

## CONSUMER-DIRECTED PERSONAL CARE SERVICES FOR OLDER PEOPLE IN THE U.S.

**"Independent living is not doing things by yourself,  
it is being in control of how things are done."**

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### Introduction

People with disabilities in America today include persons of all ages. This diverse population ranges from younger persons who have experienced incapacitating illnesses or injuries to older people suffering from Alzheimer's disease or the effects of strokes, hip fractures, or other debilitating conditions.

For people of all ages with disabilities, retaining control over their lives is a major concern. People with disabilities wish to live as independently as possible in their own homes, and value the ability to choose the services and workers to help them with everyday activities. A 2002 AARP survey found that more than three-fourths of Americans age 50 and older would prefer to have control over money and management of their workers if they need home care services rather than an agency having control (AARP April 2003).

That desire for control and choices may be limited, however, for people with disabilities who receive publicly funded home care services provided by home care agencies that select a worker for the client and arrange a schedule and scope of services. That agency model began to be challenged in the 1970s by the disability rights and independent living movement, which advocated for self direction and choice in publicly funded

programs, most especially in programs that served younger persons with disabilities (DeJong et al., 1992).

This newer service model has come to be called "consumer direction" by many policy-makers and advocates. As defined by the National Institute on Consumer-Directed Long-Term Services, consumer direction is "a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive." Consumers assess their own needs, determine how and by whom these needs should be met, and monitor their services.

Consumer direction is a concept that has been increasingly embraced by states in recent years for all populations with disabilities, even for persons with cognitive disabilities. Some administrators and policy makers have expressed concern, however, about the appropriateness of consumer-directed services for older persons who may be too sick or too frail to direct their own care, or may be vulnerable to abuse or threats to their safety.

Nonetheless, several states have been operating CD programs for more than 20 years that include a significant number of older persons without any evidence of significant problems for older consumers. In addition, several recent

major studies have conducted extensive evaluations of the experiences of older people in consumer-directed programs, and found that older participants were "highly satisfied" with the program or reported "greatly improved satisfaction" with services (Doty et al., April 1999; Mathematica Policy Research, Inc., March 2003).

This Issue Brief begins by describing consumer-direction models, and then reviews several surveys of the attitudes of older consumers toward consumer-directed services. The paper describes the range and evolution of CD programs in four states (Colorado, Michigan, Oregon, and California) and one cross-state demonstration program (Arkansas, New Jersey, and Florida) to highlight how such programs function. These programs and various studies illustrate efforts to address concerns of policymakers and administrators while offering people who receive publicly funded services many of the options available to people who pay privately for their services. The paper ends with policy implications suggested by the state examples and studies.

### **Consumer-Direction Models**

The consumer responsibilities typically considered to be key to consumer-direction models include: 1) recruiting, hiring, and training a worker; 2) defining the aide's duties and work schedule; 3) supervising the aide in specific tasks; 4) giving performance feedback; and 5) firing the aide if his or her work is unsatisfactory (Flanagan and Green, 1997).

State CD programs are extremely varied in the number and range of these tasks

for which the consumer may assume responsibility. The models for such programs generally fall into categories: direct pay, fiscal intermediary, supportive intermediary, or variations of these models (Scala and Mayberry, 1997). Under a *direct pay* system, the consumer is the employer of record and handles hiring/firing, training, supervising, and scheduling a worker, as well as payroll and tax responsibilities. Under a *fiscal intermediary* model, a state agency or program (or a private agency designated by the state) handles payroll, taxes, and any other paperwork, while the consumer selects, trains, and otherwise manages the employee.

The *supportive intermediary* model involves the provision of supportive services by a state agency or program; such services may include recruitment assistance, criminal background checks, and training for the consumer and/or worker.

