Scripps Gerontology Center

Scripps Gerontology Center Publications

Miami University *Year* 1997

Consumer-directed home services : issues and models

Marisa Scala* Pamela Mayberry†

*Miami University, commons@lib.muohio.edu
†Miami University, commons@lib.muohio.edu

This paper is posted at Scholarly Commons at Miami University.
http://sc.lib.muohio.edu/scripps_reports/30

Ohio Long-Term Care Research Project

CONSUMER-DIRECTED HOME SERVICES: ISSUES AND MODELS

Marisa A. Scala
Pamela S. Mayberry

July 1997

Scripps Gerontology Center Miami University Oxford, Ohio 45056

Marisa A. Scala is a Research Associate for the Ohio Long-Term Care Research Project at the Scripps Gerontology Center of Miami University. She received her Master of Gerontological Studies degree from Miami University and her B.A. in Sociology from the College of the Holy Cross. Her research interests include consumer direction and management of home services, consumer education and training, personnel issues in long-term care, older adult education, and religiosity/spirituality.

Pamela S. Mayberry is Coordinator of Academic Programming at the Scripps Gerontology Center of Miami University. She received a Master of Gerontological Studies degree from Miami University. She was recently involved in two federally-funded projects titled *New Initiatives in Home Care Service Delivery* and *African-American Elders Long-Term Care Preferences and Choices*. Her research interests include women and aging, perceptions about long-term care options, frontline worker issues in long-term care, and consumer direction of home services.

This research was funded as part of a grant from the Ohio General Assembly, through the Ohio Board of Regents to the Ohio Long-Term Care Research Project. Reprints are available from the Scripps Gerontology Center, Miami University, Oxford, OH 45056; (513) 529-2914; FAX (513) 529-1476.

Consumer-Directed Home Services:
Issues and Models

Marisa A. Scala
Pamela S. Mayberry

Scripps Gerontology Center
Miami University
Oxford, OH 45056

July 1997

Executive Summary

Consumer direction of services is the most recent manifestation of consumerism in long-term care, particularly in services for older adults. Consumer direction embodies the notion of consumer-centered or consumer-driven services by incorporating consumer choice and control into the management of long-term care services. While the recognition of clients' ability to self-direct has long been a hallmark of the independent living movement and personal assistance services for younger adults with disabilities, it has been much slower to develop in aging services.

The aim of this study was to explore issues and barriers that planners and administrators of home services programs must address when considering a move toward consumer direction. To accomplish this, we conducted an extensive review of the literature and interviewed administrators of fourteen home services programs that employ some form of consumer direction. Interviews explored models of consumer direction, liability, involvement of family members, training for consumers and staff, cost, quality assurance, and the balance between autonomy and risk.

Major findings and recommendations from this study include:

- Consumer direction takes a wide variety of forms in practice. For some consumers, it may mean assuming complete responsibility for service management, while for others, it may simply mean having adequate information about the service system in their area or being able to offer feedback about workers' performance.

- Models that include a range of options for consumer direction within programs appear to be best for serving older adults in the home environment. Using state funds to supplement Medicaid provides flexibility and a wider range of options within programs.

- Consumer direction is not necessarily for everyone. While many consumers may welcome the opportunity to be more involved in service management, others may not wish to take responsibility for directing and managing their own services.

- Training of professionals, assistants, and consumers and their families is an essential **early** step for programs moving toward a consumer-directed approach to serving disabled elders.

- Use of independent providers rather than agency employees may result in better matches, increased client satisfaction, more control for consumers, and lower administrative cost to programs.

- ***However,*** low wages and lack of benefits for personal assistants result in problems finding and keeping quality providers. The use of independent providers will not solve the recruitment and retention problem in long-term care.

Acknowledgements

We wish to thank Simi Litvak and Amy Gup from the World Institute on Disability for their assistance in program selection. In addition, Robert Atchley, Jane Karnes Straker, and Larry Weiss of Scripps Gerontology Center and Diana Kubovcik of the Central Ohio Area Agency on Aging provided helpful comments during the review process. Finally, we are grateful to the program administrators whom we interviewed for their willingness to share their time and their expertise.

Table of Contents

INTRODUCTION AND BACKGROUND 1

What Is Consumer Direction? 1
What Are Personal Assistance Services? What Is Entailed in Service Management? . . . 2
History and Trends 3

METHODS 4

FINDINGS 5

Sample 5
Perceived Benefits and Challenges 5
Models of Consumer Direction 8
The Big Dilemma: Autonomy vs. Risk 9
Consumer Preferences 11
Involvement of Family Members 12
Quality Assurance 13
Training 14
Personal Assistants 15
Liability 17
Cost 20

CONCLUSIONS AND IMPLICATIONS FOR PROGRAMS SERVING OLDER ADULTS 20

REFERENCES 22

APPENDIX: Program Summary Descriptions 25

List of Tables

Table 1
Consumers in Consumer-Directed Programs 6

Table 2
Funding for Consumer-Directed Programs 7

Table 3
Types of Providers Used in Consumer-Directed Programs 7

Introduction and Background

Recent years have seen the burgeoning of consumer choice and empowerment in long-term care. As program administrators struggle to define "quality" long-term care services, consumers (whether service recipients or caregivers) and their experiences within the long-term care system have become a primary focus. Administrators and researchers emphasize consumer satisfaction with services as a measure of quality assurance, in addition to more structural and practice-related measures. Similarly, the terms "client-centered" and "client-driven" have become buzzwords in the description of long-term care services. Finally, consumers have also become increasingly involved in the planning and management of their own services.

Consumer direction embodies the notion of consumer-centered or consumer-driven services by incorporating consumer choice and control into the management of long-term care services.

Consumer direction of services is the most recent manifestation of consumerism in long-term care, particularly in services for older adults. Consumer direction embodies the notion of consumer-centered or consumer-driven services by incorporating consumer choice and control into the management of long-term care services. As a philosophy, consumer direction recognizes the ability of service recipients to "assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services they receive" (National Institute of Consumer-Directed Long-Term Services, p. 4). However, while the recognition of clients' ability to self-direct has long been a hallmark of the independent living movement and personal assistance services for younger adults with disabilities, it has been much slower in developing in aging services.

As one might expect, there are a variety of issues and barriers that planners and administrators must deal with when considering a move toward consumer direction, particularly within the aging network. The aim of this study was to explore these issues and barriers both in the literature and with administrators of existing home services programs that employ some form of consumer direction, while also presenting some basic information about each of these programs. We will begin with a definition and history of consumer direction and related topics and then describe some of the issues and barriers to consumer direction that have been detailed in the extant literature and that were identified by our respondents. Findings from our interviews will be incorporated into corresponding sections, and more detailed summaries of interviews may be found in the appendix.

What Is Consumer Direction?

According to the definition developed by the National Institute on Consumer-

Directed Long-Term Services, consumer direction represents both “a philosophy and [an] orientation” to service delivery (National Institute, p. 7). In philosophy, it signifies a commitment to the concepts of consumer choice and control with the understanding that “individuals have the primary authority to make choices that work best for them, regardless of the nature or extent of their disability or the source of payment for services” (National Institute, p. 7).

In practice, consumer choice and control take form in decision-making and management of services. As Eustis and Fischer discuss in their study of younger and older home care clients, there is more to consumer direction or "taking charge" than hiring, firing, and paying one's own personal assistant. It can mean giving consumers adequate information about home care services and providers, inviting consumers to join in the care planning process, having consumers select their provider(s) and assistant(s), training assistants, and offering feedback to assistants about their work and to providers about workers' performance and service needs (Eustis & Fischer, 1992).

What Are Personal Assistance Services? What Is Entailed in Service Management?

A term often used when discussing consumer direction is personal assistance services (PAS); within aging services, this is more commonly referred to as home/community-based long-term care. The term “personal assistance services” has been more widely accepted among younger disabled adults because it suggests that services are not only bound to the home, but can also be delivered outside the home, such as in schools or in the workplace. In addition, “personal assistance services” implies more of a social than a medical model of service delivery as well as more consumer control (Kane, 1996).

Personal assistance services refer to assistance with “tasks...that individuals would normally do for themselves if they did not have a disability” (Litvak, Zukas, & Heumann, 1987). More specifically, they consist of help with:

- ***personal care/activities of daily living***, including bathing, dressing, eating, mobility, toileting, and transfer;
- ***instrumental activities of daily living***, including meal preparation, menu planning, laundry, housekeeping, shopping, money management, and transportation;
- ***communication***, such as reader services for the blind and interpreter services for the deaf;
- ***paramedical services***, including, but not limited to medication administration, catheterization, injections, and ventilator care.

PAS might also involve home modifications, assistive devices and technologies, case management, and other services (Doty, Kasper, & Litvak, 1996). The persons who provide this assistance may be called personal assistants, attendants, aides, home care workers, or consumer-directed care attendants.

Not surprisingly, management of personal assistance services entails a significant number of responsibilities. These include employee-related tasks, such as recruiting, screening, interviewing, hiring, training, supervising, paying, withholding taxes, and if necessary, firing assistants. Other tasks involved in having a personal assistant are self-advocacy, quality assurance, and possibly conflict resolution. Programs or agencies providing personal assistance services may also offer additional supportive services such as case management, training for consumers, and conflict mediation (Litvak, 1996).

History and Trends

The roots of the movement toward consumer direction within aging services lie in the independent living model. The independent living model/movement was developed during the 1970s as persons with disabilities began to assert their rights to be integrated into mainstream society. The basic premise of this movement is that persons with disabilities are hindered or impaired by barriers in their environment rather than by their physical or mental disabilities. If these barriers or obstacles were removed, then the disabled person could function more "normally." One such barrier has been the lack of "appropriate" long-term care services, specifically personal assistance. Within this model, persons with disabilities are viewed as independent, autonomous consumers who are able to manage and direct their own services as well as their own lives (Batavia, DeJong, & McKnew, 1991). This premise has begun to gain more prominence in aging services during the past several years.

