

THE  
MYTHS AND  
REALITIES  
OF  
CONSUMER-DIRECTED  
SERVICES  
FOR OLDER PERSONS

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and  
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# Who We Are

“Promoting Consumer Direction in the Aging Network” is a national initiative of the National Association of State Units on Aging and The National Council on the Aging, funded by the Robert Wood Johnson Foundation. This three-year project will develop a series of white papers, convene a national invitational conference, develop a database of consumer-directed programs for older persons, identify promising practices, and produce a newsletter. Please visit our Web site at [www.consumerdirection.org](http://www.consumerdirection.org).



The National Council on the Aging is the nation's first national, nonprofit group of people and organizations dedicated to promoting the dignity, independence, well-being, and contributions of older people. Founded in 1950, NCOA helps community organizations to enhance the lives of older persons through research, training, leadership and advocacy. Over the years, NCOA has helped develop Meals-on-Wheels, Foster Grandparents, the BenefitsCheckUp and dozens of other innovative programs for older Americans. NCOA's members include senior centers, area agencies on aging, adult day services, faith congregations, senior housing, health centers, employment services, senior housing, health centers, employment services, and consumer organizations.



The National Association of State Units on Aging is a private, nonprofit national organization whose membership is comprised of the nation's 57 state and territorial government agencies on aging designated by the governor and state legislatures as the focal point for issues related to older persons. The mission of the Association is to advance social, health, and economic policies responsive to the needs of a diverse aging population and to enhance the capacity of its membership to promote the rights, dignity and independence of, and expand opportunities and resources for, current and future generations of older persons, adults with disabilities and their families. NASUA is the articulating force at the national level through which the state agencies on aging join together to promote social policy in the public and private sectors responsive to the challenges and opportunities of an aging America. The Association's priority aging and disability policy and program areas include health and long-term care; elder rights; consumer information, education and assistance; and workforce development.

# Acknowledgements

The emergence of consumer-directed services in the United States is directly attributable to the courageous leadership of younger persons with disabilities who refused to accept the lack of choices they were given about where to receive care and from whom. Too few older persons and their advocates are aware of the great debt we all owe to Ed Roberts, Judy Heumanns, Hale Zukas, Bob Williams, Diane Coleman and their colleagues who demanded more autonomy and control for people with disability as a matter of civil rights, human dignity and common sense.

In the mid-1990's, private philanthropy and the federal government began to fund a series of research and demonstration programs to help develop the field of consumer direction. The Retirement Research Foundation (with leadership from Marilyn Hennessey, Brian Hofland and Monsignor Charles Fahey) funded an "Autonomy in Long-Term Care Initiative" which helped lay the intellectual and philosophical groundwork for increased consumer direction. The Robert Wood Johnson Foundation (with leadership from Jim Knickman and Rosemary Gibson) funded a variety of national efforts including the Cash & Counseling Demonstration Program, Independent Choices (a series of 13 research and demonstration projects), and Self-Determination Initiative (for people with mental retardation and developmental disabilities.) The Office of the U.S. Assistant Secretary for Planning and Evaluation (with leadership from Robyn Stone, Nancy Eustis, Bob Williams and Pam Doty) deserves special credit for bringing the federal government as a key partner in many of these programs.

The "Cash and Counseling" demonstration program (a term coined by the late Arthur Flemming) was one of the most ambitious and sophisticated long-term care experiments in U.S. history. Innovative leaders in three states (New Jersey, Arkansas and Florida) conducted a randomized-controlled trial of what happens when consumers are given supplemental income to spend as they need instead of a set of services prescribed by a case manager. Special kudos goes to Kevin Mahoney for his wise leadership and extraordinarily patient nurturing of this important social experiment.

The Independent Choices Program, also funded by the Robert Wood Johnson Foundation, supported thirteen different research and demonstration projects designed to push the envelope on various aspects of consumer-directed long-term care. We salute each of the following pioneers for their contributions to the growth of consumer-directed services:

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Ted Benjamin of UCSF has made many contributions to this field both through his outstanding evaluation of the California IHHS demonstration program and through his efforts to study the work of the Independent Choices grantees. We also owe a great debt to Tom Nerney and his colleagues, who practically invented and then so ably led the Self-Determination movement that revolutionized the delivery of services to persons with mental retardation and developmental disabilities.

The National Council on the Aging (NCOA) had the privilege of administering the Independent Choices Program. I would like to especially acknowledge the leadership and contributions of my colleagues in developing and managing this effort, Kathleen Cameron and Linda Velgouse. Marie Squillace gets the credit for synthesizing the findings from these projects into this publication.

