

Spouses and Children of Disabled Elders: How Large a Constituency for Long-term Care Reform?

ROBYN I. STONE and PETER KEMPER

*National Center for Health Services Research
and Health Care Technology Assessment*

THE AGING OF THE POPULATION HAS INCREASED concern about the financing and delivery of long-term care to the elderly population. Numerous strategies for public and private financing of long-term care are currently being debated (see, for example, Rivlin et al. 1988; Ball 1989). Regardless of the options pursued, the family is, and will continue to be, a critical component of the long-term care system.

Policy makers have begun to recognize the link between long-term care policies and family needs. The Medicare catastrophic legislation passed in 1988 authorized Medicare to pay for up to 80 hours of home care annually to provide respite to primary informal caregivers once the catastrophic medical cost deductible has been met. Although this legislation was repealed in 1989, efforts to help caregivers are continuing at the state level. A number of programs provide modest respite care benefits, and some states without programs are considering establishing them (Stone 1985). Several states have programs that pay family members to give care (Linsk, Keigher, and Osterbusch 1988).

Particular attention is now focused on employed caregivers who juggle work and elder care responsibilities. Proposed federal legislation would require employers to give 10 weeks of unpaid leave over two years and continued health insurance coverage to employees who must take time off to care for a disabled parent (U.S. General Accounting

Office 1989). Four states already have enacted such legislation (Wisensale and Allison 1988). Corporations (e.g., IBM, AT&T, Johnson & Johnson, Dupont, Aetna Life and Casualty) have initiated employer-based programs to assist working caregivers. These include support groups, individual counseling, computerized data banks with information on long-term care services, adult day care at worksites, and respite care.

Although probably among the most intensely affected, those who balance primary care responsibility and work are not the only people with a direct interest in policies concerning long-term care of the disabled elderly. Many caregivers do not have competing work responsibilities; others help with care but do not assume primary responsibility. A still broader group, all those with a disabled elderly relative, are affected by the relative's need for care even though they are not active caregivers. Some may help by giving financial, emotional, or case-management support; most are touched in some way by often difficult decisions about how care is to be provided. This broader group of family members are potential beneficiaries of expanded public or private financing of long-term care and also the group whose behavior may change in response to long-term care policy initiatives.

Although some information is available on the population actively giving care to disabled elders (Stone, Cafferata, and Sangl 1987; Opinion Research Corporation 1988), almost no information on the broader group of potential caregivers is available. Researchers at the New York State Office on Aging (1983) used aggregated data to construct a "family care dependency ratio"—the number of functionally disabled elders divided by the number of people in the cohort of their children. While such a ratio provides a crude estimate of the number of children who are potential caregivers, it reveals little about the actual availability of caregivers to the particular elders who are disabled and nothing about potential caregivers' characteristics.

The purpose of this article is to describe the population potentially affected by long-term care policy as family members—both the larger population of immediate kin who are potential caregivers and the smaller population of active caregivers. Specifically, the article estimates the number of persons in the United States who are spouses or children of disabled elders, describes their characteristics, and compares them to the entire United States population. The article then estimates the number of spouses and children who actually give care and estimates

the prevalence of caregiving among age groups. Finally, it estimates the size of the population affected most intensely, i.e., active caregivers who have competing responsibilities for child care or employment.

Data and Methods

Estimates are based on data derived from the 1984 National Long-term Care Survey, a survey of a nationally representative sample of chronically disabled elders. The elderly person, a proxy respondent, or a staff member of an institution was asked for information about the elders and their spouses and children.

"Disabled elders" in this study are persons aged 65 or older who are in institutions or are disabled and in the community. Institutions include nursing homes, mental health facilities, and chronic disease hospitals. (Elders in personal care homes without a health professional on duty 24 hours a day are treated as community residents.) Disabled community elders are persons who require human assistance (hands-on help or supervision) with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs) for at least three months. The ADLs are eating, transferring, toileting, dressing, and bathing. The IADLs are meal preparation, light housework, laundry, getting around outside, grocery shopping, telephoning, taking medication, and financial management. Excluded from this definition are elders who have ADL or IADL limitations but are able to perform the activities with special equipment. (For further detail on the definition of disabled elder used in this analysis, see Stone and Murtaugh 1988.) The spouses and children of these disabled elders are the "potential caregivers" who are the subject of the analysis.

The National Long-term Care Survey did not collect information on other relatives unless they were caregivers or lived with the elderly respondent. Spouses and children are, however, the dominant informal caregivers. Of the 7.3 million informal caregivers (defined as relatives, friends, or others who are not paid or from a helping organization) who provide help with ADLs or IADLs, close to three-fifths are spouses and children. Almost three-quarters of primary caregivers are spouses and children. (A table describing the relation of active caregivers to disabled elders is available from the authors on request.) Spouses and children are also the most likely beneficiaries of caregiver programs. For

example, the proposed federal legislation to extend unpaid leave to employees for elder care would limit benefits to children and spouses.

