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Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy

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Summary

Many trends have combined to prompt concern about whether the supply of family caregivers to the elderly will be sufficient to meet demand. One trend — the increased commitment of women to the labor force — has proved worrisome because of their major role in unpaid caregiving: a caregiver to a frail elder is quite often a married woman who is a middle-aged daughter if her mother is deceased. Although studies tend to confirm that paid work lessens the likelihood of a daughter becoming an informal caregiver, many employed women nonetheless assist older relatives, friends, and neighbors.

Some analyses find that full-time work in particular decreases the time spent caregiving. The reduction in caregiving hours could be mitigated if care users have multiple unpaid helpers. However, the comparatively low fertility rate of the baby-boom generation suggests that there will be fewer potential caregivers per recipient in the coming decades. Elders could hire home care workers to compensate for needs no longer being met by unpaid caregivers, but this might strain their budgets and cause them to enter nursing homes, which could raise government spending. Coverage of home care services could be expanded to offset a reduction in family caregiving, but this too would affect the government's budget.

Despite their multiple responsibilities, employed caregivers spend many hours assisting elders. In order to do so, they often make workplace adjustments (e.g., arrive late/leave early and take leave). Just as accommodation of employees' informal caregiving to paid work may affect the budgets of elders and of government, so too might the adjustment of work to caregiving affect various parties. The productivity of caregivers could be reduced by their concern over frail parents living alone, for example. Caregiving could also increase employers' costs if they must replace employees who take leave or quit. The earnings and retirement income of caregivers who choose to sharply cutback their supply of labor could be reduced as well. This might not only diminish their own standard of living, but also lead to increased government dependency. A slower growing labor force also could curb the rate of economic growth and hence, of the nation's standard of living.

Congress passed legislation to encourage caregivers to continue working by making it easier for them to fulfill their many commitments. The Family and Medical Leave Act (FMLA) provides job-protected, unpaid leave to eligible employees at covered employers so that they might, among other things, care for parents and spouses with serious health conditions. In addition, Congress turned to the tax code to offer employees incentives to start or continue caregiving (the Dependent Care Tax Credit and the Dependent Care Assistance Program). Caregivers to the elderly, regardless of employment status, also may receive assistance through the National Family Caregiver Support Program and through home and community-based waivers under Medicaid (e.g., respite care).

This report will not be updated.

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Family Caregiving to the Elderly by Employed Persons: The Effects on Working Caregivers, Employers, and Federal Policy

Family members most often fulfill the non-medical needs of frail older adults who live in their own homes or those of relatives. In the first half of the 1990s, for example, family members accounted for 72% of unpaid and paid caregivers to functionally impaired persons over age 70 living in the community.[1] In particular, women — often wives, daughters, and other female relatives — comprised 58% of informal (unpaid) caregivers to the noninstitutionalized population age 65 or older who required long-term care.[2] Yet, over the last several decades, women have become more attached to the paid labor force. As a result, the rate of full-time employment rose from 23.0% in 1984 to 27.5% in 1994 among female primary caregivers to chronically ill or disabled, elderly parents and spouses living in the community; the share of female secondary caregivers employed full-time rose from 49.2% to 56.0%.[3]

The reallocation of women's time among family and household obligations, paid employment, and leisure could affect the availability and intensity of informal caregiving to elderly relatives, friends, and neighbors. Indeed, between 1984 and 1994, the share of potential spouse and adult child caregivers who actively provided long-term care to chronically ill or disabled elders declined.[4] Some analysts have argued that — given women's greater labor force participation and other sociodemographic factors that could constrain the future supply of family caregivers (e.g., lower birth rates) *in addition to* the expected increase in demand for elder care services due to the greater longevity of the U.S. population and to the size of the

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[1] National Academy on an Aging Society, "Caregiving: Helping Elders with Activity Limitations," *Challenges for the 21st Century: Chronic and Disabling Conditions*, no. 7 (May 2000).

[2] William D. Spector, John A. Fleishman, Liliana E. Pezzin, and Brenda C. Spillman, *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality (AHRQ) Publication No. 00-0049, 1998. (Hereafter cited as Spector et al, *The Characteristics of Long-Term Care Users*.)

[3] Brenda C. Spillman, and Liliana E. Pezzin, "Potential and Active Family Caregivers: Changing Networks and the "Sandwich Generation," *The Milbank Quarterly*, vol. 78, no. 3 (2000). (Hereafter cited as Spillman and Pezzin, *Potential and Active Family Caregivers*.) Note: Primary caregivers are those identified by elderly care users in the National Long-Term Care Survey as their main helpers.

[4] Ibid. Note: The living spouses and adult children of community-dwelling individuals age 65 or older with chronic illnesses or disabilities comprised the potential caregiving population.

aging baby-boom generation — "we can no longer expect to rely on informal caregivers to bear the burden of long-term care without support structures and incentives in place" (e.g., respite care services and preferential tax treatment).[5]

Observers often focus their attention specifically on the "sandwich generation" of caregivers, which is a term applied to those trying to meet the demands of their children and older relatives. The baby-boom generation (now in its late 30s through mid-50s) is the group most likely to be devoting time and financial resources to care for older and younger family members while also holding jobs. Some baby-boomers delayed childbirth, and consequently, are raising children while their aging parents are still alive. For example, 44% of baby-boomers between 45 and 54 years old reported in 2001 that they had at least one child under age 21 and a living parent.[6] In contrast, the cohort that preceded the baby-boomers is less likely to have many working members given their ages and, for the same reason, to have both dependent children and living elderly relatives. Although generation X parents also are less likely to have functionally impaired older family members, more of them could well become caregivers as their baby-boom relatives age.[7] Thus, informal caregiving to the elderly often has been characterized as an intergenerational issue rather than as a women's issue per se.

Nonetheless, the trend toward greater employment among women has spread the impact of elder care beyond caregivers and care recipients to include employer organizations. From the employer perspective, "[e]lder care will be to the 21st century what child care was to the last few decades."[8] Some companies have modified their human resources programs to reflect employees' family responsibilities and thereby to maintain a productive workforce, among other things. "Family friendly" employers have made such adjustments as initiating flexible work schedules, providing elder care resource and referral services, and offering long-term care insurance.[9]

The effects of employees assisting older relatives, friends, and neighbors extend beyond the workplace. If, for example, informal caregivers sharply reduce their hours of employment in order to strike a better balance between work and family responsibilities, the supply of labor would be reduced as would the employed caregiver's earnings. The former could limit the rate of U.S. economic growth and hence, of improvement in national living standards. The latter could diminish caregivers' retirement income which, in turn, might decrease tax revenues and

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[5] Linda S. Noelker, "The Backbone of the Long-Term-Care Workforce," *Generations*, spring 2001; and Lisa Alecxih, "The Impact of Sociodemographic Change on the Future of Long-Term Care," *Generations*, spring 2001.

[6] AARP, *In the Middle: A Report on Multicultural Boomers Coping with Family and Aging Issues* (July 2001).

[7] Stephanie Armour, "More Gen Xers Juggle Jobs, Parents' Care; Aging Boomers Need More Help," *USA Today*, Apr. 26, 2002.

[8] Susan J. Wells, "The Elder Care Gap," *HR Magazine*, May 2000.

