

Chapter 12

Financing Long-Term Care for Persons With Dementia

“[Most people would] prefer to live as short a time as possible, once they have become permanently and seriously demented, but think it important not to suffer pain or indignity so long as they do live. . . . People would purchase only enough insurance coverage to provide minimum conditions of dignity, and to relieve pain; they would not seek to ensure funds, at the greatly increased premium charges that would be required, for life-prolonging medical treatment. ”

—Ronald Dworkin
“Philosophical Issues in Senile Dementia” contract report for the Office of Technology Assessment,
U.S. Congress, August 1986.

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Financing Long-Term Care for Persons With Dementia*

Individuals with dementia and their families must deal not only with the emotional and physical burdens of this tragic condition but also with its financial consequences. The care needed by someone with dementia is an enormous drain on a family's resources. People do receive help from friends, from private charity, and from government at the local, State, and Federal levels, but for a variety of reasons the help is less effective than it might be. For example, families complain about the need to impoverish themselves to obtain assistance, inflexibility in the forms in which aid is provided, arbitrary variations in availability with place of residence and family structure, and a host of other problems. In an era of fiscal constraint, government administrators worry about meeting Federal and State requirements and balancing the needs of those with dementia against the needs of others. Recent hearings before the

*[his chapter is a contract report by Mary Ann Bailly, George Washington University, Washington, DC.]

Public/Private Sector Advisory Committee on Catastrophic Illness, sponsored by the U.S. Department of Health and Human Services, have emphasized the spotty and inconsistent coverage of services needed by those with dementia and other chronic diseases.

This chapter considers current private and public sources of financing for the care of persons with dementia, emphasizing long-term care. The focus is not on the problems of financing long-term care in general, but on financing care for individuals with dementia, a large portion of the population using long-term care, especially in formal settings. The best estimates place the prevalence of dementia among nursing home residents at more than 50 percent (12). By sheer numbers, then, the problems of the long-term care system are the problems of persons with dementia. Moreover, these people fall into two subgroups facing stricter limits on financing: individuals requiring personal care and those requiring care because of impaired mental functioning.

SIZE OF THE FINANCING PROBLEM

As summarized in chapter 1, estimates of dementia's total cost to society range from \$24 billion to \$48 billion (4,24). Gauging such costs is unusually difficult and there is a large margin of uncertainty in all cost estimates.

Individuals with dementing disorders need many services. They need acute medical care both to diagnose their disease and monitor its progress, and to treat other conditions that may worsen symptoms of dementia (see ch. 2). And they need long-term care—not only nursing but also counseling, personal care, and social services. Patients can live as long as 25 years after the onset of the disease; the average duration for the most common forms of dementia is 6 to 8 years (3). Over that period, medical care costs may be dwarfed

by those of providing supervision and assistance in activities of daily living. Finally, it can be argued that the cost of care for dementia includes counseling and respite services for family members, who are also, in a sense, victims of the disease (see ch. 4).

Individual needs vary. Exactly which services are appropriate and in what quantities depend on the severity of an individual's symptoms, the personal and financial help that can be expected from family and friends, and the services available in the community. Thus, estimates of aggregate cost require information not only on the prevalence of dementia but also on its distribution along dimensions relevant to the cost of treatment, such as age at onset, severity of symptoms,

place of residence, and family situation. Moreover, given the complexity of each situation, exploring the needs and available resources—case management—may be an important part of the cost of care.

Measuring the cost of any specific treatment plan is not straightforward. The true cost of required medical services included is difficult to determine, since cost accounting in health care is underdeveloped and charges to the individual or to a third-party payer often bear little relation to true economic cost. Nonmedical services may be even more difficult to value. Where should the line be drawn between ordinary living costs and costs attributable to the disease, and how should services provided by family and friends be valued?

The answer depends on the use to be made of the numbers. If the object is to minimize Federal outlay, only the charge to the Federal Government matters. If the object is to consider what the Federal share should be, then the full economic cost of care must be determined. The time and energy

invested by family and friends in caring for the person have a social value, although they do not represent cash outlays. If true costs, including those borne by family and friends, are not measured, cost comparisons will give misleading results. For example, nursing home costs usually include room and board, whereas estimates of the cost of home care do not; that inflates the cost of nursing home care relative to home care.

Estimates of the cost of care that exist are based on small samples and methods constrained by practical reality. Moreover, current cost figures are based on current patterns of care. If—as previous chapters have suggested—many individuals are receiving inadequate care, it could cost more to bring care to an acceptable level. On the other hand, not enough is known about the most effective ways to manage the care of someone with dementia. Research might make it possible to achieve the same or higher levels of quality at lower cost.

PROPER DISTRIBUTION OF RESPONSIBILITY FOR FINANCING CARE

Who should bear the financial burden? Lack of agreement on the answer is a major obstacle to policy formation. In the absence of an answer, programs for persons with dementia have been shaped by historical accident, rather than by considered principles.

The problem does not exist in isolation. It is part of the Nation's larger unsolved problem of financing and delivering all forms of health care. It is widely accepted today that Americans should be able to obtain important health care regardless of whether they can afford it. But there is no consensus on what care is important, how much a person should be able to obtain, what share of the cost that person should pay, and who should pay the rest. Currently, the level of access to care and the distribution of its cost are determined in an ad hoc manner.

Perhaps this is not surprising, since questions of how much and who should pay are hard to

answer. Ensuring access to all beneficial care would be prohibitively expensive. Rather, implicit in American health policy is the assumption that only a basic level of care must be available to everyone—a “decent minimum” or “adequate level” (34). Deciding what this “adequate level” comprises, however, requires assessing relative benefits and costs and comparing relative need among patients. These judgments are so difficult that no one wants to make them—yet if they are not made, it is difficult to decide who should pay.

Taking on the responsibility to help others is unappealing when the responsibility is open-ended. When individuals bear the full cost themselves, at least they have the incentive to consider the cost as well as the benefit of care; with less direct financial responsibility, they may use more services. Existing public programs to ease the burden of health care costs show the tension between the desire to help people in need and the concern that public subsidies will get out of control. The

tension is often resolved by writing generous programs and then restricting the availability of **services** in indirect and arbitrary ways.

The problem is particularly **severe** in long-term care. For a patient with appendicitis, there may be relatively few choices in formulating a treatment plan; for a person with a chronic illness, there is likely to be a wider range of choices at different levels of quality and **cost**. In these circumstances, the definition of need is particularly elastic, and no clear line **exists** between health needs and the need for housing and general income support. Moreover, since families **can** supply many of these services, the benefits and **costs** depend **not only on the person's health** but also on the availability of informal support. Finally, the costs of caring for a severely debilitated person can be enormous, and the benefits of the care may be more controversial, particularly for those who are very old or cognitively impaired. For all these reasons, it is particularly difficult to reach a **consensus on what is a decent minimum of long-term care**.

Two types of **care have** been especially problematic: personal services (i.e., assistance with activities of daily living such as eating, bathing, and dressing); and mental health services. The **consensus** is less clear about the extent to which these kinds of care should be part of a decent minimum. Moreover, **use of these services is thought to be more responsive to price**. Thus, the existing long-term care system places more restrictions on funding for these services than for medical and skilled nursing services.

In deciding who should pay for care, the key issue is the extent to which individuals and their families should be responsible for the **cost of their own health care**. This country has a strong tradi-

tion of individual responsibility; Americans are expected to provide for their **own** needs. **Yet it is** recognized that this may not always be possible, given the potentially catastrophic **cost of health care** and natural limits on the ability to provide for the future. Moreover, the need for **care is** quite uneven and largely outside an individual's control.

In the case of long-term care, the issue of family responsibility takes on special importance. Families have always been the major providers of care for elderly and disabled relatives. Their personal involvement with the care of individuals is irreplaceable. Yet **society is** undecided about how much they should be expected to bear, especially when the burden falls so unevenly. Children whose parents die suddenly at age 65 are in a much different position from those whose parents live until 90 and require years of costly custodial care. Elderly people who have several children with the resources to help them are in a different position from the childless. Is there a societal obligation to even out the burdens on these different groups? Even if there is **no** obligation, would we make a collective decision to do so as a matter of prudent policy—since we do not know to which group we are likely to belong?

If the responsibility for care is to be shared, the challenge is to develop a system for sharing it that is both efficient and equitable. It must deliver a level of **care** that balances individual need and societal resources, and it must distribute the cost so that all pay their fair share. The amount of care received and the cost paid should not vary arbitrarily; those with similar needs and similar personal and financial resources should receive similar amounts of help. The existing system does not always meet this ideal.

PRIVATE FINANCING

Direct Financing by Individuals and Families

Most long-term **care is** financed directly by the recipient and the family at the time of need (see chs. 1 and 4). The majority of care is informal,

consisting of goods and services provided by family and friends. For example, the 1982 Long-Term Care Survey showed that 77 percent of elderly persons needing assistance with activities of daily living received no formal long-term care services (45). Much of the cost of formal care is paid out

of pocket: Half of nursing home expenditures, which average \$22,500 annually per person, are made directly by residents or their families. Since outside assistance is more limited for personal service care, home-based care, and mental-health services than for medical and skilled nursing care, families of individuals with dementia probably bear an even higher share of costs over the course of an illness than do families of other long-term care recipients.

The provision of informal support is often a serious drain on family resources. Moreover, trends in family composition and working patterns may be making it more difficult for families to provide support. Smaller family size, greater instability of marriages, geographical mobility, and greater involvement in work outside the home are all likely to increase the number of people with dementia who are isolated and without family members available to help (6,9) (see ch. 4).

When formal care is required, the heavy burden of costs is a major threat to financial well-being. Five to ten percent of individuals who develop dementia do so before age 65 (12). They are particularly vulnerable since the disease interferes early with their ability to work. Loss of employment not only means loss of income; it may also mean loss of employer-provided group health insurance, and higher out-of-pocket costs for acute care. (The loss of employment-based health insurance will be delayed for many by the passage of Public Law 99-272, which extends the options of group health insurance for 18 months to 3 years after termination from a job in most cases.) The person is not eligible for Medicare until totally and permanently disabled, and even after disability has been established, the waiting period is about 2 1/2 years (see ch. 11).

Those stricken after retirement may also find themselves in serious difficulty, although the financial position of the elderly as a group has improved considerably in recent years, thanks to improved private pension systems and social security. Poverty rates for those age 65 or older dropped from 35.2 percent in 1959 to 12.4 percent in 1984 (16). One study found that the elderly have about 90 percent of the income of the nonelderly after adjustments for tax rates, asset income, and living arrangements (45). Medicare

now provides important protection against the cost of hospital and ambulatory care. Nevertheless, two studies of Massachusetts residents revealed that two-thirds of individuals and one-third of couples aged 65 and older would spend themselves into poverty within 13 weeks if they developed a chronic illness requiring nursing home care (39). Elderly women and members of minority groups are particularly likely to lack the financial resources to meet extraordinary medical and personal care expenses (26,31).