In June 2001 the Office of the Assistant Secretary for Planning and Evaluation (U.S. Department of Health and Human Services) sponsored the “Independent Choices: National Symposium on Consumer Direction and Self-Determination” in Washington, DC. Several excerpts and examples in this publication have been drawn from that conference which brought together practitioners and researchers from all parts of the country to exchange ideas and experiences. It was a landmark event in the development of consumer-directed care.

NCOA salutes these leaders for their important contributions to the development of consumer-directed services in the United States. Current and future generations of older persons will benefit from their pioneering efforts.

James P. Firman

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# Introduction

Our society is facing a major challenge: how to provide compassionate and cost-effective assistance to the burgeoning numbers of people with long-term disabilities. One approach to improving long-term services is called “consumer direction.” Consumer direction is based on a belief that people with disabilities should be empowered to have greater autonomy and control over what services they receive, and from whom, when and where.

In the past decade, there was an unprecedented number and variety of groundbreaking research and demonstration projects designed to test new models of consumer choice and consumer direction in home and community-based services. These initiatives include the Cash & Counseling Demonstration program, the Independent Choices program, the Self-Determination program and the California IHHS demonstration project; they were funded by The Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services (Office of the Assistant Secretary for Planning and Evaluation) and the Centers for Medicare and Medicaid Services. The Acknowledgements Section salutes many of the extraordinary individuals who have contributed to this new knowledge.

This publication summarizes and synthesizes some of the most important things that these research and demonstration programs have learned about consumer direction, especially as they apply to older persons. Our goal is to provide leaders and practitioners in the field of aging with a common framework of understanding for our next challenge: To build upon current knowledge and to make “consumer direction” an integral part of the options available for all older persons who may need long-term care.

# Myths and Realities

*Consumer direction<sup>1</sup> is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. The unifying force in the range of consumer-directed and consumer choice models is 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.<sup>2</sup>*

**Myth 1** Consumer Direction offers no great benefits for persons who need long-term care.

**Reality** Consumer Direction can provide substantial benefits for persons of all ages, cultures and backgrounds. The values articulated by consumers are clear: Rights, choice, freedom, respect, independence, empowerment, responsibility, and dignity.

Older people who have participated in consumer-directed programs are clear and articulate about the benefits they derive from them. Selected examples from Medicaid beneficiaries and their family experiences illustrate how consumer-directed programs can help individuals who need long-term care. Consumer-directed services:

Individualize service plans so goods and services are better suited to meet a particular individual's or family's needs and circumstances.

Lisa Mangieri, "Personal Preferences" (Cash and Counseling Demonstration) consumer in New Jersey, explains how receiving the experimental cash allowance and being able to purchase the goods and services she thinks will best meet her needs, including being able to employ her own aides, has changed her life for the better. "My disability is limiting physically, yet with this demonstration project I have become a truly empowered person," she says. Most able-bodied individuals cannot understand the importance of having choice and control in their daily lives. Waking up and facing daily decisions of what foods to eat, what clothes to wear, and whether I should shower or take a bath are freedoms that are inherent in most lives. With the Personal Preference Program I have been granted total choice and control over my personal care needs. I think this program is great. Every consumer needs consumer direction."

# Myths and Realities

## Allow for more creative use of funds.

Tammy Svihla, another New Jersey “Personal Preferences” program participant explains: “I’ve been able to purchase certain needed equipment around the house... it has allowed for not necessarily bigger things, but for me, more important things that Medicare or Medicaid do not pay for...different things that I tend to think of as personal care needs. With my MS I needed a couch because my couch is very soft and is sunken in when I sit down. So, I can’t get up out of it. Instead, I’m going to get a lift chair, which is actually a lazy-boy that lifts you out. This is more logical.”

## Help people obtain consistent care.

Alan Garry, a Florida caregiver for his father with Alzheimer’s disease, explains the burdens his family faces without choice of service delivery: “My dad has been living with my wife and I. He has severe Alzheimer’s. We got an agency to come in and take care of him...[but] a problem we faced is when the agency calls up in the morning to cancel out. This gives me no respite at all because you have to be there 24/7 for an Alzheimer’s patient. When they call up and say ‘sorry we won’t be there today’ there is nothing you can do about it...we had no other choices until my coordinator told us about this new program.”