One combination of the direct pay and fiscal intermediary models is the three-year *Cash-and-Counseling* Medicaid demonstration project in Arkansas, New Jersey, and Florida, with funding from The Robert Wood Johnson (RWJ) Foundation and the U.S. Department of Health and Human Services. Medicaid beneficiaries select their personal care worker, and may choose to receive cash to pay the aide or use a fiscal intermediary to handle payroll functions. Counseling helps the consumers manage the cash and handle payroll and tax matters or decide to use a fiscal intermediary. Other counseling functions include training for recruiting and hiring personal assistants, budgeting, and record-keeping. (For a more detailed description of this program, including

the results of extensive evaluations of participant experience, see below.)

### **From the Older Consumer's Perspective**

Research on the attitudes of older persons toward consumer direction has been increasing in recent years. These surveys find that a significant proportion of older persons prefer to manage their own care, preferably with the assistance of family and friends. An AARP national survey of Americans age 50+ with disabilities, conducted in September 2002, found that almost half (46 percent) of the respondents said they wanted more direct control over what long-term care services they receive and when they receive them. When asked about three possible ways in which publicly funded home care services could be provided, a majority (53 percent) of the respondents preferred having funds go directly to them to manage and pay their workers. Another 25 percent wanted to manage their workers and services, but have an agency pay the workers. Only 15 percent wanted an agency both handling services and paying workers (AARP, 2003).

Researchers at the University of Maryland Center on Aging working on the development of the Cash-and-Counseling Demonstration projects assessed consumers' interest in receiving cash to purchase personal assistance services, rather than continuing to use agency-directed services. The Center conducted telephone surveys in 1996-1997 in each demonstration state (Arkansas, New Jersey, Florida, and New York, although New York subsequently dropped out of the project).

Respondents were persons participating in Medicaid-funded home care or surrogates of the consumers. Two-thirds to four-fifths of the consumers were age 65 or older. Few of the respondents had had experience hiring, firing, supervising, or training workers. Although a smaller percentage of persons 65 and older were interested in the option, compared with persons under age 65, from 29 percent to 51 percent of the older age group expressed interest (Simon-Rusinowitz et al., 2000).

The Schneider Institute for Health Policy at Brandeis University studied the preferences of an ethnically diverse group of older consumers for different models of care delivery. The 731 respondents (African American, Chinese, Latino, and white) were asked to choose among three alternative models: a traditional care management model in which care managers control most decisions, a negotiated care management model with the consumer participating in decision making *with* care managers, or cash and counseling. Seventy percent of the respondents preferred the traditional case management approach. (The traditional model was favored by 73 percent of the African American respondents, 50 percent of the Chinese respondents, 88.5 percent of the Latino group, and 78.6 percent of the white respondents.) However, about a third of the respondents who preferred the traditional agency model still wanted to be able to exert control over service selection, decisions, and schedules within that model (Sciegaj, 2002).

A 1993 random sample of 883 clients age 60 and older of the Massachusetts Home Care Program that used agency

workers found that a quarter to a third of the respondents were willing to assume responsibility for such tasks as hiring, scheduling, and supervising a home care worker themselves. The researchers reported that certain client characteristics were associated with willingness to assume responsibility for directing a worker: prior experience directing a worker, greater length of time receiving home care services, greater current involvement in directing a worker, and lower levels of satisfaction with home care services (Glickman et al., 1997).

### **State CD Programs**

The number of publicly funded CD programs in the United States has been growing steadily in recent years. A 1998-1999 survey by the U. S. General Accounting Office (GAO) found that 31 states offered “some degree of consumer directed personal care” under the Medicaid Personal Care or Home and Community-Based waiver programs. (Waiver programs allow states to provide a range of services to specific groups, such as older persons or persons with developmental disabilities.) “While most states offered consumers choice regarding the selection and hiring of a caregiver,” the GAO reported, “consumer direction varied most often in the extent to which consumers had authority to train their own caregivers and manage the payroll” (U. S. General Accounting Office, 1999).

By October 2001, another study identified 139 programs in 49 states, and collected detailed data on 129 of the programs. Every state, except Tennessee and the District of Columbia, offered at least one CD program.

