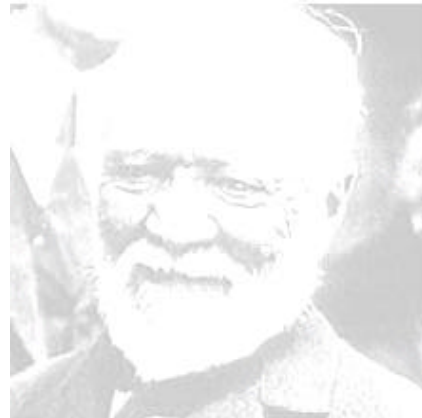


June 2001

Consumer-Directed Care: An Ethical, Empirical, and Practical Guide for State Policymakers



Larry Polivka, Ph.D. and Jennifer R. Salmon



Florida Policy Exchange Center on Aging
USF 30437 - 4202 E. Fowler Avenue
Tampa, FL 33620
Phone: 813-974-3468
Fax: 813-974-5788
e-mail: lpolivka@admin.usf.edu
website: www.fpeca.usf.edu

Table of Contents

Introduction	1
Chapter I. Ethical Basis for Consumer-Directed Care	3
Chapter II. Consumer-Directed Care and the Cognitively Impaired	7
Chapter III. Empirical Support for Consumer-Directed Care	10
State Experiences with Consumer-Directed Care	10
Arkansas	10
California	11
Oregon and Washington	14
Consumer Directed Care in Other Countries	16
Austria	16
Germany	17
France and The Netherlands	19
Summary of Empirical Rationale for Consumer Directed Care	19
Chapter IV. Barriers to Consumer-Directed Care	21
Policymaker and Provider Barriers	21
Environmental Barriers	25
Client Reluctance	26
Regulatory Barriers	27
Societal Attitudes	27
Chapter V. Implementation of Consumer-Directed Care	29
Olmstead Decision	29
Containing Fiscal Impact	32
Nurse Delegation	33
Workforce	34
Administrative Support for Consumers	34
Training and Education	35
Provider Adjustment	35
Regulation	36
Chapter VI. Conclusions	37
End Notes	40

List of Tables

Table 1. IHSS Client Characteristics-Provider Managed Model and Consumer-Directed Model	13
Table 2. A Comparison of In-Home Services Between Oregon and Washington and Between Agency and Individual Providers (1996 to 1998)	15
Table 3. Estimated Additional 1998 Cost Using Caseload Increased Between 1993 and 1998 and Unit Costs, State of Washington	16

Acknowledgement

The authors gratefully acknowledge Virginia Chaplin for her diligent assistance with this report.

Introduction

In recent years many members of the huge baby-boom generation have become involved with the U.S. long-term care systems as they helped their parents and grandparents receive the care they need. This experience and the growing awareness of what they may face themselves in 20 to 30 years is likely to make long-term care a highly visible public policy issue over the next ten years and to increase public dissatisfaction with the existing system of long-term care services. Dissatisfaction is already pervasive among those who have some knowledge of the current publicly supported long-term care system which is dominated by nursing homes.

A growing number of critics of the U.S. long-term care system are advocating a qualitative change in the methods and kinds of care now provided rather than incremental changes. One of the major qualitative changes many of these critics now support is to move the control of long-term care resources from provider agencies to those who need and use the resources—the consumer. This long-term care strategy is usually called consumer-directed care (CDC) and is defined by the National Institute on Consumer-Directed Long-Term Care as:

. . . a philosophy and orientation to the delivery of home and community-based services whereby informed consumers make choices about the services they receive. Consumer-direction ranges from the individual independently making all decisions and managing services directly, to an individual using a representative to manage needed services. Choice and control are both key elements of any consumer-directed system.¹

The cash and counseling version of CDC could theoretically be incorporated into any state or federally funded long-term or chronic-care program serving persons of all ages and many disabilities. Generally, disabled persons would have a choice of a case-managed service-benefit or a monthly cash allowance of a monetary value lower than the publicly provided service benefit. To be eligible for the monthly income supplement, an individual with a disability would have to show that she could effectively use the extra income to meet her long-term support needs. Consumers would be able to spend the money in ways they best see fit. They might choose to purchase services from a home care agency or referral service at current rates, pay a friend or a relative to provide personal assistance services, make needed home modifications, move to an assisted living facility, or make other housing arrangements.

The counseling component would involve an assessment of need, consumer information and advice about the various services, financing, and housing options available. Centers for independent living, area agencies on aging, other public or private organizations, or individuals that do not have a vested financial interest in the decisions made by the consumers would provide the counseling service. The purpose would be to provide consumers and their families with the information and assistance they need to make their own decisions and manage their own care. It also provides a system to monitor the program and prevent financial fraud, exploitation, or abuse.

Although this paper focuses on cash and counseling approaches to consumer-directed care for the frail elderly, it is important to note that the hallmark of the Centers for Independent Living program for the younger disabled is the use of Personal Care Attendants. Through the Centers and other agencies, the younger disabled can choose their own attendants who provide daily care with activities of daily living (transportation, bathing, dressing, etc.). Although the program is generally paid by the Medicaid program, it provides these very impaired consumers maximum independence and control over daily life. The Olmstead decision by the Supreme Court in 1999 interpreted the Americans with Disabilities Act (ADA) to mean that the State that provides care in the “least restrictive setting” must provide community-based alternatives to disabled individuals. This is addressed further in Chapter V.

CHAPTER I

Ethical Basis for Consumer-Directed Care

The ethical rationale for CDC is based on recognition of the value of human autonomy and the moral obligation to nurture the autonomy of impaired persons, including the frail elderly, by providing long-term care in the least restrictive manner compatible with the needs and resources of the individual. Personal autonomy is arguably the core value of American culture and the basis of identity in Western societies. Any public policy or program practice that qualitatively restricts the capacity of individuals to exercise autonomy because of impairment bears a heavy burden of justification. The implicit assumption of most long-term care programs for the frail elderly is that they must sacrifice their autonomy—their ability to exercise sufficient choice—as a condition of receiving care. The largely unquestioned rationale for this assumption is that long-term care professionals, those assessing needs, drawing up service plans and providing services in a heavily regulated command and control long-term care system, should make the decisions about care because they have the training and experience necessary to know what is best for the consumer. This is a model of professional control operating in the name of beneficiaries. Kapp (1999) notes that:

Unless there exists decisional incapacity on the older or disabled consumer's part, it should be the obligation of both the public and private sectors to empower the consumer to overcome any informational and/or intellectual shortcomings to the greatest extent possible, rather than to permit proponents of extensive regulation to latch onto those consumer limitations as a convenient excuse or pretext to foreclose consumers' options in the name of beneficence.²

Even beneficence, however, as a governing principle in long-term care, is severely restricted by the fact that providers operate in a pervasive environment of legal regulation that gives priority to following rules and uniform procedures rather than responding to the unique needs and preferences of the individual consumer. Kapp goes on to argue that:

. . . displacing command and control regulation [and service delivery] with enhanced consumer control may help address a prevalent, vexing problem with the regulatory model that I have addressed comprehensively elsewhere. That is the phenomenon that a pervasive environment of legal regulation (or a perception

that such an environment exists) generally instills in service providers, case managers, decision making surrogates for incapacitated patients, and patient advocates powerful anxieties and apprehensions about exposure to potential legal consequences that inspires forms of defensive (or at least intended to be defensive) practices that work at cross-purposes to the ideals both of autonomy and beneficence. Choices may be foreclosed to the patient/consumer because those choices are thought to expose the provider, case manager, surrogate, or advocate to unacceptable legal risk, for instance, even when those choices might have actually benefitted the well-being of the patient/consumer.³

This is not a system of care designed to achieve either consumer autonomy or beneficence. Beneficence is also undermined by the stress that follows the loss of control over her “life world” when the consumer enters the long-term care system. Kapp notes that:

. . . there is convincing evidence that it is health-promoting for individuals to make personal choices regarding their own lives since, among other things, a feeling of control reduces stress levels. Stress ordinarily is not so much a function of imposed demands as a matter of lack (or perception of lack, which amounts to the same thing practically) of control over the demands one faces. Additionally, personal choice usually boosts satisfaction with services and with coverage for services. Promoting consumer well-being by economically empowering consumers is another strategy to foster individual autonomy, beneficence, and justice concurrently.⁴

Autonomy has never been adequately recognized as a value to be achieved in the development of long-term care policy and practice. Respect for the need and desire of frail elderly people to remain as autonomous as their impairments allow by providing supportive, nurturing environments and services has been, more often than not, compromised by the needs of policymakers and providers to achieve short-term bureaucratic or fiscal goals with the implicit notion that autonomy is an appropriate or achievable goal for the dependent elderly.

One way to begin developing a compelling ethical framework for long-term care is to reconceptualize the relationship between personal autonomy and dependency that recognizes the value of autonomy to even

the most impaired without losing sight of their real physical and resource limitations. Autonomy is more than just having the power to keep others from intervening in one's life without fully informed and uncoerced consent. Autonomy is also the power of an individual, however dependent, to interact and communicate freely with others, to give and receive affection, and to initiate actions that are consistent with the person's sense of self. This positive version of autonomy is especially important in developing an ethic for long-term care.

