Consumer-Directed Home and Community Services: Policy Issues

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Occasional Paper Number 44

Assessing the New Federalism
An Urban Institute Program to Assess Changing Social Policies
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This report is part of the Urban Institute’s Assessing the New Federalism project, a multiyear effort to monitor and assess the devolution of social programs from the federal to the state and local levels. Alan Weil is the project director. The project analyzes changes in income support, social services, and health programs. In collaboration with Child Trends, the project studies child and family well-being.

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Assessing the New Federalism is a multiyear Urban Institute project designed to analyze the devolution of responsibility for social programs from the federal government to the states, focusing primarily on health care, income security, employment and training programs, and social services. Researchers monitor program changes and fiscal developments. In collaboration with Child Trends, the project studies changes in family well-being. The project aims to provide timely, nonpartisan information to inform public debate and to help state and local decisionmakers carry out their new responsibilities more effectively.

Key components of the project include a household survey, studies of policies in 13 states, and a database with information on all states and the District of Columbia, available at the Urban Institute’s Web site (http://www.urban.org). This paper is one in a series of occasional papers analyzing information from these and other sources.
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This study assesses the policy implications of consumer-directed home and community services for older persons by examining the experiences of public programs that serve this population in eight states. These programs give beneficiaries, rather than agencies, the power to hire, train, supervise, and fire workers. Most stakeholders interviewed for this case study, in addition to quantitative research, indicate that many older beneficiaries want to and can manage their services, although significant issues arise about the ability of persons with cognitive impairment to manage. Research results also point to better quality of life for beneficiaries when they direct their services, although quality of services remains a contentious issue. For workers, consumer-directed care has some disadvantages, including fewer fringe benefits. With exceptions, state agencies have not provided extensive consumer or worker support or aggressively regulated quality of care.
Consumer-Directed Home and Community Services: Policy Issues

Implications for Programs Serving Older People

A key issue in the design of home and community services programs is the extent to which clients control their services. Consumer involvement in managing publicly funded Medicaid and state-funded programs currently ranges from very little to virtually complete control over services. In their programs, states use two broad models of consumer control—agency-directed and consumer-directed services. Advocates for younger adults with disabilities insist that consumers be able to direct individual workers rather than having to rely on home care agencies for services. Among advocates for older people, however, there is some controversy about whether that population should control their home and community services in this way. This paper explores the policy implications of extending consumer direction to programs serving older people by reviewing the literature and using a case study approach to examine the experiences of eight mature state programs that permit older persons to direct services.

The agency-directed model represents one end of the continuum where consumers have relatively little direct control. Under this approach, states contract with home care agencies that are responsible for hiring and firing home care workers, directing services, monitoring quality of care, disciplining workers if necessary, and paying workers and applicable payroll taxes. The agency-directed model operates from the assumption that professional expertise matters a good deal more than the opinions of consumers. At its extreme, a “medical model” is imposed and individuals with disabilities are considered to be “sick,” as opposed to simply needing compensatory services (Parsons 1951). In the agency-directed model, beneficiaries can express preferences for services or workers but have no formal controls over them.

The consumer-directed model, offered by some Medicaid and state-funded programs, represents the other end of the management continuum. In this approach, beneficiaries are responsible for decisions about their services, including recruiting, training, hiring, directing, and firing their workers (NCOA 1996).

There are several types of consumer-directed programs (Mahoney and Simon-Rusinowitz 1997). In most programs, consumers take on all worker management tasks with the exception of paying the worker. Alternatively, some state-funded consumer-directed programs provide cash payments to beneficiaries, who then shop for services that fit their needs and budgets and pay for them. Medicaid-funded pro-
grams, however, must abide by the federal rule that prohibits Medicaid beneficiaries from receiving their benefits in cash (Flanagan and Green 1997).

Advocacy for consumer direction in the United States began during the 1970s with the Independent Living Movement and continues today. Younger adults with disabilities demand the right to receive and manage their own services in home and community settings to become part of mainstream society. The movement rejects societal perceptions that persons with disabilities are vulnerable and need protection (Cohen 1988; Simon-Rusinowitz and Hofland 1993; Wiener and Sullivan 1995). The Independent Living Movement contends that people with disabilities have the ability and the right to make the decisions about the services that affect their lives. Despite the origins of the movement among younger adults, advocates for younger people have long argued that the need to maintain independence and control applies to older people as well (Litvak 1987).

Several key observers of the long-term care system for older persons have identified barriers to adoption of the Independent Living Movement’s ideology among advocates for older persons and professionals. Cohen (1990) writes of an “elderly mystique” that dominates the thinking of older persons and their advocates, which assumes that the potential for growth, development, and involvement in the community disappears with the development of serious disabilities. In essence, there is a presumption that older people with disabilities are too sick, too frail, too disabled, and too often cognitively impaired to take on the tasks of directing their own care (Kane 1999). Moreover, given the fragmentation of the financing and delivery system, the assumption is that professional expertise is needed to navigate the system. A final supposition is that traditional agency services are necessary to provide aged beneficiaries with reliable access to good-quality care from trained workers. For older people, the agency model is intended to compensate for the perceived lack of capacity on the part of people who need services and to ensure safety.

