

Responsibility of Families For Their Severely Disabled Elders

By James J. Callahan, Jr., Lawrence D. Diamond, Janet Z. Giele, and Robert Morris

In the past 13 years, total expenditures for nursing home care under the Medicaid program have increased drastically. They show no signs of abating. Government, therefore, has become aware of the need to control this rapid increase. Families, who currently provide a large amount of informal, long-term care for their disabled elderly, are seen as a potential resource to maintain people in the community.

Although demographic elements appear to mitigate against increased family responsibility, governmental incentives may be able to reverse the trend. While demographic variables cannot be modified by public policies, programs can be developed to modify family situations, increasing family capacity—and willingness—to care for disabled, elderly adults.

Section I

Statement of the Question and Definitions

Introduction

This paper discusses issues related to the role of families in both financing and caring for member with long-term care needs. It examines these issues from the perspective of an implied question: Should the Federal government, by law and/or regulation, require some type of financial or in-kind contribution from designated kin toward the care of a relative receiving long-term care services under Medicaid as either partial payment or as a condition of eligibility for the programs?

In 1978, the University Health Policy Consortium (UHPC), composed of Boston University, Brandeis University, and Massachusetts Institute of Technology, established the Center for Health Policy Analysis and Research to conduct relevant health policy analysis and short-term research projects for the Health Care Financing Administration. This paper was prepared by the University Health Policy Consortium as part of Grant #18-P-97038/1-01 for the Health Care Financing Administration, Department of Health, Education, and Welfare.

The issue of requiring such participation of kin (which will be referred to as family responsibility) has a history going back to the Colonial era. Legal family responsibility was a common feature of locally administered, means tested, public assistance programs into the 1960's. As the Federal government began to take responsibility for income maintenance programs in the 1930's however, the concept of individual entitlement for benefits became predominant. Entitlement bestows certain rights on individuals independent of any responsibility on the part of other family members.¹

The passage of Medicare and Medicaid in the mid-1960's provided "entitlements" to specifically defined groups. Numerous court decisions over the past 13 years have reinforced the entitlement provisions of various governmental health and welfare programs.

Despite this clear trend toward entitlements, residues of previous public assistance concepts remain. This can be seen for example, in Medicaid, where certain classes of individuals are entitled to service only after they have met an income and resource means test.

¹ For the best history of family responsibility issues in public assistance, see Schorr, *The Fifth Commandment*, Social Security Administration, 1978. Also see the Technical Note which discusses this history in greater detail and attempts to relate present Federal programs to the family responsibility issue.

These two concepts, family responsibility and individual entitlement, are woven into our social policies without resolution of the contradictions they imply.

Basis of the Concern with Family Responsibility

The rapidly rising cost of institutional care under Medicaid is a major reason for the current concern with family responsibility. It is hypothesized by some that entitlement to a nursing home benefit under Medicaid has resulted in increased use of such services and a subsequent rise in public spending. There is also a concern that families have transferred assets to render themselves eligible for this benefit, or that the lack of requirements for family financial participation has served as an incentive to institutional placement. Requiring some form of family responsibility is a possible way to reduce nursing home placement and/or to recoup some of the costs from those who require care and have significant financial resources.

There is, however, a second important aspect of family responsibility, namely, the recognition of how much care in the home is being given to long-term care patients by family and friends. The availability of care at home determines, to an extent, the rate and timing of nursing home use. This relationship has been known for some time, but recent studies by the Congressional Budget Office and the General Accounting Office have given public visibility to the importance of home care. The question now raised is to what extent present or proposed HEW policy changes may affect this non-institutionalized group and increase the number of persons dependent on public programs.

Defining the Problem

The issue posed is difficult to analyze in a clear and unambiguous manner. It is loaded with value considerations around which there is great disagreement. Available data that might throw light on the issue are limited and, at times, contradictory. We have treated the issue of family responsibility by raising a series of questions and then examining available data to answer them. We have also identified gaps in information.

We examined the following questions:

1. What is included in the concept of "family responsibility?"
2. To what extent can the rising cost of long-term care services by Medicaid be traceable to increased use of the program?
3. What fraction of that use is a result of able families no longer providing care which they had previously provided?

4. To what extent can public, long-term care costs be reduced or held to a lower rate of growth by
 - a) reducing unnecessary use;
 - b) collecting additional private sums from recipients and/or their families;
 - c) providing incentives for families to care for disabled elders at home?
5. What will be the effect of certain demographic trends on the use of long-term institutional care?
6. What public policy options can minimize increased use of institutional care?

Components of Family Responsibility

The term "family" identifies several concepts, each of which must be examined separately, because law and policy treat them differently.

The term can mean:

1. the aged or disabled individual and his/her spouse, each of whom has certain rights and obligations in relation to the other;
2. a nuclear group consisting of parent(s) and children—in this case, adult children—sharing a common household;
3. parents, with adult children living in separate households (State laws differ in the definition of rights and obligations each has in relation to the others);
4. the spouses of adult children (their obligations to their parents-in-law are less clear than those of natural children);
5. other relatives, related by blood or law, whose obligations to the ill are likely to be moral and affectional rather than legal (this definition of family is excluded from this analysis).

Also excluded from this analysis are households consisting of unrelated individuals who are sometimes considered to constitute an emerging form of family.

The term "responsibility" covers at least three components:

1. financial responsibility, either by sharing living quarters or by cash payments from one member of a family to another, whether living in separate quarters or not;
2. personal attendant or physical help and care in cases of illness, including cleaning, meal preparation, shopping, dressing, transportation, mobility helps, etc.;
3. social and psychological support, through visiting, counseling, encouraging, socializing, etc.

The extent to which family members are responsible for each of these components plays a significant role in sustaining the capacity of the elderly to maintain residual physical and personal independence. This, in turn, determines the extent to which public expenditure is necessary to support alternatives to the family.

"Long-term care" spans medical, paramedical, and social services. The severely disabled and elderly require variable access to medical and acute hospital and nursing care, even when other physical and social aspects of living are attended to. Such acute medical care costs may be borne by individuals or their families. For our purposes, however, acute medical aspects are distinguished from the long term aspects (extended nursing, personal attendant, and social care) delivered in nursing homes, other congregate institutions, or private residences. We considered family and public responsibility only in relation to those non-acute elements. The ways in which such responsibilities are carried out directly affect the volume and total cost of acute hospital and medical care, but this relationship requires separate treatment.

"Disabled individuals" are persons whose physical disabilities make them partly or wholly dependent on the attention of other adults. Such individuals have, over the past 50 years, acquired a measure of entitlement to public aid for the disability, an entitlement attached to them as individuals, regardless of other family relationships. The extent of this individual entitlement varies from State to State, but it is also incorporated in Federal laws and regulations. Thus, attention to family responsibility must distinguish between 1) actions that impose family obligations and reverse individual rights already embedded in law, and 2) actions that rely on inducements to alter family behaviors voluntarily.

Section II

Costs of Care and Family Financial Responsibility

The growth of costs for nursing home care under the old public assistance titles and Medicaid has been dramatic. Costs increased from about \$800 million in 1967 to about \$6.4 billion in 1977 (Table I). The number of residents of nursing homes increased from 630,000 in 1968 to 1,335,000 in 1975. The rate of nursing home use has also changed. In 1964, 14.7 percent of persons over 85 were in nursing homes, while in 1974, 25.3 percent of this population were in nursing homes. The total institutionalized population increased from 4 percent to 5 percent of the

total population over 65 between 1966 and 1977. From 1974 to 1977, Medicaid nursing home costs went from \$3.628 billion to \$6.380 billion, a 76 percent increase.

An increase in the use of nursing homes was expected with the introduction of Medicare and Medicaid in 1965. A major reason for providing nursing home benefits was the significant number of extended stays in acute care hospitals by persons over age 65. There was also a need for such benefits in private homes and apartments, where a nursing home placement, once available, became a more practical choice of care.

It is obvious that expenditures for nursing home care under Medicaid have shown dramatic growth. The factors contributing to this growth are listed below.²

1. A shift of expenditures for care of the mentally ill and mentally retarded from State budgets to the Federal budget

A large fraction of the increase in Federal costs of Medicaid reflects action by the States to transfer patients from mental hospitals, chronic disease hospitals, and schools for the retarded (previously financed mainly by State and local funds) to nursing homes.

2. Inclusion of Intermediate Care Facilities (ICFs) under Medicaid

Inclusions of ICFs under Medicaid in 1972-1973 increased the number of persons (many of whom were already institutionalized) for whom the Federal government was making an institutional care payment.