The importance of autonomy (choice and control) is evident from the findings of our RWJF sponsored study of personal control with 294 randomly selected long-term care recipients in the Tampa Bay area. The sample included home care, assisted living, and nursing home consumers. We found that consumers highly value the capacity to maintain control over their care and their lives generally. Personal control clearly contributed to life satisfaction and to consumer satisfaction with care. Controlling for demographic and need characteristics, personal control contributed the most to explaining life satisfaction—more than health, function, having a caregiver available, and socioeconomic status. Personal control had an important impact on consumer satisfaction with care as well. Consumers showed clear preferences for control. They preferred to discuss health, housing, and financial issues with caregivers, but to make the decision themselves. In fact, nursing home respondents were more likely to want control over housing and finances than consumers in the other two settings. When provided three alternatives for how care should be provided, 34% of homecare consumers in the study endorsed consumer-directed care approaches only while 13% endorsed the traditional agency model only. The remainder showed no preference for CDC or agency models or simply did not like any of the models presented.⁵

These preferences are similar to a 1996 telephone survey of 491 Medicaid personal care clients and their families in Arkansas. Simon-Rusinowitz, et al. found that 31% were interested in a cash and counseling version of consumer-directed care, 25% were unsure, and 44% expressed no interest in a cash option. They found that among those who were interested in cash and counseling, most of the interest came from surrogate decision makers. In fact, it was the presence of an informal caregiver (who was also most often the surrogate decision maker) that explained interest in cash and counseling by the consumer. It may be that consumers feel more

confident in using cash and counseling programs if they have a family member who can act as the “backup” if the paid worker is not available or to manage the additional responsibilities that come with this program.⁶

This research, along with the empirical evidence described later in this guide, support the ethical argument for providing consumer directed care, which is summarized by Kapp as follows: 1) Autonomy is essential to the identity of individuals in Western societies; 2) CDC serves to counteract the protective instincts of providers who resist consumer direction because of concern about legal and regulatory exposure. Choices are not offered because providers feel there is an unacceptable level of risk even if those choices would improve the consumer’s quality of life. With shared risk established within a set of rights and responsibilities, these concerns may be allayed; 3) CDC can improve the continuity of care because the dollars follow the consumer and are not compartmentalized based on the setting of care; 4) CDC has a salutary effect on health status because personal control reduces stress and promotes health. Stress comes from a lack of control rather than too many demands; and 5) Choice and control increases satisfaction with services.⁷

The kind of ethical framework suggested here would support public policy designed to balance the protection of autonomy with the realities of dependency and interdependency in the provision of long-term care for the frail elderly. We have only begun to tap the potential of programs designed to accommodate dependency by providing resources for the exercise of autonomy. As shown below, however, we have learned enough from our limited initiatives to know how such resources can be effectively employed in a consumer-directed approach to long-term care for the frail elderly, including those who are cognitively impaired.

CHAPTER II

Consumer-Directed Care and the Cogni- tively Impaired

Is consumer-directed care an ethically defensible model of long-term care for the cognitively impaired? Is there a fundamental conflict between a model of care designed to protect and nurture consumer autonomy and a population whose autonomy has been compromised by dementia and whose greatest needs are security and safety? Can the moral (autonomy) and technical (cost-effectiveness) objectives of consumer direction be reconciled with the realities of cognitive impairment? The capacity of consumer-directed care to meet the needs of cognitively impaired persons is based on the following premises:

- **Autonomy is as important and practical for the cognitively impaired as the cognitively intact** as long as the former are capable of having and expressing, with assistance if necessary, values—as long as they remain valuers. This capacity is lost with late stage dementia, along with any meaningful notion of personal autonomy. Early-stage Alzheimer’s disease is usually characterized by neuronal damage of the hippocampus area of the brain which diminishes short-term memory and the capacity to hold a thought when attention shifts to something new. According to Jaworska (1999):

. . . there is no reason to think that impairment of the hippocampus would obliterate one’s ability to espouse critical interests . . . the destruction and the isolation of the hippocampus are always several steps ahead of the pathologies in the areas most likely to affect the capacity to value. Therefore, on the basis of neuropathological findings, one would expect Alzheimer’s patients to lose their sense of life as a whole even as the essence of their ability to value remains relatively robust.⁸

- **Cognitively impaired persons who are capable of holding values can be assisted by caregivers in expressing their values** and in carrying out activities consistent with their values. The autonomy of a person with moderate cognitive impairments who is still a valuer should be nurtured by providing assistance in enacting her values. According to this premise in support of CDC for cognitively impaired persons:

To properly respect the autonomy of many an Alzheimer’s patient one must do quite a bit to enhance her autonomy. . . .

This involves figuring out how her values would be best upheld in a reality she no longer fully understands, as well as helping her implement these solutions in practice.⁹

- **The caregiver and care recipient is considered a consumer dyad with the caregiver serving as a surrogate** providing reasonably defined substituted judgment for the cognitively impaired care recipient. From this perspective, CDC is designed to empower the caregiver, which is most often a family member, acting in the presumed interest of the care recipient under monitoring by a care manager or advocate. Kapp has noted that:

. . . we cannot automatically assume that substituted judgment can never work for consumer purchasing choices. Rather, we should favor the substituted judgment standard when individualized assessments indicate an adequately reliable, honest record of the consumer's own pertinent wishes.¹⁰

A consumer direction paradigm ought to reinforce the concept of assisted or supported capacity as a reasonable, workable compromise between complete independence, on one hand, and total helplessness, on the other.¹¹

Recently reported research by Feinberg, Whitlatch and Tucke (2000) provides evidence in support of these premises. The study is based on three in-person interviews with 51 persons with cognitive impairment and 51 family caregivers. The care recipients lived at home and had a mild-to-moderate-range of cognitive impairment. The average age of care recipients was 75.6, and 51% had been diagnosed as having Alzheimer's disease; the other diagnoses ranged from frontal lobe, Lewy body and vascular dementia (13.7%) to traumatic brain injury (2%). When care receivers were split into three groups based on high, medium-to-low MMSE scores, the authors found that: Persons with cognitive impairment were able to answer questions about general preferences and involvement in everyday care with a high degree of reliability and validity. It was very important to them to remain at home (78%) and not to live in a nursing home (73%), and they preferred help from family/friends to paid services. The majority of the caregivers' needs and practices were congruent with the care receivers' preferences. Both the person with cognitive impairment and the family caregiver felt it was more important to consider the best interests of the other member of the dyad above their own best

interests. Finally, care receivers were able to choose a person, most commonly the family caregiver, to make a variety of decisions for them should they no longer be able to make decisions for themselves.¹²

The authors conclude that:

The most salient findings of this study indicate that persons with mild to moderate cognitive impairment are able to : 1) state consistent preferences and choices; 2) provide valid responses to questions about demographics and their own involvement in everyday care; 3) participate in care decisions; and 4) express life long values and wishes regarding care they are currently receiving or will need in the future.¹³

In summary, CDC is appropriate for the cognitively impaired. To the extent that the cognitively impaired person is capable of forming and expressing values and has a competent caregiver, then a well-designed and monitored CDC strategy may be the preferred form of long-term care in terms of remaining in a familiar environment under the control of the consumer and the caregiver, which is important for maintaining function and a good quality of life.

CHAPTER III

Empirical Support for Consumer- Directed Care

Although CDC is rarely, if at all, available in the vast majority of states, at least five states (Arkansas, California, Michigan, Oregon, and Washington) have developed very large CDC programs and the majority of long-term care recipients in Germany and Austria are now in CDC programs. Currently available evaluation findings indicate that these programs are exceptionally popular with recipients and caregivers and are a cost-effective alternative to institutional care and agency-directed home and community-based care for many seriously impaired elderly persons. These findings provide clear evidence that CDC is as appropriate a form of long-term care for many frail elderly persons as it is for younger, disabled persons.

This chapter includes a description of several CDC initiatives along with a summary of available evaluation findings. Because California's In-Home Supportive Services (IHSS) is the largest and most carefully evaluated CDC program in the U.S. with the greatest significance for the future of CDC in the U.S., we discuss it in greater length than the other programs.

State Experiences with Consumer Directed Care

Arkansas

Arkansas is one of the three states participating in the Cash and Counseling Demonstration Project (Independent Choices) sponsored by the Robert Wood Johnson Foundation and the HHS Assistant Secretary for Planning and Evaluation (ASPE). Florida and New Jersey are also participating in the project but because Arkansas was implemented first there are preliminary research findings available. Participants are randomly assigned to either the treatment (cash allowance) or to the control group (agency services) by the evaluator, Mathematica Policy Research, Inc. The cash recipients are provided counseling and bookkeeping (fiscal intermediary) services and mainly use a representative to help manage their personal assistance services (PAS). Telephone interviews with 194 early participants in the treatment group, nine months after they applied to enter the program, found that:

- Most clients (92%) had at least one paid caregiver...[and] (86%) hired their own caregivers and used the cash allowance to do so.

