

# Consumer-Directed Models of Personal Care: Lessons from Medicaid

PAMELA DOTY, JUDITH KASPER,  
and SIMI LITVAK

*U.S. Department of Health and Human Services: Johns Hopkins University;  
World Institute on Disability*

**H**ISTORICALLY, PROFESSIONAL AUTHORITY HAS played a dominant role in the social organization of medical care and related human services (Friedson 1970). In recent years, however, a countervailing ideology, or ethic, of "consumerism" has begun to assert itself in the health and human services domain.

In this article, we compare and contrast alternative approaches to administering programs, financed under the Medicaid personal care services (PCS) optional benefit, that make attendant services available to low-income elderly and disabled persons in need of help with daily living tasks. Our analyses address the following issues:

- By how much do state Medicaid PCS programs vary in terms of their administrative features that promote greater consumer choice and control or, conversely, in their emphasis on professional oversight and accountability?
- To what extent have program administrators actively fostered consumer-directed care models?

- What are the decision-making trade-offs in terms of Medicaid PCS costs per hour of attendant service, coverage for high-need clients, perceived risks to quality, or other liability concerns associated with consumer direction versus professional management of attendant services?
- To what extent do clients report having greater choice and control over attendant services in some states' Medicaid PCS programs as compared to others?
- Does greater client choice and control result in higher client satisfaction with attendant services?

## Background

### *Philosophical Origins of "Consumer-Directed" Services Models*

The concept of "consumer-directed" personal assistance comes out of the independent living and disability rights movements (Litvak, Zukas, and Heumann 1987; Simon-Rusinowitz and Hofland 1993; DeJong, Batavia, and McKnew 1992). The term "personal assistance services" (PAS) refers to a range of human and mechanical assistance provided to persons with disabilities of any age who require help with routine activities of daily life (ADLs). These services, when provided in non-institutional settings, are also frequently referred to as "home and community-based long-term care." PAS is the term preferred by persons with disabilities and professionals in the disability and aging fields who advocate consumer-directed models of service provision as a means of maximizing the independence and autonomy of persons who need functional assistance from others. Although PAS, broadly defined, includes assistive technologies, home modifications, psychosocial rehabilitation, and a host of other specialized products and services oriented to persons with disabilities, the core service is personal assistance provided by an individual who is variously referred to as a personal assistant, attendant, or aide. "Consumer-directed" modes of financing and delivering attendant services permit service recipients—as opposed to medical or social work professionals—comparatively greater choice and control over all aspects of service provision: from hiring the attendant, to defining the attendant's duties, to deciding when and how specific tasks or services are performed. Actual programs

may be ranked on a continuum as more or less "consumer directed" to the extent that they foster greater choice and control along several dimensions such as hiring and firing, training, supervising, and paying attendants.

Advocates of consumer-directed models of service provision argue that people with disabilities should be afforded as much independence and autonomy as possible in decisions about the types, amounts, and sources of the PAS they receive—especially regarding attendant services. At the same time, the use of public funds raises significant questions of accountability—including liability for adverse outcomes—which must be faced. Traditionally, government health and human services program administrators have viewed requirements for professional standards and supervision as their main method of achieving accountability. Moreover, advocacy of formal, publicly funded "home care" has, until recently, been mainly the province of groups representing older persons and, as Eustis and Fischer (1992) have observed, advocates for the elderly, in contrast to the disability rights movement, have tended to be proponents of professional case-management and strong quality-of-care regulation.

### *The Medicaid Personal Care Services Benefit*

Medicaid is the single largest source of financing for home and community-based (HCB) long-term-care services for the disabled of all ages. Within Medicaid, the personal care optional benefit remains the major funding mechanism for personal attendant services used by the elderly and by younger, physically disabled populations. Although, as of 1993, Medicaid expenditures for HCB long-term care provided under the rubric of section 1915 (c)<sup>1</sup> waivers surpassed spending under the personal care benefit, two-thirds of this funding goes toward services for the mentally retarded and developmentally disabled, as distinct from services for the elderly and physically disabled under age 65 (Miller 1992). Although PCS has existed as an optional benefit in Medicaid since the early days of the program, relatively few states elected to provide this coverage prior to the 1980s. In fiscal year (FY) 1979, only

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<sup>1</sup> This section of Title 19 of the Social Security Act is the statutory authority for the Health Care Financing Administration to grant these waivers.

ten states provided PCS. As of FY 1994, however, 33 Medicaid programs included PCS. Total national Medicaid PCS expenditures for FY 1994 were just under \$3 billion.

### Data Sources

Data are presented here on both the administrative features of Medicaid PCS and the client perspective on care. Descriptive data on the administrative features of Medicaid PCS are from surveys of attendant services programs in all 50 states conducted in 1984 and 1988 by the World Institute on Disability (WID), and subsequent in-depth case studies in six states based on site visits carried out during 1990 and 1991. Client perceptions of their role in directing services, as well as satisfaction with care, are drawn from a 1990 survey of elderly PCS clients in three states designed by staff of the Commonwealth Fund Commission on Elderly People Living Alone and carried out by Louis Harris and Associates (Commonwealth Fund Commission . . . 1991).

The 1984 and 1988 surveys of 50 states were conducted via mail questionnaire, followed up by telephone interviews with state program officials for purposes of clarification and completion. The surveys sought to obtain information about all attendant programs serving the elderly and younger physically disabled persons—including those who are funded from sources other than the Medicaid PCS benefit. In this article, however, we report descriptive information only on Medicaid PCS programs. (For additional information about these surveys see Litvak, Zukas, and Heumann [1987] and Litvak and Kennedy [1991].)

Descriptive data on Medicaid PCS programs from the 1988 WID 50-state survey provided the basis for selecting a limited subset of programs for in-depth case study. The sites (Michigan, Maryland, Texas, Massachusetts, Oregon, and Montana) were selected, in large part, because they exemplified contrasting approaches to services financing and delivery on dimensions relevant to consumer choice and control. In Michigan, Maryland, and Massachusetts, Medicaid PCS aides were exclusively or predominantly “independent providers.” In contrast, Texas, Oregon, and Montana required all, or almost all, aides to be employees of Medicare or Medicaid certified home health agencies (HHAs). The states were also selected to represent variations among states in requirements for formal quality assurance (e.g., aide training and the nature

and frequency of supervision by registered nurses) as well as how strictly they chose to interpret federal Medicaid prohibitions against hiring family members as PCS aides. The main purpose of the case studies was to find out from state PCS program officials why various administrative features or regulations had been adopted. In particular, interviews with state officials sought to determine the extent to which state decision-making had been motivated by philosophical values (for example, a belief that certain program elements were desirable because they maximized consumer choice and control, or were supportive of family caregivers, or because they represented professional standards of quality assurance) or, conversely, whether decisions had been driven by practical considerations such as cost control or minimizing states' legal liability. (For additional information on the state case studies, see Kennedy and Litvak [1991].)