Although there are barriers to adoption of the Independent Living Movement’s precepts by the aging community, there is growing interest in applying the concepts of consumer direction to the older population. A growing number of states are incorporating consumer direction into their home care programs for older people, as are a number of other countries, including France, the Netherlands, the United Kingdom, Austria, and Germany (Tilly, Wiener, and Cuellar 2000; Cuellar and Wiener 2000; Tilly and Bectel 1999). In addition, as part of its health reform proposal in 1993, the Clinton administration would have required that all states offer people with disabilities the option of consumer-directed services. The U.S. Department of Health and Human Services and the Robert Wood Johnson Foundation are sponsoring “cash and counseling” demonstrations in Florida, Arkansas, and New Jersey, where Medicaid personal care beneficiaries of all ages are being given the opportunity to receive cash rather than service benefits. Moreover, some groups representing older people, most notably the National Council on the Aging, strongly advocate that consumer-direction principles be built into home and community services programs. Thus, a key policy question is whether programs serving older persons should provide them the opportunity to manage home and community services and, if so, under what conditions.
This paper adds to this debate by comparing publicly funded agency and consumer-directed services in relation to several issues—whether older persons want to manage and are capable of managing services, the quality of those services, and the effects of consumer direction on workers. A major focus is on state policy decisions and program design.

**Research Methods**

Data for the comparative analysis were collected through an extensive literature search and interviews with government officials and key stakeholders in eight states with coexisting agency and consumer-directed models. The goal of this strategy was to gather the views and opinions of stakeholders who had experience with consumer-directed programs that served significant numbers of older people as well as to obtain information about the structure of the programs. The authors identified relevant literature by conducting a comprehensive search of published and unpublished literature using major bibliographic databases. The search revealed a number of descriptions of state consumer-directed programs, but only four quantitative studies of consumers’ willingness to manage services and two studies that compared beneficiary or worker outcomes under the two models.

Potential case study states were identified by examining several surveys of home care programs offering consumer-direction opportunities that were conducted in the mid-1990s or later (Flanagan and Green 1997; Scala and Mayberry 1997; National Association of State Units on Aging 1998; U.S. General Accounting Office 1999). To be chosen for the study, states had to provide agency and consumer-directed services to older adults with disabilities, have at least 2,000 beneficiaries, and have at least two years of experience with consumer direction. Thus, the study states have relatively large, mature programs that permit comparisons between the two models. The states that met the selection criteria and were included in the study were California, Colorado, Kansas, Maine, Michigan, Oregon, Washington, and Wisconsin.

In each state, the authors interviewed state program officials responsible for the home and community services programs, generally state Medicaid or State Unit on Aging officials, and representatives of key stakeholder groups who have the most knowledge of consumer-directed programs—advocates for younger people with disabilities, advocates for older beneficiaries, unions, and home care agency associations. The authors gathered contact information for program officials and representatives of key stakeholders from the surveys of consumer-directed programs and from Web sites on independent living and home care agencies. In addition, each program official or key stakeholder who agreed to be interviewed was asked to nominate other stakeholders whom he or she considered to be knowledgeable about the state’s home- and community-based services system.

Program officials and representatives of younger people with disabilities in every state agreed to participate in telephone interviews. Stakeholders representing the older population were interviewed in only half of the states because program officials and other stakeholders could not identify a knowledgeable person to interview. Home care agency representatives agreed to interviews in every site except Michigan. Union representatives were identified in six states. In total, 33 sets of interviews were conducted.
conducted with government officials and key stakeholders: 8 with government officials, 8 with advocates for younger people with disabilities, 4 with advocates for older people, 7 with home care agency association staff, and 6 with union officials. Sometimes more than one state official would participate in an interview. When this occurred, their responses were considered as one. To encourage candor, respondents were guaranteed anonymity. Open-ended, structured interview protocols were developed for government officials and stakeholders that addressed program structure and the policy issues related to consumer direction for older persons. Copies of the survey instruments are available from the authors.

Program Description

In establishing their programs, the eight case study states had to make a number of program design decisions about financing, eligibility, cost containment, and quality assurance. States generally relied on a combination of Medicaid and state funds to finance their programs. Medicaid home- and community-based services play an important role in financing these services. Programs measured persons’ inability to perform daily activities when determining functional eligibility for benefits, and most programs were means-tested. Costs were limited in the number of “slots” or number of people served, or in the number of hours of service or dollar amounts of benefits available to beneficiaries. Most programs allowed beneficiaries to hire family members, with the exception of spouses, and quality assurance involved minimal monitoring of beneficiaries. Table 1 provides detailed descriptions of the programs in the eight states as of 1999.

Older Persons’ Preferences about Consumer Direction

One of the threshold issues for consumer-directed services is whether older people want to take on these management responsibilities. Available quantitative research indicates that a minority of older persons do, and stakeholders generally concur. State program structure affects consumer choice between agency and consumer-directed services.

