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# Working Caregivers: Issues, Challenges, And Opportunities For The Aging Network

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**Working Caregivers:  
Issues, Challenges, And Opportunities  
For The Aging Network**

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## Table of Contents

INTRODUCTION .....	1
SOCIAL AND DEMOGRAPHIC TRENDS INFLUENCING THE NUMBER OF WORKING CAREGIVERS .....	2
WHAT WE KNOW ABOUT WORKING CAREGIVERS .....	4
The Prevalence of Working Caregivers .....	4
The Characteristics and Caregiving Experiences of Working Caregivers .....	5
The Consequences of Working and Caregiving .....	8
Limitations of Previous Research .....	9
The Needs of Working Caregivers .....	10
Elder Care as a Workplace Issue .....	11
HOW EMPLOYERS HAVE RESPONDED TO THE NEEDS OF WORKING CAREGIVERS .....	11
The Evolution of Corporate Responses to Caregiving Employees .....	11
Factors Contributing to the Growth of Work-based Elder Care Programs .....	12
The Types of Formal Elder Care Programs That Employers Offer .....	13
GOVERNMENT RESPONSE TO THE NEEDS OF WORKING CAREGIVERS .....	15
THE AGING NETWORK AND WORKING CAREGIVERS .....	17
General Strategies for Addressing the Needs of Working Caregivers .....	17
Getting Started: Internal Considerations and General Recommendations .....	19
Tips for Working with the Business Community .....	22
CONCLUSION .....	24
REFERENCES .....	25
Appendix 1: Timeline for Development of Workplace Elder Care Programs	
Appendix 2: Work-Based Supports Available to Working Caregivers	

## INTRODUCTION

Kathy, a 39-year-old manager for a large company, is caring for her mother. She is her mother's primary care provider and has been arranging her services and taking care of her meals and errands for the past six months. Kathy agreed to respond to a survey of working caregivers and, during the interview, reported that she was struggling with the competing demands of a job, two children, a husband and the care of her dying mother. When asked about the effects of caregiving on her work she replied: "My work is fine. I am managing all of my responsibilities, and I enjoy being in my office doing things that have nothing to do with my family. And, my children are fine. However, my marriage is on the rocks."

Kathy is one of a growing group of Americans – working caregivers to elders. These workers are juggling their jobs and careers, their family responsibilities and their personal lives. Some working caregivers find caregiving a minor interlude that has positive consequences for them personally as a result of the satisfaction they experience from helping a loved one. Others discover that caregiving is a complicated and difficult set of tasks that require not only personal sacrifices, but professional sacrifices as well. And others, like Kathy, find that they cannot be successful in all parts of their lives, and their relationships, health or personal activities suffer as a result.

The precise number of American workers who are providing assistance to an older family member is not known. Based on workplace surveys, however, those with current elder care responsibilities have been estimated at 13% of the workforce (Wagner, 1999), and those involved in caregiving at some point during the past 12 months at 25% (Bond, Galinsky, & Swanberg, 1998). Regardless of the actual prevalence, we can expect an increase in the number of people, perhaps two-fold, involved in providing care in the future due to the aging of our population and the increased number of women in the workforce (Moen, Robison, & Fields, 1994).

As a result of the growing numbers of workers with elder care responsibilities, some large companies have begun work-based elder care programs. For some working caregivers, these programs provide needed support and assistance in their efforts. Employers with work-based programs tend to be the largest employers; however, since only a small proportion of the total workforce is employed by large companies, only a small percentage of working caregivers have a source of formal assistance at their workplace.

Supporting working caregivers is important for a number of reasons. One is that these working caregivers, like their non-working counterparts, are providing essential long-term services to older adults who otherwise would be dependent upon the public or private formal systems of care. A second reason is that working caregivers are making valuable contributions to the economic marketplace that need to be sustained. Supporting these caregivers so that they are not forced to choose between continuing to provide elder care and continuing to be engaged in paid work will benefit not only caregivers themselves, but also their families, the older Americans for whom they are caring, our economy, and our communities.

This paper provides an overview of the issues associated with working caregivers. We will examine the social and demographic trends influencing the growth of this group, their characteristics and their contributions to elders, and the consequences of caregiving for

caregivers and their work. Next, we will briefly describe the various employer-initiated programs currently in place to support working caregivers and the evolution of these programs, followed by federal and state governments' response to working caregivers, to date. The remainder of the paper details the potential role of the aging network in better supporting working caregivers, including current best practices and other possible strategies. We offer tips for getting started, including ideas and recommendations for internal program consideration, and tips for working with the business community.

## **SOCIAL AND DEMOGRAPHIC TRENDS INFLUENCING THE NUMBER OF WORKING CAREGIVERS**

Families have always been the primary source of support for older people in America. In fact, an estimated 80% of all the long-term care services used by older adults are provided by family and friends (Select Committee on Aging, 1987). Today, however, sweeping social, demographic, economic, and technological changes underway in the U.S. are altering the face of family caregiving and challenging families' ability to carry on this tradition. Key among these changes are: (a) the aging of the American population, (b) the aging of the American workforce, (c) an increasing number of women in the workforce, (d) changes in family size and composition, and (e) rising health care costs and the informalization of care.

**The American population is aging.** Over the last century, the proportion of older Americans tripled. This aging of the population resulted not only from increases in life expectancy, but also because of a decline in the birth rate. In 2000, there were about 35 million Americans over the age of 65 representing 12.4% of the American population (AoA, 2001, U.S. Census Bureau, October 2001). By 2020, persons aged 65 or older are expected to comprise 20% of the U.S. population (Judy & D'Amico, 1997). And by 2030, older Americans are projected to outnumber children under the age of 18 (Bronfenbrenner, McClelland, Wethington, Moen, & Ceci, 1996).

There are more than 13 million Americans with long-term care needs in the U.S., more than half of whom are over the age of 65 (ASPE, DHHS, 1995). Over the next 25 years, as the Baby Boom generation ages, some have estimated that the number of persons requiring long-term care may double (U.S. General Accounting Office, 1994a). Among the older adult population, those 85 years of age and older showed the highest percentage increase between 1990 and 2000, growing by 38% (U.S. Census Bureau, October 2001). Although the disability rates of older adults have declined (Manton, Corder, & Stallard, 1997), advanced age remains associated with an increased risk of chronic illness and need for assistance in performing activities of daily living (Bronfenbrenner et al., 1996). In fact, almost half of people aged 85+ need assistance with the activities of daily living. In addition, increased longevity may mean that there will be longer periods of dependency on middle-aged or older adult children for older people (Axel, 1985), and that adult children may become responsible for the care of family members from **two** older generations, either sequentially or simultaneously (Toseland, Smith, & McCallion, 2001).

**The combination of an aging workforce and a declining birth rate suggests that support for the growing older population will be limited.** This is supported by the decrease in family members available to help, and because public health care dollars generated through income taxes will be diminished due to the smaller workforce (Wagner, 2000).

In 1986, the median age of the labor force was 35.3. In 1996, it was 38.2. In 2006, it is projected to be 40.6 (Fullerton, 1997). Contributing to this trend is the decrease in early retirement and an

increase in post-retirement work. A recent survey of Baby Boomers found that 70% intend to work at least part-time after retirement (Committee for Economic Development, 1999). As the average age of the workforce increases, elder care and other issues related to this aging workforce are likely to overshadow childcare in importance for workers and for employers who need to retain valued workers.

**More women are in the workforce.** Ginzberg (1976, cited in Kamerman, 1983) called the entry of women into the paid labor force "the single most important phenomenon of the mid-twentieth century," affecting every aspect of society. Today, women comprise about 46% of the workforce, compared to about 37% in 1970 (U.S. Bureau of Labor Statistics, 1997). From 1986 to 1996, the number of women in the workforce increased by 18%; from 1996 to 2006, this number is expected to increase by an additional 14% (U.S. Bureau of Labor Statistics, 1997). Nearly 80% of women between the ages of 25 and 54 are in the labor force today (U.S. Bureau of Labor Statistics, 2000). Between 1988 and 2000, almost two-thirds of new entrants into the workforce were expected to be women (Johnston & Packer, 1987), and this trend is expected to continue (Judy & D'Amico, 1997). As female labor participation has grown, so too has concern for the groups traditionally cared for by women: elders as well as children.

**Family size and composition are changing.** The previously dominant family type of a sole wage-earner father with a wife/mother who stayed at home to raise children has been replaced by the dual-earner or the single-parent household. Couples often cohabituate without formally marrying, and in most couples, both partners work. Marriages occur later and are less enduring, and births are later and fewer in number. Most children have mothers who work. The number of single-parent families has skyrocketed. Many families today are "blended" families, with stepchildren and stepparents. And many families have multiple responsibilities for children and elders who are either living with the families or apart. The number of three-generation households is growing, and the number of grandparents raising grandchildren is increasing (U.S. Census Bureau, 2001). Finally, geographic mobility of families has increased, with more adult children living at a distance from their elders needing care. This latter trend has resulted in approximately seven million Americans involved in long-distance caregiving (Wagner & Neal, 1997).

