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# Paying Family Members to Provide Care: *Policy Considerations for States*

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# Paying Family Members to Provide Care: *Policy Considerations for States*

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## INTRODUCTION

Support is growing for publicly funded payments to informal caregivers (relatives and friends) of persons who need help to carry out everyday activities. At least four states—Arkansas, California, Oregon and Washington—now have large caregiver payment programs. Evaluation findings show that these are quite popular with recipients and caregivers and are a cost-effective long-term care (LTC) alternative for many frail elderly and younger, disabled persons.

The purpose of this Policy Brief is to present the ethical argument for empowering consumers through this means, describe several programs that pay informal caregivers, and review the key fiscal and administrative issues in developing programs that pay caregivers to provide care.

## BACKGROUND

Until the last few years, most support for paying informal caregivers was concentrated in the disabled-adults community. Since the mid-1990s, however, advocates for persons with developmental disabilities and mental illness and for the impaired elderly have had increasing success in making the case for paying caregivers as an alternative to conventional LTC services.

Support for paying caregivers is most frequently expressed as advocacy for a consumer-directed care (CDC) approach to LTC, an approach designed to empower the impaired person and the informal caregiver(s). The ability to choose and pay caregivers is generally considered the core component of CDC. Proponents say that CDC strengthens the informal system of care, is more cost-effective than the usual agency-directed services and especially suits the next generation of elderly, the baby boomers. Bolstering the creditability of the caregiver-

pay program (CPP) model are successes in California and in Germany, where most LTC is now provided through a cash and counseling program.

## ETHICAL BASIS FOR PAYING CAREGIVERS

The ethical rationale for caregiver pay programs is based on: (1) recognition of the value of human autonomy; (2) the moral obligation to nurture the autonomy of impaired persons, including the frail elderly, by providing LTC in the least restrictive manner compatible with the needs and resources of the individual; and (3) the need to recognize and support informal caregivers by providing some minimal compensation for the indispensable care they provide to impaired individuals. Paying caregivers qualitatively expands access to the least restrictive form of LTC and increases opportunities for the exercise of autonomy in

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the lives of impaired persons. Over the next two decades, recognizing and supporting caregivers is likely to become an increasingly salient gender justice issue too (70% of unpaid caregivers are women).

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 restricts the capacity of individuals to exercise autonomy because of impairment bears a heavy burden of justification. Nevertheless, most LTC programs for the frail elderly require the sacrifice of autonomy—the ability to exercise sufficient choice—as a condition of receiving care. The largely unquestioned rationale is that LTC professionals, those assessing needs, should make the decisions about care because they have the training and experience necessary to know what is best for the consumer. They draw up service plans and provide services in a heavily regulated, command-and-control LTC system. This is a model of professional control operating in the name of beneficiaries. Marshall Kapp (2000) notes: “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 of pretext to foreclose consumers' options in the name of beneficence.”

Even beneficence, however, as a governing principle in LTC is severely restricted. 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. As Kapp points out:

“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 ... practice 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...to unacceptable legal risk... even when those choices might have actually benefited the well-being of the patient/consumer.”

One way to begin developing a compelling ethical framework for LTC is to reconceptualize the relationship between personal autonomy and dependency. An equal emphasis should be placed on both to recognize the value of autonomy to many of even the most impaired without losing sight of the real physical and resource limitations of their lives. 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 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.

Informal caregivers are paid through several types of programs. Pamela Doty (2001) has suggested a framework for identifying differences among these programs in terms of objectives and mechanics.

- ♦ **Caregiver “allowance”** programs typically provide small stipends (\$100-\$200 per month) and are not designed to compensate family caregivers for their labor. They recognize family caregivers' unpaid effort and stress. Generally, monies are expected to cover some out-of-pocket costs (for continence pads, over-the-counter medications, occasional respite). In some programs, caregivers must provide receipts or even be “reimbursed”

for expenses. Some older programs in the U.K. and Australia require that the family caregiver who receives the stipend not be employed outside the home. However, the amounts provided cannot be described as replacement wages. They are less than what the caregiver would be paid if he or she were working, even at a minimum-wage job.