Data on Medicaid PCS client perceptions of choice and control, as well as measures of client satisfaction with attendant services, were obtained via a questionnaire survey, administered in face-to-face, in-home interviews with samples of Medicaid clients in three states. Because the Commonwealth Commission's mandate was to explore issues affecting older Americans, the survey focused exclusively on Medicaid PCS clients aged 65 and older. By design, the states included in the Commonwealth Commission client survey (Michigan, Maryland, Texas) were also among the WID case-study states.

Louis Harris and Associates completed a total of 879 face-to-face, in-home interviews between May 18 and August 19, 1991 (300 in Maryland, 276 in Michigan, 303 in Texas). In each state, about half the interviews were drawn from an urban area and half from a rural area. In all, 1,405 people were approached for interview, based on names drawn from Medicaid enrollment lists. Of these, 28 percent were ineligible: 21 percent because they were hospitalized/nursing-home resident/deceased/not at address; 7 percent based on a competency screening; 3 percent because they refused to participate; and 6 percent because they were not contacted within three attempts. If both refusals and noncontacts are regarded as nonresponses, the overall response rate was 88 percent. Because the focus of the survey was on consumer choice, individuals with indications of dementia severe enough to raise doubts about their ability to exercise choice were screened out at the beginning of the interview, using a modified version of Pfeiffer's (1975) Short Portable Mental Status Questionnaire (105 individuals in all).

## Findings

### *Access to Independent Providers in Medicaid PCS Programs*

One simple indicator that advocates of consumer direction often use as a basic threshold differentiating public programs that tend to foster consumer control from those that favor professional dominance, is whether or not a program permits personal care attendants to be "independent providers" rather than requiring them to be employees of certified home health or home care agencies. The rationale is that, without agencies (and the professionals who run them) as intermediaries, service recipients would be expected to play a much more significant role in hiring and firing, training and supervising, as well as paying their aides.

Both the 1984 and 1988 WID surveys found that PCS programs tended to require or very strongly emphasize *either* agency-employed attendants *or* independent providers. Thus, among programs classified as having "mixed modalities" (some combination of agency-employed attendants, independent providers, and/or government employees), one mode was often dominant, with the other(s) being available only rarely. As of 1988, agency-employed attendants were the required or dominant service delivery mode in 13 Medicaid PCS programs, whereas independent providers were the required or dominant mode in nine.

Although access to independent providers would seem a prerequisite for consumer control, the 1988 WID survey findings indicate that it does not guarantee consumer choice or control with respect to all aspects of managing attendant services. Among 12 Medicaid PCS programs that utilized independent providers, most (10) allowed consumers to hire and fire their own attendants, but only half (6) allowed consumers to train their own attendants, and only one-fourth (3) allowed consumers to participate in paying attendants (Litvak and Kennedy 1990).

### *State Perspectives on the Use of Independent Providers versus Agency-Employed Personal Attendants*

The WID case studies documented that some states (e.g., Michigan and Massachusetts) had consciously adopted, in at least some respects, an ideology of consumer and/or family caregiver empowerment, which was

reflected in the use of independent providers. The case study interviews also indicated, however, that in Maryland this mode of service delivery was perceived primarily as a mechanism for controlling costs.

The Massachusetts program was established in 1976 by administrators in the Massachusetts Rehabilitation Commission (MRC), who were strongly influenced by the early independent-living movement. Indeed, the MRC helped to create the client-directed independent-living centers (ILCs) that administer the program. Control of costs per case or per client appeared to have very low priority during the first 14 years of the program—probably because the program was largely under the control of advocates for persons with disabilities and because it was small, serving only 1,775 clients in 1990. (However, the WID researchers picked up indications that this freedom from bureaucratically imposed cost control measures might soon disappear, owing to the state's budget crisis and pressure to expand the program to serve a broader clientele, including mentally retarded clients.) Attendants received above-average wages (\$7.85 per hour in 1990—well above the minimum wage, or slightly above the minimum-wage level typical for both independent and agency-employed attendants in most states). An unusual feature of the Massachusetts program was that it encouraged and paid for clients to be trained in how to manage their attendants. ILCs received 24 cents per hour of attendant care for administration—well below, in percentage terms, what private agencies usually receive.

In Michigan, state officials appeared to have both types of motivations. That is, Michigan PCS program officials had a long-standing philosophical commitment to consumer and family caregiver empowerment, which they also perceived to be in harmony with the state's fiscal interest in containing both the direct service and administrative costs associated with attendant care. Thus, consumers participated in paying their attendants through the device of a "two-party check," on which the client's signature was necessary to authorize payment to the attendant. This mechanism was designed so that the attendant could be considered the employee of the client rather than the state, and it gave the attendant a very concrete motive to be concerned with providing satisfactory service to the consumer. At the program's inception, the two-party check was also seen as a device that would allow the state to avoid becoming legally bound to withhold taxes or to pay workers' and unemployment compensation (although since the WID case studies were completed, Michigan has been required by the Internal Revenue

Service and its own state labor department to take on these responsibilities). Finally, in a “rust-belt” state like Michigan, with a troubled economy and high demand for publicly funded social services, cost control was a high priority. Curbing costs per hour of service provided and per client served was seen as a way to stretch limited funds to serve larger numbers of clients. Michigan’s was one of the largest PCS programs in the country in numbers of clients served. As of 1990–91, the program had an average monthly caseload of 27,558 clients; but only 1,800 to 2,000 received attendant services in excess of \$333 per month. The low monthly payment cap for most clients existed because of federal labor requirements to provide workers’ compensation and unemployment for employees earning more than this amount. One reason why Michigan officials favored the use of family members as paid providers was that they believed it was easier to recruit reliable minimum wage workers from within the client’s family.

