

Controversy 5

SHOULD FAMILIES PROVIDE FOR THEIR OWN?

When problems arise in old age, most people turn to their families and friends for help (Feder, Komisar, & Niefeld, 2000). The vast bulk of care for the frail elderly, perhaps 80%, is furnished by families and other private individuals (Shanas, 1979). But the American family is changing at the same time that American society is witnessing changes in the proportion and character of the aging population (Burton, 1993; Cantor, 1992). Families are facing new challenges to give care and help, as well as bearing the cost of long-term care for elderly members (Brubaker, 1990).

AGING AND THE AMERICAN FAMILY

Older Americans have a rich and extended family life. For example, more than half of Americans over age 65 are married, and most of them have adult children. An equivalent proportion have at least one brother or sister, and three quarters are grandparents. According to the U.S. Department of Health and Human Services' Administration on Aging, more than two thirds of older noninstitutionalized people live in a family setting. These facts show that the popular image of old people as lonely and abandoned is inaccurate.

But advanced age frequently brings a need for caregiving. Indeed, caring for the elderly has long become a major and predictable part of the life cycle of Americans (Glick, 1977). Among married couples, the primary caregiver tends to be the healthy spouse (Stephens & Christianson, 1986). A big problem for old-old couples is that with advancing age, older spouses are increasingly likely to be impaired. In that event, older people typically turn for help to adult children, who are also the chief caregivers for older men or women who are no longer married or whose spouse can no longer care for them (Brubaker, 1985).

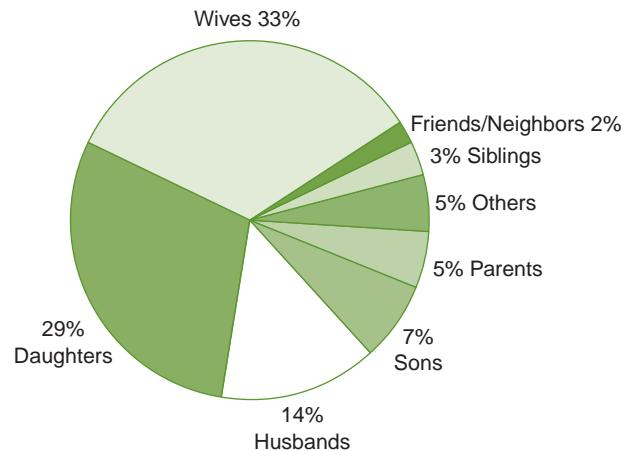
Some patterns of caregiving over the lifespan are illuminated by the **exchange theory of aging**, which is based on the idea that interaction in social groups is based on reciprocal balance (Dowd, 1975). Thus, parents care for children and spouses care for one another because they are motivated by both moral obligation and the knowledge that they can count on reciprocal help in times of difficulty (Raschick & Ingersoll-Dayton, 2004).

Many different kinds of family members can be involved in caregiving (Hays, 1984), but responsibilities still tend to be divided according to gender, as Exhibit 23 demonstrates. The overwhelming majority of care for aged relatives is still provided by women, typically wives, daughters, or daughters-in-law, who must balance the burden of care for the aged with the demands of employment and their own families. The term **sandwich generation** describes the impact of such caregiving responsibilities on middle-age women (Brody, 1985, 2004).

Watkins, Menken, and Bongaarts (1987) estimated that the average American woman will spend more years with elderly parents than she will spend caring for children under age 18. Of course, this generalization overlooks the fact that “caregiving” may entail different levels of responsibility: For some, it is a weekly telephone call; for others, it is round-the-clock support for someone with Alzheimer’s disease or for someone recovering from a stroke (American Association of Retired Persons and National Alliance of Caregivers, 1997). Still, it remains true that for many women during the middle-age years, that time will be spent with caregiving obligations. Among those 45 to 54 years of age, for example, 17% have some responsibility for a disabled older parent (Stone & Kemper, 1989).

In cases of extreme frailty or dependency, the burden on family members may prove exhausting, leading to “burnout” and perhaps even elder abuse or neglect (Stone, Cafferata, & Sangl, 1987). The burdens created by Alzheimer’s disease or other varieties of dementia would be a case in point. As the disease progresses and the patient’s behavior becomes more extreme, caregiving stress can become almost unbearable in a home setting (Corbin & Strauss, 1988; Springer & Brubaker, 1984). These conditions have led gerontologists to speak of family caregivers as the “hidden victims” of the disease (Zarit, Orr, & Zarit, 1985).

Exhibit 23 Caregivers and Their Relationship to Elderly Care Recipients



SOURCE: California’s Caregiving Resource Centers Assessment database, 1997–1998.

NOTE: Caregiver population includes primary and secondary caregivers who are caring for a brain-impaired adult.

The gloomy portrait of caregiver burden, however, should not be exaggerated. Many caregivers remain in their roles for a long time and never “burn out.” There is a normalcy to family caregiving, especially between spouses, that makes it seem nonextraordinary to those who render care.

Moreover, significant help for caregiver burden exists. Social supports, especially the informal support of family or friends, can prove helpful for caregivers under stress. In addition, caregivers may benefit from **respite care**: temporary care for dependent older people to allow the caregiver some time off (Klein, 1986). Such programs can relieve some of the strain involved in efforts to delay placing a demented or severely ill relative in a nursing home (Montgomery, 1989). Mutual-aid groups, such as those sponsored by the Alzheimer’s Association, have also proved effective for caregivers (Mace & Rabins, 1981). In all of these cases, formal support services complement informal care, serving not to replace it, but to support it (Litwak, 1985).

ABANDONMENT OR INDEPENDENCE?

There is a persistent stereotype that older people are abandoned by their children, but this stereotype is largely inaccurate. Nearly half of seniors report that they presently live or expect to live in proximity to their children, two thirds within 30 minutes of a child (Shanas, 1980). Significantly, more than 40% are in daily contact with their children, and three fourths talk on the phone at least weekly with children. Older people whose families are spread out geographically do not necessarily consider their families broken up or believe that the young have abandoned the old.

Nonetheless, a clear trend toward independence in living arrangements among the elderly has been apparent for a long time. For instance, in 1960, only one fifth lived alone; by 1984, the proportion had increased to one third. Sharing a household in an **extended family** has also dropped significantly in recent years. In 1960, 40% of older people were residing with their adult children, but by 1984, the proportion had dropped to 22% (U.S. Congressional Budget Office, 1988a), and the trend has continued unchanged since then.

The sentimental image of the family in the “good old days” is mistaken in several ways. In Europe and America, multigenerational living arrangements were never common, even in agrarian societies centuries ago (Laslett, 1972). Idealizing the extended family—that is, several generations—living under one roof is part of the “**world-we-have-lost**” myth (Laslett, 1965), in which we idealize the “golden age” of preindustrial society. Yet Western societies have tended toward a separate residence for the **nuclear family**—that is, only parents and children—for a long time.

There is also a common stereotype of elderly people as isolated from others. Yet a majority of older people live with others: Around half with their spouses, another 14% with other relatives, and smaller numbers in other living situations. Even those alone are usually within a close distance of relatives or only a phone call away. Fewer than 1 out of 20 are socially isolated, and usually they are so because they have lived that way most of their lives.

Families today typically remain in close and frequent contact. This pattern has been called “**intimacy at a distance**,” and it reflects a common desire by older people to live independently and yet still remain close enough to have regular contact with grown children. When illness or need arises, a spouse, adult child, or other relative is typically the first to help.



Most older adults who live alone have connections to family and friends.

We do need to recognize that the living arrangements of older people today are different from those of a century ago. One reason for change is simply demographic. Today, unlike in the past, vastly larger numbers of older people survive into advanced age and thus require sustained help with ADLs. In cases of debilitating chronic illness, such as stroke or Alzheimer's disease, these elderly people may live many years in conditions of dependence that exceed the capacity of family caregivers. Other older people may never have been married or may simply outlive available family members. The result is that we must increasingly rely on government to provide what families are not in a position to give.

FAMILY RESPONSIBILITY

The development of social welfare programs for older people, such as Social Security and Medicare, has meant that health care and income support for the aged have become a societal responsibility, rather than a family obligation. But in the United States, unlike other advanced industrialized countries, long-term care has remained largely a family responsibility (Buchanan, 1984). Government has been reluctant to provide coverage for long-term care, so families remain an important source of both hands-on care and financial support. When it comes to long-term care needs, elderly people first rely on spouses; **spousal responsibility** is deeply embedded in our culture as a matter of both ethics and law. If a spouse is not available to provide care, then other family members such as children or siblings take responsibility.

In some cultures, such as the Chinese, Confucian teachings inculcate filial piety or strong reverence for parents, including the duty to support parents over one's own children (Cowgill, 1986). In the United States, **filial responsibility**—that is, responsibility for care of the aged by adult children—is treated ambiguously as a matter of law, custom, and ethics (Callahan, 1985; Pillemer & Luscher, 2004; Post, 1989). In fact, half the states have laws on the books that could compel children to give financial support to aged parents, but these laws have rarely been enforced (Garrett, 1980; Lammers & Klingman, 1986) partly because of deeply conflicting public attitudes toward filial responsibility (Seltzer & Troll, 1982). In contrast, Singapore has begun enforcing stringent laws of compulsory filial responsibility that allow elderly people to sue their adult children for support (Liu & Kendig, 2000).