For many older people, the problem is not a lack of financial resources, but the fact that most of their wealth is tied up in home equity. In 1980, almost three-quarters of people aged 65 or older owned their own homes, and nearly 80 percent of these had no outstanding mortgages. In 1982, the average net equity of older people with homes approached \$60,000 (22). To use this wealth for current living expenses, such as home care services, they would have to sell the house and uproot themselves.

One solution to this problem is **home equity conversion**. There are two basic approaches: reverse mortgages and sale leasebacks. In the first, the homeowner retains possession of the house during his or her lifetime but receives monthly payments from the mortgage holder; when the occupant dies, the mortgage holder receives title to the house. Under the second, the house is sold and title transferred but the seller has the right to rent the home for his or her lifetime (2,28). These financing mechanisms could allow some people in the early stages of dementia to afford in-home care in familiar surroundings.

Only a handful of home equity conversions have been done to date. Current Medicaid eligibility rules discourage the use of home equity to finance long-term care by making a home a protected asset (see ch. 11). Moreover, the concept is unfamiliar, and the transaction entails significant risk on both sides. The risk could be reduced, although not eliminated, by developing the institutional structure and resolving legal and tax uncertainties. However, the value of home equity conversion as a source of financing long-term care depends on the extent to which the group that needs care overlaps with the group that has substantial equity, now and in the future (2). That in turn

depends on the housing market; future generations may not make such large capital gains from equity conversion, and thus the potential of this device may fade.

Another factor can reduce the incentive to convert home equity to pay for long-term care. As noted homes are generally exempt from consideration as assets in determining financial eligibility for Medicaid. Converting home equity into liquid assets removes this special protection and is thus unfavorable from the individual's point of view (see ch. 11).

To summarize, direct financing by individuals and their families is an important source of funds for long-term care. However, the large amount of resources required for the long-term care of those with dementia makes such financing difficult. Even middle-class families face impoverishment; at the very least, they find their assets eroded and the possibility of legacies to heirs diminished.

Financing Through Private Risk-Pooling

A natural response to the risk of a financial catastrophe is to seek insurance against it. Insurance would allow people to bear the costs of long-term care as a group, assuring access to care while protecting the living standard of family members and conserving assets for heirs. Although long-term care insurance seems like a desirable product, little has been sold. **In 1982, only \$200 million of the estimated \$30 billion spent on long-term care came from private insurance policies (36).**

The situation reflects both demand and supply factors. Until recently, consumers showed little interest in insurance against costs of long-term care. Relatively few people lived into their retirement years and even fewer went into nursing homes. Many retirees were poor and had trouble meeting basic living expenses. Those who felt the need to insure against heavy health care expenses saw health insurance for acute care to be more pressing.

The introduction of Medicare (and private supplemental "Medigap" insurance) met the need for acute care coverage and provided a little cover-

age for skilled nursing home and home health care. Medicaid paid for nursing home care for the eligible poor. Neither program provided good protection against the cost of long-term care, given strict limits on eligibility, scope of services, and reimbursement levels (see ch. 11). But consumers have been poorly informed about both the size of the risk and the extent of their protection. A study by the American Association of Retired Persons, for example, revealed that 79 percent of the elderly people surveyed thought that Medicare would pay for an extended stay in a nursing home (1) .

Insurance companies have also been reluctant to market comprehensive long-term care policies. Companies considered the risk difficult to insure profitably, given the problems of estimating future liability. There may be a long period between initial issuance of the policy and payout. Company expenditures depend on trends subject to unpredictable change—trends in mortality and the incidence of long-term disability, costs of services, the availability of informal social support, and the personal preferences of policyholders.

Perhaps most important, by lowering financial barriers, the insurance itself may increase the use of services, a phenomenon known as "moral hazard ." In deciding whether a service is worth having, an insured individual tends to look only at the out-of-pocket cost, not the total cost. Policyholders may realize that collectively they bear the cost in the form of higher premiums, but the cost of each decision is spread over the whole group, so no one has an incentive to economize. (The classic example of moral hazard is a group restaurant check: When people dine out and agree in advance to split the check, each person has an incentive to order more expensively than he or she would if paying separately. Yet in the end each person bears the cost of the collective "overordering" that results.)

Companies offering long-term care policies have tried to structure them to minimize such insurance-induced demand. Usually this has meant an emphasis on coverage for nursing home care and an indemnity payment structure (in which the company pays a fixed amount independent of the actual cost of the services used). The company limits the types of services covered and pays a

fixed amount per unit of service (the indemnity), leaving the individual or the family to select services. The fact that most people view nursing homes as a last resort, while coverage for home-based care is limited or absent, serves as a check on the use of services. To control utilization, policies may also impose deductibles and coinsurance rates, require a hospital stay prior to nursing home admission, exclude mental health problems, require a physician to recommend or review care, or require a firm diagnosis of organic disease (32). Clearly, many of these provisions lessen the value of the policies as protection against the cost of a dementing illness.

Companies must also allow for the possibility of a phenomenon called adverse selection. A company may accurately predict the average use of long-term care for the population and then discover that its policyholders use care at a higher rate—because people at higher risk are more likely to purchase insurance. That phenomenon occurs when risk factors for ill health and the use of care are not evenly distributed and consumers have a better idea of their risk than the insurance company. The importance of attitudes toward nursing home placement and the availability of informal support in the decision to use formal care makes adverse selection especially likely in long-term care insurance, particularly if people are free to opt in and out of the insurance from year to year.

To minimize adverse selection, companies do their best to identify risk factors and structure their coverage accordingly. They vary premiums with age, screen applicants for health status, and exclude preexisting conditions. Some exclude selected illnesses from coverage. Most insurers give themselves an escape clause in the renewable provision of the policy. All individually marketed policies reserve the right to raise premiums (32).

Marketing policies on a group basis is another way to lessen the impact of adverse selection. For example, the fact that insurance for acute care expenses is sold through the workplace—and workers have few choices of policies—decreases the importance of adverse selection in that market. Little long-term care insurance is provided

through the workplace, however (25). Younger workers prefer other benefits over long-term care coverage, given their low risk. Employer-sponsored health insurance for retirees (held by about 16 percent of the population 65 or older in 1983) is a more natural place for long-term care coverage, but these policies also have few or no long-term care benefits (43).

The prospects for expanding coverage of such costs as a retirement benefit are slim, since employers are backing away from postretirement health benefits rather than planning to add to them. When these benefits were introduced, most employers assumed they could modify the benefit at the firm's discretion, or by negotiation with a union (controlled by the current labor force). Recent court decisions have generally found to the contrary; firms cannot unilaterally alter or terminate benefits. Given the uncertainties surrounding the cost and utilization of health care and the longevity and age distribution of a firm's retirees, employers are likely to be reluctant to provide the existing benefits to new retirees, let alone add an even more unpredictable long-term care benefit (43).

The problems in developing long-term care insurance are formidable. Nevertheless, interest seems to be increasing among both consumers and insurers. Improvement in the financial status of the elderly population and growing awareness of the risk of heavy long-term care expenses are generating demand, and supply is beginning to increase. At least 25 companies already write individual policies, typically offering indemnity benefits ranging from \$10 to \$70 per day in skilled nursing facilities for 3 to 4 years (23). Some policies also cover custodial, intermediate, and home health care. Premiums vary with age, choice of indemnity level, and waiting period, generally ranging from \$20 to \$110 or more per month (8, 16)25)30,32). other insurers are preparing to enter the market, although the signs are mixed. For example, Prudential has been test marketing a long-term care policy under an arrangement with the 22-million-member American Association of Retired Persons. On the other hand, United Equitable, with more than 10 years experience, still considers the product experimental and is cut-

ting back its marketing efforts because of unexpectedly adverse claims experience.

How large a role private insurance plays in long-term care financing depends on its affordability for those who need it most—the elderly. A study done for the Department of Health and Human Services estimated what fraction of the population at least 65 could afford a long-term care policy under various assumptions about benefits, premiums, and the availability of discretionary income. For example, a \$450 Firemen’s Fund policy premium would be less than 5 percent of cash income for 47 percent of the population aged 65 to 69, and less than 10 percent of cash income for 81 percent of this age group (25). Whether that is an appropriate standard of affordability, and whether elderly Americans will actually be willing to spend that much for long-term care insurance, are unresolved questions, given the substantial out-of-pocket expenses they already incur for Medicare and Medigap insurance premiums, copayments and deductibles, and uninsured medical care,

Long-term care insurance deals only with financing; the insured person must still find the services. Moreover, premiums are not adjusted for the availability of informal support, despite its importance in the decision to purchase care. People require less formal care if they live in an environment that minimizes the demand for it. Thus the concept of combining insurance and service delivery in the same package is attractive,

One example of such packaging is the *life care community*. These provide housing tailored to the needs of an aging population and medical services as needed, including nursing home care, usually in the same complex. Each resident pays a substantial deposit, which may not be refundable if the person leaves the community, and a monthly fee (25,33). With easy access to important services and a supportive community, a person may be able to live independently for a longer time after the onset of disability. If nursing home care is eventually required, the person has automatic access to a familiar facility that he or she has chosen. These communities are expensive, however; one study estimates that only about 20 percent of the population 65 or older could af-

ford to enter one (25). Some communities levy substantial additional charges when a resident enters the nursing home. There is a risk that the facility will not be well managed—that the quality of services may not be maintained or the facility may become financially insolvent. Several life care communities have become financially unstable in recent years, and now see government-backed reinsurance as a means of reducing their actuarial risks. And depending on the exact financial arrangements, a resident may lose flexibility in later decisions about housing and health care.

Life care communities, like long-term care insurers, must consider adverse selection. A small discrepancy between the forecast number and the actual number of persons requiring heavy care can make a big difference in the organization’s financial status. As a result, life care communities require people to be healthy at entry into the community, and some exclude dementia from coverage. Such approaches limit their value for individuals with dementing disorders, especially those already exhibiting symptoms.

Another example of the packaging of insurance and service delivery is the *social health maintenance organization* (S/HMO), a new system operating on an experimental basis in some locations. Like a health maintenance organization (HMO) an S/HMO is paid a flat amount per enrollee for a fixed period. In exchange, it provides the enrollee with all needed medical care and social support services for acute and chronic conditions that period. Ideally, the S/HMO puts together a bundle of medical and nonmedical services tailored to the individual in a framework that includes incentives to weigh costs against benefits. The same objective can also be attained by financial arrangements between HMOs and nursing homes in joint ventures.