Almost half a million people (486,000) were served by these programs at the time of the study. The number of participants varied greatly by program, from as few as five participants to almost 250,000 participants (the California In-Home Supportive Services program). Fifty-eight percent of the programs served 1,000 or fewer persons (Doty and Flanagan, 2002).

Sixty-five percent of the programs relied in whole or in part on Medicaid funding, either through Medicaid Home and Community-Based waiver programs or through the Medicaid Personal Care program. (The others are funded by state general revenues or the federal Social Services Block Grant.) Seventy-three percent of the programs served adults aged 18 to 64 with physical disabilities; 51 percent, older persons; 41 percent, adults with mental retardation; and 30 percent, adults with development disabilities (Doty and Flanagan, 2002).

A few states (California, Colorado, Michigan, Oregon, Washington, and Wisconsin) have been offering varied forms of consumer direction for many years. A review of the Colorado, Oregon, and Michigan programs can help provide insights into how these programs have evolved and developed over the years and the range of state program design and policy. The Colorado Home Care Allowance program started in 1979, the Oregon Client-Employed Provider Program in 1981, and Michigan’s Home Help Services in 1982. Although the three states are still operating these CD programs, which include large percentages of older participants, two of the three have also developed newer CD

models in recent years that include training and evaluation features not found in the older programs.

The California In-Home Supportive Services program and the Cash-and-Counseling demonstration projects in Arkansas, New Jersey, and Florida have been evaluated extensively, providing valuable information about the experiences of older consumers with the CD model of service.

(It should be noted that cash allowances or monthly budgets for participants in all the programs described in this report vary widely from state to state because the states use different criteria for determining eligibility and for designing service packages.)

***Colorado Home Care Allowance:***

The Colorado Home Care Allowance program had a total caseload of about 4,800 persons in the spring of 2003, of whom slightly under half were persons age 65 and older. (Total enrollment had reached about 5,800 persons before admissions to the program were frozen in September 2002 because of state budget problems.)

**Program features.** Social workers under contract to the state assess applicants for services using a point system. The system involves assessing a total of 17 impairments on a scale of one to three, with the highest level of acuity receiving a score of three. The applicant must have a score of at least 21 points to qualify for the program. An applicant's level of need determines the amount of his or her monthly allotment using a three-tier system. With the lowest level of need, the applicant would receive \$86

a month (in 2003); the next level, \$180 a month; and the third and highest tier, \$269 a month. The monthly allotments had been nearly 50 percent higher until state budget shortfalls caused cutbacks in many state programs, including Home Care Allowance.

Since dollar amounts are capped at a fairly low level in the Home Care Allowance program, case workers who assess applicants for the program also determine whether the applicant might be eligible for the state's Medicaid Elderly, Blind, and Disabled home and community-based waiver program as well. The Home Care Allowance program provides consumers with assistance with everyday activities such as bathing and dressing and with homemaker services, while the Medicaid waiver program offers a broader range of services, such as adult day care, home modifications, and assistive technology. About 1,500 consumers received aid from both programs in fiscal year 2003.

**Hiring and paying workers.** Most Home Care Allowance participants hire family members to be their worker. Participants decide what they want to pay their workers out of their monthly allotment. A provider agreement is signed by the consumer and the worker. No training is provided to participants on budgeting or personnel issues such as hiring and firing a worker.

**Quality assurance.** A case worker visits a client about once every six months. No evaluations have been conducted of the program. State officials say there have been few problems with the program, and no evidence of fraud or abuse has been reported.

**New CD models.** Colorado officials view the Home Care Allowance program as only a modest version of a consumer-direction approach, and have been working to develop a different Medicaid model with training and evaluation built in. The Colorado legislature approved the Consumer Directed Attendant Support (CDAS) program in 1996, open to people of any age. In August 2001, the federal government approved the program as a five-year demonstration, and in September 2002, the first participants began training.