Forty percent of clients received between 20 and 40 hours of paid care from visiting caregivers during a two-week period shortly before the interview. Another 15% received more than 40 hours of care during that period.

- All respondents expressed satisfaction with their relationships with paid caregivers who had helped them recently.
- More than 9 out of 10 clients would recommend Independent Choices to others seeking greater control over their personal care services.
- More than 8 out of 10 clients said that the monthly allowance had improved their lives.¹⁴

California

The California In-Home Supportive Services (IHSS) Program is the largest and oldest consumer-directed care program in the U.S. The program receives over \$500 million dollars annually and serves over 200,000 consumers, half of whom are 65 and older. The program is also designed to allow payments to a wide range of caregivers including family and agency-managed caregivers. These facts make it the most important initiative in consumer-directed care in the U.S. and the program from which we have the most to learn about the feasibility and desirability of this approach to long-term care for the frail elderly. Our knowledge of the IHSS program has been greatly enhanced by a recent evaluation of the program by Benjamin, Matthias, Franke and Mills at UCLA and a policy analysis of the results of the study by Doty and the UCLA research team.^{15 16}

The IHSS program provides two models of care. A consumer-directed model (CDM) permits clients to hire and fire, schedule, train, and supervise their own personal assistance services providers. A full-fledged CDM imposes little or no restrictions on whom a client may hire. In particular, clients in a full-fledged CDM are permitted to choose to employ persons already known to them: friends, neighbors, or family members. CDM typically puts all of the responsibility for recruiting and selecting an aide on the individual client and any family or friends willing to assist.

In contrast, a provider managed model (PMM) program requires that aides be employees of authorized home health or home care agencies. In this model, the agency hires workers according to criteria the agency establishes and the agency also determines which of its employees will be assigned to particular clients. Within an agency, client choice of aides is

generally restricted to “veto” power; clients who are dissatisfied with a particular worker the agency sends may ask to have that worker replaced and the agency will generally honor such a request if it has a replacement worker available (although, strictly speaking, the agency is not required to do so).

A maximum of 283 hours a month is allowed in the IHSS program for the most seriously impaired clients, and reassessments are done annually. Funding per client is capped at a maximum monthly dollar amount computed as the maximum hours figure of 283 multiplied by the state minimum wage—which was recently increased to \$5.75 an hour—for a monthly dollar cap of \$1,627.25 per client.

Table 1 is a display of client characteristics in the PMM and CDM and in the family and non-family provider versions of the CDM. The consumer-directed model has much higher rates of impairment compared to the provider program: 52% are severely impaired, 43% need assistance with 3-6 activities of daily living, 92% need assistance with 3-5 instrumental activities, 47% use a wheelchair and 49% need paramedical assistance. The CDM group was slightly less cognitively impaired. Finally, and similar to the findings in the Arkansas study, 72% of the CDM group were very confident that family or friends would provide help and 67% had just one provider in the last 12 months. There is very little difference within the CDM group in terms of using a family or a non-family provider except that those with a family provider were much more confident about having help from a family or friend and they were more likely to have just one provider in the past 12 months.

The IHSS evaluation was based on a telephone survey of 1,095 randomly selected consumers and 618 workers. Consumers were at least 18 years old, not “severely impaired” and had been in the program for at least six months prior to September 1996. Of all sample members, 78% of clients and 87% of workers completed the survey.

On several key client outcome measures, the consumer-directed model clearly outperforms the professional management model. Under the most rigorous characteristics, such as severity of disability and differential availability of informal supports, the consumer-directed model of service provision consistently yielded superior results on several measurement

**Consumer-Directed Care: An Ethical, Empirical, and
Practical Guide for State Policymakers**

dimensions with respect to client satisfaction with services, empowerment, and quality of life.

Table 1
IHSS CLIENT CHARACTERISTICS—PROVIDER MANAGED MODEL AND CONSUMER-DIRECTED MODEL

Characteristic	PMM	CDM	CDM	
			Family Provider	Non-Family Provider
Percentage				
Assessed impairment rated severe	13.2	51.9	54.2	49.8
3-6 activities of daily living deficiencies	14.7	42.6	44.3	40.7
3-5 instrumental activities of daily living deficiencies	67.0	92.3	94.9	90.0
Used wheelchairs in last month	28.3	46.9	46.4	47.6
Need help with paramedical tasks	19.2	48.9	51.7	46.5
Memory, orientational, judgment, impairment	25.2	21.9	24.6	19.5
Very confident family/friends would provide help	55.4	71.9	84.0	61.6
Had one provider in last 12 months	52.7	66.5	80.3	54.2

Source: Benjamin et al. (1998)¹⁷

The professional management model did not have better outcomes with respect to client safety. Although instances of abuse, neglect, and mistreatment were occasionally reported, consumers in the consumer-directed model reported such occurrences either less frequently or no more frequently than consumers in the professional management model.

However, approximately one-quarter of CDM clients had experienced difficulties recruiting a provider. The professional agency model may be the better choice for severely disabled clients who cannot rely on informal helpers and who lack confidence in their own abilities to make alternative arrangements for backup help.

On subjective measures of job satisfaction, there were no statistically significant differences between workers in the consumer-directed and professional-management models. Here again, the findings confounded the conventional wisdom in that worker satisfaction under both models was quite high across a range of measures, although the average IHSS worker employed by an agency earns about 30% more per hour than a client-directed worker. The worker survey data offers little indication, however, that client-directed IHSS workers are generally aware of or resent that they are paid less and have less access to benefits than their counterparts who work for contract agencies.

In summarizing the evaluation, Doty et al. note that:

Critics of consumer-directed models of service delivery have expressed concerns about client safety under this model and have generally taken the view that consumer direction should be restricted to a minority of clients (primarily younger adults) who social workers judge to be capable of hiring, firing and giving direction to their workers. This study provides no evidence in support of restricting availability of the consumer-directed model. Critics have also questioned the appropriateness of allowing public program clients to hire family members as providers. This study's findings support the option of hiring family members as providers because the data indicate that, on average, family providers are more likely to provide a higher quality of service than unrelated workers.¹⁸

The IHSS program benefits are, however, by the standards of most other comparable state programs, relatively generous. In another state, with less generous monthly benefit limits, the percentage of clients with significant unmet service needs will be much greater. This would likely result in less positive client outcomes for the program as a whole, irrespective of the mode of service provision. It should be noted, however, even relatively generous payments for seriously impaired persons would be less than nursing home costs.

These findings suggest that, on balance, the advantages of permitting clients to hire family providers, in terms of ensuring access to combinations of both paid and unpaid assistance sufficient to meet assistance needs, probably outweigh the disadvantages associated with any marginal substitution of public funding for informal support which may also be taking place. Family providers have a distinct advantage over non-family providers in that they are legally permitted to perform such paramedical or medically related tasks as bowel and bladder care and administration of medications. In addition, they are available where CNAs are not.

Oregon and Washington

Oregon and Washington have used their Medicaid personal care and Medicaid home- and community-based waivers to implement CDC programs which now serve more consumers than the conventional agency-directed home care programs. Table 2 shows

Consumer-Directed Care: An Ethical, Empirical, and Practical Guide for State Policymakers

the extent of consumer-directed care in these two states. Oregon and Washington use different terms for consumer-directed care. In Washington it is called Individual Providers (IP) and in Oregon it is called Client Employed (CE). It should be noted, that while unit costs in both states are higher for consumer-directed care, the cost per hour of care for similar individuals is much less (about 50%) for consumer-directed care. The higher unit costs (cost to the state per client-per month) for consumer-directed care are due to the fact that in both states, consumer-directed care clients are much more impaired than agency home care clients, and require more hours of care.¹⁹

Table 2
A COMPARISON OF IN-HOME SERVICES BETWEEN OREGON AND WASHINGTON AND BETWEEN AGENCY AND INDIVIDUAL PROVIDERS (1996 TO 1998)

	Cases	Cases as % of age 75+ pop	Unit Costs	Expenditures
Oregon				
1996 CE	7,949	(3.9%)	482.01	45,977,558
1998 CE	9,051	(4.3%)	541.22	58,783,448
% Growth	13.9%		12.3%	27.8%
<hr/>				
1996 Agency	660	(0.3%)	193.62	1,534,458
1998 Agency	743	(0.4%)	180.53	1,608,509
% Growth	12.6%		-6.8%	4.8%
<hr/>				
Washington				
1996 IP	6,596	(2.3%)	801.16	65,993,344
1998 IP	10,388	(3.4%)	851.44	106,187,107
% Growth	57.5%		6.3%	62.1%
<hr/>				
1996 Agency	10,513	(3.6%)	382.48	48,252,487
1998 Agency	9,392	(3.1%)	488.47	55,052,234
% Growth	-10.7%		27.7%	14.1%