Spouses and children are considered potential caregivers regardless of whether the disabled elder is in an institution or the community. They are all immediate family members who face care decisions and are affected by changes in long-term care policy. They are also a group whose behavior may change in response to policy changes. A person with both young children and a disabled parent, for example, is a member of the "sandwich generation," whether the parent is in an institution or the community.

A sample of 4,639 elders meet the study definition of disabled elder and have a surviving spouse or child. They represent a total population of 4.4 million elders, 3.5 million in the community and 0.9 million in institutions. Associated with these disabled elders are 1,845 spouses and 12,735 children which together form the sample for this analysis.

In focusing on this group of spouses and children of chronically disabled elders as defined by need for help with ADLs or IADLs the analysis omits some informal care. The National Long-term Care Survey did not collect data on elders who need care due to cognitive or other impairment but do not need hands-on help or supervision with ADLs or IADLs; elderly community residents who need help for conditions that are not chronic (e.g., post-hospital care); or the nonelderly disabled. The type of help examined in this study is assistance with ADLs or IADLs at home. Data on financial or emotional support, assistance with tasks other than ADLs or IADLs, and care in institutions were not collected in the survey. (There is evidence that families and friends continue to provide unpaid assistance to disabled elders after they have been placed in a nursing home. See Clark and Pelham 1983; Hatch and Franken 1984; Montgomery 1983.)

To construct estimates of the national population of spouses and children who are potential caregivers, we adjusted the survey's weights to allow for the dual chance of selection of children with two disabled parents. (An appendix describing these weights is available from the authors on request.) In the tables that follow, estimates that may be unreliable because they are based on fewer than 75 cases or where their relative standard errors are greater than 30 percent are noted. In addition, differences are discussed in the text only if they are statistically significant at the 5 percent level.

Misreporting and item nonresponse are always problems in surveys.

They are especially understandable in this case, where disabled elders or proxy respondents were asked to provide information about spouses and children. This is particularly true for the institutionalized population, where information on spouses and children was obtained from personnel in institutions. Yet, the extent of missing data was small overall—between 0.2 and 9.0 percent depending on the item. As expected, it was concentrated in the children and spouses of institutionalized elders.

Values were assigned to missing items by first editing and then imputation. Elderly respondents in 1982 who were followed up in 1984 were asked identical questions about spouses and children in both years. Whenever possible, we used the 1982 data to fill in missing values for 1984 (e.g., children's ages and genders). The remaining missing values were imputed using a "hot deck" statistical procedure developed at the Research Triangle Institute (Iannacchione 1982).

Misreporting could have affected our estimates of the number of children. On the one hand, the disabled elders or their proxies could have failed to report children altogether, and on the other, they could have included grandchildren and children-in-law as children. (Misreporting of spouses, also a possibility, would be expected to be a smaller problem.)

No data on the children and spouses of disabled elders exist for comparison, but we can compare the number of surviving children of women reported for the full National Long-term Care Survey (including the nondisabled) with data from a special census study of number of children ever born to elderly women (U.S. Bureau of the Census 1984). Contrary to what one would expect, the National Long-term Care Survey found a smaller proportion of mothers with no children than the census survey (21.9 versus 23.7 percent). (A table comparing the two sets of estimates is available from the authors on request.) This suggests that the National Long-term Care Survey may overestimate somewhat the number of children of the elderly population, at least compared to the census special study.

Despite its limitations, the data set has unique strengths. It contains basic characteristics of all spouses and children of a large, nationally representative sample of disabled elders. It also documents the care each helper gives. The survey differs from earlier ones in that it is nationally representative and covers all spouses and children including those who do not give care.

Potential Caregivers

Approximately 13.3 million people are spouses or children of disabled elders and, therefore, have the potential responsibility for their care (table 1). The vast majority of these potential caregivers (11.4 million) are children, with roughly equal numbers of daughters and sons.

Over one-half of the potential care responsibility falls on 1.2 million spouses aged 70 or older and 6.6 million middle-aged children between 45 and 64 years old. An additional 738,000 potential caregivers are elderly children with very old parents.

As indicated, because nursing home care is one of several options available to families faced with long-term care decisions, these estimates include potential caregivers of disabled elders living in institutions as well as those in the community. Most spouses live with their disabled spouse—only 7.5 percent of wives and 9.6 percent of husbands have spouses in institutions. In contrast, most daughters and sons live apart from their disabled parents—only 11.3 percent of the daughters and 7.1 percent of sons live with their disabled parents. About 15 percent of daughters and sons have disabled parents living in institutions.

The vast majority of spouses and children have others in their immediate family networks who are potentially available to share care responsibilities. An important minority of spouses and children, however, have no other close family members to help make care decisions—14.0 percent of wives and 18.8 percent of husbands have no living children, and about 7 percent of children have neither a parent nor siblings to share in the care decision.

A little over 7 out of 10 daughters and 8 out of 10 sons with a disabled parent are married. The vast majority of potential caregivers are white.