## Help people to stay in, or return to, the community.

Lillian Brannon, an older consumer participating in Arkansas’ “Independent Choices” (Cash and Counseling Demonstration) program shared her views on whether elders would want or be able to self-direct: “...I’m 89 and I live alone. Without this program I would be in trouble. I’ve been in a nursing home four times and could not take it. I spent more days than I should have spent there and the longer I stayed, the worse I got...I have four aides that work for me. When one can’t be here the other one comes. I have no problem getting help because they’re here when I call... ‘Independent Choices’ has really changed my life so much. It has really helped me to live more independently than I ever have...I would not trade it for anything.”<sup>3</sup>

## Provide increased flexibility.

Janice Maddox, a 74-year-old widow, has diabetes and glaucoma and significant personal care needs. For five years she used an agency that contracted with Medicaid to supply aides. Then her daughter read about Independent Choices (the Arkansas Cash and Counseling Demonstration) and became the representative decisionmaker for her mother in this program. The daughter says “There’s just something about having family look after her. She doesn’t get nearly as many allergic reactions or bed sores now; and I think that’s because when it’s your own you’re looking after, you pay more attention.” Mother and daughter appreciate the flexibility of the cash allowance. They have used it to pay a granddaughter to come for two hours daily and a grandson to do chores around the house and yard. And by careful use of the allowance, they were able to pay for new dentures for Mrs. Maddox.<sup>4</sup>

# Myths and Realities

**Myth 2** Consumer-directed services are not appropriate for elderly persons with disabilities or for individuals with cognitive impairments.

**Reality** Studies have shown that many elderly individuals with disabilities and persons with cognitive impairments can express daily preferences for care and can benefit from consumer-directed programs.

## Elderly Individuals with Disabilities

As of December 2000, 77% of California's In-Home Supportive Services (IHSS) program participants were over age 65. The IHSS program serves approximately 200,000 persons with disabilities and has been allowing low-income persons with disabilities to hire/fire, train, schedule and supervise individual providers for over 30 years. Ninety-six percent of clients (elderly and non-elderly) hire independent providers to meet their personal care needs.<sup>5</sup>

Interest in self-direction among older adults, however, is not limited to the largest and oldest consumer-directed programs in the country. The ultimate way to maximize choice, for consumers of any age, is to ensure that individuals have the flexibility to use available funds to purchase the goods and services they prefer. Preliminary findings from a national social experiment testing a consumer-directed model (the Cash and Counseling Demonstration and Evaluation) reveal that 72% of program participants in Arkansas are over age 65. In this program, a cash allowance is provided to recipients of Medicaid personal care services or home and community-based services. The funds can be used to hire a worker or to purchase goods and services to meet personal assistance needs. Counselors help to develop an expenditure plan, offer skill training, and monitor consumer progress. Early results suggest that this program is successfully changing the way in which elderly individuals and persons with disabilities receive personal assistance services in Arkansas, New Jersey, and Florida.<sup>6</sup>

## Cognitively Impaired Individuals

According to a study conducted by the Family Caregiver Alliance in San Francisco, persons with early to moderate cognitive impairment (e.g. Alzheimer's, Parkinson's, traumatic brain injury) possess the capacity to express daily preferences for care and be vocal in sharing their values and preferences about care. Many request that, when they get to a more advanced stage of the disease and can no longer express themselves, that family members act as their representatives or surrogate decision-makers.<sup>7</sup> A report issued by the University of Maryland, Center

# Myths and Realities

on Aging adds evidence that not only persons with cognitive impairments, but also persons with mild to severe disabilities are capable of expressing their preferences for everyday personal care.<sup>8</sup> In addition, some family members report that consumer direction for persons with significant cognitive disabilities is possible through a micro board (a circle of friends and other close associates who know the consumer very well and can interpret his or her non-verbal expressions.) Family members also report that consumer-directed service options, for persons with dementia, have allowed for greater control in monitoring and handling homecare arrangements.<sup>9</sup>

## Surrogate or Proxy Involvement

In some instances, elderly individuals may choose to designate a surrogate or proxy representative to assist them in making decisions about their service options. In the Arkansas Cash and Counseling program, 41% of the elderly participants designated a surrogate (usually a family member). Some of these choosing a surrogate actually needed help at that time but others were looking ahead to the day when they might not feel able to make all the required decisions by themselves. Family members are often affected by decisions concerning the older relative so it is appropriate for them to be involved in making care-related arrangements.<sup>10</sup>

**Younger persons wish to direct their own services. Older adults are not interested in consumer direction.**

**Myth 3**

**Many older people, just like younger adults, are interested in consumer direction and most of them have clear preferences about personal care, daily activities, and where they want to live.**