Source: Ladd & Associates (1999)²⁰

Both states have used their CDC programs and other community-based initiatives, principally assisted living and adult foster homes, to contain the growth of long-term care costs. These states have treated home- and community-based care as if it were an entitlement, and depend upon lower nursing facility utilization to balance their long-term care budgets. Oregon and Washington (as well as Colorado) demonstrated significant savings using home- and community-based alternatives to nursing home care, even after controlling for national trends, greater impairment of nursing facility residents, and other government costs. Table 3 shows a more conservative estimate of savings in the Washington State long-term care system between 1993 and 1998. Almost 3,000 more persons were served in Washington's long-term care programs between 1993 and 1998,

**Consumer-Directed Care: An Ethical, Empirical, and
Practical Guide for State Policymakers**

saving \$4.5 million dollars. The growth of the CDC program appears to have been the major reason for increased capacity and reduced costs.²¹

Even with these success stories, Ladd has noted that although “developing and expanding a consumer directed care program is allowed under current Medicaid law, and that using current federal law to develop and expand this type of program is fairly easy. . . . only a handful of states have taken full advantage of this option. This is primarily due to state barriers to developing and expanding consumer directed care.”²²

Table 3
ESTIMATED ADDITIONAL 1998 COST USING CASELOAD INCREASED BETWEEN 1993
AND 1998 AND UNIT COSTS, STATE OF WASHINGTON

Service	1993-98 Caseload Growth	1998 Unit Costs	Additional Annual Costs
Agency	-3,328	\$488.47	-\$19,507,538
IP	5,379	851.44	54,958,749
AFH	2,518	989.24	29,890,876
ARS	-251	583.60	-1,757,803
ALF	1,353	1,083.29	17,588,296
PACE	79	2,735.65	2,593,396
Sub total			83,765,976
Ancillary	5,750	78.41	5,410,290
Sub total			89,176,266
Nursing facilities	-2,767	2,823.48	-93,750,830
Total	2,983		-4,574,564

Source: Ladd & Associates (1999)²³

**Consumer Directed Care
In Other Countries**

Austria

Austria implemented the Federal Long-Term Care Allowance Act in 1994. The program is designed to: 1) provide a uniform payment to help compensate for care-related expenses, 2) promote a self-determined lifestyle, 3) enable people with disabilities to remain in their own homes, 4) encourage families to provide care, and 5) link previously existing provincial allowances. General tax revenues and payments from employers and employees fund this program. Eligibility is fairly open: age three and older with a permanent need for 50 or more hours of personal care per month. There is no means test. Seven benefit levels in 1994 ranged from \$250 to \$2,000 per month (increasing as dependency

risers). Consumers are required to report on how money is used and local authorities can terminate the allowance if it is flagrantly misused. Consumers with cognitive impairment may have someone appointed to manage their allowance. A 1995 study of 3,120 consumers, 75% of whom were over age 65 and many were severely impaired, found that 81% used their allowance to compensate family caregivers and 29% for home modifications. Over 70% reported greater control over their caregiver arrangements and ability to handle daily pressure.^{24 25 26}

Germany

Germany's Social Dependency Insurance program is similar to Austria's Allowance Act. In 1995, insurance benefits were made available to persons with disabilities, regardless of age. The program's purposes include the following: 1) compensation of beneficiaries for the cost of care, 2) promotion of home care, and 3) improvement in the lives of beneficiaries and their caregivers.

Germany's program recognizes three levels of dependency. The lowest level applies to individuals who have limitations in two or more activities of daily living (ADLs) and need help at least once a day; the highest level is reserved for those who need 24 hour assistance. Service benefits are available for those in nursing homes if home care or day care is not possible. Beneficiaries in the home and community can select one of three options available to them: a cash benefit; agency services which have twice the monetary value of the cash; or a combination of the two. In 1996, persons with the lowest level of dependency received 400 DM (\$250 U.S.) a month, whereas the service benefit was 750 DM (\$468) a month.²⁷

In the program's first year of operation, 84% of beneficiaries with the lowest level of dependency chose the cash benefit, as did 67% of those with the highest level. The cash must be used to help meet the beneficiary's long-term care needs. Consumers who choose cash must receive periodic counseling, as well as visits from professionals who help assure quality and proper expenditure of the cash. German consumers were surveyed about the new program in 1996. The study was based on 10,400 respondents and over 75% were 65 and older. The study found that 72% felt that the program was necessary to maintain their independence. An overwhelming majority of respondents reported high levels of satisfaction with being able to decide themselves how to use their

benefits. Forty-three percent of all respondents reported that their quality of care had improved under the program and only 2% reported that quality had declined.²⁸

More recently, there was nearly unanimous agreement that Germany's cash and counseling consumer-directed care system is a public policy success. The chief reasons for this success are that the program had: 1) provided security and support to informal caregivers; 2) shifted system from an institutional to an in-home program; 3) focused on quality of care; 4) offered fiscal relief and reduced dependency on social assistance; 5) increased the supply of providers; and, 6) increased consumer choice. This successful strategy is an example of making a qualitative rather than an incremental change. It was implemented quickly and globally and yet the expenditures were considerably below projections.²⁹

Among the lessons the authors think we can draw from the German experience with consumer-directed care are the following:

. . . it is not a law of nature that new social programs, especially non-means-tested ones for long-term care, must cost far more than originally estimated. The German long-term care insurance program has an enrollment fairly close to what was originally projected, and spending has been lower than anticipated.

. . . the political success of the program can be tied to some of its design characteristics. Most importantly, the German reform plan provided substantial fiscal relief to the regional and municipal governmental units that funded long-term care.

. . . the population was able to see, in a very concrete way, what benefits they would receive for their new contributions. The program offset the limited range of services that could be covered as an entitlement by providing a cash alternative, which can be used for any purpose and thus has maximum flexibility.

The dominant long-term care policy issue in developed countries is the balance between institutional and non-institutional services. Most countries believe that they are not providing enough home and community-based services. Germany may be the only country where both a majority of the beneficiaries and a majority of the expenditures are in community-based rather than institutional benefits.³⁰

**France and
The Netherlands**

Much smaller CDC demonstration projects were implemented in France and The Netherlands during the early 1990s. The Netherlands project had an experimental design which allowed random assignment to a CDC program and a regular agency-directed program. The evaluation of the project found that consumers who received cash assistance expressed greater satisfaction with worker efficiency and continuity of care than did those in the control group. As a result of these findings, The Netherlands implemented a permanent cash assistance program for people with disabilities.³¹

**Summary of
Empirical
Support for
Consumer-
Directed Care**

The experiences of Austria, Germany, The Netherlands, and to a lesser extent, France, support the findings in the United States that a consumer-directed option provides consumers with better independence, choice, and control and as a result, there is higher satisfaction with care. In Germany, as in the United States, this greater satisfaction is coupled with reductions in the overall long-term care budget. At the same time, there are caveats. Both Germany and The Netherlands showed that older individuals were less likely to choose a cash option. As elders use the cash option earlier in their disability, this age effect may decrease because they will have more experience with the option, suggesting that this finding is actually a cohort effect.

On the whole, the findings from studies of these CDC programs, large and small, indicate considerable satisfaction with the kinds of choice and control this model provides and with the quality of care consumers are able to receive in CDC programs compared to the more traditional agency-directed programs. Furthermore, there is considerable evidence that CDC programs are less expensive than agency-based programs and more efficient in that they provide more hours of service at less cost than the agency-directed program.

This evidence suggests that a CDC approach to long-term care could provide disabled Americans and their caregivers, as well as the state and federal government the following benefits:

- Cash and counseling options provide disabled individuals with maximum flexibility, autonomy, and decision-making power. Consumers have access to information and professional advice, but each individual decides how to best meet his or her needs.
- Many disabled persons would prefer to receive help from relatives, friends or neighbors. Cash and counseling is a simple and non-bureaucratic way to support informal caregivers.
- A major barrier to the expansion of long-term care services in this country is the high unit costs of government-purchased services. For example, home care visits paid for by current state and federal programs may cost upwards of \$100 for a four-hour block of service. Cash and counseling options could enable consumers to arrange for services that are less expensive and more appropriate to their personal needs and preferences.
- By establishing the monthly cash allowance as a percentage of the case-managed service-benefit cost, states can ensure that the cost per client will be less than what it would otherwise pay. Additionally, administrative savings may be achieved because of lower billings and claims handling costs.
- By giving consumers the flexibility and independence to spend their money as they best see fit, cash and counseling encourages the evolution of long-term care services that are responsive to consumer needs rather than to government regulations.
- Providing consumers with a monthly cash allowance could be an excellent and much-needed check on case-managed service benefits and could potentially improve the market for home- and community-based services. If consumers believe their needs are best met by the service benefits offered by the government or private organizations, they will not choose the cash allowance.

CHAPTER IV

Barriers to Consumer- Directed Care

Barriers to successful implementation of consumer-directed care come from providers, environmental limitations, client reluctance, government regulations and societal attitudes. Many providers and state agencies have developed solutions to these barriers which are addressed here.