Some critics of state home care programs that rely mainly or exclusively on independent providers allege that this mode of service provision is more cost-effective than models requiring use of home health or home care agencies only because attendants working independently have no provider organizations to advocate paying them good wages and benefits. On average, across all state programs, the 1988 WID survey found that independent providers tended to receive somewhat lower wages and fewer benefits (table 1). Although both independent providers and agency-employed attendants in most states tended to receive few fringe benefits and wages that were at, or only slightly above, minimum wage, the WID surveys and case studies also found striking examples of interstate variation. Thus, independent providers in Massachusetts were found to earn much higher wages than agency-employed aides in Texas, and agency employees’ benefits in Montana were far superior to those typically offered by agencies elsewhere.

Equally important, the case studies indicated that comparisons of wages and benefits paid to direct service workers do not fully capture the unit costs to states per hour of service. For a state PCS program, the use of independent providers can be less costly per hour of service than use of agency providers—irrespective of wages and benefits paid to attendants. This is because agency rates per hour of service usually include a not insignificant percentage of administrative overhead costs and profit, on top of direct-care provider wages and benefits. States can all but eliminate these costs by encouraging the use of independent



TABLE 1  
Provider Benefits and Wages by Provider Type

	Independent providers		Agency providers		Government workers	
	1984	1988	1984	1988	1984	1988
Average hourly wage (in dollars)	3.89	4.59	5.12	6.02	3.93	8.00
Lowest	.42	1.70	3.40	3.35	3.85	4.06
Highest	8.25	8.30	9.00	11.00	4.00	8.00
Average number of benefits	0.8	0.9	3.0	2.7	5.0	4.0
Lowest	0.0	0.0	0.0	0.0	1.0	0.0
Highest	3.0	3.0	7.0	8.0	7.0	8.0

Source: Litvak and Kennedy 1991.

providers, especially when consumers screen, train, and supervise their own aides.

Some states have realized even further economies in program administration by treating independent providers as self-employed contractors for tax purposes. In Maryland, for example, as of the period from 1990 to 1991, attendants were paid "per visit" rather than by the hour, which meant that the workers themselves were responsible for paying their own taxes out of gross income (instead of having them withheld from their pay checks) and for paying both the employer and employee shares of FICA. The per visit payment rate and number of daily visits authorized varied according to several levels of client disability; however, as of 1989, the maximum daily payment per client was \$25 per day. This generally translated into an average attendant wage rate of \$5 per hour for a daily maximum of five hours of service per client. After paying the 15 percent self-employment tax, the attendant would be allowed to keep \$4.25 an hour—just a shade above the take-home pay of a minimum wage employee who pays only the 7 percent employee's share of FICA. As long as most agency-employed PCS aides earn at or near minimum wages and lack pension, health insurance, sick leave, and vacation benefits, it is difficult to make a case that independent providers earning equivalent or higher after-tax incomes are being financially "exploited." The ad-

vantage of treating attendants as "independent contractors" for tax purposes is that both the state and the client are freed from assuming the paperwork and liability obligations of "employers." The downside is that "self-employed" workers are held responsible.

The Internal Revenue Service (IRS) has estimated that approximately 28 percent of "independent contractors" (most of whom are not personal attendants but carpenters, plumbers, caterers, and others in skilled trade and services) never file tax returns (Flanagan 1994). Thus, for the IRS and state PCS program administrators to permit independent providers to have the tax status of independent contractors is viewed by some as tantamount to encouraging or condoning tax evasion. There are lots of anecdotes in circulation about personal care attendants who tell their clients that they do not want to work as aides unless they can do so "off the books." IRS representatives argue (Dan Bryant, October 1995: personal communication) that it is in workers' own best interests for government to impose and enforce tax-withholding requirements, which may include restrictions on who can claim "self-employment." This is because independent contractors who fail to report taxable income may have more cash in their pockets in the short term, but, in the longer run, they may suffer a significant penalty in lost Social Security benefits. The IRS has developed a set of criteria for determining whether or not a given worker is an employee or is self-employed. Although there is no hard and fast rule, most domestic workers who are not employed by agencies, including personal care attendants, are considered to be employees of their clients rather than self-employed, independent contractors.

It is important to note that, typically, states do not simply pocket the savings achieved from reducing their costs per hour of attendant services: they reinvest them in personal care services by providing more hours of service per client. The WID survey found that, across all state PCS programs, the use of independent providers was associated with more average hours of service use per client (table 2).

Thus, when states switch from permitting or requiring independent providers to requiring aides to be employees of HHAs, this often results in lower average service use per client. States have often made the decision to switch to agencies when federal agencies like the IRS, Social Security, and state labor departments questioned the treatment of independent providers as self-employed contractors. Some states are reluctant to take direct responsibility for withholding taxes from PCS

TABLE 2  
Average Number of Hours per Week per Recipient  
by Delivery Mode, 1984 and 1988

Delivery mode	Provider offers only one delivery mode		Program offers more than one delivery mode	
	1984 (hours)	1988 (hours)	1984 (hours)	1988 (hours)
Independent	25 (n = 17) <sup>a</sup>	22 (n = 14)	21 (n = 31)	20 (n = 28)
Agency	16 (n = 22)	15 (n = 17)	13 (n = 41)	15 (n = 34)
Government	3 (n = 4)	2 (n = 1)	10 (n = 30)	6 (n = 14)

<sup>a</sup>n = number of state programs in the WID survey in that category.

Source: Litvak and Kennedy 1991.

aides' wages and for providing workers' and unemployment compensation. In part, this reluctance is motivated by a desire to avoid the administrative burden and associated costs. However, in a number of states, the principal concern has been that assumption of these responsibilities might provide a basis for lawsuits claiming that PCS aides are de facto state employees and should be eligible for unionization and the pay, benefit, and job tenure protection associated with civil service employment. WID's state surveys documented that the minority of PCS aides who actually were government (predominantly county) employees, were more successful in obtaining better pay and benefits than both independent and agency-employed providers. In 1984, government workers' average hourly wages were similar to those of independent providers and somewhat lower than those of agency employees—although their fringe benefits were much better—but, by 1988, average wages for government providers had more than doubled to \$8 per hour, compared with \$4.59 for independent providers and \$6.02 for agency employees. This may explain why the surveys also found that the percentage of states with any government-employed PCS providers declined from 40 percent (n = 8) to 19 percent (n = 4) between 1984 and 1988.

