
Enhancing State Initiatives for Working Caregivers

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INTRODUCTION AND PURPOSE

Families have always been the first line of defense for mitigating problems associated with illness and disability. The norm of familial obligation remains strong in America today despite the complexities in our everyday lives. As unprecedented numbers of women enter and remain in the workforce, how American families work and care for one another is changing. Achieving a balance between work life and family life has become a nearly impossible task for many.

This Policy Brief reviews some of the trends affecting the work-family balance. It reviews the employer perspective on work-family issues today and discusses the important role of the states in developing initiatives that can better support our families, our workforce and our economy.

BACKGROUND

Family caregiving has become a focus of interest for policymakers and employers due to its prevalence among American families and the contribution family caregiving makes to the care of persons with long-term needs. The demographic trends that have brought this topic out of the privacy of our homes and into the public limelight include:

- ♦ An increase in the aging population – particularly those over the age of 85.
- ♦ Increasing numbers of women engaged in the workforce.

- ♦ A decrease in family size thus placing more responsibility on fewer people.

Exacerbating these demographic trends is our nation's increasing reliance upon informal care to substitute for formal health care services.

At the time of the 2000 Census, the median age of the U.S. population was 35.3 years – the highest it has ever been (U.S. Census Bureau, 2001). As the baby boom generation ages into late life, the median age will

increase. With increasing numbers of older adults in the population, we will also see an increase in the demand for family caregivers. Today more than 16 million Americans are over the age of 75, up from 13 million in 1990. Although older adults are relatively healthy and there

has been a decline in the disability rates among older Americans, advanced age is associated with chronic health conditions and an increasing risk of activity limitations due to these chronic conditions.

Families are providing assistance not just to older family members, however. Of the approximately 13 million Americans with long-term care needs in this country, nearly half are *under* the age of 65. (Assistant Secretary for Planning and Evaluation, 1995). Family members are also primary caregivers for their young children with disabilities and chronic illness, their adult children with long

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term care needs and adult siblings and other relatives in need.

The 2000 Census found several changes in American lifestyles that have implications for caregiving in the future.

- ♦ Average household size decreased from 2.63 persons in 1990 to 2.59 persons in 2000. This decrease reflects our changing lifestyle as well as decreasing family size.
- ♦ Families headed by a single female increased three times as much as did married-couple households. The number of no family households (individuals living alone or with unrelated others) increased at twice the rate of family households. Americans are redefining their lifestyles and their family composition and, in doing so, will be redefining their roles and responsibilities in caregiving.
- ♦ Nearly 80 percent of women between the ages of 25 and 54 participate in the labor force (US Department of Labor, Bureau of Labor Statistics, 2000). With the proportion of women participating in paid work today almost three times that in 1950, the implications for families, their lifestyle, their caregiving and the workplace itself is profound.

In the future we are likely to see the following caregiving trends emerge as challenges for both society and the workplace:

- ♦ Increasing numbers of male caregivers.
- ♦ Increasing numbers of non-family caregivers – providing care to a friend or neighbor who is unrelated.
- ♦ Increasing numbers of young adults (between the ages of 18 and 35) who are providing care.

Surveys of caregivers to date indicate that the majority of caregivers are providing care to family members, but as many as 15 percent of the caregivers assist older adults who are unrelated to them (National Alliance for Caregiving, 1997). A Census Bureau analysis suggests that, out of the approximately 9.3 million caregivers in their panel, more than half a million people providing care to another person were between the ages of 15 and 24 (McNeil, 1999). This same analysis found 2.6 million caregivers were between the ages of 25 and 44, and another 2.3 million between 45 and 54 years of age.

In the National Study of the Changing

“For the working caregiver, the daily tasks to manage a job or a career while ensuring that the needs of a loved one are met often require both foregoing any personal leisure time activities and making workplace accommodations.”

Workforce conducted in 1998, 18 percent of workers under the age of 30 have provided assistance to an older person, compared with 19 percent of 30 to 39 year-olds and 28 percent between 40 and 49. Workers over the age of 50 were the most likely to be actively involved in caring for an elder,

with 37 percent reporting this responsibility. (Bond, Galinsky, and Swanberg, 1998). One in five of the working parents were not only raising children and managing their work but also providing care for an older relative.

Whether it is care for an elder, a spouse, a sick or disabled child or care for a friend or neighbor, caregiving is an activity that engages millions of American men and women of all ages. Increasingly, these caregivers are working as well as managing their personal, family and caregiving responsibilities. For the working caregiver, the daily tasks to manage a job or a career while ensuring that the needs of a loved one are met often require both foregoing any personal leisure time activities and making workplace accommodations. Caregivers may change jobs

to reduce their work-related responsibilities and provide better care for a family member. Or, they seek out work settings that offer work-family benefits, flexibility in scheduling and work arrangements they need to manage caregiving. Some working caregivers actually leave the workforce entirely.