- ♦ ***Consumer-directed attendant care*** programs make family members eligible to be paid an hourly wage like any other worker. The key element here is that the disabled person (or a surrogate decision-maker, such as the family caregiver representing someone with a significant cognitive impairment, is the employer. The employee, whether or not related to the care recipient, is treated just like a non-family member from the standpoint of tax and labor law.
- ♦ ***“Mixed” models*** are exemplified by family care under the German LTC social insurance program. The German model offers several levels of coverage based on disability. The basic model is oriented toward agency services and aims not to drive out informal care. Individuals and families who opt for family care will receive only half of what professional service providers would have been paid. This cash payment is not taxed. Unlike the California In-Home Supportive Services (IHSS) program (discussed below), the caregiver is not considered a hired attendant or an employee of the consumer. The consumer/caregiver in the German family care programs receives, in effect, an “allowance” for care, albeit one more generous than those available in the state caregiver allowance.

#### STATE INITIATIVES AND INTERNATIONAL MODELS

Although CPPs currently reach only a small fraction of those receiving LTC assistance, the number of states that have at least small programs has increased steadily over the last

several years. In addition to the states whose programs are described at greater length below, Maine, Michigan, Colorado, New Mexico, Maryland and New York have substantial CDC programs that permit payments to family members. Over 70 percent of all states provided some form of compensation to family caregivers in 1990. Furthermore, the Medicaid managed LTC programs in Arizona (Arizona Long-Term Care System [ALTCS]) and Texas (Star-Plus Program) have begun to offer a caregiver-pay benefit as part of their community-based services programs. An exhaustive survey would undoubtedly discover other state initiatives and interesting variations in methods (Linsk et al., 1992).

At least four states (Arkansas, California, Oregon and Washington) now have large CPPs and the majority of LTC recipients in Germany and Austria are now in CPPs. Available evaluation findings indicate that these programs are: (1) exceptionally popular with recipients and caregivers and (2) a cost-effective alternative to institutional and agency-directed care for many seriously impaired elderly persons. CPPs are as appropriate for many frail elderly persons as for younger, disabled persons.

#### ***Arkansas***

Arkansas is one of three states participating in the Cash and Counseling Demonstration Project sponsored by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Service’s Office of the Assistant Secretary for Planning and Evaluation (ASPE). Participants who meet the project’s criteria for needs and financial eligibility are assigned to either a group receiving a monthly cash allowance or a group that receives conventional agency-driven services. The cash recipients may use their allowance to pay caregivers, including spouses. They are provided counseling and bookkeeping (fiscal intermediary) services. The evaluator (Foster et al., 2000) conducted

telephone interviews with 194 early participants in the treatment group nine months after they applied to enter the program, finding:

- ♦ Most clients (92%) had at least one paid caregiver, with most cash recipients (86%) using the cash allowance to hire their own caregivers.
- ♦ All respondents expressed satisfaction with their relationships with paid caregivers who had helped them recently and more than 9 out of 10 clients would recommend the program 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.

## *California*

California's IHSS Program is the largest and oldest consumer-directed CPP 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 allows payments to a wide range of caregivers including family and agency-managed caregivers. These facts make it the most important CPP initiative in the U.S. and the program from which we have the most to learn about the feasibility and desirability of this approach to LTC for the frail elderly. A recent evaluation of the program and a policy analysis of the results enhance our knowledge of the IHSS program (Benjamin et al., 1998; Doty et al., 1999).

The IHSS offers two models of care:

- ♦ A **consumer-directed model** (CDM) in which clients are permitted to hire and fire, schedule, train and supervise their own personal assistance providers, with little or no restrictions as to whom may be hired—family members, friends, neighbors or others. The individual client and any family or friends willing to assist have the responsibility for recruiting, selecting and managing the aide.
- ♦ A **provider-managed model** (PDM) in which the aides must be employees of authorized home health or home care agencies. The agency uses its own criteria to hire and assign workers to clients. Client choice generally is restricted to “veto” power, e.g., asking to have an unsatisfactory worker replaced. The agency usually honors such requests but is not bound to do so.