The case study of Montana's PCS program provided an especially vivid illustration of the conflicting demands that state officials face and the trade-offs that may result. When Montana began its program in 1977, all attendants were county employees. Beginning in 1979, to keep up with the growing caseload, independent providers recruited by

clients were permitted and soon became the dominant provider mode. In 1987, Montana decided to require all workers to be employees of a single statewide-contract HHA. The decision to require all aides to be employed by agencies was made for two reasons. First, the caseload had risen dramatically, and state administrators felt that they could no longer provide sufficient oversight of independent providers. However, the more important factor was a ruling by the State Department of Labor (DOL) that some independent providers who applied for unemployment compensation could be considered state employees for purposes of unemployment insurance and workers' compensation and that the state was responsible for withholding taxes and paying the employer's share of FICA. State officials feared that the DOL ruling would be used to lobby for provision of full government worker benefits to all 1,500 independent PCS providers.

Initially, the hourly amount (\$3.85) allocated for direct care workers by the state remained the same, but the contract HHA withheld 50 cents for taxes and benefits. The state paid the contract HHA an additional \$1.40 per hour for nurse supervision and administration, including 19 cents to cover the employer's share of FICA. Some aides (who may previously have been avoiding their tax liability) protested this "pay cut." The year after the new system went into effect, the contract agency determined that attendant wages were too low to retain attendants and that the amount allocated for administrative overhead was insufficient. The agency and the state negotiated a new contract that raised attendant wages by 50 cents per hour, and in subsequent years wages were increased again. Administrative overhead payments to the HHA also rose. By 1991, the state was paying the agency \$7.75 per hour of service provided, of which \$5.52 (70 percent) went to attendant wages, taxes, and benefits (including overtime), with the remainder allocated to administrative costs, nurse supervision, and training. In order to accommodate these higher unit costs per hour of service while holding down overall Medicaid PCS expenditure increases, the state cut back on the hours of PCS that could be authorized per person. During the last year in which independent providers were used, the maximum authorization was 70 hours per week; by 1991, the cap had decreased to 40 hours per week.

In some instances, states that have instituted or are considering a requirement that all services be provided through agencies are also concerned about their potential legal liability for independent providers

who provide poor quality of care. Interestingly, these concerns about liability have seldom arisen in connection with any actual complaints about poor quality of care; rather, they reflect states' growing awareness of potential vulnerability and risk aversion. WID's case studies suggested that state officials may be more anxious about possible tort liability when the PCS benefit includes coverage of paramedical services, and the state's nurse practice act provisions are particularly restrictive in requiring that paramedical tasks be performed by, or under the direct supervision of, registered nurses. State concerns about tort liability were not based on experience; a review of case law by Marshall Kapp (1990) found no record of any actual suits ever having been brought involving aides who provided paramedical services in violation of professional licensure requirements.

A strong philosophical commitment to promoting consumer choice and control led some states to develop innovative ways of addressing both labor-related legal issues and concerns about quality assurance and tort liability. In Massachusetts, for example, the state chose to pay for Medicaid PCS through specially created entities termed "personal care agencies" (PCAs), which were required to have governing boards or advisory committees composed of at least 51 percent PCS recipients, family members of PCS recipients, other persons with disabilities, or consumer advocates. The PCAs offered administrative services such as tax withholding and instruction for consumers in supervising and directing their providers.

In contrast, certain states (e.g., Texas and Maryland) emphasized accountability and the importance of meeting professionally determined quality standards. These states tended to interpose between the client and the provider more elements of professional, third-party care management. In Texas, which, as of 1990, had the country's second largest Medicaid PCS program—serving an average of 32,500 clients per month—professional supervision was assured by requiring all aides to be employees of Medicare–Medicaid-certified HHAs. State officials maintained that this rule ensured professional oversight while still providing clients with considerable choice because there were from 180 to 200 certified HHAs in the state and clients could elect to receive services from any of these agencies operating in their localities.

Income and functional eligibility determinations for the Texas PCS program were carried out by state-employed regional case managers. However, agency-employed nurses also did detailed medical assess-

ments and, together with the case managers, drew up care plans, which then had to be approved by state-employed, regional prior-approval nurses. The state had no specific training or certification requirements for attendants; however, agency-employed registered nurses were required to make home visits every 60 days. In addition, state-employed case managers and prior-approval nurses could decide to "drop in" on short notice, both to monitor attendants' performance and to reassess clients' needs for care.

In Maryland, attendants were independent providers, but strong professional oversight was provided by registered nurse "case monitors," who worked under contract for the state or county. The nurse case monitors, who typically carried a caseload of 50 clients, performed functional needs assessments to determine client eligibility and acted as clients' "case managers." The nurse case monitors were also responsible for doing in-home training of attendants and were required to make in-home supervisory visits every 60 days. In addition, they were required to respond to client complaints about problems with their attendant care, and the monitors had to sign attendants' invoices before these could be submitted to the state for payment. In principle, a client could hire anyone other than a relative to be an attendant, but, in practice, according to the WID case studies, most clients ended up relying on their nurse case monitors for attendant referrals. Although the involvement of registered nurses in Maryland's PCS program was as great, or even greater, than might be expected in an agency model, Maryland nevertheless avoided paying the 30 to 40 percent in total program costs that would likely have gone to agency overhead by contracting directly with nurses. As of 1990–91, roughly 10 percent of PCS program expenditures went toward payments for nurse case monitors, and an additional 2.5 percent went toward financial administration—with the remaining 87.5 percent of expenditures going toward payments to attendants.

*Clients' Perceptions of the Degree of Consumer  
Choice and Control in Three Medicaid  
PCS Programs*

In the Commonwealth Commission survey of Medicaid PCS clients aged 65 and older in Michigan, Maryland, and Texas, the degree of

control or direction exercised by clients over their own care was measured by several indicators: having known their aide prior to employment; being involved in scheduling and supervising; signing time sheets or paychecks; and indicating that they or their family would be involved in changing aides (see table 3 for question wording). Examining these individual indicators of client-directed care, as well as the cumulative number of indicators (from 0 to 5), by state shows a statistically significant relation between client direction and state. Almost three-quarters of those in Michigan indicated they had known their aide

TABLE 3  
Indicators of Client-Directed Care by State

Indicators of client-directed care <sup>a</sup>	State			(p) <sup>b</sup>
	Maryland	Texas	Michigan	
Total (N)	(289)	(302)	(275)	
Indicators				
Knew aide	25.6%	35.8%	73.1%	(.000)
Helps schedule aide	24.2	32.8	54.9	(.000)
Supervises aide	58.8	80.1	81.8	(.000)
Signs time sheet and/or paycheck	62.3	14.2	79.3	(.000)
Client/family would handle changing aides	9.7	13.6	26.6	(.000)
Number of indicators				
0	10.0	6.6	0.7	
1	29.1	34.8	5.1	
2	36.0	37.1	23.3	
3	21.1	18.5	32.0	
4	2.8	3.0	26.6	
5	1.0	—	12.4	(.000)

<sup>a</sup>Question wording: Did you know (aide's name) before (she/he) started working for you, or not? (1 = yes, 0 = no); Do you help schedule when (aide's name) comes to your home or was the schedule decided by someone else? (1 = client helped schedule, 0 = someone else); Do you sign a time sheet or sign (aide's name) paycheck? (1 = client signs one or both, 0 = client signs neither); Who makes sure (aide's name) does the job the way they are supposed to—yourself or someone else? (1 = client, 0 = someone else); If you wanted to change aides for any reason, how would you do this? (1 = client or family member would handle it, 0 = agency or caseworker would handle it or client does not know).

