

Consumer-Directed Services At Home: A New Model For Persons With Disabilities

How can consumer-directed programs be cost-effective, flexible, and responsive, while meeting standards of accountability in the use of public funds?

by A.E. Benjamin

ABSTRACT: The past decade has produced a wave of new state programs that have introduced consumer direction into home-based services for persons with chronic impairments. Building upon earlier models developed for younger adults with physical disabilities, consumer-directed models are now being adapted to recipients of all ages with federal, state, and foundation support. These models shift responsibility for key service decisions from professionals to recipients and challenge the traditional home care agency model. Research evidence on the impact of consumer direction is just becoming available to policymakers. This paper reviews what we have learned from program and research activity so far, and what key issues and challenges remain.

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BECAUSE OF CHRONIC ILLNESSES and conditions, an estimated twelve million Americans of all ages need some kind of long-term care, and about one-third of these require supportive assistance from another person to function in their daily lives.¹ More than 80 percent of those persons needing supportive assistance reside in the community, most at home.² While a majority of these are elderly, close to four in ten are under age sixty-five.

The past two decades have seen an expansion of publicly funded home and community-based services for persons with chronic impairments.³ These services typically are provided by home care agencies that send nurses, therapists, and aides into the home to deliver both medically related home health services and more supportive personal care assistance. Personal care assistance includes help with activities of daily living (ADLs) such as bathing, dressing, and eating, and with instrumental activities of daily living (IADLs) such as

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cooking, shopping, and housekeeping. Over the past decade the number of publicly funded programs that allow recipients independently to arrange and supervise personal assistance services at home has surged. This is known as consumer direction. First tested in public programs in the 1970s, consumer-directed home care in various forms is now offered in several European systems and in about thirty U.S. states. Consumer-directed services are authorized under Medicaid, either under the optional personal assistance benefit or federal waiver, or under state-funded programs.⁴

Several forces have stimulated the expansion of consumer direction. First, three decades of aggressive advocacy by nonelderly persons with chronic impairments (hereafter, persons with disabilities) has increased political pressure to expand publicly funded personal assistance services that give recipients more autonomy to direct their own care. Second, consumer movements have called for the “demedicalization” of some conditions (such as disability, old age, and pregnancy) and services (such as supportive home care and childbirth), so the message of consumer direction has a broader context.⁵

Third, concerns about the costs of long-term care have made federal and state policymakers receptive to home care service approaches considered to be less costly.⁶ Because consumer direction reduces or eliminates the need for home care agencies and case managers, service costs are expected to be lower. Fourth, the Supreme Court’s 1999 *Olmstead* decision has put additional pressure on states to consider diverse approaches to providing community placements and services for persons with disabilities.⁷ Fifth, the recent shortage of front-line workers also has increased receptivity to new strategies for recruiting long-term care providers. For example, if recipients can hire family and friends as workers, this may help to address widespread difficulties in attracting workers to low-paying jobs in home care.

Expanded interest in consumer direction poses challenges for policymakers. The first is simply to understand how these alternative approaches differ from traditional professional/agency-managed home care models. Second, because program diffusion has far outpaced research on program impact, policymakers must weigh the pros and cons of consumer direction on the basis of only modest evidence. Third, public officials face some programmatic issues that have provoked debate, including who should be permitted to self-direct, whether family members should be hired by consumers, how quality can be assured, how to manage quasi-medical tasks, and whether costs are truly lower when consumers self-direct. To begin to address these challenges, this paper first explores the rationale for consumer direction; next, describes the range of consumer-directed

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approaches to home care; and finally, summarizes what research and analysis have told us thus far about several issues that arise as programs are designed and implemented.

The Rationale For Consumer Direction

Disability advocates argue that throughout the long-term care system in all types of settings, persons with disabilities have insufficient opportunities to shape and direct their own supportive services.⁸ The preponderance of home care is delivered by home care agencies, typically licensed and/or certified by the state. When a program deems an applicant eligible for supportive services at home, he or she is referred to an authorized provider agency that assigns a worker and schedules service visits. The agency also defines allowable tasks, monitors workers' performance, receives any complaints from recipients, arranges backup as needed, and otherwise manages service delivery.