The CDAS program is limited to 150 persons initially; the participants must already be receiving Medicaid-funded home care services and be able to direct their own care. All eligible individuals must complete the attendant support management training and pass the attendant support management proficiency test to be enrolled in the program. Each participant will develop a plan and will hire, train, supervise, evaluate, and dismiss his or her worker. The participant will receive a monthly allocation based on his or her history of using Medicaid home health and personal care support. The participant and worker will negotiate the payment rate for the worker. An "intermediary service organization" or fiscal intermediary will handle financial and personnel administration.

Case managers will contact participants twice a month during the first three months of enrollment and once every three months thereafter to ensure their needs are being met. The CDAS program will also include a complaint hotline and participant satisfaction surveys.

***Oregon Client-Employed Provider program:***

The Client-Employed Provider (CEP) program is an option offered under Oregon's Medicaid aged and disabled home and community-based waiver program. In fiscal year 2002, about 13,700 persons were participating in CEP. (No figures were available on the percentage of older persons in the program.)

**Program features.** Financial eligibility is capped at 300 percent of Supplemental Security Income (SSI). Some consumers are required to contribute towards the cost of their care to remain eligible when their income is over \$553.70 per month (the SSI standard in FY 2003). Functional eligibility involves being at risk for nursing home placement, which is determined by a case manager assessment. The case manager and the consumer develop a plan of care, which includes identifying the person's needs and determining the number of hours of service that will meet those needs. Participants can receive assistance with daily activities such as bathing, dressing, and shopping, with 24-hour care also available.

**Hiring and paying workers.** The maximum that can be approved for in-home services is \$1,950 per month in 2003. A worker, who can be a family member (except for spouses), can be paid between \$8.33 and \$8.56 an hour in 2003 for personal care, such as helping a person bathe and dress, and \$8.33 an hour for help with other tasks (called "self-management" tasks) such as shopping. Live-in providers are paid \$2.85 an hour. The participant is responsible for hiring, training,

supervising, and firing an employee if necessary. The participant signs vouchers for the number of hours worked by the employee; the state pays the worker based on the voucher amount.

**Quality assurance.** Case managers respond to consumer complaints or issues and conduct an annual reassessment of the individual's needs. Contract registered nurses delegate nursing tasks to the workers and monitor client health, if referred by a case manager. Client-employed providers are subject to annual criminal background checks.

A 1999 survey of the program in Multnomah County (the Portland area) found "a strong and positive picture of client satisfaction with the quality of work, and the capability, reliability, and helpfulness of most workers in the Client-Employed Provider program." Three-fourths of the survey sample (client/provider pairs totaling 546 respondents) had been together in an employment relationship for more than six months; the other fourth of the sample had been together for two years or more. About half of the client sample were older people.

**New CD models.** Oregon launched a new consumer-direction initiative in the fall of 2001, the Independent Choices research and demonstration program, to offer persons with disabilities additional choice and control over their services. Persons of any age may participate. Under this program, participants have greater control over the expenditure of the funds allotted to them for their care,

with monthly amounts ranging from \$900 to \$1,200 in 2003. The state sends monthly payments to a participant's bank account. Participants manage their own personal care and other services with this money after completing a 10-hour training session. They must pass an examination to be allowed to handle payroll tasks; if they fail the exam, they are provided with a fiscal intermediary for those responsibilities.

The program is limited to 300 persons in selected areas of the state. As of April 2003, 165 persons were participating in the program. Participants are allowed to hire spouses as well as other family members to be their workers. More intensive monitoring of participants is also involved in the Independent Choices program; case managers evaluate a participant's plan of care every six months.

### ***Michigan Home Help program:***

The Home Help program, which is funded by Medicaid, had almost 42,000 participants in fiscal year 2002, of which about 60 percent were age 65 and older.

**Program features.** An applicant who applies to a local Michigan county welfare office for assistance is assessed by an adult services worker (a social worker), who determines if the individual needs assistance with daily activities such as bathing and dressing. A physician must attest to the individual's need for the services. The adult services worker then determines the number of hours to which the participant is entitled; the county determines the rate the provider will be paid.

