

Children with Special Needs and the Workplace



A GUIDE FOR EMPLOYERS



Executive Summary

The prevalence of childhood chronic health conditions has increased dramatically over the last several decades. Today, it is estimated that one in five families is caring for a child with a special health care need. As these rates have increased, so has the impact on parents who strive to satisfy the demands of their work life while caring for their child.

The relevance of work and family balance as an important business consideration and initiative has also emerged. In particular, over the last decade, these issues have received significant attention from employers and the business sector. Yet few companies have focused on employees caring for children with special health care needs (also referred to as children with special needs) when developing employee benefits or work-life programs. An estimate provided by a national EAP and work-life vendor illustrates the magnitude of the issue for employers and benefit providers — between 10 to 15 percent of the calls they receive involve issues regarding various aspects of raising a child with special needs.

This guide explores how the care of a child with a chronic condition or disability can impact an employee's work life and describes ways in which employers can address the workplace needs of these employees. The types of benefits and supports important to employees who have children with special needs include:

- ◆ Comprehensive and affordable health insurance
- ◆ Flexible work arrangements and use of leave time
- ◆ Supportive work environments
- ◆ Clear and accessible information about company benefits and how to access them
- ◆ Information about community resources and services and public benefit programs.

Many of these benefits and supports can be provided at little or no cost to the employer, such as information about community services and public benefit programs, a supportive work environment, and flexible work arrangements. In fact, many employers already offer these types of benefits. With targeted marketing to these employees, employers can maximize their investment in these benefit systems.

Practical guidelines to help an employer respond to the needs of these employees is included with a list of additional resources that can help an employer address these needs and develop responsive policies and programs.

Who Are Children with Special Health Care Needs?

Approximately **thirteen percent** of children and adolescents in the United States have a chronic condition or special health care need that requires increased health-related services.¹ For some, their condition is serious enough to result in limitation of activity or disability such as asthma, ADHD, mental retardation, cancer, and congenital heart disease.

Children with Special Health Care Needs Defined:

Those who have, or are at increased risk for, a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

—U.S. MATERNAL AND CHILD HEALTH BUREAU

Over the past decade, work-life issues have received significant attention from employers, yet few companies have focused on employees caring for children with special health care needs when developing employee benefits or work-life programs.

More families are raising children with chronic health care needs due to the growing incidence of some conditions, such as asthma, attention deficit hyperactivity disorder (ADHD), and autism, and the improved survival of children with other conditions such as cystic fibrosis and congenital heart disease. The majority of parents caring for these children are in the workforce.

As employees, they occasionally face compounded stress and challenges in managing all of their responsibilities at work and home. What they need most from an employer is a supportive workplace and appropriate benefits. In return, employees are able to **focus better on the job**, are **more productive and committed** to the employer, and are **less likely to leave** the company.

“There are more than 9 million children with special health care needs in the United States. In one of every five households, a family is caring for a child with special health care needs.”

—U.S. Department
of Health and Human
Services

“Of all the calls we receive from employees, 10 to 15 percent involve issues regarding various aspects of raising a child with special needs.”

—Ceridian EAP
and Work-Life Services
counselor

While we encourage companies to implement innovative programs to support families who have children with special health care needs, we also want to acknowledge that many of the company benefits and policies already in place can be modified or communicated in other ways to help more employees. Ways to accomplish this include:

- ◆ Increasing supervisors' understanding of the needs of employees who have children with special health care needs through targeted communications and training.
- ◆ Creating a supportive environment where employees feel comfortable discussing their issues and needs.
- ◆ Expanding employees' awareness of available benefits.
- ◆ Helping employees understand how to coordinate benefits.

For the purposes of this guide, the terms “children with special health care needs” and “children with special needs” will be used interchangeably.

¹2001 National Survey of Children with Special Health Care Needs. U.S. DHHS. Washington, D.C.

Why Should Employers Make This Issue a Priority?

A significant number of employees have children with special needs. According to the Families and Work Institute in New York, a leading nonprofit center for work-life research, 43 percent of employees in the U.S. have dependent children under eighteen.² Additionally, it is estimated that 20% of households with children in them have a child with a chronic health condition.³ Therefore, we can expect that in any given company, about 8.6 percent of its employees will be caring for children with special needs. This means that:

A large company with 30,000 employees has approximately **2,580 employees** caring for one or more children with special needs.

A mid-sized company with 2,000 employees has approximately **172 employees** caring for children with special needs.

A small company with 500 employees has about **43 employees** caring for children with special needs.