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Critics of the agency model argue that service decisions are based primarily on the interests of the agency, rather than those of the consumer. Workers are assigned to recipients, whose input about who will work with them is modest at best. Workers are rotated as agency scheduling demands require, disrupting existing service relationships. Scheduling is done by the agency, often with little regard for recipients' preferences (for example, a consumer needing assistance in going to bed must go to bed when the worker is there, even if she prefers earlier or later). For liability reasons, agencies carefully define allowable tasks for workers, so if a recipient wants curtains changed, for example, the worker may be prohibited from standing on a chair or ladder and be unable to help. Workers are trained to assist in the agency way, which may conflict with consumers' preferences about, for example, how to be bathed. Finally, agencies that promise backup assistance when a worker is sick or otherwise unavailable are in fact often slow or unable to do so.⁹

In consumer-directed approaches, most of these choices and responsibilities are shifted to the recipient or consumer. Consumer direction is based on the premise that persons with disabilities should be empowered to live as independently as possible and that physical (and even cognitive) limitations should not be barriers to expressing preferences and making decisions about the services they receive and about how they conduct their lives. Consumer (or

self-) direction shifts from home care agencies to the consumer control over which personal assistance services are received, when and how they are delivered, and by whom. Consumer direction assumes that most supportive services are essentially nonmedical, low-technology services that do not require extensive training or external monitoring. From this perspective, consumers can and should manage their own care instead of relying on professional case management.¹⁰ Although this perspective has implications for services in many settings, including nursing homes, to date most consumer-directed models have been implemented in homes.

A Range Of Models

In reality, consumer direction is not a single approach but rather a range of models that vary in terms of how much decision making, control, and autonomy are shifted from home care professionals and agencies to the consumer of services (Exhibit 1).¹¹ At one extreme is a professionally monitored approach. In Oregon's Medicaid program, for example, service recipients are able to hire (and fire) workers of their choice with guidance from case managers. The case manager assists the consumer at start-up and monitors services over time. Roughly in the middle are models that assign a case manager to determine eligibility and approved service hours, while leaving all

EXHIBIT 1
Key Features Of Agency And Consumer-Directed Home Care Models

	Agency model	Consumer-directed model		
		California	Maine	Arkansas
What is the range of benefits?	Authorized agency hours	Authorized service hours	Authorized service hours	Cash: goods and services
Are consumers screened?	No	No	Yes	Yes (financial only)
Who hires the provider?	Agency	Consumer	Consumer, with support	Consumer, with support
May family members be hired as providers?	No, only employees of licensed, certified agencies	Yes, there are no limits (state-only funds)	Yes, there are no limits (state-only funds)	Yes, there are no limits (waiver)
Who supervises the provider?	Agency	Consumer	Consumer, with support	Consumer, with support
Who provides assistance counseling?	Home care agency/case manager	Little or none from program	Contracted intermediary	Contracted counseling service
Who handles the financial tasks?	Home care agency	County-state program	Contracted intermediary	Consumer or fiscal agent
How much choice does consumer have about the model?	Variable	Low	High	High

SOURCE: Interviews by the author with state and county program representatives in California, Maine, and Arkansas.

service decisions about hiring, scheduling, supervision, and so forth to the recipient. Programs vary in the amount of assistance they give to consumers as they initiate services (such as training in consumer direction and supplying names of prospective workers). Most programs support consumers as they arrange their own services.¹²

In Maine, for example, persons with home care needs are referred to a consumer-run independent living center, which assesses their preferences and ability to self-direct, trains them (as needed) on hiring and supervising their own services, and provides a list of available workers. Those not considered good candidates for self-direction are referred to a home care agency. Innovative programs for persons with developmental disabilities in states such as New Hampshire and Utah emphasize “self-determination” through supported consumer choice, in which the consumer selects a support team to assist in decision making.¹³ In a few places, most notably California, consumer direction is widely available, but little if any program training or assistance is provided to consumers, who are responsible for making all service arrangements while a fiscal agent pays the worker. In some states the worker is paid by the state after the consumer signs a time sheet; in others payment is via a two-party check that the consumer as employer must endorse.

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At the other extreme is the cash model, which has been implemented in Germany and elsewhere in Europe but is not yet a legal option under Medicaid. The cash model is being tested in three states (Arkansas, Florida, and New Jersey) in a federal demonstration program known as the Cash and Counseling Demonstration and Evaluation.¹⁴ In this model, recipients receive a monthly cash allotment and the discretion to purchase any services or goods they consider essential. Early reports suggest that some consumers make very different choices than professionals do, especially home modifications and furniture purchases that facilitate mobility but are not covered by Medicaid. Recipients can manage the cash directly or pay a small fee to have a certified fiscal agent manage the funds; so far, most have opted for the latter. The counseling part of the program involves peer professionals who are available to provide consumers with information and advice about decisions.

