

Family Care of the Elderly: The Role of Public Policy

PAMELA DOTY

*Health Care Financing Administration.
Washington*

Children that have been the charge of their parents to bring them up to be capable of doing something, should not presently, in hope of doing better for themselves, desert their helpless parents, as thinking it now time to look for themselves and left them shift as they can (Samuel Willard, eighteenth-century Colonial preacher).

A NUMBER OF PUBLIC POLICY INITIATIVES currently under discussion in Congress and elsewhere seek to promote at-home family care for the impaired elderly. These proposals include: (1) tax incentives for family members who bring elderly impaired relatives into their homes, (2) public funding for "respite" and other supportive services, (3) cash grants to low-income families to care for elderly relatives, (4) changes in supplemental security income (SSI) and food stamp rules such that benefits are not decreased when an elderly person moves in with family, and (5) permitting family members to work as paid helpers under public programs.

Such proposals have been brought forward, in many instances, because their proponents believe that family care of the elderly is on the decline in this country and that government can and should intervene to halt or reverse the trend. In this article, I will review existing research on family care-giving—of which quite a lot has been carried out in recent years—to address several related questions. First,

how much evidence is there that American families are becoming less able to provide home care to their elderly disabled relatives? Second, what, if any, impact would government support or incentives be likely to have on family care-giving? Would institutionalization of the elderly decrease? Would the "quality of life" of the disabled elderly receiving home care and that of their family care-givers improve? Third, is it likely to make any difference what form the government assistance takes—that is, whether support or incentives are given via tax credits or cash grants or vendor payments and which services are supported or subsidized through the various means?

The Role of Family in Long-term Care of the Elderly

According to recent national surveys conducted by the Department of Health and Human Services (the 1979 Health Interview Survey (HIS) and the 1982 Long-Term Care Survey), informal care-giving by family and friends is currently the dominant mode, by far, of providing long-term care services to the functionally disabled elderly. Nearly one-quarter (22.9 percent) of all United States elderly aged 65 and older are functionally disabled. That is, they require assistance from another person with personal care (bathing, dressing, eating, toileting), with mobility (transferring into and out of chairs or beds, going from room to room) or with instrumental activities of daily living (e.g., shopping, cooking, cleaning, laundry), or they require nursing care of the sort provided by visiting nurses or by nursing-home staff. Only one in five of these elderly with long-term care needs are cared for in nursing homes; the remaining four-fifths are able to go on living in the community primarily because family and friends provide all or most of the assistance they require. Nearly three-quarters of the elderly disabled who live in the community rely solely on family and friends for the assistance they require. Most of the remainder rely on a combination of family care and paid help. Only a small minority (9 percent in the 1979 HIS survey, 5 percent in the 1982 Long-Term Care Survey) receive all their care from paid providers. Moreover, three-quarters of all such noninstitutional paid care is privately financed by the elderly themselves and their relatives; only 26 percent is government financed (U.S. Bureau of the Census 1983a; Soldo 1983a, 1983b; Manton and Liu 1984; Liu, Manton, and Liu 1986).

The 1979 and 1982 survey results replicate earlier survey findings that many of the impaired elderly living in the community and receiving family assistance are as disabled as nursing home residents and, as such, could meet medical and functional disability criteria for nursing home admission if they chose to apply (Shanas 1979a; U.S. General Accounting Office 1977). Clearly, family care enables many impaired elderly to remain in the community when, without such support, they would require nursing home placement (Barney 1977; York and Caslyn 1977; Wan 1980; Smyer 1980). Conversely, the elderly without close kin are statistically overrepresented among nursing home residents. Elderly widows and widowers are five times as likely to be institutionalized than married persons, and the divorced, separated, and never married have institutionalization rates 10 times greater than married persons (Butler and Newacheck 1981). Moreover, according to one area study by Brody, Poulshock, and Masciocchi (1978), 50 percent of nursing-home residents are childless and 20 percent have no immediate living family; however, no national figures are available.

Because the availability of families willing to provide long-term care services is such a pivotal factor in preventing or postponing nursing home placement for many impaired elderly, policy makers have reason to be concerned about the potential fiscal consequences of a trend toward reduced family effort. An estimate of the additional public expenditures that would be required for long-term care services in the state of Wisconsin alone if elderly persons currently living in the community with conditions similar to nursing home residents had no family care projected that 1983 Medicaid costs would have risen from \$315 million to \$500 million or more. In addition, it was estimated that social-services spending probably would have had to increase more than three-fold (to roughly \$194 million) (Chang and Swart 1983). Before initiating public policies to reverse the trend toward declining family care-giving, however, it is important to stop and ask whether such a trend actually exists.

Is Family Care on the Decline?

Trends in Institutional Use

It is widely believed, by many policy makers and members of the public, that families today are becoming increasingly less willing than

families were historically to care for elderly impaired family members at home. Prominent family-care researchers Ethel Shanas (1979b) and Elaine Brody (1981) refer to this belief as the "myth of abandonment" because there is little scientific evidence to support it, and, indeed, much evidence to the contrary. Elaine Brody (1985) has advanced an interesting psychosocial theory to account for the prevalence of the myth of abandonment among the general public despite the fact that more and more people are having personal experience caring for disabled elderly relatives. (Indeed, Brody asserts that providing informal long-term care to elderly relatives is becoming a "normative" experience.) Policy makers differ from the general public, however, based on the author's experience in government, in justifying their belief that families are increasingly abandoning care of the elderly to institutions by citing what at first glance appear to be convincing statistics. Closer examination of these data reveals, however, that this alleged trend rests largely on a misinterpretation of the fact that use of nursing-home care by the elderly has increased dramatically over the past half-century, and especially, over the past 25 years. A study of historical patterns in institutionalization rates of the elderly carried out for the 1980 Under Secretary's Task Force on Long-Term Care found, however, that most of the growth in the percentage of elderly aged 65 and older in nursing homes is due to two factors quite unrelated to family caregiving: (1) the shift from use of mental hospitals (and, earlier, almshouses and homes for the aged) to nursing homes, and (2) the greater percentage of elderly in older age groups (75 and older, 85 and older) which have traditionally had higher use rates for nursing home care. Until 1940 the percentage of elderly aged 75 and older in the elderly population remained relatively constant (29 percent). By 1980, however, the "old-old" constituted 38 percent of the elderly population (U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, 1981).

The task force's analysis of institutionalization rates among the elderly also found that, from 1950 to 1970, the proportion of the population aged 65 to 79 in institutions and group quarters remained virtually constant. In contrast, the institutionalization rate of the elderly aged 80 and older increased more than 50 percent over the same period. Census estimates for 1980 (based on the 1977 National Nursing Home Survey) indicate that institutionalization rates for all elderly cohorts remained essentially unchanged during the 1970s (U.S. Bureau of the Census 1983a) (see table 1).

TABLE 1
Proportion of the Elderly in Institutions and Group Quarters by Age Cohort: 1950-1980

Age group	1950		1960		1970		1980	
	In institutions	In group quarters	In institutions	In group quarters	In institutions	In group quarters	In institutions	In group quarters
65-69	1.8%	NA	1.8%	.7%	1.7%	.5%	1.4%	.3%
70-74	2.6	NA	2.6	.7	2.7	.5	2.5	.4
75-79	4.3	NA	4.3	1.3	5.1	.7	5.0	.6
80-84	6.6	NA	7.8	1.3	10.2	.9	10.4	.9
85 +	11.7	NA	12.6	1.8	17.9	1.2	23.5	1.2

Source: U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation 1981, working paper #5, table 1; updated with 1980 Census data from U.S. Bureau of the Census 1983b, table 266.

There are several theories as to why, from 1950 to 1970, the nursing-home use rate increased so dramatically among the elderly aged 80 and older. One theory is that advances in medical science increased the survival rates of individuals at higher levels of chronic disease and disability (Gruenberg 1977; Butler 1983; Katz et al. 1983; Manton 1982). In addition, the gap in longevity-increases between men and women (e.g., as of 1977 white females aged 65 could expect to live an average of 18.5 years longer as compared to 13.9 years for white males) has produced larger numbers of quite-elderly widows than existed in the past. Larger numbers of widows coupled with higher divorce rates and trends toward lower fertility may also mean that the elderly aged 80 and older not only are more disabled than they were 20 to 30 years ago but have fewer family members available to provide informal care. Crystal (1982) estimates that 10 to 15 percent of recent increases in nursing-home use are due to the fact that today's elderly have fewer children than their parents did.

Future Impact of Demographic Trends

There is evidence that these same demographic trends are likely to decrease the availability of informal family supports in the future.

Given the differential life spans of men and women and the increasing divorce rate, widowed elderly are expected to increase 33 percent by the year 2000 and the single elderly are expected to increase by 25 percent. Clinkscale et al. (1985) have analyzed fertility rates over the period 1930 to 2030 in order to produce an elderly/offspring dependency ratio. They point out that the United States is now experiencing a temporary peak in the ratio of elderly to offspring able to provide care due to low birth rates in the 1930s. They also note, however, that as the parents of the baby-boom generation move into old age, there will be more offspring available to care for the young aged (65-79). However, the burden on children of the elderly aged 80 and older (those most likely to need long-term care) will continue to increase over the next 15 years; the ratio of elderly aged 80 and older to offspring will peak in the year 2000, decline for 20 years, then reach an even higher peak in 2030.

It is worth noting here that, as life expectancy increases, the age at which the elderly are likely to become dependent on adult children for assistance increases and, as a result, the impaired elderly in need

of informal long-term care are more and more likely to have children who are themselves past retirement age. Currently, 10 percent of the population aged 65 and older have children who are also aged 65 or older (Atchley and Miller 1980). Brody and Spark (1966) identified the aging of a child as a factor precipitating institutional placement. Sussman (1979) found that willingness to take an older relative into one's home was negatively correlated with age. Gelfand, Olsen, and Block (1978) and Cicirelli (1980) suggested that it is more than a problem of decreased resources: older children reported more negative feelings and greater emotional strain associated with care-giving.