3. Elimination of provisions for family supplementation of nursing home payments

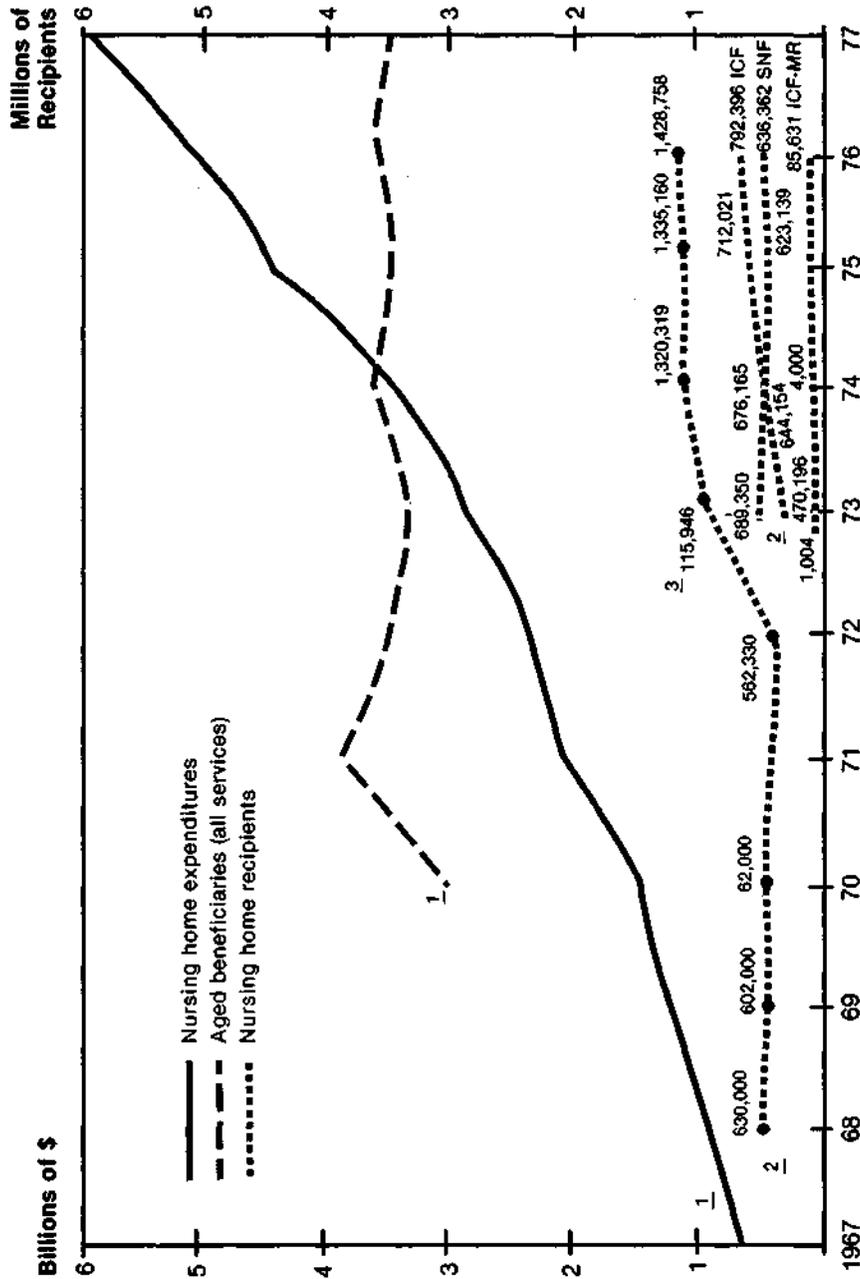
Up until 1971, some States permitted families to pay part of the cost of a member's nursing home care. This practice was prohibited in 1971. As a result, an undetermined amount of family expenditures was shifted to the Federal budget.

4. Certain provisions of Supplemental Security Income (SSI) enacted in 1974

SSI reduces benefits for beneficiaries living with others, creating the situation where a family with a disabled member may be better off economically if that member is placed in a nursing home. The program provides no extra payment for domiciliary care of a mildly disabled person. Rather than supplementing the Federal payment with State funds, some States may place these individuals in ICFs.

² For purposes of space, these factors are listed without the supporting figures. These data are contained in the full report available from HCFA.

TABLE I
Medicaid and Public Assistance Nursing Home Expenditures 1967-1977;
Medicaid Aged Beneficiaries 1970-77; and Recipients 1968-75



¹ Data on the Medicaid Program: Eligibility, Services, Expenditures Fiscal Year 1966-78. The Institute for Medicaid Management, HEW, 1978.

² Numbers of Recipients and Amounts of Payments under Medicaid. Annual Series, HEW.

³ Inclusion of Intermediate Care Facilities.

5. Rising costs of care

The effects of inflation on the medical care sector are well known. Table 1 shows the disproportionate rise in the cost of nursing home care compared to the growth in the number of recipients.

Beginning in the late 1960's, the Federal government began redefining and limiting the Medicare skilled nursing home benefit. As a result, Medicare nursing home expenditures as a percent of all government expenditures for nursing homes dropped from 23.4 percent in 1968 to 5.0 percent in 1977.

The impact of various Federal policy changes and the shifting of funds among Federal, State, local government, and families makes it difficult to determine the impact of Federal policy on family behavior. The contribution of each of the above factors to the increase in Federal expenditures under Medicaid for nursing home care has not been measured. It appears that recent nursing home use is closely related to the growth in the elderly population and that we are witnessing, to a large extent, the effect of cost shifting and cost increases.

The implication of this is that controlling nursing home use by recipients and/or requiring increased family payments will address only part of the problem of nursing home cost. Issues of cost control, cost shifting, and professional practice have a much larger effect.

Family Behavior and Nursing Home Utilization

There are two ways in which public policies requiring family participation can reduce net Federal costs: by collecting additional sums to be applied to the costs of care and by acting as a deterrent to nursing home placement. This section will review both of these options.

1. Collect additional sums from "responsible" relatives

a. *Residents without relatives* constitute at least 20 percent of the total nursing home population. These individuals have already exhausted what resources they may have had and must apply their pensions and social security to the cost of care, except for a small (\$25) personal care allowance. There are no additional sums available from this group.

b. *Spouses* comprise an unpromising source of increased payments. Between 86-88 percent of nursing home residents are unmarried, divorced, or widowed. For the remainder, their spouses, unless also institutionalized, are usually legally responsible relatives. The degree and extent of responsibility, however, vary by State.

In 1976, spouses already contributed a mean average of \$2,025 a year for the cost of nursing home care, although their mean income was only \$7,890 a year. About 35 percent of the spouses have mean incomes above \$7500, and larger contributions from this segment explain the high average contributions reported. Thus, spouses are apparently already making significant payments.

Secondly, it can be assumed that a large share of these contributions is made as part of Medicaid spend-down policies. Once assets are reduced to the Medicaid eligibility level, no significant income is produced. The proportion of spouses who retain large incomes after the institutionalized husband or wife has exhausted his/her resources is probably very small.

The elderly who transfer assets to others to establish public benefit entitlement might be considered a resource. The cost of tracing such transfers beyond one year, however, and the legal reaction certain to be aroused by what might appear to be a heavy-handed interference with intergenerational sharing of wealth, make this an option to pursue only after very careful analysis.³ The President's 1980 budget, for example, proposes restructuring SSI eligibility for persons who dispose of assets in order to qualify for benefits. The outlay reduction as a result of this step is estimated to be only \$6 million in 1980. Where assets are a subject of controversy, savings could not be realized immediately. Care to a sick person cannot be deferred and would need to be provided as controversial cases are adjudicated.

³ Such an analysis, entitled *The Treatment of Assets and Income from Assets in Income Conditioned Government Benefit Programs*, was prepared for the Federal Council on Aging in 1977. It provides a sophisticated review of all the issues connected with how wealth could be treated in a variety of government programs. Because of the interrelationships between programs (e.g., SSI, Medicaid, Housing), the report stated that a revised treatment of assets would not be undertaken solely for institutional services under Medicaid, but rather that a new across-the-board HEW policy should be developed. The Federal Council on Aging document does indicate, however, that a device such as a lien law on property at a certain level may have some benefit—at least from an equity standpoint. The political and organizational costs, measured against the sums potentially retrievable, require more analysis.

c. *Children of aged parents* may be a more significant source of money if public policy makes them legally responsible. Financial payments made by children for institutionalized parents are not high. In 1976, children contributed a mean average of \$160 per resident, and their mean income was \$14,676. Approximately 7-10 percent of all nursing home residents have adult children with incomes over \$20,000. It appears, therefore, that these children have incomes that would permit them to make financial contributions. The price to be paid, however, by a systematic policy of forcing higher than current voluntary payments for nursing home care would have to be weighed. The first obstacle is the need to define "adult child." The stereotype engendered is that of the middle-class couple living in suburbia with three children, two cars, and a home. This is an inaccurate portrayal of the reality. Many nursing home residents are in their late 80's and, for them, adult children are in their 60's—approaching the category of "elderly" themselves. Their income may soon be reduced by movement out of the labor market.