Quantitative Research

Several surveys suggest a modest level of interest in consumer-directed care by older persons, although substantially less than among younger persons with disabilities. Glickman, Stocker, and Caro (1997) surveyed a random sample of beneficiaries age 60 and older (833 respondents, a response rate of 41 percent) of the agency-directed Massachusetts Home Care Program to determine whether beneficiaries would like to take more responsibility for managing their services. Only 18 percent of older respondents said they wanted “more involvement in determining the amount and type of services” received. Using multivariate regression techniques, the researchers found that willingness to direct a worker was related to prior experience in hiring someone to help with household chores, greater length of receipt of home
## TABLE 1. Key Elements of State Consumer-Directed Home Care Programs

<table>
<thead>
<tr>
<th>California—In-Home Supportive Services and Residual Program</th>
<th>Colorado—Home Care Allowance (HCA)</th>
<th>Kansas—Income-Eligible Program (IEP) and Home- and Community-Based Services for the Frail Elderly (HCBSFE)</th>
<th>Maine—4 Programs with Consumer-Directed Opportunities</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program started</strong></td>
<td>1978</td>
<td>IEP—1995</td>
<td>1982-94</td>
</tr>
<tr>
<td><strong>Primary administrative responsibility</strong></td>
<td>Counties</td>
<td>HCBSE—1981</td>
<td></td>
</tr>
<tr>
<td><strong>Functional eligibility</strong></td>
<td>Disability expected to last 1+ years with need for services</td>
<td>Area Agencies on Aging</td>
<td>Independent Living Centers</td>
</tr>
<tr>
<td><strong>Financial eligibility</strong></td>
<td>Medicaid rules for categorically and medically needy</td>
<td>IEP—income &lt; 150% of FPL and no asset test</td>
<td>Two Medicaid programs follow Supplemental Security Income and 300% of SSI rules. Two state-funded programs have no means test.</td>
</tr>
<tr>
<td><strong>Number of beneficiaries (1999)</strong></td>
<td>218,000</td>
<td>HCBSF—32%</td>
<td></td>
</tr>
<tr>
<td><strong>Percentage of beneficiaries directing their services</strong></td>
<td>96%</td>
<td>IEP—5%</td>
<td>Approximately 100%</td>
</tr>
<tr>
<td><strong>Services covered</strong></td>
<td>Assistance with ADLs and IADLs</td>
<td>Assistance with ADLs and IADLs</td>
<td>Assistance with ADLs and IADLs</td>
</tr>
<tr>
<td><strong>Benefit amounts</strong></td>
<td>Maximum of 283 hours monthly for severely disabled, 195 for moderately disabled</td>
<td>IEP—$1,445 a month maximum</td>
<td>Generally, limited to cost of care in nursing home</td>
</tr>
<tr>
<td><strong>Program expenditures (1999)</strong></td>
<td>$1.2 billion</td>
<td>HCBSF—$2,760 a month maximum benefit as of 4/1/00</td>
<td></td>
</tr>
<tr>
<td><strong>Funding sources</strong></td>
<td>Medicaid, state, county</td>
<td>$38.9 million</td>
<td>Medicaid, Medicaid waiver, state funds</td>
</tr>
<tr>
<td><strong>Possible to hire a relative</strong></td>
<td>Yes</td>
<td>Yes except spouse</td>
<td>Varies by program</td>
</tr>
<tr>
<td><strong>Individual workers’ hourly wages/benefits</strong></td>
<td>Minimum wage/no benefits</td>
<td>IEP—$7.00 to $7.50/benefits vary by Independent Living Center</td>
<td>$7.00 to $12.14/workers compensation insurance</td>
</tr>
<tr>
<td><strong>Quality assurance</strong></td>
<td>Beneficiaries receive annual home visits from county staff. Counties must have complaint hotlines and respond to complaints within 24 hours. Some counties have more extensive quality assurance.</td>
<td>Case managers have quarterly contacts with beneficiaries; two of the contacts are home visits. Case managers determine whether beneficiaries are receiving quality care and assist beneficiaries with problems.</td>
<td>No quality assurance system for consumer-directed programs</td>
</tr>
<tr>
<td><strong>Worker training</strong></td>
<td>Training required for medically related tasks only. Nurses or consumers can do the training.</td>
<td>No training required</td>
<td>Training required for medically related tasks only for programs serving people age 60 and older</td>
</tr>
</tbody>
</table>

*Source:* Interviews with state officials.