Moreover, as the primary household configuration has changed, and with the increased proportion of women in the paid labor force, life styles have been altered (Kamerman, 1983) and there is a trend toward redistribution of traditional gender role responsibilities (Barnett, 1998). Men now play a larger role, either forced or desired, in child-rearing, performance of household tasks (Morgan & Tucker, 1991), and elder care. Although the general caregiving literature reports that women comprise about 72% of the primary caregivers to elders (e.g., Stone, Cafferata & Sangl, 1987), a different pattern emerges when working populations are surveyed. For example, in an early study of 9,573 employees in 33 organizations, Neal, Chapman and Ingersoll-Dayton (1988) found that 63% of the caregivers to elders were women, and 37% were men. More recently, the 1997 National Study of the Changing Workforce found that as many men as women in the workplace reported that they had caregiving responsibilities for an older adult (Bond et. al., 1998).

**Health care costs have risen dramatically.** This key trend has resulted in the implementation of cost containment measures and the further informalization of care, that is, increased reliance on family and friends to provide informal care to substitute for formal health care services. Older

adults who, in the past, remained in the hospital for most of their recovery period from an illness or accident are today sent home after considerably fewer days and with less “formal” support. Family members and other informal supports are left to manage the overall care of an elder and to perform sometimes very complicated health care tasks. This often comes at great personal expense and frequently with little or no training or resources from health care professionals (Estes et al., 1993; Wagner, 2000).

Taken together, these aging, workforce, family, and health care-related trends mean that there are growing numbers of people who must juggle the demands of their work with those of their families. The cost of replacing the work of these informal caregivers with paid home care has been estimated to range from \$45-75 billion (AoA, May 1999) to \$196 billion dollars per year (Arno, Levine, Memmott, 1999). This latter figure represents about 18% of total national health care spending per year. Although the American family continues to perform the basic family functions of socialization, care and nurturing of its members, the ways in which family functions are performed now differ. It is clear that for most families today, reliance on a stay-at-home spouse to handle family responsibilities is not an option. Also, increasingly there will be fewer children to care for aging parents. The implications of these trends for caregiving in the future are that there will be more elders who need care, fewer women who can devote their full attention to providing this care due to their paid work responsibilities, more men who will be involved in caregiving, more care provided by non-relatives, and more caregivers who will also be engaged in paid work. Conflicts between work and family are becoming more common and are of concern to employers and workers alike (Heymann, 2000). So, who are these working caregivers, and how many of them are there?

## **WHAT WE KNOW ABOUT WORKING CAREGIVERS**

### **The Prevalence of Working Caregivers**

Neither the precise number nor the proportion of caregivers who are working is known. The available prevalence estimates of working caregivers are based upon surveys of general households or of employees. Because people may be more likely to respond to a survey about elder care or work-family issues in general if they are personally involved in such issues, these surveys tend to overestimate the prevalence of elder care.

Moreover, existing estimates have tended to vary considerably. This is because the surveys conducted have defined “caregiving” differently. Some studies have used a broad definition to include such instrumental activities as checking on the elder by telephone, while some have used a much narrower definition requiring provision of assistance with one or more personal activities of daily living (Gorey, Rice, & Brice, 1992). Still others have designated a minimum amount of time spent per week in caregiving before the respondent is considered to be providing elder care (e.g., Neal, Hammer, Rickard, Isgrigg, & Brockwood, 1999). In addition to differing definitions of “caregiving,” studies have also varied in the age of the care recipient. In some studies, the age considered “older” or “elderly” has been 50, in some 60, and in others, 65. Obviously, higher elder care prevalence rates will be associated with studies that have cast their nets broadly in terms of care recipient age, tasks provided, or amount of time spent performing tasks. Studies of working caregivers have also differed with respect to whether they included both men and women, care to other elderly relatives besides parents, and care to elders who are not related as well as those who are. The following are the latest prevalence estimates available, first based on studies of households, then on studies of employees:

- A 1997 study by the National Alliance of Family Caregivers (NAC) and AARP found that just over 23% of all U.S. households with a telephone contained at least one person who was currently caring for, or had in the previous year cared for, a relative or friend aged 50 or over. Of these households, 76% contained current caregivers. Of the caregivers identified, 64%, or 14.1 million caregivers, were employed full (52%) or part (12%) time. Of those not working, one-third had been working at one point during their caregiving career.
- Gorey, Rice and Brice (1992) conducted a combined analysis of the findings from various workplace surveys and applied a correction factor for response rate. On this basis, they estimated that between 7.4% and 11.8% of the workforce had elder care responsibilities. In contrast, a more recent study, the 1997 National Study of the Changing Workforce conducted by the Families and Work Institute (Bond et al., 1998) suggested that the current prevalence of caregiving among employed persons was 25%. A total of 42% of the employees reported that they anticipated providing elder care in the next five years. Taking into account response bias and rate, a more conservative estimate is that 13% of the American workforce is currently involved in caregiving (Wagner, 1999). Regardless, the number of working caregivers is expected to grow dramatically, even double, in the near future (Moen, Robison, & Fields, 1994).
- Workers of all ages are involved in elder care, although workers in their 40s and 50s are somewhat more likely to have elder care responsibilities (NAC/AARP, 1997). A 1998 study by the Families and Work Institute found involvement in elder care activities by members of the workforce to be as follows: 18% of the workers under the age of 30, 19% of those between 30 and 39, 28% aged 40 to 49 and 37% of those over the age of 50 (Bond et al., 1998). Thus, employers with older workforces generally will feel greater impact from employees' elder care duties than will those with younger workforces. With reductions in the availability of family caregivers, however, it is possible that the age of onset of elder care responsibilities will decrease, as younger family members, friends, and neighbors, who also are likely to be in the paid work force, step up to help care for elders.

### **The Characteristics and Caregiving Experiences of Working Caregivers**

Early reviews of descriptive studies of working caregivers found that employed caregivers' average age was 47, they were primarily women (62%), most were married (Gorey et al., 1992), and they spent from 6 to 10 hours each week in caregiving for an average of 5.5 to 6.5 years (Wagner & Neal, 1994). The findings from more recent individual studies have generally been consistent with these, with the exception of that concerning the gender of working caregivers, where Bond et al. (1998) found equal proportions of males and females.

**Working versus non-working caregivers.** The findings from studies of the differences in the amount and nature of care provided by working versus non-working caregivers are mixed. Stoller (1983) found that employed female caregivers provided the same level of care as their non-employed female counterparts. Employed male caregivers, however, provided somewhat less care than the non-employed male caregivers in the sample. When Brody and Schoonover (1986) studied employed and non-employed daughters to determine which group was providing more help, they found no differences between the groups in the amount of help provided in five out of seven categories of tasks. On two tasks – personal care and meal preparation – did the



non-employed daughters provide more assistance than those who were employed. At the same time, there was more reliance by the employed daughters on both paid (formal) caregivers and husbands. Another study (Matthews, Werkner, & Delaney, 1989) found employed and non-employed daughters made similar contributions to the elder's care, except when the parent was in very poor health, when the non-employed daughters assumed more caregiving responsibility. Other researchers found that employment reduced the likelihood of provision of assistance in the Activities of Daily Living (Dwyer, Henretta, Coward, & Barton, 1992). Tennstedt (1992) found that employed caregivers were more likely to have assistance from secondary caregivers. She also found that employees who were secondary caregivers themselves became more involved in caregiving over time. A study of caregivers of cognitively impaired adults of all ages found that non-employed caregivers provided more hours of assistance per week than did caregivers who were employed (an average of 109 hours versus 57 hours). Still, however, the hours of assistance provided by the employed caregivers was "the equivalent of more than one and a third full-time jobs" (Enright, 1991: 379).

**Relationship.** Working caregivers and those who are not engaged in paid work do differ with regard to their relationship to the care recipient. Specifically, working caregivers are more likely to be caring for aging parents rather than for frail or disabled spouses (NAC/AARP, 1997), while among the general caregiver population the reverse is true (Stone et al., 1987).

**Male versus female caregivers.** A higher percentage of working men are involved in elder care than is the case among the general population of caregivers. A recent study of employees found equal proportions of males and females who were caregivers to elders (Bond et al., 1998), compared to an early national study of the general population of caregivers, both working and non-working, that found only 28% of the caregivers were male (Stone et al., 1987).

The findings are mixed regarding differences between working men and working women in the amount and nature of elder care provided. A study of employed caregivers to elders found no gender differences in the provision of 7 of 13 caregiving tasks, but women devoted more time per week, on average (6.1 hours compared to 4.1 hours), and were somewhat more likely to be primary caregivers (Neal, Ingersoll-Dayton, & Starrels, 1997). Although a study of working couples caring both for children and for aging parents (Neal, Hammer, Rickard, Isgrigg, & Brockwood, 1999) found several statistically significant gender differences in the amount and nature of care provided, the practical significance of these differences was minimal. For example, the wives provided two more hours of care to aging parents or parents-in-law per week than the husbands (about 10 hours compared to 8), although both husbands and wives provided, on average, the equivalent of one day of care per week. Other gender differences included: the parent to whom husbands were providing the most care was slightly more likely to be a parent-in-law (42%) than was the case for the wives (31%); slightly more of the parents for whom husbands were caring lived independently (76% compared to 69% of the parents for whom wives were caring); husbands were slightly less likely to be caring for a female parent or parent-in-law (71%) than were wives (77%); and husbands reported caring for parents who needed slightly less assistance with IADLs (6.9 on average, compared to 8.1 on a scale from 0 to 27).