The obvious advantages of the S/HMO are the elimination of arbitrary boundaries between types of care and the incorporation of the case management function. The disadvantages are also obvious. The S/HMO has an incentive to minimize the quantity and quality of services provided; it is difficult to specify the nature of the contract between the S/HMO and the person, given the wide array of options for handling each case, mak-

ing quality review difficult. Moreover, managing an ordinary HMO is a formidable task; adding these additional responsibilities makes the task still more difficult.

S/HMOs must also consider adverse selection. As in the case of life care communities, inaccurately forecasting the number of heavy users could bankrupt the S/HMO. Generally, S/HMOs have an incentive to manipulate the mix of enrollees to keep out heavy users. To minimize this problem, fees can be scaled by age or by other factors associated with greater use of services. Quotas can be established on individuals at high risk of needing expensive care. Reinsurance mechanisms (government or private insurance that limits the maximum amount a company will have to pay) can provide financial backing to S/HMOs that experience unexpectedly adverse enrollee mixes for a short time (17).

Adverse selection and the methods insurers use to handle it raise broader questions. The private insurance market groups people according to their level of risk and sets their premiums accordingly. Premiums rise with age, for instance. Society may wish to redistribute the cost of long-term care to a greater extent and along different dimensions than reliance on the market yields—for example, to include the young and the old or those with favorable and unfavorable genetic endowments in the same risk pool.

Someone already showing symptoms or with a family history of dementia would be likely to want long-term care insurance (or his or her family would want it). Given the potentially catastrophic level of costs associated with dementing diseases, the private insurance market would charge such a person a higher premium, or perhaps refuse to insure the individual at all. Requiring insurance companies to treat such people as if they were of average risk would raise premiums for all—or it might encourage companies to seek more subtle screening devices or to avoid the long-term care insurance market altogether. Including these people in a broader risk pool may require direct government intervention.

Private risk-pooling, through long-term care insurance or other means, is an attractive option

for allowing people to meet their own needs. However, the characteristics of dementia and the needs it generates make it a more difficult risk to insure privately than other conditions generating a need for long-term care. Individuals with dementia need the kinds of services that may be more susceptible to moral hazard—mental health services, personal care, chore services, and respite care. The duration of illness maybe long; the person may end up in a nursing home, staying beyond the maximum 3 or 4 years covered by private policies. The slow onset of the disease may make it difficult to administer a preexisting condition clause in a manner that allows insurance companies reasonable protection against adverse selection while maintaining the value of the policy as protection against the costs of dementia.

Private Charity

Private charity is any assistance given by people outside a person's family but not paid for by government. It may take the form of services given informally by friends or unpaid volunteers or, more formally, by professionals paid out of charitable contributions. Such assistance is important in long-term care. Neighbors help care for homebound individuals so that family caregivers can get out. Organized groups provide services in the home such as meals on wheels and friendly visitors. Churches and philanthropists subsidize not-for-profit nursing homes and life care communities. Individuals with dementia and their families benefit from the activities of support groups such as the Alzheimer's Disease and Related Disorders Association (ADRDA). A recent innovation, the consumer health cooperative, promotes the sharing of information on sources of public and private financing and the development of a network of providers offering members discounts on long-term care services.

Volunteerism and private charity provide a dimension to long-term care that cannot easily be made available in any other way. Private individuals and groups can often be more flexible than government agencies. Charitable efforts add to people's sense of community. But, private charity is inherently unsystematic. People tend to respond

to visible suffering and to victims with whom they can identify. Charitable efforts often depend on the organizational efforts of particular individuals.

Thus, private charity is limited in its ability to help meet a need as large as that of everyone with dementia.

PUBLIC FINANCING

Subsidies to Private Charity

Government provides some aid to volunteer efforts. The Administration on Aging (AOA), for example, has begun a project to support and train senior volunteers to provide in-home supervision of persons with dementia. AOA, the National Institute on Aging, and the National Institute of Mental Health have also provided training materials, seed money, and evaluation of family support groups such as ADRDA. The Department of Health and Human Services has provided a start-up grant to the United Seniors Consumer Cooperative in Washington, D.C.

Subsidies Through the Tax System

The government indirectly provides two kinds of assistance to those with dementia and their families through the tax system. One is tied to expenditures on patient care and lowers the effective cost of such care. The other is tied to other expenditures or to saving and raises the general level of family resources available for care or insurance premiums.

Examples of subsidies tied to expenditures on care are the medical expense deduction and the dependent care credit. Currently, the Federal tax code allows medical expenses above 5 percent of adjusted gross income to be deducted (this will change to 7.5 percent for 1987 and later years), provided the taxpayer itemizes deductions; it allows a tax credit for dependent care expenses when the care is required to allow the taxpayer to work. State income tax codes generally include these provisions as well.

Such tax breaks are subsidies because in forgiving a tax debt that someone would otherwise have to pay, the government loses and the taxpayer gains, just as if the government had sent the taxpayer a check. The value of the subsidy depends on the person's tax position, however, and on the amount spent and the goods purchased.

To benefit from a special *deduction*, the taxpayer must have enough deductible expenses to warrant itemizing. Middle- and upper-income people are more likely than low-income people to be in this position, especially if they are paying interest on home mortgages. The value of the subsidy is the individual's tax rate; the higher the tax bracket, the greater the subsidy.

A tax *credit* is subtracted from the individual's final tax liability, and thus does not vary with the marginal tax rate; some credits are scaled with income so that they are larger for low-income persons. But if a person is too poor to owe any tax, the tax credit is of no benefit, unless it is "refundable" (i.e., the person receives in cash the amount of the credit that exceeds his or her tax liability).

Thus, subsidies provided through the income tax system tend to vary inversely with financial need. This limits their usefulness as a method of evening out the distribution of the cost of long-term care.

In their current form, these tax provisions are of limited benefit to the families of individuals with dementia. The medical expense deduction has a medical orientation and thus does not apply to many of the expenditures caused by dementia. In the case of in-home care, only services performed for medical aid or treatment are deductible; if a nurse performs other services, the wages must be apportioned and nonmedical care cannot be deducted. Board and lodging in a nursing home are deductible only if the resident is confined for medical treatment; in judging whether to allow a deduction, the Internal Revenue Service looks to see whether the resident entered on direction of a doctor and whether the confinement had direct therapeutic effect on the individual's medical condition.

The dependent care provision does allow the credit for expenditures on personal care, but only if required to allow the taxpayer to work. The credit varies from 20 to 30 percent of expendi-

tures up to \$2400) depending on income; it is not refundable. Thus, to cite a hypothetical but not uncommon situation, a retired couple living on a low to moderate fixed income, one of whom has Alzheimer's disease and requires in-home custodial care, would get little help from these tax provisions.

Several tax code provisions potentially increase the resources available to pay for care. Elderly and disabled taxpayers receive a higher personal exemption. (This extra exemption has been eliminated in 1987, and has been replaced by a special deduction of lower dollar amount.) Medicare benefits are nontaxable and social security benefits are taxed at a lower rate than other income. The government subsidizes saving for retirement by allowing taxpayers to delay tax on income received during their working years by putting income into employer pension plans or special savings instruments known as individual retirement accounts (IRAs) or self-employment (Keogh) plans until retirement. This effectively means lower taxes, since the income earns interest over the years and will usually be taxed at a lower rate after the person has left the labor force. (This tax deferral feature of IRAs is retained in the new tax law, although new contributions to IRAs are no longer tax exempt.)

Tax subsidies for saving have similar drawbacks to those for expenditures on care. The value of the subsidy depends on the tax rate—the higher the tax bracket, the greater the subsidy. Moreover, the subsidy goes only to those who can afford to put money aside for retirement; for many, current needs are so pressing that they cannot spare money to provide for the future. For example, only 23 percent of taxpayers eligible to contribute to IRAs have taken advantage of the opportunity.

IRAs and other tax-deferred savings mechanisms are most likely to be used by middle income groups. In tax year 1983, for example, 59 percent of IRA deductions were taken by those with incomes from \$20,000 to \$50,000; 74 percent by those with incomes from \$20,000 to \$75,000 (27). Tax incentives might reduce pressures on publicly subsidized health and welfare programs by providing an alternative funding source for those

with middle and high incomes, but would not assist those most likely to become financially dependent.

On the other hand, tax subsidies, even if restricted to a minority of those needing to pay for long-term care, can nevertheless increase an individual's control over savings and spending. This may thus reduce demand for public programs that finance care, such as Medicaid.

Government Provision of Care

State mental institutions used to be a major source of care for elderly persons with dementia. The movement toward deinstitutionalization drastically reduced the population of mental hospitals and, in particular, ended the role they played as a source of care for that group. Direct government provision of care, as opposed to subsidization of care provided in private institutions, is now the exception rather than the rule.

The principal example of direct provision of care is the Veterans Administration (VA), the largest single provider of long-term care services in the country (see ch. 6). VA's role in long-term care illustrates a classic example of the ad hoc nature of the U.S. health care system. The VA system was originally developed to treat veterans with service-connected medical conditions, but gradually care for non-service connected medical conditions (including long-term care) was made available to veterans on a space-available basis. The clientele served tended to be low-income veterans who lacked access to health insurance and non-VA health care. In 1986, VA began to apply means tests to certain services for veterans with non-service-connected disabilities (see ch. 6).

Long-term care has had low priority in the VA health care system. As the cohort of World War 11 veterans reaches retirement age, however, pressure on the long-term care segment of the VA is expected to increase (see ch. 1). The cost and scarcity of nursing home care may lead veterans who would not otherwise use the VA system to press for access to it.

During the most recent Congress, however, the trend was away from extending the number and

type of benefits available to veterans at no charge. Public Law 99-272, which became law on April 7, 1986, established nine categories of veterans and criteria for how much veterans will pay for VA services. Services needed because of service-connected disability, and those delivered to veterans eligible for Medicaid or receiving VA income support, will continue to be available at no charge to the veteran. Most veterans seeking VA services because of dementia will not fit into these categories, however, and will pay a fraction of the costs of hospital, nursing home, or domiciliary care on 90-day cycles, with the maximum payment set by the prevailing Medicare deductible.

Finally, direct provision of care includes a variety of social and personal care services and mental health services provided by States, often funded partially or completely by Federal funds. Long-term care services are provided under Social Services Block Grants and Title III of the Older Americans Act, for example (see ch. 6). These efforts, like those of private charity, aid persons with dementia in an unsystematic way, with the availability of services varying arbitrarily from one locality to another, depending on factors such as local political priorities.

