

WORKPLACE
PROGRAMS
FOR FAMILY
CAREGIVERS:
GOOD BUSINESS
AND
GOOD PRACTICE

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AUGUST 2003



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WORKPLACE PROGRAMS FOR FAMILY CAREGIVERS: GOOD BUSINESS AND GOOD PRACTICE

INTRODUCTION

He was concerned that he might be viewed as lacking the proper attitude and commitment for work if he brought his family life into the office.

Ron, a 35-year-old editor for a large publishing firm, provides care for his mother who has Alzheimer's disease. During the day, Ron's mother, Alice, attends an adult day program 3 days a week and has a paid caregiver who comes to the apartment two days a week. Ron and his mother live in Manhattan in a small rent-controlled apartment that has been their home since Ron was a child. Once the disease was diagnosed and it became clear that living alone was a dangerous proposition for Alice, Ron moved back into his childhood home to manage the everyday needs of his mother.

For the past three years, Ron has come home from work in time to pick up his mother at the day program or relieve the paid caregiver, and he spends his evenings on domestic chores and caregiving tasks. Lately Ron has taken to sleeping in the same room as his mother because of her sleep problems and fear that she might injure herself when she gets up in the night. Ron's cousin, who helps on the weekend, has encouraged Ron to begin to look for care facilities for his mother. While he realizes that moving Alice to a facility is inevitable, Ron has delayed making a decision based upon frequent conversations he had with his mother over the years about her fear of moving to a care facility in old age. Like many other caregivers of persons with cognitive impairment, Ron is distressed by the changes he observes in his mother and feels guilty and conflicted about providing care for his mother and managing the beginning of his career as an editor.

Ron has curtailed all of his work-related travel and often has to leave work early or come in late in order to take his mother to doctor's appointments. Lately, on the days after his mother has had a difficult night he has also noticed that he is making small mistakes at work because of his fatigue. He hasn't spoken to his supervisor or co-workers about his mother or his caregiving situation. After hearing them speak about a woman on their team who is also caring for her mother, he was concerned that he might be viewed as lacking the proper attitude and commitment for work if he brought his family life into the office. He did, how-

ever, use the (800) number available to employees for advice on eldercare because it was confidential and he didn't have to give his name. The phone call resulted in a list of adult day programs and phone numbers that eventually led to the services his mother is now using. Ron feels increasingly isolated in his work and in his caregiving tasks—and all too aware of the fact that relief will only come when it becomes necessary for him to break a promise he made to his mother many years ago.

Ron is a member of a rapidly growing group in America—employed family caregivers. Although the exact numbers of American workers who have family caregiving responsibilities is unknown, it is estimated that as many as 15% of the workforce cares for chronically ill loved ones—a responsibility that often conflicts with work. The number of employees responsible for caring for an adult with long-term care needs is predicted to increase significantly over the next decade as more women—the traditional family caregivers—enter and remain in the workforce, the number and proportion of older persons increase, and family size decreases. In this monograph we will examine the issues confronting working caregivers, the ways in which employers have sought to address issues related to working caregivers, models of workplace programs and finally, partnerships between employers and service providers that hold promise for the future.

WORKING AND CARING: A BALANCING ACT

Caregiving has always been a primary function of the family. Today this function takes on new meaning as more women have joined their male counterparts in the workplace. Childcare and eldercare issues have become legitimate workplace issues as workers strive to balance their family and work responsibilities. For those families with seriously ill family members, managing the competing demands of work and family can become an impossible task. As many as 10% to 31% of working caregivers leave their jobs as a result of caregiving responsibilities—some elect to retire early, others quit working altogether (National Alliance for Caregiving & AARP, 1997, Statewide Resources Consultant, 2002). Most working caregivers, however, make workplace accommodations and try their best to create a balance between working and caring.

The most common workplace accommodations include:

- Coming to work late and/or leaving work early;
- Taking unpaid leaves of absence or using personal or sick days to provide care;
- Refusing relocations or work-related travel;
- Refusing overtime work or new assignments.

A recent study of workers in three large corporations found that 82 percent of the working caregivers came into work late or left early as a result of their caregiving and 55 percent modified their work schedules (Wagner, Hunt, Timmermann, & Schlenk, 2002). And, of course, for those workers who defer promotions, take leaves of absence, or otherwise reorganize their career paths in order to provide care for a loved one, there is also an adverse effect on lifetime earnings that eventually will result in reduced retirement benefits.