A maximum of 283 hours a month is allowed in the IHSS program for the most seriously impaired clients. Reassessments are done annually. Funding per client is capped at a monthly dollar amount computed as the maximum hours figure (283 per month) multiplied by the state minimum wage

(recently increased to \$5.75 an hour) – for a monthly dollar cap of \$1,627.25 per client.

The IHSS evaluator conducted a telephone survey of over 1,000 randomly selected consumers and over 600 workers. Consumers interviewed had to be at least 18 years old, not have a "severely impaired" rating on memory, judgment or orientation, and have been in the program for at least six months prior to September 1996. Of all sample members successfully contacted, completion rates were high (77.8% for clients, 86.9% for workers).

Compared to those served by the PDM, clients in the CDM:

- Are more likely to be highly impaired (52% versus 13%), with little difference between those with family and non-family providers.
- Are more confident that family or friends would provide help (72% versus 55%).
- Are slightly less likely to have cognitive impairments (22% versus 25%).
- Have about the same safety outcomes and instances of abuse, neglect and mistreatment.

On several key client outcome measures, the CDM clearly outperforms the PDM. Under the most rigorous characteristics, such as severity of disability and differential availability of informal supports, the CDM consistently yielded superior results on client satisfaction with services, empowerment and quality of life.

These findings suggest that, on balance, the advantages of permitting clients to hire family providers probably outweigh the disadvantages (e.g., any marginal substitution of public funding for informal support which may also take place).

The consumer assessment process is designed to contain the substitution effect and associated public sector costs. It limits payments as much as possible to needed services that are not already being provided within informal care arrangements. That is, the

payments are designed to fill the gap between assessed needs and already available care resources.

Family providers have a distinct advantage over non-family providers. Family members are legally permitted to perform such paramedical or medically related tasks as bowel and bladder care and administration of medications. In addition, they are more available than non-family providers.

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

Approximately one-quarter of CDM clients experienced difficulties recruiting a provider. The PMM 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.

### ***Oregon and Washington***

Oregon and Washington have used their Medicaid personal care and Medicaid home- and community-based waivers to implement CPPs, based on paying non-spouse caregiver. In both states, the CPP now serves more consumers than do conventional agency-directed home care programs. Oregon and Washington use different terms for CDC: Individual Providers in Washington, Client Employed in Oregon. While unit costs (cost to the state per client-per month) in both states are higher for CDC, the cost per hour of care for similar individuals is much less (about 50%) for CDC. In both states, CDC clients are much more impaired than agency home care clients, and require more hours of care (Ladd and Associates, 1999).

Both states have used their CPPs and other community-based initiatives, principally assisted living and adult foster homes, to contain the growth of LTC 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 LTC budgets. Oregon and Washington (as well as Colorado) have 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. Almost 3,000 more persons were served in Washington's LTC programs between 1993 and 1998, saving \$4.5 million dollars (Ladd and Associates, 1999).

According to Ladd (1999), "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 CDC."

### ***Germany***

In 1995 Germany's Social Dependency Insurance program made insurance benefits available to persons with disabilities, regardless of age. The program's purposes include: (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. At the lowest level are individuals who have limitations in two or more activities of daily living (ADLs) and need help at least once a day; at the highest

level are those who need 24-hours of 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: (1) a cash benefit, (2) agency services which have twice the monetary value of the cash or (3) 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 (Runde et al., 1996).

In the program's first year of operation, among beneficiaries with the lowest level of dependency most (84%) chose the cash benefit, as did 67 percent of those with the highest level. Consumers who choose cash must receive periodic counseling, as well as visits from professionals who help assure quality and proper expenditure of the cash, which must be used to help meet the beneficiary's LTC needs.

In a study of the new program in 1996, 10,400 respondents were surveyed, including and over 75 percent who were 65 and older (Schneider, 1997). The study found:

- ♦ 72 percent 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.
- ♦ 43 percent reported that their quality of care had improved under the program.
- ♦ Only a very few (2%) reported that quality had declined.