A second problem is that we are not now able to separate out of national data the cases where children with means above the average are not helping institutionalized parents at all. Thirty-seven percent of nursing home residents have their own income or family support as the primary source of payment. What portion of this is from children is not known. The public, however, seems to assume that for public pay patients some proportion of children are ignoring parents, despite the fact that parents are merely using programs to which they are entitled. It is, however, a matter of subjective opinion whether *many* children are abusing entitlements, that is letting public programs pay for institutional care when more appropriate arrangements could have been made. At the maximum, this would arise among approximately 10 percent of residents whose children have incomes above \$20,000.

The "average family" with an income of \$15,000 to \$18,000 or less can hardly do much without seriously reducing its living standards. Some already contribute in cash to nursing homes, and others have taken personal care of their disabled and dependent parents in their own homes before the parents were admitted to an institution.

A third problem area has to do with the capacity of the group earning over \$20,000 to do more than it now does. Its ability is circumscribed by certain conditions: whether the adult child and his or her spouse will agree, how many minor children they still have in school, and so on. The clearest case is that in which both the child and his or her spouse are working and producing joint incomes substantially above the average. But there is also the difficult legal and social issue of how to distribute responsibility among several adult children of different configurations and geographic locations. Such a policy would need to consider all children with above average family incomes. Pursuit of greater financial sharing would entail an organization adequate to follow children wherever they live and to either handle the decisions in case family members do not agree about sharing the necessary burden of payment or to impose a collective share within which family members assign the shares among themselves.

Such dilemmas have in the past been approached by proposing a universal entitlement rather than a selective, means-tested one for certain social problems which the nation considers worthy of public support. Certainly, national policy has continuously wavered between means testing for selectivity and universality as ways to avoid such uncomfortable dilemmas. For the aged, individual entitlement has had much of the character of a universal entitlement. An attempt to enlarge the scope of means testing to include family income of relatives not living in the household can be expected to arouse violent opposition and to be tested in the courts.

Recent court decisions are not encouraging in this respect. The courts seem to be saying that a person's eligibility for services can only be conditioned by income and assets that are *actually* available not by income and assets *presumed* to be available.⁴ This line of thinking would require the government to prove that children's resources were actually available to the elder parent.

⁴ *Gray Panthers v. Secretary of H.E.W.*, U.S. District Court, District of Columbia, Civ 78-0661, Dec. 8, 1978, found that deeming income from a noninstitutionalized spouse to be available to an institutionalized spouse violated the Federal Medicaid statute.

Anna Rowland et al. v. Edward W. Maher, Conn. Supreme Court, Aug. 29, 1978, found that a life care contract was not an asset "actually" available to a recipient.

Family means testing which goes beyond the spouse's income and assets would involve a reversal of the far-reaching policy in which individual and nuclear family income alone is considered for means testing. The historic tendency to encourage adult children to create their independent family lives, to improve the lot of their own children, and to meet the labor force needs of a dynamic economy would be altered. Regardless of the merits of such a change, the political effort and the time required to bring it about would be very great.

2. The deterrent effect of financial responsibility

To what extent might the imposition of financial responsibility act as a deterrent to nursing home placement? There is evidence (Schorr, 1978) that the existence of lien laws acted as a deterrent to the receipt of public assistance.⁵ People preferred to struggle by on less income rather than to mortgage their home to the State. Whether the same effect would result in a situation where a person was moving to a nursing home on a permanent basis is not known. A deterrent effect, however, has a negative side as well. Some elderly persons actually requiring nursing home care might forego it, based on an emotional attachment to their home. One would have to weigh the problem against the presumed deterrence of unnecessary placements.

Nursing home use might not be substantially affected by program policies unless certain classes are actually declared ineligible for service. A recent study of nursing home use (Scanlon, 1978) identified age, climate, and race as the significant predictors of use. Policy variables had little effect. The author argued, however, that excess demand exists for nursing home care and is constrained only by tight supply. Whether these utilization predictors would remain the same under adequate supply conditions is not known.

Summary

A complex set of factors accounts for increased Medicaid nursing home expenditures. Use of nursing homes by the elderly is not increasing rapidly at the present. The contribution of use to the cost of nursing home care is not large, with prices being the most significant factor in rising costs. Expanded asset tests with introduction of legal responsibility for selected children of institutionalized adults are not promising sources of large additional sums of money, but, in the interests of equity, the asset situation should be reexamined. The deterrent effect of devices such as lien laws is presumed but not known in the case of nursing home care.

⁵ Lien refers to a government action attaching certain assets (usually a home) as a condition of receiving public assistance.

The negative consequences of such devices could be substantial.

One cannot assume that the use of nursing homes will not change. There is solid evidence that substantial care is being provided to non-institutionalized elder citizens by their families. There is also solid evidence of changing demographic trends which may reduce the ability of families to continue doing what they are now doing. This issue will be explored in the next section.

Section III

Family Caring Responsibilities and Changing Demographic Trends

The family is an intermediate structure—a "care filter"—through which some individuals are passed to institutions for long term care. What then is the future outlook? Are more vulnerable individuals who need long term care likely to be funneled into institutions? The answer appears to be a function of at least two factors that will be treated here: 1) the overall size of the vulnerable population (as determined by aging, levels of impairment, etc.); and 2) the proportion of that population that will not have families capable of caring for them (as determined by changes in the family such as attitudes, childlessness, divorce, mobility, etc.).

Extent of Current Family Responsibility

Recent national estimates suggest that families are likely to assume the major caring function for most impaired and disabled individuals who require no regular medical attention, and who are living in home settings. The Congressional Budget Office (CBO, 1977) estimates that the current ratio of non-institutionalized personal care services to institutional services is approximately one-and-a-half to one (2.5 million noninstitutionalized persons served compared with 1.7 million institutionalized).

The recent report of the Long Term Care Task Force (USDHEW, 1978) suggests that the number of individuals receiving long-term care services at home may actually be greater than the CBO estimate—some 3.6 to 7.8 million individuals may be receiving services from family and friends or may be in need of such services but are actually making do on their own. Since the categories of the two reports are non-comparable and speculative, it is hard to establish a firm estimate. It is fair to conclude, however, that between 60 and 85 percent of all disabled or impaired persons are helped by the family in a significant way.

The family's principal role in long-term care is through direct provision of services rather than financial contributions. Such service is more likely when relatives live close by the needy person. Only about 10 percent of elderly persons presently live with their children, but a number of studies (Townsend, 1957; Shanas *et. al.*, 1968; Mahoney, 1977) have documented the high percentage of elderly parents who live close to their children. Approximately 75 percent of all elderly parents have at least one child within a half hour drive. Mahoney, in a re-analysis of Harris Poll data collected in 1974, found that 80 percent of elderly respondents reported face-to-face contact with their children within the previous week or two.

In a study of 1,552 New York inner city elderly, Cantor and Johnson (1978) found that of 224 respondents who were sick for a week or less, 60 percent were cared for by family members, 12 percent by friends and neighbors, 4 percent by formal organizations or others, and 28 percent by no one. For those who had an illness of one to two weeks duration, 70 percent reported care by family members, 15 percent by friends and neighbors, 3 percent by a formal organization, and 16 percent by no one.

In his review of current beliefs and practices involving filial responsibility, Schorr (1978) notes the generally positive tone of filial relations for so many people. They want to be close enough to visit each other frequently, and they recognize that old people living with their children have something to contribute—child care, household work, etc.—as well as something to gain. Only when the old person reaches a point where care involves a high level of inconvenience and hardship does the family begin to consider institutionalization as a possible alternative (Teresi *et al.*, 1978).

Projected Size and Needs of the Elderly Population

Projections for the size of the elderly population 20 to 40 years from now show some variation. Estimates for the year 2000 vary from a low of 11.9 percent of the total population to a high of 16 percent, based upon different assumptions about birthrates and longevity. The over-75 population will grow significantly. Regardless of which projection is most accurate, this country will have to deal with many more elderly and disabled elderly citizens.

How healthy will these older people be? Neugarten (1975) suggests that, with continuing improvements in life expectancy, older people's health in the year 2000 will begin to fall *later* in life than is presently true for people of comparable age. However, the less optimistic side of this picture is that, as more people reach a very advanced age (75 or 80±), more of them will

need assistance with personal care. Present rates of institutionalization are strongly associated with advanced age. Among all persons over 65 in 1973, between 30 and 40 percent were limited in major activity due to chronic conditions (U.S. Department of Commerce, 1977) and, of the total population over 65, about 5 percent—or nearly 1 million—were in institutions, with a high probability that at least that many required substantial care in the home (Maddox, 1975). The potential demand for long-term care among those over 65 has been estimated to be as low as 2.8 million, or as high as 4.1 million in 1985 (CBO, 1977: Table 3).

Part of the interest in these figures is in what they suggest about the absolute growth which will be required in long term facilities. If one takes the conservative estimate of 26 million people over 65 in the year 2000 and assumes that 5 percent of them will need to be institutionalized, a total of some 1.3 million long-term beds will be needed, not much of an increase over present capacity. However, if there are 35 million older people, a minimum of approximately 1.8 million beds would be needed, an increase of more than 50 percent over present capacity. *The 1976 Survey of Institutionalized Persons* found 1.2 million persons in nursing homes (U.S. Department of Commerce, 1978). Even though disagreement exists on the potential number of disabled adults, there is no question that the nation must plan for a significant increase in this group.