Future Impact of Female Labor-force Participation and Marital Disruption on Care of the Elderly

Another factor that affects both the willingness and the availability of family members to provide long-term care services informally to elders in their own or the elder's home is the compatibility of giving such care with other roles. Since most of the family care of impaired elders not provided by spouses has traditionally been provided by middle-aged adult daughters and daughters-in-law, many experts believe that the increasing trend toward women in the labor force is likely to decrease the capacity of these traditional care-givers to meet the care needs of impaired elderly relatives. Currently, 51 percent of adult women are working outside the home and three-quarters of these work full-time. Sixty percent of women aged 45 to 54 work outside the home (Brody 1981).

In principle, families could respond to the time demands that providing informal long-term care places on working caretakers in ways other than institutionalization. Males (sons and sons-in-law) might agree to share more of the care-giving role, thereby avoiding the excessive stress that might otherwise be felt by a working woman caretaker. Alternatively, families in which both spouses are working may choose to pay others to provide some or all of the home care that they themselves would have provided had they had more time available. Elderly people themselves may well favor the latter option. In an attitude survey of three generations of Philadelphia area women, Elaine Brody (1981) found that the grandmothers in the sample, while strongly endorsing family care of the aged, were more likely

(75 percent) than the daughters (61 percent) and granddaughters (59 percent) to favor paying someone for parent care rather than obliging a working daughter to leave her job.

Research findings on the actual impact of female employment on family care-giving have been contradictory. The contradictions may stem in part from the fact that rarely do these studies differentiate clearly between different types of family involvement in care-giving: actual hands-on care being provided by family members, paid care financed by family members, and combinations of paid and informal care provided in a shared housing situation. Clearly, working women cannot themselves provide hands-on care during the hours when they are at work, but the income they receive from working may increase their ability to finance paid home care. Several studies (Chiswick 1976; Johnson 1979; Soldo and Sharma 1980; Nardone 1980; Brody, Kleban, and Johnson 1984) found support for the hypothesis that labor-force participation by women diminishes their ability to provide home care for elderly relatives. Other studies (Cantor 1980; Brody 1981; Horowitz and Dobrof 1982) found that working women were no less likely than nonworking women to provide home care and that the hours of care provided were no different. Horowitz and Dobrof (1982) did find that home care was negatively correlated with part-time employment, but not with full-time work. Their study actually found that for females, being married, both with and without children at home, was more of an impediment to providing care than having a full-time job. It appeared that married women felt that their first loyalties were toward their husbands and spent less time providing home care to elderly relatives than single, widowed, divorced, or separated women.

These latter findings are contradicted by Cicirelli (1983) who studied the impact of marital disruption (divorce, separation, widowhood) on the extent of help provided by children to their elderly parents. Help was classified and measured in terms of 16 services: 6 "primary" services (homemaking, housing, income, maintenance, personal care, and home health care), 6 "secondary" services (transportation, psychological support, social and recreational activities, spiritual support, protection, and bureaucratic mediation) and 4 "tertiary" services (reading materials, career education, employment, and enrichment). Overall, the mean percentage of adult children with marital disruption providing some degree of help with the 6 primary services was 20.5 percent, compared to 35.3 percent providing help for secondary services, and

only 10 percent providing help with tertiary services. For adult children with intact marriages, the mean percentage for primary services was 26.5 percent, compared with 48.5 percent providing help with secondary services, and 11.2 percent giving help with tertiary services. The adult children with marital disruption also scored significantly lower on a scale designed to measure feelings of filial obligation than adult children with intact marriages. Both groups were asked at what point they could no longer continue to help their elderly parents. Some 29 percent of the adult children with intact marriages but only 16 percent of those with disrupted marriages felt that they could continue to help elderly parents under any circumstances. In the group with disrupted marriages, job responsibilities were cited by the majority as the main reason why their help to parents would have to be limited (Cicirelli 1983).

Willingness to Bring Elderly Relatives into One's Home

Thus far, we have focused on demographic factors that may be decreasing the availability of family members to provide informal care. Now we will focus on the willingness of family to provide informal care, in particular, the willingness of family members to provide the amounts and types of care similar to that provided in nursing homes. For all practical purposes, this means the willingness of family members to bring elderly disabled parents to live with them when they become heavily dependent for help with personal care needs: bathing, dressing, eating, toileting, or when they become so mentally confused as to require constant supervision.

Some analysts (Crystal 1982) have inferred from statistics on the decreasing prevalence of three-generation households that children are less willing to bring elderly parents to live with them than they once were. However, the great majority of elderly living independently are not disabled. Indeed, according to specialists in the demography of household living arrangements, this trend is actually the result of the improved health and economic status of the elderly, particularly the "young-old" (65 to 74). Historical studies have documented, moreover, that shared living arrangements between parents and adult children have never been a preferred cultural pattern in this country (Mindel 1979). Indeed, even in Colonial times, many families "boarded out"

their elderly relatives. So long as adult children were willing to assume the financial responsibility of supporting elderly relatives, rather than leaving it to the church or the county, "boarding out" was viewed as a perfectly acceptable way to avoid the potential family tensions that might arise from three-generational shared living arrangements (Haber 1983).

The elderly themselves have strong preferences for independent living and strong desires not to be a burden. A recent attitude survey of the elderly in the United States and four other English-speaking countries (Canada, the United Kingdom, Australia, and New Zealand) demonstrates the strength of the contemporary preference for independent living among the elderly. When asked where they would prefer to live if they became unable to care for themselves, 71 percent of American elderly (and 66 percent of the elderly across all five countries) said that they would prefer to live in their own homes; 18 percent of the American elderly (versus 22 percent in all five countries) said they would prefer to live in a nursing home. Only 9 percent in the United States (as well as across the five-country sample) said that they would prefer to live with family or friends. When asked what would be their most likely living arrangement if unable to care for themselves, 16 percent of the American elderly (versus 17 percent of the elderly across all five countries) believed that they would move in with relatives; however, 39 percent of elderly Americans (as compared to 36 percent of the total sample) believed that they would be able to stay at home. Although the preference for nursing homes over living with relatives probably reflects the elderly's desire not be a "burden" on relatives, the strongest preference by far among the elderly in all five English-speaking countries was for independent living (Louis Harris and Associates Inc. 1982).

Given the strong preference of the elderly themselves for independent living, shared living arrangements often reflect necessity more than choice. According to the Horowitz and Dobrof (1982) study of family care-giving patterns in New York, shared living arrangements among family care-givers and elderly care-receivers were more prevalent among the never-married (e.g., unmarried daughters and their elderly mothers and never-married siblings), lower income, and nonemployed persons. Such arrangements were also found to be unrelated to ethnic tradition when income was controlled. The only characteristic of those receiving care that showed a statistically significant association with the locus

of family care-giving was functional ability; elderly persons living in their children's or other relatives' homes had higher dependency (activities of daily living [ADL]) scores than those who remained in their own homes.

In sum, the evidence suggests that until the impaired elderly become highly dependent in terms of personal care needs (such as bathing, dressing, feeding, toileting) both they and their children or other family care-givers prefer to maintain separate living arrangements. Since the great majority of family care-givers live within hours—and most live within a half hour's travel time from those they care for—separate living arrangements can generally be maintained, if income permits, so long as the elderly person requires assistance with instrumental activities of daily living (e.g., shopping, cleaning, cooking, laundry) primarily (Shanas 1979b).

Survey data does indicate that, as individuals become older and more frail (i.e., reach the 75 and older and 85 and older age categories), as their spouses die, and as they become more functionally dependent, they do tend to move in with children or other relatives. Thus, in the 1979 Health Interview Survey (Soldo 1983a, 1983b) noninstitutionalized elderly persons with home care needs were found to be twice as likely (30 percent versus 14.9 percent) to live with relatives (other than a spouse) than the average elderly person. Although the percentage of elderly with home care needs living alone was virtually identical (30 percent versus 29.3 percent) to the percentage of all elderly living alone, it is impossible to interpret what this figure means in terms of family willingness to bring an elderly relative into their home in the absence of data on how many of these individuals had family members (principally living children) with whom they might have gone to live.

Sussman (1977, 1979) has attempted to measure the willingness of the average adult American to bring elderly relatives into their homes via two attitude surveys. In the first attitude survey of 356 nonelderly adults in Cleveland, Ohio, (Sussman 1977) respondents were asked whether they would be willing to accept into their home an elderly person who wanted to live with them. Fifty-nine percent said yes, 33 percent said no, and 8 percent did not know. When those who had answered no were asked whether they would ever, under any circumstances, bring an elderly person into their home, 29 percent said they would, 70 percent still said no. In sum, 19 percent of the survey respondents could envision no circumstances

under which they would accept an elderly person into their household. The second survey, carried out in Winston-Salem, North Carolina (Sussman 1979) found highly similar results. Nineteen percent were unwilling under any circumstances to take an elderly person into their home, 24 percent were unconditionally willing, the rest were willing to bring an elderly person into their home under some conditions. Sussman found that the major variables that correlated with willingness to bring an elderly relative into one's home were: extent of crowding in the house, perception of spouse's or children's favorableness to the idea, presence of other relatives nearby who could provide positive experiences with the elderly.

Although these and related findings from Sussman's survey indicate that most adult Americans are willing to consider sharing their home with an elderly relative, especially females and especially parents, it is well to bear in mind that these surveys posed hypothetical situations. Moreover, these hypothetical situations focused primarily on "lonely" elderly rather than on physically or mentally impaired elderly with significant personal care needs.

The Horowitz and Dobrof (1982) study of family care-givers in New York examined willingness to bring elderly relatives into one's home in a less hypothetical situation: among family members already involved in providing long-term care services to an elderly relative. In this study, 27 percent of the adult children care-givers and 15 percent of other relatives (primarily siblings) were already providing assistance to the older person within their own home.