Policymaker and Provider Barriers

Provider barriers to consumer control of care are largely a product of adherence to a medical model of care. According to Boldy, McCall, and Heumann (2001) the medical model:

. . . sees disability and frailty as deviations from the norm, so care is designed to reduce the gap between the norm and the pathology. This often means providing a secure and comfortable environment and providing prescribed types and levels of care based on the degree and type of disability or frailty. At its worst, it is a total inhibitor of empowerment of the individual to define the environment of care and support that will maximize personal functional independence and allow a lifestyle that yields the greatest satisfaction and dignity.³²

The domination of the medical model contributes substantially to an institutional care bias that shapes long-term care policy and practice for the frail elderly at every level- from the formulation of budget priorities (80% of all long-term care public dollars go for nursing home care) to the design and use of hospital discharge and client assessment instruments and care planning and management practices, which tend to focus more on the disabilities than the strengths of consumers. The manifestation of the medical model approach is found in how programs and policymakers respond when implementing long-term care programs. These responses are described below.

Providers resist CDC if it threatens their livelihood or their understanding of what is “good care.” Boldy et al. note that with consumer empowerment models like CDC:

. . . each and every one of the service professional roles remain as important as ever, taking on new more creative and dynamic functions as support planning becomes more

individualized. True, they cannot rely on standardized and categorical solutions, so their job becomes harder, but they also become jobs worthy of their professional title.³³

At the same time, providers will have the potential to increase their services even with CDC as the frail elderly population grows over the next several decades. For example, aging network providers will be pressed to meet the needs of those who cannot benefit from a CDC approach. On the other hand, the development of CDC programs could create a more favorable atmosphere for increased funding of home and community care, including agency-directed programs. Growth in funding for these programs has been slow or non-existent in many states for several years and CDC initiatives could help move home- and community-based care to the top of the policy agenda over the next decade. Finally, these providers will also be able to serve CDC recipients who choose to purchase services from them using their cash allowances. In fact, many consumers will want to blend CDC with some agency support. Simon-Rusinowitz et al. point out that:

. . . many [consumers] would prefer to have an agency be responsible for the administrative aspects of personal assistance services. Thus, there will always be a need for agency-based services . . . agencies may be less threatened if they understand that consumer-direction principles are not specific to an independent provider model, and they can be incorporated into an agency setting should providers want to do so. Thus, if agencies view consumer-directed services as a means to maintain or increase their business, they can modify existing programs with these principles. As CDC evolves, we are likely to better understand how traditional agency providers and consumer-directed programs can support one another.³⁴

The CDC approach to community-based long-term care will require a change in the way agencies provide case management. As consumers are empowered, case managers will have to relinquish the kind of control characteristic of conventional case management strategies and take on the role of advisor, counselor, and advocate for the consumer. The increased satisfaction this change in roles is likely to bring the consumer and

caregiver should be gratifying for the case manager as she stands in witness to lives enlarged by the exercise of autonomy under conditions of physical and mental impairment.

Policymakers must address the potential for fraud and abuse that comes with a more flexible and consumer-directed program. In a survey of 20 long-term care policy experts in the aging and disability communities, Simon-Rusinowitz et al. found that while they were generally supportive of consumer-directed care, they also expressed some reservations. Their main concerns were the potential for fraud and abuse, worker conditions, potential incompatibility with managed care and traditional provider resistance.³⁵

Although efforts must be made to prevent fraud and abuse in any program, the use of fiscal intermediaries, surrogate decision-makers and care advocates responsible for quality assurance monitoring should help states keep fraud, abuse, and neglect to a minimum. The results of the IHSS evaluation are reassuring in this respect. Most consumers, “. . . are likely to elect to have the payroll and tax withholding for their workers done for them by accounting professionals. This would greatly reduce the amount of cash that consumers receive and manage. Those consumers electing not to use accounting professionals would need to participate in a training program and demonstrate competency in payroll tasks.”³⁶

The vast majority of workers in all long-term care programs are paid low wages and many do not have benefits. CDC is not likely to make wages any worse. In fact, it is specifically designed to improve the lot of the many caregivers who are now working without any remuneration, especially family caregivers.

Managed care is evolving and changing so rapidly it is difficult to assess its current and future capacity to accommodate a CDC approach to long-term care. There does not, however, appear to be any fundamental conflict between CDC and a financing system based on capitation. Whether or not managed care would in any way enhance, or add value to, CDC is an open question that should be addressed empirically.

Providers and regulators believe that consumer-directed care cannot be implemented in institutional settings. Consumer-directed care is

most commonly addressed in the context of community-based care with the consumer paying a caregiver to provide care in the home. Consumer direction, however, can occur in residential care settings, including nursing homes as well, if providers are willing to make qualitative changes in the ways they organize their service delivery and regulators are supportive. One example of how residents can be empowered in nursing homes is the Charter of Resident Rights and Freedoms which was implemented by the Residence Yvon-Brunet in Montreal, Canada. This program is designed to create a resident-oriented balance between freedom and safety by allowing the resident to make decisions and take actions that involve degrees of acknowledged risks that may be inherent in the residents' efforts to achieve an acceptable quality of life. The Charter has five major rights which have been used to make qualitative changes in the organizational/management structure and day-to-day culture of the facility. These major rights include: 1) the right to be informed and freedom of expression, reversing the traditional balance of power between the residents and staff; 2) the right to privacy, just as the resident would have in her own home; 3) the right to respect and dignity, obliging staff to treat residents with deference and shunning familiarity, infantilism and personal prejudices; 4) the right to continuity, requiring that each resident is seen and assisted by the same staff; and, 5) the right to responsibility and participation in the organization and administration of the nursing home.

The Charter of Resident Rights became the framework for creating a balance between freedom and safety for residents and a far more comprehensive vision of the needs of residents than is allowed under the conventional medical model. By reducing our concern for the frail elderly to a focus on their physical needs and limiting the concept of quality to staffing standards, pressure sore care and other criteria contained in our current regulatory regime, adherence to the medical model of nursing home care leaves out most of what makes life worth living for most people—dignity, autonomy, emotional connection, individual identity and equality in relationships. It is precisely these values and the capacity to achieve them that the Charter of Resident Rights is designed to put back into the lives of residents.

The Charter is a resident empowerment strategy usually associated with assisted living rather than nursing home care in the U.S. where the focus has been on regulatory requirements related to the quality of medical care.

Some progress has been made by the Nursing Home Pioneers and advocates for the Eden Alternative and the Green House Project. All of these groups are committed to changing the culture and ecology of nursing homes and making them more livable environments with greater opportunities for the residents to exercise autonomy. In order for these changes to occur on a broad scale, however, policymakers, regulators, providers will have to overcome the exclusive commitment to a medical model of care and regulation along with the constant threat of litigation that is endemic to a model that provides so little room for resident autonomy and the availability to make choices that may entail some degree of risk.

Environmental Barriers

Many frail elderly persons who could benefit from consumer-directed care and other forms of community-based long-term care do not live in physical environments that support this kind of care. Heumann (2001) notes that:

If seniors want to maximize environmental support and independent living when faced with advancing frailty, they almost seem to be encouraged to look for a purpose-built retirement or assisted-living solution. There don't seem to be many program options for modifying a conventional home and staying put. Those that do exist seem to be very crude and not coordinated under a single care management model. This can only be seen as a limitation in support choices and flexibility, which limits empowerment of frail elderly people who want to retain maximum control of their support system. The added material and psychological cost of depending on others to manage a barrier-ridden environment has to take a considerable toll on personal empowerment—especially if visiting human support is entering a private home to complete tasks residents could do on their own with the right design, layout and equipment modifications. This can ultimately affect one's desire and ability to remain in what was once and could still be an independent environment. Thus, both the material and psychological costs can cause the ultimate loss of power—a premature move to a totally dependent environment.³⁷

For many frail elderly persons, the feasibility of consumer-directed care is diminished by environmental barriers which are often overlooked in the development of care plans or cannot be remedied

because of the lack of resources. Environmental assessments and provisions for adaptation/modification must become routine parts of the client assessment and care planning process in order to maximize the potential for consumer-directed care.

