENDENTCHOICES

	Number of Counselors Reporting
Types of Consumers for Whom Independentchoices Was Particularly Effective	
At risk of nursing home placement	3
Had a family member or friend in mind to hire as worker	2
Wished to purchase care-related equipment or services not covered by Medicaid	2
Dissatisfied with traditional home care/wanted more control over care	1
Types of Consumers for Whom IndependentChoices Did Not Work Well	
Unable to hire or retain suitable worker	5
Needed very little care	1
Lived in a rural area	1
Client unable to manage own care, no representative available	2
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.

NOTE: Counselors were asked to describe consumers for whom the program was particularly effective and those for whom the program did not work well. Their open-ended responses were then categorized, as noted above.

TABLE A.31

COUNSELOR OPINIONS OF AND RECOMMENDATIONS FOR INDEPENDENTCHOICES

	Number of Counselors Reporting
Recommended Changes to Counseling Activities	0
Types of Changes Recommended to Counseling Activities	
Counselors should do less for consumers (for example, play only an advisory role, not have to explain the program to the consumer)	0
Counselors should do more for consumers (for example, direct consumers to services as a social worker would, generally increase time spent with consumers)	0
Thought They Were Trained Adequately for Their Roles	7
Type of Changes Recommended for Counselor Training	
Reduce time between training and first consumer assignment/provide training refreshers	0
Make training more practical (for example, use role playing, make training manual more user-friendly, use peer counseling and shadowing)	1
Change content of training (for example, put more emphasis on the cash spending plan and program paperwork, put less emphasis on program philosophy, update training as program rules or policies change)	0
Make training longer	0
Make training shorter	0
Types of Changes Recommended for Program Features Other Than Counselor Role and Training	
Outreach: improve description of program to consumers before enrollment, invite home care agencies to refer clients, change eligibility criteria	1
Bookkeeping: make bookkeeping service more responsive	0
Representatives: encourage wider use, pay them	0
Uses of cash: make less restrictive	0
Workers: increase pay, provide training	2
Cash and cash spending plan: reduce time to review changes to plan, simplify the plan, keep consumer direction but eliminate cash payment to consumers	2
Other: provide services in languages other than English, extend program to children with disabilities	1
Average Number of Consumers with Whom Counselors Have Worked	284
Number of Counselors Responding to Survey	7

SOURCE: Mail survey of IndependentChoices counselors conducted between May and June 2000.