As a nation we have been slow to develop work and family policies that address the needs of the changing workforce. The 1993

Family and Medical Leave Act (FMLA) offers only minimal support to the millions of workers who are juggling work and family. It requires only *job protection* for leaves taken to care for family members and applies only to leaves taken to care for children, spouse, parents or self.

There are no provisions to continue pay or benefits during the leave period – a maximum of 12 weeks during a year.

Among the post-industrialized nations we stand alone in our failure to develop a national network of quality childcare. The Individuals with Disabilities Education Act (1997) provides a network of educational and support services for children with special needs but does not address the needs of working parents with special needs children. Our system of care for older Americans is fragmented and complex to negotiate, making care arrangements difficult at best, again with little consideration for the working caregivers involved in family care.

Working caregivers provide important benefits to society as well as to their family members with care needs and it is imperative that policies reflect the needs of the changing American family. One study (Arno, Levine, and Memmott, 1999) suggests that the cost of the care currently provided by informal family

caregivers would be \$196 billion if paid caregivers provided it. Public policy that helps the family to manage the changing health care system, the changing workplace and the needs of family members is not only good policy for families, but good policy for the economy as well.

EMPLOYERS AND THE WORKING CAREGIVER

For the past two decades, workplace policies, programs and benefits for employees' work-

family needs have been implemented by many employers. The work-family agenda that family advocates and professional human resource associations promote recognizes how difficult it is to juggle responsibilities at home with those at work.

Employers are encouraged to embrace a

work-family agenda not only because it creates a more positive relationship between employers and their employees, but because this agenda has positive economic effects as well. Enhancing recruitment and retention of workers, improving productivity and morale as well as increasing worker satisfaction and loyalty are some of its important benefits. Failure to address family issues can be costly for employers; lost productivity of caregiving employees may cost the nation's employers as much as \$29 billion annually (Metropolitan Life Insurance Company, 1997).

Increasing numbers of employers provide flexibility in scheduling to their workers and many large employers have comprehensive work-family programs that assist with locating childcare or eldercare, sometimes with on-site childcare or financial support for childcare. Eldercare programs have largely been resource and referral models; more recently these have encompassed decision-support services such as assistance with case

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management, financial and estate planning, legal services and assistance with insurance paperwork and processing (Wagner, 2000).

On the other hand:

- ◆ Only about one-third (34%) of companies employing 1,000 or more workers have eldercare resource and referral programs (Galinsky and Bond, 1999).
- ◆ Formal programs at work for caregivers of special needs children or younger adults with long-term care needs are lacking.
- ◆ Smaller employers are less likely to have formal work and family programs in place and the federal FMLA provisions cover only about half of the nation's workforce.

Today many employers are discussing the possibility of expanding the family and medical leave policies to support their workers' needs better. And some states have explored the idea of paying workers on family and medical leave through their workmen's compensation funds.

Despite the development of work and family policies and programs, workers still must cut back on their time in astounding numbers to take care of family responsibilities. As many as 37 percent of the working caregivers caring for an older adult must reduce their work hours or make some accommodations as a result of their caregiving (Bond, Galinsky, and Swanberg, 1997). In one study, daily interviews for a week examined the effects of caregiving for family members and found that a significant share (30%) cut back their work by at least one day, with a few (5%) needing to reduce work time by three or more days (Heymann, 2000). As in other studies of the work-family interface, this recent study found that both males and females of all ages were making work accommodations because of caregiving responsibilities.

STATE RESPONSES TO WORKING CAREGIVERS

State government has traditionally played a role in the national dialogue about work and family. Now states have the opportunity to provide leadership in the important area of caregiving.

To date only a few state-sponsored initiatives have directly targeted working caregivers. State government could strengthen the support

available to working caregivers and strengthen the efforts of employers by:

- ◆ Enhancing family and medical leave regulations.
- ◆ Providing financial incentives to employers for programs that

support working caregivers, link them to needed services and/or assist them in paying for services.

- ◆ Developing partnerships with employers to provide specialized programming for working caregivers in their place of employment.
- ◆ Coordinating the departments of state government to make working caregivers a priority area – e.g., human resource departments, social service departments, employment and economic development.
- ◆ Providing technical assistance to employers in caregiving, support for caregivers and the design of workplace programs.
- ◆ Conducting outreach activities through employers to ensure that working caregivers are aware of the network of services in the community available to assist them.
- ◆ Foster partnerships between professional service providers, human resource professionals, and researchers to address

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the issue of working caregivers on a comprehensive statewide level.