To provide perspective on the number of spouses and children faced with elder care decisions, the potential caregiver population is compared with the United States population in each age group in table 2. Of all persons aged 14 and over in the United States, 7.0 percent have a disabled elderly spouse or parent. Potential care responsibility is most prevalent among the group aged 45 to 54, where 1 person out of 6 is a potential caregiver. This proportion declines with age, but even among those aged 75 or older, 7.0 percent of the United States population are potential caregivers.

TABLE 1
 Characteristics of Spouses and Children of Disabled
 Elders in the Community or in Institutions

	Wives	Husbands	Daughters	Sons	All
Population (thousands)	1,059	803	5,838	5,589	13,289
Percentage distribution					
Age					
14-34	0.2% [†]	0.2% [†]	10.6%	10.3%	9.0%
35-44	0.6 [†]	0.1 [†]	25.3	25.9	22.1
45-54	2.5	0.5 [†]	31.9	33.3	28.2
55-64	20.2	3.7	25.3	24.5	23.2
65-69	21.2	14.3	4.8	4.5	6.5
70-74	25.6	26.6	1.9	1.2	5.0
75-84	25.6	41.3	0.2 [†]	0.3	4.7
85+	4.1	13.3	0.0 [†]	0.0 [†]	1.1
Total	100.0	100.0	100.0	100.0	100.0
Living arrangement					
With disabled elder	92.5	89.8	11.3	7.1	20.7
Separately					
Elder in community	0.0 [†]	0.6 [†]	73.5	78.0	65.2
Elder in institution	7.5	9.6	15.2	14.9	14.1
Total	100.0	100.0	100.0	100.0	100.0
Other immediate kin					
No others ^a	14.0	18.8	7.2	6.4	8.1
At least one other	86.0	81.2	92.8	93.6	91.9
Total	100.0	100.0	100.0	100.0	100.0
Marital status					
Married	100.0	100.0	71.7	80.0	79.1
Not married ^b	--	--	28.3	20.0	20.9
Total	100.0	100.0	100.0	100.0	100.0
Race ^c					
Black	10.1	8.0	14.2	12.3	12.7
White or other ^d	89.9	92.0	85.8	87.7	87.3
Total	100.0	100.0	100.0	100.0	100.0

Source: 1984 National Long-term Care Survey.

Note: Detail may not sum to total due to rounding.

^a For wives and husbands, "no others" means those with no living children; for children, "no others" means those with no living siblings and only the disabled parent.

^b "Not married" includes widowed, divorced, separated, and never married.

^c The race of spouses and children was assumed to be the same as the reported race of the disabled elder. According to the U.S. Census Bureau (1986, table 15), only 0.3 percent of all United States marriages are interracial.

^d "Other" includes Asians, Indians, Eskimos, and other races.

[†] May not be reliable; estimate is based on fewer than 75 cases or relative standard error is greater than 30 percent.

TABLE 2
Potential Caregivers by Age and by Elderly Spouse's
or Parent's Level of Disability

Age of potential caregiver	Disability of elderly spouse or parent				Total
	ADLs ^a			IADLs ^b only	
	3-5 ADLs	1-2 ADLs	Any ADLs		
Potential caregivers (thousands)					
14-34	309	349	658	544	1,202
35-44	818	790	1,608	1,328	2,936
45-54	1,057	985	2,042	1,707	3,749
55-64	1,100	778	1,878	1,208	3,087
65-74	562	407	968	565	1,533
75+	285	194	478	303	781
Total	4,130	3,503	7,634	5,655	13,289
Percentage of U.S. Population ^c					
14-34	0.4%	0.4%	0.8%	0.6%	1.4%
35-44	2.7	2.6	5.3	4.3	9.6
45-54	4.7	4.4	9.1	7.6	16.7
55-64	4.9	3.5	8.4	5.4	13.8
65-74	3.4	2.4	5.8	3.4	9.2
75+	2.5	1.7	4.3	2.7	7.0
Total	2.2	1.9	4.0	3.0	7.0

Source: 1984 National Long-term Care Survey; U.S. Bureau of the Census 1988, table 13.

Note: Detail may not sum to total due to rounding.

^a ADLs include eating, getting in and out of bed, toileting, dressing, and bathing.

^b IADLs include grocery shopping, outdoor mobility, light housework, meal preparation, laundry, taking medication, money management, and telephoning.

^c Potential caregivers as a percentage of United States population in each age category and total.

The extent of potential care responsibilities depends upon the elderly relative's level of disability. Three categories of severity of disability of the spouse or parent are shown in the table. The most severely disabled are those who require human assistance with 3 to 5 ADLs; the next most disabled are those who need human help with 1 or 2 ADLs; the least disabled are elders who only need help with 1 or

more IADLs. (All those in nursing homes who did not need help with ADLs were assumed to need help with IADLs.) Similar categorizations, which assume that the ADLs and IADLs form a hierarchy (see Katz et al. 1963; Spector et al. 1987), have been used by others (e.g., Liu, Manton, and Liu 1985; Manton 1988) to grade disability.