<sup>b</sup>Chi-square probability.

Source: Commonwealth Fund Commission . . (1991).

previously, compared to 26 percent and 36 percent in Maryland and Texas, respectively. Similarly, over half of Michigan clients indicated that they helped schedule their aide; only 24 percent and 33 percent in Maryland and Texas did so. Higher percentages of Michigan clients signed time sheets or paychecks, or indicated they would be involved in changing aides. Only for supervising aides are percentages similar—about 80 percent of both Texas and Michigan clients responded positively, compared to only about 60 percent of Maryland clients. Furthermore, using number of indicators, with 0 being no client direction and 5 being maximum client direction, almost 40 percent of Michigan clients had scores of 4 or 5, in contrast to about 4 percent of Maryland and Texas clients.

Table 4 shows the relation of both individual indicators of client choice and number of indicators to various measures of client satisfaction. Consumer satisfaction with medical care is now frequently assessed in a wide range of contexts, from hospital marketing surveys to medical effectiveness research. In a comprehensive review of the literature, Hall and Dornan (1988) identified a lengthy list of dimensions of satisfaction with care assessed in satisfaction studies; the four most common were humaneness, informativeness, overall quality, and competence. Despite the proliferation of studies of satisfaction with medical care, there is little standardization in methods, and few questionnaires have been subjected to reliability and validity testing (one exception is the Patient Satisfaction Questionnaire [Ware et al. 1983]).

In areas other than physician and hospital-based care, however, satisfaction with care is rarely assessed. The measures of client satisfaction used in the three-state survey tap three dimensions of satisfaction with care: overall quality, technical competence (aide can be counted on to be on time, aide does things well), and humaneness (aide is concerned about client's well-being, aide improves quality of life). Each item has four response categories, ranging from very to not at all "satisfied" (wording varied by question, however; see table 4 for questions and responses).

Knowing the aide prior to employment, helping schedule the aide, supervising the aide, and client or family responsibility for changing aides were significantly associated with high levels of satisfaction with the aide's competence and humaneness. The first three also were related to overall satisfaction. Of client choice and control indicators, only "signs time sheet or paycheck" was not consistently related to client satisfaction. Greater client direction also was significantly related to higher



satisfaction. Only 67 percent of clients with a score of 0 felt their aide improved their life a great deal, for example, compared with 88 percent of those with a score of 5. Similarly, 95 percent or higher of clients with a score of 4 or 5 were very satisfied overall with aide performance, in contrast to 59 percent with a score of 0 and 78 percent with a score of 1.

The highly significant relation ( $p < .001$ ) to client satisfaction of reporting that an aide was known before employment is particularly noteworthy because this variable directly reflects differences in program administration across states. Nearly half (49 percent) of survey respondents in Michigan reported that their attendants were relatives, and an additional 22 percent reported that their attendants were friends, neighbors, or persons recommended by friends or relatives. The WID case studies indicated this pattern was not only permitted, but encouraged, by Michigan program administrators. In Maryland and Texas, 82 percent and 75 percent of survey respondents reported that their attendants were strangers. In Maryland, the low percentage of aides who were family members or persons previously known to the service recipient was undoubtedly due to the state's very strict interpretation of federal rules prohibiting family members from being service providers. Maryland regulations defined virtually all recognizable degrees of kinship, including uncles, aunts, cousins, nieces, nephews, and in-laws as well as spouses, parents, stepparents, children and stepchildren—with the sole exception of grandparents—as ineligible to be PCS attendants. In contrast, Texas, like Michigan, prohibited only "legally responsible" relatives (i.e., spouses or parents, including foster parents of minor children) from being PCS attendants. However, the fact that Texas required all PCS attendants to be employees of certified HHAs appeared to pose a barrier in practice to the recruitment of relatives, friends, and neighbors to serve as aides.

Tables 5 and 6 display the results of logistic regression models examining the effects of indicators of client-directed care on overall satisfaction with aide services, controlling for other variables that might affect or account for the relation of client direction to satisfaction. Only one measure of satisfaction was used in this analysis: overall satisfaction with aide. Correlations between the indicators of client satisfaction were significant and ranged from .32 to .65. Because the outcome of interest is dichotomous (very satisfied = 1, other = 0), logistic regression was used (Hosmer and Lemeshow 1989). The odds ratios reported indicate whether the odds of a given event (e.g., positive response to an indicator

TABLE 4  
Relation of Indicators of Client-Directed Care to Measures of Client Satisfaction

Indicators of client-directed care	Measures of client satisfaction <sup>a</sup>				
	Aide improves quality of life a great deal	Aide very concerned with client well-being	Aide knows how to do job very well	Can always count on aide to be on time	Overall, very satisfied with aide
Total (N = 866)	74.4%	81.9%	87.2%	78.9%	84.3%
Indicators					
Knew aide	81.7***	91.4***	93.5***	88.8***	93.5***
Helps schedule aide	81.2***	85.3*	91.9**	84.1**	88.1*
Supervises aide	76.4*	84.5**	89.5***	82.1***	87.0***
Signs time sheet and/or paycheck	74.6	83.7	89.6*	80.7	86.4
Client/family would handle changing aides	83.8**	88.0*	92.2*	85.2*	89.4

Number of indicators						
0	66.7	62.8	66.7	66.7	66.7	58.8
1	66.0	74.4	80.8	80.8	67.9	78.3
2	72.8	82.5	88.2	88.2	77.6	85.7
3	75.0	85.4	90.7	90.7	77.7	86.8
4	77.4	92.2	97.8	97.8	86.3	95.6
5	88.1*	100.0***	97.3***	97.3***	93.2***	100.0***

<sup>a</sup>*Question wording:* How much does having (aide's name) come to your home improve the quality of your life—a great deal, quite a lot, not much, or not at all? (1 = great deal, 0 = else); Would you say (aide's name) is very concerned, somewhat concerned, concerned a little, or not at all concerned about your well-being? (1 = very concerned, 0 = else); How well does (aide's name) know how to do the things that need to be done—very well, somewhat well, not very well, or not at all well? (1 = very well, 0 = else); Can you count on (aide's name) to be at your house on time and when (she/he) is supposed to be—always, often, not often, or hardly ever? (1 = always, 0 = else); Overall, how satisfied are you with (aide's name)—very satisfied, somewhat satisfied, not very satisfied, or not at all satisfied? (1 = very satisfied, 0 = else).