The challenges of managing personal life and work demands can cause employees to be distracted and therefore less effective on the job. All parents experience stress from concerns about their children. What distinguishes parents of children with special needs from other working parents is the intensity and complexity of ongoing issues regarding their child's health and well-being, family relations, and finances. They may have limited career and work schedule options due to the ongoing care they must provide for their child. While at work, they may be distracted by concerns for their child, the constant pressure to advocate for services, phone calls to health care providers, or appointments with doctors or the school system. Finding quality, appropriate child care can be difficult and many families must make the decision to scale back on work hours, quit work all together, or change jobs to accommodate the needs of their child.

“The cost to replace an employee averages 30 to 150 percent of his/her annual salary depending on skill level.”

—American Management Association

As a result of managing family responsibilities, parents of children with special needs bring talents and skills to the workplace including:

- **Determination**
- **Resiliency**
- **Advocacy**
- **Negotiation**
- **Multi-tasking**
- **Prioritizing**

Employees with access to supportive work-life policies and practices are more:

- **Satisfied with their jobs**
- **Committed and loyal to their employers**
- **Willing to work hard to help their employers succeed**
- **Likely to stay with their employers**

—2002 *National Study of the Changing Workforce, Families and Work Institute*

Creating supportive work environments positively impacts the bottom line. Greater work-life supports on the job are powerfully related to more positive work outcomes: job satisfaction, commitment to the employer, and retention. Key components of a supportive workplace for employees with children with special needs include: an understanding and supportive supervisor, comprehensive health insurance, work schedule flexibility, and an employee assistance (EAP) or work-life program that includes child care and financial assistance.

Supporting families caring for children with special needs can often be accomplished without adding benefits. Employers may be reluctant to focus attention on employees of children with special needs because they believe the issue will require them to invest more in benefits. However, the programs and benefits discussed here already exist in many companies. Or, they can be implemented at no cost, or very low cost – such is the case with flexible work arrangements. Employers can help by understanding the support needed, finding ways to communicate what is available, and encouraging employees to seek help.

² 2002 *National Study of the Changing Workforce. Families and Work Institute. New York, New York.*

³ 2001 *National Survey of Children with Special Health Care Needs.*

What Do Employees Need From Employers?

Most employees today acknowledge that, at times, they need help managing a wide range of work and life commitments, thereby allowing them to focus better on the job. Employees caring for children with special needs often face unique challenges that require enhanced supportiveness from supervisors and managers and modified policies to meet their needs.

In interviews, families caring for children with special needs say that the most supportive workplace includes:

- ◆ **Clear and accessible information** about workplace benefits and how they can be used to meet their families' needs.
- ◆ **Flexibility** in work hours, location, and scheduling.
- ◆ **Safe and respectful work environment.**
- ◆ **Supportive supervisors and managers** they can be honest with about their child and talk openly about how to meet work and family demands.
- ◆ **Information about resources in the community** that can help support them and their families.
- ◆ **Comprehensive health insurance** benefits.
- ◆ **Help from human resources** with issues such as advocating for health benefits, negotiating flexible work schedules, and finding information about community resources.

Employees of children with special needs:

" There are lots of layers between people and the information they need... you have to be very smart and very persistent to find it."

" A sympathetic supervisor is essential."

" My supervisor met my son and educated himself on my child's condition."

What Can Companies Do to Help?

The Americans with Disabilities Act (ADA) states that child care centers and day care homes cannot deny services to a child with a disability. The law states that centers must make reasonable modifications in policies, practices, and procedures in order to accommodate children with disabilities.

Provide access to appropriate child care resources and referrals. Finding appropriate, quality, affordable child care for a child with special needs can be difficult.

Best practices include:

- ◆ Provide child care resource and referral services to employees either through an internal or outsourced employee assistance program (EAP), work-life program, or partnership with nonprofit referral agency in the community.
- ◆ Ensure that the company's resource and referral vendor has access to a child care database that allows searches for providers who have special needs expertise.
- ◆ Enhance the quality and availability of special needs child care in the community by funding/sponsoring provider training through a local referral agency.
- ◆ Offer special needs education and training to company-sponsored child care staff.
- ◆ Provide child care subsidies or other financial support recognizing the higher costs for specialized care.

Provide access to online, telephonic or in-person resources such as those offered by employee assistance (EAP) and work-life programs.

Resource and referral services typically provide assistance with a wide range of issues 24 hours a day 7 days a week. These services can help employees of children with special needs by providing information on:

- ◆ Assessing special needs.
- ◆ Understanding specific illnesses and disabilities.
- ◆ Finding child care, after school care, and summer camps.
- ◆ Properly testing for and diagnosing special needs.
- ◆ Understanding the education system and your child's rights.
- ◆ Advocating for your child.
- ◆ Locating community resources including therapy, in-home care, support groups, etc.
- ◆ Dealing with emotions of raising a child with special needs.
- ◆ Obtaining respite services.