Nationally, the trend in home care services has reflected movement toward consumer direction.

Nationally, the trend in home care services has reflected movement toward consumer direction. Although it has existed since Medicaid's inception in 1965, within the past 10 years the Medicaid Personal Care Services Optional Benefit has grown dramatically as a source of federal dollars for personal assistance services. Recently, this funding source has grown more consumer-directed in nature as the 1993 Omnibus Reconciliation Act eliminated two of its "medical model" guidelines by no longer requiring nurse supervision of services and by authorizing the provision of services outside the home. The only two other requirements are that the consumer's care plan must be approved by a physician and services cannot be provided by a consumer's family member. As of 1994, more than 30 states participated in this program (Doty, Kasper, & Litvak, 1996; Egley, 1994).

In addition, the commitment on the part of the federal government to explore consumer direction resulted in the establishment of the National Institute on Consumer-Directed Long-Term Services. The Institute is funded by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation at the U.S. Department of Health and Human Services; it represents a partnership between the National Council on the Aging, Inc. and the World Institute on Disability. There have also been a number of recent initiatives by the Robert Wood Johnson Foundation in the area of consumer direction.

A 1996 survey of state administrators, providers (formal and independent), consumers, and caregivers on consumer-directed home and community-based services by the National Council on the Aging (NCOA) identified 103 consumer-directed programs throughout the United States, including 23 cash and counseling programs (Cameron, 1996). Approximately half of these programs used a combination of federal, state, and local funding, and just over one-fourth used only state and local funds. Interestingly, the NCOA study showed that while the majority of these programs served consumers of all ages, only eight served older adults exclusively.

Methods

The source of the data for this study was a survey of administrators of fourteen consumer-directed home services programs throughout the United States. These were selected based on a careful review of the literature on consumer direction and on recommendations from consultants at the World Institute on Disability, an acknowledged leader in the study of personal assistance services and programs providing these services. The programs featured in this study are:

- California Caregiver Resource Center Respite Program
- Coalition for Independence (Kansas)
- Concepts of Independence (New York)
- Illinois Home Service Program
- Maine Personal Care Assistance Program
- Massachusetts Personal Care Assistance Program
- Michigan Home Help Service
- Ohio Personal Care Assistance Program
- Oregon Client-Employed Provider Program
- Pennsylvania Attendant Care Consumer-Directed Program
- Texas Client-Managed Attendant Services
- Vermont Attendant Services Program
- Washington Medicaid Personal Care
- Wisconsin Community Options Program

We conducted semi-structured telephone interviews (lasting approximately 45 minutes to one hour apiece) with each program's administrator in fall 1996. As the intent of the study was to explore the structure, challenges, and successes of consumer-directed programs, the interview schedule consisted of mostly open-ended questions in order to allow administrators as much freedom as possible in their responses. However, background information (including the budget and size of each program, age groups served, and types of services provided by each program) was also gathered

during the course of the interviews. (See Appendix for detailed descriptions of each program.)

Findings

Sample

The 14 programs surveyed ranged widely in size. The smallest program in the study served 44 consumers; the largest served 31,169 consumers at the time of the survey. As Table 1 shows, most programs served fewer than 1000 clients. In terms of age groups served, we found that most programs served either the 18 and older disabled population or persons of all ages (including children). Similar to the recent NCOA study, we found that only one program served older adults exclusively. In many programs, younger disabled adults also made up the majority of the client base. Only two programs had older adults (those age 60 and older) represent more than 50 percent of their client population.

Given the wide disparities in the number of clients served by different programs, it is not surprising to find similar differences in budget size. Program budgets ranged from $175,000 to $113 million, although nearly half had budgets of $2 million or less (see table 2). While most programs relied on a single source of funding, many used multiple sources of funding. These included: state funds, Medicaid waiver funds, Medicaid Personal Care Option monies, vocational rehabilitation funding, outside grants, Social Services Block Grants, and fee-for-service contracts. A majority of the programs also required a co-payment for services from consumers.

Finally, in terms of providers, only one program used contract agencies exclusively for service contracts. More than half of the programs surveyed used both contract agencies and independent providers; in the remaining programs, independent providers supplied personal assistance services to consumers (see Table 3). In addition, in the majority of programs, family members could be hired as independent providers.

Perceived Benefits and Challenges

The 1996 NCOA survey on consumer-directed home and community-based services gathered information about what state administrators, providers (both formal and independent), caregivers, and consumers perceived as the advantages and disadvantages of these services. While all groups acknowledged the importance of consumer direction in strengthening consumer choice and responsibility, there were some interesting variations among the five groups of respondents.

Not surprisingly, consumers and caregivers cited more consumer-oriented advantages to consumer direction, including that it “enhances control over service decisions”; “increases choices”; “enhances flexibility and responsiveness to [consumer/caregiver] needs”; “increases independence”; “increases empowerment”; and “improved quality of life.” Caregivers also viewed another advantage of consumer-directed services as being the opportunity to receive compensation for services they were

Table 1
Consumers in Consumer-Directed Programs

	Percentage	Number
Number of Consumers Served		
Under 200	21.4	3
200-999	42.9	6
5,000-10,000	14.3	2
10,000 and over	21.4	3
Age Groups Served		
All ages	28.6	4
18 and older	64.3	9
60 and older	7.1	1
Percentage of Consumers Age 60+ in Program		
25% or less	35.7	5
26-50%	35.7	5
51-75%	14.3	2
76-100%	7.1	1
Not available	7.1	1
Total n=14		

already providing. However, consumers and caregivers also described some of the disadvantages of consumer direction, such as problems with quality assurance including fraud and abuse; "lack of information on community resources" (and similarly, a "lack of formal training"); and "loss of support from formal agencies/difficulties in arranging back-up."

Providers (formal and independent) also responded to this survey, and their answers reflected a more business-oriented perspective. Both formal and independent providers viewed cost-effectiveness and reduction of administration as advantages of consumer direction. In addition, both groups felt that consumer direction allowed for more flexibility in meeting the needs of workers and consumers and also fostered better relationships between providers and consumers. However, both pointed to liability issues and backup/scheduling problems as being major disadvantages of consumer direction.

Finally, in terms of advantages of consumer direction, state administrators pointed to increased consumer choice and control, cost-effectiveness, improved consumer satisfaction, and a reduction in bureaucracy and administrative costs. However, similar to consumers and caregivers, they reported that "lack of oversight

Table 2
Funding for Consumer-Directed Programs

	Percentage	Number
Annual Program Budget		
Under $1 million	21.4	3
$1-2 million	21.4	3
$2.1-10 million	14.3	2
$10.1-50 million	14.3	2
More than $50 million	28.6	4
Number of Funding Sources		
1	64.3	9
2	28.6	4
More than 2	7.1	1
Funding Sources		
Medicaid Waiver	28.6	4
Medicaid PC Option	21.4	3
State funds	64.3	9
Social Services Block Grant	7.1	1
Vocational Rehab	7.1	1
Fee-for-service contracts	7.1	1
Grants	7.1	1
Consumer co-pay	92.9	13
Total n=14		

Table 3
Types of Providers Used in Consumer-Directed Programs

	Percentage	Number
Contract agencies	7.1	1
Independent providers	35.7	5
Both independent and contract	57.2	8
Family members	92.9	13
Total n=14		

and quality assurance," "fraud and abuse," "consumer management difficulties," and a "lack of adequate training" were disadvantages of the consumer-directed approach (Cameron, 1996).

Respondents to the NCOA study accurately described many of the benefits and challenges of consumer direction. In the following sections, we will outline these and others found in the literature on consumer direction and those reported by respondents in our study.

Models of Consumer Direction

Recognizing that different consumers may have different needs, abilities, and preferences regarding their involvement in service management, there is a range of consumer-directed models that vary in the level at which consumers participate in directing their services. The models listed below represent a continuum of models from most to least consumer control:

- ***direct pay/cash and counseling***-- This term is used to describe a home services program in which the client manages both funds and services. Clients are the employer of record and handle all responsibilities associated with attendant, including: recruiting, interviewing, screening, hiring/firing, scheduling, training, monitoring quality, payroll, and paperwork. Assistance and support from case managers is available to clients. Clients may receive an actual check or vouchers to use to pay for services.

- ***fiscal intermediary***-- In this model an intermediary agency (either the state/program or another agency designated by the state) handles payroll, taxes, and paperwork for clients. However, clients still manage their services, including: recruiting, interviewing, screening, hiring, scheduling, training attendants, monitoring quality, and firing attendants (if necessary).

- ***supportive intermediary***-- In this model the consumer remains the employer of record. However, the program/agency may offer supportive services to consumers and assistants on a limited basis. These services may include: recruitment assistance, criminal background checks on assistants, training, case management, and more.

- ***self-directed case management/ agency with choice***-- In this model the state/program/agency is the employer of record, handling the funds and much of the management of services (recruiting, screening, training, hiring). Client gives input as to preference for attendant, attendant responsibilities, quality assurance and reporting of problems to overseeing agency.

Most consumer-directed programs employ just one of these models. Generally, if consumers are unable or unwilling to carry out all of the responsibilities entailed in that model, they must seek services from another program. However, there is also what Flanagan, Green & Eustis (1996) call the "spectrum intermediary service model" in

which consumers can choose from among a range of consumer directed options, depending on their needs and preferences. At this time relatively few programs offer this spectrum model of service delivery (Flanagan, et al., 1996).