Size of the population needing care, however, is only one of the factors to be assessed. Another crucial factor is the availability and willingness of family members to provide alternatives to institutionalization.

Changing Family Characteristics and Capacity

While the changing age structure and life expectancy of the population have increased the number of vulnerable people who need long-term care, changes have also occurred in the structure of the family that may make the family less able to assure care or support to those members who need it. The proliferation of new family forms, coupled with an increase in divorce, decline in household size, and growth of single-parent families, raises the question of whether the nuclear family can even give personal care to those members who need it. One outcome of the increased participation in the labor force has been to raise the price of family members caring for the homebound. Potential income foregone is a real opportunity cost becoming more visible to those who must remain at home.

Earlier studies from the 1960's by Shanas and others have suggested that families of old peo-

ple provide an enormous amount of daily personal care (Shanas, 1971; Shanas *et al.*, 1968). But a recent family vignette in an historical study of Manchester, N. H. shows the old mother of one of these large families finally consigned to the care of social services such as Meals-on-Wheels (Hareven and Langenbach, 1978). More evidence is needed to chart in which direction the historical trend is headed, but it appears to be toward more reliance on community-based provision of care.

Current changes in the family, such as the recent rise in the divorce rate and the growth of single-parent families, are relevant to the family's future capacity to give long-term care to a member who may need it. The effect of these changes is presumed to be significant. At this point, however, one must speculate rather than give specific estimates. Five variables on which there is some information are considered here:

1. General trends in contemporary family structure
2. Age-related family situations and living arrangements
3. Changing longevity and life cycle of women and men
4. Impact of urbanization and mobility
5. Income in contemporary family structure.

1. Trends in contemporary family structure

Among significant changes in the contemporary family is the proliferation of varying family forms. During the 1960's, an eight-fold increase occurred in the number of couples living together without marriage (Glick, 1975). Of all families, the traditional type with husband in the work force and wife and children at home now accounts for only 15 percent. More husband-wife families (41 percent) have wives in the labor force than those who do not (34 percent), and roughly 15 percent of all families are headed by a man or woman alone (Hayghe, 1976).

Another important change relates to family size. Between 1950 and 1970, the average size of a family ranged between 3.5 members and 3.7 members. But a decline in family size is projected for the future, beginning with an average size of 3.4 persons in 1975 and reaching 3.0 to 3.1 by 1990. The projected change is due primarily to a drop in the average number of children in each family (U.S. Department of Commerce, 1977).

These changes in family form and size seem particularly relevant to questions about what is the *capacity* of a particular family constellation to give support either through financial help or personal care. Presumably, a family in which both husband and wife are employed will have different capacities for giving economic support or personal services than a single-parent family.

Similarly, families with no children, or only one, will have different resources in money or time than those with several children.

Family change is also relevant to another question: What is the likely *commitment* (in the sense of motivation or desire) of a particular family to provide care for an older relative? Here, evidence that bears on the quality of family relationships is relevant. If there has been a divorce and remarriage in the family, this presumably will color children's or other relative's commitments to care for a particular family member. Similarly, a small number of children, or absence of children, will affect the older person's chances of being considered a responsibility by family members of the younger generation.

Evidence on the demographic changes surrounding the family suggest that these issues of commitment are likely to become ambiguous in the future. With a divorce rate that doubled between 1955 and 1975 (from 2.3 per 1,000 population to 4.6), there are many more divorced persons in the population. In 1950, for example, there were 37 divorced women per 1000 in the population, compared to 77 in 1975 (U.S. Department of Commerce, 1977). The number of children under 18 living with both parents dropped from 89 percent in 1960 to 81 percent in 1975.

The ambiguity of the family's responsibility for older members is perhaps best summed up by a question used by the National Opinion Research Center in its 1973 and 1975 polls that asked whether it was a good thing for older persons to share a home with their grown children. In both years, 31 percent said it was a good idea. But between 1973 and 1975, the number who said it was a bad idea declined (from 58 to 54 percent) and the proportion who said "it depends" rose almost by half (from 11 to 15 percent, U.S. Department of Commerce, 1977). A recent study by Sussman (1979) reported that close to 80 percent of adult couples would care for an older person in their home.

2. Age-related family arrangements

The single most striking change in living arrangements of the elderly over the past 25 years has been in the proportion living alone. This is particularly true for women. Between 1950 and 1975, the number of men over 65 living alone held steady at 17 percent. But the number of women in this age group living alone rose from 24 percent in 1950 to 41 percent in 1975 (U.S. Department of Commerce, 1977). This reflects the increased economic independence of the elderly brought about by social security, SSI, and improved pension benefits.

Table 2 presents the distribution of older persons living in families when the older age group is broken down by those between 65 and 74 and those over 75 (Bane, 1976).

Table 2

Percent of Old Persons Living in Families, 1970

	Males	Females
65-74	82%	64%
75 ±	71%	51%

Table 3, in which the single and widowed are overrepresented, describes how family status is associated with living in a home for the aged.

Table 3

Percentages of Old People Living in Homes for the Aged or Other Institutions. 1970 (Bane, 1976: 46)

	Male	Female
Age 65-74: All marital statuses	2	2
Married	1	1
Widowed	5	3
Single	11	6
Age 75 ±: All marital statuses	7	11
Married	3	4
Widowed	12	12
Single	17	17

How do children affect the picture? Bane (1976) notes that almost a quarter of old people in the 1970s had no children to take them in. For those who do have children, the numbers surviving to women of various ages will actually improve between now and the year 2000. Neugarten (1975) estimates that women who are 75 in 2000-2004 will have an average of 2.65 surviving children, and those 85 years old will have 2.00 surviving children. At that time, there will also be more four-generation families, where grandparents who are themselves old have parents who are still alive.

3. Changing life cycles of women

Changing life patterns of women constitute a critical sub-set of conditions resulting from increased life expectancy and changing family forms. Women are heavily overrepresented among those elderly who need long-term care. At the same time, it is women who probably give most personal care either informally as family members or professionally as the paid personnel in home care agencies. There has been a remarkable change in women's life expectancy and an increase in their "child-free" years (now 29.6).³

³ Child-free years are calculated by subtracting median age of women at school entry of last child from the median age at death of first spouse to die.

Of particular significance for family responsibility in long-term care is the question of how women's thirty "child-free" years will be spent. The trend is toward women's increased participation in the labor force. This raises the question of whether they will be in a role allowing them time and opportunity to give much personal care to an older family member who needs it. Moroney (1976) shows that even without considering women's rising employment, the "caretaker pool" has greatly declined since the beginning of the century. Using figures from the United Kingdom on percent of total elderly in the population and the percent of women 45 to 59, he shows that the caretaker ratio (number of middle-aged women per thousand elderly) has shrunk from 830 to 490. A similar phenomenon may have occurred in the United States. If we add the fact that roughly half of these middle-aged women were employed in 1971 as compared with less than 10 percent in 1920, the drop may be more drastic.

Nor have we yet seen the completion of these trends. American women's life expectancy at birth increased by two years between 1950 and 1970, and their participation in the labor force is expected to rise by another five percentage points by 1990. The number of employed women ages 45-74 is expected to rise from 55 percent in the labor force in 1975 to 60 percent in 1990 (U.S. Department of Labor, 1977).

While a continuing decrease in the family caretaker pool seems inevitable, three countervailing trends could mitigate this change. One is a slight downward trend in men's participation in the labor force that could make more men available for home care tasks. Overall, men's participation fell from 86 percent in 1950 to 78 percent in 1975. This decline is expected to continue, particularly among men ages 55 to 64 (U.S. Department of Labor, 1977).

A second factor is that the great increase in child-free years for women may make certain women, who previously would have had child care responsibility, available for care of an older person in the home, since one can't assume that all women will seek and obtain outside employment.

Another possible ameliorating trend is that employment in paid home care services may gain in numbers and importance. Such a development could have the advantage of giving pay and recognition to persons ready and able to give service in such a field. Theoretically, growth of paid home help and home chore services could also promote greater flexibility and choice on the part of younger people able to pay, but not able to provide their own time, for care of older family members. Such services might also promote retention of a greater measure of autonomy for the older person who

is being served. At the moment, however, practical problems concerned with home care hamper realization of this ideal. Its career ladders, professional prestige, and ultimate usefulness are being questioned and, until the problems are ironed out, it is unclear whether home care occupations offer a real opportunity or merely a dead-end.

4. Urbanization and mobility

How important are mobility and proximity of family members to the care of elders? There appears to be no simple answer to this question. In a re-analysis of data from a 1974 Harris Poll which asked elderly people how much help they needed and how much they received from relatives, Mahoney (1977) found that rural and suburban elderly were best situated, whereas the urban and small town elderly were more likely to need help that was not provided by family members.

