

## CONSUMER-DIRECTED SERVICES FOR OLDER PEOPLE

"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. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received."

The National Institute on Consumer-Directed Long-Term Services. July 1996

### 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.

Those who incur disabilities face losing control over their lives and their care because they often must depend on others to help them with bathing, dressing, eating, and other everyday activities. If they can afford to pay privately for the services that will help them remain in their homes, they can decide for themselves who will provide those services and when — subject to the availability and affordability of personal care workers.

The reality is different, however, for persons with disabilities who must depend on publicly funded programs such as Medicaid to help pay for care. The traditional model for publicly funded home care services generally has been a case-managed and agency-operated system. Under that model, state programs typically contract with private-sector home care agencies to provide services.

A case manager assesses the applicant's needs, draws up a care plan, and arranges for the delivery of services. The agency provides the worker who "delivers" the services. The consumer (or "client") may have little say in the nature of the services, the selection of the worker, or the scheduling of services.

In the 1970s, many younger persons with disabilities began to challenge this model of government-funded care. The disability rights and independent living movements successfully advocated for a new "consumer-directed" (CD) model (Livak et al. 1987, DeJong et al., 1992). Under this model, the client hires her own aide and directs how and when she receives services.

The consumer direction model has been adopted in a number of Medicaid- and state-funded programs in the United States and in several European countries (Germany, Austria, France, and the Netherlands are examples). These publicly funded programs generally serve persons with disabilities of all ages. However, despite the significant participation of older persons in many of these programs, few states have conducted any rigorous research and evaluation of the specific experiences of older participants.

As a result, debate has continued about the appropriateness of consumer-directed

services for older persons. Some program administrators and advocates believe that many older people with disabilities are too sick or too frail to direct their own care, and that they may be particularly vulnerable to abuse or threats to their safety. Other advocates and consumers contend that these concerns must be weighed against an older person's desire and right to choice, autonomy, and control in the delivery of services — the options individuals have in the private-pay care system (Scala and Mayberry, 1997; Doty, Kaspar, Livak, 1996; Tilly and Wiener, 2000).

Although the research data are scant, several surveys shed some light on the preferences of older people using government-funded programs for consumer direction, the opinions of program administrator about CD for older persons, and the experiences of older persons in CD programs. This Issue Brief reviews those surveys and two recent studies of the experience of older participants in CD programs in California, Arkansas, and New Jersey. First, the paper describes several CD models and describes how states increasingly are incorporating CD in their home and community programs. Then the paper reviews several surveys that examine the attitudes of older consumers. Next, the paper reviews several surveys of program administrators that report on their attitudes about the advantages and disadvantages of CD for older people. Finally, the paper summarizes the results of two studies of consumer satisfaction in CD programs that include a sizeable proportion of older participants.

Understanding the perspective of older consumers about CD can help program administrators reduce the barriers that may make CD less accessible to some older persons. Identifying the issues that program

administrators raise can help improve program design and reduce concerns.

### **Consumer-Direction Models**

The consumer responsibilities typically considered 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) managing payroll and tax functions, including paying the aide, 5) giving performance feedback, and 6) 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 could 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 a *Cash-and-Counseling* Medicaid demonstration project being tested for three years in Arkansas,

New Jersey, and Florida under 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.

### **State CD Programs**

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 mentally retarded persons or older persons only.) “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.”

The GAO study reviewed the CD programs in California, Kansas, Maine, and Oregon, which had varied CD models. Despite these differences, the GAO said, the four states faced a common challenge in ensuring a qualified pool of workers and balancing the state’s concern about consumer safety with the consumer’s right to direct her own care (U. S. General Accounting Office, 1999).

An example of a Medicaid-funded CD program is Michigan’s Home Help Services, a program begun in 1982. Home Help

Services was funded at \$160 million in fiscal 1999, and served about 37,000 people monthly on average that year, about half of whom were age 60 or older. Under this fiscal intermediary program, 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 (Tilly and Wiener, 2001; National Association of State Units on Aging, 1998).