In this study we found that several different programs offered consumers the option of choosing different models of service provision, although most did not. Most often, this was a choice between arranging and managing one's own services and allowing an agency to carry out these responsibilities. Only one program (Pennsylvania) had what could be called a "range" of choices. Consumers could take full responsibility for managing their own services, or they could give complete responsibility for this management to an agency. A third option involved the use of contract agencies as fiscal intermediaries with consumers handling all other responsibilities.

A wide range of support was provided by different programs including case management, training of consumers and assistants, fiscal intermediary services, and maintenance of a registry list of personal assistants to assist with recruitment. One such program, Concepts of Independence in New York City, offers consumers extensive assistance with recruitment of personal assistants. This assistance comes in three forms. The first is a hotline which consists of a tape-recorded listing of the last names and telephone numbers of consumers looking for personal assistants. Personal assistants looking for work can call the hotline and then phone prospective employers directly to arrange interviews. The second form of assistance is a fax search in which Concepts faxes hotline information to area employment services. Employment services then may contact consumers directly if they have someone who might be appropriate for a particular position. The final type of assistance is called a network list. Concepts offers a listing of assistants who have worked a minimum of 500 hours without a negative evaluation from a consumer. This list is updated every two weeks.

The Big Dilemma: Autonomy vs. Risk

When considering a move toward consumer-directed services for older disabled adults, the major dilemma appears to be the balancing of consumers right to autonomy on one hand, and concerns about potential risks and the need to protect consumers on the other.

The philosophy of consumer-direction is based on the right of consumers to exercise autonomy and choice regarding assistance with their disability-related needs. When considering a move toward consumer-directed services for older disabled adults, the major dilemma appears to be the balancing of consumers' right to autonomy on one hand, and concerns about potential risks and the need to protect consumers on the other. In the aging services arena, autonomy continues to take a back seat to protection. Several factors contribute to the continued focus on protection for disabled older adults, including ageism, long-term care regulations, and professional workers' concerns about the safety of their clients.

Ageism is often a factor underlying the lack of choice and control in programs serving disabled older adults. Older disabled people are stereotyped as confused, fragile, passive recipients of help, and therefore in need of protection from abuse. Cohen (1990) observes that "the language of gerontology and geriatrics reflects a deeply embedded and generally held belief, shared by elderly people themselves, that potentials for growth, development, and continuing engagement virtually disappear when an elderly person suffers a serious disability" (p. 13). Indeed, some disabled individuals (young and old) do require protection in addition to assistance with daily activities, most often due to mental impairments or other cognitive disorders. However, the service system for disabled elders has been designed around the needs of the most dependent.

Long-term care practice standards and definitions of quality developed by regulatory organizations also emphasize safety and security over autonomy and self-direction. These standards, emerging primarily from a medical model framework, focus on very narrowly defined services, limiting flexibility that is sometimes necessary when a consumer identifies his or her own needs.

While much criticism has been leveled against the aging services world with regard to its paternalism toward older clients, much of the opposition from service professionals has to do with a fundamental tension between respecting client autonomy and managing risk on behalf of the client in a professionally responsible manner. In a study of case managers in the Choice in Supports for Independent Living (CSIL) program in British Columbia, researchers found that a large percentage of case managers who were asked about self-managed care were concerned about the quality of care and were ambivalent about whether the gains in autonomy would balance the increased risks to the client (Micco, Hamilton, Martin, & McEwan, 1995). In addition, these respondents predicted that stress levels for case managers could increase, since they would have less control over, and greater worry about, their clients' well-being. In an Ohio project, home care case managers worked to identify existing clients who might be candidates for increased involvement in managing their own services. The staff were committed to the principles of client autonomy, however, they had deep concerns about misjudging even one consumer's ability to self-advocate and self-manage. Some case managers felt that their professional responsibility to assure the safety and well-being of clients was compromised by a move toward consumer-direction (Scala, Mayberry, & Kunkel, 1996).

Advocates of consumer direction and the independent living movement have expressed doubts that the existing long-term care system can embrace a completely different philosophy in order to move towards consumer direction, suggesting instead that such a move would require rebuilding the system from ground up (Sabatino and Litvak, 1992). However, in recent demonstration projects, traditional programs are developing new approaches that incorporate consumer choice and control (i.e. cash and counseling demonstrations).

...respect for client autonomy is key to developing such a program.

The representatives of consumer-directed programs interviewed in this study emphasized that respect for client autonomy is key to developing such a program. They stressed that clients know what they need and want, and have the right to make choices about how they meet their needs. In programs that served clients of all ages, older consumers were treated no differently than were younger ones; however, some states (such as Illinois and Pennsylvania) only served elders if they had already been served by the consumer-directed program prior to age 60. Several interviewees mentioned that they sometimes had problems with contract agency staff (professionals or paraprofessionals) who had been taught that older people are to be protected, and therefore had difficulty understanding the consumer-directed approach.

When asked what advice they have for aging services programs moving toward consumer-direction, their responses related to autonomy included: "Trust the client"; "Just because a person is older does not mean they do not know what they want or need in terms of service"; "Create choices," "Consumer empowerment is essential"; "Give consumers control"; "Offering choice and control to consumers is rewarding."

Consumer Preferences

The elderly consumer will most likely want to be involved in the development of their care plan and selection and supervision of their CDCA, but less likely to want to manage all of the employer-functions.

Another barrier to consumer direction may be attitudes and preferences of consumers themselves. Some recent research has examined the preferences of consumers regarding self-direction and has found some differences between older and younger consumers. Flanagan (1994) writes that "Younger persons with disabilities generally will desire the most choice and autonomy. They are most willing to take on the full responsibilities of being the employer of their CDCAs (Consumer-Directed Care Attendants)" (p. 69). In contrast, "The elderly consumer will most likely want to be involved in the development of their care plan and selection and supervision of their CDCA, but less likely to want to manage all of the employer-functions" (Flanagan 1994, p. 69). These findings are echoed by Glickman et al. (1994), Cohen (1992), and Sabatino (1990), as well as by preliminary focus group findings of a study on consumers' preferences supporting the Robert Wood Johnson Cash & Counseling Demonstration and Evaluation (Simon-Rusinowitz, 1996). Glickman et al. (1994) found that only 18 percent of the older home care recipient respondents in Massachusetts wanted to be more involved in service planning and management.

However, while these findings generally seem to point to a reluctance to assume full management responsibilities on the part of older consumers, it must be noted that many of these older service recipients have no prior management experience and have not received training in these areas. As Bass (1996) writes in reference to the Glickman et al. (1994) study, "To be an effective manager of services, prior experience might assist the consumer in making decisions. The typical home care recipient...does not have this experience to draw upon" (p. 7).

Involvement of Family Members

There are two main ways in which family members can be involved in consumer-directed home services. The first is by serving as care managers for consumers who may be unable or unwilling to manage their own services. In cases where consumers may be cognitively impaired and unable to handle the responsibilities associated with service management, training family members to serve as advocates or care managers for these consumers can enable them to utilize consumer-directed services. Family Centered Community Care for the Elderly (FCCCE) was a care management training program for family members of elders with developmental disabilities which sought to create care management partnerships between clients' families and social workers. In her study of this program, Seltzer found that families who participated in the training program continued to serve as care managers for their older relatives long after the program had ended. In addition, she found that an additional benefit of the program was continuity in care management as families could continue to advocate for their older relatives even as agency personnel changed (Seltzer, 1992). In one program that we surveyed, the Caregiver Resource Center System in California which serves family caregivers of persons with adult-onset brain impairment, families were considered to be the care managers, advocating for the brain-impaired adults and in some cases, handling service management (although staff members were available to assist as needed).

Family members may also be involved in the direct provision of personal assistance services to individuals with disabilities. In this capacity, family members would be compensated for services they might already be providing as informal caregivers. In our interviews we learned that all programs except one allowed the use of family members as providers of personal assistance services. However, most programs tended to have some restrictions or exclusions of certain family members as providers -- usually "first degree" relatives (such as a spouse or parent) for whom there is some "obligation" for care embedded within the relationship. More often than not, these exclusions were tied to Medicaid regulations (which do not permit the hiring of family members such as spouse, responsible parent, minor child). Programs which operated either solely on state funds or on state funds in combination with some other funding source usually had more flexibility on this issue. Sometimes other restrictions were also in place; these included limiting those family members who could be hired as personal assistants to those over age 18 or those not living with the consumer.

The use of family members as providers was often tied to the availability of personal assistants in a given local area. The

field of long-term care is plagued by shortages of frontline workers (Atchley, 1996). The shortage is especially severe in rural areas where labor pools may be smaller. This was a problem faced by some of our respondents whose programs served primarily rural/agricultural areas (such as in Vermont and Ohio). Hiring family members was often a way to alleviate this problem.

However, respondents also pointed out that the use of family members as providers was viewed by some consumers as being a threat to their independence and autonomy. Within consumer-directed home services, these concepts are embodied in the employer-employee relationship between a consumer and his/her personal assistant. Family dynamics can interfere with this employer-employee relationship and impede consumers' independence and ability to manage services. As one administrator stated, "How can you fire your mother?" In one program (Ohio), the administrator reported that it was consumers who had requested the regulation against the use of immediate family members as personal assistants. However, in rural areas of the state, consumers were finding it difficult to recruit assistants. As a consequence, the program now has an ongoing pilot project in which 70 consumers now use immediate family members as providers of services. However, administrators and consumers also recognize the increased probability of abuse of funds and of services not being provided.

Quality Assurance

Assuring quality has proven to be a challenge in long-term care, and especially in home care where services are delivered in private homes and clients may be hesitant to complain about care due to their dependence on the services to remain at home. Historically, quality assurance has been closely tied to Medicare and Medicaid regulations, which set standards for structures and procedures such as training requirements, staffing ratios, and documentation requirements. Traditionally, there has been less reliance on consumer input about their satisfaction or what quality means to them (Woodruff and Applebaum, 1996).