Client Reluctance

A reviewer of an earlier draft of this paper, who is a service provider, commented that, “Clients (or applicants) most commonly express a desire for the case manager to ‘handle things’ for them. It would thus appear that the education needed is not about ‘relinquishing control’ but rather should focus on teaching case managers to encourage clients in continuing their own autonomy and independence.” In support of this perspective, Boldy et al. have observed that:

. . . awakening a desire for individual empowerment on the part of passive care recipients is a dynamic, circular process, requiring the reinforcing of trust, education and experimentation between care recipients and providers, which very often must be initiated through the encouragement of the care provider.³⁸

. . . after years of acquiescence to professional authority, many frail and disabled persons and their families are afraid of empowerment. Therefore, the proactive professionals must see their roles as becoming advocates and teachers, educating and training elderly and disabled people and the general public to this new way of thinking and acting. They face a very insecure public, many of whom are vital informal care providers, who must learn that the recipients of care actually have preferences about how and when care provision comes into their lives.³⁹

Boldy et al. conclude that:

The most important client-based impediment to empowerment is the *loss of confidence and self-esteem* that comes with a loss of independence from living in a supportive environment that does not encourage people to continue to seek independence to the margin of their ability. . . . any program or strategy that society develops to empower frail elderly people must also recognize that some older people will consciously choose dependence. We are clearly for programs and practices that are sensitive to this choice and have the flexibility to accommodate it as equally as providing full empowerment. From our perspective, however, it is the

empowerment model that our societies are having real trouble fully addressing, not dependence by choice.⁴⁰

Regulatory Barriers

The societal interest in regulating the quality of long-term care has been filtered through the medical model which dominates the current long-term care service system and is not compatible with a consumer-oriented approach to regulation. This structure (staffing standards) and process (charting accuracy) approach to regulation focuses almost exclusively on quality of care; little attention is paid to quality of life issues which often are of greatest concern to the recipient of care herself. It is not even clear that current measures of quality of care are reliable and accurate over time and across facilities, or actually measure quality of care according to the medical model.

Many people and a lot of organizational resources are invested in this heavily bureaucratic regulatory paradigm in which structure and process are more important than the specific interests and preferences of the person receiving care. It is time to question the value of this approach and to use CDC as a vehicle for making care more responsive to the needs and desires of the consumers, giving quality of life as defined by the consumer *at least* equal footing with quality of care as defined by experts. CDC has the potential to give the consumer the power to regulate quality in long-term care according to her individual preferences by taking control of resources from the provider and giving it to the consumer and her family.

Societal Attitudes

Ageist assumptions about the elderly, especially those with substantial impairments, stand in the way of consumer empowerment in long-term care. These assumptions include the stereotypical perceptions that: 1) functional impairment in old age automatically leads to dependency and a rapid decline in the values of autonomy and control, and 2) that younger disabled persons are deeply committed to maintaining as much independence as possible, but older disabled persons are not. The success of the California IHSS program and similar consumer-directed care programs in other states and in Europe, including programs for the cognitively impaired, should put to rest the notion that many impaired older persons are not interested in controlling (at least partially) their own care. Boldy et al. state:

Society must get over its *fears of aging* and its *remaining stereotypes* about the aged. This means that our goal is *not* docile, happy and secure people with disabilities. Our goal is to meet the wishes for support and values for independence through empowerment, providing flexible choices and training and explaining the options and risks associated with different choices. Beyond this, there are no institutional norms, no prescribed categorical solutions. Risks, problems and failures on the part of disabled people should *not* be eliminated, avoided or “solved” for disabled people. Nor should the allowance of risk or problems to exist in individual care planning be seen as unprofessional or project failures. These are essential parts of life being lived to its fullest. We need to define, measure and reward professional caregiving in ways that encourage empowerment in flexible, humanistic and creative ways. If we can’t find these types of solutions, there will never be any real empowerment of frail and disabled people.⁴¹

American society and our policymakers must also overcome a deep reluctance to provide financial support to informal caregivers of the impaired elderly. The declining availability of unpaid informal caregivers caused by the huge increase in formal participation in the paid labor force over the last 30 years and the escalating costs of hiring, training and retaining workers in the formal long-term care system are likely to increase the political feasibility of paying informal caregivers, including spouses to provide care.

Furthermore, baby boomers are likely to be much more insistent on exercising control over whatever long-term care services they may need as they begin to age over the next 30 years. These trends, in combination with the possibility that consumer-directed care may be at least as cost-effective as conventional long-term care services, could dramatically change the political context for paying caregivers over the next ten years.

CHAPTER V

Implementation of Consumer- Directed Care

Notwithstanding the barriers described above, States are faced with implementing home and community-based long-term care options, including consumer-directed care. This became especially important with the 1999 Olmstead decision. This court case and its ramifications are described next along with issues involved with implementing consumer-directed care.

Olmstead Decision

The 1999 Olmstead decision (*Olmstead v. L.C. ex. Rel. Zimring*, ADA) prohibits states from unnecessarily institutionalizing persons with disabilities and not serving them in the least restrictive setting that is appropriate to their needs and not a fundamental alteration of public programs. This decision has potentially major implications for long-term care of the frail elderly, especially those receiving Medicaid and general-revenue funded services. Over 80% of these funds are currently spent on nursing home care. According to Rosenbaum (2000), state and federal court cases and decisions interpreting Olmstead indicate that:⁴²

- States are not required to add Medicaid coverage for services and benefits that are necessary for community care but that the state does not already provide, however, arbitrary *expenditure caps on covered home and community services* that are surpassed and result in institutionalization violate the ADA...[and] a state must show that additional services would amount to a fundamental alteration and may not require an individual to prove that community care is reasonable.
- Courts may impose outer limits on the number of days a state has to put together an appropriate community care program for an individual who is inappropriately institutionalized and desires community care.
- The individuals protected by *Olmstead* are in institutions and could be appropriately cared for in the community and also in the community and who risk institutionalization unless they receive appropriate care.
- States must ensure that nursing home diversion programs properly avert institutionalization for potential residents through the provision of appropriate community care. Thus, while the state need not institute a nursing home diversion program, if it does so, it must fully fund the program it offers.

- States can deny the aid only at the point at which the obligation to fund appropriate community services requires a fundamental alteration of a state's program.

The Department of Health and Human Services (DHHS), through the Health Care Financing Administration (HCFA) and the Office for Civil Rights, has developed a planning framework for the states, which gives the states substantial discretion in deciding how to respond to Olmstead. The HHS planning guidelines do specify, however, that the states should be prepared to respond to the following issues vis-à-vis their long-term care Medicaid program for the frail elderly, according to Rosenbaum (2000):

- Do the states' Medicaid HCB waiver programs cover older persons as well as children and young adults?
- Do the Medicaid state plans and the HCB waiver programs provide the kinds and range of services recognized by experts as necessary for effective community integration of older persons with long-term care needs?
- Do the states effectively and accurately screen nursing home and other institutional residents to determine appropriateness of their placements?
- In the case of older persons without adequate informal caregiver arrangements, are sufficient resources available to help meet the cost of community housing, particularly assisted living?
- Does the post-Olmstead planning process include older long-term care consumers and persons who are experts in the design of home- and community-based programs and services for the frail elderly who need long-term care services?

DHHS support for major HCB initiatives in response to Olmstead was most recently and clearly articulated in a letter (Timothy M. Westmoreland, January 10, 2001) to the state Medicaid directors which described a set of "new tools" the states may use to advance their Olmstead-related program planning and development activities. These tools include \$50 million in Real Choice Systems Change grants and \$8 million in Community-Based Attendant Services with Consumer Control

grants. Both of these grant programs create opportunities for making consumer direction a centerpiece of new HCB services initiatives for the frail elderly. Although the Department seems to be thinking primarily of personal attendants for younger disabled adults, the focus on consumer control provides a clear opportunity for moving ahead with proposals to allow consumers to pay caregivers, including spouses and other family members and non-family members of the consumer's caregiving network, through new and modified Medicaid HCBS waivers. For example, two possible areas of interest to DHHS are:

- **Comprehensive long term service system reforms** : Design, demonstrate, or implement reforms for one or more target groups that create an effectively working system of comprehensive long term care services that (a) enable flexible long term service funding to follow each individual across the sites of preferred and appropriate living arrangements; (b) maximize the opportunities from community participation and ensuring the most integrated community living possible; and (c) *support self-direction and the exercise of personal responsibility* [italics added].
- **Infrastructure development that supports consumer-directed services**: Enhance system operations to support development and purchase of services that is organized around the individual and is outcome-based. Develop and implement mechanisms to further consumer-directed services, such as flexible home and community-based waiver service definitions, assistance in purchasing services (e.g., support brokerage), assistance in acquiring housing through rental or home ownership, development of provider qualifications tied to the consumer's needs, implementation of emergency back-up systems for personal assistance or other services, and involvement by people of all ages who have a disability or chronic illness (and their families) that includes personal responsibility for one's plan and budget.

These kinds of activities are most closely associated with more formal personal attendant services which have long been a priority with disabled adults and their advocacy groups. These services can also be of great value to the disabled elderly who have historically not had much of an opportunity to use them and they certainly should be part of a comprehensive initiative to empower the frail elderly and expand consumer control of long-term care. Personal attendants, however, will not be enough to give the frail elderly the kind of consumer control that

will be of greatest benefit to them. Olmstead planning should be used by state policymakers, planners, advocates and policy experts to make the case for allowing consumers to pay caregivers by funding programs like those described in an earlier section of this paper, especially the California IHSS program. A very strong cost-effectiveness case can be made for these programs and they seem to be extraordinarily compatible with the thrust of the Olmstead decision—how better to integrate the frail elderly into mainstream community life than by allowing them to make as many decisions as possible about their own lives.