Issues And Challenges

With consumer-directed programs now established in more than half of the states, various issues continue to provoke debate, while available research is only beginning to address them. Skeptics about the feasibility and impact of consumer direction are not confined to the home care industry, which is critical of service models that minimize the role of agencies and reduce the flow of public funds to

them. More substantive concerns also have been raised by policy-makers. These involve, first, who should be included in such programs? Given likely variations in appetite and ability to self-direct, should not careful screening of candidates occur? Are not persons with cognitive limitations and the elderly unlikely candidates? Second, should there be limits on who can be hired as a worker? In particular, should family members be paid to care for their loved ones?

Third, how should quality be assured in the absence of an agency employer? Since governments traditionally have depended on licensing and certifying home care agencies and providers, how can public programs meet accountability expectations when the recipient is the primary or sole judge of service quality? In particular, given the blurry line between nonmedical and medical services, how do we assure that consumer-directed workers are trained to deliver the services they are asked to provide? Fourth, is consumer direction less costly than agency-delivered care? Supporters of consumer direction argue that this model is cheaper and permits the delivery of more services within a fixed budget. Is available evidence convincing? I consider each of these areas in turn.

■ **Who should self-direct?** As discussed earlier, consumer direction initially emerged as the model of choice for working-age disabled persons. Because consumer direction is understood to require substantial energy, awareness, and judgment, many programs insist on screening applicants. Only those who prefer self-direction and can manage the tasks involved are expected to take it on; others are assigned to the traditional agency model. There seems to be growing support, however, for the view that a consumer-directed option should be available to anyone eligible for personal assistance services, regardless of age or other characteristics.¹⁵ Several states have rejected a screening approach and have chosen to offer all eligible recipients the option to self-direct. In the extreme case, Medi-Cal (California Medicaid) assigns nearly everyone (paradoxically, regardless of preference) to that model. Where cash is involved, recipients may be asked to pass a test demonstrating their ability to manage and account for funds and to handle tasks related to unemployment insurance and benefits.¹⁶

Cognitive impairment. An obvious challenge for those who would shift service decisions away from professionals and to consumers is the prevalence of cognitive limitations among persons with disabilities.¹⁷ The challenge goes well beyond older persons with Alzheimer's disease. About 200,000 persons with mental retardation and related developmental disabilities receive home and community-based services through Medicaid. A growing number of younger adults with traumatic brain injuries survive and need supportive

services in the community. Advocates long ago recognized this issue and proposed a modified consumer-directed model using a guardian or surrogate for those with limited cognitive capacity.¹⁸

Advocates for persons with mental retardation and developmental disabilities have both extended and challenged this approach by arguing not for surrogacy but for supported self-determination. In this approach, the person with cognitive limitations actively participates in decisions not only about services but also about broader resource allocation (such as for housing and education). The recipient chooses a support team of family members, advocates, and professionals to assist in making these decisions. Various methods have been developed to facilitate the clarification and expression of personal preferences by those with cognitive impairments.¹⁹ These have been applied in various state programs, first through the federal Community Supported Living Arrangements demonstration program in the 1990s and currently through a program funded by the Robert Wood Johnson Foundation called Self-Determination for Persons with Developmental Disabilities.²⁰

Other research has examined the limits and possibilities of consumer direction for older persons with mild to moderate cognitive impairment. A recent study found that cognitively impaired older persons answered factual questions accurately and consistently, expressing specific preferences about their lifestyle, service needs, and roles in making decisions.²¹ Numerous areas of difference also were identified between what family members thought persons with cognitive impairment valued and what the persons themselves expressed. Echoing a growing body of other research, this study concluded that persons with mild to moderate cognitive impairments could express their preferences clearly and consistently and that family members as surrogates only imperfectly echo these views.²² Research continues to investigate ways to expand the roles of people with cognitive limitations in defining their own service priorities and determining their own futures. As yet, no studies have carefully examined service outcomes for this population.