A 1995 White House Mini-Conference titled "Quality, Autonomy, and Safety in Home and Community-Based Long-Term Care: Toward Regulatory and Quality Assurance Policy" resulted in recommendations for rethinking and revamping quality assurance. A group of aging services professionals, researchers on quality assurance, elders, and leaders of senior membership groups (i.e. Older Women's League, Grey Panthers) recommended that state and federal legislators, policy makers, and long-term services quality assurance professionals pay attention first to consumer desires and information about problems with quality. They stressed the importance of "dignity, autonomy, continuity of preferred lifestyle, right to take risks, and consumer satisfaction" (Kane, 1995).

Consumers have identified a number of factors that contribute to quality home care, including the opportunity to maintain independence, autonomy and choice; a good consumer/worker relationship; flexibility of care plan and worker tasks; and reliability, honesty and competence of workers.

In recent studies of home care quality assurance, consumers have provided information about their perceptions of quality. Consumers have identified a number of factors that contribute to quality home care, including the opportunity to maintain independence, autonomy and choice; a good consumer/worker relationship; flexibility of care plan and worker tasks; and reliability, honesty and competence of workers. (Woodruff & Applebaum, 1996; Kane, Kane, Illston, & Eustis, 1994; Eustis, Kane & Fischer, 1993). In a Commonwealth Commission survey of Medicaid Personal Care Services home care clients, consumers' overall satisfaction with assistants was found to be related to higher levels of control, including knowing the assistant prior to employment, helping to schedule the assistant, and supervising the assistant (Commonwealth Commission, 1993; Doty, Kasper & Litvak, 1996).

Most important is the inclusion of older service recipients themselves in the process of defining quality, and in the design of quality assurance policy.

A change toward consumer direction in home services for older adults must be accompanied by changes in our methods of assessing and assuring quality. Most important is the inclusion of older service recipients themselves in the process of defining quality, and in the design of quality assurance policy (Woodruff and Applebaum, 1996). In a majority of programs surveyed for this project, quality monitoring was considered to be a shared responsibility between the consumer and the home services program.

Training

Adequate training of consumers and staff as to the nature of consumer direction and service management responsibilities can help with the problems of clients apprehensions about and lack of experience with service management, and can also help to alleviate fears of professional staff as to clients ability to self-direct.

The lack of adequate training and information -- both for consumers and staff -- is another impediment to consumer direction. Consumer direction represents a significant change in philosophy and practice from traditional home care services for older adults; thus, training is especially crucial in home services programs considering a move to consumer direction. As Sabatino and Litvak (1992) wrote, "A prerequisite of self-management...is the need to offer training for clients in the management of their

services" (p. 56). Adequate training of consumers and staff as to the nature of consumer direction and service management responsibilities can help with the problems of clients' apprehensions about and lack of experience with service management, and can also help to alleviate fears of professional staff as to clients' ability to self-direct.

Service providers and administrators of home services programs recognize the importance of training. "Training of providers, caregivers, and or consumers" was listed as the top technical assistance priority in a National Council on the Aging study of consumer-directed home and community-based services, with more than 75 percent of respondents identifying it as a technical assistance need (Cameron, 1996). In addition, consumers who responded to this survey also pointed to a "lack of information about community resources" as a disadvantage of consumer direction. However, relatively few programs include service management training to consumers at this time (Sabatino & Litvak, 1992).

Most of the programs in this study were generally characterized by a lack of formal training for consumers, personal assistants, and professional staff. Most often, the training that did exist was usually just for consumers, and tended to be solely printed resources, such as guides or tax manuals. For programs that offered some training to consumers, the training was generally done by independent living centers. Typically, these independent living centers were already in the business of providing training to younger disabled adults to help equip them with the skills to live independently and manage their lives with the help of personal assistants.

We also learned that the lack of formal training for assistants was linked to liability issues. When discussing training issues, respondents pointed out that if a program provided training to assistants, then that organization might be considered liable if the assistant was negligent in some way. Thus, in most cases, consumers -- particularly those listed as the employer of record -- generally trained their assistants.

However, the need for training has been recognized, as the NCOA study shows, and this need is presently being addressed by some programs. Several programs have already created training manuals or guides for consumers in their programs. One program in particular, the Coalition for Independence in Kansas City, Kansas, is particularly progressive in terms of training consumers and personal assistants. The Coalition received a national grant (which had just ended at the time of the interview) which focused on the development of training programs and materials for consumers. As a part of the grant, they developed a training manual for consumers and a video on self-advocacy; they also offered consumer training on such issues as how to be an employer, consumers' and assistants' rights, and service management issues. In addition, they also provided an orientation for assistants on respecting consumer rights and choice. Basic home care skills training was also available to assistants at contract agencies affiliated with the Coalition.

Personal Assistants

When considering personal assistants within the context of a consumer-directed program, the major controversy appears to be whether to use independent providers or

formal home health agencies as providers of services. Independent providers are those who are hired directly by consumers themselves, and in most cases, consumers are the employer of record and handle all of the service management (including recruiting, interviewing, training, supervising, and terminating workers, as well as payroll and taxes for workers). In some cases, independent providers have been considered to be self-employed contractors, and thereby responsible for submitting their taxes (however this approach is not recommended by experts in the area of employment benefit liability). In contrast, agency-based providers are employed by home health agencies that handle service management. As mentioned previously, over half of the programs in our study used both independent and agency-based providers. Most of the remaining programs used independent providers alone, and only one program relied solely on agency-based providers.

As Doty, et al. (1994) describe, the debate on this issue has focused mainly on the issues of cost, quality, and control. Advocates for independent providers assert that this approach costs less, due to the absence of the administrative overhead associated with home health agencies. Recent research has shown this to be true (Feinberg & Whitlatch, 1997; Egley, 1994). In rebuttal, supporters of home health agencies point to the need for "formal organizational structures and processes" in order to prevent "instances of financial fraud, poor quality care, abuse, neglect, and mistreatment of vulnerable clients, as well as any other accidental or negligent harm that could occur to either clients or attendants while services are being provided" (Doty, et al., 1994, p. 65). However, the debate also centers on the model under which services are provided -- whether this should be the traditional medical model or one that is more consumer-controlled or directed (Doty, et al., 1994).

On a regulatory level, state Nurse Practice Acts influence the choice between independent and agency-based providers. Nurse Practice Acts describe nursing tasks within a particular state. More importantly for consumer-directed programs, they are the main piece of state legislation that deals with the delegation of nursing tasks to unlicensed personnel. Many Nurse Practice Acts allow various tasks to be delegated to para-professionals such as home care workers or personal assistants, and families are nearly always exempt from these Acts. But "often, nurses remain responsible and liable for the safe performance of the delegated task" (Nadesh, 1997, p. 4). As the results of a 1996 conference entitled "Autonomy or Abandonment: Changing Perspectives on Delegation" showed, nurses are also concerned about the safety and well-being of consumers receiving services from unlicensed personnel and worry that the use of unlicensed personnel has more to do with cost-cutting than with consumer autonomy (Nadesh, 1997).

As the principles of consumer direction state, consumers are best qualified to determine the quality of the services that they are receiving, without nursing supervision to decide that for them.

However, persons with disabilities often feel differently. They feel that they

have the right to assume that risk with regard to assistance with activities of daily living. As the principles of consumer direction state, consumers are best qualified to determine the quality of the services that they are receiving, without nursing supervision to decide that for them. Doty, et al. (1994, p. 65) wrote,

> the 'dependency' of persons with disabilities who require attendant services is reinforced when government programs or other third party payers require that recruitment, training, supervision, and payment of attendants be carried out under the direction of medical personnel like registered nurses and/or under the auspices of certified or licensed home health or home care agencies.

Liability

As the results of the 1996 NCOA study on consumer direction show, liability is often cited as a concern about using a consumer-directed approach to serving older people, especially when the approach includes the ability for consumers to hire independent providers as assistants. State programs and home care organizations focus on three types of liability: 1) liability for personal injury to clients; 2) responsibility for employment taxes and benefits for independent providers, and 3) compliance with federal and state regulations regarding the provision of long-term services.

...there has been very little litigation for negligence against agencies or privately hired assistants.

Liability for personal injury to clients by a home-care agency worker or privately hired personal assistant is perhaps the most often cited concern in cases where the consumer has a great deal of choice and control. In reality, however, there has been very little litigation for negligence against agencies *or* privately hired assistants (Kapp, 1991). Personal injury to privately hired personal assistants may actually prove to be the greater problem, since a majority of states do not require workers' compensation coverage for personal assistants. Therefore, personal assistants, who may be injured during lifting and other strenuous caregiving tasks, often have no protection against such on-the-job injuries.

Programs that allow consumers to hire independent providers have addressed the issue of personal injury to consumers and workers in the following ways.

- Assure that the consumer is the employer of record. This relieves the program of liability for the actions of the provider. Many programs that use independent providers require that the client and assistant sign a contract stating that the consumer is the employer.

- Train consumers in areas of interviewing and supervision.

- Clearly delineate the responsibilities of the consumer and the program.

- Have eligibility criteria stating that a client must be able and willing to be consumer-directed (i.e. be an employer or manage their own services, depending upon the

program design) in order to be enrolled in the program.

- Have a range of consumer direction within the program that allows for more support and help with management from a social worker or case manager, if needed.

- Require criminal history checks on providers.

- Provide workers' compensation as part of the benefits package for personal assistants (Concepts of Independence program).