*ADL = Activity of daily living, IADL = Instrumental activity of daily living, FPL = Federal poverty level.*
<table>
<thead>
<tr>
<th></th>
<th>Michigan—Home Help Services</th>
<th>Oregon—Client-Employed Provider Program (CEP) and Oregon Project Independence (OPI)</th>
<th>Washington—Medicaid Personal Care Program (MPCP), Community Options Entry System (COPES), and Chore Personal Care Services (CHORE)</th>
<th>Wisconsin—Community Options Program (COPS) and Community Options Program Waiver and Community Integration Program II</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary administrative responsibility</td>
<td>Counties</td>
<td>Area Agencies on Aging or local offices of Senior and Disabled Services</td>
<td>Area Agencies on Aging</td>
<td>Counties</td>
</tr>
<tr>
<td>Functional eligibility</td>
<td>1 ADL or IADL</td>
<td>CEP—Nursing home eligible (2 of 6 ADLs)</td>
<td>MPCP—at risk of institutionalization and needing personal care</td>
<td>Severe medical problems; substantial medical problems with no informal support and disability; chronic mental impairments; or discharge from nursing home</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OPC—1+ ADLs</td>
<td>COPES—2+ &quot;critical care tasks&quot; or cognitive impairment with 1 task</td>
<td>CHORE—1 ADL and one unmet need for services</td>
</tr>
<tr>
<td>Financial eligibility</td>
<td>Medicaid rules for categorically and medically needy</td>
<td>Medicaid rules for 300% of SSI</td>
<td>MPCP—Medicaid rules for categorically needy</td>
<td>COPS only requires an asset test of $65,000. Medicaid programs use categorically and medically needy standards as well as Medicaid rules for 300% of SSI</td>
</tr>
<tr>
<td></td>
<td></td>
<td>OPC—No income or asset test, but there is income-related cost-sharing. People with countable incomes above 200% of FPL pay the full cost of their services.</td>
<td>COPES—Medicaid rules for 300% of SSI</td>
<td></td>
</tr>
<tr>
<td>Number of beneficiaries (1999)</td>
<td>37,000</td>
<td>13,440</td>
<td>21,721</td>
<td>24,000</td>
</tr>
<tr>
<td>Percentage of beneficiaries directing their services</td>
<td>100%</td>
<td>CEP—100%</td>
<td>Approximately 50%</td>
<td>Unknown</td>
</tr>
<tr>
<td>Services covered</td>
<td>Assistance with ADLs and IADLs</td>
<td>Assistance with ADLs and IADLs</td>
<td>Assistance with ADLs and IADLs</td>
<td>Any services the beneficiary needs</td>
</tr>
<tr>
<td>Benefit amounts</td>
<td>Program does not pay for 24-hour care</td>
<td>No individual limits</td>
<td>184 hours a month for consumer-directed clients; 112 hours a month for agency services, with exceptions permitted</td>
<td>No limits</td>
</tr>
<tr>
<td>Program expenditures (1999)</td>
<td>$160 million</td>
<td>$84.95 million</td>
<td>$155 million</td>
<td>$163 million</td>
</tr>
<tr>
<td>Funding sources</td>
<td>Medicaid</td>
<td>Medicaid waiver, state funds</td>
<td>Medicaid, Medicaid waiver, state funds</td>
<td>Medicaid, Medicaid waiver, Older Americans Act, state funds</td>
</tr>
<tr>
<td>Possible to hire a relative</td>
<td>Yes, except spouse</td>
<td>CEP—yes, except spouse</td>
<td>Yes, except spouse in the two Medicaid programs</td>
<td>Varies by county, but majority of counties permit use of COPS funds to pay spouses</td>
</tr>
<tr>
<td>Individual workers’ hourly wages/benefits</td>
<td>$5.15 to $8.00/program pays Social Security and unemployment taxes</td>
<td>$7.50 to $8.02/unemployment benefits only</td>
<td>$6.68/workers can buy into Washington Basic Health Plan</td>
<td>$6.00 to $15.00/benefits vary by county</td>
</tr>
<tr>
<td>Quality assurance</td>
<td>Beneficiaries receive semi-annual home visits from case managers. Case managers respond to complaints.</td>
<td>Beneficiaries receive annual home visits from case managers. Case managers respond to beneficiary complaints.</td>
<td>Beneficiaries receive annual home visits from case managers. Case managers respond to beneficiary complaints.</td>
<td>Case managers must have monthly contact with all beneficiaries. In addition, a private organization does a paper review of all Medicaid waiver beneficiaries’ care plans and takes a statistically representative sample of all beneficiaries. The sample receives home visits. The state is developing outcome measures that include the extent to which consumer preferences are honored.</td>
</tr>
<tr>
<td>Worker training</td>
<td>No training required</td>
<td>Workers subject to criminal background check. No training required.</td>
<td>Workers subject to criminal background check, 22-hour training course required and 10 hours a year of continuing education.</td>
<td>Workers must receive training or demonstrate competence in six areas including personal hygiene, beneficiary conditions, and consumer direction. Consumers may train workers.</td>
</tr>
</tbody>
</table>
care services, greater current involvement in directing a home care worker, and less satisfaction with home care services.

The University of Maryland Center on Aging surveyed Medicaid personal care beneficiaries in Florida, New Jersey, and New York to determine their willingness to participate in a demonstration project that would provide cash assistance in lieu of personal care services (Desmond et al. 1998; Mahoney et al. 1998; Simon-Rusinowitz et al. 1998). A random sample was taken of Medicaid beneficiaries in each state. Respondents age 65 and older were significantly less willing to receive cash assistance in lieu of their current personal care benefits than younger persons, although about a third to a half of older beneficiaries in all three states expressed interest.

Several factors limit the generalizability of the findings of these four studies. Response rates for the surveys were relatively low (41 percent in the Glickman study, and ranging from 23 to 48 percent in the University of Maryland studies). Poor health was a major reason why people did not respond to the University of Maryland surveys. In addition, because the University’s studies presented hypothetical situations to respondents rather than asking them to make an actual choice between agency-directed and consumer-directed care, it is not certain what their behavior would be if faced with a real decision.

**Government Official and Stakeholder Opinion**

The views of government officials and stakeholders varied on whether older persons want to direct their own care. Three of eight government representatives said that older persons prefer consumer-directed care. They contended that personal circumstances are the most important influences on a beneficiary’s desire to direct services, arguing that people of all ages who are assertive and have informal caregivers who can help recruit independent providers or may be available to become workers are most likely to want to direct their own care. In contrast, two government officials said that older people prefer agency services. The remaining respondents did not believe that older persons prefer one model over the other.

The seven disability advocates representing the views of those under age 65 promoted consumer direction, but most noted that at this point the concept is not well known among the older population. Three representatives said that people of all ages want consumer direction, but one of these representatives contended that older persons are less likely to articulate such a preference. Three of the disability representatives said that older people prefer agency services, and one of these representatives added that older persons are accustomed to the medical model. One aging representative commented that people of all ages prefer consumer direction, and another said that older persons prefer agency services. Two of the aging representatives said that older people did not prefer one model over the other.