[9] Marty R. Seaward, "The Sandwich Generation Copes with Elder Care," *Benefit Quarterly*, second quarter 1999.

increase government dependency. Alternatively, employees could curtail their supply of unpaid caregiving which might adversely affect the finances of older persons needing care and of government if publicly funded programs were substituted for once "free" home care services.

This report begins with a discussion of the size and characteristics of the population providing unpaid help to frail older adults living in the community, and then narrows its focus on a subset of this population, namely, employed informal caregivers. The report next expands upon the above-mentioned implications of unpaid caregiving for the employees providing assistance, their employing organizations, and society. It closes with an overview of the approaches that employers and the federal government have taken to help employed elder caregivers.

The Size and Characteristics of the Informal Elder Caregiving Population

In order to determine the number and characteristics of informal caregivers to older adults living in the community, one first must have a definition of caregiving.

> The choice of definition greatly influences estimates of the number of family caregivers, the magnitude of burden on individuals, families, employers, and the society, and the costs of different policy options.[10]

Consensus on the definition of informal elder caregiving is lacking, however. Caregivers have been defined by their relationship to care users (e.g., exclude friends and neighbors). Caregivers also have been defined based on the amount of assistance provided (e.g., limit helpers to those who provide the most assistance, namely, primary caregivers). In addition, the characteristics of care users have served as criteria (e.g., setting a minimum age for care users). Definitions have been framed, as well, in terms of the timing of the help (e.g., when the survey is being administered or at some point during the preceding year). Further, the definition of care has ranged from broad to narrow. An example of the latter is specifying that the older adult cannot perform without personal assistance one or more basic or instrumental activities of daily living (ADLs/IADLs). ADLs include eating, dressing, bathing, and toileting; IADLs include doing housework and laundry, preparing meals, shopping, taking medications, and managing finances.

How Many Are There?

Due in part to the absence of a commonly shared definition of elder care, *estimates of the size of the elder caregiving population range from between 5.9*

[10] Robyn Stone, "Defining Family Caregivers of the Elderly: Implications for Research and Public Policy," *The Gerontologist*, vol. 31, no. 6 (Dec. 1991).

million and 7 million individuals[11] *to 22.4 million households with at least one care provider.*[12] The surveys from which these estimates were developed differ in many respects, some of which are identified below.

- The lower figures were derived from the government-funded 1994 National Long-Term Care Survey (NLTCS). The NLTCS is a nationally representative household survey of *Medicare beneficiaries age 65 or older* who live in the community and who *must have* assistance in order to perform one or more *ADLs or IADLs* because of illnesses or disabilities that have lasted or are expected to last at least 3 months (i.e., *chronic conditions*).[13] Members of the NLTCS sample are asked to identify the primary and secondary informal caregivers *currently* assisting them, who then are queried.[14] Informal help means providing hands-on assistance to the disabled elder (e.g., performing light housework)[15] and supervising their performance of ADLs or IADLs (e.g., reminding them of the order in which clothes should be put on).
- The higher figure was developed from a nationally representative telephone survey of English-speaking households that was sponsored by the National Association of Caregivers (NAC) and AARP. It asked in 1996 whether there was someone in the household who was *currently* assisting, or who had *within the past 12 months* assisted, *persons age 50 or older* who needed help caring for themselves. *No minimum duration of impairment* is required; therefore, the higher estimate includes caregivers to individuals with acute but short-term conditions (e.g., the flu).[16] The survey has a *broad definition of help* as well (e.g., a respondent could identify herself as a caregiver if she visited an elderly person to check on them).

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[11] Spector et al, *The Characteristics of Long-Term Care Users*, and U.S. Department of Health and Human Services, *Informal Caregiving: Compassion in Action*, 1998. (Hereafter cited as HHS, *Informal Caregiving*.)

[12] National Alliance for Caregiving (NAC) and AARP, *Family Caregiving in the U.S.: Findings from a National Survey*, June 1997. (Hereafter cited as NAC and AARP, *Family Caregiving in the U.S.*)

[13] If respondents say that they do not usually perform a particular IADL but could if they had to, they are not counted as being limited in that activity. The ADLs common to both NLTCS-based studies are eating, getting in/out of bed, dressing, bathing, toileting, and getting around indoors. The IADLs common to both NLTCS-based studies are light housework, laundry, meal preparation, shopping, getting around outdoors, money management, taking medications, and using the telephone.

[14] The core NLTCS, which was administered in 1982, 1984, 1989, 1994, and 1999, asks less in-depth information about informal caregivers than is gathered through the survey's less frequently administered companion, the Informal Caregiver Survey.

[15] Both NLTCS-based studies excluded care recipients who only required help performing heavy housework. According to Spector et al (*The Characteristics of Long-Term Care Users*), the estimate of care users would have been 75% higher had these individuals been taken into account.

[16] More than one-tenth of caregivers in the NAC/AARP survey reported that their care recipient's illness/condition was expected to last less than 3 months.

The difference of approximately one million between the two lower estimates of caregivers illustrates the importance of definitions in estimating the size of the family caregiver population. One of the IADLs asked about in the NLTCS is transportation (i.e., the ability to go places beyond walking distance). The estimate of 5.9 million caregivers excludes older care users who only had difficulty with transportation, and hence, excludes their caregivers. The estimate of more than 7 million caregivers includes them.[17]

What Are Their Characteristics?

A number of elements affects who becomes an informal elder caregiver, and particularly, who becomes the primary helper. These elements include whether an individual has time available to provide care, whether he or she is willing to do so on an uncompensated basis, how much the potential helper is concerned for the well-being of the person in need, and how close he or she lives to the care recipient.[18] Not surprisingly, then, *the marital status of care users is an important indicator of who will be their primary family caregiver.*

> When available, a spouse provides the majority of care. In the absence of a spouse, a daughter is most likely to assume the role. In the absence of a daughter, a son will assume the role although there is considerable evidence that sons transfer many care tasks to their spouses. In the absence of offspring, more distant family members become responsible. The person designated to be the primary caregiver also tends to be the person with the fewest competing family or work obligations.[19]

Marital status affects other characteristics of the informal caregiving population. *If spouses provide assistance, they more often live with the care users*;[20] *typically spend longer hours (40-60 a week on average) providing care; and more often perform such tasks as meal preparation and personal care (e.g., bathing and toileting).* In contrast, adult children generally spend fewer hours (15-30 a week on average) and their efforts are concentrated on such activities as shopping and

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[17] CRS discussions with the reports' authors determined this to be the likely explanation for much of the discrepancy between the two NLTCS-based estimates.

[18] Marc A. Cohen, Maurice Weinrobe, and Jessica Miller, *Informal Caregivers of Disabled Elders with Long-Term Care Insurance*, Jan. 2000. (Hereafter cited as Cohen et al, *Informal Caregivers of Disabled Elders*.)

[19] Rhonda J.V. Montgomery, and Karl D. Kosloski, *Change, Continuity and Diversity Among Caregivers*, an issue brief prepared for the U.S. Administration on Aging's conference the National Family Caregiver Support Program: "From Enactment of Action," Washington, Sept. 2001. (Hereafter cited as Montgomery and Kosloski, *Change, Continuity and Diversity Among Caregivers*.)