Among those care-givers who did not live with those they cared for, more than 60 percent said they would not consider having the older relative live with them, 10 percent were indecisive, and slightly less than a third (30 percent) were willing to envision a shared living arrangement. Younger care-givers were more willing to consider bringing an elderly impaired relative into their home than older care-givers. Of those who said they would not consider a joint household, one-third cited the older person's desire for independence as the primary reason. Approximately one-fourth (22 percent) said they did not like or would not get along with their older relative. Another 18 percent cited anticipated family conflict (with spouse or children) as the principal barrier. Housing conditions (primarily space limitations or architectural barriers) were prohibitive for an additional 18 percent. Six percent had had either this or another older relative in their home previously, the situation had not worked out, and they did not wish to repeat

the experience. Eight percent cited their employment as an obstacle; 4 percent cited their own health problems.

Clearly, the major barriers to willingness to bring elderly disabled into the home are emotional ones. On the one hand, there is the resistance of the elderly themselves toward giving up their own homes and moving in with relatives; on the other hand, there are the family care-givers' concerns about interpersonal tensions and conflicts.

How amenable are such reasons likely to be to public policy influences? Sussman's studies also investigated attitudes toward various types of government programs designed to support families who bring elderly relatives into their homes. Although 90 percent of those who said they would bring an elderly individual into their home indicated a willingness to participate in a government program to support care-giving, only 13 percent of those who said they would not take an elderly person into their home indicated that government incentives might influence them to change their minds. Sussman concluded therefore that "incentives may at best facilitate the process for those already committed and do little to change the minds of refusers."

These findings are in line with other research which suggests that family care-giving is motivated primarily by three factors: love and affection felt toward the individual, a sense of gratitude and desire to reciprocate care-giving or other help that was previously provided by the impaired elderly person to the spouse or adult child, and allegiance to a more generalized societal norm of spousal or filial responsibility (i.e., the family care-giver is responding to what he or she believes to be society's expectations concerning morally correct or approved behavior). Among Horowitz and Dobrof's sample of New York care-givers, familial responsibility was the most frequently mentioned reason for providing long-term-care assistance to an elderly relative; this motivation was spontaneously cited by 58 percent of the care-givers. The second most common motivation mentioned was love (51 percent), followed by reciprocity (e.g., acknowledgement of past assistance received), which was cited by 17 percent.

Length of Care-giving

Horowitz and Dobrof found that while feelings of affection toward the impaired person were not a necessary precondition for relatives to undertake care-giving (a sense of family responsibility was often enough),

both past and current feelings of affection were strongly correlated with the amount of time family members, especially adult children, were willing to commit to care-giving, as well as families' willingness to consider institutional placement.

Thus, the key issue seems to be not only whether family members are available and willing to provide home care, but how much care and for how long? The willingness of families to make an open-ended commitment to the amount and length of care-giving appears to be a major factor determining likelihood of institutionalization. A comparative study by Smyer (1980) of matched samples of institutionalized and noninstitutionalized elderly persons with equivalent functional disabilities revealed that the single most important difference between the two groups was the family's self-reported ability to care for the client as long as needed. In contrast, there was no significant difference between families of the institutionalized and noninstitutionalized samples in reported willingness to provide help every now and then (e.g., running errands, visiting, etc.). The policy question is whether or not some form of government support—whether in the form of direct services (e.g., respite care, “gap-filling” services, or counseling and referral), cash subsidies, or tax incentives—might be effective in preventing or postponing families' decisions to place elderly impaired relatives in nursing homes. In order to gauge which, if any, of such efforts might be effective, we need to review what is known about how and why families make the decision to discontinue informal home care and seek nursing home placement for an impaired elderly relative.

Reasons for Institutionalization

A review of the research literature indicates that the single most common precipitating factor in family decisions to institutionalize an impaired elderly relative is the elderly individual's worsening health. For example, in one recent study (Smallegan 1983, 1985) of 288 new admissions to 28 nursing homes in Michigan and North Carolina, the most frequently reported reason for institutionalization was a deterioration in the patient's condition. Sixty-four percent of the patients had become less well shortly before admission. Deterioration in health status was serious enough so that two-thirds of the patients were admitted directly from a hospital. The most common medical conditions precipitating admission were: frequent falls (27 percent),

general debility (25 percent), confusion (21 percent), fractures (14 percent), stroke (13 percent), incontinence (13 percent), and difficult behavior (13 percent). All but 7 of the patients in this study had been receiving some informal long-term care from family members prior to admission. Of those patients with children ($N = 212$), more than 86 percent had received care from them before institutionalization. Fifteen percent of patients had received home care from relatives (spouse, children, others) for more than 5 years prior to admission. At the other extreme, 13 percent had been receiving care for less than 1 month and 25 percent had received care for 1 to 8 months. Nearly half were cared for from 8 months to 5 years before nursing home admission. In addition, the care provided was often intensive: over the years, consistently 15 to 25 percent of those needing care were highly dependent for assistance with activities of daily living. Somewhat over one-third of informal care-givers were faced with too much work to be able to continue to manage the patient at home. In one-fifth of the cases, the admittee was considered a difficult person who could no longer be managed at home.

In another recent study, Arling and McAuley (1983) examined the factors precipitating family decisions to stop providing home care and seek institutional placement among persons being screened for nursing home admission by Virginia's preadmission screening program. At the time the study was conducted, the program screened all nursing home applicants who were community residents at the point of application for admission and were eligible for Medicaid or would be within 90 days of nursing home entry. For each nursing home applicant, a "significant other" (e.g., spouse, child) was interviewed about the reasons for the decision to seek institutionalization. A decline in the older person's health was reported as the primary reason for seeking institutional placement by 68 percent, and by 18 percent as the second most important reason. Changes in the informal support system causing a reduced capacity for care were cited as the most important reason by 20 percent, and as the second most important reason by 28 percent. A physician's recommendation was named as the most important reason by 7 percent, and as the second most important by 11 percent. Three percent reported that family concern about the older person's ability to live independently was the most important reason, and 19 percent cited this as the second most important reason. (Only 19 percent of the nursing home applicants were living alone at the time

of application, the rest lived with a spouse, adult child, other relative or nonrelative.) None of the significant others mentioned financial considerations as the most important reason and only 4 percent mentioned finances as the second most important consideration.

A second study of the Virginia Pre-Admission Screening Program (Harkins 1985) revealed that families are more likely to institutionalize elderly relatives where the need for long-term care first develops as the result of an acute condition producing a sudden, sharp drop in functional ability versus a slow decline in functioning associated with a chronic illness. The findings of this study suggest that informal family support systems function best where they have time to gradually adjust to an elderly individual's increasing needs for assistance. When an elderly individual who was previously independent precipitously develops moderate to heavy dependency needs, the family does not have time to adjust to the change and the result is institutional placement.

Other studies of families' decisions to seek institutional placement for elderly impaired relatives or to seriously consider seeking such placement (Zarit, Reever, and Bach-Peterson 1980; Lebowitz 1978; Silverstone 1978; Sainsbury and Grad de Alarcon 1970; Brody and Spark 1966; Lowenthal 1964; Sanford 1975) have cited as major motivations the following: caretakers' lack of time for themselves and other family members due to the constant burden of care-giving, difficulty in dealing with incontinence or confusion and behavioral problems associated with senility, inability to meet the physical demands of caring for someone with severe paralysis, and caretaker fatigue due to sleep disturbances when relatives require care during the night. In some cases, a change for the worse in the care-giver's own health status was found to be a precipitating factor in the decision to institutionalize someone. In addition, lack of privacy and insufficient space were major reasons given for not taking into one's home an elderly person who otherwise requires institutional placement.

Social and Psychological Stresses of Care-giving

The research literature on informal family care-giving also emphasizes the social and psychological stress that care-givers experience (Sangl 1983). Care-givers studied often expressed feelings of worry, burden, frustration, being "tied down," and complained of social isolation due

to friendship patterns being interrupted and mobility impaired (Fengler and Goodrich 1979). Conflicting family obligations can also cause psychological strain. Responsibilities to parents may take precedence over responsibility to spouse, children, or others because the former is seen as the more pressing need. However, this is usually felt as a forced choice. There may be a marked impact for the worse on the marital and other family relations of an adult child who is the principal care-giver of an elderly parent. The care-giver's spouse and children may feel neglected, deprived, bitter, jealous, or resentful (Seelback 1977).

All of these stresses were found among the family members of persons applying for nursing home care in the Virginia Pre-Admission Screening study (Arling and McAuley 1983). In this study, the family members of the nursing home applicants were asked about the changes in their lives that had taken place during the six months prior to the decision to seek institutional placement. Forty-three percent said that they had to consider their impaired elderly relatives in planning activities with others. Forty-two percent said they had less time for themselves. Forty-one percent reported mental anguish or worry. Thirty-one percent reported that their social or recreational activities decreased. Twenty-eight percent said that they had less time with their spouse or children. The social/emotional stresses were more pervasive than interference with work or financial strains, which were reported by only 11 percent and 10 percent of family members.

According to preliminary data from the nationally representative 1982 Long-Term Care Survey of the noninstitutionalized disabled elderly and their care-givers, 27 percent of the care-givers surveyed reported that they are unable to leave their elderly disabled relatives alone at home. Fifty-four percent of adult children caring for their elderly disabled parents reported that their social life or free time had been limited by care-giving, 26 percent also reported lessened privacy, and 28 percent said that their elderly disabled parent required almost constant attention. Again, social/emotional losses and sacrifices were reported more frequently than financial strain. Only 15 percent of adult care-givers said that their parents' care cost more than they could really afford (Kenneth Manton, Duke University Center on Aging, personal communication).

Sometimes such stress severely damages the relationship between the elderly person and the family care-giver and may affect the quality

of the care provided. Confusion or anger may be felt on both sides where there is a role reversal of the parent-child relationship (Horowitz 1978). Strained affections between an adult care-giver and the parent who is being cared for are another not uncommon negative consequence that has been reported of care-giving. In one study, it was found that before extensive care-giving began, the aged parents more likely labeled themselves as being "closest to" the child, but not afterwards (Tobin and Kulys 1979).