In America, however, filial responsibility continues to be practiced not as a matter of law, but as a matter of ethics or custom, and gerontologists have documented rich intergenerational ties in American families (Pfeifer & Sussman, 1991). The unresolved question is how government programs should interact with spousal and filial caregiving duties and financial responsibilities, and this question is faced by societies around the world (Bengtson & Lowenstein, 2003).

Global Perspective

Singapore's Law Requiring Support of Aged Parents

The Bible's Fifth Commandment says "Honor Thy Father and Thy Mother." At least one country, Singapore, has passed laws making this duty legally enforceable. Singapore, a small city state in Southeast Asia, holds adult children legally responsible for support of their aging parents. Other nearby countries, such as Malaysia, subsidize adult day care or other support services helping children care for elderly parents. In traditional Asian societies, the elderly would live in extended, multigenerational households and depend largely on their adult children for support and care. But today that traditional family support system is less viable. Singapore is unique in its "Maintenance of Parents Act," passed by its legislature in 1995.

In its first years of operation, more than 400 parents petitioned a tribunal to compel their children to support them. The court has some discretion in case children were neglected or abused, and orders for maintenance for parents take into account an adult child's duty to maintain spouse and children of their own. But four out of five elders have obtained court orders compelling their children to support them. Court administrators note that often, the adult children who were negligent had become unemployed or were too busy to pay quickly.

Singapore's law reflects several assumptions: first, that the family, rather than government or society, should provide care for older people; second, that children have the financial means to support their aged parents; and, third, that older people actually want more direct care from their families. Although Singapore is distinctive in its approach to filial piety, its law is not entirely unique. Countries like India, Israel and Taiwan have had laws enforcing support for aged parents, and Britain had such a law itself until 1967. A number of American States, including California and Illinois, have similar laws but they are rarely enforced. Those who promoted Singapore's law argue that it promotes traditional family and religious values and offers government sanction as a last resort.

SOURCE: Tiong, T.N. and C.E. Bentelspacher, "Elder Care in Singapore: Not by Law Alone," *Ageing International*, 22: 4 (Dec., 1995).

MEDICAID AND LONG-TERM CARE

Under Medicare, the U.S. health care system provides near-universal coverage for acute diseases among the old. A majority of Medicare beneficiaries do not realize that, in fact, Medicare does not cover long-term care to any great extent. Financing of acute and long-term care remain separate. About half the money spent on long-term care in nursing homes comes from some branch of government, chiefly Medicaid, and Medicaid is the primary payor for two thirds of nursing home residents (Hagen, 2004).

Medicaid, a joint government program supported by federal and state funds, was created in 1965 to provide health care for the poor. But over the years, it has become the primary government mechanism to pay for long-term care for the aged and disabled. Medicare pays only 2% of those nursing home costs; Medicaid pays 36%. Medicaid is a large and expensive program, and its cost is increasing rapidly. As the number of oldest-old in the 85+ population increases, long-term-care expenses are likely to become even higher.

Although created as a health care program for poor people, Medicaid has, in fact, become a key factor in nursing home coverage for middle-class elderly people. Three fourths of Medicaid recipients are low-income parents with children, but these families receive only about a quarter of total Medicaid dollars. About two thirds of all that Medicaid spends goes to institutional care for the elderly, disabled, or mentally retarded.

FINANCING LONG-TERM CARE

Presumably, middle-class families rely on Medicaid for long-term care because they do not have the financial capacity to bear the cost of care (Cohen et al., 1987). Long-term care already consumes a larger portion of the private health care dollar for the elderly than any other type of expenditure. The cost of a year in a nursing home today can range up to \$75,000 or more. Few individuals or families can afford that cost on an extended basis. Of those who enter a nursing home as “private-pay” patients, after only 3 months, nearly 70% have reached the poverty level, and within a year, 90% are impoverished.

In the likely event that long-term-care costs exceed savings, those who face such costs have few options. One option is to qualify for Medicaid. But Medicaid is a means-tested entitlement program. That is, it makes use of eligibility rules based on income and assets to determine whether people qualify for Medicaid coverage. A nonmarried applicant for Medicaid can keep nonexempt assets of only \$2,000 or less, excluding the value of a home. Married couples, taking advantage of recent changes in the law, can keep up to \$66,000 in such assets. Thus, all but a limited portion of a spouse’s assets are assumed to be available to pay for the partner’s long-term care (Tilly & Brunner, 1987).

Many of those who do not qualify for Medicaid still do not have enough assets to pay for long-term care themselves. They face a cruel choice: struggle to provide home-based care or do what is necessary to obtain Medicaid. To qualify for Medicaid, it is necessary to “spend down” lifetime accumulated assets to become impoverished and thereby eligible for assistance (Liu & Manton, 1991). Under regulations of the Medicaid law, spouses of those thus impoverished may obtain some protection, but children and grandchildren lose their share of accumulated life savings. One major problem with Medicaid financing of long-term care is that it introduces inequities across families, age groups, and social classes (Arling

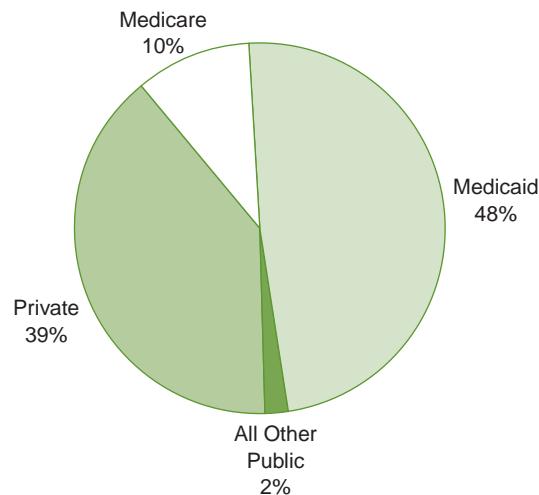
et al., 1991). For example, should people who become poor in old age be treated the same as those with a lifetime of poverty? Should families that contribute their own labor for caregiving have that contribution taken into account?

According to public opinion surveys, 82% of the general public recognize that they cannot afford to pay the cost of long-term care either at home or in a nursing home. They also know that they cannot rely on the family alone: 86% want the government to help pay for long-term care instead of leaving it entirely up to the family. Significantly, in an era of strong sentiment against taxes, a majority of adults say they would be willing to pay for a long-term-care program with increased taxes.

But despite such clear public sentiment, a universal public insurance program for long-term care is still not available in the United States. On the contrary, Medicaid has become the public program of last resort to pay nursing home costs. In fact, it is the fastest-growing component of state budgets, and it is increasingly becoming an old-age program. Nearly 40% of all Medicaid benefits go to the elderly, chiefly for nursing home care (see Exhibit 24).

The growing burden of Medicaid on the government has prompted a search for more affordable alternatives. For years, aging advocates have sold the idea of home care to legislators and to the public with the argument that home care is more humane, in keeping with people's preferences to stay at home, and also more cost-effective. Unfortunately, the facts are not so clear. National demonstration projects and other studies have shown that

Exhibit 24 Distribution of Funding for Freestanding Nursing Home Expenditures for All Payers, 2000



SOURCE: Centers for Medicare and Medicaid Services, Office of the Actuary: National Health Statistics Group (2005).

NOTE: Hospital-based skilled nursing facilities are excluded.

home care may be more desirable, but it doesn't necessarily save money. One reason may be the so-called "**woodwork effect**" (Fama & Kennell, 1990): Government policymakers are afraid of people coming "out of the woodwork" to demand services that families would have provided otherwise or that weren't provided before (Arling & McAuley, 1983). Once the government is willing to pay, people may ask "someone else" to pick up the tab (Doty, 2000). Many of the same issues arise when we consider the question of whether government should pay family members to give care that they might be giving anyway (Simon-Rusinowitz, Mahoney, & Benjamin, 1998).

It is often said that older people should go into nursing homes only as a matter of their own choice, not for the convenience of the family. But when family members give the bulk of hands-on care, it is not so simple to say that the legitimate interests of the family are to be disregarded (Dill et al., 1987). The reality is that virtually no one enters a nursing home as a matter of choice. Government financing of nursing home care under Medicaid does introduce a certain financial incentive, but few would be inclined to take advantage of this incentive without some compulsion. People go into nursing homes, by and large, as an act of desperation, when the needs of the older care recipient exceed the abilities of the family to provide care and they have reached a point where they have no other alternative.

MEDICAID PLANNING

As older people and their families have become more aware of the cost of long-term care, middle-class families have found ways of qualifying for Medicaid. In doing so, families have tried to avoid the harsh requirements of **Medicaid spenddown**—that is, impoverishing themselves by spending all income and assets to qualify for Medicaid coverage. Both attorneys and financial planners urge a variety of strategies to enable middle-income families to qualify for Medicaid coverage of nursing home costs. The heart of these strategies comes down to **divestment planning**, that is, appearing to be poor by taking advantage of legal loopholes to "avoid the Medicaid trap" (Budish, 1989).