Working caregivers tell us that their needs include flexibility in work schedules, information about services and aging in general, support from coworkers and supervisors, and help in making decisions about care options and related issues (Neal & Wagner, 2001). Many working caregivers provide long-distance care. For these caregivers, making decisions from a distance and ongoing concerns about the well-being of their older family member can take a toll on their energy and enthusiasm about work. One respondent in a study of working caregivers described her situation:

I leave work every other Friday at noon to catch a plane for the East Coast. I return very early Monday morning after spending an emotionally draining weekend and rarely feel like I can put in a productive workweek. However, I am doing everything I can to make sure that my work doesn't suffer because of my family responsibilities and actually don't want my co-workers or supervisor to know about my family caregiving. If they knew, they might assume that I cared more about my family than my job and I would be passed over for promotions or pay increases.

Working caregivers handle the same types of caregiving tasks as their nonworking counterparts, but have the additional challenge of balancing work and family responsibilities. Most of the workers provide care to an elderly parent or parent-in-law.

A national survey found that, in 1997, 41 percent of the families who were providing care for an elder had children under the age of 18 in the household.

Surveys of working caregivers suggest that there is a higher incidence of male caregivers than is found in the general caregiving population studies and a relatively large number of younger workers involved in caregiving. In a national study of caregivers conducted by the Families and Work Institute (Bond, Galinsky, & Swanberg, 1998), 37 percent of the working caregivers were younger than 40. The average age of employed caregivers is late 40s and early 50s.

WORKPLACE PROGRAMS FOR CAREGIVERS

Historical Development of Workplace Programs

In the 1980s research began to examine the prevalence of working caregivers and the workplace issues that arose as a result of working caregivers. A survey conducted by Travelers Insurance, for example, suggested that 25 percent of the workforce of this company was providing care for an older adult and that nearly half of those who were caregiving also had responsibility for young children. This group, “the sandwich generation,” is a growing segment of the caregiving population, a result of the trend towards delayed child bearing as more women prepare for their careers. A national survey found that, in 1997, 41 percent of the families who were providing care for an elder had children under the age of 18 in the household (National Alliance for Caregiving & ARRP, 1997). Companies that had been planning for childcare programs in order to support their employees and improve productivity were now confronted with a new “work-family” issue—eldercare. A year after the Travelers survey, the New York Business Group on Health conducted a survey of managers and found that many managers were concerned about eldercare and productivity issues that were likely to emerge as a result of caregiving. These managers were concerned, for example, about “excessive” employee phone use during work, reduced productivity and missed workdays to manage family matters. In 1989, a survey of Fortune 500 CEOs revealed that many CEOs were concerned about *their own* ability to do their jobs if they were caring for an aging parent. The issue of eldercare was on the business pages of newspapers and professionals were designing workplace programs to support working caregivers.

Key Events in the Development of Workplace Eldercare Programs

Year	Event
1985	The Travelers Employee Caregiver Survey
1986	Hallmark Cards begins "Family Care Choices" resource center
1987	Herman Miller begins eldercare Resource and Referral Program National survey of caregivers conducted by AARP and The Travelers
1988	IBM begins Eldercare Program for 260,000 employees NYC Department on Aging begins first public/private partnership to provide workplace eldercare to Phillip Morris, American Express and J.P. Morgan employees
1989	Fortune Magazine and John Hancock survey Fortune 100 CEOs
1990	CWA, IBEW, AT&T create Family Care Development Fund and national eldercare referral program
1991	Wall Street Journal begins "Work and Family" column as a regular feature
1992	American Business Collaborative established to enhance the quality and availability of child care and eldercare
1993	Family and Medical Leave Act passed by Congress
1994	GAO survey of US employers regarding workplace eldercare policies and practices
2000	National Family Caregiver Support Program passed by Congress
2002	California enacts first Paid Family Leave Law

Adapted from: Wagner, D. L. (2001). The development and future of workplace eldercare. *Dimensions of family caregiving: A look into the future*. Westport, CT: MetLife Mature Market Institute.

The first workplace eldercare program was started by Hallmark in 1986 and was quickly followed by programs at IBM and Herman Miller, an office furniture manufacturer. Fashioned after models in place for childcare, the first generation of workplace eldercare programs were resource and referral programs designed to link workers with services in the community that would be helpful to older persons in need of assistance. Union negotiators put eldercare on the bargaining table in the late 1980s and dependent care accounts were set up to assist employees in paying for needed services. Dependent care programs, however, were more likely to be started as a proactive response to demographics than as a response to employee requests (Kossek, DeMarr, Backman, & Kollar, 1993). Studies conducted by the General Accounting Office (1994) and others have found that employers who established

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programs to assist their caregiving employees did so for the following reasons:

- To enhance worker recruitment and retention;
- To improve morale among workers;
- Personal experiences of managers and supervisors;
- Interest in being a “family friendly” company;
- Research about caregiving and demographics.