Representatives of home care agency associations and unions generally believed that older persons prefer agency services. Six of seven agency representatives and four of six union representatives believed that older persons preferred agency services because they are too “tired” or frail to manage services.
Program Structure

In the case study states, government officials’ estimates of the percentage of people directing services in these programs ranged from 5 percent to 100 percent. States differ, however, in the extent to which program structure influences choice between the agency and consumer-directed models. In Colorado, for example, the consumer-directed program has a benefit limit of $396 a month. Therefore, people who have high service needs are more likely to participate in the state’s agency-based Medicaid home- and community-based services waiver because of its higher benefit limits. In contrast, as a way of limiting costs, Washington requires beneficiaries who need more than 112 hours of services per month to use the consumer-directed model rather than agency services. Under state law, California’s 58 counties must offer consumer-directed services, but only about a dozen counties offer beneficiaries a choice between consumer-directed and agency-directed services.

Older Persons’ Capacity to Manage Services

No research has been performed on the extent to which people with disabilities have the individual management capabilities necessary to handle the responsibilities of consumer-directed services, but some observers compare the skills required to manage an attendant to those required to run a small business (Sabatino and Litvak 1992). The views of government officials and stakeholders on the management capability of older persons varied, and state programs provide limited assistance to beneficiaries in the consumer-directed model.

Government Official and Stakeholder Opinion

Although home care agency and union representatives tend to believe that older people are less capable of managing services than younger people, the majority of the other observers did not believe there was a difference in capabilities. Government representatives from five of the eight states felt that the ability to direct services does not vary by age; one of them said that everyone is capable of directing services with sufficient training and support. Government officials from the other three states contended, however, that older persons find consumer direction more burdensome or are less capable of management than younger persons.

Disability representatives from six of the eight states believe that age does not affect capabilities; one said that anyone is capable of consumer direction with training and support. Disability advocates from the other two states, though, believe that younger people are more capable of managing services. Only one of four aging representatives argued that older persons are less capable than younger persons, contending that older persons want help in making decisions.

Home care agency and union representatives tended to agree that older persons are less capable of management than are younger persons. Four of seven agency representatives believed that older people are too weak or tired to manage services or that they get overwhelmed by the management tasks. Three of six union representatives took similar views. Other respondents did not believe that capabilities vary by age.
Program Structure

Older people with disabilities may have little experience with hiring and firing workers, and the management tasks associated with consumer direction are complex. Thus, some advocates of consumer-directed services stress the importance of providing information and counseling to aid persons with disabilities in finding and accessing services (Cameron and Firman 1995).

States vary in the amount of training or assistance with management tasks they provide to beneficiaries, but stakeholders generally characterized the amount of assistance available to beneficiaries as limited. In addition, programs generally use fiscal agents to pay workers, which complies with Medicaid’s prohibition against giving cash to beneficiaries and can help decrease beneficiaries’ management tasks. Fiscal agents also take care of the administratively complex task of withholding and paying federal and state income, Social Security, Medicare, and other taxes.

A variety of mechanisms offer some help to consumers. Case managers provide information, such as advising beneficiaries about how to recruit a worker, but large caseloads mean that this assistance is rarely extensive. Wisconsin is an exception. Case managers typically have caseloads of only 40 beneficiaries, and those case managers assigned difficult populations (e.g., homeless older people) may have caseloads as low as 10 clients. In addition, local independent living centers—private, nonprofit organizations funded by the Rehabilitation Act of 1973—provide supportive services, such as training and advocacy for beneficiaries, within their limited funding. Moreover, independent living centers in Kansas and Maine act as fiscal agents responsible for paying workers. In a recent innovation, about half a dozen counties in California have established independent public authorities that perform such functions as maintaining registries of screened workers, setting up worker referral systems, arranging for emergency backup services, and providing management training to consumers. San Diego County, California, is developing a consumer cooperative designed to oversee a worker registry and to arrange for emergency backup services. Each participating consumer would have to work five hours per month at the cooperative to obtain benefits.

States differ in their policies on whether persons with cognitive impairments can participate in consumer-directed programs. Although the ability of persons with cognitive impairments to manage services is uncertain, in each of the eight states these people can participate in at least one consumer-directed program. As in consumer-directed programs serving the population with developmental disabilities, six states try to minimize risk to beneficiaries with cognitive impairment by requiring surrogate decisionmakers, but two states have no such requirement. Surrogates are family members or personal advocates of some kind who act on the client’s behalf. Thus, the decisionmaker in these cases is not actually the client. The assumption is that the surrogate will act as the client would if he or she were cognitively intact. Making consumer direction work safely for persons with cognitive impairments can require considerable ingenuity on the part of case managers. Wisconsin, for example, tries to keep people with cognitive impairments at home with individual workers by recruiting neighbors to alert the case manager to deviations in the beneficiaries’ normal routines.
Quality of Services

The quality of consumer-directed services is probably the most highly contested issue facing policymakers. Traditional home and community services programs for older persons attempt to assure quality by relying heavily on government regulation that requires the provision of services by professionals, training requirements for paraprofessional staff, and agency supervision of paraprofessionals. Almost all of these mechanisms are lacking in consumer-directed care. The limited quantitative research and opinions of interviewees are generally consistent with the view that consumer-directed services provide quality of care and life that is at least comparable to agency-directed care, if not better. However, these results relate to measures of consumer satisfaction and not to other measures, such as delay of functional decline or absence of avoidable hospitalizations, that may be important indicators of quality. Government officials and stakeholders expressed concern about the quality of services delivered to those with cognitive impairment, and states do not impose comprehensive quality monitoring systems on consumer-directed programs.