There has been nearly unanimous agreement that Germany's cash and counseling CDC system is a public policy success. The chief reasons are that the program:

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- ◆ Provides security and support to informal caregivers.
- ◆ Shifts the system from an institutional to an in-home program.
- ◆ Focuses on quality of care.
- ◆ Offers fiscal relief and reduced dependency on social assistance.
- ◆ Increases the supply of providers.
- ◆ Increases consumer choice.

Germany's strategy was implemented quickly and globally. Yet its expenditures have been considerably below projections.

SUMMARY OF POTENTIAL BENEFITS OF  
CAREGIVER PAY PROGRAMS

On the whole, the findings from studies of current CPPs, large and small, indicate considerable satisfaction with: (1) the kinds of choice and control this model provides and (2) the quality of care consumers are able to receive in CPPs compared to the more traditional agency-directed programs. Furthermore, CPPs are less expensive than agency-based programs and more efficient. They provide more hours of service at less cost than agency-directed programs. A CPP approach to LTC could provide the following benefits to disabled Americans, their caregivers, and the state and federal government:

- ◆ **Maximum flexibility, autonomy, and decision-making power.** Consumers in cash and counseling programs have access to information and professional advice, but the decision about care is the individual's.
- ◆ **Support for informal caregivers.** Cash and counseling is a simple and non-bureaucratic way to realize the preference of many disabled persons who prefer to receive help from relatives, friends or neighbors.
- ◆ **Less expensive and more appropriate services.** A major barrier to expanding LTC services in this country is the high unit costs of government-purchased services. For example, home care visits may cost upwards of \$100 for a four-hour block of service. Cash and counseling options could enable consumers to make better, more cost-effective arrangements for their personal needs and preferences.
- ◆ **Lower cost per client and lower billings and claims handling costs.** Establishing the monthly care allowance as a percentage of the case-managed service-benefit cost ensures savings.
- ◆ **Evolution of responsive services.** By giving consumers the flexibility and independence to spend their money as they best see fit, cash and counseling

encourages services that respond to consumer needs rather than government regulations and administrative decisions.

Finally, there is growing evidence that client satisfaction is related to consumer choice and control. Allowing LTC recipients to hire attendants, especially family members, clearly expands the range of choice and is very likely to increase consumer satisfaction as shown in the IHSS evaluation and the early results from the Arkansas cash and counseling project (Benjamin et al., 1998; Doty, Kaspar, and Litvak, 1996).

Some aging policy experts and advocates have taken the position that CDC based on paying caregivers may be appropriate for cognitively intact frail elderly persons, but not for the cognitively impaired. These groups clearly differ in their capacity to benefit from consumer direction, but the difference should not be made absolute by drawing a bright line between them and blocking access to consumer direction for persons with cognitive impairment. 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.

#### CHALLENGES FOR POLICYMAKERS

Paying caregivers through CDC represents a paradigm shift in the objectives and management of LTC services. It presents policymakers with a number of difficult transition tasks. As demonstrated by the successful efforts described earlier, these tasks are not intractable. Among the tasks (and opportunities) policymakers should be prepared to address are: (1) containing fiscal impact, (2) administrative support for consumers and caregivers, (3) training and

education, (4) program structure, (5) provider adjustment, (6) regulation and (7) the *Olmstead* Supreme Court decision.

#### ***Containing Fiscal Impact***

A major issue confronting state and federal policymakers in developing and implementing a program as attractive as a caregiver pay program is how to contain its cost, or what is often referred to as "the woodwork effect." 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 CPP. In some measure, the cost-effectiveness of CPPs depends on containing this likely demand by implementing reasonable eligibility criteria and monitoring the extent to which assistance continues to be needed. The "woodwork effect" concerned policymakers during the early stages of the home and community-based services (HCBS) waiver programs, which involved agency-directed services, in the 1980s. They feared HCBS would not prove to be cost-effective in terms of containing the need for nursing home care. Many states' experience over the last 15 years and research results since 1990 generally show otherwise: States have learned how to contain the woodwork effect and the HCBS 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 HCBS experience can be used to control the demand for CPPs and keep expenditures within budget limits. For example, eligibility can be limited to those who meet clear criteria related to need (functional capacities), resources (income and assets) and support network (availability of caregiver). Such an assessment process appears to be working effectively in the

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caregiver pay programs described earlier. During the initial stages of implementation, the criteria can be kept relatively restrictive. These can be modified later as policymakers, administrators and care counselors gain experience with the unique strengths and challenges of CPPs, with adjustments based on monitoring and evaluation information.

