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# For Love and Money: Paying Family Caregivers

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*A question of fundamental assumptions about care and work.*

Families have long been the cornerstone of caregiving in the United States. For twenty-five years, we have quoted the statistic that 80 percent of the day-to-day assistance older people receive is provided by their families (U.S. General Accounting Office, 1977). The clear salience, prevalence, and centrality of family caregiving encouraged the development of a research literature about the multiple layers of this phenomenon, including motivations, meanings, and interpersonal and personal experiences of stress, burden, joy, and unfolding family dynamics. The public policy implications of a long-term-care system that is built largely on voluntary, unpaid, and mostly female participation have also received significant attention (Stone, 2000).

The recent emergence of options for compensating family caregivers has raised a host of new issues. Paying family members for providing care has brought to the forefront policy questions about the intrusion of public systems into family life; ethical and ideological issues about obligation and accountability; and pragmatic concerns about health, safety, and quality of services. In addition, compensating family members who provide long-term care has added to the growing dialogue about economics, family values, and the nature of "care work." Understanding the tensions about paying family members to provide care requires an examination of some fundamental assumptions about care and work. What is the difference between the work people do for love and the work people do for money? What does society expect and require families to do for love, without expectation of money? What are the reasonable limits to those expectations? Proponents of compensating family caregivers argue that it is a way to strengthen, expand, and sustain the natural support system. Critics of paid family care worry that compensation for some of the work will erode family obligation, create a strain on the public system, and put older people at greater risk of abuse and poor care.

In this paper we discuss the dilemmas, debates, assumptions, and evidence regarding paid family caregiving. While direct payment to caregivers is the model of compensation that brings the debate into sharpest focus, it is only one of several types of compensation. Several excellent reviews of programs, policies, and models for compensation of caregivers are available (see, for example, Stone and Keigher, 1994;

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Polivka, 2001; Linsk et al., 1992; Simon-Rusinowitz et al., in press). In the broadest sense, financial supports for caregivers can include direct payment for services provided, tax credits, unpaid leave, and cash allowances to cover expenses related to caregiving.

Here we focus only on direct payments to family members for caregiving work. The prevalence of this phenomenon has increased significantly over the past decade, as a direct result of the consumer-direction movement in home and community-based long-term care. In a recent inventory, Doty and Flanagan (2002) identified 139 home and community-based support programs with some consumer-directed option; half of these programs offered the option to older clients. Consumer direction is both a philosophy and a practice that emphasizes the right and ability of consumers to assess their own care needs, decide how best to have those needs met, and evaluate the quality of the services provided. One of the meaningful ways that consumer direction has been put into practice is in care-provision programs in which payers (either government or private plans) allow individuals to hire and manage their own workers. A significant majority of older people who have services that they themselves direct choose to hire a family member (Doty et al., 1999; Dale et al., 2003). Consumer-directed long-term care, then, provides a focus for a review of the issues and evidence related to paying family caregivers. For purposes of discussion, we have categorized the issues as ideological, ethical, professional, and personal-interpersonal. To provide evidence on each of the issues raised under these categories, we rely heavily on two consumer direction programs in Ohio and on the National Cash and Counseling Demonstration and Evaluation project.

## Ideological Concerns and Empirical Realities

U.S. culture places great importance on the primacy of the family. However, our public policies related to caregiving reflect a reluctance to legislate supports for family care. For example, the United States was very late among industrialized nations to adopt employment policies in support of family care. The number of programs and the amount of public expenditure in support of family caregiving (for children, older people, or others who need assistance) are very low. For these reasons, paying family caregivers represents a significant shift for U.S. policy: use of public dollars to support what had been considered a private and obligatory activity, and the involvement of government in family life.

Critics of paying for family care have voiced a range of specific concerns about how this practice might undermine social values. If informal caregivers are paid, critics hypothesize, there would be a major shift away from caring as part of normal family responsibility. They suggest that in this and other ways, payment would decrease the quality of the caregiving experience for care recipient and caregiver, with paid services substituting for unpaid care now provided. Because family care is the dominant mode of provision in long-term care, such a shift would place tremendous burdens on public expenditures. Critics also anticipate that the cost increase could be compounded by a likely increase in the number of homecare recipients choosing this more flexible benefit.

To address these concerns, we rely on evidence from recent evaluation studies of consumer-directed programs, in which a high proportion of consumers have chosen to hire family members.