**Elder care from a distance.** Many working caregivers are providing long-distance care. According to a survey conducted in 1997 for the National Council on the Aging (Wagner & Neal, 1997), there are an estimated 7 million long-distance caregivers. These long-distance caregivers, defined by these researchers as caregivers who provide care for an elder who lives at

least an hour away, are also more likely to be working full-time than indicated in general population surveys of caregivers. The NCOA survey found that over 60% of those providing long-distance care were fully employed, as compared with the NAC/AARP (1997) general caregiver population survey results of 52%. Interestingly, even the long-distance caregivers are involved in “hands-on” care activities for their older care recipient and, when they visit, take care of the instrumental activities of daily living, much like those caregivers who live near the care recipient. Their responsibilities, however, are complicated by distance and travel logistics, and most of these caregivers report that they have a family member or friend who lives close to the elder and who assists them in their caregiving (Wagner & Neal, 1997).

**Multiple caregiving responsibilities.** Many working caregivers have multiple caregiving responsibilities, not just for more than one elder or adult with disabilities, but for children, as well. As more women decide to delay childbearing until their later 30s or 40s, and as more women enter or return to the paid workforce, there is increased likelihood that workers will have responsibility for dependent children in addition to responsibility for their aging parents (Rosenthal et al., 1996). These adults who provide help to their frail or disabled parents, or other elders, and who also have responsibility for dependent children have been dubbed the “sandwich generation” (Fernandez, 1990), in that they are sandwiched between the needs of their children and their elder, and often, their jobs.

The NAC/AARP study (1997) found that of all caregivers of persons aged 50 and over, 41% also had children under the age of 18 living in their households. Similarly, Neal et al. (1993) found in their study of employees in 33 different companies that 42% of the employees who were caring for elders also were caring for children; this group comprised 9% of the sample of employees overall. A national telephone survey of households with adults aged 30 to 60 conducted to identify working couples in the sandwiched generation found that between 9% and 13% of these dual-earner households had responsibilities for aging parents and dependent children aged 18 and younger (Neal et al., 1999).

**Race and ethnicity.** The few studies that have addressed racial and ethnic differences among caregivers generally have not focused specifically on working caregivers. One exception is a study by Lechner (1993), which found that African-American caregivers reported less support from supervisors and less flexible policies regarding family concerns than White caregivers. Also, the NAC/AARP study found that Hispanics (18%) and Asians (22%) were more likely than Whites (10%) to take a leave of absence from work. Finally, although the findings are equivocal, there seems to be a slightly higher prevalence of caregiving among African-American and Hispanic families as compared with White families (Fredriksen, 1993).

**Especially difficult caregiving situations.** Certain caregiving situations make it more difficult for working caregivers to combine paid work and informal caregiving for an elder. For example, research by Gottlieb, Kelloway, & Fraboni (1994) found the following risk factors negatively affected caregivers’ abilities to manage both their work and caregiving situations:

- co-residence with the elder,
- having more elder care crises,
- providing ADL support, and
- providing managerial assistance with finances and community services.

## The Consequences of Working and Caregiving

**In essence, performing paid work, in addition to caring for one or more elders, means that working caregivers have yet another set of responsibilities to juggle in a fixed amount of time.** This increases these caregivers' chance of experiencing conflict or overlap between their various roles. Some of the consequences of combining work and elder care are described below, first in terms of the effects on work, and then in terms of the effects on caregivers' personal well-being.

**Negative effects on work.** Employees' caregiving responsibilities can have a variety of negative impacts on their work. Some of these include: 1) lost time from work; 2) decreased productivity; 3) lost career opportunities; 4) unpaid leaves of absence; 5) early retirement; and 6) decreased lifetime earnings.

In their review of the findings from several surveys of working caregivers, Wagner and Neal (1994) found that the consequences of elder care can include time lost from work, reduced productivity, and lost job or career opportunities. The Families and Work Institute study (Bond et al., 1998) found that 37% of the caregivers of older adults reduced their work hours or took time off to provide care. The NAC/AARP (1997) study found that over half of the working caregivers surveyed had to make at least some form of workplace accommodation because of their caregiving responsibilities for someone aged 50 or over. Just over 49% had changed their work schedule, went in late, left early, or took time off during the work day. Eleven percent took a leave of absence, and 7% either worked fewer hours or took a less demanding job. Three percent turned down a promotion. Some working caregivers leave work altogether, quitting their jobs or taking early retirement because of their elder care responsibilities (NAC/AARP, 1997; Stone, Cafferata & Sangl, 1987; Stephens & Christianson, 1986). In the NAC/AARP study, 6.4% of working caregivers reported quitting their jobs, and 3.6% chose early retirement.

Making work accommodations frequently has a serious financial impact on caregivers. The MetLife Juggling Act Study (Metropolitan Life Insurance, 1999, cited in Hunt, 2000) conducted in-depth interviews with 55 of the NAC/AARP study participants who were at least 45 years old and very involved in caregiving, providing at least eight hours of assistance per week and helping with at least two caregiving tasks. That study found that caregiving had cut respondents' earnings, which in turn would significantly impact their future Social Security benefits and pensions. The loss to each of these caregivers over their lifetimes was calculated to total, on average, \$659,139.

Some groups are particularly vulnerable to negative work-related consequences of being a working caregiver. Women, ethnic minorities, and gays and lesbians are examples of such groups. Women generally are the ones who reduce their employment hours and make other work-related accommodations that have negative financial and/or career implications. A recent study by Brockwood, Hammer, Neal, & Colton (2002), found that, among dual-earner couples caring both for children and aging parents, wives made more frequent accommodations both at home and at work than did husbands. Minorities tend to feel less support from supervisors and have less access to flexible schedules and places of work, and thus can experience more stress. Lastly, few gays and lesbians are able to use employee benefits, such as family leave, for the care of their partners (Lechner & Neal, 1999).

In addition to surveys of working caregivers concerning the effects of caregiving on work, surveys of employers also have been conducted to determine their perceptions of the workplace consequences of caregiving. The Retirement Advisors Study (1987) was one of the first studies of this nature. According to managers and supervisors, “excessive phone use,” missed time at work, and concerns about productivity were problems among working caregivers and required intervention. Similar findings were reported in the New York Business Group on Health’s 1986 study (see Creedon, 1987). The Fortune Magazine and John Hancock Financial Services survey of Fortune 100 chief executive officers (1989) reported that nearly half (48%) of the CEOs surveyed felt that they personally would have difficulty doing their own job if they had elder care responsibilities.

**Positive effects on work.** It is important to note that, although most of the research conducted to date has focused on the negative effects of being engaged in paid work while providing elder care, work can also have positive benefits for caregivers. Specifically, some caregivers report that work provides them not only with financial resources, but also a respite from caregiving as well as an enhanced sense of competence (Enright & Friss, 1987; Stoller & Pugliesi, 1989).

**Negative effects on personal well-being.** The literature on caregiving is mixed when it comes to effects of caregiving on personal well-being. Some findings point to the positive benefits of the caregiving experience, although most studies focus on the stress, burden and negative health effects of caregiving. Research has shown that caregiving can put caregivers at increased risk of becoming depressed (Neal, et al., 1999; Schulz, O-Brien, Bookwala, & Fleissner, 1995), feeling stressed, strained, exhausted or fatigued (NAC/AARP, 1997) and reporting more health problems (e.g., arthritis, insomnia, diabetes, obesity, weight gain) (Schulz et al., 1995). Besides the stress associated with physical exhaustion and deteriorating physical health, previous sibling or parental conflicts may arise once again, adding to the caregiver’s psychological distress (Toseland, Smith, & McCallion, 2001). Also, the demands of caregiving may cause some caregivers to cope by restricting their social contacts with friends, neighbors, and others, resulting in a loss of social support (Neal, Hammer, Isgrigg, Brockwood, & Newsom, 2000, Toseland et al., 2001).

**Positive effects on personal well-being.** A few studies have focused on identifying the positive benefits of caregiving. Positive benefits of caregiving include increased self-esteem and self-respect, satisfaction with having fulfilled one’s obligations, a sense of competence and mastery in managing caregiving tasks, feeling needed or useful, and resolution of previously unresolved issues or feelings (Toseland, Smith, & McCallion, 2001).