To the popular mind, there appears to be an increase in mobility among Americans; yet the numbers of movers and migrants have held fairly steady for the last 30 years among all age groups. Slightly over 3 percent of the population moves between different States every year; about the same number moves between different counties within the same State; and 12 percent moves within the same county (U.S. Dept. of Commerce, 1977). The problematic element in all this is not so much in the amount of moving as in the effects of the move. As life spans increase, middle-aged movers will inevitably leave more surviving family members behind.

With urbanization and the construction of retirement villages, age-segregated housing, and other spatial arrangements for the aged, one sees the development of other mechanisms than family proximity for concentrating services and care. Golant (1975), in describing trends in the distribution of the elderly, shows that the number living in urbanized areas has grown from 44 percent in 1950 to 55 percent in 1970. This reflects both mobility of the elderly and the expansion of areas defined as urban. He expects the trend in metropolization to continue, with older persons concentrated at particular nodes such as age-segregated housing projects dispersed throughout the metropolitan region. Such an arrangement may give the elderly greater access to needed supports such as transportation, medical, and social services. At the same time, it makes them accessible to relatives located in other parts of the metropolitan area. Coupled with these trends are technological advances in transportation and electronic communications likely to reduce the impact of distance on interpersonal ties.

These observations on spatial location of the elderly merely scratch the surface in understanding the relation between mobility, proximity, the closeness of family ties, and the family's commitment and ability to care for the older person. More needs to be learned about the prevalence of kin networks, who is included, and what kinds of services they perform. To this should be added questions about how mobility affects the network. Can the telephone and other technological advances (e.g., air travel) make up for loss of proximity? Can non-kin (neighbors, friends, volunteer networks) substitute for family members in giving long-term care? Until some answers to these questions are known, the effect of current patterns of mobility and urban living on family responsibility in the care of the elderly will remain unclear.

5. Variations among families by income and race

In addition to questions of family composition, the changing roles of men and women, and rural-urban differences, there are major class and race differences both in the need for care and in the capacity of the family to give such care.

Disability rates suggest that needs of older persons differ by family income and race. Among persons 65 years and over with an income under \$3,000, 45 percent were limited in major activity due to chronic conditions, compared with 30 percent of those who had an income of \$15,000 or more.

Data on next-of-kin suggest class and race differences in family capacity to provide care. Moroney (1976) summarizes the research of the last two decades that shows class differences in the kind of care that families provide:

Lower income groups provide physical care, household help, child-minding and recreation, while middle-income groups tend to help financially.

Stack (1974) documents the rich helping networks that exist among poor black people. Comparable studies are needed among whites and the middle class.

In sum, with respect to variation among families by class, race, or sub-cultural difference (such as region or ethnicity), it appears that every other major factor—needs of the aged, changing family forms, roles and resources, family networks and proximity—must be considered to see how a particular subgroup is most likely to define family responsibility.

Differences in the nature and extent of family financial responsibility and caring point up the potential variability in family capacity to give

care. Such capacity is contingent on the *balance* between patient need and family resources. It is, therefore, crucial to identify both the general social forces and specific policy initiatives that will sustain that balance.

Factors that have not been discussed above are inflation, energy, and housing. We do not know what impact these may have on long term care. On the one hand, inflation could make services prohibitively expensive. On the other hand, the housing and energy crunches may force families to double up, thus resulting in more caretakers being available. The impact of these factors on family life needs further study.

Section IV

Potential Policies for Limiting Institutional Care Under Changing Demographic Conditions

The previous section suggests that the ability of families to continue their present efforts on behalf of the elderly and disabled may decrease in the future. One cannot, however, predict such a change with absolute certainty. While we know that more middle-aged women are entering the labor force, we do not know if these are the same people who now care for a disabled adult. Neither do we know to what extent people *leave* the labor force to care for disabled adults. It is wise, however, to develop policies that will reinforce or give incentives to families so that choices other than institutional care will be available to disabled adults and their families.

A recent study gives some insight into how incentives might encourage families to care for older persons (Sussman, 1979). Sussman concludes that demographic variables, such as age, sex, race, etc., have less to do with willingness of families to care for the elderly than situational variables. Families are more willing under certain conditions: if they have the physical space, if they have not had a previous negative experience caring for an elder, if spouse or children do not object, and if some outside help may be available. Demographic variables cannot be modified by public policy, but public policy can create programs that modify family situations and therefore increase both family capacity and willingness to care for older adults. For example, if adequate space is a requirement, a program to fund "granny units" as annexes to homes may be feasible. If housing alternatives are required, congregate housing units can be constructed. If the availability of outside help is important, it can be provided. Sussman's study

showed that the most desired benefit was an additional monthly check to help pay for the care of the elder. These findings offer some encouragement that the future of long-term care can be influenced by public policy.

Reducing Incentives for Institutionalization

Inducements to institutional care might be limited by using an approach in which funds for nursing home care can be used for non-institutional care if the latter cost is not over some fixed percent (e.g., 75 percent) of the former. These funds could be applied to divert pending institutional admissions. New ways to administer such a program could increase the rate of sharing so that public expenditure could be further reduced.

The first step in such a program would be to identify persons at imminent risk of institutional admission. There must be caution not to widen too broadly the use of funds for home care purposes other than those related to cost control. Otherwise costs will increase, and the intent of the program will be vitiated. Controls should be applied to both eligibility and use.

Synchronization of Home Care Services

Current efforts to control nursing home use can be efficient if fine-tuned and closely correlated with expansion of home care services. Eligibility for certain home care supplements could be more closely synchronized with nursing home eligibility. The lack of synchronization makes it difficult or impossible to use home care as a substitute in those cases where institutional care is less necessary on medical grounds. This is especially important when disposition decisions are made in a crisis, as in the case of discharge from a hospital or the illness of a caretaking relative.

Similarly, public financing for home care services could be given the same safeguards which surround nursing home reimbursement, thus encouraging expansion and stability of non-institutional alternatives. Nursing home rate-setting formulas provide a built-in allowance for capital or start-up cost, protection against staff "down" time, and cost-of-living inflation increases.

There is also lacking (except in a few demonstration areas) application of methods to assure that low intensity services *substitute* for high intensity ones rather than developing an add-on cost. Steps can be taken to increase the likelihood of substituting among service options rather than pyramiding their growth. For example, a home-delivered meal may substitute in some cases for a homemaker. The possibility of no reduction in aggregate institutional expenditures while alternative costs grow can be

avoided by stricter pre-admission screening linked to public reimbursement commitments. The difficulties inherent in developing this linkage are real but may be less difficult than other possible options.

Any effort to concentrate institutional care on the most needy and seriously disabled cases will increase the per diem cost of institutional care, but for a smaller population. It is a reasonable hypothesis that the net cost for a smaller population in institutions, when added to the costs of home care substitutes, will still be less than attempting to meet the needs of an aging population through growth in institutional care. When these efforts are taken along with incentives for increased family help, their effects may be substantial.

Providing Incentives for Family Care

A minimum incentive for families would be public recognition that families who elect to care for their relatives need periodic respite from what is often a taxing physical burden. An increase in the existing number of day hospitals or day centers for the disabled would bring additional respite to many families who now provide care without help. Such centers can be used for a few days, at periodic intervals, to relieve families; they can also be used daily if all responsible related adults are employed. Payment for such respite care can either be subsidized, or shared on a sliding scale geared to income.

According to one study (Eggert, 1976), family ability or willingness to continue home care drops by one-half after a second hospitalization of the disabled elder. Any effort to reduce this attrition of family willingness would be useful in slowing down institution rates.

As in the case of other incentives, an assessment mechanism is necessary to encourage families to use respite help rather than resorting to more extreme and costly actions.

Possible Mechanisms for Sharing Responsibility

Some variation of coinsurance or deductible concepts might be applied to long term care programs. The raw evidence is available to set thresholds for family obligations (of spouse and/or adult children). Such "coinsurance" or threshold—perhaps a point system—can take into account these elements of sharing: the professionally assessed amount of hours of personal or attendant care a disabled person needs, the severity of the condition, and a fair measure of the hours that a family member can reasonably and fairly be expected to give for care of an aged parent. This expected family care can be constructed from information about

the amounts of time families now give, plus the length of time such care is continued. Further work will be necessary to refine this concept of "fairness."

If the care determined to be necessary by professional personnel exceeds the fair threshold measure, then access is given either to an institution or to home care supplements. The decision between the two would be determined by which form of care best meets the needs of the individual.

Some variation of cost sharing seems especially promising for several reasons. It represents to the very large number of relatives now caring for persons outside of institutions a sign that their efforts are recognized and will be aided, without their succumbing to current incentives to institutionalize. Their sense of being ignored and unappreciated would be diminished. A tendency to turn to the only available escape—a nursing home—could then be restrained.

An appropriate incentive mechanism would need to appeal to two-worker families to balance their efforts in providing attendant care with their own labor (i.e., by reducing work) and in paying for agency attendant care, and still retain the incentive to continue working. This incentive would have to leave working families with the conviction that their labor is worth continuing *and* that others who exert themselves less are not being helped more by public programs.