In both the Cash and Counseling demonstration and the Ohio projects, consumers received the same dollar allocation that they would have under the traditional service system. This allocation is based on health, functional, and cognitive status. Consumers are then able to decide on a payment rate for workers, but the total cost is fixed. In some instances, consumers who directed their own care used a higher rate than that paid to agencies; in other cases, the rate paid in consumer-directed care was lower.

In the Ohio programs and in Cash and Counseling there were differing policies on who could be a paid worker. Some programs did not allow spouses to be paid, while others did. All programs paid worker compensation, unemployment insurance, and Social Security taxes. Training needs were determined by the consumer.

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 Volume xxvii, Number 4. Pages 74–80

Data from the National Cash and Counseling Demonstration and Evaluation found significant increases in the satisfaction levels of both consumers and caregivers (Foster et al., 2003a; Foster et al., 2003b). Consumers in the demonstration, about 80 percent of whom hired family members, reported large and consistently higher rates of satisfaction compared to a randomized control group (Dale et al., 2003;Foster et al., 2003a). For example, more than 90 percent of the demonstration's consumers older than 65 were very satisfied with their relationship with their paid caregiver, compared to close to 80 percent for the control group (Foster et al., 2003a). Just over one-quarter of control group members felt neglected by their paid caregiver, compared to 11 percent of demonstration consumers. When comparing consumers who hired family members to those who hired nonfamily workers, findings showed significantly higher satisfaction rates (99 percent versus 91 percent) for those with family workers (Simon-Rusinowitz et al., in press). Interviews with caregivers also showed large and significant differences in favor of the option of hiring family members. Demonstration program caregivers' reports of satisfaction showed them to be significantly more satisfied with overall care arrangements and significantly less worried about whether the care recipients had enough help in their absence (Foster et al., 2003b).

There did not seem to be any negative effects on the overall relationship between the paid family caregiver and the consumer. In response to questions such as whether the caregiver and care receiver get along very well and whether the current relationship is better than at enrollment, there were no differences between the two groups (Foster et al., 2003b). Caregivers participating in the demonstration program were significantly more likely to talk with consumers about personal care needs, and the program consumers were significantly more cooperative. Program caregivers also reported significantly lower emotional strain and significantly higher satisfaction with life. In combination, these data indicate that there is no evidence in the demonstration that family relationships are negatively affected by the payment option.

Data from the Cash and Counseling and from the Elderly Service Program consumer-directed project in Ohio indicate that when consumers are able to pay family members and others, the number of hours of care provided by family members decreases slightly (Foster et al., 2003b; Kunkel and Nelson, 2003). The Cash and Counseling study found no change in the number of days that family care was provided (six days per week) but about a 6 percent decrease in the number of care hours provided by family members in comparison to the control group. Preliminary data from the Ohio sites have shown that nearly half the consumers reported an increase or no change in the number of unpaid care hours after implementation, with about half reporting a reduced number of hours; the overall average decrease was about two hours per day.

While the slight reduction in unpaid hours of care might be used to argue that family support is being eroded by paid hours of care, there are other interpretations of these data. For individuals with high levels of need, who may be receiving up to twenty-four hours of care per day, it is logical that paid hours of care might reduce the unpaid hours of care, since there are a finite number of hours per day. More important, we might suggest that a reduction in unpaid hours of care actually attests to the value of the program: The consumer's services needs are being met, *and* the caregivers are getting some respite. Perhaps the discussion should focus not on whether paid hours of care substitute for unpaid care, but on how paid family care supports and sustains the caregiving network.

One factor that could prove to be a limitation in analysis of the Cash and Counseling project and the Ohio programs is that consumer access to all of these was limited. Consumers were required to demonstrate financial eligibility and need based on level of disability. Because the vast majority of older people who reside in the community are not eligible for Medicaid or other public programs, the potential pool of program participants is restricted. Additionally, of those eligible to participate, approximately 11 percent chose Cash and Counseling (Foster et al., 2003a). In one of the Ohio programs, about 10 percent of the eligible group have chosen to participate

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in consumer direction. In a telephone survey of Medicaid personal care clients in New Jersey, researchers (Mahoney et al., 2002) found that about 40 percent were potentially interested in a cash option, but older people were 2.7 times less likely than the younger clients to be interested in this option. In addition, in all of the consumer-directed demonstrations, even consumers who do choose to hire their own workers do not always hire a family member. Taken together, the findings suggest that these programs do not bring consumers "out of the woodwork" to use services they would not otherwise seek.