In cases where adults assume care-giving roles vis-a-vis parents with whom they have had a troubled relationship in the past, a combination of feeling frustrated and angry at having to do so can lead to ineffective care-giving and even abuse (Horowitz 1978). In one study an abuse rate by care-givers of almost 10 percent was found (Tobin and Kulys 1979).

When the strains of family care at home have become acute, the elderly person's entry into a nursing home can actually improve the emotional quality of family relationships. In one study (Smith and Bengtson 1979), 45 percent of families experienced an improved relationship with the elderly parent following nursing home placement.

Tolerance for Stress

Although the literature on family care-giving repeatedly cites stress and "burnout" as causes of institutionalization, very little is actually known about how this process operates. The relation between emotional stress and the decision to institutionalize an elderly relative is a complicated one because some research suggests that it is precisely the care-givers who are emotionally closest to the impaired person and most committed to providing home care who experience the greatest stress (Cantor 1983). Spouses, in particular, show a strong tendency to maintain care-giving whatever the social/emotional costs and stop only when deterioration in their own health physically prevents them from providing the services. Children appear to have a lower tolerance for stress, especially continued high stress over time, than spouses.

As Johnson and Catalano (1983) point out, however, other adaptive mechanisms are available besides institutionalization for coping with stress. In their eight-month follow-up of dependent elderly discharged from hospitals, Johnson and Catalano found that children were more

likely than spouses to turn to formal supports (use of physicians and social workers for advice, and employment of paid homemakers) or to seek assistance from other family members. Others developed psychological distancing mechanisms that enabled them to continue to meet the needs of their disabled parents, with minimal emotional commitment. In a quite different fashion, some care-givers adapted to the heavy demands on their time and sacrifices (of leisure time, social life, etc.) required of them by intensifying their involvement and emotional investment in the care-giver role. For elderly spouses, this entrenchment in the care-giver role can compensate for the loss or attrition of other roles with aging. In other words, some elderly care-givers who might otherwise suffer from feelings of "uselessness" benefit from feeling needed. Similarly, for children, intensifying the care-giving role can substitute for a failed marriage, widowhood, or an erratic employment history. It can also be used as a rationalization for delayed independence from parents or a solution for a child's own economic difficulties and inability to maintain an independent living situation.

In another study, Poulshock (1982) investigated the level and source of stress experienced by family care-givers who have been caring for elderly impaired relatives for long periods of time in shared living arrangements. The care-givers studied ($N = 614$) had cared for their elderly impaired relatives in a shared household for an average of over six years. A majority of the impaired elderly in the study sample had multiple and severe disabilities; two-thirds had three or more personal care dependencies, and over half were incontinent. Thirty-eight percent were completely dependent in the area of personal care. Higher levels of stress among care-givers were associated with impaired relatives having greater numbers of personal care dependencies, more symptoms of mental impairment, and, most especially, more disruptive or "acting out" behavior.

Much recent research on the social/emotional stress associated with care-giving has been concerned with identifying specific care-giving tasks that family members tend to find most stressful. Clark and Rakowski's review of the literature on care-giver stress (1983) identifies the following tasks as especially difficult or stressful: performance of basic activities of daily living (i.e., bathing, dressing, feeding, toileting); compensating for emotional drain from constant responsibility; compensating for or recovery of lost personal time; gaining knowledge about the disease/condition; avoiding severe drain of physical

strength/health; resolving guilt over “negative feelings” toward the person being cared for; resolving disappointment or feelings of guilt over one’s performance; making up for or avoiding loss/restrictions on future plans; balancing the giving of assistance with responsibilities to other family members; managing feelings toward other family members who do not regularly help; and interacting with medical, health, and social service professionals.

Government Policies to Promote Family Care

Based on the preceding review of the research literature on why families choose to discontinue home care and seek institutional placement for elderly relatives, we are now in a better position to evaluate the likelihood that various public policy initiatives that have been proposed would be effective in promoting family care. Note, however, that it is important in evaluating the various options under consideration to be clear about the objective being pursued. Is the objective of family support policies to deter or postpone institutionalization by motivating family members to provide informal care that they would not otherwise have provided? Or is the purpose to support families in providing care that they would have provided anyway in such a manner that such care does not impose an excessive burden? Is it important that family members themselves provide the care or is it an acceptable policy goal to provide or to enable family members to purchase paid home care that they would not otherwise be able to afford?

In order to evaluate the effectiveness of various different types of family support policies, it is also important to understand how these policies serve to meet (or fail to meet, as the case may be) the actual needs of family members. Behind each of the various family support proposals under discussion are different sets of beliefs about what caregivers require in order to motivate or to sustain long-term care-giving at home.

Meeting Intensive Care Needs

As was noted earlier, research findings indicate that the single most common factor reported by family members as having precipitated institutionalization is a decline in the elderly person’s health status. In the author’s experience, such findings often elicit skepticism among

home and community-based care advocates, who apparently believe that family care-givers find it more socially acceptable to claim that their elderly relatives had medical or nursing care needs that they could not meet rather than admit that they find care-giving too burdensome. However, in a recent analysis of the 1982 Long-Term Care Survey, Soldo and Manton (1985) found that being on a waiting list for nursing home entry is statistically associated with having had a previous nursing home stay, hospital use during the previous 12 months, extreme activities-of-daily-living dependency, more than one care-giver, and use of paid providers to supplement informal care-giving. Manton and Soldo further found that among the extremely disabled elderly living with spouses, use of formal providers tends to occur after the elderly person develops both medical care needs and incontinence; for those living with adult children, when need for extensive supervision combines with medical needs and incontinence. Manton and Soldo's findings suggest that among those family members willing to undertake a substantial commitment to home care, the decision to seek nursing home care is made only after care needs become more than the family can handle alone and often after supplemental paid-care alternatives to institutionalization have been tried. For these elderly and their family care-givers, it would appear that probably only intensive formal services (perhaps on the order of 20 to 40 or more hours of personal care assistance weekly) could prevent institutionalization. New York is currently one of the few states that will finance this level of intensive personal care service under Medicaid, and New York's program is by far the broadest. In New York, where nursing home care is considerably more expensive than in other parts of the country, it is possible to finance intensive personal care at home at lower cost than nursing home care in many, though not all, cases. For states that pay lower Medicaid nursing home rates, this trade-off would probably be more costly.

Coping Skills: Training and Support Groups

A more limited approach might be to help families cope with specific conditions (such as behavioral disturbances and combative behavior, serious mental confusion, and incontinence) that have frequently been found to precipitate family decisions to seek nursing home placement for an elderly person who had been receiving care at home. It has

been suggested that training and counseling programs and support groups have been successful in helping families cope better with the problems posed by stroke (Mykyta et al. 1976), aphasia (Bardach 1976), and Alzheimer's disease (Lazarus et al. 1981; Safford 1980). For example, such programs have reportedly been able to help relatives of the mentally impaired deal with two problems that have been identified as especially stressful for them as care-givers. These are resentment at the need of the elderly person to deny memory loss (which often results in purposeless argument) and the feelings associated with being the focus of an elderly impaired relative's paranoid ideation (often related to the caretaker kin having had to take control of the elderly person's finances for practical reasons).

Other studies (Haley 1983; Reifler and Eisdorfer 1980) have suggested that families could be taught behavior modification techniques that have been used successfully in nursing homes to deal with a wide variety of behavior problems (urinary incontinence, screaming, self-injurious behavior, and agitation) or to train elderly impaired individuals in more adaptive behaviors (e.g., self-care in dressing and feeding, participation in recreational activity, social interaction, and ambulation).

Respite Services

Many experts believe that families would be better able to tolerate the long-term stress of caring for a disabled elderly person—particularly one afflicted with Alzheimer's disease or some other form of dementia or one with heavy personal care assistance needs—if they were able to obtain periodic respite. Respite care could take many different forms ranging from temporary stay in a nursing home while the family takes a vacation to a few hours per week of "sitter" service so that the principal care-giver of an elderly person who cannot be left alone can have some regular time off. Adult day-care programs can also provide respite for family members when the individual requiring care has heavy personal care needs or must have constant surveillance at night and on weekends. Reliance on day care may also be the only potentially affordable means for working care-givers to manage home care of Alzheimer's or other mentally impaired, heavily dependent elderly.

According to Rathbone-McCuan (1976) day care often represents a "last ditch" effort by the family to maintain an elderly person at

home. A more recent evaluation of a day care program for Alzheimer's patients concluded that such a program can provide an alternative to nursing homes as relief to families caring for a person suffering from Alzheimer's disease or a related disorder in the home. This conclusion, however, was not based on the results of a controlled experiment but rather on "the stated intentions of family members prior to 'discovering' day care rather than a direct comparison with nursing home patients." Costs in 1981 were \$23.35 per day or \$583.75 per month for care for five days per week (Sands and Suzuki 1983).

Government support for services other than day care has also been advocated for purposes of providing family respite. Horowitz (1978) found that when care-givers were provided with services—primarily homemaker, housekeeping and/or companion-aide—two major benefits were identified: (1) freedom to engage in other activities because more time was available, and (2) freedom from the emotional pressure of having primary responsibility for the parent's well-being.

Where resentment was felt by the care-giver in the role reversal of the parent-child relationship, the introduction of an outside source improved the affective quality of the relationship. Gross-Andrews and Zimmer (1977) also found that family care-givers reported alleviation of stress or of disruption in their lives in emotional, physical, social, and financial terms when provided with up to four services: companion aide, personal care worker, homemaker/home attendant, and housekeeper. Provision of services also leaves the care-giver more time and energy to satisfy the emotional needs of the elderly (Dunlop 1980). A study of the Community Service Society of New York's Family Support Program (Frankfather, Smith, and Caro 1981) also found similar benefits in terms of alleviation of stress on care-givers. At the same time, this study also reported that establishing and stabilizing home care services "was not always a smooth process nor was it always productive." The turnover rate among home services providers tended to be high (only 31 percent of clients who had homemakers after one year of service still had the same homemaker and 25 percent had had four or more). Turnover itself and the reasons for it (personality clashes, incompetence, failure to appear regularly or on schedule) can be sources of stress to the disabled elderly and their families.

