

# Consumer Choice in Long-Term Care

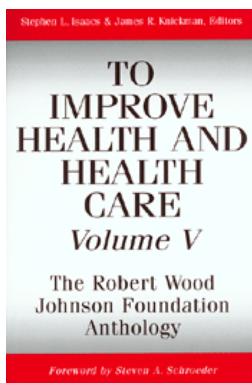
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## *Editor's Introduction*

Consumer choice exists for goods and services in most markets, and it can also play a role in long-term care. This concept is attractive to advocates for the rights of people with disabilities, since it enables disabled people themselves to make choices about the services they will receive. At the same time, consumer choice appeals to those who want greater efficiency in government programs, for the individuals whose lives are affected can be expected to choose more wisely than outsiders—such as government officials.

Although this simple concept is gaining in popularity, it is still controversial. Many people believe that older citizens or those with developmental disabilities are not able to make proper choices about their care. There is also concern among traditional home care agencies that disabled people will choose to pay family members, rather than outside agencies, with funds that become available under consumer choice programs.

Beginning in the early 1990s, the Robert Wood Johnson Foundation funded three national programs to test various ways of giving consumers more choice in the services they use and the people who provide them. The first awarded grants to states for programs that enabled people with developmental disabilities to make their own decisions about the care they receive. The second program provided poor elderly people with money to buy home care services, and gave them additional support with such tasks as financial planning and bookkeeping. The third program tested a wide range of approaches to giving people with disabilities greater choice in the kind of care they receive.

In this chapter, A. E. (Ted) Benjamin, the chair of the Department of Social Welfare at the University of California, Los Angeles, and the evaluator of one of the programs, and his colleague Rani Snyder, a research associate and doctoral candidate at UCLA, examine each of the programs and draw preliminary lessons from them.

The Foundation's method of increasing consumer choice in long-term care illustrates three ways it approaches issues. First, it designed a series of programs focused on different aspects of a common theme; the Foundation's size allows it to make very large, mutually reinforcing investments that address a single issue. Second, the three programs focus not on one specific subgroup of the chronically ill; rather, the programs are aimed at groups as diverse as the elderly disabled, the non-

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elderly disabled, and people with developmental disabilities, many of whom are children. Third, the Foundation timed the initiatives to take advantage of a rising wave of change. In the early 1990s, a number of groups representing disabled people were focusing on the issue of consumer direction. By working with these groups, the Foundation could help shape the direction of the wave and amplify the efforts of others working to increase the choices available to people needing long-term care.

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Most people with chronic conditions don't live in nursing homes or hospitals. They live at home or in other community housing. While their medical care is obviously important to them, so is the assistance that allows them to live successfully in their communities. For many people with long-term disabilities, such assistance involves fairly prosaic tasks far removed from medical science and technology—tasks such as help with bathing, dressing, and other routine activities, along with assistance in housekeeping, chores, and transportation. Family members have traditionally taken on these tasks. There is mounting evidence, however, that many people who need assistance live apart from their families, and that many families are not able to manage the demands placed on them by members in need. How can society respond to the needs of frail elderly people and younger people with disabilities in ways that are helpful, sufficient, and cost-effective?<sup>1</sup>

Since the early 1970s, representatives of younger people with disabilities have suggested an innovative approach. They have argued that rather than invest further in agency-based services run by professional nurses and social workers, society should instead channel resources directly to people with disabilities so that they might control the services they need. This argument, which has roots in both the civil rights and consumer movements of the 1960s, suggests that it is a mistake to think that people with disabilities primarily need medical services at home; what they most need is supportive services at home and in their community that do not require medical supervision. So, rather than organize supportive services through medically oriented, professionally run, and expensive home care agencies, what is needed are supportive services programs that rely less on professional staff and procedures and more on the strengths and the preferences of the people in need.<sup>2</sup>

Over the years, a few states such as California, Oregon, and Maine have established home-based supportive services programs based on the principles of consumer control, in which services are authorized and paid for by the state but all or most decisions about whom to hire and which supportive services are provided are made by those who receive the services.<sup>3</sup> While consumer-directed programs for

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younger people with disabilities are more common than those for older people, some prominent state programs, California's among them, reimburse such services for disabled people of any age.<sup>4</sup> Because professionals and home care agencies play a minor role in such programs, administrative overhead is relatively low, and a higher percentage of resources are devoted to services that go directly to those in need.<sup>5</sup> These programs have nonetheless been the targets of persistent criticism: How can we spend public funds without professional scrutiny and accountability? How can recipient safety be assured without professional oversight? How can we know that service needs are being met without professional monitoring? How can we be sure that frail older people are as able as younger disabled people to assume the demands of self-direction?