### **Limitations of Previous Research**

With regard to the findings concerning the characteristics of caregivers, the nature of the care provided, and the effects of caregiving, it is important to note three major limitations. First, knowledge of the positive effects of caregiving is extremely limited due to the small number of studies that have examined these effects in comparison with the number of studies that have assessed burden or other negative consequences of caregiving. Second, the findings of most studies to date have been limited because they are based upon cross-sectional data that represent only a “snapshot” in time. Third, most studies rely exclusively on caregivers’ self reports, which can sometimes be inaccurate.

Longitudinal research following working caregivers over a period of years is needed to examine how their caregiving and their work situations change over time, and the effects of these changes, positive and negative, on caregivers and their work. In addition, studies involving the collection of data from sources in addition to the working caregivers themselves, such as from supervisors at work or the elders being cared for, would shed further light on these issues.

### **The Needs of Working Caregivers**

Little systematic research has been conducted explicitly on the needs of working caregivers. Rather, policies and services have been developed primarily based on needs inferred from the results of research and/or anecdotal reports from working caregivers concerning their situations and needs. One need is for flexibility, particularly in the scheduling of work hours. A second set of needs centers around information and assistance – an area in which the aging network has considerable expertise. A third area of need is that for emotional support, and a fourth is for other tangible assistance, such as with health insurance paperwork.

**Flexibility.** Working caregivers routinely note the importance of both flexible work hours and being able to take unscheduled time off when needed to handle caregiving responsibilities (Daly & Rooney, 2000). A recent study of working sandwiched generation couples found that couples who felt they had work schedule flexibility experienced less work-family conflict (Hammer, Neal, Brockwood, Newsom, & Colton, 1999). Work schedule flexibility and other work-based supports offered by employers to their employed caregivers have generally been perceived quite positively on the part of the caregivers. This, in turn, has led to increased loyalty and satisfaction with those employers (Wagner & Hunt, 1994; Wagner, 2000).

**Information and assistance.** The needs of working caregivers vary according to the care situation and the needs of the care recipient. Regardless, however, just as do their non-employed counterparts, working caregivers need information on the community services that are available to support the needs of elders. Most caregivers of elders have had little or no previous experience either with providing care to an elder or with negotiating the aging services system. Thus, information about caregiving, health conditions, and where to turn for help is a critical need for working caregivers. Because of the complexity of many elders' health care situations, working caregivers, like other caregivers, can find it difficult to know even what is needed, let alone decide which service approach is best for their elder. Professional expertise can be invaluable for assessing the elder's needs, providing referrals and advice, determining eligibility and payment options, and packaging together the needed services.

However, it can often take many telephone calls before the necessary help is located due to the fragmented aging services system. The names of AAAs in each community vary, making it difficult for caregivers to locate the agency's number in the telephone book, even if they know of the AAA's existence. The Eldercare Locator number, if working caregivers know of it, can be used to locate the appropriate AAA. At present, however, many community services and most AAAs are open only during the work day, Monday through Friday. As a result, many working caregivers are forced either to use work time for making telephone calls or to take time off in order to gain access to needed services for their elders or themselves. One study on the effectiveness of a set of workplace interventions for working caregivers in four worksites found, unexpectedly, that absenteeism increased after a seven-session educational seminar series. The probable reason for this increase was that the newly-informed caregivers needed to take time off to access the community services about which they had just learned (Ingersoll-Dayton,

Chapman, & Neal, 1990). The findings from the studies of managers and supervisors mentioned earlier uncovered similar problems of access for working caregivers, resulting in heavy personal use of the telephone at work and increased absenteeism.

**Emotional support.** Emotional support for working caregivers can come in the form of support from co-workers and supervisors at the workplace, support from other family members, and support from friends. A recent study found that, not surprisingly, lower levels of family-related supervisor support were associated with higher levels of work-family conflict. Similarly, a less supportive workplace culture was associated with work-family conflict (Barrach & Shultz, 2001).

**Other tangible assistance.** Working caregivers need help with legal, financial, and health insurance matters and the paperwork associated with these. Helping an elder manage the paperwork associated with his or her medical care is a daunting task. Similarly, securing and completing the legal forms for durable power of attorney, wills, reverse mortgages, and the like can be frustrating and time-consuming (Wagner, 2000).

### **Elder Care as a Workplace Issue**

It is important to point out that some working caregivers are reticent to accept services related to elder care at work. They report that elder care is a “family affair” and not a workplace issue. A few also report that they fear retributions for revealing their elder care responsibilities. Some even report that they would never think of using any “services,” work-based or community-based, since they are just being a “good daughter” or “good son.” They do not see themselves as belonging to a special group called “caregivers” (Wagner & Hunt, 1994).

Despite increased media coverage of caregiving issues, the fear of reprisals for revealing elder care responsibilities still persists. For example, Neal et al. (1999) found that both men and women reported greater levels of comfort in talking about their child care responsibilities than about their elder care responsibilities, with co-workers or with supervisors. Not surprisingly, both men and women were more comfortable talking to co-workers than to supervisors about both types of caregiving responsibility. Also, women were consistently more comfortable than men in talking to either supervisors or co-workers about both types of family responsibilities.

Many employed caregivers today began working years ago, when employers were refusing to hire women with family responsibilities and when there was a belief that work and family were separate, non-overlapping spheres of life. It is likely that future cohorts of working caregivers will experience less fear of retribution for disclosing their elder care responsibilities, due to changing expectations and norms in the workplace.

## **HOW EMPLOYERS HAVE RESPONDED TO THE NEEDS OF WORKING CAREGIVERS**

### **The Evolution of Corporate Responses to Caregiving Employees**

In recognition of the negative effects that caregiving can have on employees and their work, some U.S. employers have initiated various work-based supports for their employees with elder care responsibilities. In actuality, there is a long history in the U.S. of employer concern for individual employees and their familial circumstances (see Neal, 1999, for a review). Specifically, family-oriented benefits in the U.S. date back to the industrial revolution, when

women (and children) began to work outside the home in the first factories and mills (Kamerman, 1983; Morgan & Tucker, 1991). It was during this time, in 1825, that Robert Owen, an English businessman, established the first employer-sponsored child-care center in the U.S., in New Harmony, Indiana (Morgan & Tucker, 1991).

Typically, however, employer concern has been manifest only during periods of our history when women were needed in the workplace, and employer provision of child care was seen as a strategy to attract and retain needed workers. Except for the years during the two World Wars, when women were recruited to fill jobs left by men serving in the military, for most of the 19<sup>th</sup> and 20<sup>th</sup> centuries managing the intersection of work and family was seen as the sole responsibility of the workers themselves. This began to change in the late 1970's and 1980's, as increasing numbers of women began to enter and remain in the workforce. The prevailing belief that family life and family responsibilities should and could be left at home was challenged by the realities facing workers as they struggled to balance work and family obligations. Increasing awareness of the demographic and social changes affecting the workforce created a shift in the philosophy of both employers and employees regarding the "appropriateness" of employer involvement in the family-related aspects of employees lives (Neal, 1999) and spurred the development of work and family benefits and programs. At this time, child care benefits and programs became more available to American workers.

In the mid-1980s, American employers began to introduce elder care programming to its array of work-family programs. These programs were fashioned after the child care programs that included resource and referral services (Wagner, 2000). Appendix 1 presents a timeline of the development of workplace elder care programs (Wagner, 2000).

### **Factors Contributing to the Growth of Work-based Elder Care Programs**

Several inter-related factors provided the impetus for employers concern for working caregivers and the growth of work-based elder care programs. These factors included: (a) the recognition of the growing numbers of workers who were providing assistance to an older family member or friend; (b) the personal elder care-related experience of managers and key decision-makers; (c) research findings on the potential and actual negative consequences of caregiving on employees and their work; (d) the involvement of organized labor; (e) concerns about worker retention and recruitment; and (f) the goals of remaining competitive and improving morale (Galinsky & Stein, 1990; General Accounting Office, 1994b).

The early elder care programs developed in the mid-1980s were begun largely as a result of research on the numbers of working caregivers and the demographic imperative of an aging America. The Travelers Insurance conducted one of the first workplace surveys of caregiving employees, and several workplace surveys quickly followed (see Wagner, Creedon, Sasala, & Neal, 1989). Between 23% and 32% of the employees responding to these surveys reported having at least some elder care duties and "the prevalence estimate of 25% became a benchmark for employers, who initiated workplace programs to assist their caregiving employees" (Wagner & Neal, 1994, p. 646). However, as reported in Kossek, DeMarr, Backman, and Kollar (1993), IBM's nationwide elder care referral service, which was one of the first such programs, "was developed not as a response to employee demand, but rather a proactive response to undeniable demographic trends" (p. 634).

In addition to the impetus provided by research documenting the numbers of working caregivers, employers were encouraged to develop formal elder care programs by several studies that attempted to quantify the costs to them of working caregivers. One early estimate of these costs suggested that companies without formal elder care programs could lose about \$2,500 a year per caregiving employee in lost productivity. (Scharlach, Lowe, & Schneider, 1991). More recent estimates (Coberly & Hunt, 1995) suggest these costs might be as high as \$3,142. A 1997 MetLife analysis estimated that the aggregated costs of caregiving employees to employers nationwide ranged between \$11.4 billion per year and \$29 billion per year.