The following are some of the key strategies the specialists recommend:

- Transfer assets at least 30 months ahead of applying for Medicaid
- Transfer assets between husband and wife
- Seek protection through a court order
- Keep assets in a form exempt from Medicaid
- Set up a trust account

It is not known exactly how many middle-class older people presently take advantage of loopholes in the Medicaid law to appear impoverished and thus protect their family wealth. But the numbers are large enough to have sustained a rapidly growing body of **elderlaw** attorneys, who have now established their own association, the National Elderlaw Academy. As Medicaid divestment planning has become more widespread, the practice has attracted criticism. Some equate the practice with the deception used by some poor people to qualify for welfare payments and with schemes by rich people who dodge taxes through loopholes. In 1997, Congress enacted legislation making it a criminal offense to use professional consultation as a way of "spending down" to qualify for Medicaid coverage.

Regardless of whether middle-class spenddown is technically “legal,” the critics argue that this form of Medicaid planning is socially irresponsible. This moral criticism is another way of insisting that taxpayers in general should not pay to protect the inheritance wealth of affluent families (Freedman et al., 1983). When Medicaid spenddown becomes a form of estate planning, critics say, it is a means of cheating the government and using public money intended for those in genuine poverty. However, it is not possible to understand what is at stake in this about family responsibility without seeing the importance of inheritance and the intergenerational transfer of assets (Lee, 2002).

It is easy enough to recognize that family abandonment of the elderly is a myth and to acknowledge that families are already taking care of their own by giving time and effort. But it is not easy to agree on whether families have an obligation to go further and make use of a portion of their assets to pay for long-term-care costs even if doing so eliminates inheritance.

Similarly, we know that informal supports enable frail elders to remain at home when the only alternative might be entering long-term care. But people disagree about whether families should be paid in cash by the government for giving the kind of hands-on care that they customarily give. Knowledge of the facts is essential for debating the issue. However, because at the heart of the debate is the relationship between family members and thus feelings and values are involved, the debate will not be settled by facts alone.

In the readings that follow, strong opinions are expressed about whether families should take care of their own and what role government should have in providing long-term care. The first issue is whether people should take advantage of Medicaid eligibility laws. On one side of the debate are Peter Strauss and Nancy Lederman, both elderlaw attorneys who believe that families should realistically plan ahead for nursing home costs and that this planning may involve Medicaid. Planning ahead to qualify for Medicaid, they believe, is not immoral or illegal. Don’t make the mistake of thinking that Medicaid is only for the poor, they tell us.

On the other side of the debate, Jane Bryant Quinn finds transfer of assets to be a troubling practice at the borderline of legality and social morality. Quinn voices a widely shared opinion. It seems wrong for some families to preserve an inheritance while others are forced to impoverish themselves to pay for long-term care. In his article, Stephen Moses focuses directly on this phenomenon of impoverishment due to nursing home expenses. Moses urges us to look carefully at the facts about paying for long-term care.

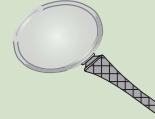
What about directly paying family members to take care of older people at home? C. J. Blaser rejects any proposal to have taxpayers support payments to family caregivers. The author argues that experience has shown that there are dangers of exploitation, fraud, and abuse in such arrangements. For example, when a family member is paid for providing home care services, who verifies that the services were actually given? The vast majority of care is already provided by family members, so if the government were to pay them to do what they do anyway, it would just drive up the total cost of care without any new services being added. Blaser concludes that, instead of direct payments, it is better for government to support family members in their normal caregiving activities.

In contrast, Suzanne Kunkel and coauthors argue that recent research suggests that concerns about neglect, safety, and fraud have been exaggerated. New evidence suggests that older people at home are quite satisfied if they are able to pay other family members instead of strangers to give them the care they need. For some, this kind of arrangement seems desirable, and most older people in need of care do prefer to have the right to decide

who will provide them with what they need. Giving them the right to pay members is the best kind of consumer-directed health care and should be supported by government policy.

FOCUS ON PRACTICE

Long-Term-Care Insurance



Many middle-income elderly people and their relatives have been following the debate over Medicaid coverage of long-term care with great interest. In recent years, there has been dramatic growth in privately paid long-term-care services, especially assisted living and home- and community-based long-term care (Bonifazi, 1998). Those who don't have enough financial resources to pay for an extended stay in a nursing home or who have a strong desire to pass along an inheritance have had to face the daunting prospect of bankrupting themselves to qualify for Medicaid. Today, however, families that want to plan ahead for long-term-care costs have another option: purchasing private long-term-care insurance. More than 100 insurance companies now offer these policies, and more than 2.5 million policies are now in force. Still, present private long-term-care insurance provides only 7% of total funding for long-term care in the United States while out-of-pocket expenditures cover nearly 25%.

Private long-term-care insurance typically covers nursing home care and sometimes other community-based services. The best of policies pay for medically necessary services for a period from 1 year up to a lifetime, but usually with a maximum period of coverage. Good policies are guaranteed to be renewable and need not require a prior hospital stay, as Medicare does.

Long-term-care insurance is bought mainly by people over age 55; half the current policyholders are in their 60s. The age when a policy is first purchased is important because the premium paid, although it remains level once the policy is purchased, rises sharply with age at purchase. For example, the same policy that goes for \$250 a year at age 50 would cost up to \$2,000 a year at age 70. But as more employers include such insurance in benefit programs, it is likely that more younger people will participate, and group rates may bring costs down. Less than 4% of the older population is covered by such policies (U.S. General Accounting Office, 1991).

Because paying for long-term care is an expensive and widespread problem, one might wonder why more people do not buy private long-term-care insurance. One answer is that older people and their families mistakenly believe that Medicare will cover such expenses. Another reason is that many policies are simply not affordable when purchased at an advanced age. The best estimates are that only a tiny proportion of the older population can afford to buy private long-term-care insurance (Wiener, 1998). Furthermore, many consumers, as well as state governments, lack confidence in the products on the market.

Is long-term-care insurance a good buy? Consumer advocacy organizations have raised doubts. Long-term-care policies have many exclusions and limitations that complicate comparisons of competing products. For example, insurance companies

generally will not write insurance for preexisting conditions—an exclusion that covers many chronic diseases. Still another problem is that long-term-care policies generally pay a fixed dollar amount for each day of care covered, in contrast to Medicare, which pays a percentage of customary or reasonable fees regardless of inflation. Without inflation protection, a person buying long-term-care coverage at age 60 may find the policy inadequate when it is needed, say at age 80.

Private long-term-care insurance is now regulated entirely by state governments, but states differ in the regulations they apply. Without some kind of federal regulation, many states appear unlikely to implement standards for long-term-care insurance to protect vulnerable consumers, such as protection from forfeiture of the policy should a single payment be missed.

As long as government funding for long-term care is explicitly income based or means tested, as under Medicaid, middle-class elderly people will naturally look to private insurance to protect themselves. Government policies have begun to encourage private long-term-care insurance. The Health Insurance Portability and Accountability Act of 1996 gives more favorable tax treatment to long-term-care insurance (Guttchen & Pettigrew, 1998). Still another option might be to organize public long-term-care coverage funded through some combination of tax revenues and individual contributions premiums. But until such insurance is available, older people and their families will need to be familiar with all practical options for covering long-term-care costs. Private long-term-care insurance is certainly one of those options.

Reading 21

Medicaid and Long-Term Care

Peter J. Strauss and Nancy M. Lederman

Medicaid is a public assistance grant program, the twin Great Society benefit signed into law along with Medicare by President Lyndon B. Johnson in 1965. Financed jointly by federal and state moneys, it provides health benefits to 35 million low-income people who are aged, blind, or disabled as well as those who are poor.

Although designed to serve low-income people of all ages, Medicaid has become a lifeline for the elderly, providing essential services that Medicare doesn't—home health care and long-term nursing home care.

Medicaid is the major payer of long-term care for those who can't afford the average yearly cost of \$40,000 or more (more than double that amount in some areas). Medicaid covers the “nonskilled” but unbelievably expensive custodial care services that Medicare doesn't. Thousands of middle-income Americans have found themselves divesting themselves of their assets or “spending down” to eligibility levels in order to qualify for benefits under Medicaid. Medicaid pays for 42 percent of all nursing

SOURCE: From *The Elder Law Handbook: A Legal and Financial Survival Guide for Caregivers and Seniors* by Peter J. Strauss and Nancy M. Lederman. Copyright © 1996 by Peter J. Strauss and Nancy M. Lederman.

home costs nationwide. It covers over 60 percent of all nursing home patients.

Administered by the states, Medicaid represents the fastest-growing component of many state budgets. States pay approximately 45 percent and the federal government 55 percent of Medicaid costs. The federal share amounts to 6 percent of federal outlays. Nearly one-third of Medicaid spending goes to home health services and long-term nursing home care. Total costs for Medicaid reached \$142 billion in 1994.

Medicaid rules must be understood in context. One target for budget cuts has been the benefits furnished to middle-income people who have made themselves eligible for Medicaid to avoid the astronomical costs of long-term care. Stricter eligibility rules have made qualifying for benefits harder than ever before, and service and program cuts have affected both home care and nursing home care as well as programs such as adult day care. Additional changes and restrictions are being contemplated by Congress and several states. These events make it more important than ever that you understand the rules and how Medicaid works.