Research conducted in the early 1990s found that working caregivers could cost employers money as a result of lost work time, lower productivity, replacement costs for workers who leave the workplace to provide care, etc. A 1991 estimate put this cost at \$2,500 per worker involved in caregiving (Scharlach, Lowe, & Schneider, 1991). A 1997 analysis suggested that the cost of employee caregiving on a national basis was between \$11.4 billion and \$29 billion per year (Metropolitan Life Insurance Company, 1997).

MODELS OF WORKPLACE PROGRAMS

Despite concerns about the costs of employee caregivers to business, programs to assist working caregivers at work continue to lag behind programs for childcare (Wagner, 2001). And, most companies with established programs are large corporations (more than 100 employees). The Families and Work Institute estimates that one out of four of the employers with more than 100 employees has a program in place to assist employees with caregiving responsibilities.

Policies regarding flexible hours and time off are perhaps the most important support an employer can provide caregivers, and the one benefit that helps all employees, regardless of their age or family situation. There is also a range of dependent care accounts, insurance options and other benefits that employers have put in place to assist employees in a range of family-related situations. The specific workplace eldercare/dependent care programs that have been developed rely largely upon a resource and referral model. This is the most widely available model among large employers and includes phone support for the identification of service options and information resources to help working caregivers better manage their caregiving. Most large corporations rely on vendors to provide workplace eldercare programs for employees. These vendors provide employers with a set of turn-key options that may include:

- Support groups and counseling services;
- Access to direct eldercare services such as adult day services, respite care services or home health providers;
- On-site information resources (lending libraries of printed and video material);
- Educational seminars and occasional “caregiving fairs.”

Resource and referral case study

Jane, a 45-year-old worker, is offered a promotion by her employer. The promotion, however, requires that she relocate to a state more than 800 miles from her current home. She is concerned about leaving her elderly mother for whom she has been providing care and knows that her mother would not want to move away from her old friends and long-time home. Jane’s supervisor suggests that she call the eldercare program resource and referral line to explore options. The professionals staffing the eldercare program help her design a program of support for her mother using local services and provide counseling to Jane about her decision. In the end, Jane takes the promotion, and although she misses her mother, she is gratified to see that her support strategy is working and both she and her mother are able to live their lives as they wish and continue to have a close relationship through frequent phone calls and visits.

Although little evaluative data exists on workplace programs and the extent to which these programs reduce costs associated with caregiving employees and/or provide support for the working caregiver, the models of workplace programs have been refined and modified over time by the vendors.

The current model being implemented in more progressive companies is a “decision-support model” consisting of an on-site or off-site care manager to provide individualized services to employees and help with care planning and the complex issues related to insurance and legal matters (Wagner, 2001). This model of employee support can be a vendor-supplied service or an employer-provided approach. For example, employers can hire their own geriatric care manager or put an elderlaw attorney on retainer or they can contract with a vendor to supply a care manager or a geriatric care management system to support employees. However it is managed, the “decision-support service” model is a promising model that reflects a more sophisticated understanding of the complexities of family caregiving than previous child-care oriented models.

Family caregiving for an adult is complex, unpredictable, often intermittent with periods of intensity. Caregiving situations are as heterogeneous as the adult population and individualized solutions are required in order to take into account the needs and preferences of the care recipient as well as the caregiving family.

FUTURE TRENDS

A number of demographic and social trends are likely to influence the prevalence and importance of providing adequate support to working caregivers (U.S. Bureau of Labor Statistics, 2000). These trends include the following:

- Population aging in the U.S. will likely lead to an increasing number of families involved in providing support to an older adult in the future.
- Decreasing family size will result in fewer adults to provide assistance when it is needed.
- An increase in single-person households.
- Delayed childbearing will continue to result in families with both eldercare and childcare responsibilities.
- The involvement of women in the workplace, currently at nearly 80 percent, will ensure that family issues continue to be a factor in the workplace.
- The number of working women and changing family lifestyles will lead to an increase in the number of male caregivers in the workplace as caregiving becomes a family issue rather than a “woman’s issue.”
- The demand for workplace eldercare programs and “family friendly” employers is likely to increase.