Despite such concerns, having consumers direct their own home care is an idea that no longer resides on the fringes; it has become a mainstream part of long-term care policy debates. Even with its anti-professional rhetoric, the theme of consumer direction has begun to appear regularly on the agendas of professional meetings and in articles published in professional journals.

### ONE THEME, THREE PROGRAMS

Chronic care has been a priority of the Robert Wood Johnson Foundation since 1991. Before then, Foundation funding initiatives had targeted issues related to a few specific chronic diseases like AIDS and Alzheimer's. Early in the 1990s, Foundation staff members recommended a broader approach to the challenges that seemed common to these and other chronic conditions, namely to redirect the thinking about chronic services to go beyond treatment of acute illness provided by physicians and toward the development of community care that would expand the choices available to people with chronic impairments. While many policymakers tended to equate issues of chronic, or long-term, care with elderly people, Foundation staff members had already been made aware of the diversity of people who needed long-term care services.

In 1990, the Foundation announced a series of grants to independent living centers under a program called Improving Service Systems for People with Disabilities. Independent living centers are local non-profit organizations, typically run by younger adults with physical disabilities, that advocate for and provide services to disabled people. This small initiative encouraged the centers to explore new ideas for improving services and for strengthening the networks that provided them. More important, perhaps, the program served as an introduction for the Foundation to the Independent Living Movement, whose leaders, themselves people with disabilities, emphasized two themes: first, expanding public support for services to help younger adults with physical disabilities live independently and productively in their

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communities; and, second, developing and disseminating models that emphasized consumer choice and control over core services that are considered essential to independent living—most notably, personal assistance.

In 1995, the Foundation joined with the federal Administration on Aging and the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services to establish the National Institute on Consumer-Directed Long-Term Services to bring together representatives of older people (the National Council on the Aging) and younger people (the World Institute on Disability). The idea was that these representatives could foster increased opportunities for consumer choice and direction in services for adults with disabilities. The collaboration produced a document that addressed the basics of this approach and provided a definition of the key elements of consumer direction:

Consumer direction is a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. They can assess their own needs, determine how and by whom these needs should be met, and monitor the quality of services received. Consumer direction may exist in differing degrees and may span many types of services. It 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 ... 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 the payment for services.<sup>6</sup>

In 1995, the Foundation also launched three initiatives designed to strengthen the role of disabled consumers in shaping decisions about their own lives. Each of the initiatives supported consumer-directed service models for different disabled populations. Because of the variety of constituencies—elderly people, young adults with disabilities, developmentally disabled people, children with special health care needs, the chronically mentally ill, and others—and the range of separate funding systems, each with distinctive constraints, designing a single initiative was simply not considered realistic. The three initiatives were Self-Determination for Persons with Developmental Disabilities, Cash and Counseling, and Independent Choices: Enhancing Consumer Direction for People with Disabilities.

#### THE SELF-DETERMINATION FOR PERSONS WITH DEVELOPMENTAL DISABILITIES PROGRAM

Lynn is a young woman who was paralyzed from the neck down in a childhood accident. Although her

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disabilities were physical, she had been declared incompetent and confined to a nursing home for years. She was contacted by people from Wayne County's Health and Community Services in Michigan and was asked for the first time since her accident what she wanted to see happen with her life. After identifying people she wanted in her support circle, she was given a budget (drawing from Medicaid funds that would have gone to the nursing home) and assisted in planning her life outside the institution. She arranged to hire a personal assistant and found a home to rent. The home was modified to accommodate her disabilities. She later persuaded a male friend she had met in the nursing home to share the house with her; he too has a fund drawn from Medicaid that he manages for himself. Lynn now has a new life and the freedom to plan and dream for the future and has been able to arrange the supports she needs to manage her own life.<sup>7</sup>

Arthur is a 54-year-old man with a developmental disability who had lived with his (now aging) parents all his life. After looking at group homes and finding them unappealing, Arthur became part of a new program at the Hudson Valley Developmental Disability Service Organization in New York State. Arthur enlisted family members to work with him and his service coordinator in finding an apartment that met his needs and that allowed him easy access to his job at the local YM/YWCA. He was able to use his service fund to hire someone to help him shop and cook and to hire others to assist him in learning to budget and to use a computer. Arthur hopes to develop computer skills that will get him a better job; for now, he communicates with his support circle via e-mail. Recently, after an arduous process, he was able to purchase the co-op unit in which he had been living. Arthur is now a proud home owner.<sup>8</sup>