Before learning how to qualify for Medicaid, you should understand what benefits you're trying to obtain. In general, Medicaid pays for doctors and hospital stays, like Medicare. It also provides coverage for long-term nursing home care not covered by Medicare. Nursing homes operate according to a Medicaid plan which requires doctor certification of the need to enter the facility and periodic review of the need for continued care.

Medicaid also covers home health care services, medical supplies, and equipment. It commonly pays for at-home services supplied under state plans for people who would otherwise be institutionalized, covering part-time skilled nursing, home-health, and homemaker services provided by certified home health agencies.

“SPENDING DOWN” FOR MEDICAID

For millions of older Americans, Medicaid is the only means by which long-term custodial care can be supported. Each year half a million people “spend down” their assets in order to qualify for long-term care assistance available under Medicaid. Some actually pay for their care until their assets are used up. Others purchase “exempt” items or transfer their assets, all legitimate Medicaid-planning strategies to allow them to keep their independence and autonomy without sacrificing their life savings.

These strategies all follow one basic rule. *All* your income and assets above specified levels must be spent to pay for care before you will qualify for Medicaid. Various planning strategies using statutory exemptions, spousal protections, and asset transfers are described below.

Plan ahead! This is one area in which advance planning is critical. Depending on your circumstances, it may take time to spend down or otherwise divest yourself of your assets in order to meet eligibility levels—and the law imposes penalty periods after transfers before you can qualify for benefits. Last-minute action may not work.

Although financing long-term care in this manner is entirely legal, Medicaid planning has become a major political issue. So many people have been forced to try to qualify for Medicaid benefits that the various methods for achieving that goal are under continuous attack.

APPLYING FOR MEDICAID

Applying for Medicaid entails verification of your financial resources as well as citizenship and residency requirements.

Financial requirements are strict. You will be asked for your bank statements, tax returns, and other financial records reflecting your income, assets, and expenses.

More and more older people seeking Medicaid for nursing home and home care services are enlisting professional help in obtaining Medicaid, using lawyers or social workers familiar with the process and its requirements. We recommend this approach highly. Regardless of whether you need to avail yourself of other Medicaid-planning strategies to protect assets, you want to ensure that you get the health care coverage you need.

As we've described, Medicaid is a *means*-tested program. In order to qualify, you must establish financial eligibility by meeting [an] income and assets test set by the states. Depending on where you live, you can qualify for Medicaid under one or more of these programs: Eligibility rules in the states are confusing even for experts. Many states distinguish between nursing home and other home- and community-based care in determining Medicaid eligibility for those services. In some states there is a "medically needy" option for nursing home care only but not for general services.

Don't make the mistake of thinking that Medicaid benefits are limited to the very poor. Medicaid is a complex, confusing, but important government program which has become the life-line for many middle-income families who need

help paying for long-term care in order to avoid impoverishment.

Originally intended for the poor, it has become the payer of last resort for persons of modest means. Spousal protections for resources and income clearly indicate Congressional intent that Medicaid continue as a program for middle-income Americans. Yet the use of Medicaid to finance long-term care, particularly nursing home costs, has had a profound impact on state budgets and resulted in attempts to restrict access to the program and limit benefits through calls for block grants.

Despite intended overhaul, with the federal government unlikely to increase Medicare benefits in the foreseeable future, Medicaid is likely to continue as the only government-funded program that deals with long-term care.

There may be any number of reasons not to apply for Medicaid, including personal, family, and psychological reasons; quality-of-care issues; and tax consequences. Nevertheless, it is an option that deserves serious consideration. While access to Medicaid is complicated and may not be available to or right for everyone, it is a possible source of financing for long-term care—even for those who may not now imagine they can take advantage of it.

Reading 22

Shame of the Rich

Making Themselves Poor

Jane Bryant Quinn

As the population ages, Medicaid spending on nursing homes could easily lurch out of control.

That is, unless it's limited to the people who really need it.

SOURCE: "Shame of the Rich: Making Themselves Poor" by Jane Bryant Quinn, The Washington Post, June 3, 2001. Copyright © 2001, The Washington Post Writer's Group. Reprinted with permission.

Medicaid is supposedly for the poor. But increasingly, it's being exploited by the well-to-do. Instead of buying nursing-home insurance or using their personal savings, they're getting the government to cover their bills.

Medicaid is a state and federal welfare program, providing various kinds of medical assistance to low-income people. Its charter includes nursing-home coverage.

If you need nursing-home care and are too poor to pay, Medicaid picks up the cost. But if you have personal savings, you're supposed to cover your own expenses.

When your savings drop below a certain level, Medicaid steps in. From that point on, the taxpayers support you for the rest of your life.

Growing numbers of middle- and upper-middle-class people don't like these rules.

They're willing to take care of themselves as long as they maintain their health. If a nursing home looms, however, they decide to quit being responsible. They look for ways of leaving their own money to their children, while forcing the taxpayer to provide their care.

I suspect that some of the well-off people who weasel their way onto Medicaid are vigorous supporters of big income-tax cuts. But where do they think the money for Medicaid comes from? Chocolate bars?

In general, their gambits are legal. The state laws on who's eligible for Medicaid conceal many weak points that let moneyed people onto the rolls.

To me, exploiting these weaknesses is unethical. The question for families is whether money will always trump morals.

In determining whether you're eligible for Medicaid, the states look mainly at your assets. If your assets are too high, you can't go on the welfare program. What's "too high" varies by state.

Married couples might not qualify if their savings exceed \$87,000, plus house, car, personal property, pension income and other

items. (That assumes one person in a nursing home and the other at home.)

Singles might not qualify if they have more than \$2,000 to \$4,000 in savings. They, too, might be able to keep a paid-up home and other assets, even though they'll be in the nursing home for the rest of their lives.

If you give away money to get yourself under the savings limit, there's a waiting period before you can collect benefits. Anyway, that's the way the law is supposed to work.

But there are loopholes. So-called "Medicaid planners" use the loopholes to make you instantly "poor." You can qualify for taxpayer help without a waiting period.

That turns Medicaid into an "inheritance insurance plan for the middle-class," says Stephen Moses of the Center for Long-Term Care Financing in Bellevue, Wash. Parents go on welfare so they can leave their money to their kids.

Here are some of the Medicaid-planning ideas promoted at a recent Elder Law Symposium in Vancouver, sponsored by the National Academy of Elder Law Attorneys:

- *Cut your spouse loose.* When one spouse enters a nursing home, assets can be moved into the name of the healthy spouse, says attorney Daniel Fish of Freedman and Fish in New York City. The healthy spouse signs a statement, refusing to support the nursing-home spouse. That spouse then goes on welfare (Medicaid).

The state can sue the healthy spouse to recover the money, but Fish says that's "not frequent." He thinks there are around 100 such lawsuits a year in New York City.

- *"Buy" lifetime personal care from your child.* You use your savings to pay for that care in advance, and solidify the deal with a written contract. You're now out of money and can go on Medicaid immediately, says attorney Scott Solkoff of Solkoff & Zelian in Boynton Beach, Fla.

- *Put your assets into a small business or farm.* Medicaid generally doesn't require you to use business assets to help pay the nursing-home bill, as long as you or your spouse are active in the business in some way. You could even hire someone to start a business for you, says attorney Lee Holmes of Oklahoma City, although he says he's never done that.
- *Put your assets into an annuity.* The income would go toward the nursing-home cost. But

you could arrange for an heir to get payments if you died early.

Bottom line—Medicaid is in serious trouble. The government isn't spending enough for quality care. The more people with money exploit the system, by not paying for themselves, the worse the care is going to be for everyone.

Reading 23

The Fallacy of Impoverishment

Stephen Moses

The debate over how to solve the long-term care financing crisis has reached a new and perilous stage: stalemate. Big government solutions are out of favor, but private sector initiatives appear inadequate. When a problem seems intractable, wise counsel is to check your premises. Is there a missing piece in the long-term care financing puzzle? Does a false assumption underlie the deadlock on this issue?

Conventional wisdom holds that eligibility for Medicaid, the nation's single largest financier of long-term care, requires the spenddown of assets and income to impoverishment. Federal and state laws, regulations, and policies seem to say that a person must spend down to the poverty level or below before qualifying. If this is true, elderly people and their heirs should seek private risk-sharing protection aggressively, but they do

not. If it is false, private sector options such as long-term care insurance are severely handicapped—people only insure against real risks.

This [essay] describes research that casts doubt on the belief that Medicaid requires impoverishment. It also explores the broader social and policy ramifications of such a finding.

BACKGROUND

Although originally intended to ensure access to mainstream health care for the poor, Medicaid has become the major payor of nursing home care for the middle class (Rymer, Burwell, Adler, & Madigan, 1984, p. 122). The program funds 44% of America's nursing home costs

SOURCE: "The Fallacy of Impoverishment" by Stephen Moses, *The Gerontologist*, vol. 30, no. 1, pp. 21–25, 1990. Copyright © The Gerontological Society of America. Reprinted by permission. This essay is based on research conducted by the Office of Inspector General of the Department of Health and Human Services and published in *Medicaid Estate Recoveries* (OAI-0986–00078), June 1988, and *Transfer of Assets in the Medicaid Program: A Case Study in Washington State* (OAI-09–8801340), May 1989. The views expressed herein are those of the author. Neither the Office of the Inspector General nor the Department of Health and Human Services reviewed the paper in draft and no endorsement by them should be inferred. The author was the project director for the studies cited above.