While the above studies suggest that supportive formal services can reduce the stress on the care-giver, it is yet unclear whether they will prevent or delay institutionalization. If one assumes that social services

programs, by providing instrumental assistance, will permit the caregiver to attend to the elderly person's emotional needs (Seelback and Sauer 1977) and that such emotional support can be crucial in preventing or delaying deterioration in physical functioning (Dunlop 1980), institutionalization may also be delayed or prevented. In a study by Sager (1978) of hospital patients who were to be discharged to nursing homes, the discharge planner believed that three-fourths of the families would have been willing to maintain the patient at home if supportive outside services had been available. In another study, Eggert et. al. (1977) found that family willingness to provide home care to an elderly person following a hospitalization dropped from 70 percent following the first hospitalization to 38 percent following the second hospitalization; the authors speculated that families' initial willingness or capacity to provide home care "appears to be significantly eroded over time when, as it may be assumed, the burden is not shared by supplementary social provisions."

Financial Supports

Another form of governmental assistance to families providing care to elderly impaired relatives that is frequently advocated is financial relief, either in the form of cash payments or expanded tax allowances. As noted earlier, research has found that financial strain is rarely a significant motivation for families to seek nursing home placement for the elderly (Arling and McAuley 1983; Horowitz and Shindleman 1983; Smallegan 1983). Many advocates of financial assistance or relief to family members who care for elderly impaired relatives nevertheless believe that, because there is more government funding of nursing home care than of home care, there are, therefore, financial advantages for relatives (primarily children) to institutionalize the impaired elderly. Thus, it is argued that cash payments or tax allowances for home care would redress or at least cancel out these perverse incentives.

It is by no means evident, however, that these often-cited financial advantages to institutionalization really exist. First, elderly nursing home residents with income and assets above the level that would qualify them for supplemental security income (SSI) payments are required to "spend-down" these resources on a private pay basis before they receive any Medicaid coverage of their nursing home care. Family members who hope to preserve an inheritance would thus do better

financially by providing home care informally in order to avoid the more rapid exhaustion of the individual's assets that would occur if he or she were placed in a nursing home. It is alleged that adult children or other family members often avoid such forfeiture of anticipated inheritances by having their elderly relatives transfer their assets just prior to their entry into a nursing home. Most states, however, have enacted laws prohibiting such transfers of assets within two years of seeking eligibility for Medicaid nursing home coverage. While these laws have certainly not been completely effective in closing all loopholes, they are enforced with sufficient frequency and severity to deter most asset transfers that are not carefully thought out years in advance. In addition, many nursing homes require applicants for admission to commit to remaining private paying patients for specified periods of time before seeking Medicaid coverage. Facilities do this because private pay rates are almost uniformly higher than Medicaid rates. Where the resident is expected to spend-down to Medicaid eligibility prior to the end of the term specified, the family is actually the guarantor that private-pay status will continue and, indeed, some nursing homes require relatives to sign these admissions contracts as "responsible parties." Many families apparently agree to make such payments either because they are unaware that, where brought to court, this practice has been ruled illegal or because they feel that, regardless of legality, this is the only way that they can assure their elderly relative's admission to the nursing home of their choice (National Senior Citizens Law Center 1982, 1983). Currently, such payments to nursing homes on the part of family members other than spouses are not tax-deductible.

On the other side of the equation, financial strain on families caring for the elderly at home is already relieved in several ways. First, most elderly do have some income of their own (even if only Social Security) and often assets (such as a home that can be sold), and these funds can then be used to purchase necessary equipment or formal services not already covered by Medicare, Medicaid, or private insurance. In addition, family members can obtain tax relief for expenditures incurred in caring for elderly relatives under certain limited circumstances (U.S. General Accounting Office 1982).

The child and dependent care tax credit, for example, allows taxpayers a credit against tax liabilities for "dependent" care expenses incurred because they are working. To claim the credit (up to \$2,400 for each

of two dependents), a taxpayer must meet the following conditions: (1) the expenses for care must have been incurred in conjunction with the taxpayer's necessity for gainful employment; (2) the dependent, whether a child or an elderly relative, must have received more than half of that year's support from the taxpayer; (3) the dependent must have a gross annual taxable income of less than \$1,000; and (4) the dependent, if older than 15, must be dependent physically or mentally.

Out-of-pocket vs. In-kind Costs

Unfortunately, there is not enough data available to make a definitive comparison of the out-of-pocket costs to relatives of the impaired elderly of institutional versus noninstitutional care. The data that are available suggest, however, that, where adult children are concerned, the differences may be less than are commonly supposed. For example, according to the Census Bureau's 1976 Survey of Institutionalized Persons, children of the institutionalized elderly contributed a mean annual average of \$160 per resident toward the cost of nursing home care (Callahan et al. 1980). Although this is not a high level of financial support, the amount is remarkably similar to what the U.S. General Accounting Office's (1982) 1976 study of home care of the elderly in Cleveland, Ohio, found to be the average out-of-pocket expenditures by family and friends for at-home care of the elderly disabled—\$172 (in 1975 dollars). According to more recent (but still preliminary) data from the 1982 survey of noninstitutionalized disabled elderly, nonspouses (primarily adult children) caring for the elderly had spent, on average, \$31.07 in extra money on care for disabled elderly in the previous month (which would amount to approximately \$373 per year). Unfortunately, no similar figures are available for 1982 out-of-pocket expenditures by children of nursing home residents.

Clearly, most family care-givers are currently spending far less out-of-pocket on long-term-care expenses than they can currently claim as tax credits under existing tax laws if their relative meets Internal Revenue Service tests of dependency. Their financial contributions to their elderly relatives are primarily in-kind services.

In order for nonworking care-givers to receive financial compensation for the unpaid labor of care-giving, however, tax law would need to be amended to permit credits for the imputed market value of the long-term-care services these relatives provide. The General Accounting

Office's 1976 Cleveland study assigned an imputed annual market value of \$1,748 to the in-kind services (e.g., shopping, doing laundry, preparing meals) provided to the elderly disabled by family care-givers. Horowitz and Dobrof (1982) in a study of a sample of family care-givers in New York City found that adult children spent an average of 18 hours per week providing long-term care informally to their impaired parents. Using the minimum wage to assign "market value" to these services yields a dollar value of slightly over \$3,000 annually. Preliminary data from the 1982 Long-Term Care Survey indicates that the average number of extra hours per day spent by adult children on providing informal long-term care to their impaired elderly parents is 3.7, or almost 26 hours per week (Kenneth Manton, personal communication). Costed out on the basis of the minimum wage, this would have an imputed market value of \$4,529.

Presumably, family members who care for disabled elderly living in the community spend more hours providing in-kind services to their elderly relatives than do family members of elderly impaired relatives in nursing homes. Nevertheless, there is evidence that family members do continue to provide various types of in-kind services to institutionalized elderly. In one study, which questioned relatives of the institutionalized elderly about which services or activities nursing home staff were responsible for and which families were responsible for, it was found that family members saw themselves rather than the nursing home as having primary responsibility for a rather lengthy and presumably time-consuming list of services (Shuttlesworth, Rubin, and Duffy 1982). In sum, if the market value of "in-kind" service were to be considered in estimating costs to relatives who provide home care, then it should be borne in mind that, insofar as relatives of the institutionalized elderly continue to perform many of the same services, they too incur such costs.

The attribution of "market value" to in-kind services is obviously problematic for a number of reasons. First, tax policy has not traditionally recognized any such "expenditures," a major issue if policy makers wish to look to tax allowances to compensate family care-givers. In addition, it is difficult, especially where the person being cared for resides with the care-giver, to separate out strictly those activities performed for the elderly person from those that the care-giver would have performed anyway. It is also not clear that either the minimum wage or the average wage paid to professional home-care workers are

accurate measures of the financial costs borne by family care-givers who would be able to obtain a higher-paying job outside the home.

Compensation vs. Reward

From the standpoint of family members, providing home care probably is perceived most typically not as a form of unpaid employment but in terms of forfeiture of alternative uses of leisure time. This can be inferred from the fact that when asked about the burdens of care-giving, family care-givers typically mention loss of or interferences with personal time rather than work time. The issue is, thus, not at what rate would such work be paid on the market, but what amount of money could be said to represent a just reward or adequate compensation for sacrificing most of one's leisure hours to the care of an elderly relative? Viewed from this perspective, economic incentives for family care might perhaps be better described as having primarily a symbolic value of rewarding persons for acting in accord with shared societal values emphasizing filial responsibilities, despite personal hardship and sacrifice. The question arises, however, if the purpose is to reinforce filial responsibility as a societal value, whether an economic reward is appropriate. As a general rule, altruistic behavior is rewarded in a different currency, or to phrase it another way, behaviors that are social-psychologically rather than economically motivated are usually rewarded "in-kind" in the form of honor, gratitude, and esteem.

In the case of home care, this "psychic transaction" generally takes place between the caretaker and the person being cared for. That is, the caretaker expects and feels that he or she deserves expressions of gratitude from the person being cared for. According to Poulshock (1982) this exchange of gratitude for care-giving is one of the major unspoken "rules" of the care-giving relationship and care-givers feel deeply aggrieved when this rule is broken. Indeed, it appears that providing care to Alzheimer's patients is particularly stressful to family care-givers because, owing to the nature of the personality changes associated with this disease, patients are frequently not only unappreciative of the efforts family members make on their behalf but may be openly hostile, uncooperative, and combative.

