

BOSTON COLLEGE

CENTER FOR WORK & FAMILY

EXECUTIVE BRIEFING SERIES

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Exploring the Complexities of Exceptional Caregiving

Many researchers agree that the challenge of finding affordable, quality child care drove the work-life agenda in the 1980s – and into the 1990s. As the country ages and family demographics continue to shift, it is likely that caregiving will similarly drive policy development and employer responses through the next decade.

"Caregiving touches us all. Either we have been caregivers, we are caregivers, we will be caregivers, or we will need caregivers. Because of rising life expectancies and the ability of medical science to prolong the lives of people who require long-term care, the need for caregivers is not going to go away."

— ROSALYNN CARTER, FORMER FIRST LADY

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Caregiving has become more complex for many reasons:

- Americans are living longer, and due to advanced medical care and sophisticated technologies, they often live longer with disabilities and chronic illnesses.
- The traditional family structure and lifestyle with a breadwinner father and stay-at-home mother has changed dramatically as dual-income couples, single parents, and grandparents raising grandchildren head more households.
- People are choosing to have children – and fewer of them – later in life.
- Families that once lived for generations within limited geographical boundaries are moving many miles apart.
- Children with severe disabilities and chronic illnesses are living longer and staying home with their families as opposed to being placed in institutional care.
- Mid-career workers are addressing their own aging and self-care needs, while raising children and caring for parents – and even grandparents.

This Briefing focuses on *Exceptional Caregiving*, a term we have coined to describe caregiving situations that have emerged from these societal shifts to extend beyond the traditional scope. Whether we refer to them as the sandwich generation, elder caregivers, parents of children with special needs, or well spouses, these exceptional caregivers are feeling the squeeze — between family and career, guilt and ability, time and distance, and finances and responsibilities.

According to the Family Caregiver Alliance, an informal or family caregiver is “anyone who provides [unpaid] assistance to someone else who is, in some degree, incapacitated and needs help: a husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; a child with muscular dystrophy; a friend with AIDS.”

Who Are the Caregivers?

- **One out of five adults**

44.4 million adults (representing 21% of the U.S. adult population) are unpaid caregivers for an adult aged 18 or older (National Alliance for Caregiving and AARP, 2004).

- **Elder caregivers**

33.9 million adults (representing 16% of the U.S. adult population; 35% of the workforce) provide unpaid care to adults aged 50+. Of all wage and salaried workers, equal proportions of men and women have elder care responsibilities (National Alliance for Caregiving and AARP, 2004; Families and Work Institute, 2003).

- **Sandwich generation**

9% to 13% of households with one or more persons aged 30 through 60 are comprised of dual-earner, sandwiched-generation couples caring for elderly parents and children aged 18 or younger. 8% of the workforce is estimated to be in the “sandwich generation” (Neal, M.B. & Hammer, L.B., 2001; CCH Incorporated, 2004).

- **Adult children caring for parents or other relatives with dementia**

8.9 million caregivers (20% of adult caregivers) care for someone aged 50+ who has dementia (Alzheimer's Association and National Alliance for Caregiving, 2004).

- **Parents of children with special needs**

9 million children younger than 18 (12.8% of all children) have special health care needs (U.S. Department of Health and Human Services, 2001).

- **Spouses or partners of people with chronic illnesses or disabilities**

6% of adult caregivers provide care for an ill or disabled spouse (National Alliance for Caregiving and AARP, 2004).

Caring for People With Alzheimer's Disease

Caregiving for persons with Alzheimer's is physically and emotionally demanding. Nearly two-thirds (61%) of Alzheimer's caregivers provide the most intense care compared to fewer than half (46%) of other caregivers.

- 65% assist with the most intimate of daily tasks including feeding, bathing, and dealing with incontinence.
- 23% of caregivers provide constant care and commit 40 or more hours per week to caregiving.
- 32% provide care for five years or more (Alzheimer's Association and National Alliance for Caregiving, 2004).

Alzheimer's caregivers confront overwhelming challenges on a daily basis that have a negative impact on their work and family lives. The estimated annual cost of Alzheimer's disease to U.S. businesses is more than \$61 billion (Alzheimer's Association, 2002).

- 50% of Alzheimer's caregivers are working full-time.
- Two-thirds of employed Alzheimer's caregivers report they have missed work due to their caregiving responsibilities.
- 14% gave up work entirely or chose early retirement.
- 13% reduced their work hours or took a less demanding job (Alzheimer's Association and National Alliance for Caregiving, 2004).

What Distinguishes Exceptional Caregiving?