Organized labor also has played a significant role in the development of elder care policies and programs, both through collective bargaining and through education regarding the importance of work-family benefits and policies. The CWA, IBEW and AT&T contracts negotiated in 1990 represented a significant milestone for unionized workers. This latter contract resulted in the Family Care Development Fund of AT&T, which provided funding for specific aging network services that benefit union members and enhancement of the quality of available elder care programs (i.e., adult day service and senior centers) (Wagner, 2000).

Underlying all of these factors has been a concern with productivity and profitability. In fact, concern with the “bottom line” has been the primary catalyst for employer response to employees' family-related needs. Changes in personnel practices are motivated less by concerns about the personal and family lives of employees than by specific business problems, such as absenteeism and tardiness, difficulties in recruiting and retaining employees, employee reluctance to relocate, poor labor-management relations, or rising benefit costs (Axel, 1985). The quality of care available for children and elders has also been of concern to employers, for similar reasons: To the extent that care provided by non-family members is substandard, employees may decide to quit work to provide care themselves, jeopardizing the productivity of American business (Morgan & Tucker, 1991).

Despite the evidence provided by research in regard to the prevalence and costs of elder care among employees, work-based programs addressing employees' elder care needs continue to lag behind child care programs in the workplace (Wagner, 2000). Moreover, large employers are much more likely than smaller employers to offer elder care programs at work. One current estimate of access to elder care programming is that one in four companies with more than 100 employees offer such programs (Bond et al., 1998). Smaller employers are considerably less likely to have formal elder care programs in place for their employees, and most workers in the U.S. are employed by small businesses. For example, 87% of American employers have fewer than 20 employees (Neal, 1999). At the same time, small and mid-sized companies are more likely to have *informal* policies that support working caregivers. For example, sometimes supervisors will allow workers to take time off during the day when needed to handle their family caregiving responsibilities and then make that time up later (Daly and Rooney, 2000).

### **The Types of Formal Elder Care Programs That Employers Offer**

Organizations offer a variety of workplace supports to help their employees manage their work and family responsibilities. Some, such as flexible work schedules, job sharing, leave policies, flexible benefits plans, and employer-sponsored group long term care insurance, are not intended specifically or exclusively for employees who have elder care responsibilities, but they can be extremely beneficial to working caregivers. The feasible approaches for a particular organization vary with the size and culture of the organization.



Appendix 2 shows a matrix of various types of family-friendly work-based support options that employers have offered to date. The options have been categorized as policies, benefits, or services, although the distinctions between the types are not always clear cut (Neal, et al., 1993). **Policies** provide guidelines for dealing with certain situations, such as when, where and how work is to be performed. Research indicates that flexibility in the structure of work is one of the most important and desired types of support that an employer can offer employees who have family care responsibilities. **Benefits** are forms of compensation that protect against loss of earnings, pay medical expenses associated with illness, injury, or other health care needs, or provide paid time off for vacations or personal needs. Benefits may also include provision of full or partial payment for services, such as legal, educational, or dependent-care services. **Services** are provided directly by or through the employer and are programs that address the specific needs of working caregivers. Typically, these services involve the provision of information and referral, education, case management, or direct services for elders. For a more detailed description of the full range of support options and their advantages and disadvantages for employees and employers, see Neal et al., 2001.

Examples of non-caregiving-specific employer-provided supports that may be especially useful to working caregivers include:

- flexible work schedules,
- telecommuting,
- family leave (preferably paid),
- exercise facilities/wellness programs/or club memberships at reduced cost (as employees who have elder-care responsibilities often do not take the time to look after their own health needs),
- avoidance of mandated overtime, and
- minimizing required transfers, but when they are necessary, assisting in the search for elder care resources and providing job-finding services for the employee's spouse in the new location.

Employers can also provide employees access to telephones both on and off-site, (e.g., cell phones), pagers, and the like to reduce stress for employees who are concerned about their elders or the elders' care providers not being able to reach them in a crisis. Finally, the provision (directly or through contracting) of concierge services (e.g., running errands for employees, such as picking up or dropping off dry cleaning, taking cars to the mechanic, and shopping) can allow working caregivers to spend more time at work, on caregiving tasks, or taking care of themselves.

With regard to work-based programs specifically for working caregivers of elders, corporate America has experimented with a range of such programs for the past 17 years. Despite the lack of systematic evaluation, formal elder care supports have been modified, enhanced, and reformulated based primarily upon demand from employees. For example, in an early effort by Stride-Rite, few workers were helped by on-site adult day services, and the center became more of a community resource than an employee-driven service. Counseling services have also had a mixed response, with some groups of employees (e.g., women, non-management) more likely than others to attend counseling sessions or support groups. Today, the most common form of

elder care-specific work-based programming is a resource and referral service that offers a telephone linkage to needed community services and is supplemented by educational information and resources.

For the most part, the large employer-based programs in place today were put in place by private vendors of services, not the aging network. This has meant that the aging network has not benefited from this corporate investment in elder care (General Accounting Office, 1993). Two exceptions are the New York City Department on Aging, an early aging network pioneer, and a more recent developer of programs, Atlanta Regional Commission's Area Agency on Aging. Both of these agencies contract with certain employers to provide services directly to their employees.

Despite this lack of direct financial benefit through business partnerships with employers, the aging network has gained financial support through employer investment in community services. Such support has come through individual employers' support of local services as a component of their overall community investment strategy and through coalitions of businesses formed to invest funds in local services that benefit their employees and which support quality improvement in selected aging services. An example is the American Business Collaboration for Quality Dependent Care (ABC), a consortium of 137 companies, including 11 large corporations (e.g., IBM, AT&T). The ABC has as its goal the enhanced quality of and access to child care and elder care (Lechner & Neal, 1999).

New approaches to work-based elder care programs are currently being developed. This next generation of formal elder care programs has been referred to as decision-support services (Wagner, 2000). Rather than relying solely upon resource and referral models, these programs strategically address key needs of working caregivers - enhanced information and resources through geriatric care professionals, information on legal and financial matters, and help with insurance paperwork.

## **GOVERNMENT RESPONSE TO THE NEEDS OF WORKING CAREGIVERS**

At the governmental level, our nation has been slow to develop policies that address the needs of working caregivers, lagging far behind other post-industrial nations (Wagner, 1999). Federal and state governments have responded to the needs of working caregivers primarily via six basic initiatives.

1. The first of these, initiated in 1976, was the federal dependent care tax credit. This program enables qualified employed persons to deduct some employment-related dependent care expenses from taxes they paid in the previous year (Lechner & Neal, 1999).
2. A second governmental response, also a tax policy, is the Dependent-Care Assistance Plan (DCAP). DCAPS, which are also known as dependent-care reimbursement accounts, were authorized in 1981 under Section 129 of the U.S. Internal Revenue Code. These are accounts into which employees with dependent-care responsibilities can allocate either their own pre-tax dollars or credits or flexible benefits dollars given to them by their employer. DCAPS are available only when set up by employers for employees and may or may not involve direct employer contributions. They are established for reimbursement of dependent-care expenses that are work-related and

incurred by the employee for the care of dependent children under the age of 13 or for spouses or dependents who are unable to care for themselves, regardless of age, and who regularly spend at least eight hours each day in the employee's household. A maximum of \$5,000 per year (\$2,500 in the case of married individuals filing separate tax returns) can be set aside in a DCAP (Neal et al., 2001, 1993).

Given the tax advantages for both employees and employers, DCAPS serve a valuable purpose for working caregivers and their employers alike. There are, however, several limitations associated with DCAPS. These include: not all caregiving-related expenses are eligible for reimbursement; care must be provided by someone other than an employee's dependent (e.g., child or nonemployed spouse); payments made to in-home care providers who wish to avoid reporting their earnings to the IRS cannot be reimbursed through a DCAP, as receipts or invoices indicating the provider's name, place of business, and Social Security or tax identification number must be submitted; dollars placed in a DCAP will be of little use if the services that they are intended to purchase are not available or in short supply in a community; any unused funds in a DCAP are forfeited at the end of the year; and DCAPs are less useful for employees caring for an elder with whom they do not share a household (Neal et al., 1993). A final limitation is that the amount of pre-tax dollars to be set aside can be made only at the end of the year for the next tax year, thus reducing their usefulness for addressing elder care-related crises.