In the case of Alzheimer or other mentally impaired patients, it might thus be argued that tax or other financial incentives might

possibly provide the recognition, the "thanks," that the patients themselves are unable to give. Balanced against this argument, however, is the concern that economic rewards even if intended primarily for purposes of recognition may tend to erode or subtly corrupt altruistic motives. Schorr (1980) argues that financial incentives for family care would create a bureaucratic nightmare and, in the long run, subvert filial attachments and responsibility. He asks: "Why would one help a parent for nothing if it seemed that everyone else was being paid?" Arling and McAuley (1983) voice similar concerns that a financial payment system could subvert family values. Payment for care would formalize the family's obligations and its role in care-giving. Does this change the nature of care? Do family members feel more accountable and responsible, or do they become more detached or impersonal, separating their emotional commitment from their "duties" as paid care-givers?

Compensation for the Opportunity Costs of Forgone Employment

A different question is whether family members who would be willing to stay home to provide informal long-term care to elderly impaired relatives but feel that they cannot afford to forgo the income generated by paid employment could be adequately compensated via government-financed financial assistance for the opportunity costs of choosing to remain at home. Such compensation is clearly most feasible in the case of care-givers who forgo employment that would have been paid at or near the minimum wage.

A few states have effectively elected to pursue such a strategy. By far the largest such program is California's In-home Support Services Program funded jointly by state and federal funds under the Community Services Block Grant (formerly known as Title XX). As of 1980, 55.5 percent of the providers of services purchased with these funds were family members or friends of the disabled person (California Department of Social Services 1980). The program is widely perceived as serving an income-maintenance function for the care-givers, the assumption being that without the wages earned by providing these services, many of these individuals, both relatives and nonrelatives of the service recipient alike, might themselves require public assistance (University of California, San Francisco. Aging Health Policy Center 1983).

Subsidizing Paid Care

Government aid to families of the impaired elderly might also take the form of purchasing formal services from nonfamily members, whether directly via service programs or indirectly via cash payments or tax allowances. There are several different purposes for which families might desire formal services. One is to substitute in whole or in part for informal care that family members do not wish to provide or—probably the more frequent case—cannot provide because they are employed.

Family members might also wish to purchase formal services in order to supplement family care, i.e., to meet certain unmet needs that family members either cannot or do not wish to fulfill. Although most impaired elderly living in the community have most of their long-term care needs met informally by family, some also still report additional unmet needs for care (Soldo 1983a; Stoller and Earl 1983; Branch 1980). The third purpose for which family members may wish to purchase formal care is to obtain "respite": that is, time off from care-giving to alleviate stress and prevent "burnout." Although these various purposes can be distinguished analytically, in practice they are often difficult to disentangle. This is problematic insofar as it is frequently a stated aim of policy makers to support respite and supplemental care but not substitute for family effort.

"Substitution" effects are difficult to measure and evaluate because, by definition, respite services intentionally substitute some formal services for informal services (Urban Systems Research and Engineering 1982; Greene 1983). The assumption is that some small-scale, short-term substitution is permissible if it leads to a desired outcome such as prevention or postponement of institutionalization or decrease of emotional stress on care-givers.

Financial vs. Service Strategies

If, fundamentally, the purpose of government assistance is to help families finance paid services outside an institution, the question then arises whether financial strategies such as cash payments or tax allowances or direct services are more appropriate. Cash payments or tax allowances have the apparent advantage of permitting greater flexibility in making arrangements for care, although by the same token they place a greater burden on families to recruit, evaluate the capabilities of, and supervise

the provision of care by paid helpers. From government's point of view, the principal trade-off between tax subsidies for paid care and direct service programs is whether or not cost-sharing by families makes up for or at least balances out against the substantial opportunities such a provision opens up for taxpayer fraud and abuse in the form of filing claims for expenditures never made or overstating payments. State officials in Idaho, which has established a state tax credit for care of the elderly, strongly suspect that a substantial number of the claims made under this provision are fraudulent or "in error" (Bjornstadt 1984). The Internal Revenue Service estimates that 54 percent of current federal tax allowances being claimed for the support of dependent parents are wrongful or erroneous (Health Care Financing Administration, Office of the Actuary, 1982 memorandum).

Another drawback to the use of tax allowances is that they tend to provide the greatest benefit to higher income persons who, presumably, are better able to afford to pay for services privately. Persons on Social Security or SSI or welfare would not even be eligible for assistance via tax allowances except in the form of refundable tax credits, which many would argue are simply cash grants provided through a particularly cumbersome, ill-suited administrative mechanism.

A main argument against both tax allowances and cash grants is that these initiatives are nearly always presented as targeted toward filial adults in order to motivate them to provide care or to compensate them for the imputed economic costs of home care. Most experts, however, believe that the greatest need is for formal services to meet the unmet needs of elderly persons living alone or to provide supplementary or respite care to spouse care-givers.

Many long-term care experts also criticize existing tax allowances and cash grant proposals because they typically require the elderly to live with their care-givers. Horowitz and Dobrof (1982) note that shared households are the least preferred option both to filial adults and their impaired parents. The shared household was also found to be the most stressful pattern of care-giving. Horowitz and Dobrof found risk of institutionalization to be correlated not with actual hours of care provided but with the care-givers' perception of negative consequences of care-giving. Perceptions of negative consequences in turn were highest when care-givers and care-receivers lived together rather than apart. Horowitz and Dobrof note that "it is ironic that a shared household, which is usually an unavoidable response due to

limited financial resources, would be the only care-giving pattern eligible for cash grants, a support which would have made this arrangement unnecessary.”

Arling and McAuley (1983), who studied Virginia elderly applying for Medicaid-financed nursing home care and their families, also argue that to target payments exclusively to families who care for impaired elderly is to target inappropriately. A direct income supplement to the older person, to be used at his or her discretion, could increase the older person's autonomy and allow the individual to choose the method of care that he or she views as most appropriate. It might also reduce dependency upon family members and give the older person a major role in making decisions about the form of care to be employed. Payments made directly to families or other informal care-givers may detrimentally shift control and responsibility away from the impaired older person and increase the feeling of loss or helplessness associated with a disabling condition. In addition, direct income supplements to the impaired elderly would increase the opportunity for those who live alone or who share their households with nonfamily to benefit from the program. To be most effective, direct payments should be made only to those impaired elderly who are mentally competent to handle their own finances, but the design and administration of competency tests would lead to ethical and practical problems as well as increased expense.

Service programs have the advantage of being more readily targeted toward the elderly without close family, especially those who are mentally impaired who are at greatest risk of institutionalization. It is also more practical to administer means tests and/or sliding-scale cost sharing by income in the context of a service program. This is an important point, because, even though severity of disability and low income tend to be correlated, there is great variation in the economic situation of the elderly disabled. Many elderly disabled and their families can afford to pay for or at least share in the costs of the supportive formal services they require. Preliminary data from the 1982 national Long-Term Care Survey indicates that those elderly who are currently using some formal services are paying out-of-pocket (in some cases with help from family) an average of \$164 per month (Liu, Manton, and Liu 1986). Because the elderly and their families clearly have some capacity to pay for formal home care services, many experts argue that government financing for such care should be

restricted to the poor or the near-poor, with the exception of referral and case-management services which should be made available regardless of income to all disabled elderly and their families at no or low cost. The Department of Health and Human Services "channeling" agency demonstrations are currently testing and evaluating such an approach; results of the evaluation are expected to become available in late 1985 or early 1986 (Mary Harahan, U.S. Department of Health and Human Services, Assistant Secretary for Planning and Evaluation, 1984, personal communication).

A number of experts (Pollak 1973; Gruenberg and Pillemer 1980; Feder, Holahan, and Scanlon 1980) see vouchers as a potentially attractive way to reconcile the best features of both the financial payment and service program options. The State of Wisconsin experimented with vouchers for long-term care services in its Consumer-Directed Services Project as a means of empowering the disabled, and, on balance, evaluated the results as favorable (Griss 1984). Vouchers resemble cash in that they permit greater flexibility and exercise of client preference than direct service programs, yet they do not require as high a level of competence as it takes to manage cash. Under a voucher program, elderly clients and their families could compensate for problems of mental impairment or lack of adequate information about appropriate and available services by electing to purchase case management or referral services. Several experts (Frankfather, Smith, and Caro 1981; Horowitz and Dobrof 1982; Poulshock 1982) argue that direct-service programs or voucher approaches designed to support family care should focus formal services on those tasks that family members find particularly onerous or stressful, rather than on those tasks that a professional judges to be most appropriate based on patients' disabilities.

Preferences of Family Care-givers

Existing research findings suggest that families actually involved in providing home care (as opposed to survey respondents asked about a hypothetical situation) prefer direct-service programs to either cash payments or tax allowances (Sussman 1977, 1979; Horowitz and Shindleman 1983). In the Horowitz and Shindleman study, 203 individuals providing informal care to impaired elderly relatives in New York City were asked to rank their preferences for various different types of service and economic support programs. Eighty percent of

the care-givers selected a direct-service program, with the most common preferences being for at-home medical services or homemaker services. Among the economic support options offered, cash payments in the form of a monthly check were by far the most popular; however, only 10 percent of the total sample ranked this as their preferred option overall as compared to 26 percent whose preferred option was homemaker services, 25 percent who preferred medical services, and 12 percent who preferred social day care. Only 1.5 percent of the family care-givers cited a tax deduction as their preferred mode of obtaining governmental support.

The Harkins (1985) study of the Virginia Pre-Admission Screening Program asked family care-givers of the elderly seeking nursing home placement what supportive public policies, had they been available, might have prevented or delayed the family's decision to seek nursing home placement for the elderly relative. The policy options that family care-givers said were least likely to have prevented or postponed institutionalization were a \$500 to \$1,500 tax credit and respite care; 88.5 percent said that a tax credit for costs of care would have had no effect on their decision, and 87.4 percent said the same for respite care. In contrast, 22 percent of the family care-givers said that 20 to 40 hours of direct-service provision (including personal care, meal preparation, etc.) would have delayed their relative's nursing home entry by 6 months or more and another 14 percent said that availability of these services would have postponed institutionalization for a short period (less than six months). Even though direct services were the most-preferred option, nearly two-thirds of care-givers said that these services would not have prevented or postponed institutionalization. It is important to note that 71 percent of those approved for nursing home entry required constant supervision. Of those who did enter a nursing home, 50 percent had been cared for in the community for two years or more prior to seeking nursing home admission; 25 percent had been receiving home care for over five years before entering a nursing home.