Employment tax and benefit liability generally refers to paying minimum wage, reporting earnings to the IRS and withholding Social Security, Medicare, and unemployment taxes, and paying workers' compensation insurance. State programs are particularly wary of being deemed the employer of huge numbers of personal assistants when a consumer-directed approach to service delivery using independent providers is being considered, because of the high cost of state wages and benefits. In state programs that use agency providers, the assistant is clearly the employee of the home care agency.

Responsibility for employment tax and benefits depends in large part on the employer-employee relationship and the classification of the worker according to the Internal Revenue Code. Research in this area has revealed that the IRS generally considers personal assistants employees under the household/domestic service workers category, as opposed to self-employed independent contractors who would be responsible for their own taxes and benefits. (Flanagan, 1994; Sabatino & Litvak, 1995). Therefore, as employers of personal assistants, consumers are responsible for tax and benefits for their employees.

Employer obligations for those who employ domestic services/household workers differ in some ways from those of other employers. Sabatino & Litvak (1995) have summarized the obligations and exceptions that apply for those employing domestic/ household workers. These include:

- The obligation to withhold and submit federal income tax is not required of those employing domestic service workers in a private home (reporting of annual wages <u>is</u> required of the employer).

- Employers generally pay unemployment tax, the employer's share of FICA tax, and withhold and pay the employee's share. This is not required for domestic service in a private home if wages are less than $1000 per year (adjusted annually), and does not apply to family employees and workers under the age of 18.

- Minimum wage requirements do not apply to domestic service workers if wages are less than $1,000 per year (adjusted annually).

- The requirement to pay for workers' compensation insurance does not apply to domestic services/household workers in most states (although it *is* required in Ohio). In some states, a wage/hour threshold exists above

which workers' compensation insurance is required.

In the programs surveyed, tax and benefit liability was addressed in a number of ways. Programs stressed the importance of making clear that the consumer is the employer, relieving states of potentially exorbitant costs of providing benefits to thousands of personal assistants. Programs that used a fiscal intermediary model obtained official IRS Fiscal Intermediary Status which allows the program or contract agency to handle payroll and related withholding without assuming the other responsibilities related to being the employer of record.

The Concepts of Independence program in New York offers an extensive package of benefits for assistants, including medical and dental insurance as well as workers' compensation coverage; the program considers this benefits package one of their major successes. The Oregon Client-Employed Provider program, a huge state program with nearly 3,000 active independent providers, considered lack of benefits for assistants a major challenge for the program. Similarly, the majority of those interviewed mentioned low wages and a lack of benefits as critical issues in consumer-directed programs.

Even though 12 of the programs surveyed used client-employed assistants, only in the Maine, Ohio, and Kansas programs were all consumers responsible for all employer-related activities (reporting income to IRS and paying employer FICA and Medicare taxes). All others used some form of fiscal agent, whereby the program or a contract agency collected assistant time sheets, paid FICA, Medicare and sometimes unemployment taxes, and reported earnings to IRS. The Massachusetts Personal Assistance Services Program contact advised programs considering a move towards consumer direction to "deal with..... liability and tax withholding issues from the start."

Regulatory liability is another concern for consumer-directed programs. Federal and state regulations control the organizations and people allowed to provide certain health-related services. For example, Health Care Financing Association regulations set standards for Medicare and Medicaid-funded programs. Sabatino and Litvak (1995, p. 85) state that "For individual providers, a question of regulatory liability arises if they provide services that licensure or certification standards restrict to registered nurses, certified nurse assistants, home health aides, or some other defined group of health providers for which the state has established training, education or practice standards." As discussed earlier, state Nurse Practice Acts provide important guidelines for the licensure required to provide specific types of medical care. In interviews, representatives of the New York, Michigan, and Oregon programs stressed the importance of their state Nurse Practice Act which provided exemptions for certain types of providers and situations, as well as options for delegation of nursing tasks to personal assistants.

Cost

Researchers found that cost per hour for the independent provider model was almost half that of the agency models.

A desire to reduce program costs may be another motivation for considering a consumer-directed approach to home services. The World Institute on Disability compared several program models in terms of program cost and support for independent living. Researchers found that cost per hour for the independent provider model was almost half that of the agency models. The majority of this cost difference was explained by reduced administrative costs rather than lower wages and benefits for independent providers (Egley, 1994).

Although we have evidence that program costs are lower when independent providers are hired, trained and supervised by consumers, we know less about the cost of programs that offer a range of consumer-directed options, including fiscal and supportive intermediary services to those who desire this support. Flanagan (1994) warns that although vendor models in which the vendor agency assumes minimal functions (such as payroll) can be more cost-effective, if the vendor agency takes on multiple functions not previously paid for by the state or program (such as training or maintaining a registry of independent providers), this model could cost more than traditional models.

Although we did not collect detailed information about program costs, several respondents remarked that their programs (Maine, Wisconsin) offer the type of services clients want at reduced cost. In addition, in a recent study of direct pay and agency-based respite users in the California Caregiver Resource System, Feinberg and Whitlatch (1997) found that although there was no significant difference between the two groups in terms of monthly bill amounts, direct pay respite users received more hours of service each month at a significantly lower hourly cost.

Conclusions and Implications for Programs Serving Older Adults

The adoption of a consumer-directed approach to the delivery of home services for older adults presents planners and administrators with unique benefits and challenges. As the literature and the results of this study describe, consumer direction represents a significant philosophical and practical departure from the traditional medical or informal models under which long-term care services have previously been delivered. There are also issues of training, liability, and quality assurance that must be addressed.

However, as the literature and many of our respondents described, the results of using this approach can be quite beneficial for consumers and professional staff alike.

For consumers, this approach can mean the opportunity to regain control of their lives. It can allow them to choose the personal assistant who is best for them and may also afford them additional service hours and flexibility in terms of scheduling those hours. For professional staff, consumer direction can offer the chance to focus time and energy on clients who may require more case management. Consumer direction, especially the use of independent providers, may also provide administrators with ways of stretching service dollars (i.e. being able to provide existing clients with more services or being able to accommodate additional clients).

Findings and recommendations from the results of this study include:

- Models that include a range of options for consumer direction within programs appear to be best for home services for older adults. Using state funds to supplement Medicaid provides flexibility and wider range of options within programs.

- Training of professionals, assistants, and consumers and their families is an essential **early** step for programs moving toward a consumer-directed approach to serving disabled elders.

- Use of independent providers may result in better matches, increased client satisfaction, more control for consumers, and lower administrative cost to programs.

- ***However***, low wages and lack of benefits for personal assistants result in problems finding and keeping quality providers. The use of independent providers will not solve the recruitment and retention problem in long-term care.

Consumer direction is still in its infancy within the aging services world. As a consequence there is much need for future research in this area, including: options desired by older consumers in various situations; how to best assess consumers' desire and ability to self-direct; effects of consumer direction on agencies (including administrative burden and cost of service packages), and the optimal program structure to serve older adults.

When making the decision to establish a consumer-directed program or to introduce consumer direction into an already existing program, it is important to remember that consumer direction is not necessarily for everyone.

When making the decision to establish a consumer-directed program or to introduce consumer direction into an already existing program, it is important to remember that consumer direction is not necessarily for everyone. While many consumers may welcome the opportunity to be more involved in service management (and may, in fact, already be doing so), still others may not wish to assume the responsibility of directing and managing their services. However, where consumer direction is most valuable is in its emphasis on placing that choice where it most belongs -- in the hands of consumers themselves.

References

Atchley, R.C. (1996). Frontline workers in long-term care: Recruitment, retention, and training in an era of rapid growth. Oxford, OH: Scripps Gerontology Center.

Bass, S. (1996). Quandaries persist, but consumer choice calls for experimentation, education. Perspective on Aging, 25(4), 4-7.

Batavia, A.I., Dejong, G., & McKnew, L.B. (1991). Toward a national personal assistance program: The independent living model of long-term care for persons with disabilities. Journal of Health Politics, Policy, and Law, 16, 523-524.

Cameron, K. (1996, November). State demonstrations and initiatives in consumer choice and direction: Findings from the national survey of states. In D. L. Wagner (chair), Consumer-directed long-term care services. Symposium conducted at the annual meeting of the Gerontological Society of America, Washington D.C.

Cohen, E. S. (1992). What is independence? Generations, 16, 49-52.

Cohen, E. S. (1990). The elderly mystique: Impediment to advocacy and empowerment. Generations, 14 (supplement), 13-16.

Commonwealth Fund Commission on Elderly People Living Alone (1993). The importance of choice in home care programs: Maryland, Michigan, and Texas. New York: Commonwealth Fund.

Doty, P., Kasper, J., & Litvak, S. (1996). Consumer-directed models of personal care: Lessons from Medicaid. The Millbank Quarterly. 74(3), 377-409.

Doty, P., Kasper, J., Litvak, S., & Taylor, H. (1994). Consumer choice and the frontline worker. Generations, 18, 65-70.

Egley, L. (1994). New federal PC Option PAS funding rules: Summary. Berkeley: World Institute on Disability.

Eustis, N. N. & Fischer, L. R. (1992). Common needs, different solutions? Younger and older home care clients. Generations, 16, 17-22.

Eustis, N.N., Kane, R.A., & Fischer, L.R. (1993). Home care quality and the home care worker: Beyond quality assurance as usual. The Gerontologist, 33(1), 64-73.

Feinberg, L.F. & Whitlatch, C.J. (1997, March). Family caregivers and consumer choice: Options for in-home respite care. In L.F. Feinberg (moderator), State of the art: Research on consumer-directed care. Symposium conducted at the annual meeting of the American Society on Aging, Nashville, Tennessee.

Flanagan, S. (1994). Consumer-directed attendant services: How states address tax, legal and quality assurance issues. Cambridge: SysteMetrics.

