

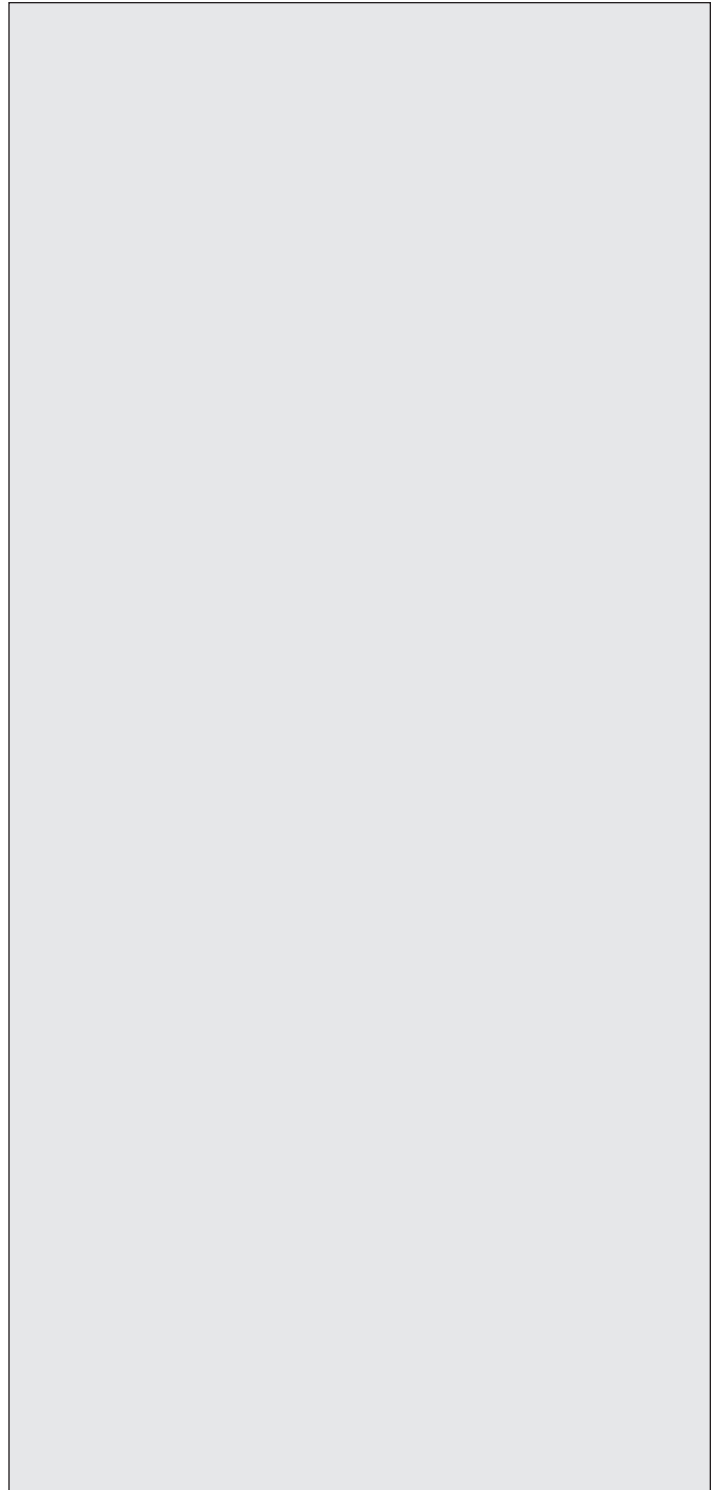
# BOSTON COLLEGE

CENTER FOR WORK & FAMILY

E X E C U T I V E   B R I E F I N G   S E R I E S

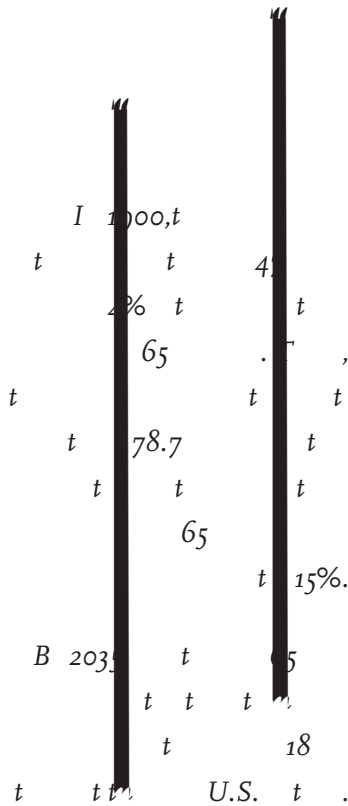
## Who Are the Caregivers?