3. A third governmental response came in 1993, when the U.S. Congress passed the Family and Medical Leave Act (FMLA). This Act provides job protection for employees who need to take a leave of absence for the purpose of caring for a family member or for their own health care needs. The legislation applies to organizations with 50 or more employees and provides employees 12 weeks of unpaid leave to be used during a 12-month period. The leave may be taken all at once or intermittently within the 12-month period. After taking leave, the employee returns to his or her job or to a job with equivalent pay and status (Neal et al., 2001, 1993). Today, 19 states have enacted legislation with expanded provisions for family and medical leave, including provisions that apply to employers with fewer than 50 employees, leave taken related to children's educational activities and other purposes not covered by federal law, leave taken to care for individuals under an expanded definition of "family," and provisions extending the periods of protection for leave (National Partnership for Women and Families, 2001). The federal FMLA, as well as the expanded provisions enacted by states, represent increased awareness of the intersection of work and family and the belief that minimizing the negative effects of this intersection is the responsibility not just of individual workers but also the government. At the same time, these laws provide job protection only; there are no provisions for continuation of pay or benefits during the leave period (Wagner, 2000). Thus, because many employed caregivers cannot afford to take leave without pay, they are unable to avail themselves of this support.
4. A fourth response to caregivers, whether engaged in paid work or not, was the initiation by the Administration on Aging of the Eldercare Locator program. The AoA supports this nationwide, toll-free information and assistance directory, 1-800-677-1116, which helps individuals seeking assistance for relatives or friends to find the appropriate AAA to help them. The program is staffed Monday through Friday, 9:00 a.m. to 8:00 p.m., Eastern

Time (AoA, 2001). Until recently, as described below, the focus of the aging services network, and Area Agencies on Aging (AAAs) specifically, was on serving elders directly, not their caregivers. As a result, many AAA staff have not been trained, instructed, or provided the necessary resources to be aware of and responsive to the needs of caregivers, especially those who are also in the paid labor force.

5. A fifth governmental response, initiated in 2000, was the designation of November as National Family Caregivers Month. This designation places added emphasis on formally recognizing and honoring family caregivers (AoA, 2001).
6. Finally, the most recent governmental initiative related to working caregivers came when the enactment of the Older Americans Act Amendments of 2000 (Public Law 106-501, Title III – Part E) established the National Family Caregiver Support Program. This program provides funding to the aging network for the explicit purpose of serving family caregivers, as well as elders. It was enacted by Congress in response to increasing awareness of the crucial role played by family caregivers in the provision of long-term care, and it provides formal recognition of the importance of family caregivers in the overall well-being of older Americans. It should also be noted that a related program, the Native American Caregiver Support Program was also established within the Older American Act Amendments of 2000 (AoA, 2001).

## **THE AGING NETWORK AND WORKING CAREGIVERS**

The recently enacted National Family Caregiver Support Program represents an opportunity, as well as a challenge, to the aging network. By addressing the needs of working caregivers, the quality of life of the elders for whom they are caring will be enhanced. At the same time, the NFCSP dramatically expands the service population of area agencies on aging and their contract agencies, making it incumbent upon them to serve not only older Americans themselves, but also their family caregivers. Indeed, the statement, “The local AAA is one of the first resources a caregiver should contact when help is needed” [[aoa.gov/carenetwork/NFCSP](http://aoa.gov/carenetwork/NFCSP)] has truly profound implications for the aging network. With as many as 22 million family caregivers and 35 million older Americans nationwide, the aging network will have to explore creative options for services in order to fulfill its legislative mandate to serve caregivers. Increasingly, these caregivers are involved in paid employment.

### **General Strategies for Addressing the Needs of Working Caregivers**

The National Family Caregiver Support Program provides funding for specific services for caregivers. At the same time, it opens the door for AAAs, state units on aging (SUAs) and other aging network organizations to explore creative and alternative ways in which service offerings can support family caregivers.

Partnerships with employers, such as those of the New York City Department on Aging and the Atlanta Regional Commission’s Area Agency on Aging, are one option for serving working caregivers, thereby enhancing service to older Americans. These two models of partnerships are sophisticated vendor-like models that have evolved over several years and require substantial investments in infrastructure in order to meet the needs of area employers and their employees.

Most states have begun a general caregiver initiative, such as a respite care program or entitlement, or information and referral for caregivers. However, few have developed programs

specifically to address the needs of working caregivers. New Jersey is one state that is in the planning stage of a systematic effort on behalf of these caregivers. The state commissioned a study and planning process, funded by the Grotta Foundation, that included outreach to the business community, the caregivers and the aging network in order to strengthen the support available through partnerships (Wagner, Hunt, & Greene, 2000). The State of Delaware has also recognized the importance of work-family issues to economic development efforts and has a link to information and resources on its Economic Development Office Web page for current and potential Delaware businesses. The State of Oregon launched the Oregon Business and Aging Coalition, with a focus on educating businesses to understand the needs of their employees with elder care responsibilities and how they could best support these employees. Funding for state staffing is no longer available, but the Coalition continues to meet and pursue its goals as an interest group of the Oregon Gerontological Association.

In the fall of 2001, a new demonstration project for working caregivers in St. Louis, Missouri, was funded by the Administration on Aging. Specifically, St. Andrew's Resources for Seniors was awarded funds to create a comprehensive model for cost-effective elder care management services. Project objectives include identifying employers' awareness of the issues and barriers to their participation, quantifying costs of employee caregiving, collaborating with organizations to design cost-effective elder care management approaches; improving access to services and support; and educating employers on the issues and their impact. Project staff will establish a business advisory council, conduct a pilot project with 10 employers to evaluate alternative elder care approaches and provide assessments and services to approximately 1,000 caregivers, and conduct a general business education campaign (P. Janik, Office of State and Community Programs, Administration on Aging, personal communication, October 31, 2001).

A variety of other more modest approaches, as well, are possible for aging network organizations to assist working caregivers, and service innovations are likely as implementation of the National Family Caregiver Support Program evolves. These options can help move us toward a common goal: supporting caregivers at work so they are not required to abandon either care or work and are able to continue to work productively for their family and our economy.

Additional strategies for meeting the informational and service needs of working caregivers include:

1. Providing information about local services and the Eldercare Locator to area businesses and employee assistance programs;
2. Assisting area businesses in identifying and meeting the educational and resource needs of employees who provide care to an older relative or friend;
3. Assisting area businesses in developing family-friendly programs and policies, including management training in work and elder care issues;
4. Entering into contracts with area businesses, either singly or via consortia of employers where work settings are clustered in close geographic proximity, to organize caregiving fairs and/or provide education and training sessions, care planning, support groups and on-site adult day services (the latter only if the base of employees is quite large) for employees;

5. Working with labor unions to increase access of working caregivers to services and other family-friendly benefits, such as leave options;
6. Providing information about local aging services in other commonly visited state and local government offices, such as Motor Vehicles offices. Post offices could provide another opportunity for information dissemination, as could leaflets and advertising on public transportation vehicles, such as buses or subways; and
7. Developing plans that will enhance the aging network's delivery of direct services to working caregivers (e.g., extension or modification of business hours, provision of information and referral services in the evenings and on weekends, assistance via the internet, development of training and educational seminars for caregivers and offering these seminars at times that are convenient for working caregivers).

The first five of these strategies involve using caregivers' place of employment or labor unions as the means for reaching caregivers with needed resource information and education in an efficient manner. The sixth strategy entails disseminating information to key community agencies typically visited by working caregivers. This is a small but potentially very effective way of demonstrating a commitment to the well being of working caregivers, as well as the elder for whom they are caring. The final strategy involves creating a plan for addressing the needs of working caregivers, including examining some internal aspects of the aging network agency.

Although each of these strategies is potentially helpful to working caregivers, and the employers who are trying to support these caregivers, this last strategy is the most basic and important one for the aging network. A plan for how a particular agency can best address the needs of working caregivers is crucial, as is addressing certain structural elements.

### **Getting Started: Internal Considerations and General Recommendations**

1. If the aging services professional is to assist both elders and their caregivers, she or he must be familiar with the issues faced by the rapidly growing number of working caregivers (Wagner & Neal, 1994). Thus, the first step is to educate staff about these issues.
2. Extending the hours of operation of aging network agencies should be considered. For working caregivers, in particular, this step will be very beneficial. A true commitment to working caregivers may require aging network agencies to make operational changes similar to those being instituted by other governmental departments who are attempting to meet the needs of working citizens. For example, many states' Departments of Motor Vehicles have established extended evening and weekend hours to accommodate the needs of working drivers.
3. Charging a nominal fee for services delivered may increase the perceived value of the service and not necessarily diminish participation. For example, when a \$10 fee was charged for the seven-session seminar series, participation did not drop, and the average number of sessions attended actually increased (Ingersoll-Dayton et al., 1990).
4. A plan to provide active outreach and direct services to working caregivers, whether via their employers or not, should be developed. Working caregivers need information about caregiving and available community services. Moreover, this information is needed not

only by working caregivers who are currently involved in elder care, but also by those who expect to have caregiving responsibilities in the future. For example, of the participants in the educational seminars described earlier, more than one-third were anticipatory caregivers (Ingersoll-Dayton, et al., 1990). The following section describes some direct services that aging services agencies may consider including in their plan to address the needs of working caregivers.

**Education.** A variety of educational programs and written materials have been developed to assist employees with caregiving demands. AAAs, SUAs and contract agencies can provide such programs and access to materials either directly to working caregivers or through their employers. They can also encourage employers to provide other educational supports, such as providing Internet access, which is a relatively low-cost support option.