Lynn and Arthur are two participants in a Robert Wood Johnson Foundation-funded program called Self-Determination for Persons with Developmental Disabilities. The roots of this program can be traced back to the deinstitutionalization movement of the 1960s and 1970s, when community living had become a major theme among advocates for people with developmental disabilities. In state and federal policy debates, families had been arguing that they, rather than mental health services professionals, should be making basic decisions about how family members with developmental disabilities should live. In reality, the dominant option for many families had become the "intermediate care facility—mental retardation." These facilities generally had 15 or more beds and provided residential and supportive services. State Medicaid programs pay dearly for this care, approaching \$100,000 a year per resident. States had also developed programs, funded under Medicaid waivers, tailored to meet individual needs of people with developmental disabilities in their homes or communities. Trends toward community living and stronger consumer roles for those with developmental disabilities were also fueled by passage of the

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federal Community Supported Living Arrangements Act in 1990, which funded supported living projects in up to eight states for those who would otherwise need to be placed in intermediate care facilities.<sup>9</sup>

In 1993, the Robert Wood Johnson Foundation funded a small pilot project in community living in New Hampshire called the Monadnock Self-Determination for People with Developmental Disabilities Project. In the project, a case manager worked with individuals—mainly those who had been institutionalized in state facilities—and their friends and families to develop a plan for procuring needed services in the community. Not long after, the founders of Monadnock brought to the Foundation a proposal to expand the approach and develop a larger community service system designed by people with developmental disabilities and their circle of friends.

The Robert Wood Johnson Foundation authorized a \$5 million, three-year program called Self-Determination for Persons with Developmental Disabilities in October, 1995 and issued a Call for Proposals in 1996. The program guidelines encouraged states to create new and enhanced opportunities for developmentally disabled people to choose what support and services they would receive, how they would live in their communities, and where they would find jobs or other meaningful roles. Self-determination is based on the principles of freedom, authority, support, and responsibility:<sup>10</sup>

- *Freedom*: the ability of disabled people to choose those making up their support system, to decide where and with whom they want to live, and to determine with whom they choose to spend their time. They may select family members or friends to help them.
- *Authority*: the ability, with help as needed, to make all decisions about support and to control funds in order to buy needed services; it includes the ability to modify priorities over time.
- *Support*: needed by many developmentally disabled people to take responsibility for decisionmaking and to live fully in the community, yet it must truly be support—not supervision. People with disabilities may wish to rely on family, friends, or one or more contracts for help with discrete tasks.
- *Responsibility*: the notion that public dollars must be used wisely.

Through the Self-Determination program, grants were made to 19 states. Additional sites in ten other states were chosen for smaller technical assistance grants. Thus, more than half the 50 states have been engaged in assessing the status of their current systems of care for developmentally disabled people and exploring new options aimed at helping them shape their own lives. At the heart of the Self-Determination program is the direct involvement of people with developmental disabilities in planning and overseeing implementation of their service systems: from making policy and serving as members of advisory boards to preparing their own plans and budgets. Each of the 29 projects shares three features. Plans are developed by users and their support groups, and budgets controlled by the users. They provide

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for monitoring by state project teams to insure that people with disabilities identify and obtain the individually tailored supports they want. And each project provides for administrative support—a state, for example, might contract with fiscal agents to assist local projects and recipients in developing and managing individual budgets—so that state systems work effectively.

A project in Massachusetts illustrates how the Self-Determination program works. In the Boston area, the project created family governing boards to represent major ethnic groups in the community, including Haitian, Asian, Latin American, and Ethiopian populations. The governing boards generally consist of six to eight families, overall representing more than 500 families. They meet on a quarterly basis. Most of the boards are linked with community agencies (rather than traditional mental retardation agencies), and the community agency hires a staff on behalf of the families. The boards are charged with working together to determine how the mix of state and federal funds are spent. The money is pooled rather than individually allocated.

One important element of this arrangement is that the contracts are between the family governing board, rather than a government agency, and the providers of services. Knowing that choices and payments are controlled by the family governing board, the providers of services must be responsive to the boards and the consumers. This strategy invites more family and community involvement than has historically taken place. As news of this initiative spreads through the community, more families have come forward to participate in the process.