**Hiring and paying workers.** The consumer hires the worker, schedules services, and signs the worker's timesheet. The state acts as fiscal agent, deducts taxes, and sends the paycheck to the consumer, who signs the check and delivers it to the worker.

Over half of the program's participants choose a family member to be their worker. If no family member or friend is available, the adult services worker will recommend private agencies. More than half of the participants receive between \$100 and \$300 a month to pay for services, with participants receiving on average about 10 to 15 hours of service a week. Rates vary depending on prevailing wages in the county in which the participant lives, generally ranging between \$6 and \$8 an hour.

**Quality assurance.** Adult services workers make two in-home visits a year. State officials say visits used to be quarterly, but budget cuts forced a reduction. The Michigan Family Independence Agency, which manages the Home Help program, conducted a telephone survey of a sample of Home Help recipients in August 2000. About 43 percent of the 750 persons interviewed were age 65 or older. Almost 98 percent of the consumers were either "very" or "somewhat" satisfied with the services they received. Those persons who were dissatisfied cited fewer hours of services being available to them or that the provider was slow or did not want to do the work (Michigan Family Independence Agency, 2000).

The recent extensive studies of the California In-Home Supportive Services program and of the Cash and Counseling demonstration program in Arkansas,

New Jersey, and Florida shed some light on the experiences of older consumers with consumer direction.

### ***California's In-Home Supportive Services Program***

In 1996-1997 California researchers surveyed participants of a home care program funded by Medicaid and state and local funds, the California In-Home Supportive Services (IHSS) program, which uses both traditional home care agencies and CD as service delivery models. The purpose of the study was to review differences in the two service models, and to assess whether these differences were important for consumers.

**Program features.** California has the largest CD program in the nation, requiring all of its 58 counties to provide home care services under a Consumer-Directed Model (CDM) to persons eligible for public funding; counties also can offer services through home care agencies. Twelve counties offer the Professional Agency Model (PAM), as it is called in the study, as well as the CDM. About 60 percent of the consumers in the CDM model were age 65 or older, as were 75 percent of the consumers in PAM model.

SSI criteria are used to assess financial eligibility. A county worker determines the number of monthly hours of needed services (up to a maximum of 283 hours a month) after assessing the applicant's ability to perform basic daily activities and the applicant's cognitive functioning. The program provides personal care, household chores, paramedical supervision, protective supervision, and medical transportation services.

**Hiring and paying workers.**

Consumers in the CDM are responsible for recruiting, hiring, training, and supervising their workers. They may hire family members as their worker, including spouses. The monthly budget for a participant is based on the number of hours of service for which he or she is eligible, multiplied by an hourly wage for the worker.

The hourly wage varies from county to county, because unions in some counties negotiate with the employer of record. In 2003, hourly wages for the workers ranged from a low of \$6.75 an hour in a number of counties to a high of \$10.50 an hour in Santa Clara County. Participants averaged about 80 hours of care monthly in June 2003; the average payment for services totaled about \$698 a month.

**The research study.** The researchers stratified IHSS participants by service model (CDM and PAM), by age (over and under age 65), and by client impairment (severe and not severe), and then conducted a telephone survey of 511 participants in the consumer-directed model and 584 in the professional-agency model. About 53 percent (274) of the CDM participants in the sample were age 65 or older, as were about 50 percent (293) of the PAM participants.

A little more than half (51.5 percent) of the persons age 65 or older in the CDM sample hired family members to provide their services. These participants experienced less worker turnover during the course of a year than did CD participants who hired other persons or PAM participants. Four of five CDM participants with family members as

providers used a single provider in the last year, compared to two-thirds of CDM participants overall and about half of the PAM participants. About a quarter of PAM participants had three or more workers in the last year (see Table 1).

One significant problem for consumers directing their own care, however, was finding a backup worker in a service emergency. Almost one-quarter of CDM participants *not* using a family member reported being without backup help, a higher percentage than all other groups.