### ***Educational Seminars***

Many companies provide educational forums for employees. Since most employees are unprepared for the responsibilities of elder care, seminars can provide basic information about the aging process, caregiving concerns, and resources available. AAAs can develop and provide such seminars at the worksite.

### ***Caregiving Fairs***

Some businesses have implemented caregiving fairs, along the lines of health fairs, where employees may obtain information from a variety of different agencies and organizations at one time. Employees can stop at booths, talk to service providers, and obtain written information about specific community resources. AAAs or SUAs could organize such fairs for the employees of one large employer or several smaller employers.

### ***Enhancing Internet Access***

A tremendous amount of information on work-family issues is available on the Internet. Providing employees access to a computer and printer to get the information they need is a low-cost way that employers can support their employees with elder care responsibilities. In addition, Multnomah County, Oregon's local AAA (Aging and Disability Services) developed the idea of facilitating access to Web resources by creating and distributing a desktop icon for installation on employees' computer screens, at work and/or at home, that would link them to the agency's Web site on-line and also provide links to other useful Web sites. A Compact Disk containing this Web site information would be available to employees without access to the Internet and could also be used at home or at work. A related product would be a refrigerator magnet or removable sticker listing the ADS Web site address, 1-800 number, and the ADS 24-hour Helpline phone number (Multnomah County, Oregon, Care to Work Initiative, 2001).

### ***Newsletters and Paycheck Inserts***

An effective way to inform a large number of employees about caregiving issues and resources is through newsletters and inserts in paycheck envelopes. Single articles can be prepared or entire newsletters can be focused on caregiving concerns. AAAs or SUAs could prepare such articles or inserts.

**Information and Referral/Case Management.** Some company-based programs are intended to inform employed caregivers about specific services that are available to them and their dependents and to help them locate these services.

### ***Information and Referral***

Also known as information and assistance or resource and referral, this service involves informing working caregivers about specific services that are available to them and their elders and helping them locate these services. These are the most common form of direct services provided by employers. Generally, the service is performed by an in-house employee assistance program (EAP), or more often, by a private, for-profit organization. In other words, a parallel private system of support has been developed in response to perceived deficiencies in the public system of aging services support. However, AAAs could link to caregivers directly by publicizing their existing information lines. Also, AAAs in a position to do so could potentially tailor specific services for some employers on a contractual basis. This option of using the AAA as a vendor may be especially attractive to small employers, for whom in-house programs are not feasible, and contracted services are too expensive unless cooperatives with other employers are formed.

### ***Case Management***

This is a more intensive and individualized service for working caregivers who need help in assessing, addressing, and monitoring an elder's multiple needs. To date, some employers have offered it via their internal employee assistance program or, more typically, through an external vendor. AAAs and their contract agencies could provide this service to employers for their employees, ideally at the workplace, and/or at the agency, with expanded evening and weekend hours.

**Emotional support.** Some workplaces have convened support groups at the worksite. In some cases, groups have been facilitated by a professional. In others, they have been led by peers. Such groups typically provide information to members, as well as emotional support. Suggestions based on evaluations of demonstration projects have included the following: that attempts be made to identify and further support existing informal support networks (Ingersoll-Dayton et al., 1990); that at least some groups be held after work, as opposed to on the lunch hour, in order to attract more male caregivers and management; that separate groups for management and non-management be held to enhance willingness to discuss problems; and that groups be promoted as “informational” to overcome discomfort with the possible “psychological” overtones of a “support group” (Edinberg, 1987, cited in Creedon, 1987). AAA staff can be of assistance in organizing and/or convening such groups.

**Tangible assistance.** Many companies have a human resource professional who is experienced in working with health insurance companies. Although not commonly done, this person could hold workshops at lunchtime or after work, or meet individually with working caregivers to assist them with health insurance paperwork. Trained volunteers in local agencies can also provide help. Providing access to elder law professionals through workshops or through a listing of such professionals would be of great benefit to caregivers (Wagner, 2000). AAAs can arrange for these topics to be included in educational seminars and identify local resources, volunteer and fee-for-service, with expertise in health insurance and elder law matters.



**Direct Services for Elderly Care Recipients.** Some companies help employees to deal with their dependent care needs directly, by providing subsidies, vouchers, or discounts for particular services, such as adult day service and respite programs, or by sponsoring on-site or near-site day-care facilities. AAA contract agencies can make arrangements with employers for working caregivers to use their adult day or respite services at a discount or through subsidies or vouchers. AAAs can also be of assistance in establishing registries of respite care workers. And they can set up cooperatives among employers for the purpose of establishing other needed services.

### **Tips for Working with the Business Community**

The following suggestions are offered for helping aging network organizations establish relationships with employers for the purposes of providing services to working caregivers.

1. Establish a Business Advisory Council.

To identify the most suitable ways of approaching and working with local businesses, as well as the most appropriate persons with whom to work in these businesses, establish a Business Advisory Council. Such a council could be comprised of local business leaders (e.g., owners, chief executive officers, chief financial officers, vice presidents for human resources or employee benefits, board chairpersons), owners of firms of employee assistance professionals (EAPs), members of the local chapter of the Society for Human Resource Management, and/or members of the Alliance of Work/Life Professionals. Council members can be identified through queries to existing contacts in the business community, telephone calls to the local Chamber of Commerce, to EAP companies listed in the telephone book, and through the SHRM or AWLP's Web sites [[www.shrm.org](http://www.shrm.org); [www.awlp.org](http://www.awlp.org)].

Another way to select members for the Council and/or identify ways of working with local businesses would be to hold a series of focus groups with representatives from the above groups. One or more focus groups could be held with each stakeholder group (e.g., CEOs, human resource managers) to identify their suggestions and concerns. Representatives from the different groups could then be selected to serve on the Council.

2. Consider working with local small businesses to form consortia for service delivery purposes.

Some services, such as caregiver fairs, educational seminars, or support groups, require a certain number of caregivers in order to be maximally effective, with regard both to cost and substance. To achieve adequate numbers of working caregivers or anticipatory caregivers who could benefit from such services, aging network organizations can contact small business owners who are in close geographic proximity to one another and offer to provide services to them as a group. This will result in cost savings for individual businesses, as well as increasing the usefulness of the services for working caregivers and enhancing contacts among them to minimize feelings of isolation.

At the same time, it is important to be aware of and address structural barriers that can impede the formation of partnerships or consortia. These include organizational differences based upon the culture, language and norms of the organizations involved (Wagner et al., 2000).

3. Work with the employer(s) to conduct a needs assessment of employees to determine which programs could be most useful.

One method for collecting information about employees' needs involves administering a survey. To ensure equity, such a survey should be administered to all (or a sample of all) employees, regardless of their family care responsibilities. Typically, employee surveys are distributed via the employer's internal mail system, although advances in technology now allow surveys to be administered electronically, over the Web. Preserving the anonymity of the employee is crucial, regardless of the method employed; no names or other specific information identifying the employee should be requested. Preserving anonymity of employees can be especially challenging in organizations with small numbers of employees. Administering a survey to employees at several small companies simultaneously can help to reassure employees, as can having surveys returned via U.S. mail or electronically directly to the aging network agency, university, or other contractor conducting the survey. A sample needs assessment instrument is provided in Neal et al. (2001), as are additional suggestions for implementing employee needs assessments and analyzing their results.

4. Help employers identify why they should care about working caregivers and the wide range of family-friendly support options that can be provided.

There are several reasons why employers should consider providing family-friendly work-based supports:

- Offering family-friendly supports can increase the attractiveness of the organization to prospective applicants, improving the overall recruitment of employees, especially during tight labor markets;
- Employers who offer family-friendly workplace supports tend to have more loyal and happy employees; and
- Providing such supports helps employees with work and family responsibilities better manage the stress that they experience from competing demands, leading them to be more effective employees.

A list of a range of work-based support options has been provided here (see text and Appendix 2). For additional details, see Neal et al. (2001, 1993) and/or Wagner et al. (1989).

5. Provide training for managers regarding the needs of working caregivers and the ways in which managers can help them (e.g., by being sensitive and flexible).

Training programs can be offered for managers in individual companies and also through local human resource, work-life, and health and wellness professional associations (e.g., Society of Human Resource Managers). At the same time, it is important to note that training alone is not likely to be effective in modifying attitudes and practices within a work setting. True organizational commitment to a change in workplace culture with respect to family friendliness is required to address this problem. Improvements in job quality and supportive working conditions, although not necessarily seen as "elder care benefits," are the likely first step for employers who want to design policies and benefits that promise the returns of retention, commitment, and productivity of their workforce (Wagner, 2000).

6. Be prepared to actively market whatever supports are offered for working caregivers.

As noted by Creedon (1987), “an intensive and sustained information campaign is necessary to gain employee awareness and/or participation” in any support program (p. 31). Ingersoll-Dayton et al. (1990) found this, as well, in their workplace supports demonstration project.