Almost three-fifths of the potential caregivers (7.6 million persons) have the potential responsibility for the care of an elder who needs human help with at least 1 ADL, and 4.1 million have a disabled elderly spouse or parent with 3 or more ADL limitations. Nearly one-half of those with potential responsibility for the most severely disabled are aged 55 or older. Older potential caregivers may, on the one hand, be less physically able to respond to these heavier care needs, but on the other hand, they are less likely to have other responsibilities (e.g., child care, employment) which compete with elder care.

Active Caregivers

Of the 13.3 million spouses and children, 4.2 million actually provide help with ADLs or IADLs to disabled elders in the community (table 3). (Those who are not active caregivers rely on other family members, paid caregivers, or nursing homes to provide care; in a few cases the elder reportedly receives no care.) More wives are caregivers than husbands, and more daughters give care than sons. More children than spouses are caregivers—2.7 million compared with 1.6 million. This reflects the high rates of widowhood of disabled parents and the fact that more than one child sometimes cares for a parent.

To distinguish the level of involvement when more than one person helped, caregivers were classified as primary or secondary. For elders dependent in ADLs, primary status was assigned to the caregiver whom the elderly person (or a proxy respondent) identified as "helping the most" with ADLs. Elders dependent only in IADLs were not asked who helped the most. For their caregivers, primary status was assigned to the helper assisting with the greatest number of IADLs. If two caregivers assisted with the same number of IADLs, ties were broken in the following order: (1) the helper reported to be helping on the greatest number of days each week; (2) the helper assisting with the tasks most likely to require frequent help according to the following assumed or-

TABLE 3
Spouses and Children Who Are Active Caregivers (thousands)

	Primary caregivers ^a			Secondary caregivers ^b	Total
	Elder disabled in ADLs	Elder disabled in IADLs only	Total		
Wives	521	377	898	40 [†]	938
Husbands	319	228	547	66 [†]	613
Daughters	440	457	897	827	1,724
Sons	109	167	276	692	968
Total	1,388	1,229	2,618	1,625	4,243

Source: 1984 National Long-term Care Survey.

Note: Active caregivers do not include caregivers of disabled elders in institutions. Detail may not sum to total due to rounding.

^a Primary caregiver is the person who helps the most. See text.

^b Secondary caregiver is any helper identified by the elderly care recipient in addition to the primary caregiver. See text.

[†] May not be reliable; estimate is based on fewer than 75 cases or relative standard error is greater than 30 percent.

der: medication management, meal preparation, housework and laundry, grocery shopping, helping elders get around outside, providing transportation, financial management, and telephoning; and (3) the relation most likely to be the primary caregiver: spouse, daughter, son.

According to this classification, 2.6 million persons are primary caregivers, with 1.6 million assuming secondary responsibilities. Among primary caregivers, 1.4 million provide assistance to spouses or parents who are disabled in ADLs. Spouses bear a greater share of the primary care responsibility, while children are dominant among secondary caregivers. Among children who are primary caregivers, daughters outnumber sons by more than 3 to 1; among primary caregivers of more disabled elders, the ratio is even higher—4 to 1.

These estimates are consistent with Shanas's (1979) and Cantor's (1980) previous research findings that wives are most likely to be primary caregivers, followed by husbands, daughters, and sons in that order. When spouses are alive, they are usually the primary caregiver, but many disabled elders are widowed, leaving the primary care responsibility to children or other relatives.

All care-giving spouses and children comprise 2.2 percent of the

United States population aged 14 or older; primary caregivers, 1.4 percent (table 4). The likelihood of being a caregiver increases with age until one reaches the age of 75. One and one-half million active caregivers—over one-third of all caregivers—are aged 65 or older. The vast

TABLE 4
Spouses and Children Who Are Active Caregivers of Disabled Elders by Age and Level of Responsibility

Age of caregiver	Primary caregivers ^a			Secondary caregivers ^b	Total
	Elder disabled in ADLs	Elder disabled in IADLs only	Total		
Active caregivers (thousands)					
14-34	41 [†]	52 [†]	93	191	284
35-44	97	121	218	389	607
45-54	146	209	355	481	837
55-64	337	282	619	382	1,001
65-74	488	364	852	117	970
75+	280	201	480	64	544
Total	1,388	1,229	2,618	1,625	4,242 ^c
Percentage of U.S. Population ^d					
14-34	0.0% [†]	0.1% [†]	0.1%	0.2%	0.3%
35-44	0.3	0.4	0.7	1.3	2.0
45-54	0.6	1.0	1.6	2.1	3.7
55-64	1.5	1.3	2.8	1.7	4.5
65-74	2.9	2.2	5.1	0.7	5.8
75+	2.5	1.8	4.3	0.6	4.8
Total	0.7	0.7	1.4	0.9	2.2

Source: 1984 National Long-term Care Survey; U.S. Bureau of the Census 1988, table 13.

Note: Active caregivers do not include caregivers of disabled elders in institutions. Detail may not sum to total due to rounding.

^a Primary caregiver is the person who helps the most. See text.

^b Secondary caregiver is any helper identified by the elderly care recipient in addition to the primary caregiver. See text.

^c Detail does not sum to total due to rounding.

^d Caregivers as a percentage of United States population in each age category and total.