**Reality**

A report issued by the U.S. Department of Health and Human Services and the University of California, Los Angeles suggests that age is not an inevitable barrier to self-direction. When consumers' experiences and outcomes were compared in client-directed and professional management methods of service delivery, on most outcomes and most statements of preferences, consumer direction worked for older people just as well as for younger people. The consumer-directed method outperformed the professional agency method within three broadly defined areas: satisfaction with services, empowerment, and quality of life. No significant differences were found in outcomes between the two methods in client safety and unmet needs.<sup>11</sup>

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The Schneider Institute for Public Policy of Brandeis University conducted a study that addressed preferences of elderly home care services recipients for three methods: 1) traditional care management; 2) negotiated care management (e.g. Social Health Maintenance Organization, which involves a high degree of consumer involvement in decision making and a consultant/resource role for care managers); and 3) cash and counseling. Key findings suggest that 70% of elders preferred a traditional case management method; however, among those elders who chose the traditional case management model, approximately 32 percent expressed the preference for having *complete control* over care planning decisions, including service selection and scheduling. Because many elders either prefer more consumer-directed models or more control within existing case managed models, the study concludes that there is a need for consumer-directed long-term care systems to develop a range of consumer-directed care options.<sup>12</sup>

Another part of the report issued by the Schneider Institute for Public Policy of Brandeis University explained older consumers' preferences regarding service delivery methods for persons of diverse cultures, ethnic and racial backgrounds. The findings suggest there are both differences in preferences for consumer direction between and within racial or ethnic groups. For example, being Chinese or Latino were significant predictors for being less likely to select the traditional case management model than white elders. However, when considering the interaction of race or ethnicity with other significant model characteristics, African American elders, who desired control over their workers, were more likely not to choose the case managed model. Finally, Latino elders who desired more control over their services were likely to choose the case managed model while Latino elders who desired more control over their worker were more likely not to choose this model.<sup>13</sup> While this is an area that has only recently been studied, the variety in the findings to date makes a strong case for the appropriateness of consumer direction in response to individual needs and preferences.

The "Cash and Counseling" consumer direction experiment also confirms minority preferences for self-direction and maximum choice (having the cash to purchase the services they prefer). Thirty-three percent of the participants in the Arkansas, who are receiving a cash allowance to hire a worker or to purchase goods and services to meet personal care needs, are African American and 6.5% are American Indian.<sup>14</sup>

# Myths and Realities

Older individuals are “vulnerable” and need to be “protected.” Consumer-direction places older adults at greater risk.

**Myth 4**

**There is no evidence that the consumer direction model of service delivery is inherently “riskier” than professionally managed services.**

**Reality**

When consumers’ experiences and outcomes were compared in consumer-directed and agency-based programs, no significant differences were found in client outcomes in the areas of client safety and unmet needs. In fact, clients in the consumer-directed model who hired family members as their personal care attendants had better outcome measures related to safety and sense of security.<sup>15</sup>

Advocates for increased consumer direction maintain that the fear of increased risks needs to be balanced against the benefits to be gained from freedom to make personal choices and live as independently as possible. There should be a presumption of competence on the part of program participants to make decisions rather than placing the burden of proof on consumers and families to convince program officials or case managers that they are competent.

Self-directing consumers will “misuse funds” or “be exploited.”

**Myth 5**

**People who self-direct show a strong sense of responsibility in regard to the services they use and the funds expended.**

**Reality**

In the “Cash and Counseling” experiments, for example, consumers are using their allowances to purchase needed services so they can remain in their own homes. In practice, most beneficiaries prefer to have their funds held for them by agents called “fiscal intermediary organizations” which conduct bookkeeping and accounting services to help consumer direction beneficiaries manage their individual budgets and pay taxes for their workers. The development of an infrastructure of fiduciary services—in particular, fiscal intermediary organizations and counselors—can minimize concerns about misuse of funds or financial exploitation of vulnerable individuals while diminishing the administrative responsibilities placed on self-directing consumers.

# Myths and Realities

Evidence shows that many people would not have enrolled in the Cash & Counseling program if they had to handle the cash payments, complete tax forms and perform other financial management duties. Fiscal intermediaries were very important to the high “take up” rates in Arkansas.<sup>16</sup>

**Myth 6** There is no need for consumer direction because traditional agency based services can fully meet the needs of persons requiring personal assistance services.

**Reality** Consumer-directed services can sometimes meet needs that the traditional service delivery systems are unable to meet.

In the traditional system (using a plan developed by a professional case manager or a professional agency), choices typically are limited to certain kinds of services and providers on a Medicaid authorized list. Many clients in the traditional system have unmet needs because they want a different mix of services, often from different sources. Furthermore, many professional agencies send workers to their clients' homes at specified times (only during regular workday/workweek business hours) resulting in clients receiving assistance when it is available, instead of when they may actually need or want it. Moreover, many providers have waiting lists of people they cannot serve.