Subsidies for the Purchase of Care

Most public assistance to individuals with dementia comes through the Medicare and Medicaid programs. Medicare was initiated in 1965 to provide standard health insurance for people over 65; disabled and end-stage renal disease patients were added 7 years later. These groups had difficulty obtaining insurance because the private health insurance system was based on employment, leaving those outside the labor force at a serious disadvantage. The program's coverage structure was based on private policies, which emphasized medical care for acute conditions and did not cover long-term care.

Medicaid provides medical assistance to indigent people, another group largely left out of the private health insurance system. It was not introduced as a new national program designed to meet the needs of all the poor, however, but rather as an afterthought to the Medicare bill—a consolidation of existing Federal-State programs to pay

for medical care for people in certain federally assisted welfare programs. Thus, unlike Medicare, a uniform national program, Medicaid's structure varies considerably among the States.

Like Medicare, however, Medicaid emphasizes medical care for acute conditions and was not originally designed to meet long-term care needs. As there was no other source of funding for the growing population in need of long-term care, Medicaid took on the role. The program has become a backup financing source for nursing home care for middle-class people, not just for poor individuals. The high cost of residential care, the limited availability of affordable alternatives, and the relative absence of a private way to insure against this financial risk have created a group of people who are poor because expenditures on nursing home care have exhausted their resources. It has been estimated that 30 to 40 percent of nursing home residents supported by Medicaid "spent down" until they reached eligibility standards (36).

In discussing Medicare and Medicaid as financing sources for dementia patients, four aspects are important: eligibility, scope of services, reimbursement, and administration. Chapter 11 describes these in detail. This chapter reviews more briefly the features most relevant to policy options.

Eligibility

Eligibility standards for Medicare are national and independent of financial status. For people at least 65 who receive social security (the overwhelming majority), eligibility is automatic. People under 65 must qualify on the basis of permanent disability. To do so, they must have worked in social security covered employment for 5 of the 10 calendar years before becoming disabled, and prove they meet the program's definition of permanent disability. The definition and the regulations and administrative processes that interpret it impose a heavier burden of proof on the mentally impaired than on the physically impaired. Many patients in the early stages of dementia have difficulty establishing their eligibility. Moreover, after establishing it, they must wait nearly 2-1/2 years before benefits begin. The House and Senate Appropriations Committees have asked the So-

cial Security Administration to review these policies in consultation with the National Institutes of Health.

Medicaid eligibility is more complicated. Enrollees must meet two kinds of requirements, categorical and financial, that vary by State. The categorical requirements are based on the eligibility requirements for certain federally assisted welfare programs. To meet them, the applicant must belong to one of several categories of persons considered in need of help, defined by age (at least 65), disability (either blindness, or total and permanent disability), or family status (member of a family containing dependent children deprived of the support of one parent for a reason such as absence, disability, unemployment, or death). Most individuals with dementia establish eligibility on the basis of age or disability. Proving disability under Medicaid raises the same problems for these people as it does under Medicare.

The financial eligibility requirements set the maximum net income and assets (after certain exclusions) a person can have and still be eligible for Medicaid. The upper limits vary across categories and by State but are always low (generally \$1,500 or less in gross assets); to qualify, families must have incomes below the poverty line. Moreover, the rules on exclusions cause the impact of these financial requirements to be quite uneven among beneficiaries. Individuals with the same level of wealth receive different treatment depending on their State of residence, marital status, and the form in which they hold their assets or receive their income.

Some States have fixed income tests, others have flexible income tests. Under the first, the limit is applied without regard to medical expenses; under the second, the upper limit applies to the level of income after the cost of medical care has been deducted (in other words, the individual may "spend down" to a net income that makes him or her Medicaid-eligible). In either case, when someone enters a nursing home, the person's income above a small personal allowance, including any financial resources received as gifts, must generally be applied to the cost.

States can consider the financial assets of some family members determining whether the appli-

cant meets financial eligibility requirements. If the spouse of an applicant, or the parent of an applicant under 21, has income and assets, these may be "deemed" to be available to the applicant (whether they actually are accessible or not) and thus included in the applicant's income. On the other hand, if the applicant's resources are deemed to be required to support a spouse or children, some portion may be excluded from consideration in applying the tests. Specific rules vary from State to State, but they are generally quite restrictive, and require that family members live at an impoverished level. Since deeming from family member to applicant usually ends with nursing home placement or divorce, it has the perverse effect of encouraging these events.

The financial assets of other family members, such as adult children, are generally not taken into account. According to the Health Care Financing Administration, States have the option of requiring relatives to contribute toward nursing home costs and a few have considered experimenting with "relative responsibility" laws (7). However, that interpretation of the Medicaid statute is disputed. Moreover, if the option does exist, the laws must be carefully drawn to be consistent with other provisions of the statute, such as the requirement that any provision in the State program must be "of general applicability."

Idaho, the only State to put a relative responsibility program into effect, found the results disappointing. The amount collected was low, it proved impossible to collect from out-of-State relatives, and the law was politically unpopular. The experiment ended after only 7 months when the Idaho Attorney General ruled that the law did not conform to the general applicability requirement (7).

The long duration of a dementing illness and the high probability that nursing home care will eventually be required makes Medicaid eligibility extremely important to persons with dementia and their families. These factors also mean that these people may be more likely than other long-term care recipients to be able to plan ahead for Medicaid eligibility and to use legal methods to arrange financial affairs appropriately. However, such planning takes a measure of financial aware-

ness and possibly money for legal advice. Paradoxically, given Medicaid's welfare orientation, it may be the better-off families who gain the maximum advantage from the program, because they are sophisticated enough to appreciate the need for advance planning and can afford good legal advice. That adds a further inequity to the substantial ones inherent in the program's structure.

Scope of Services

Medicare covers only some of the services needed by individuals with dementia, and then only to a limited extent. A major problem is its orientation toward curative, narrowly defined medical services, reducing the coverage of care related to mental functioning or to nonmedical personal needs, outpatient coverage for counseling and psychotherapy is limited to \$250 per year. Coverage for personal care is restricted to skilled nursing care: services ordered by a physician, requiring the skills of technical or professional personnel such as registered nurses or physical therapists, and furnished by or under the supervision of such personnel. The coverage is designed to allow someone who has had an acute illness to convalesce briefly in a nursing home or at home rather than in a hospital to save on hospital expenditures—not to provide long-term care to someone chronically impaired.

If nursing care is provided in a nursing home, the facility must be certified as a skilled nursing facility (SNF). Coverage comes into effect only after a hospital stay of at least 3 days, and cannot exceed 100 days. Each case is reviewed retrospectively to determine whether the person actually needs that level of care; if not, reimbursement is denied. The actual average length of stay is only 30 days. As a result of these provisions, Medicare pays for less than 2 percent of nursing home care (15). If care is provided at home, no limit is imposed on the number of visits, but the definition of skilled care and the supervision requirements effectively restrict coverage to persons recovering from acute illness.

It is more difficult to summarize the scope of services under Medicaid, since coverage varies by State. Like Medicare, Medicaid is medically oriented. Federal requirements mandate coverage of certain basic services such as inpatient hospi-

tal services, physician services, laboratory and X-ray services, and they allow States to select others from a list of additional medical services; nonmedical services are generally not eligible for Federal cost-sharing. States may limit the amounts of services as long as the limits are applicable generally. This has been interpreted to mean unrelated to health condition or place of residence within the State; payment is usually restricted to a fixed number of hospital days per year or physician visits per month.

The major difference between Medicare and Medicaid is in the coverage of nursing home care. Medicaid reimburses for care at an intermediate level as well as at the skilled nursing level. Purely custodial care is nominally excluded from coverage, but the definition of intermediate care is sometimes interpreted to cover it. Unlike Medicare, Medicaid does not impose fixed time limits on the amount of nursing home care that will be reimbursed. As a result, Medicaid is a major source of financing for nursing home care, paying nearly 43 percent of total national expenditures (7).

Medicaid funding for home- and community-based services is more limited. Also, under both Medicaid and Medicare, if a person is cared for in the community, room and board costs remain the responsibility of the individual; if the person is placed in a nursing home, not only is the necessary medical care covered, but also room and board. Although Medicaid recipients must surrender income, except for a small personal allowance, any family contributions, in money or in kind, can cease. It has been argued that this creates a bias toward nursing home placement. Studies suggest that the physical and emotional burdens of care are more important than the financial incentive in the decision to move someone to a home (6,11). Nevertheless, that feature clearly leads to inequity in the distribution of the cost of care. Families that accept the burden in time and emotional strain of providing personal care to a dependent relative also bear a greater share of the financial cost than families of nursing home residents on Medicaid.

For those with dementia, a major weakness in both Medicare and Medicaid is that they direct services entirely toward program enrollees and thus do not cover services needed by the families,

such as counseling. This orientation also leads to undervaluing of the benefits of services to individuals that at the same time provide respite for family caregivers. Adult day care, a few hours a day or week of personal services, or a week or two a year of institutional care can lighten the burden of caregiving to family members and perhaps enable them to remain effective in that role for a longer time (see ch. 4).

Concern over the high cost of nursing home care, and awareness of Medicaid's bias toward nursing home placement, led to a modification in the Medicaid statute that allows States to experiment with covering of home- and community-based services as a cost-containment measure. The "2176 waiver" program, introduced in 1981, allowed States to request waivers of standard Medicaid requirements in order to introduce new programs on a trial basis. For example, they could fund special programs for groups defined by health condition or place of residence and broaden the scope of services to include nonmedical ones (e.g., case management, homemaker and home health aide services, or adult care). Several States have used the 2176 waiver program to set up special programs for persons with Alzheimer's disease (20,44).

The value of the 2176 program has been limited by its emphasis on preventing nursing home placement, rather than on improving the care available to all patients in need. States had to demonstrate that the program would not cost any more, nor serve any more people than would have been served without the waiver. In other words, the program had to be narrowly targeted at those who would otherwise have entered a nursing home. It is difficult to predict who will enter a nursing home solely on the basis of physical and mental condition. Moreover, targeting those who would have entered a nursing home for special services raises questions of fairness. On the other hand, if subsidized home- and community-based care are simply made more available, expenditures are likely to rise, since many people in the community now receive inadequate care because of insufficient funds or unavailability of appropriate services (20,38,44).

Reimbursement

Eligibility for Medicare or Medicaid gives a person the financing for services, but imposes no requirement on anyone to provide them. Reimbursement largely determines whether individuals are able to obtain care, how much care they receive, what services they can use, and the quality of what they obtain. Although generous reimbursement does not guarantee good quality—particularly for those with dementia, who are poorly equipped to monitor provider performance—low reimbursement levels ensure that even the most dedicated and competent providers cannot deliver acceptable quality.