Flanagan, S. A., Green, P. S., & Eustis, N. (1996, November). Facilitating consumer-directed personal assistance services (CD-PAS) through the use of intermediary service models: Eleven states' experiences. Paper presented at the annual meeting of the Gerontological Society of America, Washington, D.C.

Glickman, L. L., Brandt, K. J., & Caro, F. G. (1994). Self-direction in home care for older people: A consumer's perspective. Boston, MA: Gerontology Institute and Center, University of Massachusetts-Boston.

Kane, R. (1996, August). The quality conundrum in homecare. Aging Today, p. 7-8.

Kane, R.A. (1995) Quality, autonomy, and safety in home and community-based long-term care: Toward regulatory and quality assurance policy. University of Minnesota: National Long-Term Care Resource Center.

Kane, R.A., Kane, R.L., Illston, L.H., & Eustis, N.N. (1994). Perspectives on home care quality. Health Care Financing Review, 16 (1), 69-89.

Kapp, M.B. (1991). Improving choices regarding home care services: Legal impediments and empowerments. Saint Louis University Public Law Review, 10, 441-484.

Litvak, S. (1996, October). Supportive intermediaries. Presentation at the first annual Cash and Counseling Demonstration and Evaluation Meeting, Arlington, VA.

Litvak, S., Zukas, H., & Heumann, J. E. (1987). Attending to America - Personal assistance for independent living: A survey of attendant service programs in the United States for people of all ages with disabilities. Berkeley: World Institute on Disability.

Micco, A., Hamilton, A.C.S., Martin, M.J., & McEwan, K.L. (1995). Case manager attitudes toward client-cirected care. Journal of Case Management, 4, 95-101.

Nadesh, P. (1997, Winter). Symposium debates delegation issues. Consumer Choice News, 2.

National Institute on Consumer-Directed Long-Term Services. (1996). Principles of consumer-directed home and community-based services. Washington D.C.: The National Council on the Aging.

Sabatino, C. P. (1990). Lessons for enhancing consumer-directed approaches in home care. New York: The Commonwealth Fund.

Sabatino, C.P. & Litvak, S. (1995). Liability issues affecting consumer-directed personal assistance services: Report and recommendations. Berkeley: World Institute on Disability.

Sabatino, C. P. & Litvak, S. (1992). Consumer-directed home care: What makes it possible? Generations, 16, 53-58.

Scala, M. A., Mayberry, P. S., & Kunkel, S. R. (1996). Consumer-directed home care: Client profiles and service challenges. Journal of Case Management, 5, 91-98.

Seltzer, M.M. (1992). Training families to be case managers for elders with developmental disabilities. Generations, 16, 65-70.

Simon-Rusinowitz, L. (1996, November). Determining consumers' preferences for a cash option vs. traditional services: A three-part study to support the cash & counseling demonstration and evaluation. Paper presented at the annual meeting of the Gerontological Society of America, Washington, D.C.

Woodruff, L. & Applebaum, R. (1996). Assuring the quality of in-home supportive services: A consumer perspective. Journal of Aging Studies, 10 (2), 157-169.

*** *For a more comprehensive bibliography of literature on consumer direction, contact Marisa Scala at (513) 529-2914 or scalama@muohio.edu*

Appendix

Program Summary Descriptions

CAREGIVER RESOURCE CENTER SYSTEM RESPITE PROGRAM

Address: Family Caregiver Alliance[a]
425 Bush St., Suite 500
San Francisco, CA 94108

Phone: 415-434-3388
Contact: Lynn Friss Feinberg

Number consumers served (1994-95)[b]: 820[c]
% family consumers over age 65: 40
Ages served: 18 and older
Providers: Contract agencies
Independent providers (called the direct-pay model)

Budget (1994-95)[d]: $1.1 million
Funding: State funds
Consumer co-pay: Yes
Family as providers: Yes (no restrictions)

CONSUMER DIRECTION

Service Management Responsibilities:
2 different models of in-home respite service[e]:

Direct-pay model
Consumer: Recruit, interview, hire, schedule, train, pay, and fire workers; payroll and withholding taxes; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Agency model
Consumer: Choose agency (from those contracted by CRC system); assist with monitoring quality.
Contract agency: Recruit, interview, hire, schedule, train, pay, and fire workers; payroll and withholding taxes; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Training:
- No formal training on service management, but receive some information on recruiting, interviewing, screening, hiring, and firing respite assistants from staff.
- Consumers also receive information on respite services, community service options, coping skills, and brain impairments.

Highlights:
- Families are considered to be the case managers under this system.
- Families use vouchers to "pay" for respite services (whether under agency or direct-pay model).

- Families have flexibility in scheduling respite hours (e.g. may use a few hours a week or save up hours/service dollars for a long weekend).
- Families and assistants sign contract outlining their rights and responsibilities.
- Centers offer options such as respite camps or retreats for caregivers or patients.
- Families are also eligible to receive a range of other family support services (e.g. legal and financial consultations with attorneys, family consultations for care planning, individual and family counseling, psychoeducational groups).

Challenges:
- Availability of funding to provide respite services (currently 3000 families on waiting list for services).
- Currently considering time limits on services.

Successes:
- Development of new respite options (such as camps or retreats for caregivers or patients).

Advice:
- Consumer choice and options are only as good as the resources available.
- Consumers need to have enough information to make informed choices; the direct-pay model may not be for everyone.

---

[a] Family Caregiver Alliance is the lead agency in California's Caregiver Resource Center (CRC) system (established by the California Department of Mental Health), serving as the statewide resource consultant for the eleven regional non-profit centers designated as CRCs in the state of California.

[b] Under the CRC system, family members of brain-impaired adults (e.g. those with Alzheimer's Disease, stroke, Parkinson's Disease) are considered to be the consumers. 78% of the patient population cared for by family members are age 65 and older.

[c] Figures given in this section represent the respite program ONLY for the entire CRC system throughout the state of California.

[d] This is the direct cost of respite services. Excludes costs of staff time for arranging and monitoring respite services and for administrative costs. The total state appropriation for 1994-95 was $5.047 million.

[e] In addition to the 2 different models of in-home respite service, families can also choose adult day services, overnight respite in facilities for short-term respite care, or weekend respite options in retreat settings.

COALITION FOR INDEPENDENCE

Address: 4631 Orville, Suite 102
Kansas City, KS 66102

Phone: 913-287-0999
Contacts: Jenny Hatfield-Reed
Ed McInnis

Number consumers served (1995): 528
% consumers age 60 and older: N/A
Ages served: All ages

Providers: Contract agencies
Independent providers

Budget (1995): $175,000
Funding: Medicaid waiver
Fee-for-service contracts
Grants
Consumer co-pay: Yes
Family as providers: Yes

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Interview, hire, schedule, train, and fire assistants; payroll and withholding taxes; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Program: Recruit assistants; provide training for assistants and consumers; conflict resolution; monitor quality.

Contract agency: May also provide training for assistants.

Training:

- Training for consumers includes: how to be an employer, service management issues (recruiting, interviewing, training, payroll and taxes, etc.), consumer and assistant rights, self-advocacy; problem-solving, quality monitoring; also includes a video on self-advocacy and a manual for training assistants.
- Program provides orientation/training for assistants, which includes respect for consumers and consumer choice.
- Agencies also train assistants as to basic home services skills.

Highlights:

- Extensive training programs for consumers and assistants.
- Liability insurance is written into agreements with consumers.
- Program maintains registry list of approximately 200 assistants, half of whom are available for work.
- Program received national grant to provide training to consumers.

Challenges:

- Tempering consumer choice with consumer responsibility.
- Volume of calls from people needing services.

Successes:

- 90% of assistants are still with the same consumers after 3 months.
- 50% of consumers would be institutionalized if not for these personal assistance services.
- 30% of consumers are able to stay employed because of these services.

Advice:

- Programs must set limits in terms of services and responsibilities and stick to them.
- Cannot expect consumer to self-direct without giving them training; programs must train both consumers and assistants.

CONCEPTS OF INDEPENDENCE

Address: 120 Wall St., Suite 1010
New York, NY 10005-3902

Phone: 212-293-9999
Contacts: Ed Litcher
Maria Arias

Number consumers served (1995): 418
% consumers over age 65: 21.3
Ages served: 18 and older

Providers: Independent providers

Budget (1995): $18.3 million
Funding: Medicaid PC Option
Consumer co-pay: Yes
(if income above Medicaid level)
Family as providers: Yes
(if not living with consumer; excludes spouse, parents, and children)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Program: Handle time sheets; payroll, taxes, and benefits; monitor quality; provides assistance with recruitment of assistants.

Training:

- No formal training for consumers.
- Manual for consumers (*The Consumer Directed Personal Assistance Program Guide*).

Highlights:

- Board of Directors (which hires program staff) consists solely of program consumers.
- Consumers and assistants sign an "Employment/Wage Agreement" outlining their respective responsibilities.
- Program provides Recruitment Assistance Services which include the following:
    1. Hotline - program maintains a tape-recorded listing of the names and addresses of consumers looking for personal assistants (includes job descriptions). Persons looking for personal assistance work call the hotline and then call Consumers directly to arrange interviews.
    2. Fax Search - a copy of the hotline information is faxed to 40 free employment services. Employment services then contact consumers directly if they know of someone who may fit consumer job criteria.

3. Network List - the program maintains a list of former personal assistants (including names, addresses, and desired schedule) who have worked 500 hours without a negative evaluation. This list is sent to consumers every 2 weeks. Consumers then contact assistants directly.

- Extensive benefits package for assistants, including medical, dental, and prescription plans.