### Ethical Concerns and Empirical Realities

Some of the concerns about paid family caregiving are related to the values of beneficence and avoidance of maleficence, the desire to do good and to do no harm. These values translate into a heavy emphasis on protection and minimizing risk for those receiving publicly funded services—which critics call well-intentioned but paternalistic. In the early days of homecare, some suggested that in-home service recipients would be at greater risk of receiving poor quality care. Worker fraud, abuse, and neglect were expected to be a much greater problem in the home when compared to the nursing home setting, because there was only limited agency supervision in that venue. Ironically, this same logic has been expanded to suggest that family and other non-agency-based workers present a higher degree of risk than agency- based workers. Anecdotal reports from providers and homecare program administrators have identified concerns about fraud and poor quality provided in consumer-directed programs (Blaser, 1998). In a survey of state-contracted homecare agency administrators, Linsk and colleagues (1992) found that fraud and abuse were the most frequent concerns about paying family members. The concerns ranged from potential exploitation of the system and of the consumer to failure to provide the services that were paid for.

Findings from studies of the previously mentioned demonstration projects and from an evaluation of the California In-Home Supportive Services Program show no significant differences in safety risks between clients receiving agency-based services and those using consumer-directed services. On many variables, consumers under the self-directed model have better health and safety outcomes. For example, in the Cash and Counseling demonstration program there were no differences in accident rates or falls, but consumers with self-directed care were significantly less likely to have bedsores or to have seen a doctor because of a cut or burn (Foster et al., 2003a). The project also reported large and significant reductions in the proportion of consumers with self-directed care reporting helpers arriving late or failing to arrive at all and in rates of theft. A study of the California program, the largest consumer-directed option in the country, reported no differences on a series of health and safety measures that examined such areas as abuse, harmful behaviors, theft, injury, and neglect (Doty et al., 1999).

Data on quality of service also indicate that consumers hiring family members report better care. For example, among consumers hiring family members, the Cash and Counseling demonstration reported large and significant reductions in the proportion of consumers feeling neglected or being rudely treated by workers. These sizable differences also were evident in satisfaction rates in the delivery of care (Foster et al., 2003a). Findings from the California study found self-directed consumers of care to be more satisfied with the quality of their workers and the services provided (Doty et al., 1999). Preliminary results from the Ohio demonstration suggest that consumers who directed their own care rated the quality of services highly, at a level equivalent to those receiving agency-based services (Kunkel and Nelson, 2003).

A final area of concern involved fraud on the part of the consumer or their family. The three sites participating in the Cash and Counseling demonstration invested considerable resources in monitoring the development of the service plan and in reviewing expenditures. Using social service professionals in a support and monitoring role with consumers and a systematic bookkeeping system to assist and review expenditures, the effort found minimal auditing concerns.

These demonstration programs clearly support the notion that consumers can make good

*Volume XXVII, Number 4. Pages 74–80*

decisions about their own care, even when family members are providing that care. Paid family workers did not abuse the system, exploit the consumer, or fail to provide good services. Consumers hiring primarily family members were healthier, safer, and are more satisfied with services. Program funds appeared to be spent according to plan.

Based on evidence from consumer direction, we can argue that paying family caregivers provides an "acid test" for the notion that beneficence and lack of harm can only be achieved in a formal, public system. The success of the consumer-employed family caregiver arrangement suggests that the values of health and safety might be reframed in ways that engage, and give primary voice to, the consumer of services, moving us from paternalism to participation (Polivka, 2001), with no loss of good care and no increased harm.

### Professional Concerns and Empirical Realities

One of the issues facing programs in which consumers can choose whom to hire is how to manage the benefit. Programs that use public resources require monitoring and accountability for both services and expenditures. In most instances, programs use a variant of the home-care case-manager model. In this model, individuals—usually called consultants, support coordinators, or consumer-directed case managers—serve as a resource to consumers in development of their service plan and then assist the program in monitoring program activities. Typically, support coordinators are experienced in the traditional long-term-care system and have had professional training. Shifting from this orientation to one in which the services are driven by consumer demand can be a programmatic challenge. As Polivka (2001) has written, "the largely unquestioned rationale is that 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."

Focus groups conducted with case managers working in one of the Ohio demonstrations provide some insights into the types of concerns faced by health and social service professionals. These case managers, who also operated in the traditional system, expressed some a priori concerns about consumers who employed family members (Nelson et al., 2002). Several case managers wondered whether services could be delivered by family members in a way that is comparable to those provided in the existing system. One case manager asked, "What if the client is happy and the worker is not doing a thing?" Other concerns included consumer difficulty in understanding the materials, consumers unwilling or unable to take on responsibility for directing their services, and concerns about the factors motivating family members to accept payment for caregiving. A focus group with consultants working in the Cash and Counseling demonstration also identified how difficult it was to shift between traditional case management and this new and different role in consumer-directed programs (Applebaum et al., 2001).