[20] Spousal caregivers, who accounted for 23.4% of all primary and secondary caregivers to community-dwelling chronically disabled elders in 1994, all lived with their mates according to Spector et al, *The Characteristics of Long-Term Care Users*. In contrast, 15.1% of all caregivers were adult children living with the care recipient and 10.6%, more distant relatives coresiding with care users.

transportation.[21] Although not as often living with their care users, they tend to reside nearby.[22]

Nonspousal caregivers also are more likely to be working, perhaps 2.4 times more likely according to one estimate.[23] Spousal caregivers typically gave retirement as their reason for no longer working. Thus, their withdrawal from the labor force probably was more related to age than to their caregiving obligations.[24]

Typically, the share of elder caregivers with paid jobs decreases with age. According to the NAC/AARP survey, slightly more than three-fourths of caregivers between 18 and 49 years old worked compared to 60% of those between 50 and 64 years old and to 12% of those age 65 or older.[25]

The kinship relationship between primary caregivers and elderly care users may be affected by the availability of private long-term care insurance. As shown in **Table 1**, private insurance claimants more often had spouses as their primary caregivers compared to uninsured frail elders (53% and 38%, respectively). Because spouses can supplement their caregiving efforts with those of home care workers, the authors suggest that these spouses could be better able than the uninsured to avoid shifting to others (e.g., daughters) the major role in informal care provision.[26] However, while both samples included similar proportions of married couples, there might have been other differences between the two groups that influenced the kinship relationship between care user and caregiver.[27]

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[21] Montgomery and Kosloski, *Change, Continuity and Diversity Among Caregivers*.

[22] According to the NAC/AARP survey, excluding the 21% of care users age 50 or older who lived with their care providers, 55% resided within 20 minutes while only 6% resided more than 2 hours away.

[23] Metropolitan Life Insurance Company, *The MetLife Study of Employed Caregivers: Does Long Term Care Insurance Make a Difference?* 2001. (Hereafter cited as MLIC, *The MetLife Study of Employed Caregivers*.)

[24] Cohen et al, *Informal Caregivers of Disabled Elders*.

[25] Caregivers in the NAC/AARP survey tend to be younger than those in the NLTCS due to their different definitions of care users. As a result, the share of caregivers with jobs is likely to be higher in the former survey. (The average age of caregivers in the NAC/AARP survey was 46 years old. The age distribution of elder caregivers in the NLTCS is shown in **Table 2**.)

[26] Cohen et al, *Informal Caregivers of Disabled Elders*.

[27] For example, if relatively more married-couples in the long-term care insurance claimant sample were younger, more spouses in the insured group than in the non-insured group might have been capable of assisting their mates. Thus, age could have affected the kinship relationship between care user and caregiver regardless of insurance status.

Table 1. The Relationship between Primary Informal Caregivers and Elderly Care Recipients

Relationship of primary caregiver to recipient	Recipients using private insurance benefits[a]	Recipients not likely to be privately insured[b]
	100%	100%
Spouse	53%	38%
Daughter or daughter-in-law	24%	33%
Son or son-in-law	11%	9%
Other relatives, friends, or neighbors	12%	20%

Source: Marc A. Cohen, Maurice Weinrobe, and Jessica Miller, *Informal Caregivers of Disabled Elders with Long-Term Care Insurance*, Jan. 2000.

[a] Recipients with private long-term care insurance were at least 65 years old and identified by their insurance companies as having already received at least one payment for home/community-based services. The claimants and the primary informal caregivers they identified were surveyed between November 1997 and February 1999.

[b] Recipients not likely to be privately insured were derived from the 1994 NLTCS. Specifically, they were Medicare beneficiaries age 65 or older who required assistance with at least two of six ADLs or who were cognitively impaired.

Consistent findings across surveys reveal that *married women, particularly daughters, often are informal primary and secondary caregivers*. (See **Table 2**.)[28] *Among primary caregivers, in contrast, spouses are more prevalent than daughters*. (See **Table 1**.)

Between 1984 and 1994, sons' share of primary caregivers to frail elderly parents and spouses rose by 50%; nonetheless, in 1994, sons comprised just 15% of primary caregivers compared to the daughters' share of 35%.[29] In addition to their gender, adult children's marital status influences whether they assist their parents and the amount of care they provide: unmarried children more often help their parents, and they generally spend more hours doing so.[30] *Leaving aside marital status and other potentially intervening variables (e.g., the care user's degree of disability), women spend significantly more time than men caring for older adults* (18.8 and 15.5 hours per week, respectively, according to the NAC/AARP survey).

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[28] Similarly, results from the NAC/AARP survey show that 73% of informal caregivers are women, 66% are married or living with a partner, and 40% are daughters/daughters-in-law assisting mothers/mothers-in-law.

[29] Spillman and Pezzin, *Potential and Active Family Caregivers*.

[30] James N. Laditka and Sarah B. Lakitka, "Adult Children Helping Older Parents," *Research on Aging*, vol. 23, no. 4 (Jul. 2001).

Table 2. Characteristics of Primary and Secondary Informal Caregivers to Elderly Care Recipients

Characteristics of caregivers	Percent distribution
Gender	100.0%
Female	63.1
Male	35.1
Marital status	100.0%
Married	58.7
Widowed, divorced, separated or never married	17.4
Relationship	100.0%
Wife	13.4
Husband	10.0
Daughter	26.6
Son	14.7
Other female relative	17.5
Other male relative	8.6
Other female non-relative	5.7
Other male non-relative	1.8
Age	100.0%
14-34	5.3
35-44	10.7
45-54	16.9
55-64	15.2
65-74	15.8
75-84	10.5

Source: William D. Spector, John A. Fleishman, Liliana E. Pezzin, and Brenda C. Spillman, *The Characteristics of Long-Term Care Users*, Agency for Healthcare Research and Quality (AHRQ) Publication No. 00-0049, 1998.

Note: Not all distributions add to 100.0% due to missing or unreliable data. Care users, derived from the 1994 NLTCS, were Medicare beneficiaries at least 65 years old who needed assistance performing one or more of six ADLs or of eight IADLs.

One discrepancy between surveys in caregiver characteristics is the prevalence of *the sandwich generation*, which is probably most related to the varying minimum ages used to define care users. Caregivers identified by surveys with higher age cut-offs are older themselves. The older the providers, in turn, the less likely they are to have competing child care responsibilities. For example, 41% of caregivers to persons age 50 or older had children under age 18 living at home.[31] Alternatively, only 6% of primary caregivers to private long-term care insurance claimants age 65 or older had children under age 25 living with them.[32] Similarly, 7.9% of primary caregivers to chronically ill or disabled parents or spouses age 65 or older also had children under age 15.[33]

Studies of workers found relatively few members of the sandwich generation among them. According to a Families and Work Institute survey, the minority of working parents (20%) who provided care to children and to someone age 65 or older were estimated to account for 9% of employed U.S. wage and salary workers.[34] Another analysis similarly concluded that 9% of the workers at 33 employers who were surveyed belonged to the sandwich generation.[35]

Employed Informal Caregivers to the Frail Elderly

The implications of individuals having work and family commitments could intensify if the share of workers with elder care obligations grows as anticipated. According to one estimate, 42% of U.S. wage and salary workers expected to provide informal elder care during the 1997-2002 period — up from the 25% who had done so at some time in 1996.[36]

Work and Elder Caregiving

Empirical analyses of employed caregivers to the elderly typically study women given their predominance in the general caregiver population. The focus of studies often narrows to adult daughters who are more likely to be employed than women from earlier generations. *These analyses tend to conclude that a daughter having a paying job reduces her probability of caring for a parent, "with the daughter who*

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[31] NAC and AARP, *Family Caregiving in the U.S.*.