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Source: Commonwealth Fund Commission . . . (1991).

of client-directed care) are significantly related to the outcome of interest (being very satisfied), controlling for other explanatory variables.

Two models are shown in table 5. One uses individual indicators of client-directed care (model 1), and the other uses the cumulative number of indicators from 0 to a maximum of 5 and covariates reflecting client characteristics. Other client characteristics entered in the model are age (65 to 74, 75 to 84, 85+); gender; self-reported health (excellent/good vs. fair/poor); presence of any ADL limitation (dressing, bathing, feeding oneself, getting in and out of bed or chairs, using the toilet, mobility indicated by "in a wheelchair"); presence of any IADL limitation (meal preparation, shopping for groceries, money management, using telephone, light housework); rural versus urban residence, hours of care a week (< 10, 10 to 14, 15+, don't know); time aide has worked for client (< 6 months, 6 to 12 months, 1 year, 2 years, 3 years, or more). When all five indicators of client-directed care were entered in the model (model 1, stage 1), only two remained significantly related to being very satisfied overall with aide performance: "knew aide prior to employment" and "supervises aide." These relations held when client characteristics were entered (model 1, stage 2). Controlling for other client characteristics, clients who knew their aide previously were three times as likely to be highly satisfied, and those reporting that they supervised were almost twice as likely to be very satisfied as others. Among client characteristics, only rural residence, hours of care per week, and length of time that the aide had worked for the client significantly affected the odds of satisfaction (more hours and longer time with aide led to greater satisfaction).

When cumulative number of indicators is considered, despite the fact that only two individual indicators were statistically significant, there is a relation between increasing opportunities for client direction and satisfaction (model 2, stage 1). Clients who reported positively on four or five indicators were significantly more likely to report being "very satisfied" than those who reported positively on no indicators. Again, introducing client characteristics to the model does not change the significance of this relation (model 2, stage 2).

Table 6 tests the effects of adding "state" (Maryland and Texas, with Michigan as the reference category) to the model. The bivariate analyses reported in table 3 showed a relation between state and opportunities for client-directed care. State was not found to be significantly related to overall aide satisfaction when either individual indicators of client-

directed care or number of indicators is included in the model along with other client characteristics. However, when the indicators of client-directed care are excluded, Maryland PCS clients are only two-fifths as likely to be highly satisfied as Michigan clients. The difference in likelihood of being highly satisfied between Texas and Michigan clients is not statistically significant, although the direction of the relation is as expected, given the higher prevalence of client-directed care in Michigan (as shown in table 3).

These analyses were also conducted on the subgroup of individuals who did not know their aide previously, because this variable had the greatest effect on satisfaction. None of the relations changed, although "signs time sheet or paycheck" reached significance among the client-directed care indicators in addition to "supervises aide." Whether the client signs paychecks and/or time sheets is closely tied to state program design (see table 3) and also reached significance in table 6 when dummy variables for states were entered in the regression. This may indicate that the relation of signing a time sheet and/or paycheck to satisfaction varies by state. In Texas, where care is agency based, it rarely occurs. In Michigan, it is part of a broader philosophy of increasing client-directed care, but, in Maryland, it may be viewed by clients as a requirement imposed by the state to monitor behavior of both clients and aides. These relations cannot be successfully disentangled from these data. The analyses point to the need for greater refinement of indicators of client-directed care, however, as well as attention to how program philosophy and environment affect interpretation of such indicators.

## Discussion

Most Medicaid PCS clients interviewed in the Commonwealth Commission survey reported high satisfaction with their aides. Indeed, fewer than 10 percent of clients surveyed in any state reported being not very satisfied or not at all satisfied with their aides. Nonetheless, both bivariate and multivariate analyses of the Commonwealth Fund Commission client survey data found strong statistical associations between indicators of consumer choice and indicators of consumer satisfaction.

Descriptive data on individual state PCS programs collected via the World Institute on Disability's mail questionnaire surveys of all Medicaid PCS programs in existence in 1984 and 1988 and from the 1990-91

TABLE 5  
Relation of Client-Directed Care to Overall Satisfaction with Aide (logistic regression)

Covariates	Model 1: with indicators of client-directed care (odds ratio)		Model 2: with number of indicators (odds ratio)	
	Stage 1	Stage 2	Stage 1	Stage 2
Client-directed care indicators				
Knew aide	3.94***	3.01***	—	—
Helps schedule aide	1.24	1.27	—	—
Supervises aide	1.90**	1.87**	—	—
Signs time sheet and/or paycheck	1.21	1.38	—	—
Client/family would handle changing aides	1.11	1.01	—	—
Number of indicators <sup>a</sup> :				
1	—	—	.93	1.01
2	—	—	1.78	2.28
3	—	—	1.95	2.34
4	—	—	3.11*	3.71*
5	—	—	6.53*	7.01*
Client characteristics				
Age <sup>a</sup> :				
75–84	—	1.00	—	1.03
85+	—	1.23	—	1.20
Gender <sup>b</sup> :				
Self-reported health <sup>b</sup>	—	.76	—	.74
	—	.77	—	.76

Any ADLs <sup>b</sup>	—	.90	—	.85
Any IADLs <sup>b</sup>	—	1.07	—	1.06
Rural residence <sup>b</sup>	—	1.70*	—	1.92**
Hours of care a week <sup>a</sup> :				
10-14	—	1.80*	—	1.86*
15+	—	1.74*	—	1.94*
Does not know	—	1.14	—	1.70
Time with aide <sup>a</sup> :				
6-12 months	—	1.64	—	1.77*
1 year	—	2.43**	—	2.81***
2 years	—	3.20***	—	3.42***
3+ years	—	4.34***	—	5.34***

<sup>a</sup>Reference categories are 0 for number of indicators; 65 to 74 for age; <10 hours a week for hours of care; and <6 months for time with aide.