Reimbursement methods also affect the level and distribution of cost. Payment incentives influence a provider's attention to efficiency. When reimbursement covers less than full cost, the rest must be paid by the provider, the recipient, the person's family, or other people receiving the service.

Reimbursement policy under Medicare and Medicaid shows the conflict among access, quality, and cost objectives. Historically, Medicare and Medicaid have reimbursed facilities on a cost basis and individual providers on a fee-for-service basis. That system minimizes problems in access or quality if the full cost of care is covered and if physician fees match fees in the private sector. Hospitals and nursing homes may be able to charge higher prices to private individuals in the short run, but unless there are barriers to entry into the industry, new beds will be added until all who want care are placed. But such a system exerts no restraint on expenditure.

Fear of excessive impact on Federal and State budgets has caused restrictions on reimbursement, especially in State Medicaid programs. Cost formulas restrict allowable costs. Government payments for service are maintained at below market levels, especially under Medicaid, and limits are placed on the type and amount of services covered.

In the case of hospital *care*, rising expenditures have led Medicare to introduce a prospective payment system for hospitals based on case mix. Pa-

tients are classified by medical condition and other easily measured variables into 468 groups expected to require roughly the same resources. These are known as diagnosis-related groups, or DRGs. Hospitals are paid a fixed price for each patient's care based on the patient's DRG (except for a small number of "outlier" patients with unusually high resource use for their DRG). When the system is fully implemented in October 1987, the DRG price will be a national price based on average cost in a base period, adjusted for the hospital's urban or rural location and the area wage rate. Special payments are made for the direct and indirect costs of medical education, and the cost of capital is reimbursed separately, although efforts are now under way in Congress to find a way to include the latter in the new system (40).

Most State Medicaid programs still reimburse hospitals on a cost basis, although the cost formulas and restrictions on the amount of reimbursable services make the effective reimbursement rate lower for Medicaid patients than for others. A few States have adopted the Medicare payment system, however, and others are expected to do so in the future.

Reimbursement for *nursing home care* has been a particular target for budget-cutters. Medicare interprets the skilled nursing care benefit narrowly, reviewing cases retrospectively and often denying payment (18). (This policy was more important than the actual reimbursement level in limiting Medicare expenditures for nursing home care.)

Five State Medicaid programs pay nursing homes a flat per diem rate for all patients, whatever their condition, based on statewide limits on allowable costs. Equally important, many States restrain increases in nursing home capacity, creating a shortage of beds and therefore a queue for placement (38). The majority of Medicaid programs pay for nursing home services on a facility-specific cost basis but limit the degree to which costs are assessed.

Reimbursement restrictions often mean reimbursement at less than full cost, especially for individuals using more than an average level of resources. The national average rate for intermediate care under Medicaid was \$38 per day in

1983. Providers have the choice of operating at a loss, lowering quality, manipulating resident mix by accepting only those who would have low costs, or avoiding Medicare or Medicaid recipients altogether. Also, because of low reimbursement levels, many private practice physicians choose not to participate in Medicaid; as a result, Medicaid patients have difficulty getting outpatient care in physicians' offices, and often end up in more costly settings such as hospital emergency rooms.

Nursing homes are reported to take private pay residents ahead of Medicaid and Medicare recipients (18,38). Nursing homes that are reimbursed on a flat-rate basis have an incentive to choose the lowest cost individuals from the queue, sometimes those who do not need to be in a nursing home at all. To ensure that Medicaid nursing home placement is appropriate, some State Medicaid programs have introduced preadmission screening. People often circumvent this screening process by "jumping the queue" centering a nursing home on a private pay basis, then applying for Medicaid after spending down their assets; at that point, continued nursing home placement is likely to be the only realistic alternative (38).

To eliminate the bias against heavy-care nursing home residents and provide more equitable compensation to homes that accept them, seven State Medicaid programs have adjusted reimbursement for case mix (the type of residents). Some derive an overall average rate for each facility based on a case-mix index of the facility's population; others set a rate for each individual based on the level of care a person requires. One particularly comprehensive system (RUG-II) is conceptually similar to Medicare's new system for hospital reimbursement. Individuals are classified into 16 groups expected to be predictable in their use of resources; these are called Resource Utilization Groups, or RUGS.

The RUG classification is based on an assessment of need for skilled nursing and rehabilitative care; ability to perform three basic activities of daily living (eating, toileting, and transferring to and from bed or chair); and manifestation of four severe types of problem behavior (regression, aggression, verbal abuse, and hallucinations). Each RUG is assigned a fixed price per unit per

day derived from average historical cost, and the nursing home is paid that amount for each resident based on the RUG classification. Residents are reassessed every 6 months and the RUG classification is adjusted, if necessary. The system has just been implemented in New York State (35). Other States are considering adopting their own case-mix-based reimbursement systems.

Current case mix systems were developed before special care units for those with dementia were widespread. They may thus understate the true costs of care tailored to the needs of those with dementia (see ch. 7). Special nursing home units report additional costs of \$5 to \$15 per day, although the basis for these costs has not been publicly documented. If these higher costs are borne out in further studies, case mix reimbursement may need to take account of eligibility for care on special units, or to revise upward the reimbursement levels for those who have dementia.

The effects of Medicare's new prospective payment system for hospitals are not yet known. However, certain effects are likely, given the financial incentives created. For example, DRGs create incentives for increased admissions but rapid discharge, economizing on the use of services during a person's stay, and for avoiding patients who use more resources than average. Since patients are likely to be sicker at time of discharge from a hospital, the new payment system increases the likelihood that patients will be discharged to nursing homes for short-term nursing care rather than to their homes. That may cause pressure to reduce the availability of beds for longer-stay nursing home residents, such as those with dementia.

In considering the effects of reimbursement on access, quality, and cost, it is important to recognize both the great variability in reimbursement levels and restrictions on supply across the country. Thus the impact of reimbursement on individuals depends very much on where they live, particularly for Medicaid recipients. (See table 10-1 inch. 10, for a summary of Medicaid nursing home reimbursement rates by State.)

Looking specifically at the effects of reimbursement on individuals with dementia, a key question is whether they are, or are perceived to be, persons who use disproportionate amounts of

staff time or require services for which reimbursement is unusually low in relation to cost. It is dangerous to generalize about the answer to this question (see chs. 6 and 7). Persons with dementia vary greatly in their ability to care for themselves and their tendency to exhibit hostile or disruptive behavior. Systematic data are lacking on the distribution of symptoms across individuals and over time, as well as on the effects of symptoms on the cost of different types of care, under either existing or optimal conditions.

What data there are relate to overall nursing home care. For example, data collected for the RUG-II nursing home reimbursement system showed that persons with dementia were distributed across all groups, but on average used 5 to 6 percent more resources because they were more heavily concentrated in the higher disability groups (19). The designers of the RUG-II system found that the cognitive measures they used did not prove to be significant in designing the resource utilization groups. Assessment of the medical need, activities of daily living, and behavioral variables already mentioned was sufficient to group patients for cost purposes. In other words, once these characteristics were assessed, the additional information that the person has dementia is not a strong predictor of additional resource use for that individual. (If it is shown that residents benefit from services and activities specifically designed for those with dementia, then such services should be assessed in future case-mix studies.)

That result has been controversial. Identification of persons with dementia in the data is based on recorded diagnosis and an index of cognitive and behavioral variables. Some critics have argued that residents with dementia in the sample may not have been correctly identified, because the diagnoses were inaccurate and the measures of cognitive and behavioral variables used are inadequate. In particular, it has been argued that the RUG-II data did not discriminate well between those with dementia and others in the group of residents with the lowest levels of medical need and physical disability (19).

The intensity of the debate about whether persons with dementia require extra care suggests

that even if they do not, many providers believe they do. That perception may lead to problems with access. Documenting the extent to which individuals with dementia experience greater than average problems with access to care is not easy, given the problems in identifying them. A study by the General Accounting Office showed that patients with mental and behavioral problems and those with significant dependency in activities of daily living were the ones who were likely to be found in hospital beds awaiting admission to a nursing home (38; see also 17). That finding and the extensive anecdotal evidence collected in an OTA survey of Medicaid programs suggest that access to care is a problem for individuals with dementia (10).

People may obtain access to care but then fail to receive appropriate care. Reimbursement policy must be made jointly with quality assurance policy, especially when providers can receive financial benefits by cutting quality (see ch. 10). Moreover, the policy must allow for change over time. For example, when reimbursement is adjusted for case mix, it is based on existing patterns of resource use. If persons with dementia are receiving suboptimal care now, that pattern may be frozen in place, since providers will not be adequately reimbursed for more appropriate care if it is more costly to provide.

In addition to the effects on access and quality, current reimbursement methods lead to inequitable distribution of the cost of care. The extent of subsidy varies arbitrarily across types of care, geographical areas, and providers, leading to quite different cost burdens for families with similar needs,

Administration

A program's structure on paper tells only part of the story of its impact on beneficiaries. The actual administration of the program is equally important.

Administrative barriers to obtaining Medicare services do exist. It is often difficult to obtain information about eligibility and scope of services from fiscal intermediaries and local social security offices. It may take several years to overturn an initial incorrect denial of eligibility for disability benefits. Administrative hearing rights are limited to situations in which the amount in question is at least \$100; judicial review is only available if the amount is at least \$1,000.

Medicaid has similar barriers. Its complexity makes the problem of obtaining accurate information about eligibility and coverage even more difficult than for Medicare. Eligibility determinations are often subject to substantial delays over and above those associated with the underlying social security or welfare determinations. Although Medicaid recipients have a broad legal right to administrative hearings in the event of erroneous actions by agencies and providers, quality control information collected by the Department of Health and Human Services suggests that fewer than 5 percent of recipients challenge incorrect negative case actions (i.e., actions to withhold, terminate, or deny benefits in violation of Federal law) (see ch. 11). Moreover, the only penalty a State incurs if it does make an error is disallowance of the Federal fraction of payment. Thus, there is no meaningful Federal check on giving a Medicaid enrollee too few benefits, but a substantial financial penalty for giving too many.

Administrative barriers exist for all individuals but are likely to be a greater problem for uneducated, poor, minority-group, and mentally handicapped persons. Those with dementia are likely to have problems unless they have active, involved family members to ensure that they get the services to which they are legally entitled. Particularly troubling is the indirect evidence that black individuals with dementia may have greater unmet needs (31). In OTA's survey of State Medicaid programs, in nearly every State that had utilization data available by race white Medicaid recipients 65 or older were receiving about twice as many services as black recipients (10).