[32] Cohen et al, *Informal Caregivers of Disabled Elders*.

[33] Spillman and Pezzin, *Potential and Active Family Caregivers*.

[34] James T. Bond, Ellen Galinsky, and Jennifer E. Swanberg, *The 1997 National Study of the Changing Workforce*, (New York: Families and Work Institute, 1998). (Hereafter cited as Bond, Galinsky, and Swanberg, *The 1997 National Study of the Changing Workforce*.)

[35] Margaret B. Neal and Donna L. Wagner, *Working Caregivers: Issues, Challenges, and Opportunities for the Aging Network*, an issue brief prepared for the U.S. Administration on Aging's conference the National Family Caregiver Support Program: "From Enactment to Action," Washington, Sept. 2001. (Hereafter cited as Neal and Wagner, *Working Caregivers*.)

[36] Bond, Galinsky, and Swanberg, *The 1997 National Study of the Changing Workforce*.

lives nearby and who has the least competing demands being most likely to become the caregiver."[37]

Clearly, however, employment does not preclude women from helping older relatives, friends, or neighbors. According to the NAC/AARP survey, 61% of women who are caregivers to persons age 50 or older also work for pay or profit.

Prevalence and Characteristics of Employed Caregivers. A growing share of all informal caregivers to older adults are working, with 64% estimated by the NAC/AARP survey to have paying jobs. Nonetheless, *employed elder caregivers represent a minority of U.S. workers. The size of the minority ranges widely*. One-fourth of U.S. employees had provided "special attention to or care for someone 65 years or older" at some time during the year before administration in 1997 of the Families and Work Institute's nationally representative telephone survey of households with wage and salary workers age 18 or older.[38] The survey found about half as many workers (13%) were providing informal help at the time of their interviews. Researchers who examined 17 studies from the 1980s that measured the prevalence of informal elder caregivers in the U.S. workforce concluded that the wide range of estimates (from 1.9% to 46.0%) was associated with bias due to nonresponse and with differences in definitions of caregiving. A tentative reestimate of the studies' findings narrowed the variance in the proportion of employees who are elder caregivers to between 7.4% and 11.8%.[39]

Unlike in the overall caregiving population and unlike the findings of some other studies of employed caregivers, the Families and Work Institute's survey showed women and men comprising fairly equal shares of employed elder caregivers (52% and 48%, respectively).

Hours of Caregiving and of Employment. Despite the claims on their time made by paid work and family/household obligations, *employees spend many hours providing unpaid services to older adults*. They average 11 hours per week assisting elderly relatives, friends, and neighbors, according to the Families and Work Institute survey. The survey also found that employed women and men spend similar amounts of time in this endeavor. In contrast, other sources estimated that working women devote significantly more time than men to elder care after a variety of mediating factors are taken into account (e.g., personal and job-related characteristics

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[37] Maaike G. H. Dautzenberg, Jos P.M. Diederiks, Hans Philipsen, Fred C.J. Stevens, Frans E.S. Tan, and Myrra J.F.J. Vernooij-Dassen, "The Competing Demands of Paid Work and Parent Care," *Research on Aging*, vol. 22, no. 2 (Mar. 2000).

[38] Some other studies estimated similar prevalences of elder caregiving among employees. See for example Karen I. Fredriksen-Goldsen and Andrew E. Scharlach, *Families and Work: New Directions in the Twenty-First Century* (New York: Oxford University Press, 2001). (Hereafter cited as Fredriksen-Goldsen and Scharlach, *Families and Work*.)

[39] Kevin M. Gorey, Robert W. Rice, and Gary C. Brice, "The Prevalence of Elder Care Responsibilities Among the Work Force Population," *Research on Aging*, vol. 14, no. 3 (Sept. 1992).

of the caregiver, characteristics of the care recipient, and characteristics of the caregiving situation).[40]

There has been particular interest in *elder caregivers with full-time jobs* because they could have more difficulty reconciling their multiple roles. The NAC/AARP survey found that a small majority of all caregivers work full-time (52%). When the sample is confined to primary caregivers to frail parents and spouses, however, the rate of full-time employment was estimated to be much lower (27.2%).[41] This disparity is perhaps due to primary elder caregivers often being spouses who are themselves elderly and thus likely to be retired.[42] Indeed, full-time jobholding was estimated to be more than twice as prevalent among secondary caregivers (58.9%) who often are middle-aged children.[43] Although full-time employment also appears to be more common among long-distance caregivers than among all caregivers on average (over 60% and over 50%, respectively), most employed long-distance caregivers say they have family members or friends living within an hour of the care recipient who help them with caregiving.[44] *If individuals can share elder caregiving responsibilities, then full-time workers might more easily balance their family and work responsibilities. However, the comparatively low fertility of baby-boomers suggests that the pool of potential family caregivers per recipient will shrink in the next 20-30 years.*[45] *For this reason, some believe the unmet needs of elders could grow in future years (all else remaining the same).*

One means of employees reconciling their work and caregiving obligations would be to cut back the amount of informal help given to elders. Some empirical studies found little difference in the time devoted to care regardless of the caregiver's employment status or hours worked, but others came to the opposite conclusion. Based on data from the 1989 NLTCS' Informal Caregiver Survey, for example, employed female primary caregivers to elders unable to perform ADLs and IADLs provided 18 hours per week of assistance on average (16 hours by full-timers and 21 hours by part-timers); female primary caregivers who were not working for pay helped an average of 33 hours per week. The disparity between the amount of care

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[40] See for example Margaret B. Neal, Berit Ingersoll-Dayton, and Marjorie E. Starrels, "Gender and Relationship Differences in Caregiving Patterns and Consequences Among Employed Caregivers," *The Gerontologist*, vol. 37, no. 6 (Dec. 1997).

[41] Spillman and Pezzin, *Potential and Active Family Caregivers*.

[42] Rachel F. Boaz, "Full-Time Employment and Informal Caregiving in the 1980s," *Medical Care*, vol. 34, no. 6 (June 1996). (Hereafter cited as Boaz, *Full-Time Employment and Informal Caregiving in the 1980s*.); and Pamela Doty, Mary E. Jackson, and William Crown, "The Impact of Female Caregivers' Employment Status on Patterns of Formal and Informal Eldercare," *The Gerontologist*, vol. 38, no. 3 (1998). (Hereafter cited as Doty et al, *The Impact of Female Caregivers' Employment Status*.)

[43] Spillman and Pezzin, *Potential and Active Family Caregivers*.

[44] Neal and Wagner, *Working Caregivers*. Note: The nationally representative survey of adults in the U.S. population, cosponsored by the National Council on Aging and the Pew Charitable Trusts, defined long-distance caregiving as requiring the caregiver to travel at least one hour to reach the care recipient. Caregiving was defined as providing or managing care, services, or financial/legal assistance of persons age 55 or older.