Also, a number of states operate their own state-funded CD home care programs to assist individuals who are not eligible for Medicaid. States may also use state general revenues for cash payments to CD participants to allow the participants to purchase services or supplies, or to hire spouses as workers, neither of which is generally permitted under Medicaid.

One state-funded CD program, the Colorado Home Care Allowance program, has been in existence since 1979; this program served 5,786 persons and was funded at \$16 million in 1999. About 65 percent of the program’s participants were age 60 or older in that year. An individual may choose a family member, independent worker, or an agency to provide services, schedule services, and pay the worker with cash provided by the state (Tilly and Wiener, 2001; National Association of State Units on Aging, 1998).

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

The limited research available on the attitudes of older persons to consumer direction indicates varying degrees of interest in CD services. These studies, conducted in the 1990s, found that some older people did not want to direct their own care. Individuals who chose a CD option,

however, generally were very satisfied with the care they received.

In 1990, a study by the Commonwealth Fund Commission on Elderly People Living Alone examined satisfaction with care among 879 persons aged 65 or older who were receiving home care services in Maryland, Michigan, and Texas. Participants could choose either agency services or varying degrees of consumer direction.

Researchers concluded that the more control the consumer had, the greater was his/her satisfaction with the worker and the services. “Knowing the aide prior to employment, helping schedule the aide, supervising the aide, and client or family responsibility for changing aides were significantly associated with high levels of satisfaction with the aide’s competence and humaneness” (Doty et al., 1996).

When Eustis and Fischer (1992) interviewed a small group of Minnesota home care clients (20 adults under age 65 and 34 adults age 65 and older), they found that two-thirds of the younger adults hired their worker themselves while the overwhelming majority of the older clients used an agency worker. However, about one-third of the older clients said they participated in training and supervising their worker.

A 1993 random sample of 883 clients age 60 and older of the Massachusetts Home Care Program that used agency workers found a “substantial minority” of respondents willing to hire and direct a worker themselves. A quarter to a third of the respondents indicated they would be willing to assume responsibility for such tasks as hiring, scheduling, and supervising a home care worker themselves. The researchers found that certain client characteristics were

associated with willingness to assume responsibility for directing a worker: prior experience directing a home care 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).

More recently, researchers at the University of Maryland Center on Aging working on the development of the RWJ Cash-and-Counseling Demonstration projects sought to assess consumers’ interest in receiving cash to purchase personal assistance services, rather than continuing to use traditional 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 (Simon-Rusinowitz et al., 2000).

The surveys showed that a sizable segment of consumers (32 percent to 58 percent) and surrogates (56 percent to 62 percent) were interested in the cash option. (Although a smaller percentage of persons 65 and older were interested in the option than persons under age 65, from 29 percent to 51 percent of the older age group expressed interest.)

Most of the interested respondents wanted help or training with payroll (77 percent to 84 percent) and taxes (71 percent to 86 percent), and would elect to have accounting professionals handle payroll and tax

withholding for their workers, if offered that choice (Simon- Rusinowitz et al., 2000).

### **The Views of Administrators**

Several researchers have also sought the perspective of public officials who manage home care programs as to whether consumer direction is appropriate for older people.

Scala and Mayberry surveyed the administrators of 14 consumer-directed home services programs throughout the United States in the fall of 1996. The smallest program in the study served 44 consumers; the largest served over 31,000 at the time of the survey. Most of the programs served either the 18-and-older disabled population or persons of all ages.

The researchers reported consensus among the administrators that the best strategy for serving older persons would be to offer a range of CD options within a program. The administrators also agreed that “an essential early step” in CD programs was training of the professional staff, personal assistants, and consumers and their families (Scala and Mayberry, 1997).