To illustrate the distinguishing characteristics of exceptional caregiving of adults, elders, and children, the chart below compares it to the care provided while raising a typically developing, healthy child.

In 1900, the average life expectancy at birth was 47 years and only 4% of the population was aged 65 or older. Today, the average life expectancy at birth is 77.6 years and the percentage of the population aged 65 or older has risen to 12%. By 2030, 20% of the population will have passed their 65th birthday.

— U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES, 2005; U.S. CENSUS BUREAU, 2000

Typical Child Care	Exceptional Care
Constant care that diminishes over the years	Constant care that escalates over the years
Extraordinary input of time and energy	Extraordinary input of time and energy
Easier as time goes by	Harder as time goes by
Few interruptions are emergency-driven	Many interruptions are emergency-driven
Child grows increasingly independent	Individual grows increasingly dependent, or never develops independence
Requires some caregiver and family lifestyle adjustments	Requires numerous caregiver and family lifestyle adjustments
Challenges and successes are easily shared in casual conversations with friends and colleagues	Challenges are rarely shared in casual conversations except with the closest of friends and colleagues; successes are fewer and farther between
Caregiving creates heightened exposure to the satisfaction and joy of celebrating lifetime achievements	Caregiving creates heightened exposure to illness, hospitalization, and even death
<p>Additional Challenges of Exceptional Caregiving</p> <ul style="list-style-type: none"> Navigating the health care system Researching and making complex legal and financial decisions Locating and applying for federal and state programs Understanding the rights of children with disabilities in the school system Understanding the rights of people with disabilities in the workplace Depending on others for information, support, and services Affording the cost of care Obtaining a flexible work schedule Having time for self and respite 	

The Exceptional Caregiver on the Job

- 59% of caregivers are employed (48% full-time and 11% part-time) while providing care (National Alliance for Caregiving and AARP, 2004).
- 62% report that caregiving responsibilities have affected their work. Those with the most intense care responsibilities report much higher levels of work adjustments (National Alliance for Caregiving and AARP, 2004):
 - Arrive late, leave early, take time off (57% of all caregivers, 83% of caregivers with the most intense caregiving responsibilities)
 - Take leave of absence (17%, 41%)
 - Reduce work hours (10%, 37%)
 - Quit work (6%, 35%)
 - Turn down promotion (4%, 14%)
- 48% of parents of children with mental health disorders reported that at some time they had to quit work to care for their children, and 27% indicated that their employment had been terminated because of work interruptions due to care responsibilities. Of those who were unemployed (17%), 11% reported that they were currently unable to find a job because of the demands of caregiving (Rosenzweig, J.M. & Huffstutter, K., 2004).
- Sandwich generation employees use several strategies to manage work and family responsibilities. The most common strategies used at work include reducing the number of hours worked (31% of wives, 17% of husbands), refusing or limiting travel (27% of wives, 23% of husbands), choosing a job that gave them more flexibility (24% of wives), and refusing or deciding not to work toward promotion (21% of wives) (Neal, M.B. & Hammer, L.B., 2001).

“Just as child care defined the work-life policy agenda in the 1980s, the new millennium is bringing adult caregiving to the forefront as a human resource issue.”

— MOEN, P. & SHELLBACK, K., 2002

Cancer and Careers

59% of men and 61% of women diagnosed with survivable cancer will continue to work during treatment (Short, P.F., et al, 2004). Cancer is a life-and-death issue for the employee. Co-workers are often unprepared to watch the struggle unfold as an employee faces his or her own diagnosis and treatment, or that of a loved one (Harris Interactive, 2004).

Employees with cancer (or employee caregivers) want to remain engaged at work as much and as normally as possible, however, they are often overwhelmed with insurance claims and responsibilities.

- They need time off for treatment without losing pay
- They need flexible schedules with intermittent part-time or work-at-home options

Whether employees are dealing with their own cancer or caring for loved ones, employers represent vital lifelines. Employers can support employees and their families in many ways, including:

- Offering alternative options to continue employment
- Maintaining compensation and/or offering paid time off
- Providing access to resources
- Helping navigate health insurance
- Training managers on how to support employees and workgroups
- Providing flexibility and encouraging managers to offer options
- Sustaining professional development opportunities

For more information and resources visit <http://www.cancerandcareers.org/>

“The decision to disclose at work about a child’s mental health is a strategy that ... may gain greater access to benefits and improve work/family integration. However, disclosure is not a strategy without risks. Revealing personal family information can be misperceived, leaving the parent vulnerable to discrimination in the hiring process, job evaluations, work assignments, or promotions. It can also lead to job insecurity or job loss.”