In areas of the country where there are shortages of paraprofessional workers and/or high turnover rates, consumer-directed options may be particularly helpful. The Arkansas experience is particularly illuminating. Participants in both the experimental and the control groups were individuals with an average of three ADL limitations. About 75% of both groups were elderly and 25% were younger persons with disabilities. The control group received traditional case-managed services and the experimental group received cash supplements (usually administered by a fiscal intermediary.) The Control had an 18% higher rate of nursing home placement than the experimental group. Program staff attribute this negative outcome to the fact that the control group used fewer services than were authorized because there was a shortage of workers. In addition to fewer nursing home placements, the experimental group reported fewer unmet needs and higher rates of overall satisfaction with services provided.

# Myths and Realities

There is no role for professional expertise in a consumer directed system.

*Myth 7*

**Professional expertise is an essential part of the menu of choices available to people who self-direct.**

*Reality*

As more states begin to offer consumer-directed programs similar to cash and counseling, there will be several opportunities for professionals and service agencies. These opportunities include, but are not limited to:

- Fiscal Intermediaries
- Consumer Advisors, Counselors and Care Coordinators
- Providers of Gap-Filling Services

## Fiscal Intermediaries

As consumer-directed services grow, there will be an increased demand for services that help consumers to manage their budgets or allowances. Fiscal intermediary services are favored by consumers because they don't have to be burdened with paperwork and financial issues related to paying people, filing taxes, etc. These services are also favored by sponsoring government agencies (such as Medicaid or a State Unit on Aging) because they provide an extra measure of quality control and protection against potential misuse of funds.

## Consumer Advisors, Counselors, and Care Coordinators

There will be an increased demand for professionals who can help consumers to understand their choices, navigate the system and maximize their resources to achieve personal goals. These professionals will function in a manner similar to how many private Geriatric Care Managers serve private-pay clients: working in a cooperative relationship with consumers. Their roles may include, but are not limited to, asking questions and facilitating thinking with respect to how a consumer wishes to spend his or her available resources, and being someone who calls the consumer periodically to see how things are going and to help with problem solving. Other consumers will want professionals to be more actively involved in their situations including helping them to locate and hire services or providers and to coordinate and manage services that are provided.

## Providers of Gap-Filling Services

Consumer-directed programs are likely to lead to an increased demand for companion services; registries of independent providers, innovative household technologies and/or equipment; home modification options; transportation services; and "concierge" services, making arrangements for occasional services.

# Myths and Realities

## A Role for All Professionals

An important role for virtually all professionals is to help identify people who are currently in a traditional service delivery system and whose needs could better be met by a consumer-directed option. Clearly consumer direction is not for everyone. However, it may often be the right option for individuals who want a different mix of services and/or from different sources—people who want to make greater use of family caregivers; individuals on waiting lists; and individuals who require personal assistance services during non-traditional times.

**Myth 8** Providers cannot receive adequate pay or benefits under a consumer direction model.

**Reality** Receiving adequate pay and benefits is possible under a consumer direction model. The consumer direction model often appeals to workers because of the one-to-one working relationship it creates.

When clients have control of their budgets and are able to buy from an organized provider or people they hire on their own, they are also empowered to negotiate support staff costs in accordance with the value of the service being provided to them. Under cash models, for example, hiring workers at higher rates is possible. In the New Jersey “Personal Preferences” (Cash and Counseling) program the personal care benefit is cashed out to consumers. On average, consumers in this program have paid their personal care workers a higher hourly rate because they value worker reliability and skill level. Consumers in New Jersey are also budgeting worker benefits into their cash management plans.<sup>17</sup>

There are other successful innovations for improving worker pay and benefits and for making it easier for self-directing consumers of long-term care to find qualified workers. Public Authorities in California are allowing clients and workers to organize and have a voice. The Public Authority method was conceived as a way for in-home supportive services to improve so that consumers could improve the quality of their lives and the lives of their home care workers. The IHSS Public Authorities have several major roles:

- act as “employer of record” with respect to collective bargaining over wages and benefits for consumer-employed workers;
- establish registries to help IHSS program participants find workers; provide training and support for consumers and workers; and establish advisory groups;
- establish an “On-Call” program that operates outside of regular business hours for consumers who have an urgent need for personal care.