Quantitative Research

Two quantitative studies of Medicaid programs with consumer-direction features have been conducted, one focused on Medicaid recipients in California and the other on beneficiaries in Maryland, Michigan, and Texas. In the California study, Benjamin et al. (1998) conducted a telephone survey of a stratified random sample of about 1,100 cognitively intact respondents (78 percent response rate) in the consumer-directed and agency-directed models. About half of consumer-directed and agency-directed respondents were age 65 and older.

In California, consumer-directed respondents reported more satisfaction than agency-directed clients with their services and the freedom to select them, a stronger preference for managing services, higher perceived quality of care, and higher emotional, social, and physical well-being. Consumer-directed respondents also reported greater satisfaction with the providers’ ability to assist them in doing things inside and outside of the home than did agency-directed clients. Other differences in outcomes between the two groups were not significant. Somewhat disconcerting is that about 37 percent of agency workers in California reported little or no supervision.

Within the consumer-directed model, provider type was a significant predictor of four client outcomes. Respondents with family providers reported a higher sense of security, more satisfaction with their services and selection of them, a stronger preference for managing services, and greater satisfaction with the providers’ interpersonal manner than clients with nonfamily providers. Other differences in outcomes between family and nonfamily providers were not significant.

In the second study of Medicaid programs with consumer-direction features, Taylor, Leitman, and Barnett (1991) conducted in-person interviews with 879 Medicaid beneficiaries who were receiving personal care in Maryland, Michigan, and Texas; Michigan has long had a consumer-directed program that provides a great deal of choice to consumers. Survey response rates were above 90 percent in each of the three states. About 80 percent of respondents were age 70 or older, and half the
sample had difficulty performing two or more activities of daily living. None of the respondents had cognitive impairments. In an effort to determine how consumer choice affects beneficiaries’ satisfaction with their lives and their workers, the researchers constructed an index of choice to compare the responses of those who reported little or no choice about their home care providers with those who had a great deal of choice.

Taylor et al. (1991) found that those with a great deal of choice consistently reported more satisfaction with their services than those without choice. For example, about 60 percent of those reporting little choice were very satisfied with their aides, compared with 90 percent of those reporting a great deal of choice. About half of those reporting little choice, but 90 percent of those reporting a great deal of choice, said that their aides came to work as expected. Further, about half of those reporting little choice said their aides knew how to get things done very well, compared with almost all of those reporting a great deal of choice (Taylor et al. 1991; Doty, Kasper, and Litvak 1996). A major limitation of this study, as well as with the California study, is that it did not include persons with cognitive impairment.

**Government Official and Stakeholder Opinion**

Six of eight government representatives believed that beneficiaries with consumer direction are more satisfied, have more control over services, or have better quality of life than those receiving agency services. None of these representatives thought that quality is worse under consumer direction. The opinion of disability representatives was uniform—they all believed that consumers have better quality services under consumer direction, and they cite reasons similar to those of government representatives. Three of four aging representatives shared these opinions.

Again, the majority of home care agency and union opinions were consistently different from those of the government officials and advocacy representatives. Most believed that there are no differences in quality between the two models. However, one of seven agency representatives and two of six union representatives believed quality under consumer direction to be better than with agency services because of consumers’ ability to make choices about service delivery.

When it came to people with cognitive impairment, virtually every government official and stakeholder expressed concern about the potential for problems with quality of care. Respondents worried that individual workers might not deliver the services they were paid to deliver and that people with cognitive impairment might have trouble with management responsibilities under consumer direction.

No respondent believed that quality would be better for those with cognitive impairment under the consumer-directed model. Three of eight government representatives believed that people with cognitive impairment would receive worse quality of care under consumer-directed systems; the rest said that quality would be the same under both models. Although on other dimensions disability representatives were vigorous advocates of consumer-directed care, half of the eight disability representatives thought that quality of care under consumer direction was worse for persons with cognitive impairment; the other half said quality would not differ between the two models. One of four aging representatives said that quality would be worse
for those with cognitive impairment. Five of seven home care agency representatives and three of six union representatives believed that agencies provide higher-quality services to persons with cognitive impairment than do independent providers.

**Program Structure**

In the eight study states, beneficiaries are primarily responsible for quality assurance in consumer-directed programs. Governmental quality assurance activities in consumer-directed programs are fairly minimal, consisting mostly of responding to complaints, periodic home visits, and telephone contact with beneficiaries. Two of the eight states limit their quality assurance activities primarily to responding to beneficiary complaints, and three states maintain hotlines dedicated to receipt of complaints. Five states visit beneficiaries at least once each year to assure quality. Two states have regular telephone contact with beneficiaries. Wisconsin contracts with a private group to visit the homes of a sample of beneficiaries in addition to county-level quality assurance activities. Six states use a combination of methods.

Consumer-directed workers in four states are required to have some formal training, but one of those states permits consumers to instruct workers. Thus, workers in at least half of the states do not necessarily receive the training required of certified nurse assistants or home health aides, despite the fact that they do nearly identical work. Similarly, only two states require criminal background checks for consumer-directed workers. For the most part, consumer-directed workers provide unskilled care, but Washington and Oregon amended their nurse practice acts to allow nurses to delegate certain medically related tasks, such as medication management, to unlicensed workers. Washington has the most comprehensive requirements for workers, requiring individual and agency workers to undergo a criminal background check, a 22-hour training program, and 10 hours of continuing education each year.