Challenges:
- Getting the modification to the Nurse Practice Act passed.
- Trying to keep program budget expanding.
- Keeping lines of authority and responsibility clear.
- Keeping program policy close to original intent (to permit self-directed consumers to remain independent in their own homes by allowing them to self-manage personal assistance services).

Successes:
- Going from 4 to 457 consumers during program history.
- Getting the modification to the Nurse Practice Act passed.
- Being recognized by the community as a benchmark consumer-directed personal assistance program.
- Developing Recruitment Assistance Services.
- Benefits program for assistants.

Advice:
- Need to keep lines of authority clean -- have clear responsibilities for consumers and for the program. To maintain a positive liability position, programs cannot take on responsibility that would interfere or overlap with consumer authority over their home services program.
- Consumer rights and responsibilities must be in balance.

ILLINOIS HOME SERVICES PROGRAM

Address: Illinois Dept. of Rehabilitation Services
Division of Home Services
623 E. Adams
P.O. Box 19509
Springfield, IL 62794

Phone: 217-782-2722
Contact: Randall Tomlin

Number consumers served (1995): 16,182
% consumers age 60 and older: 13% (all received services prior to age 60)
Ages served: All ages
Providers: Contract agencies
Independent providers

Budget (1995): $98.4 million
Funding: Medicaid Waiver
State funds
Consumer co-pay: Yes
Family as providers: Yes (except for spouse, parent, minor child)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer-employed provider model

Consumer: Recruit, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; time sheets; conflict resolution; share responsibility for monitoring quality.

Program: Payroll and withholding (pays assistant); quality monitoring.

Agency model

Consumer: Selects agency; involved in care plan development.

Program: Case manager contacts provider agency, agency coordinates services.

Training:

- Consumers may receive training from independent living centers or rehabilitation centers; no formal training from program.
- Consumers who employ assistants receive booklet on managing personal assistants.

Highlights:

- Over 72% of consumers employ their assistants.
- Home Services Program pays consumer-employed providers; with this model, customer and provider sign agreement that customer is employer.

Challenges:

- Low pay for assistants is obstacle to finding reliable assistants.
- Large system to process pay for up to 18,000 personal assistants.

Successes:

- Growth of the program; had 5,000 consumers in 1987 and expect 16,600 in 1996.

Advice:

- Try to simplify process with fiscal intermediary or vouchers.
- Be aware that problems with assistants are not limited to consumer-employed models.

MAINE CONSUMER-DIRECTED PERSONAL CARE ASSISTANCE SERVICES

Address: Office of Rehabilitation Services
Division of Vocational Rehabilitation
35 Anthony Avenue
Augusta, ME 04333-0150

Phone: 207-624-5309
Contact: Patton Williams

Number consumers served (1995): 125
% consumers age 60 and older: Approximately 10%
Ages served: 18 and older
Providers: Independent providers

Budget (1995): $1.8 million
Funding: State funds
Consumer co-pay: Yes
Family as providers: Yes

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; payroll and withholding taxes; conflict resolution; monitor quality.

Contract agency: An independent living center (ILC) provides consumer instruction. Receives time sheets, pays consumers, maintains waiting list, conducts initial evaluation and annual reevaluation, provides minimal case management.

Training:
- Consumers receive training about employing and managing assistants through the ILC.
- Consumers train assistants.

Highlights:
- An ILC is contracted to implement the program.
- All consumers must be capable of being an employer.
- Consumers receive the funds, do withholding, and pay assistants.
- Any family member may be hired as an assistant.
- Innovative formula for determining consumer co-pay considers income, assets, and household expenses.

Challenges:
- Political challenges; traditional home care people think they are providing too much service.
- Not enough funding to increase hourly wage for assistants.
- Difficulty recruiting assistants.
- No increase in funding to allow growth.

Successes:

- This is a well-constructed program with low administrative costs.
- Consumers love it -- makes a big difference in their lives.
- Provides consumers with management skills which can be useful to other parts of their lives.

Advice

- Look at a different provider network (one not providing traditional home care services).
- Don't take one step toward consumer direction until you have an advisory group of disabled consumers. Have a consumer consultant who understands consumer-directed services.
- Make sure the effort is staffed by someone committed to a consumer-directed approach.

MASSACHUSETTS PERSONAL CARE ASSISTANCE PROGRAM

Address: Massachusetts Rehabilitation Commission
27-43 Wormwood St.
Boston, MA 02210

Phone: 617-727-4828
Contact: Kevin Farrell

Number consumers served (1995): 50
% consumers age 60 and older: 5 or less
Ages served: 18 and older
Providers: Contract agencies
Independent providers

Budget (1995): $950,000
Funding: State funds
Consumer co-pay: Yes
Family as providers: Yes
(excluding spouse, parents, and children)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, pay, and fire workers; submit time sheets to ILCs; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Assistants: Pay quarterly taxes on earnings.

Contract agency (Independent Living Centers): Process time sheets and checks.

Training:

- Local ILCs offer training modules on: consumer rights; "getting the most out of your assistant"; service management issues (recruiting, interviewing, screening, hiring, training, firing assistants); payroll and tax-related paperwork; quality monitoring.

Highlights:

- Program has not accepted new consumers since 1988 (when a program called Commonhealth which provides Medicaid cards and personal assistance services to younger persons with disabilities who work was established).
- Consumers must be employed and able to manage services in order to qualify for the program.
- Assistants are considered to be self-employed.
- Program is currently considering using an outside agency as a fiscal intermediary in order to handle payroll and taxes.

Challenges:

- Availability of assistants, particularly in rural and high crime areas.
- Assuring that assistants submit their quarterly taxes to federal and state governments, especially considering the low wages paid to assistants.
- Training of assistants.

Successes:
- With these services, consumers are able to work and raise families.
- Program allows people to work without losing benefits and services.

Advice:
- Program looking to move toward consumer direction need to deal with state and federal laws, liability and tax withholding issues from the start.
- Programs need to build in mechanisms to cover consumers and assistants in terms of liability.

MICHIGAN HOME HELP SERVICE

Address: Independent Living Services Division
Family Independence Agency
Office of Adult Services
P.O. Box 30037
Lansing, MI 48909

Phone: 517-373-8535
Contact: Ralph Young

Number consumers served (1995): 31,169
% consumers age 60 and older: 50%
Ages Served: All ages
Providers: Contract agencies
Independent providers

Budget (1995): $113.6 million
Funding: Medicaid PC Option
Consumer co-pay: Yes
Family as providers: Yes (not spouse)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, and fire assistants (in cases of system abuse program fires); coordinate services provided by multiple assistants; time sheets; share responsibility for conflict resolution & monitoring quality.

Program: Payroll and withholding (writes two-party check to consumer and provider) share responsibility for conflict resolution & monitoring quality.

Training:

- Program provides no formal training; consumers and assistants receive training from home health agency, hospital, nursing home and independent living center staff. Assistants are also trained by family members. About 30% of providers report formal training from home health, hospital or nursing home programs before working for consumers.

Highlights:

- Home Help program uses both agency and consumer-employed providers; 94% of providers are consumer employed.
- All consumers have a caseworker.

Challenges:

- Getting program staff and county directors to buy into the independent living philosophy. Many staff members have been trained to protect elderly consumers.

Successes:

- Consumers like it.
- Program scored high on consumer empowerment in survey by Commonwealth Commission.

Advice:

- Avoid the medical model; don't attempt to adapt home health model for home care.
- Give consumers control.

OHIO PERSONAL CARE ASSISTANCE PROGRAM

Address: Ohio Rehabilitation Services Commission
400 E. Campus View Blvd., SWSC
Columbus, OH 43235-4604

Phone: 614-438-1272
Contact: Zelpha Rinehart

Number consumers served (1995): 272
% consumers over age 60: 7
Ages served: 18 and older

Providers: Independent providers

Budget (1995): $2.1 million
Funding: Vocational rehab. funds
State funds
Consumer co-pay: Yes (sliding scale)
Family as providers: Yes
(if not living with consumer; excluding spouse, parents, children, siblings, grandparents, grandchildren)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, and fire assistants; payroll and withholding taxes; coordinate services provided by multiple assistants; conflict resolution; monitor quality.

Contract agency (Independent Living Centers): Assist with recruitment and training.

Training:

- No formal training, although local ILCs may provide some training.
- Tax guide for consumers.

Highlights:

- Independent providers are considered to be domestic help.
- In order to qualify for program, consumers must be capable of supervising assistants.
- Program has 4 priority area in terms of eligibility for services:
  1. those employed full- or part-time.
  2. those seeking employment.
  3. those receiving employment training.
  4. those who require personal assistance services to live independently.
- Currently piloting program in which consumers use immediate family members as assistants.

Challenges:

- Locating quality assistants (at low wages), especially in rural areas.

Successes:

- With these services, consumers are able to maintain jobs.
- Program was able to get funding for personal care assistance in Ohio.
- Keeping people out of nursing homes (50% of consumers would be in institutions if not for this program).
- Improved quality of life for many consumers.

Advice:

- Home service programs need to move more toward consumer direction, and have fewer restrictions (less of a medical model).
- Just because a person is older does not mean they do not know what they want or need in terms of services.
- Programs looking to employ more consumer direction need to be aware of potential abuse situations; providing consumers with training as to interviewing skills can help with this issue.

OREGON CLIENT-EMPLOYED PROVIDER PROGRAM

Address: Senior and Disabled Services Division
Policy and Program Development
500 Summer St. NE
Salem, OR 97310-1015

Phone: 503-945-6394
Contact: Susan Dietsche

Number consumers served (1995): 8000
% consumers age 60 and older: 50
Ages served: 18 and older

Providers: Independent providers

Budget (1995): $45 million
Funding: Medicaid waiver
Consumer co-pay: Yes
(if income is above 300% SSI)
Family as providers: Yes
(Family members over 18, excluding spouses)

CONSUMER DIRECTION

Service Management Responsibilities:

Consumer: Recruit, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; monitor quality.