(Letsch, Levit, & Waldo, 1988) and is the principal payor for over 63% of patient days (Dean, personal communication, Oct. 20, 1989). Nevertheless, from the enactment of the Medicaid statute in 1965 until 1981, no federal rules existed against transferring assets to qualify for assistance. People who needed nursing home care could give away their property in order to qualify for Medicaid.

In 1981, Congress took the first step to limit this practice with the Boren-Long amendment. This statute allowed states to restrict asset transfers made for the purpose of qualifying for Medicaid. But Boren-Long did not apply to exempt property. Inasmuch as Medicaid exempts the home, and 70% of the net worth of the median elderly person is in a home (U.S. Bureau of the Census, 1986), Boren-Long excluded large amounts of property from the transfer restrictions.

Congress corrected this shortcoming and developed a more comprehensive approach in 1982 with the Tax Equity and Fiscal Responsibility Act (TEFRA). The TEFRA authorized states to (1) restrict asset transfers within 2 years of Medicaid nursing home eligibility, (2) place liens on the property of living recipients, and (3) recover from the estates of deceased recipients. Each of these procedures was optional for state Medicaid programs. Nevertheless, the expressed intent of Congress was “to assure that all of the resources available to an institutionalized individual, including equity in a home, which are not needed for the support of a spouse or dependent children will be used to defray the cost of supporting the individual in the institution” (U.S. Code, 1982, p. 814).

In 1985, a draft report of the Health Care Financing Administration revealed lax state enforcement of the TEFRA asset control authorities (Moses & Duncan, 1985). For example, transfer of assets rules were fraught with loopholes, only one state (Alabama) fully used the lien power, and although 18 states recovered from estates, most did so with very

little success. Based only on telephone inquiries to state Medicaid programs and a valid random sample of cases in Idaho, this report speculated that estate recoveries could leap from \$36 million nationally per year to \$535 million if all states followed the asset control methodologies of Oregon’s exemplary program. Although it remained unpublished, the report was released to the Office of Inspector General (OIG) of the Department of Health and Human Services and to the General Accounting Office (GAO). Both the OIG and the GAO began national studies of Medicaid estate recoveries in 1986.

OIG AND GAO MEDICAID ESTATE RECOVERY STUDIES

Office of Inspector General (1988)

The OIG sent a 17-page questionnaire to all 50 state Medicaid programs probing their policies and practices on transfer of assets, liens, and estate recoveries. The objective of the study was

to find out exactly what States have done since 1982 to implement TEFRA’s asset control authorities . . . to determine the extent and effectiveness of Medicaid estate recovery programs throughout the country . . . to report on “best practices” . . . [and] to examine State Medicaid eligibility policy with regard to transfer of assets and liens, because estate recoveries are obviously moot if no property is retained in recipients’ possession that can be recovered after their deaths. (OIG, 1988, p. 2)

Both the Health Care Financing Administration and the Office of Management and Budget approved the OIG’s survey instrument in advance. All 50 states and the District of Columbia responded. The study team did extensive telephone follow-up with Medicaid eligibility and estate recovery staff in three-fourths of the responding programs.

The OIG found very weak enforcement of asset transfer restrictions: “The States report that Medicaid eligibility rules permit knowledgeable individuals to transfer or shelter property from Medicaid resource limitations in a manner reminiscent of income tax avoidance” (p. ii). Three pages of quotations from Medicaid eligibility staff across the country supported this conclusion. For example: “People are starting to use a lot of fancy footwork to avoid losing the ‘family fortune’” (Maryland). “Many, many, many attorneys call on a daily basis looking for ‘loopholes.’ There are lots of welfare specialists who help people avoid welfare resource limits” (Minnesota). “We recover from people who are not clever enough to transfer their property, and everyone else goes scot-free” (California).

Only two states had implemented TEFRA’s lien provisions to secure property for estate recovery. Most states found the lien authority too restrictive to administer cost effectively. For example: “Liens are too difficult to administer because of Federal restrictions. Other property retention techniques, such as aggressive identification of assets, reversing illegal transfers, and challenging every possible resource shelter, are more effective under the circumstances” (Oregon, p. 20). Commenting on the ineffectuality of transfer of assets and lien rules, the OIG observed, “States cannot recover what is not there” (p. 23).

Twenty-three states and the District of Columbia recovered \$42 million from the estates of Medicaid recipients in 1985, according to the OIG. But most states were very inefficient at recoveries. Even under the existing restrictive laws, regulations, and policies, the OIG concluded that “if all States recovered at the same rate as the most effective State (Oregon), national recoveries would be \$589 million annually” (p. 46).

General Accounting Office (1989)

The GAO study sought to “assess the extent and effectiveness of state efforts to reduce

program costs by using the estates of Medicaid nursing home recipients or their surviving spouses to recover all or part of the costs of care paid for by Medicaid” (GAO, 1989, p. 14). The agency reviewed 200 randomly selected nursing home cases in Oregon and seven other states. Oregon was chosen “to identify the key elements of a successful estate recovery program because it reported annual recoveries per nursing home recipient more than twice those reported by any other state” (p. 14). It recovered “about \$10 for every \$1 spent administering the program. . . .” (p. 3). Projections of potential estate recoveries in the other states were based on their use of Oregon’s policies and procedures.

The GAO found that “. . . two-thirds of the amount spent for nursing home care for Medicaid recipients who owned a home could be recovered from their estates or the estates of their spouses. If implemented carefully, estate recovery programs can achieve savings, while treating the elderly equitably and humanely” (p. 3). The six states GAO studied that lacked recovery programs “could recover \$85 million from recipients admitted to nursing homes in fiscal year 1985” (p. 4). Only “about 14 percent of the Medicaid nursing home residents in the eight states GAO reviewed owned a home . . .” (p. 4). The GAO did not account for the discrepancy between this percentage and the well-known statistic that three-quarters of elderly people own their homes (Rivlin & Wiener, 1988, p. 123). One presumes that people are either selling their homes and “spending down” before going on Medicaid or they are effectively transferring or sheltering the home’s value.

Thus, both the OIG and the GAO studies confirmed that large amounts of private resources (\$589 million nationally and \$85 million in six states, respectively) pass to heirs each year instead of being used for long-term care costs or to reimburse Medicaid. Additionally, for reasons discussed in the next section, the OIG and GAO projections may be vastly underestimated.

MEDICAID ASSET SHELTERS

Assets that do not remain in an estate until the death of a Medicaid recipient are obviously not recoverable and would not show up in studies like the OIG's and GAO's. Therefore, the extensive anecdotal evidence of asset transfers and shelters discovered by the OIG in its estate recovery study raised another serious question. If people are jettisoning property before they apply for Medicaid nursing home care, how could we possibly know how much money is diverted from private to public long-term care costs? The OIG conducted further research that bears on this question (OIG, 1989). It found that people initially denied but subsequently approved for Medicaid nursing home benefits in Washington state for 1 year possessed \$27.5 million in assets at the time of their denial. These assets had to be disposed of before they could qualify for assistance. Over 80% of the assets had been sheltered: 59% were transferred to a spouse, 11% were transferred to adult children, and 11% were retained as exempt. Only 8% were consumed for long-term care. The remainder was of uncertain disposition.

To account for the magnitude of these figures, the OIG interviewed 32 professional advisers on Medicaid eligibility. These people described a network of private "elder law" attorneys, publicly funded legal services attorneys, social workers, and even Medicaid staff who counsel families on how to qualify an infirm elder for Medicaid while preserving income and assets. The sheltering techniques recommended by such advisers included: interspousal and other legal transfers, trusts, purchase of exempt assets, "intent to return" to the home, life estates, joint tenancy with right of survivorship, gift and estate planning, durable power of attorney, guardianships, divorce, relocation, care contracts, and nonsupport suits. One attorney, whose bag of tricks is highlighted in the OIG report, guaranteed Medicaid eligibility within 30 days for a \$950 fee. . . .

Finally, the OIG observed that "financial abuse of the elderly, according to study respondents, is 'commonplace,' 'bigger than anyone thinks,' 'rife.' We heard many stories about people forced onto Medicaid when their income or resources were taken" (OIG, 1989, p. 11).

MEDICAID ASSET SPENDDOWN

A common understanding, often referenced in the literature, is that half or more of all nursing home patients on Medicaid were private pay until they spent down to poverty (Branch et al., 1988, p. 649; Burwell, Adams, & Meiners, 1989, p. 2; Davis, 1984, p. 3; DHHS, 1987, p. 19; Dobris, 1989, p. 10; NAIC, 1987, p. 2). Tragically, many people actually do sell their homes and spend their life savings on nursing home care before they qualify for Medicaid. Evidence is mounting, however, that such draconian measures are both unnecessary and less common than previously supposed. Impoverishment is not the only path to Medicaid nursing home eligibility, according to the OIG work. Financially sophisticated people who are accustomed to dealing with attorneys, accountants, and financial planners can find ways to protect their assets and still qualify for Medicaid. Others, with less financial savvy, often lose what little they have before they learn how the system works (OIG, 1988, p. ii).