- **40 million family members, partners, or friends**  
About 40 million family members, partners, or friends in the United States provide an estimated 37 billion hours of care to adults with self-care needs (AARP



## 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.



— U.S. CENSUS BUREAU, 2018;  
WORLD BANK, 2015;  
POPULATION REFERENCE BUREAU, 2016

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

### Additional Challenges of Exceptional Caregiving

- Navigating the healthcare 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

- 60% of caregivers—24 million individuals—are employed (56% full-time and 41% part-time) while providing care (AARP Public Policy Institute, 2016; National Alliance for Caregiving and AARP, 2015).
- 70% 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, 2015) including:
  - Reduced work hours or took a less demanding job (25% of individuals with intensive caregiving responsibilities, 10% of those caregiving 20 hours or less per week)
  - Gave up work entirely (12%, 4%)
  - Retired early (8%, 3%)
  - Turned down promotion (4%, 14%) (National Alliance for Caregiving and AARP, 2015)
- Parents of children with developmental disabilities are less likely to remain in paid employment and more likely to work part-time, to earn less money, and to reduce work hours when compared with parents of typically developing children (Rosenweg et al., 2008).
- Caregivers age 50 and older who leave the workforce to care for a parent lose, on average, nearly \$304,000 in wages and benefits over their lifetime (AARP Fact Sheet 2012).

## Cancer and Careers

73% of cancer patients and survivors want to work, and 69% agreed that work aids in treatment and recovery (Cancer and Careers, 2015). Work is a way for cancer patients and survivors to feel normal and maintain their identity; however working as a patient or survivor comes with challenges (Cancer and Careers, 2015).

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

Benefits of these accommodations for employers include:

- Retaining a valued employee (90%)
- Increasing the employee's productivity (72%)
- Avoiding the costs of training a new employee (60%)
- Increasing the employee's attendance (55%) (cancerandcareers.org)

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

## Caregiving for Children with Special Needs

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 (Health Resources and Services Administration, 2018). 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. Seven in ten caregivers of children with special needs indicate they were employed at some point while they were caregiving (National Alliance for Caregiving and AARP, 2009).

- 20% of youth ages 13-18 live with a mental illness. 11% of youth have a mood disorder; 10% a behavior or conduct disorder; 8% an anxiety disorder (National Alliance on Mental Illness, 2018).

Attention deficit hyperactivity disorder (ADHD) is characterized by inattention, hyperactivity, and impulsivity.

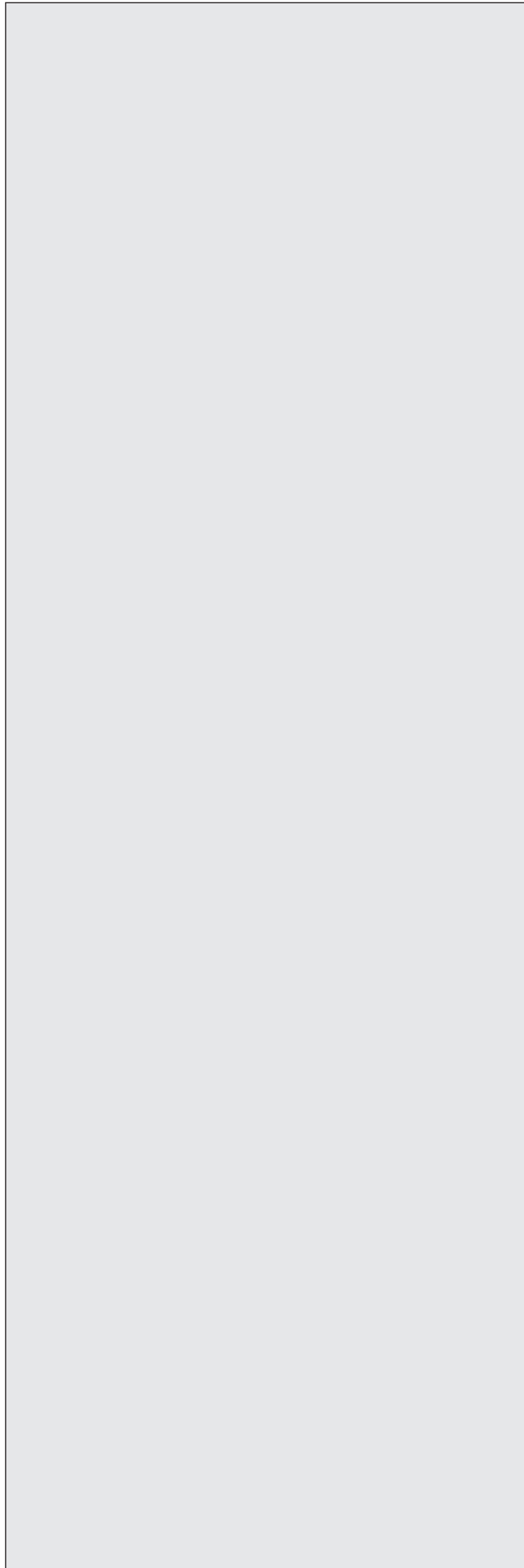
An estimated 9% of children ages 3-17 have ADHD (National Alliance on Mental Illness, 2015).

Suicide is the third leading cause of death in youth ages 10-24. 9% of those who died by suicide had an underlying mental illness (National Alliance on Mental Illness, 2018).

Type 1 Diabetes in children requires consistent care and daily management of the condition (Mayo Clinic, 2017). During 2011-2012, an estimated 17,900 children and adolescents younger than age 20 were newly diagnosed with type 1 diabetes in the United States (CDC National Diabetes Statistics Report 2017).

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