Containing Fiscal Impact

One of the major issues confronting state and federal policymakers in developing and implementing a program as attractively consumer- and family-oriented as CDC is how to contain its cost, or what is often referred to as “the woodwork effect.” That is, how to keep the program affordable, given the probability that many frail elderly and their families and caregivers who shun nursing home care and most home- and community-based services would seek assistance from a CDC program. In some measure, the cost-effectiveness of CDC is dependent on containing this likely demand by implementing reasonable eligibility criteria and monitoring the extent to which assistance continues to be needed. The “woodwork effect” was a major concern of policymakers during the early stages of the development of agency-directed home- and community-based services in the 1980s. They were also concerned that HCB services would not prove to be cost-effective in terms of containing the need for nursing home care.

The experience of many states over the last 15 years and the results of research conducted since 1990 generally show that states have learned how to contain the woodwork effect and the HCB programs are cost-effective alternatives to nursing homes if efficiently targeted to those at risk of nursing home placement and designed to individualize service provision. Lessons derived from the administration of agency-directed HCB programs can be used to control the demand for CDC and keep expenditures within budget limits. For example, eligibility can be limited to those who meet clear levels of need (functional capacities), resource (income and assets) and support network (availability of caregiver) criteria. During the initial stages of implementation, the criteria can be kept relatively restrictive and then modified later as policymakers,

administrators and care counselors gain experience with the unique strengths and challenges of CDC and make adjustments based on monitoring and evaluation information.

States should begin their CDC programs on a relatively small scale and expand them steadily as they gain experience, review the results of evaluation research and become confident of their ability to contain costs and identify those who are appropriate for the CDC program. To the extent feasible, states should use current program structures to administer CDC programs, rather than implementing new organizational structures from the ground up. Many states have home- and community-based programs that provide some form of support to caregivers and careful consideration should be given to modifying these programs in whole or part for CDC. In Florida, for example, the Home Care for the Elderly (HCE) Program, is a general revenue funded program that began almost 20 years ago and provides a very small reimbursement to caregivers for products and services purchased for the purpose of providing in-home care for a relative. The program could be qualitatively changed and expanded to become a full-fledged consumer-directed care program similar in design to the program in California, Oregon, and Washington. The major changes would include: converting HCE to a cash program with several levels of payment based on assessed functional needs and financial resources; developing a counseling component designed to provide information, advice and protection against fraud and abuse to caregivers and recipients; and, implementing a fiscal intermediary program to manage payments, taxes and other financial transactions consumers may not want or be able to handle themselves.

Nurse Delegation

Another way of containing costs and making CDC more affordable is to pass nurse delegation legislation which would make it possible for non-family caregivers without a nurse's license to dispense medicine, give shots and provide other healthcare-related services under the supervision of a nurse. A few states have nurse delegation statutes which are designed primarily to make assisted living more affordable. The same affordability rationale applies to CDC. Oregon has had a nurse delegation statute for several years and it seems to have worked well. Family members in all states already have the right to provide these services.

Workforce

The number of informal, unpaid caregivers is likely to decline significantly over the next three decades. The number of baby boomers with no children, or only one or two children, will be substantially greater than previous generations and the percentage of women who constitute more than 70% of informal caregivers, in the paid labor market is likely to increase from the already historical high of 50%.

The troublesome gap between the demand for and the supply of formal long-term care workers is likely to grow with increases in the number of frail elderly persons over the next several years. The cost of reducing this gap in terms of wages and benefits will create a huge demand on public resources.

Paying informal caregivers may be the most cost-effective method of using public resources to strengthen the informal care system and expand its capacity to divert frail elderly from more expensive formal system programs, including nursing homes and assisted living facilities, or substantially delay their use by reducing caregiver burnout extending the length of time care is given. The true potential of CDC to substitute for more expensive formal programs is still a matter of debate and will only become known through continuing evaluation of CDC programs as they are implemented and expanded. It would appear, however, that the cash and counseling program in Germany, which has generated high consumer satisfaction ratings, has not cost the government more than the nursing home dominated long-term care programs of the pre-1995 period. The California IHSS program is serving a large population (100,000 plus) of substantially impaired elderly for less than \$20,000 annually, or half the cost of nursing home care; and Washington has contained the overall costs of long-term care by expanding its CDC program. These experiences with current CDC programs suggest that the cost-effectiveness potential of CDC is very substantial and worth extensive testing.

**Administrative
Support for
Consumers**

Policymakers and administrators should anticipate that most consumers and caregivers will need the services of a fiscal intermediary in managing payments, payroll taxes, worker compensation and other financial transactions. Experiences with current CDC programs indicate that 75 to 80% of consumers chose to handle these arrangements through a fiscal intermediary and states should be prepared to fund these services

accordingly and provide them through contracts (following a bidding process) with third-party organizations.

Training and Education

States will have to develop a systematic and well-managed capacity to train consumers, caregivers, eligibility and assessment workers, care counselors and fiscal intermediaries in the advantages and risks of CDC and in the mechanics of its operation. Training for all participants in CDC is critical to the success of the program and should be funded accordingly. CDC represents a paradigm shift in long-term care services and will be a challenge for everyone involved. This means that training should include ample exposure to the fundamental rationale (philosophy) for CDC, as well as the operational detail. Training for consumers and caregivers should be designed to acquaint them fully with the roles they will have to play and the risks inherent in taking a qualitatively more active approach to controlling the provision of care. The training protocols developed by the states with extensive CDC experience should be carefully reviewed and adopted, or adapted as appropriate.

Provider Adjustment

The needs and concerns of provider agencies should be carefully and thoroughly addressed during the formulation of CDC policy and the implementation of the program. These agencies represent the backbone of the aging network and the foundation of home- and community-based long-term care. Their experiences, community credibility, support, and their commitment to the frail elderly make them prime candidates for providing care counseling in CDC. Some of these agencies may, at least initially, feel threatened by CDC and every effort should be made to protect their current budgets for agency-directed HCB services. CDC will not meet every frail elderly persons' needs and that the growth of the older population over the next several years will generate a steady increase in need for agency services, even with CDC. Agency representatives should be involved in the planning and development process for CDC and priority given to contracting with them for the care counseling and training components of the CDC program and overall administration of the program at the service delivery level.

Regulation

Policymakers should avoid imposing a heavy-handed regulatory scheme on CDC. The regulatory objectives for CDC should be the prevention of fraud, abuse and neglect and maintaining an acceptable quality of life from the perspectives of the consumer and the caregiver(s). The care counselor should be trained to identify and respond appropriately to fraud, abuse and neglect. Responding appropriately would include prompt referrals to Adult Protective Services for further investigation and possible police intervention and legal action in cases of suspected criminal intent. The counselor should also be prepared to offer advice and support in situations that may create a threat to the well-being of the consumer but do not involve criminal intent or willful neglect. Support may entail referrals to other agencies or less formal groups (caregiver support groups) for more extensive counseling and supportive services. The counselor, however, must be trained to not intervene too forcibly and risk undermining the autonomy and privacy of the consumer and her caregiver(s), especially when the counselor may disagree with the decisions and actions of the consumer. The counselor's job is to help maximize the consumer's capacity to manage risk without clearly becoming a danger to herself or the victim of someone else's fraudulent or abusive behavior.

Counselor caseloads should not be so large as to prevent at least monthly contact with consumers and caregivers and more frequent contact when circumstances (i.e., change in caregiver) require more active assistance. As a rule, this level of involvement will probably consist of caseloads no greater than 40-to-50 consumers. Counselors working with cognitively impaired consumers should have smaller caseloads and receive training that will prepare them to deal effectively with needs of these consumers and their caregivers, who will often need more support and assistance than the caregivers of cognitively intact consumers.

The structure and process focus of conventional long-term care regulation is only partially applicable in the context of consumer direction. The counselor certainly needs to ensure that caregivers know their job and that necessary services (i.e., home health care) are being appropriately provided. But the regulatory priority in CDC must be on quality of life and the extent to which criteria based on the concepts of autonomy, dignity, emotional well-being and general life satisfaction are being met. Information on these criteria should be gathered through face-to-face interviews with consumers and caregivers conducted at regular intervals and on an

as-needed basis. The principle focus of this approach to care monitoring is the quality of the consumer's relationship with the caregiver, service providers and others rather than the more material conditions of the consumer, except as they bear on her satisfaction with her quality of life.

CHAPTER VI

Conclusions

The ethical and empirical case for consumer-directed long-term care may be summarized as follows:

- Human identity in Western societies is substantially based on a strong sense of autonomy and personal agency. There is substantial evidence, in fact, that the value of autonomy to identity and life satisfaction among Americans is growing, and sustaining maximum autonomy will be the major concern of the baby boom. Physical and cognitive impairments may limit an individual's capacity to act autonomously, but they do not diminish the significance of autonomy as a pillar of identity—as an organizing principle of the sense of self.
- The limited research done on the importance of choice and control to recipients of long-term care services indicates that a substantial percentage want greater control over the delivery of care and that the ability to exercise choice and control greatly affects the recipient's perceived quality of life.