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The San Francisco IHSS Public Authority has achieved unprecedented success. These efforts have resulted in a 50%+ increase in support staff wages (from \$4.25 per hour in 1995 to \$9.70 per hour in 2000) and full health care benefits (including dental) for independent providers who continuously work 25 or more hours per month.<sup>18</sup>

**Agency-employed providers offer higher quality services because workers are better trained, monitored and supervised.**

**Myth 9**

**There is no clear evidence that agency-employed providers offer higher quality care than providers in consumer-directed programs.**

**Reality**

Although consumer-directed workers may not have received as much formal training as agency workers, there is evidence to suggest that providers who are trained by the consumer provide a higher quality service because their training is tailored to the needs and preferences of the individual.

A report issued by the U.S. Department of Health and Human Services and the University of California, Los Angeles suggests that consumers in the consumer-directed model reported more satisfaction with service quality and impact when compared to agency-based services. They not only reported more satisfaction in the interpersonal sense, but also more satisfaction in the technical sense.<sup>19</sup>

**There is no place for consumer direction in managed care.**

**Myth 10**

**Managed care and consumer direction can work together. Some of the states that pioneered consumer-directed services are now experimenting with new approaches within a managed care system.**

**Reality**

At the same time interest in consumer direction has grown, there has been a remarkable growth in the number of persons who receive their health care through managed care organizations (MCOs) and an increasing interest in folding in

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long-term care.<sup>20</sup> Many states are seriously considering a capitated managed care approach for funding and delivering long-term care services. A paper published by the University of Maryland, Center on Aging concludes that although experience is limited, managed care and consumer direction can work together. A surprisingly large number of the MCOs appear open to a cash and counseling approach for at least some of their clients. Given the synergy in the objectives, this study provides a baseline to assess further development of compatibility.<sup>21</sup>

Wisconsin offers one example of innovation. Their “Family Care” program (a new county-run managed care system for home and community-based services) has successfully eliminated long waiting lists for home and community-based services while incorporating opportunities for self-directed supports for individuals and families eligible for HCBS waiver services, regardless of age or type of disability.

**Myth 11** The United States is the only country that is promoting consumer direction.

**Reality** Consumer-directed service options are becoming increasingly popular in many countries in Europe.

Consumer direction in European countries usually involves providing a “cash allowance” or giving control over an “individual budget” to eligible public program beneficiaries. A report issued by the National Council on the Aging found that these allowances usually fall into one of four categories:

- cash disability allowances or income supplements,
- cash or service options,
- client budget arrangements, or
- flexible case managed cash benefits.<sup>22</sup>

Across Europe there are similarities and differences in systems and approaches to consumer direction based on the background against which these developments take place. Predictably, they look different in different countries and cultures.<sup>23</sup> While Sweden is credited with beginning the movement of promoting consumer independence and rights in relationship to physical disability, other countries (Austria, Germany, France, the Netherlands, the U.K., and others) are also involved in directly empowering people to manage their own services.

# Myths and Realities

Consumer direction is just an experiment.

## Myth 12

## Reality

**Consumer direction has progressed beyond the experimental phase. It is becoming a movement embraced by a growing number of consumers, advocates, policy makers and program administrators.**

There has been significant growth of consumer-directed programs in the United States.

An inventory, completed in September 2001, found 139 consumer-directed service programs operating in every area of the country except the state of Tennessee and the District of Columbia. Although 58 percent of consumer-directed service programs serve fewer than 1000 individuals, the estimated total number being served is close to half a million (including elders, adults of working age, and children whose physical and/or mental disabilities are associated with a wide range of chronic illnesses or medical conditions). Two-thirds of the programs were found to have come into existence since 1990, 17 percent just within the past two years.<sup>24</sup> Some of the long-standing programs have grown quite large, proving that consumer direction can be successful on a large scale.

Public support for consumer-directed services is also growing. Recent studies of consumer-directed programs with a high percentage of older consumers show that their satisfaction with consumer-directed services is strong. Older consumers said they liked having control over their services, schedules and workers and they were particularly pleased at being able to hire family members.<sup>25</sup>

Consumer-directed programs appeal to state governments for their potential for cost savings, expanding the pool of caregivers, and their ability to empower consumers to be proactive recipients of services.

Because of this growing interest in consumer-directed home and community-based services across the country, the Office of the Assistant Secretary for Planning and Evaluation in the U.S. Department of Health and Human Services joined with other federal and private sponsors to host “Independent Choices: A National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities,” June 10–12, 2001 in Washington, D.C. The purpose of the symposium was to identify future directions for policy development and research to promote effective and responsive consumer-directed service systems for the elderly and persons with disabilities. More than 200 leaders from across the U.S. participated in this conference, shared their experiences and began to shape an agenda for the future.