Tax Credits

The potential for more suitable income tax credits or tax deductions should be explored. It is estimated that the 20 percent tax credit for dependent care (IRS, 1976) came to \$458 million, with about 10 percent attributed to disabled dependents and spouses. It would be worth studying legislative language and tax alternatives to identify the home care of severely disabled dependents. At the same time, an incentive for relatives to sustain or to increase the amount of care at home enough to retard transfer to institutions and to restrain Federal nursing home financing could be provided.

States as a Resource

It is also possible to reduce the growth of Federal expenditure by acting on the fact that a significant part of the growth is due to a transfer of State and local costs to Federal programs—i.e., the mental hospital, chronic hospital, and boarding home cases. Reversing the trend would require a policy of simultaneously restricting Federal payments for institutional

care and transferring in-home care costs and program development to the States. The major defect with this approach is that it places on the States the *burden of dealing* with the most explosive and, ultimately, the most costly aspect of the problem. Over time, the combination of increasing proportions of aged persons without children, the increase in female employment in two-worker families, and rising inflation will place great strains on family as well as on State capacity.

If, on the other hand, national health insurance is enacted and lifts the States' share of Medicaid costs, such sums could be used by the States to finance the home care options discussed above. Escalating nursing home costs and use could then be restrained without Federal expense or large, new tax burdens on the States. It would be necessary to examine variations of "maintenance of effort" techniques

to assure that State actions are of the kind which target on populations most likely to enter institutions. Certainly any new Federal initiatives in long-term care should be analyzed as to the expected behavior of States to reduce their costs.

Modifying Existing Programs

A wide range of modifications to Medicare, Medicaid, and Title XX have been suggested, both within the Executive branch and before Congress. None has been systematically reviewed from the perspective of family responsibility issues. Technical Note A considers these programs and identifies the family responsibility issues connected with them. Any modification of these programs should be undertaken only after consideration of their potential impact on each other.

Technical Note A

Major Long-Term Care Programs and Family Responsibility

Legal Traditions Affecting Government Policies on Family Responsibility

Government programs and policies affecting family responsibility for long-term care have a long history of development through both poor law and common law traditions. Poor laws, as they evolved in Colonial America, provided guidance regarding responsibility for indigent family members and established hierarchical lines of responsibility. These included not only nuclear family members, but the wider family network as well. State common laws during the past century have evolved in a different direction, focusing on obligatory assistance for the poor and indigent as well as on assistance to institutionalized family members. Several States established family expense acts which assigned responsibility for husband to spouse, husband and spouse to children, spouses to each other, and needy parents to adult children. Unlike previous poor law traditions, however, definitions of responsibility have rested primarily with the nuclear family and not the extended family, though some States even identify specific responsibility of extended family members.

These common law traditions and statutes have been greatly modified, through the development of government entitlement programs. Beginning with the passage of the Social Security

Act in the 1930's, government policies have systematically expanded entitlements through the Old Age Assistance Program, Aid to the Blind and Permanently Disabled, Medicare, Medicaid and OASDI. Simultaneous expansion of supportive programs such as Title XX, the Older Americans Act, has also occurred. The later programs developed to fill needs left uncovered through the income and service entitlement programs for vulnerable populations listed above.

Government entitlement programs have developed based on a philosophy of complete public assumption of responsibility. Operationally, these guiding principles have eliminated many State statutes on family financial responsibility. Several States, however, maintain policies of shared family responsibility through Medicaid or SSI deeming of spouse's income (an issue now being settled in the courts and through new HEW regulations). Some States impose legal responsibility for co-payments for special long-term care services, such as those to institutionalized mentally disturbed or developmentally disabled children.

This Technical Note reviews major government programs and policies affecting family responsibility in light of the dual traditions and precedent of State statutes and Federal program regulations and guidelines. Specifically, it

presents an analysis of major entitlement, public assistance, and categorical grant programs as they affect responsibility in long-term care.

Though no one government program is intended primarily as the single long-term care program, the cumulative effects of differing eligibility criteria, scope and type of benefits, resource intensity, and care provider pool under existing programs have major impact upon access to long-term care services and family responsibility capacities and options for caring and financial support.

A major concern of government policymakers regarding interventions in the long term-care arena is that unintended consequences of these many disparate programs may have created an intricate web of eligibility requirements, scope of benefits, and income maintenance formulae facilitating institutionalization rather than in-home care. This assumption is analyzed here, along with the frequently contradictory operational goals of selected government programs. This section is intended to review evidence of program impact of families' financial and caring behavior around long-term care patients.

Medicare

The Medicare program is the most universal of all Federal health programs for the elderly, servicing essentially the entire elderly population. The funds provided under Medicare, however, are spent largely on acute hospital care and physicians' services, not long-term care. Of the \$20 billion budgeted for the program in FY 1977, slightly less than \$400 million was spent on nursing home services and approximately \$.5 billion on home health care services (HEW Task Force, 1978).

The immediate impact of the Medicare program on the question of family responsibility relates directly to restrictions placed on both skilled nursing and home health care services. Medicare is currently the largest government purchaser of home health care services, yet the operational definition of home health care vendors and home health care benefits is more restrictive than for the other government programs which purchase these services [Medicaid, Title XX, Title III (OAA), and the VA program]. The Medicare definitions of home health and home health entitlements limit these services to approximately 12 to 15 percent of the total needy population (based on the CBO estimates). Within this target group, the number of home health visits is limited to no more than two per week on the average. All of the related personal care needs of those receiving home health care services must be provided through other resources, with families as a prime resource for this task.

Medicare's restrictions on the number of days per year in skilled nursing facilities, and the corresponding incremental build-up of copayment after an initial twenty-day period, can quickly drain individual and family resources, facilitating spend-down to Medicaid eligibility. These restrictions are primarily responsible for the increasing long-term care burden shouldered by the Medicaid program, and the large residual private pay portion of the long-term care bill born by middle and upper middle income families.

Medicare, being the lone Federal health insurance program with a universal entitlement for those over 65, is of relatively little benefit for those elderly with comprehensive long term care needs. It remains for families or for other government service and income benefit programs to fill the wide gap of residual need.

Medicaid

The Medicaid program is the largest single government provider of long-term care services (approximately 77 percent, \$8 billion yearly). It is also the most limited purchaser among major government programs of home health and personal care services (\$200 million nationally, 2 percent of the Medicaid budget), and the majority of these expenditures (80 percent) are in New York State (HCFA, 1978). Medicaid's role as the prime government purchaser of nursing home services is thus analogous to Medicare's role in the purchase of hospital services.

Although Federal regulations for home health benefits under Medicaid are more liberal than under Medicare, States have significant leeway in implementing these benefits. Though no Federal limit is placed on the number of annual visits, many States have established their own limits. A further item of particular relevance is the State option to cover or not cover certain nursing care and related home health care services; many States do not provide such coverage. Medicaid reimburses home health aide visits and also may reimburse personal care assistance in the home rendered by agencies or self-employed individuals (only nine State Medicaid plans currently provide for in-home personal care reimbursement).

The national Medicaid expenditure and services utilization figures suggest several issues affecting family responsibility. First, State eligibility requirements and service restrictions place many marginally poor elderly beyond the scope of needed services. Second, Medicaid reimburses all institutional costs for eligibles. This not only favors institutional settings, but discourages shared family financial supports. (Efforts are underway, however, to recoup portions of these costs through new consolidated

SSI-Medicaid deeming guidelines and State programs to collect fixed percentages of family income on a sliding scale basis.) Third, there is some evidence that selected nursing home operators discriminate against Medicaid placements, causing lengthy delays and burdens on individuals and family members. Finally, the insignificant Medicaid expenditures directed toward home health and personal care services place the government support burden on the limited categorical grant monies available through Title III, OAA, and Title XX to meet the large volume of unmet need.

Title XX

The Title XX program, though only a few years old, has quickly become the major government provider of a variety of social and personal support services facilitating economic and functional independence of vulnerable populations. Though closed-ended at \$2.5 billion nationally, Title XX provides 15 percent of its funds for in-home services to the elderly and disabled at an annual cost of just under \$400 million. (It is estimated that the 1.6 million elderly and disabled are serviced through the Title XX program [OHDS, 1976].) The primary services provided are homemaker, chore, transportation, day care, and counseling services. Their scope varies greatly from State to State.

Unlike Medicare and Medicaid, vendor requirements, reimbursements, and scope of service benefits are left entirely to the State's discretion under Title XX. States must make SSI recipients eligible for Title XX services; beyond this requirement, eligibility is left to them. Many marginally poor elderly are thus likely to remain outside the scope of the Title XX delivery network, a coverage problem similar to that noted in Medicaid and SSI. There is also evidence that many of the elderly who are eligible for Title XX services are not now receiving them. This may reflect the stigma attached to the program (through its means test) and the resource limitations matched against the broad scope of needs and target groups.