Age. Skeptics continue to question whether consumer direction is appropriate for older persons. The preferences and experiences of those over age sixty-five may seem to differ in important ways from those of younger persons with disabilities. Older persons may be accustomed to services arranged by case managers and delivered by medically oriented home care agencies. The elderly may have more unstable medical conditions and thus may need more professional monitoring at home than is true for younger persons with disabilities. For elderly persons, the focus of supportive services has been to maintain current levels of functioning at home and to slow what is

seen as inevitable decline. In contrast, younger recipients tend to view home-based services not as an end in themselves but as a means to a better life. For them, quality of life is defined not solely in terms of maintenance at home but of education, employment, recreation, and other activity outside the home. Younger persons with disabilities are seen as more grounded in “independent living” ideals and as having stronger preferences for directing their lives.²³

Research indicates that while older persons are somewhat less enthusiastic about the benefits of self-direction, their expectations and experiences generally mirror those of their younger counterparts. A higher percentage of younger disabled persons may prefer self-direction, but recent evidence suggests that at least a large minority of older persons also do.²⁴ While generational differences seem to be real, older persons are not much different when choices involve daily living, personal services, and home settings. Like others, they prefer to have a say in what is done, when, and how.²⁵ On average, however, older recipients may need more outside support in getting started and making consumer direction work. They are also more likely to prefer hiring family members as workers.²⁶ In light of this, policymakers will need to consider marketing consumer direction to older consumers and tailoring programs to their specific support needs as they implement self-directed services.

■ **Who can be hired as a provider?** Debate about implementing consumer direction is further complicated by controversy over hiring family members as paid providers. Federal Medicaid regulations proscribe federal payment to “legally responsible” family members (such as spouses or parents of minors), and states vary in the extent to which other family members may be reimbursed with public funds. Some states have a long list of excluded relations, including grandparents, grandchildren, and in-laws.²⁷ By contrast, recipients in Medi-Cal’s personal assistance program may hire anyone as their workers, including immediate family members such as a spouse or child. California (like Maine) complies with federal regulations by using state funds to pay immediate family members hired by program recipients. Why? In a program that requires recipients to recruit their own workers, it is argued that choice about hiring should not be limited and that in a tight labor market recipients need maximum latitude to recruit help. Practically, family members represent a large pool of helpers for persons with disabilities.

Using public funds to pay family members for services to their relatives has provoked heated debate. Taking care of family members is generally seen as fulfilling a moral duty.²⁸ Also, critics worry that public payment weakens the moral bonds that support family commitments. Critics (often state officials) also suggest that the

opportunity is great for fraud and abuse by families. As a result, it may be more expensive administratively to provide the training and monitoring that family payment requires. Critics worry that costs will explode if the availability of public payment persuades large numbers of family members now providing services out of moral duty to demand payment instead. Debate about paying family members is further complicated by the argument from some disability advocates that family members should be the last choice in hiring, since familial ties complicate what should be an employer-employee relationship between consumers and workers.²⁹

There is relatively little research to illuminate this debate. One study indicates that about one in five paid family providers had not been providing unpaid services to the recipient prior to hiring, so the pool of available help expanded as a result of allowing payment to families. The same study finds that some service outcomes (including sense of security and choice) are more positive for consumers when the provider is a family member.³⁰ Early findings from the Cash and Counseling Demonstration (where consumers select their workers) indicate little fraud and abuse in either family or non-family provider arrangements.³¹ Even in the face of some unsettling anecdotal evidence, there are few if any systematic data to compare abuse of consumers or program funds in agency care, services by consumer-hired nonrelatives, and paid family arrangements.³² Policymakers are left to draw on ideology and common sense in sorting through these issues.

■ **How can quality be assured?** Quality assurance in home care traditionally begins with the licensing and certification of home care agencies, which in turn agree to hire appropriate workers and train and supervise them. If workers' performance is unsatisfactory to the recipient, the agency is expected to take action. If an agency supervisor judges performance as unsatisfactory, a worker may be replaced or otherwise sanctioned. In consumer-directed approaches, decisions about workers' performance are left to the consumer. States may establish registries of available workers and may arrange for intermediaries to train the consumer to self-direct (including how to fire a worker), but the public role is confined to providing these resources to the consumer, not directly resolving problems with worker performance.

Critics of consumer direction worry that providers recruited and supervised by recipients will essentially be unscreened, untrained, and unmonitored and thus more likely to neglect and abuse their clients. In addition, concerns are raised that recipients on their own will be unable to arrange for backup assistance or manage service emergencies. Assessing the quality of home-based services is com-

plex, because it involves service delivery in relative isolation in millions of sites; service goals that are broad and diverse; and dimensions of quality involving technical and interpersonal competence.³³ Given the growing availability of professionally designed approaches to quality assessment, should we adopt models that rely on the consumer to judge the quality of care and that may involve unacceptable risk for persons with disabilities?