7. Be aware of barriers to providing workplace elder care programs.

Several such barriers have been identified by Wagner, Hunt, and Reinhard (2000) and include:

- concerns about the costs of providing workplace programs;
  - a lack of information about low- or no-cost elder care program strategies;
  - a mistaken belief that because employees have not requested them, employees have no need for elder care-related programs or services; and
  - a lack of evaluative research demonstrating the efficacy of elder care programs.
8. Establish mechanisms at the outset to evaluate the effectiveness of any programs or services initiated.

It is important to gather data at the beginning of programs and periodically throughout their provision, so that concrete evidence of their benefits can be presented in the face of questions about program/service utility and/or in difficult economic times when budget cuts loom. The lack of such evidence of utility has been cited as one reason for employer reluctance to address the needs of working caregivers.

## **CONCLUSION**

Managing both work life and family life has become a major issue for a large and growing number of family caregivers and their employers. With the aging of the Baby Boom generation will come a dramatic increase in the long-term care needs of our population. As policy-makers consider our options for meeting these needs, supporting working caregivers takes on national importance. Federal and state governments have begun to address concerns about caregiving in earnest through the passage of Family and Medical Leave Act, the National Family Caregivers Support Act, and other initiatives designed to better support our nation's caregivers. Many employers, as well, are recognizing the problems confronting the working caregiver and the need to better support workers who have caregiving responsibilities.

The aging network, to date, has played a latent role in supplying working caregivers. It now faces both the challenges and opportunities of designing the support system needed to keep our workplaces, families and long-term care system healthy and working to care and provide for our growing population of older Americans.

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## APPENDIX 1

### Timeline of the Development of Workplace Elder Care Programs

YEAR	EVENT
1985	The Travelers Employee Caregiver Survey
1986	Caregivers in the Workplace Survey, AARP Hallmark Cards starts "Family Care Choices," Resource Centers New York Business Group on Health Survey of Managers
1987	"Issues for an Aging America: Employees and Eldercare" Conference, The Conference Board, Administration on Aging (DHHS). National Association of Area Agencies on Aging National Survey of Employers and Employees Retirement Advisors Survey of Employers Washington Business Group for Health Survey of Members reveals concerns about workplace consequences of employee caregivers. "Caregivers in the Workplace Kit" developed by AARP Herman Miller begins eldercare Resource and Referral Program for employees. Remington Products Starts Paid Respite Care Program for Employees State of Connecticut passes Family and Medical Leave Act covering State workers National Survey of Caregivers, AARP and The Travelers Work and Elder Care Survey, Portland State University
1988	IBM starts Eldercare Program for its 260,000 Employees. Public/Private Partnership on eldercare started between NY City Department on Aging, Phillip Morris, American Express and J.P. Morgan. International Union of Electrical Workers and General Electric begin Dependent Care Reimbursement Account for dependent care services. Social Security Administration begins pilot eldercare program for employees in Atlanta Region.

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- 1989** Fortune Magazine, John Hancock survey of Fortune 100 CEO's re: Eldercare
- Stride-Rite begins on-site adult day care program
- "Employees and Eldercare: Designing Effective Responses for the Workplace" with support of Administration on Aging (DHHS)
- National Teleconference on Work and Eldercare, Administration on Aging, NCOA.
- 1990** Communication Workers of America, International Brotherhood of Electrical Workers, AT&T create Family Care Development Fund and national eldercare Referral program.
- Administration on Aging distributes advisory to State Units on Aging regarding public/private partnerships and eldercare.
- 1991** Wall Street Journal begins "Work and Family" column as regular feature. Includes eldercare issues.
- National Eldercare Institute on Business and Aging, Washington Business Group on Health and American Society on Aging, funded by Administration on Aging.
- Employers Guide to Eldercare, Washington Business Group on Health.
- Elder Care and the Work Force: Blueprint for Action* published (Scharlach, B. Lowe, E. Schneider).
- 1992** American Business Collaborative established.
- Society for Human Resource Manage (SHRM) Work and Family Survey finds eldercare programs lagging behind childcare programs.
- 1993** Family and Medical Leave Act (FMLA) passed by Congress.
- GAO study finds limited returns for AAAs in public/private partnerships for eldercare.
- Employee Benefit Research Institute survey finds increase in eldercare programs among large employers.
- Work and Family Network of Maryland started.
- Balancing Work and Caregiving for Children, Adults, and Elders* published (M. Neal, N. Chapman, B. Ingersoll-Dayton, & A. Emlen)

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- 1994** Harvard Union of Clerical and Technical Workers and Harvard University begin option of using up to 12 sick days a year to care for ill dependents.
- GAO Survey of US Employers re: Eldercare Programs for Employees
- GAO Survey of Governments re: Eldercare Programs for Employees
- Career/Life Resource Center with eldercare resources begun at Social Security Administration's Baltimore Headquarters; national eldercare resource services available to SSA employees.
- Elder Care Connection developed by National Association of Area Agencies on Aging and Employee Assistance Professionals of America (EAPA). Resources to bridge the gap between business and area agencies on aging.
- 1995** Met-Life Study of Employer Costs For Working Caregivers (based upon one company).
- 1996** Hewitt Associates Survey finds increase in eldercare programs at work.
- 1997** Service Employees International Union Local 1877 and Apcoa, Inc. allow employees to use unused sick or personal days for paid family leave.
- National Alliance for Caregiving and AARP National Survey of Caregivers
- 1998** The MetLife Study of Employer Costs for Working Caregivers  
The 1998 Business Work-Life Study, Families and Work Institute, finds 23% of companies with 100+ employees have eldercare resource and referral programs in place.
- A Manager's Guide to Elder Care and Work* published (J.P. Marosy).
- 1999** Service Employees International Union Local 535 and Labor Project for Working Families start paid Family and Medical Leave for eligible workers.
- Met-Life Juggling Act Study documents personal and professional consequences of caregiving for employees.

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Adapted from Wagner, D.L. (2000). The development and future of workplace eldercare. In *Dimensions of family caregiving: A look into the future*. Westport, CT: MetLife Mature Market Institute.

## APPENDIX 2

### Work-Based Supports Available to Working Caregivers

<u>Policies</u>	<u>Benefits</u>	<u>Services</u>
<u>Flexible work schedules:</u> <ul style="list-style-type: none"> <li>• Compressed work weeks</li> <li>• Flextime</li> <li>• Cross-trained employees</li> </ul>	<u>Flexible benefits plans:</u> <ul style="list-style-type: none"> <li>• Cafeteria plans</li> <li>• Flexible spending accounts</li> <li>• Dependent-care assistance plans</li> </ul>	<u>Education on caregiving:</u> <ul style="list-style-type: none"> <li>• Corporate libraries</li> <li>• Newsletters and guidebooks</li> <li>• Educational seminars</li> <li>• Caregiving fairs</li> <li>• Internet access</li> </ul>
<u>Reduced work hours:</u> <ul style="list-style-type: none"> <li>• Part-time employment</li> <li>• Job-sharing</li> <li>• Voluntary reduced time (V-time)</li> <li>• Phased retirement</li> <li>• Phase-in schedule after leave</li> </ul>	<u>Tax benefits:</u> <ul style="list-style-type: none"> <li>• Earned income credit</li> <li>• Dependent-care tax credits</li> </ul>	<u>Resources on caregiving:</u> <ul style="list-style-type: none"> <li>• Elder-care information and referral</li> <li>• Case management</li> <li>• Support groups</li> <li>• Peer support</li> <li>• Wellness programs</li> </ul>
<u>Options for leave:</u> <ul style="list-style-type: none"> <li>• Sick leave (days, hours)</li> <li>• Family leave</li> <li>• Personal leave (earned time)</li> <li>• Vacation leave</li> <li>• Family leave (FMLA), unpaid or preferably paid</li> </ul>	<u>Insurance:</u> <ul style="list-style-type: none"> <li>• Health insurance</li> <li>• Dental insurance</li> <li>• Disability insurance</li> <li>• Life insurance</li> <li>• Long-term care insurance</li> </ul>	<u>Direct services:</u> <ul style="list-style-type: none"> <li>• Adult day-care center</li> <li>• Child/adult day-care consortium</li> <li>• Subsidies, vouchers, discounts for child/elder care, including respite</li> </ul>
<u>Where work is done:</u> <ul style="list-style-type: none"> <li>• Telecommuting</li> <li>• Relocation policies</li> </ul>	<u>Employee assistance programs:</u> <ul style="list-style-type: none"> <li>• Substance-abuse treatment</li> <li>• Stress management</li> <li>• Consumer counseling</li> <li>• Crisis intervention</li> <li>• Bereavement counseling</li> <li>• Personal and family counseling</li> </ul>	<u>Community involvement:</u> <ul style="list-style-type: none"> <li>• Stimulating care-related resources</li> </ul>
<u>Management sensitivity:</u> <ul style="list-style-type: none"> <li>• Management training in work/life issues</li> </ul>		

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Adapted from Neal, M. B., Hammer, L. B., Brockwood, K., Caubet, S., Colton, C., Hammond, T., Huang, E., Isgrigg, J., Rickard, A., (2001). *Supporting employees with child and elder care needs: A work-family sourcebook for employers*. Portland, OR: Portland State University.