Family and Medical Leave

Most of the state policy work affecting working caregivers has focused on family and medical leave policies.

- ♦ The first family and medical leave act was enacted by the State of Connecticut in 1987 to cover its state workers – six years before the federal act was passed.
- ♦ By 1999, 19 states had enacted their own versions of the family and medical leave act that were more generous than the FMLA (National Partnership for Women and Families, 2001).

States have expanded the federal FMLA provisions in several ways:

- ♦ Applying leave provisions to employers with fewer than 50 employees.
- ♦ Providing leaves for participation in children’s educational activities.
- ♦ Allowing leaves for family medical needs that are not covered by the federal law.
- ♦ Expanding the definition of “family.”
- ♦ Extending the periods for family and medical leave.

Three states require that private employers with fewer than 50 employees offer family and medical leave: Oregon (25 or more employees), Vermont (15 or more employees for medical and 10 or more for new child) and the District of Columbia(20 or more employees). Several states or territories require that all employers provide leave for maternity or a new adopted child (Kentucky, Hawaii, Montana, Puerto Rico). Others have provisions for fewer than 25 employees in regard to maternity or new child.

Massachusetts and Vermont allow limited leave to accompany a child, spouse or elder to routine or other medical appointments.

California, Connecticut, the District of Columbia, Louisiana, Oregon, Puerto Rico, Rhode Island and Tennessee provide for longer periods of family and medical leave for any event covered by the FMLA or specifically for maternity complications or disability.

Definitions of family have been expanded by the District of Columbia (all relatives and people with whom the employee lives),

Hawaii (in-laws and grandparents) and Oregon and Vermont (spouse’s parent).

Even with an expanded family and medical leave in place, however, many employees cannot take time

off due to a loss of income and the need to pay their company-provided health care insurance premiums. Only one jurisdiction, Puerto Rico, requires that employers pay half of the employees salary during maternity disability leaves.

Caregiver Programs

Many states have begun special programs to assist caregivers. The National Family Caregiver Support Program passed by Congress in 2000 is likely to yield new statewide initiatives in service to many caregivers, especially those who are caring for an elder. While these programs are not targeted at working caregivers, they provide valuable services to all caregivers.

- ♦ At least 18 states have a formal respite care program in place, ranging from respite for caregivers to persons with Alzheimer’s Disease to lifespan respite programs. (For further information, see the Policy Brief entitled “Respite Care: State

“State initiatives targeted specifically at working caregivers are extremely limited nationwide.”

Policy Trends and Model Programs” by Mina Silberberg.)

- ◆ California has caregiver resource centers for family caregivers of adults with cognitive impairment.
- ◆ Other states such as New Jersey have developed “one-stop shopping” service access to caregivers of the elderly.
- ◆ Nevada has a web page for caregivers with comprehensive information about resources and a vehicle for discussion of topics relevant to caregivers.

For the most part, however, the only workers who receive information about services and caregiving issues are those whose employers have invested in work-family programs through privately contracted vendors. *State initiatives targeted specifically at working caregivers are extremely limited nationwide.*

Among the few that exist are these:

- ◆ In 1993, the Work and Family Network of Maryland began to bring together employers under the auspices of the state unit on aging to address issues related to working and caring. Funding for state staffing and support of this network is no longer available, but corporate members continue to meet on a regular basis.
- ◆ With funding from The Grotta Foundation, New Jersey’s Department Health and Senior Services launched an initiative to enhance the support available to working caregivers in the state. This initiative included a survey of state employers, training of area agency professionals, and the development of a plan to strengthen integration of state-government and private-sector efforts on behalf of working caregivers.
- ◆ In Delaware, the Economic Development Office Resource web page includes issues

central to work and family. Employers can get information about childcare resources, family and medical leave, and elder and adult services by going to the Workforce Development section of this site and looking under “Retention.” This innovative positioning of work and family issues provides a valuable service to state employers and highlights the importance of these issues to overall economic development.

- ◆ Georgia has one of the most innovative public sector programs in the country for working caregivers who assist the elderly. The program, developed by the area agency on aging (AAA) in the Atlanta area (Atlanta Regional Commission AAA) provides enhanced services to employers as well as the traditional services of an AAA. Employers can get support to develop and manage workplace eldercare

programs, access to databases and information about aging services, the older population and training. This program model has wide applicability. It is a good example of the resources and expertise possible when the public

sector takes a leadership position.

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POLICY RECOMMENDATIONS

State governments are in an important position to develop the partnerships to address, comprehensively, the needs of working caregivers. States’ leadership to support their caregiving residents also promotes the efforts of the business and industry, providing economic stability and growth. In designing specific state strategies, however, it is important to consider not only how today’s families are managing caregiving, but also changes that will occur in the future.