**Workers in Consumer-Directed Programs**

Workers in traditional home care programs receive their salaries from agencies, work under agency rules, and are not directly answerable to beneficiaries, whereas consumer-directed workers are. How do workers’ experiences compare with those of agency workers? Quantitative research and interviews with government officials and stakeholders suggest that consumer direction most likely improves individual workers’ relationships with beneficiaries and working environments, but leaves workers at somewhat of an economic disadvantage compared with their agency counterparts. Paid family caregivers play a key role as independent workers. Interviews indicate that labor shortage is a major problem for both models in the case study states, and some of these states are developing initiatives to address labor shortage and other worker issues.

**Quantitative Research**

The literature search identified only one study that compared the experiences of agency- and consumer-directed workers. In California, about 75 percent of individual workers knew the consumers before they started work, versus only 7 percent of
agency workers (Benjamin et al. 1998). Moreover, the average agency worker had about four clients, compared with 1.4 clients for independent workers. As a result, individual workers may have the time and the opportunity to build good relationships with beneficiaries. Family caregivers who worked for California beneficiaries were more likely to feel close to beneficiaries, but they reported more emotional burden than other individual workers (Benjamin et al. 1998). For example, family workers were more likely than other individual workers to worry about beneficiary safety.

Probably because of the closer personal relationships, and perhaps the living arrangements, individual workers were more likely to provide unpaid care. About 75 percent of individual workers were family members or friends of the beneficiaries (Benjamin et al. 1998). About 61 percent of independent workers in California provided unpaid assistance to consumers, compared with 12 percent of agency workers. Moreover, about 80 percent of family workers provide unpaid assistance, whereas 43 percent of other individual workers did so.

The California study illustrates the typical compensation problems facing home care workers, with virtually all individual providers reporting no fringe benefits. In contrast, about 40 percent of agency workers received health benefits, paid sick leave, and paid vacation, and about 60 percent of these workers received paid holidays and payment for travel costs (Benjamin et al. 1998).

**Government Official and Stakeholder Opinion**

Government and stakeholder opinion was largely consistent with the results of the California study, with government and consumer representatives pointing out the advantages of being an individual worker and agency and union representatives pointing out the disadvantages. Government and consumer representatives said that individual workers have better, closer working relationships with beneficiaries than do agency workers because individual workers tend to know beneficiaries before they become the beneficiaries’ employees, to have fewer clients, and to stay with consumers for long periods of time.

With the exception of half of the union representatives, government officials and stakeholders also said that individual workers have more control over their work day than do agency workers because consumer-directed workers are not subject to agency rules governing schedules and the types of tasks they can perform. As one agency representative put it, individual workers are “happier because they have more authority over their tasks and feel more accomplishment as a result.” In contrast, half of the six union representatives said that individual workers had less control over their schedules than agency workers because individual workers have to be responsive to beneficiaries’ preferences about what should be done and how.

Informal caregivers play a major role in most consumer-directed programs. Government representatives from four of the eight study states estimated that half or more of consumer-directed beneficiaries hire friends or relatives to be their paid workers; the other four states could not provide estimates. Although federal Medicaid policies permit the hiring of relatives, paying spouses is specifically prohibited. Supporters of paid family caregivers argue that hiring family members supports the informal system, expands the labor pool, and results in high-quality care because of
close family relationships. A minority of agency and union representatives were opposed to hiring family, saying that caregiver payments become an income stream for the family, rather than a way of increasing services for beneficiaries. Most agency and union representatives argued that family workers should have the same training, benefits, and oversight as other workers.

Although individual workers may have better personal relationships with clients and more control over their work, there are downsides to being an individual worker. Union representatives argued that family workers often work without pay. In addition, according to union and agency representatives, individual workers may have little supervision, isolating them from their peers and from more highly trained staff.

Stakeholders agreed that agency workers tend to have more fringe benefits than individual workers; however, benefits are often restricted to employees working a minimum number of hours, which varies by agency but is often 32 or more hours a week. Given the part-time nature of many home care jobs, many agency workers may not have access to benefits.

Although agencies receive higher payment rates than do individual workers, this does not necessarily result in higher wage rates for agency workers. In the case study states, wages were reported to be about the same for individual and agency workers. Government and consumer representatives in Kansas, Maine, and Wisconsin said it is even possible for individual workers to receive higher wages than agency workers if the former have longevity with a beneficiary or perform certain medically related tasks. For example, individual workers in some Wisconsin counties that recognize these factors make between $6.00 and $15.00 an hour, whereas agency workers earn the minimum wage.

There was universal agreement that consumers and agencies face significant challenges in recruiting workers because of a labor shortage, with respondents using such terms as “crisis” to describe the situation. While some research has found that there is not a single labor market for long-term care and other service workers, respondents said that entry-level workers could get better salaries and benefits from fast food establishments, such as McDonalds, and casinos (Pindus, Dyer, and Ratcliffe 1997).

Program Structure

California, Wisconsin, and Washington have begun to address some of the reported disadvantages of being an individual worker. Some counties in California and Wisconsin have begun developing supportive services for individual workers such as setting up opportunities for interaction and mutual support. In California about half a dozen counties have set up quasi-governmental public authorities that serve as the individual workers’ employer of record and provide worker support networks. In 1999, the legislature passed budget provisions designed to give individual employees collective bargaining rights by requiring counties to designate a single employer of record for all workers in the county (Bureau of National Affairs 1999). Under Wisconsin’s Community Links program, 27 counties received a one-time grant to develop innovative approaches to recruitment, retention, and support of individual workers. Some counties have funded private “employment agencies” that
coordinate training of workers, set up worker registries, and provide consultation and peer support groups to workers.