[45] Spillman and Pezzin, *Potential and Active Family Caregivers*.

provided by employed and non-employed caregivers narrowed when other variables were taken into account. Despite the diminution in the gap, *working women — particularly those employed full-time — were found in this analysis to provide significantly fewer hours of care. However, the care recipients of employed female primary caregivers were able to completely offset the 6.66 fewer caregiving hours per week by relying more on informal secondary caregivers and on formal caregivers.*[46]

Another study similarly found that the full-time employment of primary (mostly female) caregivers to very disabled elders reduced caregiving time by 25 hours per week in 1982 and by 22 hours per week in 1989. The 3-hour difference was not statistically significant, nor was the increase in the share of primary caregivers employed full-time (from 15.8% in 1982 to 19.3% in 1989). At least during the 1980s, then, the adverse effect of full-time employment on caregiving hours appears not to have intensified. *These findings suggest that full-time employment of primary caregivers has not worsened unmet need for assistance.*[47] The researcher noted two factors on the demand (i.e., need) side that might compensate for decreases in the future availability of family caregivers, namely, a rise in the use of assistive equipment and a decline in the disability rate of the elderly.[48]

The Effects of Elder Caregiving

Employees. Employees may reconcile their work and caregiving obligations by cutting back hours of employment. According to the NAC/AARP survey, 54% of employed caregivers to older adults make some type of workplace adjustment to accommodate their elder caregiver role. Changes to the daily work schedule are the most frequently noted, with 49% of employed elder caregivers arriving late or leaving work early. Far fewer stop working briefly (11% took a leave of absence) or permanently (6% quit and 4% retired early). About 7% take other measures to reduce workplace demands, such as switching to part-time jobs. Studies based on more restrictive definitions of caregiving yield similar results.[49]

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[46] Doty et al, *The Impact of Female Caregivers' Employment Status*.

[47] Boaz, *Full-Time Employment and Informal Caregiving in the 1980s*.

[48] Kenneth G. Manton and XiLiang Gu confirm Boaz's speculation about the diminished disability rate among the elderly. See Kenneth G. Manton and XiLiang Gu, "Changes in the Prevalence of Chronic Disability in the United States Black and Nonblack Population Above Age 65 from 1982 to 1999," *Proceedings of the National Academy of Sciences*, vol. 98, no. 11, (May 22, 2001).

[49] For example, 22% of the potential working population of caregivers to Medicaid patients certified as eligible for nursing home placement but who instead enrolled in a community-based program curtailed their hours of employment or quit in order to assist family members. See Kenneth E. Covinsky, Catherin Eng, Li-Yung Lui, Laura P. Sands, Ashwini R. Sehgal, Louise C. Walter, Darryl Wieland, G. Paul Elezer, and Kristine Yaffe in "Reduced Employment in Caregivers of Frail Elders: Impact of Ethnicity, Patient Clinical Characteristics, and Caregiver Characteristics," *Journal of Gerontology*, vol. 56A, no. 11, (2001). (Hereafter cited as Covinsky et al, *Reduced Employment in Caregivers of Frail Elders*.) Note: The potential working caregiver population was composed of those who were employed or who said they would be employed had they not been providing care.

Results are mixed concerning the impact of these workplace adaptations on the supply of labor by caregivers (i.e., rate of participation in the labor force and number of hours worked) and on their financial condition. The differences among studies could be related to such factors as whether the caregiver resides with the care user, the number of caregiving hours, the relationship of the caregiver to the care user, and the sex and age of the caregiver.[50]

Wages and Retirement Income. One recent analysis based on data from the Health and Retirement Study, a nationally representative longitudinal survey, looked at women and men who ranged from 53 to 65 years old in the mid-1990s and who were caring for a parent.[51] It estimated that a daughter who assisted her parents either with ADLs or IADLs for at least 100 hours in a 12-month period significantly curtailed her supply of labor by 459 hours a year. The cutback by a son who similarly helped a parent was virtually the same at 462 hours a year. Given the gender difference in total hours worked, the figures represented a 28% reduction in paid work hours for men and a 43% reduction for women. Fairly few people nearing retirement in the mid-1990s spent 100 or more hours providing care to parents during the course of a year; however, the "opportunity cost" was high for those who did. The researchers estimated that the reduced hours of working women who devoted a great deal of time to parental care late in their worklives produced an average loss in pre-tax wages of about $7,800 a year (in 1994 dollars).

The opportunity cost of providing informal assistance could extend beyond a caregiver's working years. Social Security benefits might be depressed due to lower lifetime earnings and fewer total years of employment.[52] Private pension benefits might be reduced for similar reasons. These costs have rarely been quantified. The NAC and National Center on Women and Aging at Brandeis University attempted an estimate utilizing information gathered from in-depth interviews of a small subset of participants in the NAC/AARP survey, specifically, 55 caregivers age 45 or older (1) who made work adjustments because of the caregiving they had provided for 6 months or longer and (2) who assisted with at least two tasks for a minimum of 8 hours per week (i.e., at least 416 hours a year). The present value of lost wages was estimated to average $566,443 over a caregiver's working life, and forgone Social Security benefits were estimated to average $25,494 over a caregiver's retirement years (based on information provided by 30 of the 55 individuals who said that caregiving directly affected their earnings and who gave sufficient monetary data).[53]

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[50] Susan L. Ettner, "The Impact of 'Parent Care' on Female Labor Supply Decisions," *Demography*, vol. 32, no. 1 (Feb. 1995).

[51] Richard W. Johnson and Anthony T. Lo Sasso, *Parental Care at Midlife: Balancing Work and Family Responsibilities Near Retirement*, The Urban Institute, The Retirement Project, brief series no. 9 (Mar. 2000).

[52] See for example two studies that use the same database but whose results have differing implications for public policy are Eric R. Kingson and Regina O'Grady-LeShane, "The Effects of Caregiving on Women's Social Security Benefits," *The Gerontologist*, vol. 33, no. 2 (1993); and Steven H. Sandell and Howard Iams, "Caregiving and Women's Social Security Benefits: A Comment on Kingson and O'Grady-LeShane," *The Gerontologist*, vol. 34, no. 5 (1994).

[53] MLIC, *The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs*

(continued...)

Elder caregiving also was estimated to reduce an individual's pension benefits by $67,202 on average (based on information provided by 10 of the respondents).[54] Thus, the average lifetime opportunity cost of a caregiver in this small, nonrepresentative sample who made workplace adjustments to fulfill her very time-consuming caregiving responsibilities was estimated to be $659,139.

Non-Pecuniary Impact. Employed caregivers to the frail elderly could experience other financial costs, which might in turn have non-pecuniary effects. Employees report paying for such things as the food, transportation, and medication needed by care recipients. Some say these out-of-pocket payments on behalf of elders mean less money for their own savings/investment and for current expenses.[55] Although caregiving seems to be less of a financial hardship for working than for non-working caregivers,[56] the results of a study of female elder caregivers at 37 workplaces suggest that such economic consequences may significantly affect whether employees feel care-related strain.[57]

Gender appears to be an important moderator of elder caregiving's potentially adverse impact on the well-being of unpaid helpers. For example, an empirical analysis of elder caregiving among a university's workers determined that women feel significantly more role strain (family, work, and personal) and more caregiving strain (physical, emotional, and financial) than men.[58] Other studies concluded that women — particularly daughters and daughters-in-law — are more apt than men to make workplace adjustments,[59] and that these accommodations significantly increase caregivers' burden (emotional, physical, and time strains).[60]

Working caregivers are less likely than others to experience physical or mental health problems due to elder care provision, according to the NAC/AARP survey. This may be the case because work affords caregivers an opportunity to receive

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[53] (...continued)
Involved, 1999.