The value of autonomy has been largely ignored in the development of long-term care policy for the frail elderly which is one of the major reasons our publicly supported long-term care system is dominated by nursing homes. This is a far more flagrant case of neglect of the frail elderly than would occur under any system of CDC, which is designed to nurture the autonomy of the frail elderly and respond to the realities of dependency. Many non-affluent frail elderly persons who need and qualify for publicly supported long-term care services avoid them for fear of losing their autonomy and ending up on a slippery slope into a nursing

home. They also fear getting caught up in a bureaucratic environment that may erode their privacy and the intimate arrangements of their daily lives. This is why many frail elderly persons struggle with their impairments well beyond the time when they could benefit from outside assistance and then they have no choice but to surrender virtually all of their autonomy and enter a nursing home.

- Currently available evaluation findings indicate that consumer-directed programs are exceptionally popular with recipients and caregivers and are a cost-effective alternative to institutional care and agency-directed care for many seriously impaired elderly persons. These findings provide clear evidence that CDC is as appropriate a form of long-term care for many frail elderly persons as it is for younger, disabled persons.

Consumer-directed care is not for every frail elderly person in need of long-term care services but it could be for far more consumers than are currently provided this option. The available empirical findings suggest that CDC is the most flexible form of long-term care in that it can be designed to permit not only the paying of individual caregivers, but also allow consumers to pay for community-residential care and, if necessary, nursing home care. In short, CDC could be designed to empower the consumer across the spectrum of long-term care services by allowing dollars to follow consumers rather than going directly to providers.

Some aging policy experts and advocates have taken the position that CDC may be appropriate for cognitively intact frail elderly persons, but not for the cognitively impaired. There is clearly a difference between these groups in terms of their capacity to benefit from CDC, but the difference should not be made absolute by drawing a bright line between them and blocking access to consumer direction for the cognitively impaired. As long as the cognitively impaired have the capacity to form and express values and have competent caregivers, they should be considered legitimate candidates for CDC.

From this perspective, CDC is not just a means of empowering the consumer, it is also a program to empower the caregiver-consumer unit and enhance the capacity of the informal system to provide high quality care for much longer periods of time than many unsupported caregivers can sustain. A CDC design that incorporates family caregivers is likely to be not only more effective than a design that excludes them, it can also be argued that it is more compatible with a broad commitment to the value of public policies that strengthen the family and support its capacity to care for impaired relatives.

Our attitudes toward the elderly generally, and the needs, values and preferences of the frail elderly have changed considerably over the last several decades, though we still struggle with the damaging effects of ageism and the limitations of the medical model approach to care.

Moody (1976) developed a continuum of responses to aging issues to demonstrate that current public policy is based on a paternalistic and bureaucratic approach. A more enlightened approach would encourage much greater participation by the elderly in the policy-making process and control over the delivery of services.⁴³

CDC and other forms of consumer empowerment, including those appropriate to residential care settings, represent the most promising means of making greater improvement in the quality of our long-term care services and moving public policy along Moody's continuum from paternalism to participation and eventually to the development of policies that explicitly recognize the value of self-actualization across the entire lifespan and the realities of individual autonomy in the 21st century.

**Consumer-Directed Care: An Ethical, Empirical, and
Practical Guide for State Policymakers**

Endnotes

- ¹ Wagner, D., Nadash, P., Friedman, A., Litvak, S., & Eckels, K. (1996). *Principles of consumer-directed home and community-based services*. Washington, DC: National Council on the Aging.
- ² Kapp, M. (2000). Health care in the marketplace: Implications for decisionally impaired consumers and their surrogates and advocates. *Ethics, law and aging review: Consumer-directed care and the older person, Vol. 6* (p. 15). New York: Springer Publishing Company.
- ³ Ibid, p. 17.
- ⁴ Ibid, p. 18.
- ⁵ Salmon, J.R. and Polivka, L. (2000). Study shows link between control and consumer satisfaction. *Consumer Choice News* 4, n 4, p. 4, 6 & 8.
- ⁶ Simon-Rusinowitz, L., Mahoney, K. Desmond, S. Shoop, D. Squillace, M. & Fay, R. (1997). Determining consumer preferences for a cash option: Arkansas survey results. *Health Care Financing Review, 19*(2). p. 87.
- ⁷ Supra, note 2, p. 18.
- ⁸ Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philosophy & Public Affairs* 28(2), p. 128.
- ⁹ Ibid, p. 130.
- ¹⁰ Supra, note 2, p. 25.
- ¹¹ Supra, note 2, p. 25.
- ¹² Feinberg, L. Whitlatch, C. & Tucke. (2000, May). *Making hard choices: Respecting both voices*. Final report prepared by Family Caregiver Alliance for Robert Wood Johnson Foundation: San Francisco.
- ¹³ Ibid, p. 89.
- ¹⁴ Foster, L., Brown, R. Carlson, Phillips, B. & Schore, J. (2000, Oct). *Cash and Counseling: Consumers' Early Experiences in Arkansas*. Mathematica Policy Research, Inc.: Washington DC.
- ¹⁵ Benjamin, A., Matthias, R., Franke, T. & Mills, L. (1998). *Comparing client-directed and agency models for providing supportive services at home: Final Report*. Los Angeles: University of California.
- ¹⁶ Doty, P., Benjamin, A., Matthias, R. & Franke, T. (1999, Apr.). *In-home supportive services for the elderly and disabled: A comparison of client-directed and professional management models of service delivery*. Non-technical summary report prepared by U.S. Department of Health and Human Services and the University of California, Los Angeles.
- ¹⁷ Supra, note 15.
- ¹⁸ Supra, note 16.
- ¹⁹ Ladd & Associates (1999). *Opportunities for developing and expanding consumer directed care*. Prepared for the National Council on Aging: Washington, DC.
- ²⁰ Ibid.
- ²¹ Ibid.
- ²² Ibid.
- ²³ Ibid.
- ²⁴ Badelt, C., Holzmann-Jenkins, A. Matul, C. & Osterle, A. (1997). *Analyse der Auswirkungen des Pflegevorsorgesystems*. Translated by Jon Peter Hopperger. Bundesministeriums für Arbeit, Gesundheit Und Soziales Wien, Austria.
- ²⁵ Rubisch, M., Wotzel, W. & Phillip, S. (1995). *Provision for long-term care in Austria*. Translated by Peter Stallybrass. Vienna, Austria: Federal Ministry of Labour and Social Affairs.
- ²⁶ Keigher, S. (1997). Austria's new attendance allowance: A consumer choice model of care for the frail and disabled. *International Journal of Health Services, 27*(4)4: 753-65.
- ²⁷ Runde, P., Goese, R., Kerschke-Risch, P., Scholz, U. & Wiegel, D. (1996). *Einstellungen und Verhalten zur Pflegersicherung und zur Hauslichen Pflege*. Translated by Jon Peter Hopperger. Hamburg, Germany: Universitat Hamburg.
- ²⁸ Schneider, U. (1997). *Germany's new long-term care policy: Profile and assessment of social dependency insurance*. Policy Paper #5, AICGS Seminar Papers. Washington DC: American Institute for Contemporary German Studies.

**Consumer-Directed Care: An Ethical, Empirical, and
Practical Guide for State Policymakers**

- ²⁹ Ibid.
- ³⁰ Cuellar, A. & Wiener, J. (2000). Can social insurance for long-term care work? The experience of Germany. *Health Affairs*, 19(3): 8-29.
- ³¹ Miltenburg, T. Ramakers, C. & Mensink, J. (1996). *A personal budget for clients: Summary of an experiment with cash benefits in home care in the Netherlands*. Nijmegen, Netherlands: Institute for Applied Social Sciences.
- ³² Boldy, D., McCall, M. & Heumann, L. (2001). Empowerment of frail elderly people and the vision of a self-actualized society. In L. F. Heumann, Mary E. McCall & Duncan P. Boldy (Eds.), *Empowering frail elderly people* (p. 241) Westport, CT: Praeger
- ³³ Ibid.
- ³⁴ Supra, note 6.
- ³⁵ Supra, note 6.
- ³⁶ Supra, note 16.
- ³⁷ Heuman, L. (2001). The role of the built environment in holistic delivery of home- and community-based care services to frail elderly persons. In L. F. Heumann, Mary E. McCall & Duncan P. Boldy (Eds.), *Empowering frail elderly people* (p. 134) Westport, CT: Praeger
- ³⁸ Supra, note 32, p. 245
- ³⁹ Supra, note 32, p. 242
- ⁴⁰ Supra, note 32, p. 243.
- ⁴¹ Supra, note 32, p. 245.
- ⁴² Rosenbaum, S. (2000, Nov.) *In brief: Olmstead v L.C.: Implications for older persons with mental and physical disabilities*. AARP Public Policy Institute: Washington, DC. http://research.aarp.org/health/inb30_disabilities.html, p. 1-2.
- ⁴³ Moody, H.R. (1976). Philosophical presuppositions of education for old age. *Educational Gerontology* 1:1-6.