ISSUES AND OPTIONS

Clearly, there are problems with the existing system of financing long-term care for persons with dementia. In evaluating proposals for change, decisionmakers must consider several basic questions. This section presents several key issues that must be addressed by public policy and then describes various proposed options. Because many of the options touch on several different issues, the discussion of issues and options is different from that in other chapters.

Issues

ISSUE 1: How Much Responsibility Should Government Take For the Care of Persons With Dementia?

One answer is, the government should take no responsibility. The problem of financing care for persons with dementia could be considered a private one, to be solved by individuals and their families, with the help of insurance markets and voluntary private charity. Although the private market and private charity have not solved the problem in the past, the future might be different. People are becoming more aware of the risk of developing a dementing illness and the needs such an illness creates, so there will be more private initiatives. The long-term care insurance market is developing, introducing new policies and marketing strategies. The population most at risk has greater financial resources than in the past. Financing devices such as home equity conversion may help free assets to pay long-term care insurance premiums. As the condition achieves higher visibility, more private charity will become available.

On the other side, however, there is reason to question the ability of the private market and private charity to solve the problem. Long-term care insurance is expensive, and moral hazard and adverse selection limit the degree of risk-spreading that can be achieved privately, especially for persons with dementia. Even if prudent members of the middle and upper classes could provide for themselves through private insurance, the poor and the imprudent would remain. Although the financial status of older Americans as a group has

improved considerably, there are still major subgroups that are too poor to provide for long-term care at the time of use or through insurance. And there will always be those who can afford insurance but out of ignorance or poor judgment do not buy it. Given the expense of care, private charitable efforts are unlikely to be sufficient to meet their needs.

A decision that no government assistance is in order would be radical, since government at the Federal, State, and local levels already provides some assistance to persons with dementia. Withdrawal of government aid from these people, or from all who need long-term care, raises serious issues of fairness if other government health programs are left intact. It would be difficult to justify providing extensive assistance through Medicare for those who need hospital care and providing no assistance for long-term care, when long-term care can clearly be a greater burden.

A second position is, the government should encourage private initiatives to finance care but should not finance the care itself. In the case of dementia, government might encourage the development of long-term care insurance, home equity conversion, continuing care communities, social health maintenance organizations and long-term care savings funds. Government might encourage the formation of self-help groups and volunteer networks. Government might also fund research on the disease and educate the public about the need to make provisions for long-term care.

In the long run, these actions might help middle-class individuals with dementia but they will not solve the problems of the poor and the improvident. Therefore it might be argued that the government should subsidize the provision of long-term care. If it is decided that access to adequate long-term care should be guaranteed to all, special provision must be made for the poor and for those who fail to provide for their own needs in advance. Such provisions could be in addition to facilitating the development of private solutions. This position is implicit in existing policy. However, it raises complex questions about the proper

structure of the subsidies, and these differ markedly among the various options described below.

ISSUE 2: Should Special Subsidies Be Set Up for Persons With Dementia?

Many proposals have been made for special treatment for those with dementia, such as extra tax deductions and exemptions for families and special services under Medicaid. It would be convenient to be able to help individuals with dementia and their families without having to fix the entire long-term care system, or the entire health care delivery system. It is widely recognized that these systems require fundamental changes, but the changes will not happen overnight; in the meantime, this group is suffering.

On the other hand, the categorical approach raises questions of fairness. Individuals with dementia have characteristics in common with others needing long-term care, who are also suffering. It is the combination of problems that makes the situation so difficult for someone with dementia, not the uniqueness of any one problem. There is also a practical difficulty. As chapter 8 discussed, there is no easy way to identify the members of the category. People with dementia already form a large fraction of the long-term care population; if there were financial incentives to having the diagnosis, instead of disincentives (as now), the number of people so classified would almost certainly increase.

ISSUE 3: Should Subsidies Be provided on a Social Insurance or a Welfare Basis (i.e., be made available to all or only to the poor)?

Restricting subsidies to the poor and relying on private, market-oriented approaches to solve the problems of the other income groups would require a smaller government outlay. It would also be more in accord with American traditions of personal responsibility and limited government involvement in the health care system. Private enterprise may be more efficient and more responsive to consumer preferences than government bureaucracy.

On the other hand, history suggests that it can be difficult to maintain subsidies at a level suffi-

cient to guarantee adequate care, when the subsidies are provided only to a group with little political power. Government outlays may be lower under a welfare approach, but total social outlays may be greater in a mixed public-private system without the control over utilization and adverse selection that would be possible in a broad-based, compulsory social insurance system. A universal, compulsory system would also eliminate the inequity that results when prudent middle-class taxpayers must provide not only for themselves and the poor, but also for the imprudent.

ISSUE 4: How Should the Cost of the Subsidies Be Distributed?

If subsidies take the form of social insurance, should there be redistribution across generations, or should each generation bear the full cost of its own long-term care? Should there be redistribution across income classes? If subsidies are provided as welfare, what should be the income limits? Should close relatives be held responsible for the cost of care, and to what extent? Whatever the solution pursued, financing mechanisms should strive to avoid the abrupt discontinuities in program eligibility by income and in types of covered services that plague the current system.

ISSUE 5: What Is the Proper Relationship Between the Long-Term Care Subsidy Program and the Rest of the Health Care System?

Whether government subsidization is designed as welfare or social insurance, policymakers must consider the fit between public and private sectors, between long-term care and acute care delivery, between third-party payment for acute and long-term care, and between subsidies for health needs and subsidies for other needs, such as housing and nutrition. Because Medicare and Medicaid are such a large part of the health care market, they exert a profound effect on the entire delivery system. Coverage and reimbursement policies lead providers toward provision of services that are covered and reimbursed and away from others. Innovation and integration of services must take place within a structure that creates financial incentives for them. This assessment has described the inefficiencies and inequities that re-

suit from lack of coordination in the existing system. Moreover, government programs sometimes fail to solve a problem, yet by their very existence weaken the incentive to solve the problem privately. For example, some argue that Medicaid has been an obstacle to the development of private long-term care insurance, even though it hardly provides satisfactory protection against the long-term care risk, because the public does not realize how strict Medicaid income and asset restrictions are.

ISSUE 6: To What Extent Should the Availability of Assistance Vary With Place of Residence?

It would be impossible to provide exactly the same level of services everywhere in the United

States, in remote rural areas and in large cities. On the other hand, in the existing system, the assistance available to those with dementia varies dramatically and arbitrarily with place of residence.

ISSUE 7: What Is the Role of Each Level of Government—Federal, State, and Local—in Subsidizing Care?

Providing assistance at the State and local levels puts it closer to the populations being served. On the other hand, it increases the likelihood of inequitable variations in access to services and distribution of cost.

POLICY OPTIONS *

The Federal Government could encourage private initiatives to attack the financing problems of dementia patients. Some efforts could be directed specifically at persons with dementia; equally important, Government could ensure that the special characteristics of that population are kept in mind when considering solutions to the long-term care financing problem in general. Some activities could be carried out without additional Government expenditure, e.g., by refocusing the activities of existing agencies or by serving as a catalyst for efforts funded by private entities. Other activities would require some funding but would not involve continuing subsidies to individuals. These include the following:

Develop the Knowledge Base About the Disease.—Information about dementia's epidemiology, progression, and optimal management would obviously be desirable for medical reasons. It is also of vital importance for developing private financing mechanisms, such as long-term care insurance.

Educate the Public About the Size of the Risk and the Need To Protect Against It.—It is tempt-

ing to allow Medicare recipients and their families to continue to believe that they are better protected against the costs of long-term care than they are. Only an unfortunate minority will discover the truth; the rest have peace of mind without the budgetary expense required to make the illusion of protection real. But an equitable and efficient solution to the long-term care problem requires a more accurate public perception of its nature and importance.

Promote an Appropriate Regulatory Framework.—Government regulation sets the framework within which private initiatives can occur. In the case of private long-term care initiatives, the objective of regulation is consumer protection. That objective is pursued through standards for product design and disclosure of information, and rules for the promotion of orderly competition and adherence to contracts among suppliers. Home equity conversion, private long-term care insurance, and life care communities are examples of issues subject to government regulation. The potential for exploitation and abuse—particularly of individuals with dementia—is clearly substantial. On the other hand, if not carefully structured, regulation can stifle innovation and deprive consumers of the benefit of new ways to meet their needs.

● Substantial parts of this section are based on "Financing Care for Patients with Alzheimer's Disease and Related Disorders," a paper commissioned by OTA from Karen Davis and Patricia Neuman (13).

Table 12-1.—Federal Policy Options (for explanation of options, see text)**Encourage private initiative to finance long-term care:**

Develop knowledge base about dementia.
 Educate public about risk and need for protection.
 Promote appropriate regulatory framework.
 Sponsor reverse mortgage insurance demonstration.
 Provide reinsurance for private long-term care (LTC) insurance.
 Promote efforts of private organizations to aid persons with dementia.

Subsidize individual efforts to meet LTC needs privately:

Subsidize savings for LTC through tax system.
 Modify IRAs to allow tax-free withdrawal for LTC expenses after age 59 and allow tax-free accumulation to continue until age 75.
 Authorize tax-deferred contributions solely for health and long-term care expenditures through IMAs (Individual Medical Accounts).
 Subsidize family contributions to care through tax system.
 Allow an additional exemption for dependents with dementia.
 Allow itemized deduction or exemption for contributions toward care of a parent, whether or not parent is a dependent or child contributed more than 50 percent of parental support.

Increase direct Federal provision of services:

Expand VA LTC system with special emphasis on dementia-related services.

Modify Medicare and Medicaid:**Modify eligibility:**

Make dementia a presumptive cause of disability for Medicare.

Combine above with elimination of two-year waiting period.
 Develop a uniform national treatment of income and assets for Medicaid eligibility.

Allow people to avoid Medicaid spend-down by purchasing private LTC insurance.

Modify scope of services:

Expand Medicaid and/or Medicare benefit package to include some or all of: case management, adult day care, personal care, chore services, attendant care.

Increase coverage for mental health services; include counseling for caregivers.

Include respite care services.

Modify reimbursement:

Adopt case-mix reimbursement for nursing homes, with provision for any dementia-related extra costs.

Give a major role to S/HMOs.

Modify administration:

Provide better information about programs to those seeking services.

Develop effective Federal sanctions for incorrect denial of benefits.