The researchers examined “outcomes” for consumers in five categories: safety, empowerment, unmet needs, service satisfaction, and quality of life. To determine how safe consumers felt with their workers, for example, researchers asked questions about any threatening or yelling behavior by the worker, about being hurt or neglected by the worker, or whether the participant was suspicious about stealing by the worker. For consumer satisfaction, the researchers examined such factors as provider competence and training, punctuality, receptivity to direction, interpersonal manner, and attentiveness. The researchers found no statistically significant difference between age groups (Benjamin and Matthias, 2001).

Although *both* CDM and PAM participants were generally satisfied with their care under the IHSS program, people in the consumer-directed model reported more positive outcomes in certain areas, most especially in “greater compatibility, including interpersonal bonding, between clients and their workers” (Doty et al., 1999).

<b>TABLE 1. California In-Home Support Services Program, Client Experience with Providers</b>				
	<b>PAM (N=584)</b>	<b>CDM (N=511)</b>	<b>CDM with Family Providers (N=240)</b>	<b>CDM with Non family Providers (N=271)</b>
<b># Providers in last 12 months (%)</b>				
1	52.7	66.5	80.3	54.2
2	22.8	19.8	13.8	25.1
3+	24.5	13.7	5.9	20.7
<b># Current providers (%)</b>				
1	83.7	88.0	89.9	86.3
2	11.1	8.1	7.1	8.9
3+	5.2	3.9	2.9	4.8
<b>Years with provider (mean)</b>	3.0	3.8	4.3	3.3
<b>Needed help finding provider (%)</b>	45.7	7.8	6.7	8.9
<b>Easy to locate a suitable provider? (%)</b>				
Very Easy	N/A	46.2	7.4	36.8
Somewhat Easy		20.7	7.3	23.8
Not Sure		7.2	6.8	7.8
Somewhat Difficult		12.7	7.6	17.5
Very Difficult		12.5	11.0	14.1
<b>Provider recruitment, Someone...(%)</b>				
You found alone	4.2	55.5	64.3	48.1
You found with help from friend /relative	4.0	25.4	21.4	28.7
Sent by agency	73.1	5.5	2.1	8.6
Help from county	16.7	9.4	8.8	10.1
Other	1.9	4.1	3.4	4.5
<b>Ever replaced a provider (%)</b>	43.8	41.9	22.5	59.0
<b>Time it took to get a new provider (%)</b>				
Less than a week	53.4	47.8	57.4	44.8
A week or more	46.6	52.2	42.6	55.2
<b>Source:</b> Benjamin et al., 1998				

Consumers who had family members as workers reported a greater sense of security, more choice about when and how service tasks are done, and greater satisfaction with the amount of choice they had, than did consumers with

agency providers. “From a client perspective, having a family provider meets certain security, choice, and satisfaction needs when compared to receiving assistance from a nonrelative,” the study notes (Benjamin, 1998).

### ***Cash and Counseling Demonstration Projects in Three States***

The Cash and Counseling Demonstration is using a randomized design to compare quality of care under two different approaches: a traditional agency model and a cash and counseling model under which consumers hire and train their workers and manage their own care. Mathematica Policy Research, Inc., has been evaluating the projects in Arkansas, New Jersey, and Florida, and has published several reports of the experiences of participants in each state program. At the time Mathematica conducted its first interviews, participants had been receiving cash allowances for nine months to hire workers or purchase services or supplies.

The demonstration projects operate within the Medicaid Personal Care program in Arkansas and New Jersey, and within Medicaid home and community-based waiver programs in Florida. Arkansas began enrolling participants in December 1998, New Jersey in November 1999, and Florida in June 2000. The enrollment goal for Arkansas and New Jersey was 2,000 elderly and adult disabled persons, with half of the consumers randomly assigned to a "treatment" group whose members receive cash and counseling and the other half to a "control" group whose members receive traditional Medicaid services. Florida had an enrollment target of 3,000 because the populations served also included children with developmental disabilities.