## THE RATIONALE BEHIND THE CASH AND COUNSELING AND INDEPENDENT CHOICES PROGRAMS

While a network of independent living centers, financed by Medicaid or state funds, and other programs giving choices to physically disabled young people have existed since the 1970s, those who represent older Americans have been slower to warm to the idea of self-direction, believing that older people are less interested in and less capable of directing their own services. As a result, experience with older consumers and self-direction has been comparatively limited.<sup>11</sup> In the last decade, however, influential individuals such as James Firman, who is executive director of the National Council on the Aging (and who, in the past, was a program officer at the Robert Wood Johnson Foundation), have been calling for expanded consumer choice in service programs for elderly people. Across age groups, advocates have called for providing recipients with cash rather than services; that is, turning over the direct control of service funds to eligible people with disabilities to use as they wish, typically within some constraints. Others have suggested that most people, including the very old, would welcome more control over their



home and community services but may be hesitant about directly handling and accounting for public funds. In this context, in 1995 the Foundation authorized two programs to support a range of approaches to expanding consumer direction: Cash and Counseling, a four-year program approved at a \$2.1 million level, and Independent Choices, a four-year program approved at a \$3.4 million level.<sup>12</sup> In both programs, the Foundation also wanted to understand what happens when consumer direction is extended to elderly people. The first approach was the cash model, offering consumers a cash allowance in lieu of services provided by social agencies. It was expected to provide the maximum of flexibility in services by leaving most decisions to the consumer and to reduce overall costs by minimizing professional services, such as those provided by home care agencies. There was some concern, however, that a cash program alone was not enough; people might need assistance in getting started as their own case managers. Thus was born the idea of Cash and Counseling—of giving control of resources to the recipients and providing support they needed to deal with expanded choices. In the second approach, the Foundation authorized a broader initiative that would support various innovative approaches, apart from cash, for fostering choice and control in long-term care. This was called Independent Choices.

### THE CASH AND COUNSELING PROGRAM

The Cash and Counseling program was based on careful background analysis. The Foundation had commissioned a study of programs in other countries that permitted long-term care recipients to choose between cash benefits and information services, vouchers, and traditional case-managed, agency-based services. This study had found that cash and counseling programs were popular in other countries and seemed to save money when compared with traditional programs. What was now being proposed was a large-scale demonstration and a rigorous evaluation in this country. The idea had also attracted the

Ms. F. lives alone at age 92. Recently recovered from broken bones and surgery to implant a heart pacemaker, she is determined to remain independent and does as much for herself as possible. She uses her Cash and Counseling allowance to pay her daughter to help her and be available when needed, especially when she gets ready for church and visits to the senior center. She uses some of the allowance to purchase personal care supplies and over-the-counter medications.

attention of federal officials, and the Office of the Assistant Secretary for Planning and Evaluation within the U.S. Department of Health and Human Services offered to contribute a significant share of the evaluation costs. In early 1996, a national program office at the University of Maryland Center on Aging began soliciting proposals from states interested in setting up demonstration programs.

Four states—Arkansas, Florida, New Jersey and New York—were chosen from among seventeen that applied for funds. In late 1998, the programs began in three of those states; for a variety of reasons, New York was dropped from the demonstration. While many details vary, the basic design is the same in all



three states. Consumers are Medicaid-eligible adults who qualify for personal assistance services because of significant functional limitations with activities of daily living, such as bathing, dressing, toileting, or eating. They are offered a choice between receiving home care services or cash allowances to buy these services themselves. The value of each cash allowance is set at approximately the cost of the traditional care plan. (Because this is designed as an experiment, those who choose the cash allowance are randomly assigned to cash or to traditional services.) Those who get the cash allowance can also receive counseling services and assistance with fiscal tasks and bookkeeping. Counselors are available to help the participants develop a cash plan, locate, train and manage workers, gain access to community resources, and develop a backup plan.<sup>13</sup> The participants in the program are required to spend their allowance on their personal assistance needs. They can return to the traditional program at any time.