[54] The average loss was used in the case of caregivers who could not provide pension information.

[55] MLIC, *The MetLife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved*, 1999.

[56] NAC and AARP, *Family Caregiving in the U.S.*.

[57] Janice M. Keefe and Sheva Medjuck, "The Contribution of Long Term Economic Costs to Predicting Strain Among Employed Women Caregivers," *Journal of Women & Aging*, vol. 9, no. 3 (1997).

[58] Karen I. Fredriksen, "Gender Differences in Employment and the Informal Care of Adults," *Journal of Women & Aging*, vol. 8, no. 2 (1996).

[59] Covinsky et al, *Reduced Employment in Caregivers of Frail Elders*.

[60] Betty J. Kramer and Stuart Kipnis, "Eldercare and Work-Role Conflict: Toward an Understanding of Gender Differences in Caregiver Burden, *The Gerontologist*, vol. 35, no. 3 (1995).

support from co-workers and supervisors.[61] Some of the 94 employed caregivers included in one study reported other positive effects, including elder caregiving

> making them more sensitive to the feelings and needs of their customers and co-workers or by helping them to feel more competent in their ability to handle difficult problems ... For most respondents, combining work and caregiving seemed to have both positive *and* negative implications.[62]

Employers. In addition to curtailing their hours of employment to accommodate elder care commitments, employees sometimes conduct care activities while at work. They may use work time to telephone care recipients or to search the Internet for elder care information. These activities could diminish job performance, as could having difficulty concentrating fully on the task at hand because of concern about a parent living alone, for example.

It is widely acknowledged that workplace adaptations to elder caregiving impose a financial burden on employers. Cost estimates have rarely been made because of a lack of good data. In order to develop an estimate, *The MetLife Study of Employer Costs for Working Caregivers* pulled together data from a variety of sources (e.g., NAC/AARP survey respondents employed full-time who performed at least two ADLs and at least four IADLs and a 1995 study prepared for the Metropolitan Life Insurance Company on the prevalence of workplace adjustments among respondents to three employer-based surveys). According to the analysis, elder caregiving cost employers over $11 billion per year ($1,142 per employee) due to its impact on employee productivity and management/supervisory time. The total is the sum of the expense of replacing workers (e.g., recruiting and training costs as well as the lower productivity of new-hires compared to experienced workers) — $4.9 billion; of full- and part-day absences — $886 million; of ordinary workday interruptions (e.g., work time spent in care-related telephone calls) — $3.8 billion, and workday interruptions prompted by crises (e.g., parents having to move into an assisted living facility) — $1.1 billion; and of supervising employed caregivers (e.g., providing them with emotional support, arranging coverage for their absences, and advising them about available benefits) — $805 million.[63]

Some believe this to be a conservative estimate because it does not consider such things as leaves of absence and the increased utilization of health services by employees due to their caregiving duties. The estimate also excludes caregivers employed part-time, long-distance caregivers, and those who provide less intensive assistance to older adults. "If all these additional employed caregivers were included in the calculations, the total costs to U.S. business [of employees having elder care responsibilities] would exceed $29 billion per year."[64]

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[61] Fredriksen-Goldsen and Scharlach, *Families and Work*.

[62] Andrew E. Scharlach, "Caregiving and Employment: Competing or Complementary Roles?" *The Gerontologist*, vol. 34, no. 3 (1994).

[63] Metropolitan Life Insurance Company, *The MetLife Study of Employer Costs for Working Caregivers*, 1997.

[64] Ibid.

Another study examined the cost to business of one health condition closely associated with the elderly, namely, Alzheimer's disease (AD). The authors note that because they base business' cost upon the 4 million people currently estimated to have the disease, they believe it to be a conservative figure in light of the large baby-boom cohort not yet having reached the typical ages of vulnerability.[65] (Some research has found evidence of declining cognitive impairment among older persons, however.[66]) In 2002, AD caregiving was estimated to cost business $61.1 billion.[67] This is double the aforementioned figure of at least $29 billion.

Caregiving to AD patients by employees, estimated at $36.5 billion, represents the largest portion of the $61.1 billion total. Of the $36.5 billion, $10.2 billion is associated with absenteeism; $18.0 billion, with lost productivity due to absenteeism; $6.3 billion, with replacing caregivers employed full-time and part-time who permanently leave their firms each year; $0.7 billion, with the fees paid to agencies for temporary replacement of caregivers on leave who usually work full-time and $1.2 billion, with continuing the insurance of these caregivers; and $0.06 billion, with the additional utilization of employee assistance programs by those caregivers employed full-time who have access to the programs. The remainder of the cost to business ($24.6 billion) largely comes from estimated employer payroll and corporate tax payments to Medicare and Medicaid, for example, for the health care costs of persons with AD ($24.4 billion).

Society. As previously discussed, individuals may reconcile their work and elder caregiving roles by making adjustments to one or both obligations. That is to say, they may cut back the amount of labor and/or of unpaid caregiving supplied.

The economic consequences of individuals reducing their employment are borne not only by their families (e.g., lower incomes and lost health benefits), but also by society. A slowdown in the rate of labor force growth (absent productivity improvement) would dampen the rate of increase in the production of goods and services, and hence, in the U.S. standard of living. In addition, the forgone earnings and retirement income of employed caregivers who substantially reduce their work time or totally withdraw from the labor force could translate into reduced tax revenues and increased government dependency.

If employed caregivers take the latter course, namely, greatly limiting the amount of elder care provided, both older members of society and government could experience a financial impact. If the frail elderly had needs that no longer were being met by family members, they might try to hire home care workers — a group already considered to be in short supply. At present, government programs typically cover a limited amount of in-home assistance to the non-poor elderly, which suggests that

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[65] Michael J. Moore, Carolyn W. Zhu, and Elizabeth C. Clipp, "Informal Costs of Dementia Care: Estimates from the National Longitudinal Caregiver Study," *Journal of Gerontology*, vol. 56B, no. 4 (2001). (Hereafter cited as Moore, Zhu, and Clipp, *Informal Costs of Dementia Care*.)

[66] Vicki A. Freedman, Hakan Aykan, and Linda G. Martin, "Another Look at Aggregate Changes in Severe Cognitive Impairment: Further Implications into the Cumulative Effect of Three Survey Design Issues," *Journal of Gerontology*, vol. 57B, no. 2 (2002).

[67] Moore, Zhu, and Clipp, *Informal Costs of Dementia Care*.

the budgets of low and moderate income elders could be the most strained by a reduced supply of unpaid caregivers. Without an ample supply of "free" or publicly subsidized home care, frail elders living in the community presumably would have to move into more expensive settings where a substantial percentage of the cost would be borne by taxpayers. To forestall elders making moves that would be costly to the public, the government could expand coverage of home care services, but replacing the "free" assistance that families provide to older adults would not be without considerable expense.