Conclusion

There is little evidence to support the belief that families have become or are becoming less willing to provide home care to elderly impaired relatives than in the past. Informal family care-giving remains at a

high level. Some current demographic trends (such as fewer children, the differential life expectancy of men and women, and the increasing rate of divorce, all of which result in more elderly women living alone) are also likely to result in a lesser availability of family members to provide home care in the future. Increasing labor force participation by women may or may not erode family care-giving; the research results are contradictory.

The primary motivations for families to provide informal long-term care to an impaired elderly relative are a sense of family responsibility, affection for the individual, and a desire to reciprocate past help given by the impaired elderly person. Family members frequently undertake to provide home care based on a sense of family responsibility alone, despite a troubled relationship, but care-giving tends to be less intense (in terms of hours per week) and burnout occurs more rapidly where the care-giver feels little affection for the impaired elderly relative. Family members' primary reasons for refusing to undertake or to continue a significant home care commitment appear to be based on a perception that the impaired elderly relative requires more care or a level of care (e.g., professional medical/nursing services) than the family member is able to provide and/or a perception that providing care will interfere with other family duties or be emotionally disruptive (e.g., because the care-giver's spouse and the elderly impaired person do not get along). Financial motivations are rarely an issue.

Because the motivations both for and against family willingness to undertake or to continue providing significant amounts of informal long-term care are primarily emotional, it appears unlikely that cash grants or tax allowances would have much effect in terms of preventing institutionalization by motivating family to provide home care they would not otherwise have provided. Moreover, an irony in trying to use tax incentives to support family care-giving is that families who themselves provide home care services to their relatives have no "expenditures" to claim. In order to benefit from tax allowances, families would need to hire paid care-givers to replace or supplement their own efforts. Public policies aimed at alleviating the emotional stress associated with care-giving (i.e., training, counseling and support groups, and direct-service programs that offer respite or that relieve family members of certain tasks they find especially onerous or stressful) are likely to be more effective in preventing or postponing institutionalization. At the same time it is questionable at best whether the

impact of such programs in terms of preventing or postponing government-financed nursing home care would be sufficient to produce net cost savings. The main effect of programs undertaken by government to support family care-givers of the impaired elderly would be to reduce the negative consequences (i.e., the emotional stress, fatigue and loss of personal time) to families who have made a commitment to provide informal home care to their disabled elderly relatives and who would continue to provide such care with or without government aid.

References

- Arling, G., and W.J. McAuley. 1983. The Feasibility of Public Payments for Family Caregiving. *Gerontologist* 23:300-6.
- Atchley, R.C., and S.J. Miller. 1980. Older People and Their Families. In *Annual Review of Gerontology and Geriatrics*, vol. 1, ed. C. Eisdorfer, 337-39. New York: Springer.
- Bardach, J.L. 1976. Group Session with Wives of Aphasic Patients. *International Journal of Group Psychotherapy* 19:361-65.
- Barney, J.L. 1977. The Prerogative of Choice in Long-term Care. *Gerontologist* 17:309-14.
- Bjornstadt, P. 1984. Tax Benefits for Long-term Care of the Elderly: The Idaho Experience. In *Long Term Care Financing and Delivery Systems: Exploring Some Alternatives*. Conference Proceedings. Washington: Health Care Financing Administration.
- Branch, L. 1980. *Vulnerable Elders*. Gerontological monographs no. 6. Washington: Gerontological Society of America.
- Brody, E. 1981. Women in the Middle. *Gerontologist* 21:471-80.
- . 1985. Parent Care as a Normative Family Stress. *Gerontologist* 25:19-29.
- Brody, E., M.H. Kleban, and C. Johnson. 1984. Women Who Provide Parent Care: Characteristics of Those Who Work and Those Who Do Not. Paper presented at the Annual Meeting of the Gerontological Society, San Antonio, November.
- Brody, S., S.W. Poulshock, and C. Masciocchi. 1978. The Family Caring Unit: A Major Consideration in the Long-term Support System. *Gerontologist* 18:556-61.
- Brody, E., and G. Spark. 1966. Institutionalization of the Aged: A Family Crisis. *Family Process* 5:76-90.
- Butler, L.H., and P.W. Newacheck. 1981. Health and Social Factors Relevant to Long-term Care Policy. In *Policy Options in Long-term*

- Care, ed. J. Meltzer, F. Farrow, and H. Richman, 38–75. Chicago: University of Chicago Press.
- Butler, R.N. 1983. An Overview of Research on Aging and the Status of Gerontology Today. *Milbank Memorial Fund Quarterly/Health and Society* 61:351–96.
- California. Department of Social Services. 1980. *In-Home Supportive Services: April 1980 Survey of Selected Characteristics*. Sacramento.
- Callahan, J.J., Jr., L.D. Diamond, J.Z. Giele, and R. Morris. 1980. Responsibility of Families for Their Severely Disabled Elders. *Health Care Financing Review* 1:29–48.
- Cantor, M. 1980. Caring for the Frail Elderly: Impact on Family, Friends, and Neighbors. Paper presented at Annual Meeting of the Gerontological Society of America, San Diego, November.
- . 1983. Strain among Caregivers: A Study of Experience in the United States. *Gerontologist* 23:597–602.
- Chang, T.Y., and C. Swart. 1983. *Natural Caregiving and Frail and Functionally Impaired Elderly in Wisconsin: A Profile Report on Supports for Natural Caregivers*. Madison: Office on Aging, Bureau of Human Resources, Division of Community Services, Wisconsin Department of Health and Social Services.
- Chiswick, B.R. 1976. The Demand for Nursing Home Care: An Analysis of the Substitution between Institutional and Noninstitutional Care. *Journal of Human Resources* 11:295–316.
- Cicirelli, V.G. 1980. Personal Strains and Negative Feelings in Adult Children's Relationship with Elderly Parents. Paper presented at the Annual Meeting of the Gerontological Society of America, San Diego, November.
- . 1983. A Comparison of Helping Behavior to Elderly Parents of Adult Children with Intact and Disrupted Marriages. *Gerontologist* 23:619–25.
- Clark, N.M., and W. Rakowski. 1983. Family Caregivers of Older Adults: Improving Coping Skills. *Gerontologist* 23:637–42.
- Clinkscale, R., B. Burwell, C. Brudevold, G. Jones, and S. McCue. 1985. *Financial Incentives for Family Care*. Rockville, Md.: LaJolla Management Corp. and SysteMetrics, Inc.
- Crystal, S. 1982. *America's Old Age Crisis: Public Policy and the Two Worlds of Aging*. New York: Basic Books.
- Dunlop, B. 1980. Expanded Home-based Care for the Impaired Elderly: Solution or Pipe Dream? *American Journal of Public Health* 70:514–19.
- Eggert, G., C. Granger, R. Morris, and S. Pendleton. 1977. Caring for the Patient with Long-term Disability. *Geriatrics* 32:102–14.
- Feder, J., J. Holahan, and W. Scanlon. 1980. *A Proposal for Extending*

- Medicaid to Cover Noninstitutional Long-term Care Services*. Working paper no. 1438-00. Washington: Urban Institute.
- Fengler, A., and N. Goodrich. 1979. Wives of Elderly Disabled Men: The Hidden Patients. *Gerontologist* 19:175-83.
- Frankfather, D.L., M.J. Smith, and F.G. Caro. 1981. *Family Care of the Elderly*. Lexington, Mass.: Lexington Books, D.C. Heath.
- Gelfand, D.W., J.K. Olsen, and M.R. Block. 1978. Two Generations of Elderly in the Changing American Family: Implications for Family Services. *Family Coordinator* (October):395-403.
- Greene, V.L. 1983. Substitution between Formally and Informally Provided Care for the Impaired Elderly in the Community. *Medical Care* 21:609-19.
- Griss, B. 1984. *The Role of Vouchers in Long-term Support*. Madison, Wisconsin: Department of Health and Social Services, Division of Community Services, Office of Program Initiatives.
- Gross-Andrews, S., and A. Zimmer. 1977. Incentives to Families Caring for Disabled Elderly: Research and Demonstration Project to Strengthen the National Supports System. Paper presented at the Annual Meeting of the Gerontological Society of America, San Francisco, November.
- Gruenberg, E.M. 1977. The Failures of Success. *Milbank Memorial Fund Quarterly/Health and Society* 55:3-24.
- Gruenberg, L., and K. Pillemer. 1980. Disability Allowance for Long-term Care. In *Major Reforms in Long Term Care*, ed. S. Wallack and J. Callahan. Waltham, Mass.: Brandeis University, Center for Health Policy Analysis and Research. (Unpublished.)
- Haber, C. 1983. *Beyond Sixty-five: The Dilemma of Old Age in America's Past*. Cambridge: Cambridge University Press.
- Haley, W.E. 1983. A Family Behavioral Approach to the Treatment of the Cognitively Impaired Elderly. *Gerontologist* 23:18-20.
- Harkins, E. 1985. *Family Support and Costs of Services for the Frail Elderly: Final Report*. HCFA grant no. 18-P-98080/3. Richmond: Virginia Center on Aging, Virginia Commonwealth University.
- Horowitz, A. 1978. Families Who Care: A Study of Natural Support Systems of the Elderly. Paper presented at the Annual Meeting of the Gerontological Society of America, Dallas, November.
- Horowitz, A., and R. Dobrof. 1982. The Role of Families in Providing Long-term Care to the Frail and Chronically Ill Elderly Living in the Community. Final Report. Health Care Financing Administration grant no. 18-P-97541/20-02. (Unpublished.)
- Horowitz, A., and L. Shindelman. 1980. The Impact of Caring for an Elderly Relative. Paper presented at the Annual Meeting of the Gerontological Society of America, San Diego, November.