#### *Arkansas:*

By spring 2003, Mathematica was able to report its findings on consumer satisfaction with the cash and counseling

demonstration based on its evaluation of the Arkansas program, which had had the earliest start (Mathematica Policy Research, March 2003). In Arkansas, Mathematica was able to interview 1,739 individuals (out of a total of 2,008 persons who initially enrolled in the program) between September 1999 and February 2002. Seventy-two percent of the participants (1,266 persons) were age 65 and older.

Monthly cash allowances were based on the number of hours in a participant's personal care plan, which depended on the person's physical limitations, needs, and other source(s) of paid and unpaid assistance. The average allowance during the demonstration was \$320 per month, based on care plans recommending an average of about 47 hours of services a month.

Almost all participants used their monthly allowance to hire family members or friends and some bought assistive equipment, personal care supplies, and medications. Consumers said the single most attractive program feature was being able to hire family members. "Having a family member as a worker provided consumers with security and peace of mind; they disliked having strangers come into their homes," the researchers said. Participants did not like the amount of paperwork required or the restrictions on the use of the cash, especially the restriction on hiring spouses (Mathematica Policy Research, May 2002).

Compared to the agency-directed model, the researchers concluded, the consumer-directed approach "markedly increased the proportions of consumers who were very satisfied" with their personal care services. The participants

were more satisfied than persons using the agency system "with the timing and reliability of their care, less likely to feel neglected or rudely treated by paid caregivers, and more satisfied with the way caregivers performed their tasks." Mathematica reported that these results had been obtained "without discernibly compromising consumer health, functioning, or self care."

The researchers concluded that older people randomly assigned to the consumer-directed model "were more satisfied with their personal care and with how they were spending their lives than were elders who relied on agency services" (Mathematica Policy Research, March 2003). See Table 2 for satisfaction scores on worker reliability.

Most participants in the Arkansas program chose to have fiscal agents handle their accounts for them and

withhold taxes. Mathematica reported that the participants were "managing their cash budgets responsibly, without any major instances of fraud or abuse. They are spending their money the way the program intends."

*New Jersey:*

The Mathematica evaluation of the New Jersey Personal Preference program is based on the nine-month experiences of 240 early clients of the program in the treatment group who were interviewed between August 2000 and early May 2001. These early results were published by Mathematica in October 2002. Slightly more than half (53.8 percent) of the interview respondents were age 65 or older. At the time of the interview, 76 percent of the participants were still enrolled, 17 percent had disenrolled, and 7 percent had died.

<b>TABLE 2. Cash and Counseling: Consumers' Experience in Arkansas Satisfaction with Caregiver Reliability and Schedule (Participants Age 64 and Older)</b>		
<b>OUTCOME</b>	<b>TREATMENT GROUP (%)</b>	<b>CONTROL GROUP (%)</b>
Completed Tasks		
Always	65.8	47.2
Usually/Sometimes/Rarely	15.4	36.2
Arrived late or left early		
Never	56.3	36.0
Often	9.4	19.3
Did not come as scheduled	17.7	30.1
Very satisfied with caregivers' schedule	82.9	68.7
Could easily change schedule	47.8	45.1
<b>Source:</b> Mathematica Policy Research, Inc. March 2003		

More than one-third (36.8 percent) of the participants age 65 or older rated their health as poor, and 87 percent had at least one chronic condition that required care. Three-fifths (60.7 percent) of this group said bathing would be "difficult or impossible without help," as was getting in or out of bed for more than one-third (34.2 percent) of the group.

Of the participants who used their grants to hire caregivers, 63 percent hired family members, and 20 percent hired friends, neighbors, or church members. Many participants hired more than one caregiver. More than 88 percent of the participants age 65 or older reported they were satisfied with their overall care arrangements. All the participants in this age group (100 percent) who hired workers with their cash allowance reported having satisfying relationships with their workers. They were satisfied with how their workers handled personal care duties, medication and routine health care, and household duties. Seventy-six percent of the 65+ age group said the program improved the quality of their lives "a great deal" compared to 24 percent who said the program "somewhat" improved the quality of their lives (Mathematica Policy Research, October 2002).