<sup>b</sup>Dichotomous variables are coded 0,1. A value of 1 was assigned to responses of "yes" to client-directed care indicators; male (gender); fair/poor self-reported health; presence of 1+ADLs; presence of 1+ IADLs; rural residence. ADLs were dressing; bathing; feeding oneself; getting in/out of bed or chairs; using the toilet; in a wheelchair. IADLs were meal preparation; shopping for groceries; money management; using telephone; light housework.

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Abbreviations: ADL, activity of daily living; IADL, instrumental activity of daily living.

Source: Commonwealth Fund Commission . (1991).

TABLE 6  
Relation of State to Overall Satisfaction with Aide, with and without Client-Directed Care Indicators  
in Regression Models (logistic regression)

	Model 1: with indicators of client-directed care and other covariates" (odds ratio)	Model 2: with number of indicators and other covariates" (odds ratio)	Model 3: with other covariates <sup>a</sup> only (odds ratio)
Client-directed care indicators			
Knew aide	2.75***	—	—
Helps schedule aide	1.19	—	—
Supervises aide	1.67*	—	—
Signs time sheet and/or paycheck	1.82*	—	—
Client/family would handle changing aides	1.01	—	—



Number of indicators <sup>b</sup>			
1	—	.99	—
2	—	2.08	—
3	—	2.13	—
4	—	3.16*	—
5	—	5.39*	—
State <sup>b</sup>			
Maryland	.76	.57	.38***
Texas	1.65	1.16	.78

<sup>a</sup>Other covariates in the model are age; gender; self-reported health; any ADLs; any IADLs; rural residence; hours of care a week; and time with aide.

<sup>b</sup>Reference categories are 0 for number of indicators, Michigan for state.

\* $p < .05$  \*\* $p < .01$  \*\*\* $p < .001$

Source: Commonwealth Fund Commission . . . (1991).

site visits to six programs (including those in Maryland, Michigan, and Texas) make it possible to identify administrative features that tend to facilitate or, alternatively, to inhibit consumer choice and satisfaction. Consumer choice and satisfaction appear to be maximized when a public program not only permits, but also actively encourages, clients to hire their own attendants directly (that is, when the PCS program attendants are treated as employees of the client—in contrast to being employees of a home health or home care agency or to acting as independent contractors who obtain their jobs through recommendations from registered nurses, who subsequently provide on-the-job training and supervision). An important corollary is allowing consumers to hire whomever they wish. The data suggest that when consumers are permitted to hire attendants directly and face few restrictions on whom they may hire, they tend to favor persons already known to them: family members, friends, neighbors, and individuals who are known to and come recommended by family, friends, and neighbors. The result, for many clients, is an integration of their formal and informal support systems.

Several policy implications are suggested by the findings. First, administrators of home- and community-based long-term-care programs now have empirical evidence to cite in support of making consumer and family caregiver empowerment the cornerstone of their quality assurance strategies. This same evidence suggests that the traditional regulatory emphasis on requirements for professional standard-setting and supervision may not only be less effective than promoting consumer and family caregiver empowerment; it may actually prove counterproductive to the extent that professional management tends to limit or inhibit client and family caregiver involvement in such critical areas as hiring and firing decisions and the scheduling and day-to-day supervision of aides.

During the late 1980s and early 1990s, when the research that forms the basis of this article was conducted, federal Medicaid law required PCS services to be prescribed by a physician and supervised by registered nurses. Disability-rights and independent-living advocates, who felt that these requirements caused an unnecessary and unwanted “medicalization” of PAS, succeeded in persuading Congress to remove them in the Omnibus Reconciliation Act of 1993. However, this legislation does not preclude states that consider professional oversight by physicians or nurses to be a necessary quality safeguard from imposing such

requirements under state law and regulations. (We do not know how many states—if any—have dropped requirements for physician prescription and/or nurse supervision in response to OBRA 1993. However, as of November 1995, the administrative features of the Medicaid PCS programs in Texas, Maryland, and Michigan remained essentially the same as described in the World Institute on Disability's 1990–91 case studies.)

The argument could be made that public program administrators ought to define and enforce some "objective" standards of quality, given that the taxpayers are footing the bill. We accept the legitimacy of concerns for public accountability. However, because medical expertise is irrelevant to the ability to assess the quality of nonmedical services, a medical professional's judgment about an attendant's competence in performing typical housekeeping and personal care tasks is not a clinical one based on scientific criteria. On the other hand, it is possible to define expectations or norms that are so widely agreed-upon by the community at large that they can serve as objective measures because anyone could apply them. In principle, virtually any adult American could be hired by the state and, without much special training, be sent to the homes of Medicaid PCS clients to judge the adequacy—based on nothing more than ordinary, everyday cultural standards—of aides' housekeeping, cooking, and other skills in performing specific tasks as well as their compliance with other normative expectations such as punctuality and courteous, respectful demeanor toward the client. However, this would be costly and intrusive. Moreover, what is the justification for concluding that persons with functional disabilities who are not demented or otherwise mentally incompetent are any less capable than any nondisabled average citizen of knowing and applying standard cultural expectations in judging a personal care attendant's job performance? To assume that the state needs to send an inspector to have an objective judgment of how well an aide cleans a client's home and the like reflects, at best, a patronizing attitude that all consumers with disabilities are "childlike" in their need for protection. Alternatively, this could imply negative stereotypes about "people on welfare" who depend on Medicaid to pay for their personal care attendants.

Evidence of dangerously poor judgment and inability to understand and uphold community norms are precisely the kinds of criteria that Adult Protective Services workers and the courts use in making determinations about whether persons with dementia disorders, serious men-

tal illness, traumatic brain injury, mental retardation, or severe substance abuse problems are incompetent to manage their own affairs. The real issue, then, is not whether there is a need for "objective" standards and measures of quality assurance for PAS over and above—or possibly in opposition to—consumer "subjectivity." Rather, the central problem is: for the minority of consumers who are incapable of making sound judgments and taking appropriate actions, who can government rely upon to do so on their behalf?