[†] May not be reliable; estimate is based on fewer than 75 cases or relative standard error is greater than 30 percent.

majority of these elderly caregivers assume the primary responsibility for care. At younger ages, people are more likely to be secondary caregivers. These differences in level of responsibility by age reflect the fact that spouses are likely to be primary caregivers, while children often assume secondary responsibilities.

Childrearing and Employment

Family members most intensely affected by long-term care decisions are likely to be those who have competing child care or job responsibilities.

Childrearing

Approximately 1.7 million women—6.6 percent of all women with children under the age of 15 in the United States—are faced with elder care decisions in addition to their child care responsibilities (table 5).

TABLE 5
Potential and Active Caregivers Who Have Children Less than Age 15

	Potential caregivers	Active caregivers		
		Primary	Secondary	Total
Men				
Number (thousands)	1,865	33 [†]	206	239
Percentage, U.S. fathers ^a	8.5%	0.1 [†] %	0.9%	1.0%
Women				
Number (thousands)	1,745	164	272	436
Percentage, U.S. mothers ^a	6.6%	0.6%	1.0%	1.6%
Total				
Number (thousands)	3,610	198	478	676
Percentage, U.S. parents ^a	7.4%	0.4%	1.0%	1.4%

Source: 1984 National Long-term Care Survey; March 1984 Current Population Survey.
Note: Active caregivers do not include caregivers of disabled elders in institutions. Detail may not sum to total due to rounding.

^a Potential and active caregivers as a percentage of United States population with children less than age 15 (excluding related and unrelated subfamilies) for each gender and total.

[†] May not be reliable; estimate is based on fewer than 75 cases or relative standard error is greater than 30 percent.

(The National Long-term Care Survey did not ask explicitly about child care; having one or more children less than the age of 15 was used as a proxy for child care responsibility.) These daughters have been referred to as members of the "sandwich generation" because they have the potential responsibility for the care of both the younger and the older generations. The relatively small number of such women confirms the findings of Boyd and Treas (1989) based on aggregated data.

Of these potential caregivers, 164,000 are primary caregivers of disabled parents and children. Approximately 70,000 daughters are primary caregivers of parents disabled in ADLs (not shown because the estimate may not be reliable due to the small number of cases). Stone, Cafferata, and Sangl's (1987) analysis of the 1982 Survey of Informal Caregivers also found that the number of women with child and elder care responsibilities is small. Their estimate, 154,000, includes secondary as well as primary caregivers of parents disabled in ADLs and counts them if they have children up to the age of 18 instead of 15.

Approximately 1.9 million men are part of the "sandwich generation," although because men typically do not take primary responsibility for either child or elderly care, they are much less likely to have both responsibilities.

Employment

Many potential caregivers, predominantly children, face demands from their jobs. Over one-half of spouses and children of disabled elders—7.4 million people—work full time (table 6). (Full-time employment is defined as 30 hours or more per week; information on employment less than 30 hours per week was not collected.) They represent 9.2 percent of the United States population employed full time. Approximately 43 percent of the daughters and wives of disabled elders, and 69 percent of the sons and husbands work full time.

Just over 1.5 million people—1.9 percent of full-time workers—are children or spouses who are active caregivers, with 37.8 percent of them assuming the primary care responsibility. Among these employed primary caregivers, almost 2 out of 5 care for parents or spouses disabled in ADLs. Women working full time are over four times more likely to be primary caregivers than are men—1.3 percent of women employed full time are primary caregivers compared with 0.3 percent of men.

Our estimate that just under 2 percent of the population employed

TABLE 6
Potential and Active Caregivers Who Are Employed 30 Hours
or More per Week (thousands)

	Active caregivers					
	Potential caregivers	Primary caregivers			Secondary caregivers	Total
		Elder disabled in ADLs	Elder disabled in IADLs	Total		
Men						
Number (thousands)	4,418	58 [†]	110	168	523	691
Percentage, U.S. employed men ^a	9.2%	0.1%	0.2%	0.3%	1.2%	1.5%
Women						
Number (thousands)	2,952	166	243	409	425	834
Percentage, U.S. employed women ^a	9.2%	0.5%	0.8%	1.3%	1.3%	2.6%
Total						
Number (thousands)	7,370	224	353	577	948	1,525
Percentage, U.S. employed ^a	9.2%	0.3%	0.4%	0.7%	1.2%	1.9%

Source: 1984 National Long-term Care Survey; March 1984 Current Population Survey.

Note: Active caregivers do not include caregivers of disabled elders in institutions.

^a Potential and active caregivers as a percentage of United States population employed 30 or more hours in the last week for each gender and total.