PERSISTENT ISSUES IN THE DESIGN OF EFFECTIVE WORKPLACE CAREGIVER PROGRAMS

Availability and Use of Workplace Programs

Few American workers have access to workplace programs. Although nearly 25 percent of the companies that employ 100 workers or more report that they have some type of program in place, most American workers are employed by small companies. Smaller employers are less likely to have formal workplace programs or to rely upon informal mechanisms to support the caregiving employees. Even within companies that do have programs, there may be a level of reticence about seeking help with family matters at work (Wagner & Hunt, 1994). And, some human resources professionals report that caring for an older person can carry with it a stigma not found in managing childcare.

Also, since eldercare is often unpredictable and intermittent, information and referral services may not be adequate to support employees facing a crisis and limited time available to resolve the crisis. These employees, as well as those who are caring for someone at a distance, need help designing and implementing a care plan that is tailored to the needs of their older family member. And, too often, employees are unaware of available help at work when it is needed and unfamiliar with community-based services and programs to help.

Reports from vendors and human resource professionals suggest that utilization rates for workplace programs remain low—sometimes as low as 1 – 2 percent of a workforce. All of the factors described above and others can play a role in relatively low utilization rates. However, concerns about bringing family issues into the workplace may be a cohort issue that will dissipate as younger workers more accustomed to working in “family friendly” cultures, are themselves faced with family caregiving issues.

Research also suggests that utilization is affected by the culture of the organization itself. Even if an employer has a workplace program in place, a range of benefits for caregivers, and policies in place to support working caregivers such as flextime and flexplace, the culture of the workplace must support these programs, benefits and policies in order for them to be fully accessible to those in need. Vendors offer a range of options to train supervisors and managers about workplace programs and strategies for fostering the use of these programs. These training options may not be used by employers because of concerns about time and cost, however. And, in surveys and focus groups of employees, many employed caregivers report that they are discouraged from taking advantage of flexible hours, leaves of absences or other options by non-supportive supervisors and/or coworkers. As more working men find themselves with caregiving responsibilities, gender may become a factor in workplace support and use of workplace programs. For example, men are less likely than women to discuss their caregiving with supervisors or co-workers (Wagner, Hunt & Deviney, 2002).

Persistent Issues in Workplace Programs

- Workplace programs are primarily found in large corporations
- Utilization rates of workplace programs are low
- Attitudes of managers and supervisors as well as the corporate culture can discourage use of workplace programs
- Many employees do not know programs are available
- Program design issues may limit use

Future Issues Affecting Workplace Programs

- Younger workers with experience in “family-friendly” companies may demand better support with work-family issues
- More male employees will need assistance
- Fewer family members available to provide care will lead to higher demand for workplace solutions that are individually tailored; e.g., decision-support services that include individual care assessment and management, help with insurance paperwork and coverage issues, legal assistance, etc.

EFFECTIVE WORKPLACE PROGRAMS

Although we are lacking research about the extent to which workplace programs are effective in supporting workers with conflicts between work and family, we do know something about the needs of working caregivers and the characteristics of those most at risk for work-family conflicts. Research suggests that employees most at risk of complicated work-family conflicts are those involved in:

- Sharing a residence with the elder;
- Responsibilities for arranging and managing services (meals, home health, transportation or other home and community-based services) and daily living tasks;
- Providing assistance with the Activities of Daily Living (ADLs) such as bathing, toileting and other personal care;
- And, having multiple “crises” in the care trajectory (Gottlieb, Kelloway, & Fraboni, 1994).

Even those workers who do not have responsibility for helping with ADLs find it difficult to get the information they need to manage services and daily living tasks such as handling their loved one’s finances. Most of the agencies that provide necessary services, such as home health care, adult day services or transportation and escort services, are open during the “regular” work-

week, necessitating taking time away from the job to make calls or visits to select providers or service options. And, since the network of services for adults with long-term care needs is fragmented and complex, many caregivers report difficulty getting the information they need for assessing quality and selecting appropriately.

Ideally, effective support programs in the workplace for working caregivers require the following program dimensions:

- Flexibility in hours and where work takes place (telecommuting options).
- In-depth information about community resources, health and aging on an ongoing basis and in a format that minimizes the time required accessing and using resources—web-based or print materials available, for example.
- Professional assistance over the phone or online to help employees make decisions about service options, eligibility and choices.
- Referrals to elder law professionals and services to assist in processing insurance paperwork.
- Care management services for help in designing care strategies that are acceptable and appropriate for the care recipient and family caregivers.
- Procedures for the use of workplace programs that respect the privacy of employees and minimize the time required during work hours.
- Programs that reflect the changing cohort needs over time and new and emerging issues related to a changing workforce.