Advocates of consumer direction argue that uniform professional standards are likely to have only limited relevance to how people judge the quality of their supportive services and relationships with their workers. In this view, professional oversight may be unnecessary for services that are intimate and personal and only minimally medical or technical.³⁴ Where personal services in the home are involved, values and preferences will vary about what are essentially quality-of-life issues, such as what is appropriate, adequate, comfortable, and secure. In this case, adequate performance can reasonably be judged by the person to whom services are provided.³⁵

A small number of studies suggest that the actual risks to consumers associated with self-direction seem no greater than those with agency-based services. A study of elderly Medicaid recipients in three states found a strong association between participation in a consumer-choice program and recipients' satisfaction with personal assistance services.³⁶ A small study of younger recipients of consumer-directed services in Virginia found that they reported higher satisfaction and greater work productivity than those receiving agency or informal services.³⁷ In a federally funded study of recipients assigned to agency-delivered versus consumer-directed services in California, service outcomes for the self-directing group were no different from those of agency recipients on measures of safety and unmet needs and more positive on measures of service satisfaction and quality of life.³⁸ The absence of differences on reported abuse and neglect and on unmet needs seems noteworthy. This study also found that home care agency workers received less service training than expected, while consumer-hired workers received more than predicted, although from diverse and unplanned sources (such as from a family physician or home health nurse).

As noted, a central tenet of consumer direction is that most personal assistance is not medical, but that medically related procedures such as assistance with medications, injections, catheters, and ventilators are part of daily life for many persons with disabilities. Assuring the adequate oversight of medically related services delivered at home remains a challenge to policymakers. States have adopted nursing practice laws that define nursing tasks and prohibit nonlicensed personnel from engaging in them. Typically, fam-

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ily members are free of such restrictions.

Debate about quality is certain to persist. As a result of accountability pressures and professional demands, policymakers seem to prefer erring on the side of too much rather than too little protection.³⁹ The quality of the worker pool from which consumers hire is the primary target of state efforts, with initiatives to screen and do background checks, develop registries, and provide basic worker training. Most states have turned to contracted intermediaries to train consumers to be their own “watchdogs.” Although we know very little about how these approaches work, research is needed to assess the impact of providing advice and support to consumers to both direct and evaluate their own services. Policymakers have legitimate concerns about public accountability and quality assurance. While professional standards are still relevant, there is growing interest in incorporating consumer-identified needs, values, and preferences into approaches to quality review.⁴⁰

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■ **Is consumer-directed care less costly?** There is a paradox at the heart of recent growth in consumer-directed programs. Even as supporters invoke philosophical themes of independent living and empowerment, public officials seem drawn to consumer direction primarily because its services promise to be less costly than agency-based ones. Consumer direction is touted as being more economical in the complete absence of research on this topic. In a home care industry in which workers make low wages, a substantial share of traditional home care cost involves agency overhead. When that overhead is minimized or eliminated because the self-directing consumer assumes the employer role, the hourly cost to public programs can drop sharply. However, this depends on other program features, including the benefit level and caps, the generosity of support services for consumers needing assistance in making self-direction work, and the level of workers’ wages and benefits. In some states consumer-hired workers average lower wages than do agency employees and receive far fewer benefits.⁴¹ Even in states where support services are relatively generous, there seems to be consensus among policymakers that given the same pool of dollars, more consumer-directed service hours than agency hours can be purchased. Research on home care has shown that savings are sometimes achieved because costs are shifted to unpaid helpers, such as family members.⁴² Fortunately, the Cash and Counseling Evaluation

promises to provide policymakers with the first careful assessment of the cost side of consumer direction.

What Next?

More than half of the states have introduced consumer direction into public home care programs, and others are likely to join them over time. The appeal of this approach seems to lie in its potential to be less costly than agency-delivered services, to be more flexible in allowing recipients to meet needs not explicitly included in program benefits, and thus to be more responsive to individual values and preferences in the delivery of personal assistance services. The primary challenge to policymakers is determining how to design and implement consumer-directed programs so that they are cost-effective, flexible, and responsive, while also meeting public standards of accountability. This challenge has been taken up despite a dearth of research and policy analysis to assess the impact of different programs on persons with disabilities and on the public purse.