Although the evaluation of the Cash and Counseling program will not be completed until 2003, early analysis from the three states reveals some interesting lessons. If the cash option is carefully presented, many frail elderly people and others eligible for personal assistance services traditionally provided by agencies are willing to try it.<sup>14</sup> The vast majority of enrollees choose to hire a family member or a friend as a paid provider. Most enrollees choose to have a state-contracted "fiscal intermediary" handle employer and bookkeeping tasks, thus easing state concerns about accountability and liability. Early experience also

Ms. M. is a very large person in her 80's who needs assistance with most activities. She has had a difficult time arranging for agency home care, because workers prefer clients with fewer needs. Ms. M. has used her Cash and Counseling allowance to hire a granddaughter to assist with personal care tasks like bathing and dressing and also to pay a grandson to stay with her in the evenings when her daughter (with whom she lives) is away. She is saving any unspent funds to make payments on the badly needed dentures she bought after entering the program.

suggests that the small number of enrollees who want to perform these tasks themselves can be trained to do them adequately. In Arkansas, recipients may use some of their monthly cash allowance for items other than personal assistance services. In that state, most funds were used to pay workers for direct home-based services, but about one in six dollars went to buy or repair equipment related to their care and safety or to do modest home modifications.<sup>15</sup>

Some of the program challenges involve people other than those who receive services. For example, it has proven difficult to teach case managers to market the cash option to their clients and to become non-directive counselors and consultants. Also, home care workers must be educated about the new options, since they may view consumer direction as a threat to their employment. Overall, there is more to be learned about how people regard the cash option, how well workers and case managers adapt to their new roles, and the types and amounts of counseling assistance that are most needed.

## THE INDEPENDENT CHOICES PROGRAM

Independent Choices was designed to complement the Cash and Counseling program by supporting smaller-scale demonstration projects and research. Both programs seek to advance consumer choice in long-term care services. Unlike the Cash and Counseling approach, which tested a single strategy in different locations across the country, the Independent Choices program used a portfolio approach, with individual projects chosen to address diverse populations and different concepts. The broader approach has allowed the Foundation to fund a continuum of consumer-directed models in a variety of settings, but has precluded a standardized evaluation of the program, since each project was highly individual. Although this approach makes it harder to assess program impact, it also opens the door to a range of projects designed to move the concept of consumer direction more into the mainstream.

The National Council on the Aging has served as the National Program Office for the Independent Choices initiative. It was charged with helping to identify and develop projects that would represent the full spectrum of challenges facing consumer-directed home and community-based services for people of all ages with chronic disabilities. The Foundation issued a Call for Proposals in 1996 to develop and test approaches other than the cash option to empower the consumers of long-term care. To the surprise of almost everyone, nearly 500 applications for Independent Choices funding were received. In the summer of 1997, the National Council on the Aging selected thirteen sites for funding.

Of these sites, four were research projects and nine were demonstrations. The four research projects were chosen to increase understanding about people's preferences for consumer direction and how these preferences might differ across consumer groups. The nine demonstration projects have focused on new approaches to delivering consumer-directed care for different population groups.

At the Family Caregiver Alliance in San Francisco, for example, a study was fielded to understand more about how people with mild to moderate cognitive impairment might adapt to consumer-directed services. How well do people with cognitive limitations express their own preferences, and how consistently do they present them over time? How well do the views of family members reflect the preferences of their cognitively impaired relatives?

Project staff members conducted three lengthy interviews with each of 50 pairs of clients and primary caregivers. The results of these interviews indicated that people with mild to moderate cognitive impairment could reliably answer questions about demographics, general life style preferences, health care preferences, and making decisions. They answered factual questions accurately and consistently and

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expressed specific wishes and values. Since most clients had family members helping them in their lives, it was surprising to find numerous differences between what family members thought their relatives with cognitive impairment valued in the way of services and what those people themselves valued. In effect, those with mild to moderate cognitive impairments could express their preferences clearly and consistently, and family members were imperfect spokespersons for them. The findings open up more possibilities for consumer direction to be tailored to those with cognitive problems but, at the same time, are distressing because the system relies so heavily on family members to speak for those who are judged unable to speak for themselves.<sup>16</sup>

Another research project, at the Schneider Institute for Health Policy at Brandeis University, was designed to examine the preferences of older disabled Bostonians about self-direction in long-term care services, and whether those preferences varied by race or ethnicity. Staff members for this project conducted face-to-face interviews with 731 low-income elderly persons with chronic illness or disability who were already receiving home care services through various state and local programs, none of which offered the option of services directed by the consumer. Four separate populations of elderly people were interviewed: African-American, Chinese-American, Latino, and Western European. While the results are still being analyzed, they indicate that there are significant differences based on race or ethnicity in elder preferences regarding consumer direction. For example, when given different options, elderly Chinese and African-Americans are more likely to select the cash and counseling option than are elders in the other two groups. Researchers are exploring the reasons for these differences, but this study has already laid the groundwork for understanding how cultural differences can influence the way different groups respond to different service arrangements.