# Consumer Direction

## Threat or Opportunity?

Consumer direction in services for older persons with disabilities is like a train that is leaving the station. Aging service providers and policymakers can react in one of three ways: we can lie down on the tracks and try to stop the train, we can stand by as the train leaves the station, or we can get on board and drive the train.

Make no mistake about it—the train is leaving the station. Greater empowerment and choice for people who need long-term care are not only a matter of common sense and general sensibilities. As the U.S. Supreme Court indicated in the recent *Olmstead* decision, consumers now have a legal right to receive care “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>26</sup> President Bush has also issued an Executive Order about “The New Freedom Initiative” ordering Federal agencies to increase autonomy and choice for people who need long-term services.<sup>27</sup> As these judicial and executive decisions evolve into policies and practices, it is certain that they will help promote greater consumer direction in publicly funded long-term care programs.

The trend toward increased consumer direction in the U.S. reflects a desire to make government-sponsored long-term care programs (especially Medicaid) more cost-effective, more market-oriented and more responsive to consumer preferences. This shifting emphasis from government-controlled to market-oriented services is part of a trend that is evident in the economies and social welfare programs of virtually every nation in the world over the past twenty years.

For some agencies that rely on government funding (especially Medicaid), consumer direction appears to be a threat. It can be disconcerting to realize that, if consumers have a choice, some might not choose to purchase the services that the agency offers—thus leading to a short-term reduction in revenues. Agencies can choose to oppose greater consumer direction and they may even succeed in delaying reform, but consumer empowerment, civil rights and market forces are difficult to stop once they get started.

Agencies can also choose to ignore consumer direction and go about their business as usual. Some agencies will take comfort in the fact that consumer-directed options will most likely complement rather than replace the traditional service delivery system. For many people, traditional case managed services are exactly what they want and need and many empowered consumers will continue to purchase traditional services.

Alternatively, agencies can recognize that consumer direction is likely to be an increasingly important part of the future of long-term care in the United States and that it creates many opportunities for service providers. For example, most consumers who want to hire and fire their own workers will still want to purchase fiscal intermediary services, use registries and purchase what wealthier people know as “geriatric care management” services. Many agencies, currently receiving direct government funding to provide long-term care services could easily retool themselves to offer these services and therefore better position themselves to compete for government-subsidized consumers.

# Consumer Direction

Empowering older adults to make better decisions—by providing more structure and better consumer information; revising attitudes toward safety and protection; and providing outside supports—will help older individuals gain the necessary tools and skills to make consumer-direction work.<sup>28</sup>

There is also a very practical, “bottom line” reason for aging service providers to embrace consumer direction. By learning how to be more responsive to the needs and preferences of consumers, agencies will also position themselves to compete much more effectively for private-pay clients. Tapping into the private pay market will enable agencies to expand their revenue base, continuously improve their services in response to consumer demand and do a better job of serving their government-subsidized clients. The most successful agencies of the future will be the ones that successfully solve the challenge of how to successfully blend public and private resources to help people stay at home. Embracing consumer direction is an important success strategy for agencies that want to thrive in the future.

Consumer direction is fundamentally about maximizing choice and control for people with disabilities and their families. Enabling, empowering and encouraging consumers to self-direct has great potential for improving the quality of life for consumers and can help foster more cost-effective and compassionate systems of care. Consumer direction is not a silver bullet or a panacea for the nation’s long-term care challenge, but it is an important part of the solution.