Recent federally supported research and evaluation is beginning to fill this gap, but more research is clearly needed. At least four areas of study have been discussed here: (1) analysis of who thrives and who does not under consumer direction, and why, as well as whether training and supports make a difference for those initially considered less promising candidates to self-direct; (2) analysis of the impact of hiring different types of providers (family, friends, strangers) on the consumer, the worker, and program costs; (3) comparison of professional, consumer-centered, and blended standards and approaches to quality assessment; and (4) design and implementation of careful studies that examine both the comparative public costs of agency and consumer-run services and the private costs to consumers, families, workers, and others. In addition, research is needed that examines what happens to consumers and families over time as they implement self-directed services, with attention to diverse disability groups such as those over age eighty-five, those with developmental disabilities, and children. We know little about the “careers” of persons with disabilities generally and nothing about the relative impact of consumer direction over time. We also need evaluation of new initiatives, still to be designed, that are likely to introduce consumer-directed approaches into other settings, especially assisted living facilities and nursing homes. Consumer direction also appeals to private insurers, which are experimenting with cash allocations in place of detailed service plans.⁴³ As before, more research on experience and impact is needed.

As consumer direction is disseminated more widely, there seem to be two primary threats to a fair test of its impact. The first is that

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for the sake of cost control, new programs may be inadequately funded. States face growing numbers of persons with chronic care needs and continued pressure to comply with the *Olmstead* decision and to provide community services for persons with disabilities. States will be pressed to provide more resources while also containing long-term care costs. Consumer direction is most likely to receive a fair test if public programs offer adequate benefits and supportive assistance to facilitate the shift to self-direction, and this will add to the unit costs of services. In the oldest and largest such program in this country, California and its counties have been slow to subsidize support services for self-directing consumers. Other states, as well as the Cash and Counseling Demonstration, have included support resources as an integral part of the model.

The second threat is more pervasive and possibly more serious. With the push to include training for consumers as they start self-direction, along with training for workers and family members, and the pressure to introduce satisfactory quality assurance measures, there is a risk that consumer-directed services will become so layered with service providers, case managers, support teams, and quality assessors that they will be transformed into another professional model of care. This push to reprofessionalize (and remedicalize) consumer-directed programs is an ongoing subject of concern for disability advocates. For policymakers the power of the agency model is enduring, since it permits delegation of responsibility to organized provider organizations with professionally conferred credentials. Where the consumer is in charge, there are few if any buffers between public officials and a calamity in the home. The fact that there is little evidence, anecdotal or otherwise, that calamity occurs any more often with consumer direction than with agency services seems to satisfy some but not all policymakers.

Soon, nearly every state is likely to offer persons with disabilities an option for some version of consumer-directed home care under Medicaid or state-only programs. Soon, extending these approaches to the elderly and those with mild-to-moderate cognitive impairment will no longer seem experimental. Cash variants have been introduced in European nations with relatively little resistance and are being tested in the United States. Consumer direction is becoming less an experiment than an established feature of the long-term care policy menu. Its appeal is the promise of empowering low-

income persons in need but without the limitations and stigma of traditional welfare programs. Its vulnerability lies in public doubts about conferring authority over public resources to citizen-recipients rather than to professionals.

CONSUMER DIRECTION IS NOT A PANACEA for the challenges facing policymakers in long-term care. It does not address pressing issues of public reluctance to invest more resources, coverage restrictions that leave many needy persons without services, worker shortages, and the poor integration of acute and long-term care services.⁴⁴ However, consumer direction is a promising mechanism for organizing services for persons with disabilities in ways that may prove to be more responsive and flexible than agency services for recipients and may do so at a reasonable cost to the public purse. While many questions remain, the search for answers is under way.