PARTNERSHIP STRATEGIES FOR PRACTICE PROFESSIONALS

To date, the majority of the companies that offer workplace programs designed to assist family caregivers contract with vendors specializing in providing worklife services to employees. And, although the “aging network” offers unique expertise about aging and home and community-based services, this network is conspicuously absent in the human resource departments of employers of all sizes as they plan and implement solutions to employees’ work and family problems. An important exception has been the New York City Department on Aging, a public sector organization that has been providing services to employers since the mid-1980s. This Area Agency on Aging (AAA) was one of the early generation of “vendors” to large corporations seeking elder-care solutions for caregiving employees. And, although the vendors providing workplace programs for caregiving employees rely

The Atlanta Commission on Aging Services Division provides a full range of services to employers and businesses including information and resource assistance for working caregivers, retiree health assessment services, data on demographics and trends, care management and assessment. The Division has developed effective marketing material to ensure that they are reaching the workplace with their message.
www.agingatlanta.com

upon the “aging network” and other service providers, the vendor serving as broker has reaped the financial benefit (U.S. General Accounting Office, 1994).

As publicly-funded services are stretched by scarce resources, many agencies have found it difficult to include working caregivers and their employers in their outreach efforts. Some AAAs, for example, had only limited success negotiating contracts with neighboring employers and abandoned the idea in favor of meeting the needs of elders whom they were mandated to serve. Others were unable to make the initial investment in staff time or resources to develop a professional outreach approach to area businesses.

With the passage of the National Family Caregiver Support Program in 2000, however, all AAAs now have a mandate to address the needs of family caregivers. Working with area employers is an excellent and cost-effective way to reach out to caregivers. Whether it involves a contract to provide services or merely providing information to area employers to pass on to their employees as an outreach effort, working in partnership with employers is good practice. New Jersey, for example, has implemented a program to increase the capacity of its AAAs to reach out and support working caregivers through partnerships with local employers. In the survey of New Jersey employers conducted in conjunction with this initiative, employers reported that they would appreciate and use information about aging, community services and resources from state offices, but had no previous experience working with the state (Wagner, Hunt, & Greene, 2000).

AN AREA AGENCY WORKING FOR THE WORKERS

One excellent model of practice has been developed in the Atlanta Regional Commission by the Aging Services Division. This Area Agency on Aging not only provides resources and professional assistance to employers to support their caregiving employees, but provides other corporate services as well to assist area employers to better manage an aging workforce. Their services to employers for working caregivers range from consultation and referral, employee seminars, caregivers support groups, and retiree assessment to care management services.

Across the country, nonprofits and community agencies are also designing practice models in partnership with employers and business groups such as the Chambers of Commerce and Rotary Clubs to address the many issues associated with an aging society and working caregivers.

And, finally, professional providers have an important role in the new decision-support models currently being put in place in the workplace. For example, professional care managers are working onsite and as consultants to design individualized programs for working caregivers. Trained volunteers in AAAs are skilled in advising consumers about insurance matters and could be integrated into a workplace program. And professional providers can provide employers with online forms and resource information as well as workshops to address specific issues that affect workers.

PARTNERSHIPS FOR THE FUTURE

Professional service providers are essential in supporting working caregivers in the future. Working in partnership with local employers, providers can provide the link between the workplace and the service network—a link that has been missing in many workplaces. Reaching out to caregivers through local employers is also an efficient and cost-effective way to address the goal of community education about issues and services.

Potential Provider Roles:

- Workplace training for caregivers or managers and supervisors
- Individual care management services
- Consultation in designing effective workplace programs for working caregivers
- Training and consultation in managing difficult work situations including death and loss of a co-worker or co-workers' loved one
- Organizing and designing community-wide coalitions to meet the needs of small business and independent workers
- Partnerships with business to address service needs in the community more effectively for working caregivers
- Providing information and access to community services, disease-specific organizations, health education and counseling and support services

Cost-effective consortia to address work-family issues and support family caregivers can be developed by professionals to provide information about local resources to the many American workers who do not have access to workplace programs for caregivers: those who work for small businesses and contingency workers. Community-wide health and caregiving events can reach many caregivers who do not have programs at work by targeting the outreach for these events through business organizations and publications. Partnerships between service providers

and local employers, business and trade associations and the local workforce makes for good practice and good business.

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