[†] May not be reliable; estimate is based on fewer than 75 cases or relative standard error is greater than 30 percent.

full time has elder care responsibilities is much lower than the estimates of 23 and 28 percent that have been reported previously for specific employers (Scharlach and Boyd 1989; Travelers Companies 1985). They include caregivers other than spouses and children, include part-time workers, and use a broader definition of elderly (aged 60 or older and aged 55 or older). The greatest difference between their studies and ours, however, is a much broader definition of help—financial and emotional support as well as help with ADLs and IADLs are included. When the definition is narrowed to include only help with ADLs, Scharlach and Boyd's estimates indicate that only 1.8 percent of workers are caregivers. There is also reason to believe that these employer-

based surveys may be biased due to low response rates (52 percent for both studies). If, as seems likely, caregivers are more likely to respond to the survey than noncaregivers, then the estimates of the percentage of workers who are giving help based on these surveys are biased upward.

The only published national estimate of employed caregivers is of full- and part-time workers who help with ADLs. Stone, Cafferata, and Sangl's (1987) analysis of the 1982 Informal Caregivers Survey estimated that there were 464,000 such spouses and children of disabled elders. The estimate of primary and secondary caregivers helping with ADLs from the 1984 National Long-term Care Survey (not shown) is 413,000. Because this does not include part-time workers, it suggests that estimates based on the reports from the 1984 survey of elders and their proxies are, if anything, somewhat higher than those from the 1982 survey of caregivers.

Both Childrearing and Employment

Further analysis (not reported in the table) indicates that 0.9 million women with a disabled parent have *both* a full-time job and children under the age of 15. These dual demands compete with caring for the disabled parent and are likely to influence a woman's decision to do so. Nonetheless, about 1 in 5 of these working mothers—198,000 women—provide elder care, although only about one-third assume primary responsibility.

Discussion

The impression given by many articles in the popular press is that there are large numbers of caregivers, adult children in particular, who are squeezed by the multiple responsibilities of elder care, child care, and employment. This impression is based on human interest stories supported by some employer-based surveys that have used broad definitions of elder care, including emotional and financial support. If the definition of care is limited to help with ADLs or IADLs provided to disabled elders, however, the numbers of children and spouses who provide elder care in the face of child care or employment responsibilities are relatively small.

The 164,000 daughters who take the primary responsibility for the care of a disabled parent while they also have their own children make up only 0.6 percent of women with children under the age of 15. Even broadening the definition to include secondary caregivers, only 1.6 percent of women with children under the age of 15 also take on elder care responsibility. The relatively small number of women with dual care responsibilities is not surprising given that almost two-thirds of daughters of disabled elderly parents are either middle-aged or elderly themselves and are more likely to be grandparents than parents of minor children.

Although almost twice as large a group, workers caring for disabled elderly spouses or parents are not a large proportion of the work force either. Primary caregivers comprise only 0.3 percent of men and 1.3 percent of women employed 30 or more hours per week. Including secondary caregivers increases these percentages to 1.5 and 2.6 percent, and adding part-time workers who had quit their jobs to give care and caregivers other than spouses and children (for which data were not available) would increase it further. Even so, assuming that employers would use help with ADLs or IADLs to define caregiving, only a relatively small percentage of full-time workers would be eligible for the unpaid leave benefits in proposed federal legislation. Not all industries would be affected equally, however. Because working women are more likely to take responsibility for elder care than men, female-dominated industries are most likely to be affected by work/caregiving conflicts and by policies directed at working caregivers.

Comparison with the care of young children may help place these numbers in perspective. Assume for purposes of comparison that the mother or father in a single-parent family, and the mother in a two-parent family takes primary responsibility for child care. Under this assumption, data from the 1984 Current Population Survey indicate that 4.2 million women and 163,000 men are primary caregivers of children under the age of 6 and are employed 30 or more hours per week. There are, thus, over 7 times as many people working full time and caring for young children as there are children or spouses of disabled elders balancing work and primary elder care responsibilities.

By indicating that the prevalence is relatively low, we do not intend to minimize the problems of those who juggle elder care and work or child care. For those who do, the time demands are often great and the emotional stress, severe. While comparison of elder care with child care

provides a frame of reference, the difference in size of the populations should not be equated with the difference in the magnitudes of responsibilities or the stress they create. Although child care is demanding, particularly during the preschool years, most parents can look forward to increasing independence of their children as they age. In contrast, for disabled parents, dependence is likely to increase with age. And while tasks such as dressing, bathing, and changing diapers of a child are the norm, similar norms do not exist for elder care (Brody 1985).

Caregivers with child care or work responsibilities are, moreover, only a subset of the much larger group giving care to disabled parents or spouses—2.6 million primary and 1.6 million secondary caregivers. These 4.2 million caregivers are about one-sixth the size of the population with children under the age of 6 (including all mothers and fathers to be comparable to primary and secondary caregivers). They are the direct beneficiaries of care-giver programs such as support groups, educational seminars, and respite care services. Next to the elderly population, active caregivers also stand to benefit the most from federal proposals to expand home and community-based care as well as to provide public subsidies for nursing home care.

Active caregivers are not the only family members affected by long-term care policy. As indicated at the outset, a still larger group of family members are affected by the disability of their elderly relatives as potential providers of care, financial assistance, or emotional support. For example, while the number of women who have both child care and primary elder care responsibilities is relatively small, 3.6 million men and women are in the "sandwich generation," i.e., have both a disabled elderly parent and one or more children under the age of 15. They represent 1 out of 13 persons with children under the age of 15. This is the population most directly affected by the lack of a comprehensive family policy in the United States. Their child care and elder care decisions would be influenced by public policies designed to help families address multiple care needs.