Observation of demonstration participants suggests that consumers have been able adjust to their new roles. Consultants and case managers have described a range of cases in which the consumer and the family became accomplished managers of their care situation. Consumers were able to be more involved in their services. For example, in the Ohio demonstration, results of an independent audit found that program consumers were much more likely than traditionally managed clients to know who their case manager was. In addition, these consumers were very satisfied with the availability of advice from the case manager.

### Personal/Interpersonal Issues: Care as a Commodity

The caregiver–care recipient relationship can be emotional, intense, and challenging, whether the individual providing services is a family member or not. "Care work" is an inherently problematic concept in U.S. culture. How can something so clearly emotional in content and motivation as "care" be considered "work"? "Paid caregiving" is similarly incongruous. If care is something we give, from the heart, doesn't the introduction of payment demean that dimension of the relationship? These questions are magnified when the person being paid for care work is a family member.


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These difficult philosophical concerns can be better tackled when put into cultural context and translated into more specific questions. When considering the cultural values that shape the debate, we find that the deep concern over maintaining lines between the work we do for love and the work we do for money, between "care" and "work," is unique to the United States. Linsk and colleagues (1992) document the "remarkable worldwide expansion of provisions in support of caregivers," and the prevalence of policies of government compensation for family and other informal care providers that has been widespread for a number of years. Whereas, as noted earlier, in the United States we have placed greater value on the separation of government and family as a reflection of the value we place on the primacy of the family. That the introduction of public dollars into the private family domain of caregiving would cause concern in the United States is, therefore, predictable.

We can address that concern more directly in the form of two specific and interrelated issues: how and whether payment changes the relationship between caregiver and care receiver, and the difficulties old and frail consumers may have in taking on the role of employer of their own family members. Does payment change the caregiver–care recipient relationship? Probably so. However, the assumption that these changes must be negative has not been borne out by the demonstration projects. In focus groups and phone interviews, consumers consistently talk about the sense of empowerment that they get from being in charge of their own workers and their own services. They also consistently report that hiring their own worker—very often family members—makes them feel more secure and more in charge of their lives. They were more confident that their workers would show up. They were hiring people they knew, people who knew them and their preferences, people they trusted.

In exchange for receiving services from a trusted worker, these consumers are able to give them something tangible in return: money. The demonstration programs typically arrange for the workers' paychecks to be sent to the consumers, who, as employers, can hand them to their employees. This practice helps to make roles and responsibilities clear and helps to even out the balance in relationships between the caregiver and the care receiver. Empowered consumers seem to be successful at managing their workers, giving feedback, and making sure that their services are being provided in the best way possible. Earlier discussion in this paper pointed out that fraud and abuse were not significant problems in consumer-employed provider models. This finding, and the overall sense of empowerment and responsibility voiced by consumers, supports the notion that consumers, even when they are old and frail, can manage their workers successfully, even with the overlay of family dynamics.

Caregivers also appreciate role clarity and recognition of their work. Linsk and colleagues (1992) found that family caregivers were the most positive (compared to policy makers, program administrators, agency service providers, and consumers) about programs that compensated family care. Even though they sometimes felt overwhelmed by their caregiving responsibilities, the family caregivers appreciated the program for helping their family member stay at home. Caregivers also reported that they felt the program supported the family, acknowledged their work, and had positive effects on family relationships (1992: 217). Some caregivers suggested that payments allowed expression of love and caring (1992: 221), illustrating that sometimes there is no difference in the work we do for love and the work we do for money.

## Conclusion

Families have long been the bedrock of long-term care, and all indicators suggest that they will continue to be so in the future. Despite this strong foundation, societal changes in such areas as longevity patterns, workforce participation, and family composition suggest that caregiving will grow in both importance and difficulty. Social policy in support of family care must continue to evolve.

This paper contributes to the growing literature that indicates that paying family members works. Empirical evidence from well-designed research demonstrates that recipients of paid family care are more satisfied, as are the caregivers. Anecdotal concerns about neglect, safety,

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and negative effects on family relationships have been dispelled in the studies now available. Although the policy debates about paying family members will continue, this work reinforces earlier studies in concluding that caring for love *and* money is possible, and, for some, desirable. Compensating family workers, and having consumers hire and manage their own workers, can be good for consumers, family members, and the long-term-care system overall.

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