- . 1983. Social and Economic Incentives for Family Caregivers. *Health Care Financing Review* 5:25–33.
- Johnson, C. 1979. Impediments to Family Supports to Dependent Elderly: An Analysis of the Primary Caregivers. Paper presented at the Annual Meeting of the Gerontological Society of America, Washington, November.
- Johnson, C., and D.J. Catalano. 1983. A Longitudinal Study of Family Supports to Impaired Elderly. *Gerontologist* 23:612–18.
- Katz, S., L. Branch, M. Branson, M. Papsidero, J.C. Beck, and D.S. Greer. 1983. Active Life Expectancy. *New England Journal of Medicine* 309:1218–24.
- Lazarus, L.W., B. Stafford, K. Cooper, B. Cohler, and M. Dyken. 1981. A Pilot Study of an Alzheimer Patients' Relatives Discussion Group. *Gerontologist* 21:352–58.
- Lebowitz, B. 1978. Old Age and Family Functioning. *Journal of Gerontological Social Work* 2:111–18.
- Liu, K., K.G. Manton, and B.M. Liu. 1986. Home Care Expenses for Noninstitutionalized Elderly with ADL and IADL Limitations. *Health Care Financing Review* (in press).
- Louis Harris and Associates, Inc. 1982. *Priorities and Expectations for Health and Living Circumstances: A Survey of the Elderly in Five English-speaking Countries*. A study for the Commonwealth Fund. New York: Harris and Associates.
- Lowenthal, M.S. 1964. *Life in Distress*. New York: Basic Books.
- Manton, K.G. 1982. Changing Concepts of Morbidity and Mortality in the Elderly Population. *Milbank Memorial Fund Quarterly/Health and Society* 60:183–244.
- Manton, K.G., and K. Liu. 1984. The Future of the Long-term Care Population: Projections Based on the 1977 National Nursing Home Survey and the 1982 Long-Term Care Survey. Paper presented at the Hillhaven Third National Leadership Conference on Long-Term Care Issues, The Future World of Long-Term Care, Washington, March 7–9.
- Mindel, C. 1979. Multigenerational Family Households: Recent Trends and Implications for the Future. *Gerontologist* 19:456–63.
- Mykyta, L.J., J.H. Bowling, D.A. Nelson, and E.J. Lloyd. 1976. Caring for Relatives of Stroke Patients. *Age and Aging* 5:87–90.
- Nardone, M. 1980. Characteristics Predicting Community Care for Mentally Impaired Older Persons. *Gerontologist* 20:661–68.
- National Senior Citizens Law Center. 1982. Nursing Home Private Pay Admissions Requirements. *Nursing Home Law Letter*, no. 55 (January). Los Angeles and Washington.

- . 1983. Private Pay Duration of Stay Contracts. *Nursing Home Law Letter*, nos. 75, 76 (August, September). Los Angeles and Washington.
- Pollak, W. 1973. *Federal Long-term Care Strategy: Options and Analysis*. Washington: Urban Institute.
- Poulshock, W. 1982. The Effects on Families of Caring for Impaired Elderly in Residence. Executive Summary, Final Report. Administration on Aging grant no. 90-AR-2112. (Unpublished.)
- Rathbone-McCuan, E. 1976. Geriatric Day Care: A Family Perspective. *Gerontologist* 16:517-21.
- Reifler, B.V., and C. Eisdorfer. 1980. A Clinic for the Impaired Elderly and Their Families. *American Journal of Psychiatry* 137:1399-1403.
- Safford, F. 1980. A Program for Families of the Mentally Impaired Elderly. *Gerontologist* 20: 656-60.
- Sager, A. 1978. Learning the Home Care Needs of the Elderly: Patient, Family, and Professional Views of an Alternative to Institutionalization. Final report to the Administration on Aging, grant no. 90-A-1026. Washington.
- Sainsbury, P., and J. Grad de Alarcon. 1970. The Effects of Community Care on the Family and the Geriatric Patient. *Journal of Geriatric Psychiatry* 1:23-41.
- Sands, D., and T. Suzuki. 1983. Adult Day Care for Alzheimer's Patients and Their Families. *Gerontologist* 23:21-23.
- Sanford, J. 1975. Tolerance of Debility in Elderly Dependents by Supporters at Home: Its Significance for Hospital Practice. *British Medical Journal* 3:417-73.
- Sangl, J.A. 1983. The Family Support System of the Elderly. In *Long Term Care: Perspectives for Research and Demonstrations*. eds. R.J. Vogel and H.C. Palmer, 307-36. Washington: Health Care Financing Administration.
- Schorr, A. 1980. Thy Father and Thy Mother Social Security Administration publication no. 13-11953. Baltimore, Md.: Social Security Administration.
- Seelback, W. 1977. Gender Differences in Expectations for Filial Responsibility. *Gerontologist* 17:421-25.
- Seelback, W., and W. Sauer. 1977. Filial Responsibility Expectations and Morale among Aged Parents. *Gerontologist* 17:492-99.
- Shanas, E. 1979a. Social Myth as Hypothesis: The Case of the Family Relations of Old People. *Gerontologist* 19:3-9.
- . 1979b. The Family as Support System in Old Age. *Gerontologist* 19:169-74.

- Shuttlesworth, G., A. Rubin, and M. Duffy. 1982. Families versus Institutions: Incongruent Role Expectations in the Nursing Home. *Gerontologist* 22:200-8.
- Silverstone, B. 1978. The Family is Here to Stay. *Journal of Nursing Administration* 8:47-51.
- Smallegan, M. 1983. How Families Decide on Nursing Home Admission. *Geriatric Consultant* (March-April):21-24.
- . 1985. There Was Nothing Else to Do: Needs for Care before Nursing Home Admission. *Gerontologist* 25:364-69.
- Smith, K., and V. Bengtson. 1979. Positive Consequences of Institutionalization: Solidarity between Elderly Parents and Middle-aged Children. *Gerontologist* 19:438-47.
- Smyer, M. 1980. The Differential Usage of Services by Impaired Elderly. *Journal of Gerontology* 35:249-55.
- Soldo, B.J. 1983a. *In-home Services for the Dependent Elderly: Determinants of Current Use and Implications for Future Demand*. Washington: Urban Institute.
- . 1983b. *The Home Care Population: National Prevalence Rates. Select Characteristics and Alternative Sources of Assistance*. Washington: Urban Institute.
- Soldo, B.J., and K.G. Manton. 1985. Health Status and Service Needs of the Oldest Old: Current Patterns and Future Trends. *Milbank Memorial Fund Quarterly/Health and Society* 63:286-319.
- Soldo, B.J., and M. Sharma. 1980. Families Who Purchase versus Families Who Provide Care Services to Elderly Relatives. Paper presented at the Annual Meeting of the Gerontological Society of America, San Diego, November.
- Stoller, E., and L. Earl. 1983. Help with Activities of Everyday Life: Sources of Support for the Noninstitutionalized Elderly. *Gerontologist* 23:64-70.
- Sussman, M. 1977. Incentives and Family Environments for the Elderly. Final Report to Administration on Aging grant no. 90-A-316. (Unpublished.)
- . 1979. Social and Economic Supports and Family Environments for the Elderly. Final Report to the Administration on Aging. grant no. 90-A-316(03). (Unpublished.)
- Tobin, S., and R. Kulys. 1979. The Family and Services. In *Annual Review of Gerontology and Geriatrics*, ed. C. Eisdorfer, 370-99. New York: Springer.
- U.S. Bureau of the Census. 1983a. America in Transition: An Aging Society. *Current Population Reports*, special studies, series P-23, no. 128. Washington.
- . 1983b. *Census of Population: 1980*. Vol. 1. Characteristics

- of the Population. Chapter C. Detailed Population Characteristics. Part 1, U.S. Summary. Washington.
- U.S. Department of Health and Human Services. Assistant Secretary for Planning and Evaluation. 1981. *Working Papers on Long-Term Care Prepared for the 1980 Undersecretary's Task Force on Long-term Care*. Washington.
- U.S. General Accounting Office. 1977. Home Health: The Need for a National Policy to Better Care for the Elderly. Report no. RD-78-19. Washington.
- . 1982. Assessment of the Use of Tax Credits for Families Who Provide Health Care to Disabled Elderly Relatives. Report no. GAO/IPE-82-7. Washington.
- University of California, San Francisco. Aging Health Policy Center. 1983. California Case Study: State Discretionary Policies and Services in the Medicaid, Social Services, and Supplemental Security Income Programs. HCFA grant no. 18-P-97620/0. (Unpublished.)
- Urban Systems Research and Engineering. 1982. *In-home Services and the Contribution of Kin: Substitution Effects in Home Care Programs for the Elderly*. Final Contract Report to the Office of the Assistant Secretary for Planning and Evaluation, Department of Health and Human Services. Boston.
- Wan, T.H. 1980. Effects of Family and Informal Network on the Use of Skilled Nursing Facilities among the Disabled Elderly. Paper presented at the Annual Meeting of the Gerontological Society of America, San Diego, November.
- York, J.L., and R.J. Caslyn. 1977. Family Involvement in Nursing Homes. *Gerontologist* 17:492-99.
- Zarit, S., K. Reever, and J. Bach-Peterson. 1980. Relatives of the Impaired Elderly: Correlates of Feelings of Burden. *Gerontologist* 20:649-55.

Acknowledgments: The author is grateful to Kenneth Manton of Duke University for performing some special runs on the 1982 Department of Health and Human Services Long-Term Care Survey, to Joshua Wiener, Judy Sangl, Marni Hall, and Brian Burwell for helpful comments on previous drafts of this paper, and to Anita J. Moore for her efficient secretarial assistance. The findings and conclusions of this article are the sole responsibility of the author and do not represent the views or policies of the Health Care Financing Administration.

Address correspondence to: Pamela Doty, Ph.D., Office of Legislation and Policy, Health Care Financing Administration/DHHS, Room 345-G, Humphrey Building, 200 Independence Avenue, S.W., Washington, DC 20201.