Support comprehensive reform of long-term care financing: (for all who need LTC or dementia patients only)

Davis-Rowland proposal: Add a new *voluntary* LTC benefit to Medicare, financed by income-related premiums and general revenues. Benefits include nursing home, expanded home health, and community services. Benefits are subject to copayment with ceiling on total out-of-pocket expenditures per year.

Harvard proposal: Add *mandatory* LTC coverage to Medicare financed by beneficiary payments, payroll tax, and general revenues. Benefits include expanded nursing home, home health, and mental health services with copayment; geriatric assessment teams for case management. Nursing homes are reimbursed on prospective basis subject to a national or regional cap.

Kane and Kane Canadian model: Provide mandatory, universal LTC insurance coverage to all regardless of age or income, financed by block grants to states. Benefits are based on degree of impairment as assessed by gatekeepers; they include nursing home care, home nursing services, and homemaking services. Home care is free but subject to cap.

LTC Block Grants to States: Provide general Federal block grants to States for LTC; specify eligible population, covered benefits, payment and control mechanisms, or leave these entirely to States.

Bowen proposals: Support a major public education program; allow tax-free withdrawals from IRAs for long-term care expenses; create Individual Medical Accounts to encourage tax-free savings accumulation and limited risk-pooling; encourage long-term care insurance through a tax credit for premiums, expanding income-accumulation, and removing employer disincentives to cover long-term care as an employee benefit; add long-term care as an optional benefit for Federal employees.

SOURCE: Office of Technology Assessment, based on K. Davis and P. Neuman, "Financing Care for Patients With Alzheimer's Disease and Related Disorders," paper prepared for the Office of Technology Assessment workshop on Financing Care for Patients With Alzheimer's Disease and Related Disorders, May 19, 1986

Most of the regulatory activity occurs at the State level. The Federal Government could, however, encourage States to consider appropriate regulation that accounts for the particular characteristics of those with dementia, and could encourage cooperation among States to ensure more uniformity in market conditions.

Sponsor Reverse Mortgage Insurance on a Demonstration Bask. -Freeing up home equity could

provide funds for the direct purchase of long-term care services or private long-term care insurance. This might save money in the Medicaid program by enabling people to provide for their long-term care needs out of their own assets, without forcing them to leave their homes. Development of home equity conversion instruments is hampered by the absence of mortgage insurance. A Federal demonstration program could stimulate the market and encourage private insurers to move in;

it could also be used to provide a model of disclosure and consumer counseling—important given the significance of the consumer's decision and its unfamiliarity.

Provide Reinsurance for Private Long-Term Care Insurance. Government could set standards on private long-term care insurance and make qualified plans eligible for Federal Government reinsurance against adverse risk selection or high expenses. Reinsurance protection could include a stop-loss provision that would protect private plans against losses above a given level, or could assume coverage once some threshold was passed (e.g., 3 years of nursing home care or \$100,000 per beneficiary).

An obstacle to developing long-term care policies is the profound uncertainty companies have about their future liability, given the unknowns of adverse selection; moral hazard; and trends in mortality, morbidity, and cost of long-term care. The availability of reinsurance might make companies more willing to experiment with long-term care policies. The reinsurance might more than pay for itself if the availability of private risk-pooling decreased the number of people who spent down to Medicaid eligibility. And even if it did not pay for itself, there might still be a substantial social benefit if many people were able to avoid the painful and demeaning spend-down process and government funds were targeted to the most needy. Such an approach would be of special value to those with dementia, since they are particularly likely to experience catastrophic expenses and thus to be considered unattractive risks by insurance companies.

On the other hand, if insurance companies are not effective in controlling insurance-induced demand and if the availability of third-party payment causes long-term care costs to rise significantly, reinsurance could be costly, and could drain funds from more needy groups to subsidize those able to afford long-term care insurance.

Promote Private Voluntary Efforts to Aid Persons With Dementia.—The Federal Government could encourage the activities of specialized organizations such as ADRDA in developing support groups, consumer cooperatives for the purchase or exchange of long-term care services, and in-

formation networks and referral services for individuals and families. It could encourage private organizations with a general health and welfare mission to pay attention to the special needs of those with dementia. Government encouragement could include coordinating, providing information, providing seed money for demonstration projects, or ongoing subsidies. This would encourage private innovation and initiative, while stretching scarce government funds to help more people. Its effectiveness would, of course, be limited by the availability of that private initiative.

The Federal Government could **increase its direct** provision of services. This approach would be more costly.

Expand the VA Long-Term Care System, with Special Attention to Services for Persons With Dementia.—VA already has experience in providing long-term care. Direct provision of services provides the opportunity for direct control of cost and quality. The population the VA has traditionally served is aging, will require a large volume of services in the years to come, and may expect to receive it from VA. By accepting responsibility for this group, VA would decrease the pressure on the rest of the system.

On the other hand, it may not be easy to control cost and quality in a large, geographically dispersed public system serving the chronically ill. Singling out veterans for better access to care for a non-service-connected disability raises questions of fairness. Fairness suggests that if the Federal Government is to provide long-term care services directly, it should be in a context of more general availability.

The Federal Government could directly **subsidize** the efforts of private individuals to provide for their long-term care needs. This approach would also be more costly.

Provide tax subsidies to encourage savings for the purchase of long-term care.

Modify Individual Retirement Accounts (IRAs) to Encourage their Use for the Purchase of Long-Term Care.—IRA savings withdrawn and used for health or long-term care after age 59 could be exempted from income taxation. IRA savings withdrawn and used for other purposes would be

counted as taxable income, as at present. The current requirement that savings be withdrawn by age 70-1/2 could be extended to age 75 or 80, when individuals are more likely to require long-term care.

Authorize Additional Tax-Deferred Contributions through Individual Medical Accounts (IMAs) with the Proceeds Restricted to Health and Long-Term Care Expenditures.—DHHS Secretary Otis R. Bowen and Thomas R. Burke have outlined a plan with the following features (5). At age 40 or 45, individuals would be given the option of procuring an IMA. Contributions would be sheltered from income and estate taxes, and would be held by the Federal Government in a health bank and invested at money market or high-yield government securities rates. If an individual dies before using the IMA funds, the original contributions, with some share of the investment income, would be returned to his or her estate. There would be no long-term care insurance component; individual's would have access only to those funds they saved. If long-term care expenses exceeded the IMA contributions, however, the balance would be met from the interest income that accumulates in the health bank. Individuals choosing not to contribute to IMAs would be at risk for all chronic care expenses and would have to spend down to Medicaid eligibility should they require long-term chronic care.

These options encourage individuals to save for future long-term care expenditures and give families the flexibility to use savings for services they feel best meet their needs. They also encourage the private sector to develop and market more services.

The value of the subsidy increases with income. Experience with IRAs suggests that they do little to increase total savings but merely shift savings from one form to another. Moreover, as noted, less than a quarter of taxpayers eligible to contribute to IRAs took advantage of the opportunity; these were predominantly higher income individuals (27). Savings incentives, however, could reduce the likelihood of reliance on Medicaid for a fraction of the population. These options do not pool the risk across individuals and provide no assurance that savings will be adequate to meet long-term care needs.

Modify Tax Laws.—Possible changes to tax laws could include the following:

- Provide tax subsidies to families contributing to the care of persons with dementia.
- Allow an additional tax exemption for dependents with dementia.
- Permit adult children of persons with dementia to claim an itemized deduction or exemption from income for financial contributions toward medical equipment, drugs, home health, and personal and nursing home care. This would not necessarily be conditional on demonstrating that the parent was a dependent or that the adult child contributed more than 50 percent toward the care of the parent.

The tax code, even after reforms made in 1986, already contains many subsidies for other purposes. They are intended to encourage people to do socially useful things by lightening the tax burden of those who do them. Taking care of someone with dementia is socially useful, and the families are certainly as much in need of help as those with other kinds of deductible expenses. It would be easier to get congressional approval for assistance in this form, since it does not appear in the budget. The cost might be offset to some extent by savings in the Medicaid program.

On the other hand, like tax subsidies for savings, subsidies for care would benefit higher income individuals more than lower income individuals, and would provide only minimal help to families in greatest need. This is particularly undesirable if there are direct subsidies to the poor and indirect subsidies to the better off; the poor are likely to be subjected to stricter limitations than middle and upper income groups. (The rising cost of Medicaid has attracted much more legislative attention than the rising cost of tax subsidies to health insurance for the employed.) The current trend is toward simplifying the tax code and eliminating rather than adding tax subsidies. Unlike direct expenditure programs, tax subsidies do not provide any opportunity for directly controlling the price or assuring the quality of long-term care services. Tax subsidies targeted specifically at individuals with dementia and their families raise issues of fairness, and would be difficult to administer given the uncertainties in

diagnosis. Finally, the lower overall tax rates for 1988 and beyond make tax subsidies less valuable.

The Federal Government could support incremental modifications in Medicare and Medicaid to improve their ability to meet the financing needs of persons with dementia. The following possible modifications could be adopted individually or in combination:

Modify Eligibility

- Make it easier for those with dementia to establish eligibility for Medicare on the basis of disability by making dementia a presumptive cause of disability. This could be combined with a specification of an appropriate diagnostic procedure.
- Combine the above option with elimination of the 2-year waiting period.

These options would make acute care coverage available to those not eligible for Medicare on other grounds. However, the second option gives Medicare another diagnosis-specific category of patients in addition to end-stage renal disease.

- Develop a uniform national treatment of income and assets for eligibility for Medicaid.

The differences in treatment by income, assets and their composition, marital status, and place of residence area major source of inequity in the existing Medicaid program. They also create perverse incentives with respect to purchase of private long-term care insurance, transfer of assets, and contributions to care in money and in kind by family members.

On the other hand, national standards would decrease State autonomy, and it would be difficult to achieve a consensus on a fair plan, given the wide differences in existing eligibility standards and State ability to pay.

- Allow people to avoid Medicaid spend-down by purchasing private long-term care insurance. For example, someone who purchased a specified level of long-term care coverage (e.g., 4 years of nursing home coverage or \$100,000 of total long-term care expenses) could become eligible for Medicaid automat-

ically if his or her expenses exceeded the coverage level, without spending down assets. This option might foster the development of private long-term care insurance and thereby decrease Medicaid expenditures on the middle class. On the other hand, it would change the orientation of the program from welfare to social insurance and could conceivably raise expenditures rather than lower them, if utilization increased.

Modify Scope of Services

- Expand the Medicare, Medicaid, or both benefit packages to include some or all of the following: case management, adult day care services, personal care services, chore services, attendant care.
- Increase the limit on covered expenditures for mental health services; include counseling for caregivers.
- Include respite care services. For example, the benefit could be a specified number of days (e.g., 30 days for persons with severe dementia) during the year, which could be used by caregivers to spend time away from the ill person. They could have the option of taking the days in blocks of time (e.g., 2 weeks twice a year) or on an ongoing basis (e.g., half a day every week). The care could take the form of an attendant in the home or placement in a nursing home or hospital. Alternatively, the value of the benefit could be specified in dollar terms.