Washington is the only state to address lack of access to health insurance by allowing individual workers who work at least 20 hours per week to buy into the Washington Basic Health Plan, which is a state-sponsored health insurance program. However, the cost of this plan may be beyond the reach of low-income home care workers.

**Conclusion**

As the United States explores ways of expanding home and community services for older and younger people with disabilities, policymakers increasingly are considering the potential role of consumer direction. Although consumer-directed services are well established for younger people with disabilities, they are less common among programs for older people. This paper assesses some of the policy issues related to whether consumer direction should be expanded for older beneficiaries by reviewing existing quantitative research, interviewing stakeholders in eight states currently operating consumer-directed programs for older people, and analyzing the program structure in these states. Stakeholders in the eight study states were sharply divided. On one side were consumer advocates and government representatives responsible for administering the consumer-directed program, who generally favored an expansive role for consumer direction. On the other side were home care agencies and union representatives, who are either opposed to expansion or urge caution.

This paper identified four key policy issues. First, quantitative surveys and interview results indicate that older people are less likely to want consumer direction than younger persons, but that a significant minority of older people prefer consumer direction. Giving clients the option of consumer direction will mean substantially restructuring current home and community services programs in most states. Programs should be flexible enough to allow beneficiaries to manage their own services when they want to, while providing agency services for those who do not want to manage or are incapable of management. The bottom line is that older persons are not homogeneous and they should have a choice of management models.

Second, although some older persons want to and currently do direct their own services, a significant portion of stakeholders raised questions about the capacity of older people to manage their own care, largely related to the prevalence of cognitive impairment among the older population. Despite these concerns, every study state allows cognitively impaired persons to participate in these programs, relying on surrogates to make the decisions for the consumers. Although this is a reasonable accommodation to the limits of the cognitively impaired, it should be recognized that surrogates’ decisions are likely not perfect representations of the choices that the clients would have made if they were not impaired. At least some of the decisions that the surrogates will make will reflect their own preferences, schedules, and interests rather than those of the client. Beyond the issue of cognitive impairment, most states do relatively little to help clients cope with the management tasks inherent in consumer direction, leaving clients to find their own way. An exception is that the
states use fiscal agents to pay the workers and withhold applicable taxes, which substantially reduces the paperwork that clients must complete.

Third, probably the most contentious issue surrounding consumer-directed programs relates to whether quality of care is adequate and how services should be monitored. Compared with agency-directed care, consumer-directed services lack the standard quality assurance structures of training of paraprofessionals, supervision by professionals, and provision of technical services by professionals. Nonetheless, limited quantitative research on the cognitively intact population and interviews with stakeholders suggest that consumer-directed services are at least no worse than agency-directed care and may be better because of the ability of the former to make the service conform to the preferences of the client. Stakeholders were more anxious about the quality of care for people with cognitive impairment because of their vulnerability to abuse.

Again, despite concerns about quality of services, most states have taken fairly minimalist approaches to monitoring quality, relying mostly on complaints and case manager interaction with clients to identify problems. Although most services provided in consumer-directed programs are unskilled, the lack of training requirements and monitoring is particularly striking at a time when proposals for increasing regulation of nursing facilities are commonplace. Advocates and policymakers appear to have placed greater priority on maintaining flexibility and consumer choice in the home and community services setting, fearing that increased regulation will replicate an “oppressive” nursing home setting.

In place of formal quality assurance mechanisms, consumer-directed programs rely on the ability of clients to fire unsatisfactory workers and to hire replacements to assure quality—in other words, the market. The current labor shortage, which makes recruitment difficult for all long-term care services, may threaten the quality of these services by undermining the willingness of clients to fire poor-quality workers, perhaps increasing the need for more formal quality assurance mechanisms.

Fourth, independent workers appear to fare better than agency workers in their work environment (although this conclusion is contested by home care and union representatives), but to do less well financially. Clearly, part of the attraction to states of the consumer-directed model is its low per-person cost. Payment rates for consumer-directed care are much lower than for agency-directed care, partly because there is no administrative overhead in consumer-directed care and partly because workers receive less in the way of health benefits, vacation, and other fringe benefits. At least in the study states, workers’ hourly wage rates appear to be about the same in both the consumer-directed and agency-directed models.

A major worker-related issue is that a significant portion of independent workers are family members, as many as half in some of the study states. At least in California, the vast majority were known by the client before they became paid caregivers. Many of the issues discussed above—management, training, quality assurance, and payment levels—take on a very different cast if the independent provider is a family member or friend rather than a stranger. The adage that “blood is thicker than water” may account for some of the states’ relatively laissez-faire approach to program management and for some of the positive results on quality.
In sum, the notion of consumer-directed home care challenges the protective nature of most home and community services programs for older people by asserting that clients want to manage and are capable of managing their own care. Although there seems to be little reason for cognitively intact persons not to be able to do so if they want to, the situation is much more complicated for persons with cognitive impairment, although surrogate decisionmakers may still allow participation by these consumers. In order to aid consumers, states may want to consider whether a more activist approach to providing supports such as worker registries and monitoring of client satisfaction is warranted.
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