Very little is known about the magnitude of asset spenddown. For example, Branch reported how fast people would become impoverished if they spent down in nursing homes (Branch et al., 1988). He did not tell us how often or to what degree they actually do spend down. Several recent studies have found that spenddown is actually much smaller than previously believed (Burwell, Adams, & Meiners, 1989; Liu & Manton, 1989; Liu, Doty, & Manton, 1989; Spence & Wiener, 1989). Like the Branch study, however, these studies assume that people who

had significant assets at one time, but ended up on Medicaid, must have had catastrophic care costs. None of them developed the possibility that assets were transferred or sheltered in order to qualify for nursing home assistance. Nevertheless, the techniques to transfer and shelter assets, and the counseling to learn them, are readily available, according to the OIG.

SPOUSAL IMPOVERISHMENT

Impoverishment of the spouse at home caused by institutionalization of a disabled husband or wife used to be a serious problem. Medicaid rules allowed only a few hundred dollars of income per month to be shifted from an institutionalized to a community spouse who had little or no separate income (Neuschler, 1987, pp. 48–49). The new community spouse “minimum monthly maintenance needs allowance” was designed to solve that problem at considerable public expense. We should keep in mind, however, that the same people whose income and resources will now be protected may live in homes they own free and clear. Their problem is not poverty per se, but rather cash flow.

MEDICARE CATASTROPHIC COVERAGE ACT

The Medicare Catastrophic Coverage Act of 1988 changed Medicaid long-term care eligibility in several ways that affect asset shelters and estate recovery potential. Some of the changes, such as more generous treatment of community spouse income and resources, will make Medicaid benefits easier to obtain. This could mean that more assets will remain to be recovered from estates or, alternatively, that people will have longer to find ways to protect the assets. Other changes, such as mandatory and lengthened transfer of assets restrictions, make eligibility somewhat more difficult. This could lead to liquidation of assets and greater spenddown or,

alternatively, to wider use of better planning and qualifying techniques. Most of the methods used to shelter or transfer assets legally in the past are still intact. The basic condition remains unchanged: Families can preserve significant assets while qualifying elders for Medicaid nursing home care. Without estate recovery programs, these assets pass unencumbered to noncontributing heirs and Medicaid shoulders the full brunt (minus mandatory contributions to cost of care) of the long-term care costs.

IMPLICATIONS

Medicaid requires impoverishment. Few scholarly papers or popular articles on long-term care financing say otherwise or explain further. Yet, impoverishment is neither a sufficient nor a necessary cause of Medicaid eligibility. Two-thirds of the elderly poor in America are not covered by Medicaid (Holahan & Cohen, 1986, p. 99). On the other hand, people with median and even higher income and resources often qualify for the program’s most expensive benefit (nursing home care) while preserving the bulk of their assets for heirs (Neuschler, 1987, p. 20; OIG, 1988; OIG, 1989).

Looming in the background of last year’s “catastrophic” debate was the question: What shall we do about *long-term care* costs? That predicament is front and center now. Most of the work done by the federal government on this issue has encouraged the development of private risk-sharing solutions. Private sector answers, however, have been much slower to develop than anticipated. This is a puzzle, because most of the obstacles to market-based solutions do not seem insurmountable. Experts on long-term care financing have assumed that Medicaid is not a major impediment.

In light of the findings discussed here, however, consider that elderly people are often unclear about catastrophic long-term care risks. They deny their personal jeopardy and do not

plan ahead to protect privately against financial catastrophe. They do not plan to rely on public assistance either, but once they get sick, welfare is their only option. Under today's system, they can avoid paying insurance premiums (often in excess of \$100 per month) or risk-sharing membership fees, wait to see if they are stricken by a long-term debilitating illness, and still receive nursing home care paid for by Medicaid while preserving their assets for heirs. Because of the shame felt by families forced to qualify their elders for welfare, the negative aspects of Medicaid nursing home care—dependency, loss of income, access and quality problems, institutional bias, and stigma—often go uncommunicated to others.

Therefore, the elderly population perceives no urgent need to purchase insurance, join a Social/Health Maintenance Organization or Continuing Care Community, convert the equity in their home, or save toward long-term care costs. Without a compelling need among consumers to buy (low demand), sellers of such services lack sufficient reason to invest in the necessary research, development, and marketing of private protection (low supply). This in itself could explain why the impact of private sector long-term care financing options has been disappointing.

CONCLUSION

A plan to eliminate this impasse between public and private long-term care financing options is quite simple conceptually: Give middle-class elderly people a clear choice between access to public funding of long-term care or preservation of their estates—not both. The rudiments of such a plan are evident in the OIG report's (1988) recommendations:

- Change Medicaid rules to permit families to retain and manage property while their elders receive long-term care.
- Strengthen the transfer of assets rules so that people cannot give away property to qualify for Medicaid.

- Require a legal instrument as a condition of Medicaid eligibility to secure property owned by applicants and recipients for later recovery.
- Increase estate recoveries as a nontax revenue source for the Medicaid program while steadfastly protecting the personal and property rights of recipients and their families. (p. ii)

Underlying these recommendations is the belief that we should eliminate the indignities and inequities associated with qualifying for nursing home assistance. We should not pressure people to divorce, impoverish their spouses, liquidate their property, or hire estate planners in order to qualify. Elderly people, financially independent all their lives, but stricken by catastrophic illness in their most vulnerable years, should not be compelled to rely on welfare because of temporary cash flow problems. To correct such deficiencies in the existing program, however, we would have to pay for the solution. We can do this by closing the loopholes in transfer of assets restrictions, requiring legal encumbrances on property as a condition of eligibility, and mandating cost-effective estate recoveries as a prerequisite for federal financial participation. Alternatively, we could offer middle-class seniors a line of credit secured by their estates with which to purchase home or nursing care and get them off welfare entirely.

If implemented, these recommendations would increase Medicaid estate recoveries substantially. But this new nontax revenue is not the most important aspect of the recommendations. We would also be sending a message to America's senior citizens and their families: If they do not or cannot protect themselves privately against the risk of catastrophic long-term care costs, their government will provide the necessary care. But, if they own property, they must understand that it will be recovered—when it is no longer needed for the livelihood of their immediate dependents—to pay for publicly funded care and ensure that the same benefits will be available for others. Only the remainder after

reimbursement of costs will pass to their heir and beneficiaries. So if they do not want to encumber their estate, then they or their heir should purchase protection in the private marketplace.

If we send this message, we can expect the demand for private risk-sharing products to increase. Greater demand means more suppliers, increased competition, better products, leaner pricing, thriving new industries, and, therefore, increased employment and tax revenues.

The last piece in the puzzle is to explain how seniors will pay for private risk sharing. The experts say older people lack the cash flow to purchase private long-term care protection (Rivlin & Wiener, 1988). Yet people over 65 possess more than \$800 billion in home equity (Rivlin & Wiener, 1988, p. 131). Seniors are “house rich” and “cash poor.” Home equity conversion experiments intended to solve this problem have failed. These experiments have failed, however, because Medicaid pays for nursing home care and exempts the home. Why encumber the house to buy insurance you may not need when the government will pay for your care if you need it and save the house anyway? When people know they can save the house or get Medicaid, but not both, they will be more likely to seek home equity conversion to provide the cash flow to purchase private protection. This change could make home equity conversion economically viable as private enterprise.

Finally, faced with the potential loss of their inheritances, adult children of elderly people will contribute voluntarily toward long-term care insurance premiums or other forms of financial protection for their parents. They have the cash flow and their aging parents have the assets. Both parties have an intense interest in preserving the estate, including the family home. Under the current system, the adult children of elderly people reap a windfall from Medicaid for ignoring the risk of catastrophic costs.

The proper role of government in this arena is to help those who cannot help themselves. It is not to transfer wealth from tax payers to

indemnify heirs. If we make long-term care assistance more readily available than now, but require a payback from estates, middle-class elderly people will have better access to care and stronger reasons to seek nonwelfare protection. In time, they will be freed entirely from the indignity of legal maneuvering to qualify for public assistance.

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Reading 24

The Case Against Paying Family Caregivers

Ethical and Practical Issues

C. Jean Blaser

Paid family caregiving can be the best of care and, unfortunately, the worst of care. This article will detail how paying family can produce the worst of care, and why taxpayers should not support such payments.

This position is based on experience derived from managing the Community Care Program in Illinois, which provides home- and community-based care to over 35,000 older people a month. Eligibility is based on a need

for care, as measured by a standardized instrument termed the Determination of Need. The instrument assesses functioning with fifteen activities of daily living and instrumental activities of daily living, and for each activity with which the older person has difficulty, the availability of family and informal supports is addressed. Need for care is determined by a look at those activities with which the applicant has difficulty and lacks necessary assistance. In

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this way, the program is designed to complement and supplement family support, but not replace it.