— ROSENZWEIG, J.M. & HUFFSTUTTER, K., 2004

Special Needs Caregiving

More families – one in five households with children – are raising children with chronic physical, developmental, behavioral or emotional conditions that require special health care services. This is due to the growing incidence of some conditions such as autism, attention deficit hyperactivity disorder (ADHD), and asthma, as well as the improved survival of children with conditions such as cystic fibrosis and congenital heart disease. It is estimated that one in 12 U.S. workers has a child with special needs (Massachusetts General Hospital, 2004).

- Ceridian, a leading provider of EAP and work-life services, reports that 10 to 15% of all requests for assistance involve some aspect of raising a child with special needs.
- In 2003, LifeCare®, a leading work-life services vendor, provided clients’ employees with more than 23,000 special needs referrals. Additionally, the special needs categories on their website were accessed more than 36,000 times. Since then, LifeCare has seen a 25% rise in the number of special needs cases. The most common special needs assistance requests are for help finding associations and networks; child care options and skilled care; private testing and evaluation; and legal or financial guidance.

Time Spent on Caregiving

- On average, caregivers provide 21 hours of care per week. The amount of time spent caregiving increases substantially as cognitive impairment worsens. For persons with severe dementia, informal caregivers spend 46 hours per week providing care (National Alliance for Caregiving and AARP, 2004; Langa, K.M., et al, 2001).
- Caregiving can last from less than one year to more than 40 years. In a national study, over 40% of caregivers had been providing assistance for 5 or more years; nearly one-fifth had been doing so for 10 or more years (Donelan, K., et al, 2002).

Workplace Support

Flexibility is perhaps the most important workplace tool needed by all exceptional caregivers to help them remain employed and productive. Caregivers face the challenge of juggling responsibilities and often create patchwork arrangements to provide care – the more intense the care, the more juggling. For those caregivers in the workforce, some work only when children are in school, elders are in day care, or when other caregivers are available. Couples may stagger work shifts to ensure continuity of care between household members. Still others arrange to work from home occasionally or on a regular basis, often with flexible hours and in-home help.

Even with the ability to make adjustments on the job, caregivers may still struggle in the workplace due to barriers created by unsupportive supervisors and co-workers. As a result, they may be reluctant to disclose their caregiving situations for fear of stigma, blame, or discrimination. Employee assistance programs can help by facilitating training for supervisors and co-workers to help them understand the impact of caregiving on the workplace and how they can help.

“Many older workers are also caregivers. Workplace flexibility – schedule, duties, and place – is a valuable tool to help them balance work and caregiving responsibilities. For employers, employees, and the people they care for, workplace flexibility improves lives.”

— MICK SMYER, PH.D., CO-DIRECTOR,
BOSTON COLLEGE CENTER ON AGING &
WORK/WORKPLACE FLEXIBILITY

Supporting Exceptional Caregivers in the Workplace

This Briefing includes a variety of best practice scenarios. The following is a list of benefits and work-life initiatives that can help support exceptional caregivers:

Flexibility

- Flexible schedules
- Reduced work schedules
- Telecommuting
- Leaves of absence
- Paid sick days to care for dependents

EAP and Work-Life Services

- Resource and referral services
- Emergency and backup dependent care
- Dependent care and respite reimbursements
- Geriatric case management
- End-of-life support information
- Caregiver networks or support groups

Benefits

- Comprehensive medical and dental plans
- Disability insurance
- Long-term care insurance
- Healthcare Flexible Spending Account
- Dependent Care Assistance Plan (DCAP)

Information and Educational Materials

- Manager training
- Online resources
- Lending library
- Newsletter
- Seminars
- Caregiver fairs

Business Solutions

MetLife's Division of Estate Planning for Special Kids – **MetDESK** – helps families navigate the legal and financial mazes when planning for the future of their children or other dependents with special needs. In the workplace, an employer can offer a MetDESK program at no cost to the organization or its employees. Participating employees have access to (1) telephonic consultations provided by a nationwide network of MetLife specialists who are experts in special needs financial planning, (2) workplace educational seminars on planning for the future, (3) a comprehensive website, and (4) a bi-monthly newsletter.

Pearson Inc. believes in a pro-active approach to elder care issues. Partnering with LifeCare®, Pearson established an elder care program called Prepare to Care. One day each month, a licensed Geriatric Care Manager visits six of Pearson's largest facilities to meet privately with employees. These specialists provide elder care planning consultations while employees' parents or other elder dependents are still healthy. Based on a recent employee survey, 15% of Pearson employees have elder care responsibilities and 65% anticipate having elder care responsibilities within 10 years. Of those with current elder care responsibilities, 38% also have children of high school age or younger.