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NOTES

1. U.S. General Accounting Office, *Adults with Severe Disabilities: Federal and State Approaches for Personal Care and Other Services*, Pub. no. HEHS-99-101 (Washington: GAO, May 1999); and Institute for Health and Aging, *Chronic Care in America: A Twenty-first Century Challenge* (Princeton, N.J.: Robert Wood Johnson Foundation, August 1996).
2. J. Tilly, S. Goldenson, and J. Kasten, *Long-Term Care: Consumers, Providers, and Financing—A Chart Book* (Washington: Urban Institute, March 2001); and D. Rowland and B. Lyons, eds., *Financing Home Care: Improving Protection for Disabled Elderly People* (Baltimore: Johns Hopkins University Press, 1991).
3. J. Lubitz et al., "Three Decades of Health Care Use by the Elderly, 1965-1998," *Health Affairs* (Mar/Apr 2001): 19-32; and G. Kenney, S. Rajan, and S. Soscia, "State Spending for Medicare and Medicaid Home Care Programs," *Health Affairs* (Jan/Feb 1998): 201-212.
4. M. Merlis, "Caring for the Frail Elderly: An International Review," *Health Affairs* (May/June 2000): 141-149; GAO, *Adults with Severe Disabilities*; and N. Miller, "Patient Centered Long-Term Care," *Health Care Financing Review* (Winter 1997): 1-10.
5. J.J. Glover and A. Hartman, "The Myth of Home and the Medicalization of the Care of the Elderly," *Journal of Clinical Ethics* (Winter 2000): 318-322; and K.K. Barker, "A Ship upon a Stormy Sea: The Medicalization of Pregnancy," *Social Science and Medicine* (October 1988): 1067-1076.
6. J. Feder, H.L. Komisar, and M. Niefeld, "Long-Term Care in the United States: An Overview," *Health Affairs* (May/June 2000): 40-56; J.M. Wiener and D.G. Stevenson, "State Policy on Long-Term Care for the Elderly," *Health Affairs* (May/June 1998): 81-100; and A.E. Benjamin, "An Historical Perspective on Home Care Policy," *Milbank Quarterly* 71, no. 1 (1993): 129-166.
7. S. Rosenbaum, "The *Olmstead* Decision: Implications for State Health Policy," *Health Affairs* (Sept/Oct 2000): 228-232.
8. G.S. Wunderlich and P.O. Kohler, eds., *Improving the Quality of Long-Term Care* (Washington: National Academy Press, 2001); and L.S. Noelker and Z. Harel,

- eds., *Quality of Life and Quality of Care in Long-Term Care* (New York: Springer, 2000).
9. G. DeJong, A.I. Batavia, and L.B. McKnew, "The Independent Living Model of Personal Assistance in National Long-Term Care Policy," *Generations* (Winter 1992): 89–95; and 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* (Fall 1991): 523–545.
 10. DeJong et al., "The Independent Living Model"; R. Stone, "Opportunities, Challenges, and Limitations of Consumer Direction," *Generations* (Fall 2000): 5–9; and N. Miller, S. Ramsland, and C. Harrington, "Trends and Issues in the Medicaid 1915(c) Waiver Program," *Health Care Financing Review* (Summer 1999): 139–160.
 11. Stone, "Opportunities, Challenges, and Limitations."
 12. P. Doty, J. Kasper, and S. Litvak, "Consumer-Directed Models of Personal Care: Lessons from Medicaid," *Milbank Quarterly* 74, no. 3 (1996): 377–409.
 13. T. Nerney and D. Shumway, *Beyond Managed Care: Self-Determination for People with Disabilities* (Concord, N.H.: Institute on Disability, September 1996).
 14. K.J. Mahoney, K. Simone, and L. Simon-Rusinowitz, "Early Lessons from the Cash and Counseling Demonstration and Evaluation," *Generations* (Fall 2000): 41–46; and Mathematica Policy Research, *Cash and Counseling: Early Experiences in Arkansas*, Issue Brief no. 1 (Princeton, N.J.: Mathematica, December 2000).
 15. National Institute on Consumer-Directed Long Term Services, *Principles of Consumer-Directed Home and Community-Based Services* (Washington: National Council on Aging and World Institute on Disability, July 1996); Stone, "Opportunities, Challenges, and Limitations"; and P. Doty, "The Federal Role in the Move toward Consumer Direction," *Generations* (Fall 2000): 22–27.
 16. Mahoney et al., "Early Lessons."
 17. S.L. Brown, K.C. Lakin, and B.O. Burwell, "Beneficiary Centered Care in Services to Persons with Developmental Disabilities," *Health Care Financing Review* (Winter 1997): 23–46; K.C. Lakin, "Persons with Developmental Disabilities: Mental Retardation as an Exemplar," in *Indicators of Chronic Health Conditions: Monitoring Community-Level Delivery Systems*, ed. R.J. Newcomer and A.E. Benjamin (Baltimore: Johns Hopkins University Press, 1997): 99–135; and R.L. Mollica, *Personal Care Services: A Comparison of Four States* (Washington: AARP Public Policy Institute, March 2001).
 18. DeJong et al., "The Independent Living Model."
 19. M. Brod et al., "Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument," *Gerontologist* (February 1999): 25–35; and R. Logsdon et al., "Quality of Life in Alzheimer's Disease: Patient and Caregiver Reports," *Journal of Mental Health and Aging* 5, no. 1 (1999): 21–32.
 20. Nerney and Shumway, *Beyond Managed Care*.
 21. L.F. Feinberg, C.J. Whitlach, and S. Tucke, *Making Hard Choices: Respecting Both Voices*, Final report to the Robert Wood Johnson Foundation (San Francisco: Family Caregiver Alliance, May 2000).
 22. Ibid.; H.D. Degenholtz, R.A. Kane, and H.Q. Kivnik, "Care Related Preferences and Values of Elderly Community-Based Long-Term Care Consumers," *Gerontologist* (December 1997): 767–776; and R.A. Kane and H.D. Degenholtz, "Assessing Values and Preferences: Should We, Can We?" *Generations* (Spring 1997): 19–24.
 23. Batavia et al., "Toward a National Personal Assistance Program"; N.N. Eustis and L.R. Fischer, "Common Needs, Different Solutions? Younger and Older Homecare Clients," *Generations* (Winter 1992): 17–23; and L. Simon-