The assessment process can be designed to prevent or greatly limit publicly paid care from substituting for otherwise free informal (family and friends) care. An essential part of the assessment is the rigorous determination of how much “free” care is available to the individual who needs LTC assistance. If some amount of care is needed beyond what is freely available, then it should make no difference whether the paid caregiver is a family member or not. Why should the state pay an agency to provide care while the family member goes out to another job, if the family member can do it if paid? This question is especially compelling, given the available evidence that it often costs less to pay a consumer-directed caregiver, family member or not, than to provide the care through an agency (Linsk et al., 1992).

Another way of containing costs and making CPPs more affordable is to pass nurse delegation legislation enabling 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 CPPs. Oregon's nurse delegation several years seems to have worked well. Family members in all states already have the right to provide these services.

The fiscal significance of the likely decline in the number of formal and informal (unpaid) caregivers over the next three decades should also be considered. 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 in the paid labor market is likely to increase from the already historical high (of 50%). Paying informal caregivers could become an essential incentive for maintaining the informal care system.

Policymakers should also consider that paying caregivers may be the most cost-effective method of strengthening the informal care system and expanding its capacity to divert frail elderly from more expensive formal care programs, including nursing homes and assisted living facilities. Moreover, CPPs may substantially delay the use of out-of-home options (e.g., nursing homes) by reducing caregiver burnout and extending the length of time care is given. The true potential of CPPs to substitute for more expensive formal programs is still a matter of debate. It will only become known through continuing evaluation of CPPs as they are implemented and expanded. Early returns show:

- ♦ 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 LTC 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.
- ♦ The state of Washington has contained the overall costs of LTC by expanding its caregiver pay program.
- ♦ These experiences with current CPPs suggest a very substantial cost-effectiveness potential, one worth extensive testing.
- ♦ Finally, CPPs are the most family-oriented and nurturing LTC program available. They help families, as well as non-family caregivers, maintain and enhance their caregiving role and minimize bureaucratic interference in the lives of the frail elderly and their families.

- ♦ States should begin their CPPs 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 CPPs.

### ***Administrative Support for Consumers and Caregivers***

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 CPPs indicate that 75 to 80 percent of consumers choose to handle these arrangements through a fiscal intermediary and states should be prepared to fund these services accordingly. Contracts (following a bidding process) with third-party organizations can provide these services.

### ***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, risks and mechanics of CPPs. The training protocols developed by the states with extensive CPP experience in paying caregivers should be carefully reviewed and adopted, or adapted as appropriate. Training for all participants in CPPs is critical to the success of the program and should be funded accordingly. It should include ample exposure to the fundamental rationale (philosophy) for CPPs, as well as the operational detail. Training for consumers and caregivers should 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.

### ***Program Structure***

To the extent feasible, states should use current program structures to administer caregiver pay programs, rather than

implementing whole, new organizational structures from the ground up. Many states have HCBS programs that provide some form of support to caregivers. Careful consideration should be given to modifying these programs in whole or part for CPPs. In Florida, for example, the Home Care for the Elderly (HCE) Program, which began almost 20 years ago, reimburses caregivers for products and services purchased for the purpose of providing in-home care for a relative. The average payment is small and the program has not received an increased appropriation in several years, although it is highly regarded by caregivers and consumers and it serves a highly impaired population. The program could be expanded to become a full-fledged CDC program similar in design to the California, Oregon and Washington programs. 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.