In 1996 and 1999, the National Council on the Aging completed surveys of state administrators in four departments: aging, Medicaid, vocational rehabilitation, and mental retardation/developmental disabilities. The surveys solicited the opinions of the administrators about the advantages and disadvantages of consumer direction. In 1996, the administrators identified a total of 103 consumer-directed programs; in 1999, 166 administrators reported on 188 CD programs (Lagoyda et al., 1999, Squillace and Velgouse, 2001).

The 1996 and 1999 surveys both reported that administrators viewed the major advantages of CD to be: (1) increased

consumer choice and autonomy, (2) improved quality of life and satisfaction for the consumer, (3) greater flexibility for the consumer in terms of matching services to needs, and (4) cost savings for the programs.

The disadvantages most commonly cited by the administrators in both surveys were (1) lack of quality assurance oversight, and (2) the possibility of fraud and abuse. In the 1996 survey, more than a quarter of the administrators also listed program implementation difficulties as a disadvantage; in 1999, another disadvantage cited by about a quarter of the administrators was “consumers being taken advantage of.”

On the 1999 survey, in addition to the 1996 questions, respondents were given a checklist of potential ethical and legal issues that might arise with CD services, and were asked to check all that concerned them. The three concerns listed the most among all administrators were abuse or exploitation of the consumer (78 percent of the respondents), fraud or misuse of funds by either the consumer or provider (73 percent), and quality assurance (70 percent).

In spite of their concerns, 69 percent of the respondents to the 1999 survey also expressed interest in advancing CD programs for all persons with disabilities and 65 percent for older persons. The survey reported “substantially less interest,” however, in further advancing cash and counseling programs. Only 31 percent were interested in this CD model (Squillace and Velgouse, 2001).

Tilly and Wiener also researched the perspective of state program officials about consumer direction for older people in a 1999 survey. The researchers chose eight states that provided agency and consumer-directed services to older adults with

disabilities, had at least 2,000 beneficiaries in the consumer-directed programs, and had at least two years experience with consumer direction. The states were California, Colorado, Kansas, Maine, Michigan, Oregon, Washington, and Wisconsin. The state program officials surveyed were state Medicaid or State Unit on Aging officials, who were responsible for the CD programs.

The eight officials were split in their assessment of whether older persons wanted to direct their own care. Three of the eight said that older persons prefer consumer-directed care, contending that personality and personal circumstances, not age, are the most important influences on older persons. Two other officials said that older people prefer agency services, and the remaining officials did not believe that older persons preferred one model over the other.

The eight officials were also split on the issue of the capability of older persons to manage their care. Five of the eight said that the ability to direct services “does not vary by age;” one official said that “everyone is capable of directing services with sufficient training and support.” The other three officials contended, however, that older persons “find consumer direction more burdensome or are less capable of management than younger persons.”

Six of the eight officials believed that beneficiaries with consumer direction were more satisfied, had more control over services, or had better quality of life than those receiving agency services. None of the officials thought that quality of care was worse under CD (Tilly and Wiener, 2001).

### **Consumer Use and Satisfaction**

Despite the number of consumer-directed programs operating across the country,

systematic research is limited on the quality of care for older consumers under CD and whether older people encounter any specific problems different from those encountered by younger people in these programs. Several recent studies shed some light, however, on the experiences of older consumers in self-directed programs. These include a study of a California home care program and the RWJ demonstration programs in three states.

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

In 1996-97 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 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 clients.

California has the largest CD program in the nation, requiring all its 58 counties to provide home care services under a Consumer-Directed Model (CDM) to persons eligible for public funding; the counties also have the option to 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. At the time of the survey, the IHSS program served nearly 200,000 low-income Californians of all ages with disabilities. About 60 percent of the clients in the CDM model are age 65 or older, as are 75 percent of the clients in PAM model. Consumers who direct their own care may hire family members as their

service provider, including spouses; more than 40 percent of CDM providers are relatives of the client.

In the PAM counties, county IHSS staff generally make the decisions about which clients should be assigned to the PAM model, assigning those who live alone with few other supports, those considered unable or unwilling to direct their own services, and those needing relatively few services.