- Rusinowitz and B.F. Hofland, "Adopting a Disability Approach to Home Care Services for Older Adults," *Gerontologist* (April 1993): 159-167.
24. L. Simon-Rusinowitz et al., "Determining Consumer Preferences for a Cash Option: Arkansas Survey Results," *Health Care Financing Review* (Winter 1997): 73-96.
 25. N. Miller, "Patient-Centered Long-Term Care," *Health Care Financing Review* (Winter 1997): 1-10; and Eustis and Fischer, "Common Needs."
 26. A.E. Benjamin and R.E. Matthias, "Age, Consumer Direction, and Outcomes of Supportive Services at Home," *Gerontologist* (October 2001): 1-11.
 27. D. Lewis-Idema, M. Falik, and S. Ginsburg, "Medicaid Personal Care Programs," in *Financing Home Care*, ed. Rowland and Lyons, 146-177.
 28. L. Simon-Rusinowitz, K.J. Mahoney, and A.E. Benjamin, "Payments to Families Who Provide Care: An Option That Should Be Available," *Generations* (Fall 1998): 69-75; Doty et al., "Consumer-Directed Models of Personal Care"; and Batavia et al., "Toward a National Personal Assistance Program."
 29. C.J. Blaser, "The Case against Paid Family Caregivers: Ethical and Practical Issues," *Generations* (Fall 1998): 65-69.
 30. A.E. Benjamin et al., "Consumer Direction and In-Home Services: Recipient Perspectives on Family and Non-Family Service Provision," *Journal of Rehabilitation Administration* (January 1999): 233-247; and 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* (April 2000): 351-366.
 31. Mahoney et al., "Early Lessons."
 32. Blaser, "The Case against Paid Family Caregivers."
 33. R.A. Kane and R.L. Kane, *Long-Term Care: Principles, Programs, and Policies* (New York: Springer, 1987); A.E. Benjamin, "A Normative Analysis of Home Care Goals," *Journal of Aging and Health* (August 1999): 445-468; and Feder et al., "Long-Term Care in the United States."
 34. M.B. Kapp, "Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services," *Elder Law Journal* 4 (1996): 55-97; and C.P. Sabatino and S. Litvak, "Consumer-Directed Homecare: What Makes It Possible?" *Generations* (Winter 1992): 53-59.
 35. Degenholtz et al., "Care Related Preferences"; S.M. Geron, "The Quality of Consumer-Directed Long-Term Care," *Generations* (Fall 2000): 66-73; and R.A. Kane et al., "Perspectives on Home Care Quality," *Health Care Financing Review* (Fall 1994): 69-89.
 36. Doty et al., "Consumer Directed Models."
 37. P.W. Beatty et al., "Personal Assistance for People with Physical Disabilities: Consumer-Direction and Satisfaction with Services," *Archives of Physical Medicine and Rehabilitation* (June 1998): 674-677.
 38. Benjamin et al., "Comparing Consumer-Directed and Agency Models."
 39. GAO, *Adults with Severe Disabilities*.
 40. Miller et al., "Trends and Issues."
 41. A.E. Benjamin, R.E. Matthias, and T.M. Franke, *Comparing Client-Directed and Agency Models for Providing Supportive Services at Home*, Final report to the U.S. Department of Health and Human Services (Los Angeles: UCLA School of Public Policy, September 1998).
 42. V. Mor, D.S. Greyer, and R. Kastenbaum, *The Hospice Experiment* (Baltimore: Johns Hopkins, 1988).
 43. M. Cohen, "Lifeplans: Research on Private Long-Term Care Insurance" (Presentation at Independent Choices: A National Symposium on Consumer-Directed Care, Washington, D.C., 10 June 2001).
 44. Feder et al., "Long-Term Care in the United States."