In the first years of the program, as a result of a policy decision by another state agency, a significant portion of the caseload was served by family members who were paid as personal care attendants. When the program was transferred to the Illinois Department on Aging, detected abuses led the department to close that subprogram, allowing no more clients to have personal care attendants, and to allow payments only to contracted agencies. Since that time, however, a number of agency providers have elected to hire family members as “preferred” workers, assigning them to care for an elderly family member. As a result, the department has a considerable history to draw upon regarding the problems that can occur when a family member is a paid caregiver.

EXPLOITATION

Advocates may argue that a policy of paying the family caregiver supports and strengthens basic family values. On the other hand, it can be argued that such a policy exploits family values by paying the family member less than the going “market” rate for provided services.

Under the banner of “consumer-directed care,” states can reduce the costs of home- and community-based care by providing vouchers or direct payments to clients who, in turn, hire their own workers, termed personal care attendants. By avoiding the administrative costs of recruiting, hiring, training, and supervising workers, the cost per unit of service is substantially reduced. The cost is further reduced by not having to pay mandated fringe benefits such as unemployment and workman’s compensation, although most states may pay Social Security taxes on behalf of the client. And, of course, no health insurance, retirement benefits, sick leave, or vacation are offered. Indeed, the states are careful not to pay for these

benefits lest they be open to a charge that these workers are state employees and subject to all the benefits state workers enjoy.

It is a well-established fact that reimbursements to homecare workers are inadequate in most areas of the country. In these times of full or nearly full employment, workers can demand and receive higher wages. Because fewer are willing to accept the low salary and lack of benefits paid to personal care attendants, there is a severe shortage of homecare workers.

However, family workers, who can be considered to be a subset of the larger class of personal care attendants, can be an exception to this general finding. Family members are more likely to be trapped into accepting such employment because they are unable to recruit and hire a nonfamily worker. Faced with the prospect of placing their family member in a nursing home, these family workers will sacrifice higher wages to care for their family member at home.

One such family member detailed this problem in a public hearing on providing a “living wage” for homecare workers. She reported a long and fruitless search for a competent and reliable worker. After many experiences of workers not showing up, not performing the requested tasks, or even stealing from the client, she reluctantly decided to quit her higher paying job with benefits to stay with the client as a paid family worker. She was paid minimum wage and received no benefits for this sacrifice. In addition, she again faced the difficult task of finding a replacement whenever she was ill and unable to work, her car broke down, or she needed respite. She felt trapped by a system that did not value caregiving and did not provide sufficient reimbursement to attract a qualified and quality workforce.

In a society that already exploits the in-home worker, the policy of paying family to provide the care simply continues the exploitation and, in fact, may remove any incentive to change. If family members agree to provide the care at a less-than-adequate wage, and if the policy that

allows them to do so can be cloaked in the “feel good” language of consumer choice, the pressure to increase wages and benefits for all in-home workers is reduced. And, with other potential workers able to obtain jobs with higher wages and benefits, the client and family are likely to have very little choice but a family caregiver.

POTENTIAL FOR FRAUD AND ABUSE

The above discussion focused on the better side of paid family caregiving, where the family member is more reliable, competent, and caring than a nonfamily worker. On the other side of the picture are instances in which the family member defrauds or abuses the client and program.

While the potential for fraud and abuse exists in any social service program, a program in which family members are paid to provide care creates an environment that is particularly ripe for fraud. The most common type of abuse is financial fraud, where the client and the family member collude to report services that were not delivered, in order to collect payments. In some instances, the benefits of the fraudulent payments are shared. Other times, the older client allows the family member to receive the payment, perhaps through a distorted sense of intergenerational transfer.

A recent example of collusion was detected when a case manager conducted an annual re-determination of eligibility for an elderly woman who had been served by the Community Care Program for five years. The assessment was conducted in the home of the granddaughter, who had been hired by a contracted service agency to care for her grandmother. The client was lying on the sofa and reported she was in great pain and able to do very little for herself. The case manager, who did not speak the language of the client, used the granddaughter as an interpreter and, when the assessment was completed, the client was found

to have scored 79 points, which on a scale of 0 to 100 is very impaired and represents less than 4 percent of the service population. As a consequence, the case manager authorized fifty hours of service a week, to be provided by the granddaughter.

An alert homecare supervisor, unable to contact the worker or the client at times when the worker was supposed to be serving the bed-bound client, made an unannounced in-home visit and learned from a building manager that the client did not reside in the apartment but, rather, lived in a senior highrise. The supervisor alerted the case manager, who visited the senior housing site and observed the same client participating vigorously in an activity. Upon inquiry, the case manager was advised that the client had lived in the highrise for five years, and was able to function independently. In fact, the supposedly very confused bed-bound client who did not speak English had taken English classes.

In this example, the client and the granddaughter colluded to defraud the state of more than \$48,000 in service payments. In other cases, however, the department has found the family caregiver defrauding the state without client involvement. Through a match of service records with state death records, the department has found cases in which the client has died but the family member continues to report services, forging the client’s name to the service verification records. In another case, the client moved to another state, but the family caregiver continued to bill the state as if services were still being provided. Unfortunately, these examples are not all that uncommon.

A more troubling problem arises when the older person is coerced through intimidation into signing the service receipt. Most often, the older person is fearful of losing support and is threatened with nursing home placement and so signs for receipt of services. But, in some instances, the older person has been subjected to physical abuse or neglect or financial exploitation. Neglect is the most common type

of abuse. Department staff have seen numerous examples of care provided in early morning or late evenings because the family member is holding down another full-time job, or the grandchild is the supposed worker and is using the funds in order to pay for college.

In other instances, the abuse takes the form of financial exploitation. The family member may be dependent on the pension or Social Security check of the client as well as the payment for services to the client. Case managers have reported instances in which the older person is very impaired and in need of more intensive or skilled care than can be provided by the family member, but is denied this needed care because the family member would then lose control of the client's financial resources. Staff who had talked with one such client reported that she begged for someone to get her into a nursing home and away from her daughter, who was the paid caregiver.

INCREASED ADMINISTRATIVE COSTS

With such potential for fraud and abuse, home-care providers report having to take extra measures to assure quality service from "preferred" or family workers. First, the agencies report more difficulty in assuring that the workers are trained before they start service and that they participate in required quarterly in-service training sessions. Second, the agencies have had to increase their monitoring efforts, making more calls to the home or making unannounced visits to the home when the worker is supposed to be on duty. Indeed, it is this sort of monitoring that brings to light many of the cases of fraud, as was seen in the case described earlier.

There are limits, however, to how successful such training and monitoring measures can be. In cases in which the family worker fails to attend the required training session or is not providing the care as directed, the agency will often follow its personnel policies for employee discipline and may terminate the worker. When this happens, the worker will simply go to

another homecare agency and secure employment. The client will then request to transfer to the second agency and request services from the family member. This "employer hopping" can continue until the worker finds an agency that is willing to hire family members as workers and that is less than diligent in monitoring the delivery of services.

Advocates of consumer choice will argue that such behavior is an example of the client exercising the right to choose a family member as worker rather than a stranger. A less sanguine interpretation is that the family member is exploiting the client and the service system. Otherwise, why is the family worker not content to make the same salary serving a different client, while an unrelated worker serves the family member?

Thus, agencies not only incur increased administrative costs in monitoring workers but may lose clients as a result of either refusing to assign workers to care for family members or detecting and acting upon fraud. And, the agencies that do not diligently monitor the delivery of services may be subject to loss of contracts or even payments for damages as a result of poor or nonexistent care.

INCREASED PROGRAM COSTS

In addition to the potential for fraud and abuse of the system and the client, there is the potential program cost of a policy to pay family caregivers. The financial impact of such a policy could be significant. If we are to believe the literature, about 80 percent of the care provided to older people is informal and is provided most often by family members. A systematic program to pay these family and informal caregivers, then, could increase program costs as much as five times, with no increase in actual care provided.

In states where the home- and community-based services are entitlements, which is the case in Illinois, a new entitlement, for families with older family members in the area, would be created if a formal policy of paying family workers were to be instituted. It is not too

difficult to imagine not only a significant number of families applying for the benefit once they learn of it but also family intrigues about who gets to “claim” Granny.

On the other hand, the more usual case is that the state caps the amount of funds available for home- and community-based services. In such states, the limited resources could no longer be targeted only to those who had needs beyond those that the family could meet or who had no family nearby to provide assistance.

AN ALTERNATIVE APPROACH

The issue of family responsibility has plagued policy makers for decades. Several years ago, as a response to an advocacy effort to establish payments for family caregivers, the Illinois Department on Aging commissioned an opinion survey of the provider network. The results were interesting, with an almost equal number of

respondents agreeing with each of the following statements: “strongly support,” “somewhat support,” “somewhat oppose,” and “strongly oppose” paying families to care for their older members. With such a clear lack of consensus, the department sought the middle ground.

Current department policy does not allow direct payment to family members for care but offers services to complement and support the family members in their efforts. Eligibility for services is based upon both impairment and informal support, so that individuals with moderate impairment but no informal supports are eligible, as are those with strong family support but high impairment. In this way, the program acknowledges the need for support and respite for the family. And, if the family is absent or not able or willing to provide assistance, the state will provide for the needed services. With these policies, the family is supported but the negative consequences of direct payments to the family are avoided.