These options would make it easier to put together a package of services that would meet the needs of a person with dementia. Counseling and respite services for families would reduce stress on caregivers, improving their quality of life and, in some cases, postponing nursing home placement of the person with dementia.

On the other hand, such an expansion of coverage would be costly unless effective methods for restraining the use of services were developed. It might decrease the amount of informal support provided to individuals. Costs could be limited, however, by setting a maximum dollar amount on the extent of subsidy.

Modify Reimbursement

- Adopt case-mix reimbursement for nursing homes, with careful attention to any extra costs associated with dementia.

If properly structured, case-mix reimbursement could help eliminate bias against individuals with dementia in nursing home admission and provide financial incentives to give quality care. Data collection for case-mix reimbursement systems should incorporate accurate and effective assessment measures to identify those with dementia and establish baseline resource use for these residents. Provision should be made for quality review and for changes in reimbursement to reflect changes in the technology of managing people with dementia.

- Modify reimbursement to give a major role to S/HMOs.

Currently Medicare is testing the Social Health Maintenance Organization concept on a demonstration basis. If it proves successful, it could be instituted on a nationwide basis for Medicare or Medicaid, or both.

The advantage of the S/HMO is that it integrates acute care, long-term care, and social services. In providing managed care, it can offer individuals more of the services they want and need to remain in the community and at home, while incor-

porating a mechanism for restraining utilization. It may even be able to save money by reducing inappropriate use of hospital, nursing home, and other medical services.

on the other hand, the extent of patient acceptability and the feasibility of cost savings have not been demonstrated. It would not be easy to determine cavitation rates and manage the problem of adverse selection.

Modify Administration

- Provide complete and accurate information about the programs to those seeking long-term care services.
- Develop effective Federal sanctions for incorrect denial of benefits.

These changes would probably raise program expenditures, since the evidence, although incomplete, suggests that administrative errors and lack of information are more likely to deprive people of services to which they are entitled rather than the reverse. However, the changes would reduce the burden of obtaining benefits and distribute them more equitably.

The Federal Government could **support comprehensive reform of long-term care financing**. Several major long-term care financing options have surfaced recently. These options could

Table 12-2.—Summary of Comprehensive Reform Options

	Davis-Rowland	Harvard	Kane & Kane	Block	Grants
<i>Eligibility:</i>					
Level of impairment	—	—	X	—	—
Age	X	X	—	—	—
<i>Benefits:</i>					
Assessment	—	X	X	—	—
Home- and community-based services	X	X	X	—	X
Nursing home	X	X	X	—	X
Respite	X	—	—	—	—
Case management	—	—	X	—	X
Counseling; mental health	—	X	—	—	—
Day care	X	—	—	—	—
Financial, other support for family	X	X	X	—	—
<i>Financing:</i>					
Medicare	X	X	—	—	—
Medicaid	X	—	—	—	—
General revenues	X	X	X	—	X
Copayments	X	X	X	—	—
Surcharge payroll tax	—	X	—	—	—
Public/private	X	X	X	—	—

be supported as designed, to apply to all elderly and disabled people, or they could be redesigned to apply only to persons with dementia.

Voluntary Medicare Coverage of Long-Term Care. This option would add a new voluntary long-term care benefit to Medicare and finance it with an income-related premium administered through the income tax system (14).

The option has several major features. Covered benefits include nursing home care (both in qualified skilled nursing facilities and intermediate care facilities), expanded home health services (without many of the restrictions in the current Medicare program), and day hospital services. Benefits would be subject to a 10-percent coinsurance charge and would have an annual \$3,000 ceiling on out-of-pocket costs. All persons age 60 or older would be eligible to enroll, but benefits would not be available until the person had been enrolled for at least 5 years. No one could enroll after age 70. A direct grant program to public and nonprofit community organizations would provide home services such as attendant care, personal care services, and chore services. The long-term care benefit would be financed with an income-related premium set at 4 percent of income for those who enroll at age 60 (with higher premium rates for those delaying enrollment) with a minimum annual premium of \$200. Federal general revenues would be used to meet any long-term care expenditures not covered by premium revenues. Categorical Federal grant funds would be used to finance home help service programs. Medicaid long-term care coverage would continue as a residual program for those low-income people not choosing to purchase Medicare coverage. The Federal financial participation for residual Medicaid long-term care coverage would be reduced by one-half the current contribution rate.

Provide Mandatory Medicare Coverage of Long-term Care. -A study group has recently proposed mandatory coverage of long-term care under Medicare (21). The major provisions of the option are the following. The Medicare benefit package would be expanded by removing current restrictions on home health services and mental health services subject to 10 percent copayment. Home- and community-based services such as personal

care, chore services, attendant care, respite care, and adult day care would not be covered. Coverage for nursing home care would be broadened and custodial care added. Nursing home residents would pay a residential copayment to cover the room and board cost of a nursing home. This copayment would be set at 80 percent of social security benefit payments (or, for a couple, at 80 percent of the difference between the individual's and the couple's social security benefit payments). In addition, residents would pay a one-time, one-month nursing home deductible. Geriatric assessment teams would serve as gatekeepers to determine eligibility for benefits. Nursing homes would be paid on a prospective basis, subject to national or regional budget caps. Expanded benefits would be financed through a combination of payments by beneficiaries (25 percent of total cost), payroll (55 percent of cost), and Federal general revenues (20 percent). Beneficiary contributions would include copayments as specified above, premiums, and a 10 percent income tax surcharge.

Canadian Model of Long-Term Care Financing. -Two researchers have studied universal long-term care benefits in three Canadian provinces (Ontario, Manitoba, and British Columbia) and suggested that a similar approach would be feasible and desirable in the United States (29). Universal long-term care insurance in Canada replaced an earlier system of long-term care for the indigent. Although each provincial program is slightly different, the major features of this approach as applied to this country are the following:

Federal block grants would be made to States for universal long-term care insurance to all individuals regardless of age or income. Benefits would be based on degree of functional impairment, and would include nursing home care, home nursing services, and homemaking services. Residents would pay daily copayments of \$10 to \$15 for nursing home care. Payment to nursing homes would be set by level of care (e.g., personal care, intermediate care, psychogeriatric care, extended care for bedridden residents) and type of facility. Facilities would be paid on a negotiated per diem rate or a negotiated budget basis. Access to services would be determined on the basis of assessment by specified gatekeepers such as physicians,

care managers, or home care coordinators. Homemaking services would be limited to a fixed number of hours per month or to a maximum cost not to exceed nursing home care. Home care would be free to the individual. Home nursing and homemaking services would either be provided by salaried public employees or purchased from for-profit or nonprofit agencies.

Long-Term Care Block Grants to States.—Another approach suggested in the United States is a more general long-term care block grant from the Federal Government to the States. The grant could either specify the eligible population, covered benefits, payment, and control mechanisms required in a State program as a condition of Federal financial support, or it could leave these features solely to State discretion.

The major financial burden for individuals with dementia is nursing home care. Although enabling as many people as possible to continue to function in their homes is a desirable objective, it is an unrealistic goal for many, particularly those in advanced stages of the disease. Therefore, some reform of long-term care financing will be required to provide adequate financial protection to families of those with dementia.

Otis Bowen, Secretary of the Department of Health and Human Services, recently released a report dealing with coverage of catastrophic illness. Coverage of long-term care was a major theme in the discussion, and recommendations included several options discussed in other sections of this chapter. The primary recommendations for long-term care coverage included:

- major education program involving the Federal Government and the private sector to acquaint the public with the risks, costs, and financing options for long-term care;
- tax-free withdrawal of IRA savings for long-term care payments, and establishment of Individual Medical Accounts to permit tax-free savings and permit limited risk-pooling;
- encouragement of private long-term care insurance by establishing a tax credit for long-term care premiums, permitting tax-free accumulation of savings analogous to life insurance, and removing provisions in current Federal law that discourage employers from

including long-term care insurance as an employee benefit; and

- establishment of long-term care coverage as an optional health benefit for Federal employees (41).

These recommendations are based in part on a report submitted to Secretary Bowen by the Private/Public Sector Advisory Committee on Catastrophic Illness, which held hearings and meetings throughout the country in 1986 (42). The final recommendations have been submitted to President Reagan for consideration.

All the comprehensive reform options discussed above would address coverage of nursing home care. The first three would provide financing for a broad range of long-term care services, including nursing home care. Coverage would not be conditional on an income eligibility test. Each would require some individual contributions toward nursing home care.

These options have the advantage of lightening the financial burdens now borne by those with dementia and their families. They are undoubtedly costly and would require substantial public budgetary outlays. Sources of revenue would need to be identified to meet these outlays. In addition, all the options would require mechanisms for assessing individual functional impairment in order to define eligibility and match services to needs. Each option is likely to improve the supply of long-term care services and choices among willing providers. To prevent abuses, however, each option would also require carefully designed quality control and payment provisions.

The option of voluntary long-term care benefit under Medicare has added advantages. It is designed to be self-financing and would pool risk across a large group of elderly persons. It would make spend-down less likely, reducing the need for middle-income elderly individuals to depend on Medicaid. It would expand the service options open to older Americans. Its major disadvantages are the possibility of adverse selection and the difficulties of dealing with those who require long-term care but did not enroll in advance.

Mandatory Medicare coverage would provide full coverage for all beneficiaries and pool the risk across all of them. It would not be affected by

adverse selection. It avoids any gaps for those who might fail to purchase the voluntary benefit package. Similarly, it would have the greatest impact on reducing dependence on Medicaid. Its major disadvantages are the recommended increases in the payroll tax and drain on Federal general revenues, as well as opposition to new entitlement programs. As designed, it also does not deal with the types of home care services most useful to persons with dementia.

Supporting State programs for long-term care provides opportunities to consolidate and coordinate fragmented delivery systems and target attention and resources on the long-term care population. These approaches would be less likely to

tie long-term care services to a medical model. Both run the risk of diverting financial responsibility for long-term care to the States, possibly leading to differences in adequacy of coverage, as well as political opposition from the States. Federal block grant allocations would be politically vulnerable since they are part of the annual appropriations and budget debate. Creation of a new program for long-term care could generate additional problems if it failed to coordinate with Medicare and Medicaid. Standards would need to be built into requirements for State programs to prevent the wide variations that now characterize the Medicaid program.

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