The literature on abuse, neglect, and mistreatment of disabled older persons indicates that victimization is far more common among individuals with mental impairments than among persons who are functionally disabled and even highly physically dependent but not mentally impaired (Coyne, Reichman, and Berlig 1993), although clients who are not mentally impaired are sometimes unwilling to report attendant abuse (Ulicny et al. 1990). The conventional wisdom in home care for the elderly has been to assign the protective role, formally, to home health/home care agency supervisors and/or case managers or quality assurance monitors employed by or under contract to the public funding agencies, regardless of whether or not elderly clients are mentally impaired. There is no way, however, that an agency supervisor or case manager who makes an occasional home visit can provide clients with meaningful protection against abuse, neglect, and mistreatment by their personal care aides. The reality of these situations is that when clients are unable or unwilling to speak up for themselves, only members of the disabled persons' informal support networks—family, friends, neighbors—are in a position to effectively protect the client by detecting an aide's problematic behavior or poor performance and taking action. If the aide is an independent provider that the family has hired (a very common situation in the private-pay market for eldercare services), the family is likely to act unilaterally by firing the aide and hiring another. In other circumstances, the family may be required to inform the HHA or the case manager, with the expectation that these professionals will take the appropriate actions. If the professionals do not do so, some families may be passive, but most will insist, complain, change agencies or do whatever else may be necessary to get the result they want. Thus, it would not be good public policy for public program administrators to suggest to family, friends, and neighbors that government regulation, professional supervision, and training requirements or the like can substitute for the informal support system's watchful in-

v involvement. Nor would it be advisable to give professionals in home care (i.e., HHA nurses and managers, state and local social services agency case managers) the message that they are the only recognized authorities on quality and need not be responsive to concerned family or other members of clients' informal support networks.

In the field of mental retardation and developmental disability, recognition of the importance of informal support systems has reached the point that many professionals now expend considerable time and effort attempting to create "surrogate" families for individuals who have no family or other natural supports (such as long-time institutional residents). Volunteer lay advocates are being recruited to monitor and intercede with service providers and case managers. Most elderly and younger disabled persons have not lost contact with their families and other natural supports and do not need professionals to create "family-like" support systems for them. Indeed, some specialists in aging are wary because elder abuse research findings suggest that the majority of perpetrators of elder abuse are family members, not paid service providers. Such studies have found that abusive family caregivers are typically the only source of help available to the disabled elder (Pillemer and Finkelhor 1988). There is nothing in this research to indicate that when disabled elders are able to exercise choice—particularly when they have access to publicly funded paid attendant services and permission to hire whomever they please—they would favor abusers, whether from in or outside the family.

Thus, another major policy implication of our findings is that they do not support a policy of prohibiting the hiring of family members as paid providers. The practice of hiring family members as paid service providers has become well established and accepted in some state Medicaid PCS programs (e.g., Michigan and California) but continues to be prohibited in others (e.g., Maryland and New York). The issue remains controversial because critics claim that paying family caregivers could undermine traditional societal expectations that families provide care informally. Despite the controversy, most states currently permit—albeit in varying degrees—family members to be paid providers in at least one public program. Nathan Linsk and colleagues (Linsk, Keigher, and Osterbusch, 1988) surveyed 35 jurisdictions (33 states, the District of Columbia, and Puerto Rico) in 1985 and found that 70 percent permitted payments to family caregivers in one or another public pro-

gram. This pattern was replicated in a slightly larger 1990 survey (Linsk et al. 1992).

In both the WID case studies and in the research carried out by Linsk and colleagues, states that disallowed payments to, or cited restrictions on, employment of family members as service providers in some or all of their programs frequently cited federal and/or state Medicaid regulations. During the mid-1980s, the federal HCFA published a Notice of Proposed Rulemaking (NPRM) that had a dampening effect on some state PCS programs, as it would have defined very broadly the "family members" prohibited under federal statute from serving as paid PCS providers. Under the proposed rule, the ban would have encompassed extended family such as aunts, uncles, nieces, nephews, cousins as well as close family members. Because this and other elements of the NPRM drew more negative than positive responses from states and consumer groups, the NPRM was never issued as a final rule, and therefore never took effect. Indeed, in 1995, HCFA reversed its position and issued a final rule that expressly permitted states to limit the restrictions on family members serving as paid providers to legally responsible relatives (i.e., spouses and parents of minor children).

Over the past five years, advocates for the nonelderly disabled associated with the disability-rights and independent-living movements have become increasingly active in the politics of home and community-based long-term services at both federal and state levels of government. Advocacy groups for the elderly interested in helping to forge a broader constituency to promote increased public funding for in-home and community-based alternatives to nursing homes have begun to adopt and adapt ideas and concepts from the disability-rights and independent-living movements—including the notion that services should be more "consumer directed."

At the same time, however, states wanting to foster consumer direction in public programs are being forced to grapple with and attempt to find solutions for a number of knotty administrative problems that, in the past, they often ignored. First and foremost is the issue of ensuring Social Security coverage and tax payments for personal attendants who are employed directly by persons with disabilities but paid from public funds. The so-called "Nannygate" scandals, in which several candidates for political appointments in the Clinton Administration were found to have failed to pay Social Security taxes on behalf of nannies, housekeepers, or other domestics, cast a spotlight whose harsh glare illuminated

the entire "gray market" of domestic employment, including independent providers of personal assistance to the elderly and disabled. Even before this issue came to public attention, however, state program administrators had been subjected to increasing pressure from the IRS and federal and state labor officials to explain, defend—and, ultimately, to modify—their methods of paying attendants who work as independent providers to ensure compliance with FICA (Social Security tax), FUTA (unemployment tax), and workers' compensation requirements. A number of states have now developed workable mechanisms that both ensure compliance with tax and labor laws and permit consumers to hire and fire, supervise, and train independent providers. By using "fiscal agents" to administer payments to independent providers, these states have been able to certify the consumer as "employer of record" without saddling disabled persons and their family members with complex and onerous paperwork chores. (Flanagan 1994). Legal experts are continuing to work with states and regulatory agencies to resolve these issues.

In the current political climate, the pressure on state administrators of home- and community-based services for the elderly and disabled to cut costs is likely to intensify. As our analysis has shown, states have often found themselves attracted to "consumer-directed" models of financing and delivering attendant care because they seemed to offer a means both to curb costs and to achieve positive outcomes—in terms of greater satisfaction, independence, and empowerment—for clients. Given the accumulating evidence of the value of maximizing consumer-directed care and the impending major changes in U.S. health care, development of workable models for promoting increased consumer choice and control is critical. These models must incorporate the views of clients, consideration of workers, and the concerns of government agencies responsible for managing publicly funded programs. The experience of states and the research findings reported here provide a firm base on which to proceed.

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*Address correspondence to:* Pamela J. Doty, PhD, Senior Policy Analyst, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, Room 425 E, Humphrey Building, 200 Independence Avenue, SW, Washington, DC 20201.