Reading 25

For Love and Money

Paying Family Caregivers

Suzanne R. Kunkel, Robert A. Applebaum, and Ian M. Nelson

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

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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.

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. 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.

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.

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 a social service professional in a support and monitoring role with consumers and a systematic book-keeping system to assist and review expenditures, the effort found minimal auditing concerns.

These demonstration programs clearly support the notion that consumers can make good 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, with no loss of good care and no increased harm.

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.

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.

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.

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, 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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FOCUS ON THE FUTURE

Genetic Screening for Alzheimer's Disease?



The year is 2015, and the time is 7 a.m. A voice on your home computer wakes you up. A blinking light on the screen indicates you have overnight e-mail: two messages. One is from your elderly Aunt Mabel. She's gotten back her genetic screening testing results for Alzheimer's disease, and the news is not good. They've told her the odds of her getting Alzheimer's are 90%, and she's pretty depressed by the news. She's decided that she doesn't want to live with that prospect ahead of her. Now she's having trouble finding a doctor who'll do assisted suicide for her. There are plenty of doctors who do it, of course, but she needs one who'll accept Medicare assignment for the procedure. Now she wants advice from you.

The other message is from your HMO: It's time to come in and have a blood test to determine your genetic susceptibility to hypertension and colorectal cancer. Your HMO now requires these new tests for everyone in their plan. They assure you that the genetic test is not for purposes of discrimination: You're already enrolled in their plan, so you'll be covered. But by getting genetic information about you, they insist, they'll be able to tell you how to engage in preventive health practices to limit your risk of a heart attack or cancer. The e-mail message promises that the HMO has your best interests at heart. But if you don't comply, they warn, you'll be subject to penalties. Seems like they know everything about you. It's a good thing they have your best interests at heart, you tell yourself. Time to get on the phone to Aunt Mabel.

Questions to Ponder

Researchers have recently identified a link between Alzheimer's disease and a specific genetic pattern known as apolipoprotein (ApoE-4). This form of the gene, ApoE-4, appears in around half of those with Alzheimer's. The other half of those with Alzheimer's do not carry ApoE-4, so another factor besides the gene must also be at work. Nonetheless, 90% of people who have double copies of the ApoE-4 gene will develop Alzheimer's disease by the time they reach age 80. People with double copies of ApoE-4 are only 1% of the total population, but their chances of developing Alzheimer's are about 10 times what they are for people with a different distribution of ApoE genes.

The presence of the ApoE in any of its forms doesn't give absolute prediction of Alzheimer's. An official statement on genetic testing was issued by a working group of the American College of Medical Genetics warning that DNA tests for Alzheimer's should not be used for routine clinical diagnosis or predictive testing (Wagner, 1996).

At present, then, the ApoE blood test doesn't give a definitive prediction of Alzheimer's, but it is possible, even likely, that a better genetic screening test will be developed in the future. The development of such a genetic test for Alzheimer's disease raises troubling questions, however:

- There is presently no cure for Alzheimer's. Are we justified in testing for diseases before any treatment is available?
- Who should be tested, and who will pay for testing? Who will have access to the results?

- How will insurance and health care systems be affected? Will legislative antidiscrimination safeguards be necessary?

The discovery of a new genetic screening test for Alzheimer's disease raises questions about an individual's right to know, and the right *not* to know, about a diagnosis. If there were a reliable test for predicting Alzheimer's, why shouldn't people have a right to know the results? But what if that genetic test weren't as reliable as people believe? Consumers may not understand that the current test yields only a probability estimate. People may mistakenly believe that the test is like a pregnancy test or like screening for Huntington's disease—tests that yield definitive knowledge. There has already been controversy about using genetic tests for Alzheimer's disease.

The case of Alzheimer's testing seems different from, say, cholesterol or hypertension screening, for which knowledge about genetic markers or other predictors can motivate patients to change behavior and reduce the likelihood of illness. In the case of genetic markers for colon cancer, genetic screening can lead to actions that might actually reduce the risk of disease, which is different from Alzheimer's disease, for which preventive measures are limited. In the scenario presented previously, Aunt Mabel believes that the genetic test has value for her. She has lived a full life and now prefers to end her life, rather than face some likelihood of becoming demented. We might recall that the first patient who died at the hands of Dr. Jack Kevorkian was Janet Adkins, a woman age only 54 who feared that she had Alzheimer's disease because of ambiguous symptoms.

The availability of a genetic predictor for Alzheimer's raises important questions for private long-term-care insurance. In the prior scenario, the HMO wants people to have genetic tests for hypertension and colorectal cancer. Private insurers someday might want applicants to undergo Alzheimer's genetic testing. We could pass laws prohibiting discrimination based on genetic tests. But is it fair to prohibit insurers from using genetic-risk data on Alzheimer's while the test results remain available to individuals? In that case, it seems likely that individuals who find they have a higher-than-average probability of developing Alzheimer's are likely to purchase long-term-care insurance, which could overload insurers with big claims—a classic instance of a pattern called *adverse selection*.

Furthermore, once a genetic screening test for Alzheimer's becomes widely used, would there be pressure for using it with older people under consideration for prominent positions? For example, John McCain was 72 when he ran for president of the United States in 2008. Should he have been urged to have an Alzheimer's screening test? In asking that question, we cannot forget that Ronald Reagan was diagnosed with Alzheimer's soon after leaving office and may already have had it during his second term.

We are only at the beginning of debate over the implications of genetic testing for society, and Alzheimer's is one of many diseases that will be at the center of this debate. The Human Genome Project has given us detailed knowledge of the entire genetic code, but genetics is not the whole story about human health and well-being. As we have seen, a genetic screening test for Alzheimer's yields a prediction of probability alone—a message of chance, not of fate. We misunderstand the test if we see too much of our destiny in it. It has been said that it is a blessing that prevents us from seeing our future, especially our future suffering, because each of us can bear more suffering than we can presently imagine. But new knowledge of genetics is likely to enlarge our ability to see into the future in ways we've barely begun to consider.

Questions for Writing, Reflection, and Debate

1. Elderlaw attorneys often argue that transfer of assets is perfectly right because it is permitted by law. Is this argument a convincing one? Imagine that you are an elderlaw attorney who has been suddenly

questioned about your practice by a reporter from a local newspaper. Write a detailed statement defending your practice to be distributed to the newspaper.

2. Elderlaw attorneys sometimes defend transfer of assets by arguing that Medicare treats physical illnesses differently from Alzheimer's disease or similar impairments. Is this argument a persuasive one? If Medicare were amended to provide full coverage for Alzheimer's and related disorders, would transfer of assets no longer be justified?
3. Critics like Jane Bryant Quinn have charged that for older people to deliberately transfer assets to qualify for Medicaid is a form of "middle-class welfare." Is this charge a fair one? List each of the arguments in favor and against this charge. Then look over what you've written and produce a rebuttal for each argument.
4. Some who favor the idea of transfer of assets from aged parents to adult children to qualify for Medicaid argue that elderly people have a "right to leave an inheritance." Is this a "right" that should be encouraged or discouraged by either Medicaid or the tax system? Who would benefit and who would be harmed if we were to expand that right? Who would benefit and who would be harmed if we were to limit it?
5. Many believe that frail elderly people should be able to select anyone, including a family member, to provide the services to which they are entitled and have the government pay for that care. Are there any valid reasons for prohibiting the hiring of family members to perform home care services? Draft a letter to your congressional representative suggesting why you think this practice should be permitted or why you believe such a practice is mistaken.
6. Assume you are an assistant to a U.S. senator responsible for drafting an expanded version of a national health care law to cover the whole range of long-term care, from community care to the nursing home. Write a "bill" describing the kinds of services that might be provided to the public under the new law, including the types of conditions covered. Then write an accompanying memorandum for the senator suggesting ways the new services could be paid for. What combination of taxes and fees would cover the full package of long-term-care services?
7. Rhonda Montgomery has written about what most families immediately recognize—namely, that women end up handling most caregiving for frail elderly people. Is this fact about gender differences something that the government should be concerned about, or is it an issue best left for families to work out for themselves? If we wanted to correct this apparent unfairness in the burden of caregiving, how could the government make things fairer? What are the risks of setting up a new government program to correct the problem of fairness?
8. Assume that you have a close family member who may need long-term care. Visit the following websites and identify the factors that seem most attractive about the services described on those sites: American Association of Homes and Services for the Aging (<http://www.aahsa.org>) and Assisted Living Federation of America (<http://www.alfa.org>). What questions *aren't* well addressed by the information you found at those websites?

Suggested Readings

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- Kane, Rosalie, and Kane, Robert, *Long-Term Care: Principles, Programs, and Policies*, New York: Springer, 1987.
- Linsk, Nathan, and Keigher, Sharon, *Wages for Caring: Compensating Family Care of the Elderly*, New York: Praeger, 1991.
- Wiener, Joshua M., *Sharing the Burden: Strategies for Public and Private Long-Term Care Insurance*, Washington, DC: Brookings Institution, 1994.