The following recommendations take into account the changing needs of families and workers.

1. Develop outreach efforts for state services that target residents where they work. Too often employees and human resource professionals lack information about available programs such as innovative caregiving initiatives. Many human resource professionals who provide work-family information to employees lack knowledge about their local services and programs and rely upon national vendors to link employees with needed services. A closer partnership between state agencies and employers can provide better information flow to state residents and partnerships that are sensitive to the needs of working caregivers as well.

Targeted outreach can be a relatively simple and inexpensive first step. Existing information can be distributed through workplaces, or a statewide comprehensive service website can be developed and publicized to employers using the state department of labor and business and industry associations, as Delaware has done.

2. Include work and family issues in the state's planning for economic development. Worker recruitment and retention is an important consideration in an employer's decision to remain in a state or relocate. Successful economic development depends upon coordinating the state offices that plan economic development and those that support human resource needs. Without a strong, skilled, stable and productive workforce, no economic development is possible.

3. Develop state policies that require human service agencies to consider the needs of working caregivers, making appropriate accommodations in the delivery of services for them. Working caregivers have difficulty identifying appropriate services and making care plans when service agencies are only

open from 9 to 5. Often they must take time off to arrange for service or to visit agencies to determine eligibility and care options. While the private sector has been quick to recognize that working customers need weekend and evening hours, the public sector continues to operate on a 9 to 5 schedule. This is true for just about all agencies and organizations with which working caregivers need to interact – schools, agencies that manage benefits and entitlements, social and health services. The only department within most state governments that is routinely open during hours that are accessible for working citizens is the motor vehicle department.

4. Provide technical assistance to employers to help them address their employees' needs better. Many employers report that they would welcome help from their state government particularly in the areas of community resources, eldercare issues and low or no cost options for programs to support working caregivers better (Wagner et al., 2000). This technical assistance could also include help in the development of a statewide network for work-family professionals and providers if one does not exist.

5. Develop state family and medical leave acts that are sensitive to the full range of caregiving relationships. With smaller families, blended families and an increase in non-family households, the traditional definitions of family caregivers will change. Family and medical leave policies should be developed that recognize non-family caregiving (friend or neighbor) and extended family caregiving (e.g. a niece, great-grandchild, parent of a step-sibling, etc.) as a legitimate activity. Expanded definition of "family" is an important policy change for the future if our goal is to foster both work and caregiving.

6. Explore options to provide paid leave and fully paid extended health care benefits. Many working caregivers cannot afford to take a leave to provide care when it is needed.

Leave can be particularly difficult for low-income workers. Continuing to pay the employee share of health care benefits is often difficult at best. A public-private partnership could develop options for paid leave that both the state government and the private employer find acceptable.

7. Increase the awareness of the importance of caregiving in the state’s business and industry sectors. Although many large employers have identified caregiving as a major factor in retaining and recruiting workers and in the productivity and morale of their workforce, many employers still are not aware of the importance of this issue. Small businesses, likely to be acutely aware of the importance of this issue, may believe that developing workplace programs is prohibitively expensive. States can develop conferences or other events for the business community to highlight the issues of caregiving and educate employers about state resources. Focusing these conferences or events on low cost options can help both small and large businesses and engender good relationships between state government and the business community.

8. Consider end-of-life needs in any state initiatives that are directed at caregivers and make existing state “living wills” or “advance directives” easily accessible to all state residents. Death is a natural part of life and planning for the end-of-life is an important part of caregiving. Many caregivers will have their caregiving responsibilities end upon the death of the person for whom they are caring. Most states have adopted a legally accepted version of a living will or advance directive, one that will be respected in health care settings. These forms should be easily accessible to all residents and ideally will be found in a prominent spot on the state website.

9. Set a good example. State government is a big business itself and setting a good example for other employers speaks volumes to the importance of addressing work and family

issues. Evaluate your own policies and

“No American should have to choose between a job and family responsibilities.”

benefits and make changes to ensure your own employees are able to manage their work and family obligations. Your own experience lends credibility to any discussion you have with the business community.

CONCLUSION

Setting the stage for healthy families is good business for both state government and the business community. As a nation, our economy needs a productive workforce. We also need the contributions our working caregivers are making to the efficiencies of our health care system. No American should have to choose between a job and family responsibilities.

State governments have played a pivotal role in developing policies in the past and are in a key position to continue their leadership role in the important issues of work and family. Leaving the issues associated with work and family to the private sector to resolve has not resulted in adequate support for family caregivers. We cannot expect employers to address this issue on their own. Similarly, the solution to our changing health care problems and demographics should not fall upon the individual families. A partnership between government, business and families is needed. Creative solutions can emerge when all three sectors work together to craft strategies that benefit each.

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