CDM clients are more likely to live in a household with others (some of whom become their paid workers), have greater assistance needs, and have more hours of service. Clients are responsible for recruiting, hiring, training, and supervising their workers. The state pays the workers for hours certified by the clients.

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

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. Clients in the CD program who hired family members as their worker experienced less worker turnover during the course of a year than CD clients who hired other persons or PAM clients. Four of five CDM clients with family members as providers used a single provider in the last year, compared to two-thirds of CDM clients overall and about half of the PAM clients. Almost a quarter of PAM clients had

three or more workers in the last year. (See Table 1.)

One significant problem for clients directing their own care, however, was finding a backup worker in a service emergency. Almost one-quarter of CDM clients *not* using a family member reported being without backup help, a higher percentage than all other client groups. (Three-quarters of PAM clients indicated that if a scheduled worker did not show up, another worker would be provided by the agency.)

The researchers examined “outcomes” for clients in five categories: safety, empowerment, unmet needs, service satisfaction, and quality of life. To determine how safe clients felt with their workers, for example, researchers asked clients questions about any threatening or yelling behavior by the worker, about being hurt or neglected by the worker, or whether the client was suspicious about stealing by the worker.

Researchers assessed the extent of client control through questions about the amount of choice a client had over when and how tasks were done and choice about her provider. For client satisfaction, the researchers examined such factors as provider competence and training, punctuality, receptivity to direction, interpersonal manner, and attentiveness.

Although *both* CDM and PAM clients 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).

**TABLE 1**  
**California In-Home Support Services Program, Client Experience with Providers**

	<b>PAM (N=584)</b>	<b>CDM (N=511)</b>	<b>CDM Family Providers (N=240)</b>	<b>CDM 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		46.2	57.4	36.8
Somewhat		20.7	17.3	23.8
Not Sure	N/A	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>	4.2	55.5	64.3	48.1
You found alone	4.0	25.4	21.4	28.7
You found with help from friend/relative	73.1	5.5	2.1	8.6
Sent by Agency	16.7	9.4	8.8	10.1
Help from County	1.9	4.1	3.4	4.5
Other				
<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

**SOURCE:** Benjamin et al., 1998

## CALIFORNIA IN-HOME SUPPORTIVE SERVICES PROGRAM

### Clients Say....

- \* “I was glad to be able to choose. I like being an employer, just like anyone else.”
- \* “Because I can pick who I want, put an ad in the paper that I need personal assistance. Because then I don’t end up getting someone I don’t want. Because if I had people sent in, I could always be getting someone I don’t want and that just interrupts your life too much.”
- \* “As I’m getting older, I think hiring your own person is more ideal.”
- \* “He likes helping me. He does everything, including gardening and windows. It’s his home, too.”
- \* “No one can train a person to care for me other than me.”
- \* “.... I’ve known my current provider for years. He’s a friend and I find that friends are more dependable. I feel more comfortable.”
- \* “It didn’t work out at all. She was lackadaisical about coming. Being a friend I think that there was this sense of resentment that I was telling her what to do and how to do it, and... it’s a lot of paperwork to send in. So I decided just to let the agency do it all.”

(Benjamin, 1998)

The study found statistically significant differences in how empowered clients felt in the service relationship, how satisfied they were with the technical and interpersonal aspects of services, and how they rated the quality of their lives. On each of these dimensions of care, CDM clients had more positive scores than PAM clients. The results included the following:

### *Quality of Life*

- CDM clients reported significantly higher quality of life in regard to emotional and social well-being than PAM clients. In terms of physical well-being, CDM clients with family providers reported significantly higher scores than clients whose workers were not family members.

### *Empowerment*

- More CDM than PAM clients indicate having substantial choice about who their provider is, what tasks are done, how they are done, and when services are scheduled.

### *Satisfaction*

- CDM clients rate their workers higher on technical competence and training than PAM clients.