# End Notes

- 1 “Consumer direction” or “self-direction” may be referred to as the “independent living model” among working age adults with physical disabilities, “self-determination” among persons with mental retardation/developmental disabilities and their families, and “self help” and “empowerment” among persons with severe and persistent mental illness.
- 2 From “Principles of Consumer-Directed Home and Community-Based Services” published in 1996 by the National Institute of Consumer-Directed Long-Term Care Services, under a grant to the National Council on Aging and the World Institute on Disability, sponsored by the Administration on Aging and the Office of the Assistant Secretary for Planning and Evaluation, U.S. DHHS.
- 3 The above consumer examples provided at the Independent Choices: National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities, held in Washington, DC, June 2001.
- 4 Arkansas *Independent Choices* brochure, Division of Aging and Adult Services, Arkansas Department of Human Services, Little Rock, AR. <http://www.independentchoices.com/ICBrochure2K.pdf>.
- 5 From the San Francisco IHSS Public Authority, “Report at 5 Years: Activities and Accomplishments through December 2000.”
- 6 More information on the Cash and Counseling Demonstration and Evaluation is available at: <http://www.umd.edu/aging> Current evaluation findings are available from Mathematica Policy Research on-line: <http://www.mathematica-mpr.com/3rdlevel/cashcounseling.htm>
- 7 Feinberg, L.F and Whitlach, C.J. “Are Persons with Cognitive Impairment Able to State Consistent Choices?” *The Gerontologist*, 41, No.3.
- 8 Squillace, M., Mahoney, K.J., Shoop, D.M., Simon-Rusinowitz, L., and Desmond, S.M., 2002. “An Exploratory Study of Personal Assistance Service Choice and Decision-making Among Persons with Disabilities and Surrogate Representatives.” *Journal of Mental Health and Aging* 8 (3).
- 9 Mayer, R.R., Berson, A, and Marks, J. “A Consumer-Directed Homecare Program that Works for the Cognitively Impaired.” *Generations*, 24, 3 Fall, 2000.
- 10 Doty, P. U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. Personal Communication. June 16, 2002.
- 11 To access a “non-technical” summary of the findings and policy implications of the report on “In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery” by Pamela Doty, A.E. Benjamin, Ruth Matthias, and Todd Frank go to: <http://aspe.hhs.gov/daltcp/home.htm>
- 12 Sciegaj, M., Capitman, J. & Kay, C. “Consumer-Directed Community Care: Race/Ethnicity and Individual Differences in Preferences for Control” (forthcoming).
- 13 More information on consumer preferences by race/ethnicity can be found on the Cash and Counseling Demonstration and Evaluation Web site: <http://www.umd.edu/aging>
- 14 Mahoney, K.J., Project Director, Cash and Counseling Demonstration and Evaluation, Boston College Graduate School of Social Work, Boston, Massachusetts, personal communication, April 26, 2002.
- 15 To access the full report on “In-Home Supportive Services for the Elderly and Disabled: A Comparison of Client-Directed and Professional Management Models of Service Delivery” by Pamela Doty, A.E. Benjamin, Ruth Matthias, and Todd Frank go to: <http://aspe.hhs.gov/daltcp/home.htm>
- 16 Doty, P. “Arkansas ‘Cash and Counseling’ Demonstration and Evaluation: Early Findings.” Notes from comments made during a presentation at NASUA Annual Meeting of States in the Consumer Direction Program, July 18, 2002.

# End Notes

- 17 Excerpt from William Ditto, Executive Director, New Jersey Office on Disability Services, at the Independent Choices: National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities, held in Washington, DC, June 2001.
- 18 From the San Francisco IHSS Public Authority, "Report at 5 Years: Activities and Accomplishments through December 2000."
- 19 Excerpt from Professor Ted Benjamin of the University of California, Los Angeles, at the Independent Choices: National Symposium on Consumer-Direction and Self-Determination for the Elderly and Persons with Disabilities, held in Washington, DC, June 2001.
- 20 Regenstein, M. and Stephanie, A. "Medicaid Managed Care for Persons with Disabilities." Washington, DC: Economic and Social Research Institute, Urban Institute, 1998.
- 21 Meiners, M., Mahoney, K.J., Shoop, D.M., & Squillace, M. "Consumer Direction in Managed Long-Term Care: An Exploratory Survey of Practices and Perceptions," *The Gerontologist*, 42 (1): 32-38.
- 22 Firman, J. and Cameron, K. "International and Domestic Programs Using 'Cash and Counseling' Strategies to Pay for Long-Term Care." The National Council on the Aging. 1995.
- 23 For more information on the European Social Network and to access the full report "Toward a People's Europe" see: <http://www.socialeurope.com>.
- 24 The inventory was compiled by E, P&P Consulting for the HCBS Resource Network, a technical assistance contractor providing assistance to states, funded by the Centers for Medicare and Medicaid and the Office of the Assistant Secretary for Planning and Evaluation.
- 25 Coleman, B. *Consumer-Directed Services for Older People*. 2001. AARP Public Policy Institute.
- 26 *Olmstead v. L.C.*, 527 U.S. 581 (1999). This decision interpreted Title II of the Americans with Disabilities Act and its implementing regulation.
- 27 The New Freedom Initiative, announced by President Bush on February 1, 2001, is a comprehensive plan working to ensure that all Americans have the opportunity to make choices about their daily lives and participate fully in community life. [www.hhs.gov/newfreedom/init.html](http://www.hhs.gov/newfreedom/init.html).
- 28 Benjamin, A.E. "Consumer-Directed Services At Home: A New Model for Persons with Disabilities," *Health Affairs*, 20 (6): 80-93.

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