Among the demonstration projects supported by Independent Choices, three are designed to expand the options available to those who use Medicaid's long-term home care services, especially elderly people. The most ambitious are programs in Ohio and Oregon that are attempting to expand the options available to the people receiving care. In Ohio, a project team at Miami University is working with a regional Area Agency on Aging and with the state Department on Aging to expand the options available to elders in central Ohio whose services are provided under an existing "waiver program" (these programs must receive approval from the federal government to waive existing federal Medicaid regulations in order to provide services in innovative ways). The plan is to teach current and prospective recipients what the specific options are and how to make them work, and then let those recipients choose how they want their services designed: traditional case-managed services; modified case management, in which the

consumer has more authority; or a consumer-directed option involving hiring and managing their own workers. However, the initiative has encountered problems in convincing the federal government to modify an existing waiver in order to add more consumer-directed options to the service menu.

Oregon has long offered innovative home-based and community-based services with some features chosen by recipients, and under Independent Choices the state is attempting to expand the choices available under its "client-employed provider program." Along with offering recipients a wider selection of providers and the opportunity to use their cash benefits for tasks not previously covered, the most significant new step is giving them, and not the state, responsibility for paying providers and payroll taxes. Rather than assuming that most recipients need accounting services, Oregon has argued that many of them can learn to handle the bookkeeping tasks associated with being an employer. Like Ohio and Minnesota (and a number of other Independent Choices sites), Oregon has emphasized the development of training to prepare consumers for self-direction. Oregon and the other sites are also targeting case managers, providers, and family members for training, since everyone's role is altered when the consumer is the primary decision maker about services.

Other demonstration sites, such as Forest Park, Illinois, and Oakland, California, are tackling related challenges. The Progress Center for Independent Living in Forest Park, Illinois, is forging alliances with home care agencies to help educate them about consumer direction and enable them to become collaborators in expanding consumer roles. Under current Medicaid waiver programs in Illinois, disabled people over age 60 can receive home-based services only through an agency, while those under age 60 must hire their own workers with help from programs like the Progress Center for Independent Living.

Mrs. Y is a 72-year-old woman who lives alone and has limited vision because of her diabetes. One morning, Mrs. Y's regularly scheduled worker did not arrive to assist her. Mrs. Y was alarmed because she requires meals and snacks at specific times, and she had not been bathed in several days. Mrs. Y was able to call the new program, called Rapid Response, and a substitute worker arrived within one hour. She discussed with Mrs. Y the tasks to be done and then proceeded to prepare her meals, assist with bathing, and pick up needed groceries.

Through this Independent Choices project, the staff members are attempting not only to win support from skeptical home health agencies but also to build bridges between younger and older disabled people by demonstrating how home health care agencies can be converted to the idea of consumer direction. In part because the home care industry is in such turmoil as a result of expansions in

managed care and recent cuts in reimbursement, finding agency collaborators and nurturing working relationships with them is proving much more difficult than expected.

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A public agency in Oakland, California, has developed emergency backup services for people with disabilities who suddenly find themselves without assistance. Medicaid in California provides personal assistance services to nearly 200,000 people, and most of them hire, train, and supervise their own home care workers with little or no outside assistance. One critical problem involves backup; that is, what happens when a worker someone depends on for assistance in basic activities like dressing, toileting, and eating is sick or otherwise unable to work? The Oakland program has created an emergency assistance hotline to fill this gap.<sup>17</sup>

## LESSONS LEARNED

Since many of the sites are still putting these initiatives in place and evaluating them, the lessons of the three programs are not yet fully understood. Even as more formal evaluations of these programs are being completed, some general conclusions can be drawn about their initial impact.

*First, these programs have stimulated interest in the idea of consumer choice in long-term care.*

Although some formidable barriers still confront broad dissemination, the programs are helping to position the idea of consumer choice more firmly in the mainstream, and are altering the debate. Ideologically charged questions are still being asked about whether expanded consumer choice is desirable or feasible, but attention is now being paid to more pragmatic questions about which forms of self-direction work best and under which circumstances. In other words, the long-term care field seems to have moved from issues of "why?" to issues of "how?"

*Second, while barriers do remain in extending consumer-directed services to elderly people, there is also a growing consensus that at least a substantial minority of those over age 65 want to give consumer-direction a chance.*

While numerous skeptics exist, many experts now acknowledge that there are few, if any, age-defined barriers to making consumer choice work for elderly people. While younger adults continue to be the most fervent advocates for expanded consumer choice, growing numbers of organizations that represent the aging have now joined the chorus. The National Council on the Aging, which had long backed consumer direction, became a more active and visible proponent since the Independent Choices program's inception.