Clients who have family members as providers report a greater sense of security, more choice about when and how service tasks are done, and greater satisfaction with the amount of choice they have, than clients 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.

The study researchers point out a significant problem for people who are directing their own care but who do *not* have a family member or friend to hire as their worker. For the roughly one in five CDM clients “without family and friends to rely on, a missed visit by a provider can mean uncertainty or crisis,” the researchers say. With services arranged by an agency, PAM clients do not have to worry about recruiting a provider or backup if a worker does not show up (Benjamin, 1998).

Although the study demonstrates several statistically significant differences on client outcomes between the two models, differences that “consistently favor the CDM,” the researchers also point out that clients with light to moderate needs “are generally content with PAM services” in counties that offer these services.

### ***RWJ Cash and Counseling Demonstration Projects***

Preliminary information is becoming available from the Arkansas and New Jersey RWJ Cash-and-Counseling demonstrations. 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 who receive cash and counseling and the other half to a “control” group who receive traditional Medicaid services. (Florida had an enrollment target of 3,000 because the populations served also included children with developmental disabilities.)

Arkansas began enrolling participants in December 1998, New Jersey in November 1999, and Florida in June 2000. By September 2001, 2,242 persons were enrolled in the Arkansas “treatment” group,

New Jersey had 1,652 participants, and Florida, 2,847 participants.

The researchers have scheduled preliminary evaluations of the experiences of persons in the treatment groups as soon as each project has about 200 participants in these groups. In October 2000, Mathematica Policy Research, Inc. released preliminary findings for the first 200 participants in the Arkansas program; in June 2001, the researchers provided some early data on 240 New Jersey participants. The participants in each state had been receiving cash allowances for nine months to purchase services or hire caregivers (Mathematica Policy Research, Inc., 2000, 2001).

*Arkansas results:* At the time of their enrollment in the Arkansas demonstration, 72 percent of the first 200 participants were age 65 or older. The researchers reported that participants, on average, were in poor health and had high levels of functional impairment. Within nine months of enrollment, one-third of the clients had died (9 percent) or disenrolled (24 percent).

Most program participants (86 percent) used the monthly allowance to hire a caregiver, with 78 percent of participants hiring a family member. Another 15 percent hired a friend, neighbor, or church member. (The percentages differed only slightly between the older and younger participants.) Nearly one-third of the participants bought or repaired equipment for such things as personal activities, communication, or safety. A few participants used their cash allowance for home modifications.

About 96 percent of the participants who used the cash allowance to pay for the services of a caregiver reported being satisfied with their overall care. All of these participants (100 percent) reported being

satisfied with their relationship with their caregiver. (See Table 2.) However, two-fifths of the participants said they needed more help with meals and housework, and about one-third reported needing more help with transportation and personal care.

<b>Table 2</b>	
<b>Cash and Counseling: Consumers' Early Experience in Arkansas</b>	
<b>Satisfaction with Care</b>	
	<b>% of Respondents</b>
Satisfied with:	
Overall Care Arrangement	95.6
Help with Transportation	89.8
<u>Participants Who Used Cash Allowances to Pay Caregivers:</u>	
Satisfied with How Caregiver:	
Fulfills personal care duties	99.2
Helps w/medication/routine health care	98.9
Fulfills duties in house/community	96.8
Satisfied with Times of Day Get Help	95.4
Satisfied with Relationship	100.0
<b>Quality of Life and Unmet Needs</b>	
% Satisfied with Their Lives	79.3
Needs Help but Not Getting It or Needs More Help with	
Meals and housework	41.3
Transportation	32.9
Personal care	32.5
Mathematica Policy Research, Inc. October 2000	

*New Jersey results:* When the Mathematica researchers reviewed early results from the New Jersey program, about 16 percent of the initial 234 participants had disenrolled (38 persons) from the program with six months of enrollment. Of these, 8 died while

enrolled, 8 left the program involuntarily (for example, because they became ineligible for personal assistance services), and 22 left voluntarily (for example, because they had trouble recruiting or hiring caregivers). By the six-month point, two-thirds of all participants had received help with a cash management plan.