Full-time workers with disabled elderly relatives are also a reasonably large group. About 1 in 11 persons working 30 or more hours per week is the spouse or child of a disabled elder. As potential or active caregivers, these workers are the beneficiaries of employer-sponsored programs such as educational seminars on family caregiving and computerized data banks containing information about the availability of long-term

care services. In fact, the growing recognition of this population and the desire to recruit and retain these workers influenced the recent decisions of major companies such as IBM and AT&T to offer a broad family-care package.

More generally, 7 percent of adults in the United States are spouses or children of disabled elders. Among those most likely to be affected—the group aged 45 to 54—16.7 percent have a disabled elderly parent (or, in some cases, a spouse). These numbers, moreover, underestimate the number of people who would be affected by public long-term care programs for several reasons. First, the number of potential and active caregivers are reported at a single point in time; many more people will have a disabled elderly relative over the course of their lives. Second, some of those counted are doubly affected; as many as 6 percent of children with one disabled parent may have a second one. Third, we have analyzed only potential and active caregivers of chronically disabled elders. Many families are faced with decisions about the care of disabled relatives who are not elderly (e.g., developmentally disabled children and adults, physically disabled persons under the age of 65, and AIDS patients). Finally, this study is limited to spouses and children. Another 3.1 million relatives, friends, and neighbors provide care to disabled elders, and many others undoubtedly face care decisions.

Potential caregivers will benefit directly or indirectly from long-term care policies intended to help either disabled elders (e.g., expanded home care benefits, adult day care, private or social insurance for nursing home care) or the caregivers themselves (e.g., respite care, elder care tax credits, unpaid leave benefits). It is not surprising, therefore, to find a large constituency for long-term care reform among those who are not disabled including the nonelderly, many of whom have disabled parents and many more of whom will. In assessing the effects of changes in long-term care policy, the 13.3 million potential and active caregivers should be considered along with the 4.4 million disabled elders who need long-term care. Long-term care is an issue that affects much of society, young and old.

Caregiving in the Future

There is growing concern that fewer family members will be available to provide elder care in the future (Day 1985; Soldo and Agree 1988).

While the aging of the population will increase the number of disabled elders, the size of the future potential and active care-giver populations should not be extrapolated simply from what is observed today. The generations now aged 65 or older were born in the late nineteenth and early twentieth centuries, bore children during the Depression era, and typically relied on male heads of household to earn income. Elderly generations of the future will differ not only in their longevity and health status, but also in the number of family members potentially available to care for them. Although the overall percentage of the elderly population who are married is expected to change relatively little between 1986 and 2040, the percentage married in the group aged 85 and older—where the prevalence of disability is greatest—is expected to increase from 23 to 30 percent (Wade 1988, table 21). This may increase somewhat the availability of spouses to give care. Since very old spouses are more likely to be disabled themselves, however, the percentage able to give care will probably be smaller, and more children will have the potential care responsibility for two disabled parents.

The next generation of elders will have more children available to take care of them. Women aged 45 to 64 in 1980 bore an average of 2.8 children compared to 2.3 for those aged 65 or older (U.S. Bureau of the Census 1984). Further in the future, however, the more recent decline in fertility rates will reverse this trend.

Future generations may also have a different propensity to rely on informal care. Higher incomes of the elderly population may increase their demand for paid care, and some will have private insurance to cover long-term care. Continued increases in female labor-force participation, which would increase the potential conflict between work and caregiving, may reduce the extent to which women are caregivers. On the other hand, to the extent that they are not offset by delayed child-bearing, smaller families of potential caregivers and increased active life expectancy of parents may reduce the conflict between child care and elder care.

Although difficult to predict, these changes will affect the demand for long-term care and its use under public programs. Estimates of the future cost of public programs should take changes in the availability of potential informal caregivers into account. Failure to do so may lead to incorrect forecasts of the demand for formal long-term care and the cost of public programs.