*Third, even if the idea of introducing consumer direction to people with cognitive disabilities may seem unrealistic, people with solid research and program credentials now report that it is feasible.*

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The developmentally disabled community has devised self-determination options that seem to work for a range of people with developmental disabilities. Younger people accustomed to making their own choices are likely to demand the same options as they themselves become elderly. In a sense, the last frontier in the extension of consumer choice is older people with cognitive limitations. Both research and experience suggest that these people, too, can exercise choice if given appropriate support.

*Fourth, the programs have clarified the challenges in translating ideas about consumer choice into tangible program options.*

In considering which people to enroll, most sites in the three programs have rejected screening clients and including only the most promising. Instead, sites have decided to enroll anyone who meets the program's disability requirements and then to provide them with whatever resources they need to support expanded choice. In sites with a cash option, this has often meant providing fiscal and accounting services. Other support includes training about consumer direction, assistance in finding a worker, and help with arranging a backup plan. More basically, program sites are demonstrating that a universal approach—a non-screening approach—seems feasible.

Related to this is the issue of representation. People with debilitating physical conditions—and especially those with cognitive disabilities—are typically believed to need routine assistance or supervision not only in basic life activities but also in making decisions. The family frequently assumes the role of representative for the person with disability when dealing with service systems and making service choices. All three programs recognize the importance of families and incorporate them into the process, while also recognizing that the preferences and interests of the family are not always identical with those of the person with disabilities. Even before the findings from the Family Caregiver Alliance study became available, most sites were committed to giving people with disabilities maximum independence while using family resources to further that end. (The sites for the most part have resisted surrogacy models, in which a family member or another designated representative speaks for the person with disability. This model seems most appealing where elderly people with Alzheimer's are involved.) The challenge has been to encourage the supportive character of family collaboration while also acknowledging the primacy of consumer interests.

*Fifth, if any one set of activities characterizes these three programs, it is training.*

While training in home care has traditionally been aimed at preparing workers to address the needs of

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clients, these programs have focused on training people to understand and implement consumer-directed services and on providing them with needed support. People unfamiliar with self-direction are one target: much work has been done to design and disseminate training materials for those with diverse needs—those who are illiterate, for example. Other target audiences include family members, service providers, case managers, independent brokers, and others providing services needed by people with disabilities.

*Sixth, the programs have furthered a reconsideration of case management.*

The term "case management" is not popular among those who support consumer direction. A frequent response to the term is "I am not a case, and I do not want to be managed." Yet case management is widely practiced and valued in professional circles and in public programs. Traditionally, case managers are trained to make decisions for clients after consulting with them and their families. Various sites have been working to retrain case managers to think differently about consumer roles and to incorporate consumer-directed options as they assess and enroll new clients. This has been an uphill battle. Some sites have screened case managers to identify those who are most open to consumer direction and then assigned only these people to key program roles. Others are testing the feasibility of a broader approach that attempts to reorient all case managers working with elderly and younger people with disabilities. It remains uncertain whether professionals whose early training and orientation is founded on conceptions of client dependency, dysfunction, and need can be persuaded to revise their assumptions and give more choice to the people who receive the services.

## LOOKING AHEAD

Ideas about consumer choice are now part of the mainstream discussion on the future of long-term care services for people who are aged or disabled. While not long ago many states viewed elderly people as indifferent to these options, they are now analyzing and implementing options that put authority into the hands of those who are receiving services. Rather than simply asking whether it is possible, there is now more focus on how to make consumer direction work by making it possible for people to find their own workers, arrange backup, and deal with decisionmaking issues. Even with this progress, however, major challenges remain to be met.

Approaches that shift decisions about resources are certain to stimulate resistance. Disabled consumers, who depend heavily on current services to improve their lives, are often wary of changes that might alter familiar arrangements. They worry not only about change itself but also about possible cuts in benefits and about assuming added responsibilities. Established home care agencies worry about lost business and



revenues. The network for aging services is concerned about losing control over resources, and about losing the political influence that goes with them. Budget watchers concerned with public accountability worry about fraud and abuse. Consumer direction seems like a reasonable option to those troubled by the shortage of workers willing to do home care, since it may help expand the pool by letting people hire friends and family. To others, choice seems more untenable than the current situation since consumers themselves must find scarce workers or risk going without services.