About nine months after the initial group of participants enrolled in the program, almost four-fifths of those who had used their cash grants to hire caregivers hired a family member. Close to two-fifths of the participants hired a friend, neighbor, or church member. Many participants hired more than one caregiver.

As with the Arkansas participants, after nine months in the program, 100 percent of the New Jersey participants who hired with the cash benefit reported being satisfied with how the caregiver “fulfills personal care duties,” and “helps with medication/routine health care.” More than four-fifths of the New Jersey participants would recommend the program to others (Mathematica 2001).

On the basis of these early evaluations, the researchers concluded that the participants in both the Arkansas and New Jersey demonstrations are “happy with care received and relationship (with the caregiver), flexibility, and control over who gives care and when” (Mathematica, 2001).

### **Policy Implications and Future Research**

Recent studies cited in this paper demonstrate that *many* older persons want choice and control over their care. These studies indicate a high level of satisfaction with consumer-directed services among older consumers. 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, 2000).

The research on the preferences of older persons regarding self-direction also indicates, however, that older consumers differ in the extent of control they want to exercise over their services and their workers (Glickman et al., 1997, Mahoney et al., 1998, Simon-Rusinowitz et al., 2000). Many consumers want more control over their care, but may not want to perform some employer tasks. Studies have shown, for example, that many older consumers prefer that an independent fiscal agency or a state agency handle payroll and tax matters related to employing a worker (Flanagan and Green, 1997).

Surveys of administrators of publicly funded CD programs show that these officials generally support CD, but many administrators express concerns about the potential for fraud and abuse of older consumers who may be frail and vulnerable (Squillace and Velgouse, 2000, Tilly and Wiener, 2001).

Various policies or procedures could address these concerns. States can provide a range of options, for example, for consumers who want to direct their care, but not manage all aspects of their services. States can offer a CD option and an agency model within the same program, and allow consumers who choose CD to switch back to an agency model if they encounter problems directing their own care. Even within the agency model, consumers can be encouraged to exercise as much choice and control as possible.

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 usefully identify practical steps that state programs have taken or can take to improve the administration of cash programs.

Studies have also shown that persons using agency services or hiring their own workers often face the daunting situation of being left with no help if a worker fails to show up. Hiring family members as one's worker also can present a uniquely difficult problem: how to "fire" the family member if the situation is not working out. CD administrators need to be prepared to address these situations with counseling services, training, and backup registries of workers. Emergency procedures and funds must also be available to allow clients to return to traditional services if they find they cannot or no longer want to manage their own care.

Additional information from the RWJ Cash-and-Counseling demonstrations and from state-tested CD options in Medicaid and state-funded home care programs may help 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. A greater number of CD options are being offered to older people.

Studies of CD programs that include older participants have found considerable satisfaction among this population with the autonomy, control, and choice that the programs allow. Older consumers have reported significant satisfaction with directing their own care and having control over services, schedules, and workers. In particular, many older participants have been pleased to be able to hire family members as their workers. From a public policy perspective, the use of family members also helps address current shortages of personal care workers.

Still, concerns about client safety and about the potential for fraud and abuse remain issues for some program administrators and advocates. Some older persons receiving publicly funded long-term services are not be able to manage those services on their own or do not wish to. Some consumers may be vulnerable because of cognitive impairments. These issues need to be addressed as consumer-directed programs expand.

The answer may lie in attention to design features of CD programs. For example, fiscal agents can be employed to handle tax and payroll matters, rather than assigning these tasks to the participant. Programs can build in backup support when regular workers are not available, and provide extensive training and support for consumers and families. Administrators can strengthen monitoring procedures, and require periodic reporting by program participants.

Policymakers need to develop a range of CD models with flexible options and considerable support for the participants and their families in these programs. The ongoing testing and evaluation will help

shape the future direction of CD programs as they develop for older persons.

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