### ***Provider Adjustment***

Provider agencies' needs and concerns should be carefully and thoroughly addressed during the formulation of CPP policy and the implementation of the program. These private, nonprofit agencies represent the backbone of the aging network and the foundation of home- and community-based LTC. Their experiences, community creditability and support (their capital) and commitment to the frail elderly make them prime candidates for providing care counseling in CPPs. Some agencies may feel threatened by paying caregivers and consumer-directed programs. Every effort should be made to protect their current budgets for agency-directed HCBS. CPPs will not meet every frail elderly person's

needs and the growth of the older population over the next several years will generate a steady increase in need for agency services even with CPPs. Policymakers and state administrators should involve agency representatives in the planning and development process for CPPs, give them priority for care counseling and training contracts, and perhaps turn to them for overall administration of the program at the service delivery level one it is stable. Anxiety in the aging network about paying informal caregivers is declining as providers recognize the appeal of the concept, its success in practice and the need for more agency-directed HCBS, even with the extensive use of CPPs.

### ***Regulation***

Policymakers should avoid imposing a heavy-handed regulatory scheme on caregiver-pay consumer-direction programs. Greater consumer control over the LTC delivery may well assure quality of care more effectively than the highly bureaucratized structure and process now used for LTC regulation. The regulatory objectives for CPPs should be: (1) the prevention of fraud, abuse and neglect and (2) 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. Appropriate response in cases of suspected criminal intent includes prompt referrals to Adult Protective Services for further investigation and possible police intervention and legal action. In situations that may threaten the well-being of the consumer but do not involve criminal intent or willful neglect, the counselor should be prepared to offer advice and support. Support may entail referrals to other agencies or less formal groups (caregiver support groups) for more extensive counseling and

supportive services. The counselor must be trained not to intervene too forcibly and risk undermining the autonomy and privacy of the consumer and caregiver(s), especially when the counselor may disagree with the consumer's decisions and actions. The counselor's job is to help maximize the consumer's capacity to manage risk without clear self-endangerment or becoming the victim of someone else's fraudulent or abusive behavior (Doty, Kasper, and Litvak, 1996).

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### ***The Olmstead Supreme Court Decision***

The states and federal government are sorting through the implications of the Supreme Court's 1999 *Olmstead* decision

that prohibits states from unnecessarily institutionalizing persons with disabilities. (See the Policy Brief “*Olmstead v. L.C.*: Implications for Family Caregivers” by Sara Rosenbaum.) Advocates for the elderly should make every effort to convince the public and policymakers that paying family caregivers is the best alternative to institutional care for a large percentage of frail elderly persons in nursing homes or at risk of admission to a nursing home. Our objective should be to make CPPs a principle vehicle for in-home care for the frail elderly by: (1) persuading the federal government to implement powerful incentives to move states toward the CPP model and (2) working at the state and federal levels to gain acceptance of CPPs that pay family caregivers an adequate amount to sustain good care.

### CONCLUSIONS

The ethical and empirical case for consumer-directed LTC may be summarized as follows:

- ♦ Human identity in Western societies is substantially based on a strong sense of

autonomy and personal control. There is substantial evidence 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.

- ♦ Research on the importance of choice and control to recipients of LTC services indicates that a substantial percentage want greater control over the delivery of care. Furthermore, 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 developing LTC policy for the frail elderly. That neglect is a major reason our publicly supported LTC system is dominated by nursing homes. Many non-affluent frail elderly persons who need and qualify for publicly supported LTC 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. As a result, many frail elderly persons struggle with their impairments well beyond the time when they could benefit from outside assistance. 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 LTC for many frail elderly persons as it is for younger, disabled persons. CDC is the most flexible form of LTC since it can be designed to permit the consumer to pay individual caregivers,

community-residential care providers and, if necessary, nursing home facilities. In short, CDC can empower the consumer across the spectrum of LTC 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. As long as persons with cognitive impairment 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 more 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. We still struggle, however, 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 how public policy reflects 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.

CDC and other forms of consumer empowerment, including those appropriate to residential care settings, represent the most

promising means of improving the quality of our LTC services. This approach offers a way to move public policy along Moody's continuum from paternalism to participation and eventually to policies that explicitly recognize the value of self-actualization—across the entire lifespan and the realities of individual autonomy in the 21<sup>st</sup> century.

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