There are differing estimates of *the economic value of informal caregiving*. The variability stems from, among other things, the care recipient population under consideration. Some analyses look at all adults or only older adults with a particular disease (e.g., cancer or Alzheimer's).[68] Among studies that developed an economic value for a broader group of care users (e.g., all adults regardless of the condition giving rise to their need for assistance), results differ because the researchers used varying estimates of, for example, the number of hours of informal caregiving and of the hourly wage rate applied to caregivers' time (e.g., the federal minimum wage or the average wage of home health workers).

According to one analysis, the economic value of informal caregiving to adults in 2000 was $140 billion, $257 billion, or $389 billion depending upon the number of caregivers (25.4-29.2 million), caregiving hours (24-27 billion), and the proxy for their hourly wage rate ($5.15-$12.46).[69] Other researchers put the market value of informal assistance to adults who need help with ADLs or IADLs at approximately $166 billion. They estimated the number of caregiving hours to be 18.7 billion and used $9 as the hourly wage rate (which was between the federal minimum wage of $5.15 per hour and the average wage of home health workers, $11 per hour, in 1996).[70] Thus, the economic value of informal care provided to adults is estimated to greatly exceed the cost of either formal home care ($32 billion) or nursing home care ($92 billion).

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[68] Moore, Zhu, and Clipp (in *Informal Costs of Dementia Care*) noted the wide range of estimates of the annual cost of informal caregiving to Alzheimer's patients living in the community, from $12,730 to $57,937 per patient. They included in their own estimate not only caregivers' time but also their lost income, out-of-pocket expenditures for formal services, and caregivers' excess health care costs. The authors found that the average value of informal assistance to community-dwelling Alzheimer's patients totaled $18,385 per person in 1998. The largest component costs were caregivers' lost earnings ($10,709) and the cost of caregiving time ($6,295), which varied based upon the severity of dementia.

[69] Presentation by Peter S. Arno at the February 24, 2002 meeting of the American Association for Geriatric Psychiatry in Orlando, Florida.

[70] Mitchell P. LaPlante, Charlene Harrington, and Taewoon Kang, "Estimating Paid and Unpaid Hours of Personal Assistance Services in Activities of Daily Living to Adults Living at Home," *Health Services Research*, vol. 37, no. 2 (April 2002).

Assistance to Informal Caregivers to the Elderly from Employers and Public Programs

In the interest of such things as maintaining a productive workforce, holding down turnover costs, offering a competitive benefit package, and being responsive to aging employees' needs, some employers have changed their human resources policies, benefits, and services to accommodate the caregiving roles of employees. In some instances, labor unions have negotiated with management to attain these changes for the workers they represent. Employers and unions sometimes have invested in community-based services in order to increase the availability of elder care. Caregiver advocacy groups have encouraged the enactment of legislation that supports all individuals who provide unpaid assistance. In recognition of the cost savings to taxpayers of family caregiving and of the need to promote an ample supply of labor from the smaller cohorts that antedated the baby-boom generation, Congress has enacted legislation to facilitate family-work balance and to otherwise promote informal assistance to frail elders.

Workplace Initiatives

Generic workplace policies that can be useful to elder caregivers include flexible and compressed work schedules, part-time hours, job sharing, leave time, telecommuting, and management training in work-life issues. Employers also provide benefits that similarly can be useful to elder caregivers among other employees (e.g., counseling commonly offered through employee assistance programs, flexible benefit/spending plans, and long-term care insurance). The provision of services is another means by which employers can assist specific groups of employees, including elder caregivers. Services include providing educational information through on-site libraries and seminars, for example; sponsoring resource and referral services as well as wellness programs; and establishing or subsidizing day care and respite care.[71]

The prevalence of elder care programs has been on the rise, although companies may prefer to expand the availability of programs that are useful to elder and child caregivers as well as to other members of a firm's workforce. According to a Hewitt Associates' analysis of salaried employee benefit plans, 49% of 960 major U.S. employers had elder care programs in 2002; in contrast, 74% of employers offered alternative work arrangements, including flexible work schedules and part-time jobs. Paid time off from work has long been the benefit most commonly offered by employers (e.g., vacations, holidays, and to a lesser extent sick leave). However, one form of time off — family leave — is much more likely to be offered on an unpaid than paid basis.[72]

The most common elder care benefit is widely reported to be *resource and referral services*. For example, the Hewitt study found that 32% of major companies offered contract referral services and another 6% had in-house resource and referral

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[71] Neal and Wagner, *Working Caregivers*.

[72] U.S. Bureau of Labor Statistics, *Employee Benefits in Medium and Large Private Establishments, 1997*.

services. Perhaps 25% of workers had access to elder care resource and referral services, according to the Families and Work Institute survey. (Although 40% of employers actually offer dependent care spending accounts to pay for elder care expenses, according to Hewitt, the accounts rarely are used for this purpose because of eligibility requirements in federal law. These tax-favored accounts are discussed in the following section.)

Perhaps reflecting one study's finding that the availability of *long-term care insurance* increases the likelihood that elder caregivers will remain in the labor force,[73] 27% of major companies offered the benefit in 2002 according to Hewitt. In the public sector, the federal government began to offer long-term care insurance as a benefit effective in 2003; employees and eligible family members who opt to enroll must pay the entire insurance premium.

According to U.S. Bureau of Labor Statistics' National Compensation Survey data for 2000, 7% of employees had access through their private sector employers to long-term care insurance. Employees of firms with at least 100 workers who worked full-time in professional/technical/related occupations were more likely to have access to the insurance. Access differs from enrollment, however: more than two-thirds of non-enrolled employees at nine firms of varying size and type that offer long-term care insurance stated they would be more interested in enrolling if their employer contributed to the policy premium; and, almost three out of five non-enrollees said if the government allowed them a deduction from income tax for premium costs, it also would increase their participation.[74]

Just as cost influences the inclination of employees to elect long-term care insurance coverage, it also affects the willingness and ability of employers to offer direct services to elder caregivers. Making such professionals as geriatric case managers and lawyers available to assist caregivers could prove expensive if their services are paid entirely by employers. The differing needs of working caregivers also may make it difficult for firms to determine the services that are worthwhile investments (e.g., relatively few caregivers in a given workforce might want to enroll care users in on-site adult day care).[75]

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[73] According to MLIC, *The MetLife Study of Employed Caregivers*, caregivers to community-dwelling persons age 65 or older who have limitations in at least two ADLs or who are cognitively impaired are almost twice as likely to be employed if the elder has long-term care insurance (all other things being equal).

[74] Health Insurance Association of America, *Who Buys Long-Term Care Insurance in the Workplace? A Study of Employer Long-Term Care Insurance Plans, 2000-2001*, Executive Summary, 2001.

[75] Donna L. Wagner, "The Development and Future of Workplace Eldercare," in Metropolitan Life Insurance Company, *Dimensions of Family Caregiving: A Look into the Future*, papers presented at a national conference in Washington, D.C., Sept. 12, 2000.