A recent survey of State and territorial Title XX programs compiled by the Office of Human Development Services found that 29 programs make specific provisions for selected in-home attendant care services for eligible disabled or impaired children or elderly (OHDS, 1975, 1976). In nine programs, such services could be provided by distant relatives or friends. In four, only agency providers could be used. In four others, services were restricted to care of the mentally retarded, severely disabled, or the physically abused. In the remaining eight, families could provide a range of homemaker, chore, and related home management and personal care assistance tasks, although in a few of these pro-

grams, proof of economic need by such families was required. The bulk of the attendant care service is centered in eight of the large States (principally New York and California), and there is information regarding the volume of services provided and corresponding costs incurred. There is no information yet on the particular effects on quality, continuity, or volume of family care provided in these differing contexts (Technical Note B).

Social Services Under Title III of the Older Americans Act

The Older Americans Act, as amended in 1973, provides a network of area-wide agencies on aging under Title III. In 1978, these agencies were funded at an annual level of \$450 million. Their purpose is to coordinate, fund, and advocate for a wide variety of social and personal care services aimed at the near-poor elderly over 60. This population might otherwise go unattended due either to ineligibility for the other insurance and entitlement programs noted or failure of these programs to cover needed services. Access and in-home services are two of the priorities mandated. The minority and isolated elderly are the prime target groups for these services.

Operationally, Title III funds are used for a number of purposes. Chief among these are information and referral services, transportation, advocacy, legal aid, protective services, case management, and counseling. Title III is frequently used to supplement direct services provided through Title XX, Medicaid, and other public programs. Though an increasing proportion of funds is targeted at services such as home health and related in-home services, the funds are insufficient. Additionally, the mission of Title III is too broadly defined to be of significant relief on a national scale to families and individuals in home settings who are not assisted through other public programs.

Income Maintenance Programs

SSI

The major Federal income maintenance program supporting those elderly in need of long term care is the Supplementary Security Income program. It should be noted, however, that SSI is intended to provide sufficient resources for food, shelter, and related living expenses only. It is not intended to provide resources for the long term care required for survival in home settings. Since SSI recipients receive resources for food and shelter, the financial burden carried by caretakers is lightened. This savings may then be applied to long-term care needs, if family income is at a sufficient level.

Several concerns are raised in reviewing the implementation of SSI. Morrison (1978) found that only a small percentage of institutionalized elderly (8 percent) are receiving SSI payments, since most are covered by Medicaid. These individuals receive a \$25 monthly personal allowance. A relatively small percentage of elderly who are eligible have in fact applied for SSI, perhaps due to the stigma of its being seen as a welfare payments program. The one-third reduction in benefits for those living in the household of others may discourage direct caring by family and friends and, instead, result in institutional placements. A related problem has been deeming procedures of certain States to spouses of institutionalized elderly.

The SSI program, through the regulations noted here, has had mixed impact upon family responsibility. This has been recognized, and possible reforms are under discussion.

Disability Payments Program (OASDI)

The other major Federal income maintenance program is the disability payments program of the Social Security Administration. The cost of this program has been rising dramatically in recent years, though it now seems to be levelling off. Last year, more than \$18 billion was expended at a per capita cost of \$3,000. The median age of those covered is rising as well. It is now at 55 years and still gradually increasing. The number of those covered by the programs, both in general and among the elderly, falls well below the national estimates of the functionally disabled (CBO, 1977).

Beyond the limited scope of eligibles covered by the program is the question of scope of benefits. What is provided could be considered an early retirement income, i.e., amount sufficient to provide for basic living costs only. Additional costs related to health and personal care needs must be provided through individual or family resources or through other government entitlement programs if eligibility criteria are met. As with SSI, the disability payments program as it now stands does not provide for long term care for the disabled. These needs must be met primarily with the assistance of family and friends, unless the total income level meets State Medicaid or Title XX eligibility criteria.

Effects of Income Programs on Family Financial Responsibility

The longer-term effects of income programs such as SSI are more difficult to trace. They may also be more positive in reinforcing family caring than shorter-term analysis would suggest. Thus, SSI and OASDI may explain the extensive amount of family caring for sick, elderly relatives which persists in spite of social trends which seem to work against it. It is possible (although not proven) that such programs relieve adult children with their own families of shouldering total financial responsibility for their parents. They are therefore free to give other kinds of help in case of illness or disability. If supported by more extended analysis, this would suggest the advantages of income-type public programs in dealing with long term needs.

The Veterans Administration (VA) Program: A Special Case

Of all Federal programs affecting long-term care, the comprehensive network of services offered by the Veterans Administration should be singled out as the one special case of a coordinate, integrated program combining income supplements with an expanding network of health care services through the same source. The VA operates a series of long-term care facilities, home health care programs, and reimbursed family attendant care in addition to its national network of hospitals. Several thousand disabled veterans, a few thousand of whom are elderly, are serviced through these long-term care efforts. The VA also conducts an ongoing research program on the care needs of the aged in the services network and the effects of income maintenance and service entitlements on long term-care.

The rapid growth of the VA home health care network will be likely to add moderate numbers of families to the home caretaker pool in coming years. Inadequate attention has been given to the extensive VA long term care experience as a targeted, comprehensive, balanced approach to long-term care services. For long-term care and facilitation of family responsibility, the VA program is a model which should be studied further.

Technical Note B

The California Experience with Personal Care Allowances

California is the one State with a long history and considerable documentation of family-based attendant care. State reimbursements for such services go back to 1958 under the old categorical grant programs for the elderly, blind, and disabled. During the past five years, family members have become the major State provider of Title XX homemaker, home management, and chore services. In some counties, nearly 70 percent of these services are delivered by family members; Statewide, the numbers of family members providing attendant care numbers in the tens of thousands at an annual cost of tens of millions of dollars (Ricker-Smith, 1978).

California operates a county-based network of social services under Title XX through county welfare offices. Qualified families are then entitled to flat monthly sums (\$400 to purchase homemaker and chore services for the mildly impaired, \$600 to purchase all required attendant and medical support care for the severely disabled). The individual recipients then are free to use the allowance to purchase whatever mix and level of support services are desired from either family and friends, outside agency providers, or self-employed outside individuals. It is noteworthy that 65 to 70 percent of those requiring chore and homemaker services purchase those services from family members.

The advantages of the California system are the comparatively high level of monthly allowance and the potential for real individual choice of provider mix. The disadvantages, however, are numerous; in fact, the potential for abuse is readily apparent and real in the system.

Evidence has been presented to the State Attorney General's office of overcharging, family abuse of funds, inconsistent definition of the nature and standards for services to be provided, lack of systematic quality control mechanisms, and lack of proper bidding for services available to community agency providers. Currently, legislation is pending to drastically overhaul this system in favor of a voucher system which would favor control by local providers with family members providing attendant care but linked to a provider network.

A fundamental issue raised by the California homemaker-chore network is the question of employer-employee relationships. The family members providing these in-home services are technically employees of the county, since the care is purchased from county funds. This raises questions about benefits, hours, compensation levels, and supervisory requirements for which there are no answers.

California represents the extreme case of family members receiving payments for personal care services rendered to the homebound. The majority of other States set lower monthly limits and restrict payments to distant family members, friends, or local providers for such services. This limits abuse of money and makes it more likely that additional support from the other organized and controllable agencies will be used if necessary. Several of the programs in other States, notably Texas, Oklahoma, Michigan, Wisconsin, and, more recently, New York State, have been stable and have shown growth during the few years in operation (Delgado, 1978).

References

- Anderson, O. W., "Reflections on the Sick, Aged and Helping Systems," In B. L. Neugarten and R. J. Havighurst (eds.) *Social Policy, Social Ethics, and the Aging Society*. Report to the National Science Foundation, Washington, D.C.: USGPO, 1976.
- Bane, Mary Jo. *Here to Stay: American Families in the Twentieth Century*. New York: Basic Books, 1976.
- Bishop, Christine, Alonzo Plough, and Thomas Willemain. *The Nursing Home "Level of Care" Problem*. Waltham, Mass.: Brandeis University, Center for Health Policy Analysis and Research, 1979.
- Bloom, Martin, "Evaluation Instruments: Tests and Measurements in Long-Term Care," in Sylvia Sherwood (ed.) *Long-Term Care: A Handbook for Researchers, Planner, and Providers*. New York: Spectrum Publishers, 1975.
- Branch, Laurence G. *Boston Elders: A Survey of Needs 1978*. Monograph available from City of Boston, Commission of Affairs of the Elderly, 1978.
- Branch, Laurence G. *Understanding the Health and Social Service Needs of People Over Age 65*. Cambridge, Mass.: Center for Survey Research, University of Massachusetts, and Joint Center for Urban Studies of Harvard University and M.I.T., 1977.
- Brody, Stanley J. S., Walter Poulshock, and Carla F. Masciocchi, "The Family Caring Unit: A Major Consideration in the Long-Term Support System," *The Gerontologist* 18 (6): 556-561 (1978).
- Campbell, Angus, Philip E. Converse, and W. L. Rodgers. *The Quality of American Life: Perceptions, Evaluations, and Satisfaction*. New York: Russell Sage Foundation, 1976.