*Florida:*

The Mathematica evaluation of the Florida Consumer-Directed Care program is based on the nine-month experiences of 231 early clients in the program who were interviewed between late March and late November 2001. Children made up 47 percent of the participant pool; nonelderly adults, 36 percent; and persons age 65 and older, 17 percent. Ninety-one percent of the

children were still enrolled in the program after nine months, compared with 53 percent of the age-65-and-older group. (Almost 8 percent of the older age group died, and about 40 percent dropped out of the program.)

The oldest group was more likely than were younger adults or children to be in poor health (40 percent, compared with about 17 percent for each of the other two groups). Over nine-tenths (91.4 of participants) of the 65+ age group had a chronic condition that required care, compared with seven-tenths (72 percent) of the 18 to 64 group and four-fifths (80.6 percent) of the age three to 17 group (Mathematica Policy Research, April 2002).

The average monthly allowance in the Florida program in 2003 was \$948.80. All participants age 65 or older who used their monthly allowance to hire aides were satisfied with their relationship with their aides. Of this age group, 89.5 percent said the program improved their quality of life, with 70.6 percent checking "a great deal" and 29.4 percent checking "somewhat." When the participants were asked to name the most important ways in which their quality of life improved, the highest percentages were registered for the ability to choose their own caregivers (45 percent) and the ability to obtain the personal care services they wanted (32 percent). Despite the high levels of satisfaction with their care, however, about one-third of the participants said they needed more help with meal preparation or housework (Mathematica Policy Research April 2002).

## **Policy Implications and Future Research**

Recent studies cited in this paper demonstrate that many older persons want choice of and control over their care. These studies indicate a high level of satisfaction among older consumers with consumer-directed services. Most participants believe that directing their own services improves the quality of their lives. Moreover, for many older consumers, satisfaction with services and with one's relationship with a worker or caregiver appears to be related to being allowed to hire family members as the worker (Benjamin, 1998; Mathematica Policy Research, October, 2000).

Studies have also indicated, however, that older consumers differ in the extent of control they want to exercise over their services and their workers. Many consumers want more control over their care, but may not want to perform some employer tasks (Glickman et al., 1997; Mahoney et al., 1998; Simon-Rusinowitz et al., 2000).

The answer may lie in attention to design features of CD programs. States could provide a range of options, for example, for consumers who want to direct their care, but not manage all aspects of their services. Fiscal agents can be employed to handle tax and payroll matters. States can develop and offer counseling services and training programs for consumers and workers. Programs can build in backup support when regular workers fail to show up. Emergency procedures and funds can be made available to allow clients to return to traditional services if the find they cannot or no longer want to manage their

own care. States can allow guardians or surrogates to assist in managing services for people with severe cognitive limitations.

Cash payments to consumers increase their flexibility to hire workers, to purchase products they need, or to arrange for helpful home modifications. Further research could identify practical steps that states can take to improve the administration of cash programs. Additional information from the RWJ Cash-and-Counseling demonstrations and from state-tested CD options in Medicaid and state-funded home care programs may suggest more policy options for expanding CD, and dealing with any problems associated with CD expansion.

## **Conclusion**

“To the extent that care subordinates or suppresses autonomy,” one researcher has written, “its benefits come at a dubiously high cost of human individuality and freedom” (Collopy, 1988). This sentiment animates the consumer-direction movement.

Although this movement originally focused on younger people with disabilities, interest has been growing in offering these choices to older persons as well. Still, concerns about client safety and about the potential for fraud and abuse remain issues for some policy makers and advocates. Some older persons receiving publicly funded long-term services are not able to manage those services on their own or do not wish to. Some consumers may be vulnerable because of cognitive impairments. Making CD voluntary will help address some of these issues.

Policymakers need to develop a range of CD models with flexible options and considerable support for the participants and their families in these programs. With the right options and supports, CD can represent a large step forward in meeting the needs of those with disabilities in a way that respects their individual preferences and circumstances.

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