Federal Government Initiatives

Mandated Leave. The federal government has taken a number of paths to make it easier for workers to continue their elder caregiving and other commitments. One such avenue is the Family and Medical Leave Act (FMLA). It requires private employers with at least 50 employees and public employers, regardless of size, to extend job-protected, unpaid leave to employees who meet length-of-service and hours-of-work eligibility requirements. The 12-week-per-year leave entitlement is available to covered, eligible employees to care for their own, a spouse's, child's, or a parent's serious health condition, or to care for their newborn, newly adopted, or newly placed foster child. Accrued paid leave (e.g., vacation) generally can be substituted for leave under the Act. Employers must maintain group health benefits while employees are on FMLA leave.

According to a U.S. Department of Labor survey, workers do not often use FMLA leave to care for a seriously ill parent. Employees reported attending to their own health as the predominant reason for taking leave under the Act in the late 1990s (37.8%), with caring for a parent involved in only 10.6% of FMLA leaves. This nonetheless represents an increase from an earlier survey, when there were too few instances to report accurate figures.[76]

Some states have enacted family/medical leave laws and some employers offer family/medical leave benefits that are more expansive than those provided through the FMLA (e.g., cover smaller firms and additional reasons for leave). Employees in those jurisdictions and at those employers are entitled to the more generous benefits.

Tax Policy. The *Dependent Care Tax Credit* (DCTC) is available to taxpayers with earned income for the work-related expenses they incur caring, typically, for children. The credit also may be claimed by employed taxpayers who have dependents living in their homes or spending at least 8 hours a day in their homes, and who are physically or mentally unable to care for themselves. "These restrictions represent significant barriers to the use of the program by those caregiving to older adults who are, for the most part, residentially and economically independent."[77]

The DCTC is nonrefundable, which means its value is limited to the filer's income tax liability. Families with a tax liability that it is entirely offset by their standard deduction and their personal/dependent exemptions would not benefit from the credit. For example, a married-couple with a young child and a dependent frail elder in their household having an income of up to $19,850 in 2002 would have no tax liability due to these factors.

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[76] For more information see CRS Report RL30893, *Explanation of and Experience Under the Family and Medical Leave Act*, by Linda Levine.

[77] Merril Silverstein and Tonya M. Parrott, "Attitudes Toward Government Policies that Assist Informal Caregivers: The Link between Personal Troubles and Public Issues," *Research on Aging*, vol. 32, no. 3 (May 2001).

Qualifying expenses cannot exceed the earned income of the taxpayer or the earned income of the lower paid spouse in the case of a married couple. For 2002, the DCTC is equal to 30% of qualifying expenses up to $2,400 for one dependent ($720) and up to $4,800 for two or more dependents ($1,440). The subsidy rate is gradually reduced for taxpayers with adjusted gross incomes (AGI) that exceed $10,000 until it reaches 20% for taxpayers with incomes over $28,000. Beginning in 2003, taxpayers will be able to claim a credit of 35% of qualifying expenses up to $3,000 for one dependent ($1,050) and $6,000 for two or more dependents ($2,100). The stated subsidy rate of 35% will gradually fall for taxpayers with AGIs above $15,000 until it reaches 20%.

The *Dependent Care Assistance Program* (DCAP) enables employees to exclude from gross income up to $5,000 annually ($2,500 for married-couples filing separately) in employer dependent care assistance when determining their income tax liability. The excluded amount is not subject to employment taxes of the employee or employer. The exclusion applies to both care provided by employers and to arrangements whereby employees are reimbursed for their qualifying expenses; the latter is the more common approach. Both arrangements often are funded through salary-reduction plans that enable employees to pay care expenditures with pre-tax dollars. As in the case of the DCTC, it has been said that "DCAP's are of limited usefulness for employees caring for a disabled adult because IRS regulations require that the dependent must spend at least eight hours a day in the employee's home, be unable to care for himself or herself, and must be financially dependent on the employee."[78]

The care must be performed by a person who is not a dependent of the taxpayer (e.g., someone other than a nonworking spouse). The amount of the exclusion cannot exceed the earned income of the taxpayer or the earned income of the lower paid spouse in the case of a married couple. Both the DCTC and DCAP can be used in the same year, but the maximum qualifying expenses for the DCTC must be reduced by the amount of the tax exclusion.

Grant programs. Congress created the National Family Caregiver Support Program (NFCSP) as an amendment to the reauthorization in 2000 of the Older Americans Act. It has five components: information to caregivers about services; help with gaining access to services; individual counseling, assistance with developing support groups, and caregiver training; respite care; and supplemental services (e.g., assistive devices). These activities, which are carried out by the states, are funded through a formula grant. The NFCSP is available to working and nonworking caregivers who care for persons at least 60 years old, older individuals who assist persons with developmental disabilities, and grandparents and older relatives who are caregivers to children age 18 and under. State initiatives funded from other sources and directed specifically at working caregivers are quite rare.[79]

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[78] Fredriksen-Goldsen and Scharlach, *Families and Work.*

[79] See for example Donna L. Wagner, *Enhancing State Initiatives for Working Caregivers*, policy brief no. 5, commissioned for "Who Will Provide Care? Emerging Issues for State Policymakers," Family Caregiver Alliance, Oct. 2001.

The U.S. Administration on Aging has developed the Eldercare Locator program. By calling a toll-free number (1-800-677-1116), caregivers to older adults can find the appropriate Area Agencies on Aging to help them.

Medicaid/Supplemental Security Income (SSI). One group of family caregivers may receive further support from the government, namely, those relatives who provide uncompensated personal (e.g., bathing) or non-personal (e.g., transportation) care to Medicaid/SSI beneficiaries living in the community who would otherwise require nursing facility care. Under section 1915(c) of the Medicaid statute, the Centers for Medicare and Medicaid Services may waive certain federal requirements to permit states to fund numerous home and community-based services (HCBS) requested by states and approved by the Department of Health and Human Services. Commonly provided services include case management, respite care for caregivers, and personal care.[80] Some states have used general revenues so that these support services are available to families beyond those caring for the poor elderly (e.g., the "near poor").[81]

The government, through the use of HCBS waivers, may enable employed caregivers to continue to fulfill their multiple responsibilities by providing services to Medicaid-eligible elders when their unpaid helpers are at work (e.g., adult day care). Federal Medicaid law further allows states to pay family members (e.g., adult children) other than those legally responsible for a person's care (e.g., a spouse) and to pay friends and neighbors for providing assistance that would otherwise have to be purchased.[82]

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[80] For more information see CRS Report RL31163, *Long-Term Care: A Profile of Medicaid 1915(c) Home and Community-Based Services Waivers*, by Carol O'Shaughnessy and Rachel Kelly.

[81] Wendy Fox-Grage, Barbara Coleman, and Robert B. Blancato, *Federal and State Policy in Family Caregiving: Recent Victories but Uncertain Future*, policy brief no. 2, commissioned for "Who Will Provide Care? Emerging Issues for State Policymakers," Family Caregiver Alliance, Oct. 2001.

[82] Gary Smith, Pamela Doty, and Janet O'Keeffe, *Supporting Informal Caregiving (under Medicaid)*, an issue brief prepared for the U.S. Administration on Aging's conference the National Family Caregiver Support Program "From Enactment to Action," Washington, Sept. 2001.