- Cantor, Marjorie H. and Jeffrey L. Johnson, "The Informal Support System of the 'Familyless' Elderly—Who Takes Over?" Paper presented at the 31st Annual Meeting of the Gerontological Society, Dallas, Texas, (November, 1978).
- Congressional Budget Office. *Budget Estimates for FY'77*. Washington, D.C.: USGPO.
- Congressional Budget Office. *Long-Term Care: Actuarial Cost Estimates*. A CBO Technical Analysis. Washington, D.C.: USGPO, 1977.
- DeJong, Gerben and Alan Sager. *Meeting the Personal Care Needs of Severely Disabled Citizens in Massachusetts*. Waltham, Mass.: Levinson Policy Institute, Brandeis University, 1977.
- Delgado, Denise H. and Robert Morris. *Family Policy and the Disabled*. Waltham, Mass.: Levinson Policy Institute, Brandeis University, 1976.
- Eggert, Gerald M., Carl V. Granger, Robert Morris, and Sylvia F. Pendleton. *Community-Based Maintenance Care for the Long-Term Patient*. Waltham, Mass.: Levinson Policy Institute, Brandeis University (1976).
- Eggert, Gerald M., et al., "Caring for the Patient with Long-Term Disability," *Geriatrics* (October, 1977).
- Giele, Janet Zollinger. *Women and the Future: Changing Sex Roles in Modern America*. New York: Free Press, 1978.
- Glick, Paul C., "A Demographer Looks at American Families," *Journal of Marriage and the Family* 37: 15-26 (1975).
- Golant, Stephen M., "Residential Concentrations of the Future Elderly," *The Gerontologist* 15 (February, 1975): 16-23
- Gross, Arnold and Robert Morris. *Avoiding Institutionalization of Older Blind Persons*. Waltham, Mass.: Levinson Policy Institute, Brandeis University, 1977.
- Gurland, Barry, Laura Dean, Roni Gurland, and Diana Cook, "Personal Time Dependence in the Elderly of New York City: Findings from the U.S.-U.K. Cross-National Geriatric Community Study," in *Dependency in the Elderly of New York City*. New York: Community Council of Greater New York, 1978.
- Hareven, Tamara K., and Randolph Langenbach. *Amoskeag: Life and Work in an American Factory-City*. New York: Pantheon, 1978.
- Hauser, Philip M., "Aging and World-Wide Population Change," in R. H. Binstock and E. Shanas (eds.), *Aging and the Social Sciences*. New York: Van Nostrand, 1976.
- Hayghe, Howard, "Families and the Rise of Working Wives—An Overview," *Monthly Labor Review* 99: 12-19, 1976.
- Health Care Financing Administration, DHEW. *Long-Term Care Options* (June, 1978).
- Health Care Financing Administration, DHEW. *HR 3 Report* (October, 1978).
- Jones, Kenneth J. and Priscilla Pitt Jones. *Policy Implications for the Five-Year Study of Cost and Service Needs of the Developmentally Disabled*. Waltham, Mass.: Heller School, Brandeis University, 1976.
- Kahana, Eva and Rodney M. Coe, "Alternatives in Long-Term Care," in Sylvia M. Sherwood, ed., *Long-Term Care*. New York: Spectrum Publications, 1975.
- Kahn, Alfred and Sheila Kamerman. *Not for the Poor Alone: European Social Services*. Philadelphia: Temple University Press, 1974.
- Litwak, Eugene, "Technological Innovation and Ideal Forms of Family Structure in an Industrial Democratic Society," in R. Hill and R. Konig (eds.), *Families in East and West*. Paris, Mouton, 1970.
- Maddox, George L., "Families as Context and Resource in Chronic Illness," in Sylvia Sherwood (ed.), *Long-Term Care*. New York: Spectrum Publications.
- Maddox, George L. and Ethel Shanas, "Aging, Health, and the Organizations of Health Resources," in R. N. Binstock and E. Shanas (eds.), *Aging and the Social Sciences*. New York: Van Nostrand, 1976.
- Mahoney, Kevin J., "A National Perspective on Community Differences in the Interaction of the Aged with Their Adult Children." Madison, Wisc.: University of Wisconsin-Madison, Fay McBeath Institute on Aging and Adult Life, 1977.
- Massachusetts Dept. of Public Welfare, "Proposal to Establish the Family Responsibility Plan for Medicaid Recipients in Long-Term Care Facilities," 1977.
- Moroney, Robert M. *The Family and the State: Considerations for Social Policy*. London: Longman, 1976.
- Moroney, Robert M. and Norman R. Kurtz, "The Evolution of Long-Term Care Institutions," in S. Sherwood, ed., *Long-Term Care*. New York: Spectrum Publications, 1975.
- Morrison, Malcolm, "SSI Recipients in Medicaid Institutions," *Social Security Bulletin* (Dec., 1978).
- Neugarten, Bernice L., "The Future and the Young-Old," *The Gerontologist*, 15 (Feb., 1975); 4-9. New York Community Council. *Incidence of Depression in Families Caring for the Disabled, 1978*.
- Ricker-Smith, Katherine. *An Historical and Critical Overview of the Development and Operation of California's In-Home Support Services Program*. DHEW Publications #HEW-100-78-0027. San Francisco Home Health Service (December, 1978).
- Riley, Matilda White and Anne Foner. *Aging and Society, Vol. 1: An Inventory of Research Findings*. New York: Russell Sage Foundation, 1968.
- Sager, Alan. *Estimating the Costs of Diverting Patients from Nursing Care to Home Care Services*. Waltham, Mass.: Levinson Policy Institute, Brandeis University, 1977.
- Scanlon, William J., *Aspects of the Nursing Home Market Private Demand, Total Utilization and Investment*. Washington, D.C.: The Urban Institute, 1978.
- Schorr, Alvin L. *The Fifth Commandment: The Aged and Their Children and Family Policies*. Washington, D.C. U.S. Social Security Administration Draft (August, 1978).
- Shanas, Ethel, "Measuring the Home Health Needs of the Aged in Five Countries," *Journal of Gerontology* 26 (1): 37-40, 1971.
- Shanas, Ethel, Peter Townsend, D. Wedderburn, H. Friis, P. Milhoj, J. Stehouwer. *Old People in Three Industrial Societies*. New York: Atherton, 1968.
- Shanas, Ethel and Marvin B. Sussman. *Family, Bureaucracy, and the Elderly*. Durham, N.C.: Duke University Press, 1977.

- Sherwood, Clarence C. and John N. Morris, "Strategies for Research and Innovation," in Sylvia Sherwood, ed., *Long-Term Care*. New York: Spectrum Publications, 1975.
- Sherwood, Sylvia, "Long-Term Care: Issues, Perspectives, and Directions," in S. Sherwood, ed., *Long Term Care*. New York: Spectrum Publications, 1975.
- Social Services U.S.A. 1975 and 1976 volumes. Washington, D.C.: DHEW, Office of Human Development Services.
- Social Security Bulletin* Jan. 1971, Vol. 34, No. 1, p. 12, Table 3.
- Social Security Bulletin* July 1978, Vol. 41, No. 7, p. 11, Table 4.
- Stack, Carol B. *All Our Kin: Strategies for Survival in a Black Community*. New York: Harper & Row, 1974.
- Sussman, Marvin B., "The Family Life of Old People," in R. H. Binstock and E. Shanas (eds.) *Aging and the Social Sciences*. New York: Van Nostrand, 1976.
- "Social and Economic Supports and Family Environments for the Elderly." Final Report to the Administration on Aging, January, 1979.
- Teresi, Jeanne, Ruth Bennett, David Wilder, "Personal Time Dependency and Family Attitudes," in *Dependency in the Elderly of New York City*. New York: Community Council of Greater New York, 1978.
- Townsend, Peter. *The Family Life of Old People: An Inquiry in East London*. London: Routledge and Kegan Paul, 1957.
- U.S. Department of Commerce, Bureau of the Census. *Demographic Aspects of Aging and the Older Population in the United States*. Special Studies Series P-23, No. 59. Washington, D.C.: USGPO, 1976.
- U.S. Department of Commerce, Bureau of the Census. *Social Indicators 1976: Selected Data on Social Conditions and Trends in the United States*. Washington, D.C.: USGPO, 1977.
- U.S. Department of Commerce, Bureau of the Census. *1976 Survey of Institutionalized Persons: A Study of Persons Receiving Long-Term Care*. Current Population Reports, Special Studies. Series P-23, No. 69. Washington, D.C.: USGPO, 1978.
- U.S. Department of Health, Education, and Welfare. *1978 HEW Task Force Report on Long-Term Care*. Memorandum for July 14, 1978 briefing; Major Initiative: Long-Term Care/Community Services. Washington, D.C. Office of the Secretary, Special Assistant to the Secretary.