PricewaterhouseCoopers made changes to its healthcare plan specifically to help employees who have children with special needs. The plan now pays for speech, occupational and physical therapies for children up to age five with developmental delays.

At **Toyota Motor Sales, USA, Inc.**, employees have access to three hours of elder care case management each year (in-home assessments, facility reviews, post-hospitalization assessments, and on-going care coordination) and a company-sponsored elder care support group. Recently, employees started another support group for parents of children with special needs that has drawn up to 40 parents to its monthly meetings.

As participants of the Employee Benefits Study for Children with Special Health Care Needs (www.massgeneral.org/ebs), **Ernst & Young, Progressive Insurance and Raytheon** launched a variety of supportive initiatives in the workplace including:

- Parent networks to help employees connect and share resources, successes, and challenges
- Seminars to help with a wide range of needs including finding resources and tackling financial and legal issues
- Tools to help employees make healthcare plan decisions during open enrollment
- Website resources
- Informative newsletters

“I had a newborn baby, a 10-year-old daughter and a 13-year-old stepdaughter when my father-in-law died and my mother-in-law plunged into a dark depression. The incident kicked off what was later diagnosed as Alzheimer's disease...and she came to live with us. Eventually she needed full-time supervision, so I found myself taking her and my young son to respective day care centers many miles apart every morning before I could get on the road to work.

As the disease progressed, I had to feed and bathe her. In the morning, I'd get her ready, and often she would tear off her diaper and get back into her pajamas, and we'd have to start all over again. At times, I was a nervous wreck by the time I got to work.

With the help of my company, I was able to flex my hours and find the community services and counseling we needed. As a result, this difficult situation turned into one that was workable and a win-win all the way around.”

— RAYTHEON EMPLOYEE

Since this time, **Raytheon** has further enhanced its elder care resource and referral program to include company-paid in-home safety and health assessments and care planning using certified geriatric specialists.

Business Solutions (continued)

In 1996, the **Canadian Union of Postal Workers** introduced a Special Needs Project to assist postal workers who have children with disabilities. The project provides information, a newsletter, advisor phone support, and subsidies to help ease parents' financial, physical and emotional stresses. Qualified families can receive up to \$200 each month to help pay for expenses related to child care, respite care, recreation programs, child care provider training, transportation to medical appointments, and uninsured health care, equipment or supplies. In 2005, this project was expanded to provide support to union members with adult children with disabilities.

Parents using the program report positive outcomes:

- 93% experienced a decrease in family stress
- 99% felt less stressed financially
- 81% realized improved morale and effectiveness at work

Conclusion

- One in five households with children cares for a child with special needs (U.S. Department of Health and Human Services, 2001).
- One in two men and one in three women will be diagnosed with cancer (American Cancer Society Statistics, 2005).
- One in ten people over 65 and one in two people over 85 will develop dementia (Alzheimer's Society, 2005).

Right now someone you know – a friend, a family member, a neighbor, a co-worker – is an Exceptional Caregiver. They may be struggling silently to balance the needs of their loved ones with the needs of their families and their jobs, while trying to maintain some level of self care. When forced to choose between caregiving and work, caregivers may take time off or leave their jobs altogether. Caregivers should not have to choose. Employers can offer support by providing flexibility, comprehensive healthcare plans and access to financial and informational resources. We will all face these issues – in our families, our communities, and our workplaces in some way – if not now, in the future.

The authors humbly dedicate this Briefing in honor of Sandy Shiebler (mother of Kathy Lynch) and Alex Roundtree (son of Linda Roundtree), to all Exceptional Caregivers and those they care for with dignity and grace. Our hope is that this introduction to Exceptional Caregiving will become a catalyst for conversations in the workplace and the development of support systems.

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About this Series

Written for an executive level audience, the Boston College Center for Work & Family Executive Briefing Series addresses topical and strategic issues of particular relevance to the current business climate. The series highlights research findings, data trends and best practices in a concise format, aiming to foster action-oriented dialogue within organizations. Each issue features an accompanying PowerPoint presentation that captures key points and includes a section for practitioners to customize and add organization-specific data.

About the Center

Since its founding in 1990, the Boston College Center for Work & Family has been a national leader in helping organizations create effective workplaces that support and develop healthy and productive employees. The Center provides a bridge linking the academic community to the applied world of the work/life practitioner and has three main focus areas: research, membership, and education. The Center is committed to enhancing the quality of life of today's workforce by providing leadership for the integration of work and life, an essential for business and community success.

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