References

- Ball, R.M. 1989. *Because We're All in This Together: The Case for a National Long-term Care Insurance Policy*. Washington: Family USA Foundation.
- Boyd, S.L., and J. Treas. 1989. Family Care of the Frail Elderly: A New Look at "Women in the Middle." *Women's Studies Quarterly* 17:66-74.
- Brody, E.M. 1985. Parent Care as a Normative Family Stress. *Gerontologist* 25:19-29.
- Cantor, M. 1980. The Informal Support System, Its Relevance in the Lives of the Elderly. In *Aging and Society*, ed. E. Borgatta and N. McCloskey, 131-44. Beverly Hills: Sage.
- Clark, W.F., and A.O. Pelham. 1983. Informal Support and Nursing Home Patients. Paper presented at the annual meeting of the Gerontological Society of America, San Francisco, November 20. (Unpublished.)
- Day, A.T. 1985. *Who Cares?: Demographic Trends Challenge Family Care for the Elderly*. Population Trends and Public Policy no. 9. Washington: Population Reference Bureau.
- Hatch, R.C., and M.L. Franken. 1984. Concerns of Children with Parents in Nursing Homes. *Journal of Gerontological Social Work* 7:19-30.
- Iannacchione, V.G. 1982. Weighted Sequential Hot Deck Imputation Macros. Paper presented at the seventh annual SAS User's Group International Conference, San Francisco, February 10. (Unpublished.)
- Katz, S., A.B. Ford, R.W. Moskowitz, B.A. Jackson and M.W. Jaffe. 1963. The Index of ADL: A Standardized Measure of Biological and Psychological Function. *Journal of the American Medical Association* 185:94-99.
- Linsk, N.L., S.M. Keigher and S.E. Osterbusch. 1988. States' Policies Regarding Paid Family Caregiving. *Gerontologist* 28:204-12.
- Liu, K., K.G. Manton and B.M. Liu. 1985. Home Care Expenses for the Disabled Elderly. *Health Care Financing Review* 7:51-58.
- Manton, K.G. 1988. A Longitudinal Study of Functional Change and Mortality in the United States. *Journal of Gerontology* 43:S153-S161.
- Montgomery, R.J.V. 1983. Staff-family Relations and Institutional Care Policies. *Journal of Gerontological Social Work* 6:23-27.
- New York State Office for the Aging. 1983. *Family Caregiving and the Elderly: Policy Recommendations and Research Findings*. Albany.
- Opinion Research Corporation. 1988. A National Survey of Caregivers Final Report. Final report of study conducted for the American Association of Retired Persons. Washington. (Unpublished.)

- Rivlin, A.M., J.M. Wiener, R.J. Hanley and D.A. Spence. 1988. *Caring for the Disabled Elderly: Who Will Pay?* Washington: Brookings Institution.
- Shanas, E. 1979. Social Myth as Hypothesis: The Case of the Family Relations of Old People. *Gerontologist* 19:3-9.
- Scharlach, A.E., and S.L. Boyd. 1989. Caregiving and Employment: Results of an Employee Survey. *Gerontologist* 29:382-87.
- Soldo, B.J., and E.M. Agree. 1988. *America's Elderly*. Population Bulletin no. 43. Washington: Population Reference Bureau.
- Spector, W.D., S. Katz, J.B. Murphy, and J.P. Fulton. 1987. The Hierarchical Relationship between Activities of Daily Living and Instrumental Activities of Daily Living. *Journal of Chronic Diseases* 40:481-89.
- Stone, R. 1985. Recent Developments in Respite Care Services for Caregivers of the Impaired Elderly. Policy paper prepared for the Administration on Aging under grant no. 90-AP003, University of California, San Francisco. (Unpublished.)
- Stone, R., G.L. Cafferata, and J. Sangl. 1987. Caregivers of the Frail Elderly: A National Profile. *Gerontologist* 27:616-26.
- Stone, R.I., and C.M. Murtaugh. 1988. The Elderly Population with Chronic Functional Limitations: Implications for Home Care Eligibility. Paper presented at the 116th annual meeting of the American Public Health Association, Boston, November 14.
- Travelers Companies. 1985. The Travelers Employee Caregiver Survey. Hartford. (Unpublished.)
- U.S. Bureau of the Census. 1984. Detailed Population Characteristics, Part 1, United States Summary, March 1980. Washington.
- . 1986. Household and Family Characteristics: March 1985. *Current Population Reports*, series P-20, no. 411. Washington.
- . 1988. Statistical Abstract of the United States: 1988. Washington.
- U.S. General Accounting Office. 1989. GAO's Cost Estimate of the Family and Medical Leave Act of 1989 (H.R. 770). (GAO)/T-HRD-89-4. Washington.
- Wade, A. 1988. *Social Security Area Population Projections, 1988*. SSA pub. no. 11-11549. Baltimore: Social Security Administration, Office of the Actuary.
- Wisensale, S.K., and M.D. Allison. 1988. An Analysis of 1987 State Family Leave Legislation: Implications for Caregivers of the Elderly. *Gerontologist* 28:779-85.

Acknowledgments: The views expressed in this article are those of the authors. No official endorsement by either the National Center for Health Services Research and Health Care Technology Assessment or the Department of Health

and Human Services is intended or should be inferred. A previous version of this article was presented at the annual meeting of the Gerontological Society of America in San Francisco in November 1988. We are indebted to Steven Cohen for his invaluable statistical guidance and to Thomas Gabe for tabulations of the 1984 Current Population Survey. The authors also thank William Spector, Brenda Spillman, and three anonymous reviewers for their helpful comments on an earlier draft of this article. Finally, we gratefully acknowledge the typing support of Mary Seidenberg and the programming assistance of Karen Pinkston of Social and Scientific Systems, Inc., Bethesda, Maryland.

Address correspondence to: Robyn I. Stone, National Center for Health Services Research and Health Care Technology Assessment/DHHS, Parklawn Building, Room 18A-55, 5600 Fishers Lane, Rockville, MD 20857.