Despite the barriers, consumer direction now has the attention of a much broader range of federal and state agencies, policy and program officials, and academic researchers than was the case previously. There is much more experimenting, knowledge is increasing, and consumer direction is moving from being a radical approach for younger disabled people to being a mainstream option for all people with disabilities.

## Notes

<sup>1</sup> A. E. Benjamin, "An Historical Perspective on Home Care Policy," *The Milbank Quarterly*, 1993, volume 71, pp. 129–166.

<sup>2</sup> C. W. Mahoney, C. L. Estes, and J. E. Heumann, *Toward A Unified Agenda: Proceedings of a National Conference on Disability and Aging* (San Francisco, California: Institute for Health and Aging, 1986); and G. DeJong, A.I. Batavia, and L. B. McKnew, "The Independent Living Model of Personal Assistance in National Long-Term Care Policy," *Generations*, 1992, volume 16, pp. 89–95.

<sup>3</sup> P. Doty, J. Kasper, and S. Litvak, "Consumer-Directed Models of Personal Care: Lessons from Medicaid," *The Milbank Quarterly*, 1996, volume 74, pp. 377–409.

<sup>4</sup> A. E. Benjamin and R. E. Matthias, "Comparing Consumer- and Agency-Directed Models: California's In-Home Supportive Services Program," *Generations*, 2000, volume 24, pp. 85–87; A. E. Benjamin, R. E. Matthias and T. M. Franke, "Comparing Consumer-Directed and Agency Models for Providing Supportive Services at Home," *Health Services Research*, 2000, volume 35, pp. 351–366.

<sup>5</sup> A. I. Batavia, G. DeJong, and L. B. McKnew, "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*, 1991, volume 16, pp. 523–545.

<sup>6</sup> National Institute on Consumer-Directed Long-Term Services, *Principles of Consumer-Directed Home and Community-Based Services* (Washington, D.C.: National Council on the Aging, Inc. and World Institute on Disability, July 1996).

<sup>7</sup> National Program Office on Self-Determination, *Common Sense*, July 1999, issue 4.

<sup>8</sup> National Program Office on Self-Determination, *Common Sense*, July 2000, issue 7.

<sup>9</sup> K. C. Lakin, "Persons with Developmental Disabilities: Mental Retardation as an Exemplar," in R. J. Newcomer and A. E. Benjamin, editors, *Indicators of Chronic Health Conditions: Monitoring Community-Level Delivery Systems* (Baltimore, Maryland: The Johns Hopkins University Press, 1997).

<sup>10</sup> T. Nerney and D. Shumway, *Beyond Managed Care: Self-Determination for People with Disabilities* (Concord, New Hampshire: Institute on Disability, September 1996).

<sup>11</sup> N. N. Eustis and L. R. Fischer, "Common Needs, Different Solutions? Younger and Older Homecare Clients," *Generations*, 1992, volume 16, pp. 17–23; L. Simon-Rusinowitz and B. F. Hofland, "Adopting a Disability Approach to Home Care Services for Older Adults," *The Gerontologist*, 1993, volume 33, pp. 159–167.

<sup>12</sup> The authorization for Cash and Counseling was increased by \$2.83 million in 1996, for a total authorization of \$4.93 million. This includes funds for the demonstrations and evaluation.

<sup>13</sup> K. J. Mahoney, K. Simone, L. Simon-Rusinowitz, "Early Lessons from the Cash and Counseling Demonstration and Evaluation," *Generations*, 2000, volume 24, pp. 41–46.

<sup>14</sup> L. Simon-Rusinowitz, K. J. Mahoney, S. M. Desmond, et al., "Determining Consumer Preferences for a Cash Option: Arkansas Survey Results," *Health Care Financing Review*, 1997, volume 19, pp. 73–96.

<sup>15</sup> K. J. Mahoney, K. Simone, L. Simon-Rusinowitz, "Early Lessons from the Cash and Counseling Demonstration and Evaluation," *Generations*, 2000, volume 24, pp. 41–46; and Mathematica Policy Research, Inc., "Issue Brief: Cash and Counseling: Early Experiences in Arkansas," December 2000, number 1.

<sup>16</sup> L. F. Feinberg, C. J. Whitlatch, and S. Tucke, *Making Hard Choices; Hearing Both Voices*, final report to the Robert Wood Johnson Foundation (San Francisco, California: Family Caregiver Alliance, May 2000).

<sup>17</sup> D. Wong, "Rapid Response: Development of a Homecare Worker Replacement Service," *Generations*, 2000, volume 24, pp. 88–90.