Program: Provide lists of potential assistants; payroll and withholding taxes; assist with conflict resolution.

Training:

- Manual for consumers.
- Currently piloting training program for consumers.
- Companion training program for assistants (how to be a consumer-employed provider).
- Basic skills training for assistants from RNs.

Highlights:

- Program was established in the 1970s.
- 50% of the home services in the state of Oregon is provided through this program.
- Program provides case management, depending on the needs and skills of consumers.
- Case managers assure that providers can perform services.
- Program serves as fiscal intermediary for consumers.

Challenges:

- Low pay and no benefits for assistants.
- Sometimes consumers may choose an assistant whom case managers do not believe is qualified.

Successes:

- Have found that this is the kind of help that people with disabilities want.

Advice:

- Trust the consumers.
- Provide support so that consumers can manage their own services.

PENNSYLVANIA ATTENDANT CARE CONSUMER-DIRECTED PROGRAM

Address: Pennsylvania Department of Aging
Division of Community Services
400 Market St.
Harrisburg, PA 17101-2301

Phone: 717-783-6007
Contact: Rocco Claroni

Number consumers served (1995): 44
% consumers age 60 and older: 100
(all previously received services under Dept. of Public Welfare Attendant Care program)
Providers: Contract agencies
Independent providers

Budget (1995): $250,000
Funding: State funds
Consumer co-pay: Yes

Family as providers: No

CONSUMER DIRECTION

Service Management Responsibilities:
3 different models of service:

Consumer model
Consumer: Recruit, interview, hire, schedule, train, and fire workers; coordinate services provided by multiple assistants; payroll and withholding taxes; conflict resolution; monitor quality.

Agency model
Consumer: Interview workers; monitor quality.
Contract agency: Recruit, hire, schedule, train, and fire workers; coordinate services provided by multiple assistants; payroll and withholding taxes; conflict resolution; monitor quality.

Combination model (fiscal intermediary)
Consumer: Recruit, interview, hire, schedule, train, and fire workers; coordinate services provided by multiple assistants; conflict resolution; monitor quality.
Contract agencies: Payroll and withholding taxes, and other consumer responsibilities (listed above) that the consumer does not wish to handle.

Training:
- Consumers receive training under Department of Public Welfare program guidelines.
- Assistants receive training under Department of Public Welfare program guidelines.

Highlights:

- This is an extension of the Department of Public Welfare Attendant Care Program (for those under age 60). Prior to the establishment of this program in 1995, consumers who turned 60 were forced to change over to the Department of Aging's home services program through Area Agencies on Aging (AAAs), which employed different providers and often provided fewer hours.
- Consumers must be mentally alert and capable of managing their own services.
- Consumers must have a need for basic (personal care) services before they can receive ancillary services.
- In 1996, Department of Aging established a Personal Assistance Services Program which uses a similar model to provide services to other AAA consumers.

Successes:

- No disruption of services when consumers turn 60; continuity of services and assistants.

TEXAS CLIENT-MANAGED ATTENDANT SERVICES

Address: Texas Department of Human Services
Community Care (W521)
P.O. Box 149030
Austin, TX 78714-9030

Phone: 512-438-3136
Contact: German Valtierra

Number consumers served (1995): Approx. 550
% consumers age 60 and older: 50%
Ages Served: 18 and older

Providers: Contract agencies (consumer may recruit assistants to go through contract agency)

Budget (1995): $5.4 million
Funding: State funds
Social Services Block Grant
Consumer co-pay: Yes
Family as providers: Yes (first degree relatives for start-up or emergency backup only)

CONSUMER DIRECTION

Service Management Responsibilities:
Consumer may choose 1) to receive funds directly; or 2) for contract agency to pay assistant.

Consumer: Recruit (optional), interview, select, schedule, train, and dismiss assistants; coordinate services provided by multiple assistants; time sheets; payroll and withholding taxes (if consumer selects option #1 above); conflict resolution; monitor quality.

Contract agency: Recruit; pay consumer or assistant; case management; assessment/reassessment; orientation for assistants; maintain pool of assistants; criminal history checks on assistants.

Program: Monitor quality.

Training:
- Contract agency provides orientation for assistants and trains consumer on managing their services.

Highlights:
- Contract agencies are primarily existing home care agencies. Two operate with independent living philosophies, and one is a public (city) entity.
- Consumer has choice of receiving funds and paying assistant or having agency pay assistant.
- Consumers are required to interview at least two assistants before selecting.
- Considering a program change toward fiscal intermediary model using voucher system.

Challenges:

- Provider agencies have almost all had previous contracts to provide service under other, non-consumer-managed programs. It is difficult for some agency professionals to change their thinking and ways of providing service. They receive training to make clear the roles of the provider agency and the consumer.
- Lack of funding to add consumers; program has a waiting list.

Successes:

- People living independently because of this program.
- The program was consumer originated and remains under the constant scrutiny of a consumer watchdog taskforce.

Advice:

- Contract with those who have not previously provided non consumer-directed services.
- Consult with an advocacy group for persons with disabilities.

VERMONT ATTENDANT SERVICES PROGRAM

Address: Agency of Human Services
Department of Aging & Disabilities
Advocacy and Independent Living Division
103 S. Main Street
Waterbury VT 05671-2301

Phone: 802-241-2400
Contact: Michael Meunier

Number consumers served (1995): approx. 325
% consumers age 60 and older: 48%
Ages served: 18 and older
Providers: Independent providers

Budget (1995): $1.8 million
Funding: State funds
Consumer co-pay: Yes (may supplement hourly wage for assistants)
Family as providers: Yes

CONSUMER DIRECTION

Service Management Responsibilities:
Consumer: Recruit, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; time sheets; conflict resolution.
Program: Payroll and withholding (pay assistant); monitoring quality; criminal history/abuse check.

Training:
- Currently no formal consumer training (developing a manual for consumers); no formal training for assistants.

Highlights:
- Eligibility committee for the program is composed of program participants which reviews each application after assessment, and authorizes services hours/expenditures for participants.
- About one-half of assistants in this program are family members.

Challenges:
- Finding back-up assistants.
- Funding; program has a waiting list of 180 people.

Successes:
- Keeping the program going.

Advice:
- Offering choice and control to consumers is rewarding.

WASHINGTON MEDICAID PERSONAL CARE PROGRAM

Address: Home and Community Services Division
Department of Social and Health Services
P.O. Box 45600
Olympia, WA 98504-5600

Phone: 360-493-2500
Contact: Lois Wusterbarth

Number consumers served (1995): 8,000 (in-home)
% consumers age 60 and older: 68%
Ages served: All ages

Budget (1995): $73,733,000
Funding: Medicaid PC Option
Client co-pay: No

Providers: Contract agencies
Independent providers

Family as providers: Yes (other than spouse, responsible parent, minor child)

CONSUMER DIRECTION

Service Management Responsibilities:

Client: Select qualified provider, interview, hire, schedule, train, and fire assistants; coordinate services provided by multiple assistants; time sheets; conflict resolution; monitor quality.

Program: Payroll and withholding taxes (pays provider); training assistant; quality monitoring; criminal background check, assessment, annual reassessment.

Training:
- No formal training for consumers, but support available from social workers.
- Just implementing training for all employed assistants.

Highlights:
- New training program for providers includes 22 hour initial course and annual 10 hour refresher; assistants are paid during this training.
- In 1995, approximately 40% of consumers used independent providers.
- Consumers in the program may be more or less involved in management of services by having more or less case management.

Challenges:
- Agency workers are not available during certain hours.
- Recruiting and retaining good assistants.
- Occasional problems with difficult consumers or assistants who are relatives.

Successes
- Program is growing.
- Decline in state nursing home population.

Advice
- Hold community meetings.
- Hear from people in independent living, nursing, aging fields.

WISCONSIN COMMUNITY OPTIONS PROGRAM (COP)

Address: Bureau of Long Term Support
Wisconsin Dept. of Health & Family Services
P.O. Box 7851
1 W. Wilson Street
Madison, WI 53707

Phone: 608-267-9091
Contact: John Lorimer

Number clients served (1995): 15,103
% consumers 65 and older: 61%
Ages Served: 18 and older

Providers: Contract agencies
Independent providers

Budget (1995): $104.8 million
Funding: Medicaid waiver
State funds
Client co-pay: Yes
Family as providers: Yes (Medicaid restricts spouse, responsible parent, or minor children)

CONSUMER DIRECTION

Service Management Responsibilities:
Model and mix of options vary by county. About 10% of counties use agency providers only. Approximately one-third use agency providers but allow independent providers on case-by-case basis. Several counties contract with agents as fiscal intermediaries. It is possible to pay consumer directly in some counties, using state funds.

Training:
- County agency determines consumer's ability for consumer direction and provides training if needed.
- ILCs offer training on how to be an employer.
- Consumers must find training for independent providers.

Highlights:
- This is actually two programs, COP and COP Waiver, the first funded by state revenue and the second by Medicaid waiver. With state funds, options exist for paying consumers directly, and funding family providers and services generally not covered by Medicaid.
- Although program stresses consumer choice and autonomy, degree of choice varies by county.
- In counties with agency-only structure, consumers have choice of agency and if possible, interview more than one assistant.

Challenges:
- Convincing counties that client-employed approach will not lead to chaos and lawsuits.
- Provider recruitment and retention.

Successes:
- Consumer satisfaction.
- Better consumer/provider matches.
- Reduced cost.

Advice:
- Recommends consumer-directed approach to create choice and put customer in control.
- Need state-funded program to supplement Medicaid Waivers.