Offer flexible spending accounts (FSAs).

These accounts allow employees to set aside money on a pre-tax basis to pay for certain medical or dependent care expenses.

Best practices include:

- ◆ Publicize and promote the use of FSAs with information targeted to families caring for children with special needs.
- ◆ Help employees understand how to leverage FSA and health benefits to maximize financial resources.
- ◆ Expand FSA-eligible expenses to include child care for children over twelve years old. This is permitted by federal law at the employer's discretion.

In 2003, LifeCare resource and referral services provided 23,000 special needs referrals to their clients' employees.

In addition, participants accessed special needs categories on the LifeCare Web site 36,000 times.

More than half of the companies surveyed offer flexible work arrangements:

Flex Time 55%
Telecommuting 34%
Compressed Workweek 31%
Job Share 22%

— Society for Human Resource Management, Benefits Study, 2003

Encourage open, flexible work environments.

Flexibility is essential for employees coping with the unpredictability of multiple medical conditions and numerous health care appointments. Implementing flexibility is possible in most jobs; however, it may require employees and managers working together to find the right solution to meet the needs of the employee and the demands of business.

Best practices include:

- ◆ Offer modules on how to create supportive work environments during supervisor/manager orientations, department meetings, or special training sessions.
- ◆ Develop policies that allow emergency time off, shift trades, flexible hours, etc. This is especially important for small companies who do not provide leave under the Family and Medical Leave Act (FMLA).
- ◆ Implement “paid time off banks.” Many families caring for children with special needs report that they prefer one bank of paid time off as opposed to separate sick and vacation time. This allows more flexibility and for time off without providing reasons.
- ◆ Allow employees to use paid sick leave to care for their child.
- ◆ Provide paid time off to attend teacher conferences and other school events.
- ◆ Facilitate opportunities for employees who have children with special needs to gain support from each other.
- ◆ Launch a support group of employees who have children with special needs and provide meeting space at a company location.
- ◆ Conduct seminars in the workplace for families of children with special needs on topics such as financial planning, finding appropriate child care, advocating for your child, and managing stress.
- ◆ Establish an employee resource or affinity group of parents of children with special needs. In some companies, these groups are represented on a company-wide diversity council that regularly meets with company executives and has input on policies and benefits.

Provide health insurance benefits that are appropriate for children with special needs.

Comprehensive health coverage is essential for employees who have children with special needs, both to ensure access to quality care and to provide financial protection for the family.

Best practices include:

- ◆ Expand coverage to include physical, occupational and speech therapies, and durable medical equipment.
- ◆ Eliminate or increase lifetime benefit maximums.
- ◆ Provide access to care coordination to encourage the most cost-effective use of resources and benefits.
- ◆ Develop and publicize a process to request coverage exceptions and appeal denials.
- ◆ Survey employees to determine satisfaction with health care coverage and to solicit feedback.
- ◆ Establish an emergency/catastrophic fund to help employees pay for medical treatment not covered by insurance or to provide salary continuation when an employee depletes paid time off options. One way to build a fund is by asking employees to donate unused vacation days.

Parents report increased well-being:

99% reduced financial stress

93% reduced overall family stress

86% positive difference in overall health and well-being

81% improved morale and effectiveness at work

— *Parent employees participating in The Canadian Union Postal Workers' Special Needs Project*

For many years, IBM has offered a *Special Care for Children Assistance Plan* for employees who have a child with a mental and/or physical disability, or a child with a developmental or learning disorder.

- **The Plan helps pay expenses for certain treatments and therapy outside the scope of the IBM medical and dental benefit plans.**
- **A lifetime maximum benefit of \$50,000 is available per child.**

What Can an Employer Do to Get Started?

Employers can take many steps to create a more supportive work environment for employees caring for children with special needs. Here are a few ways to get started:

- ◆ Educate executives and human resource staff about children with special health care needs. Although few recognize the term “children with special health care needs,” they can understand the potential impact of caring for a child with special needs on the workplace and the potential role that employers can play in supporting these employees.
- ◆ Open up the conversation by reaching out to employees caring for children with special needs. Since many families report that they are reluctant to identify themselves to their employers, companies should consider multiple outreach strategies, including providing information that can be accessed anonymously (e.g., via the corporate intranet).
- ◆ Offer to help families caring for children with special needs navigate and make the most of their benefits. This includes providing families caring with children with special needs with information targeted to them, and using examples of these families in corporate benefits material.
- ◆ Identify staff in your human resources department who have experience with children with special needs. Engage them in helping employees locate community resources (e.g., parent groups, parent information centers).
- ◆ Take a look at the Additional Resources section. Learn more about the issue. Find out what supports are available in your company and community. Seek out other employers and ask what supports they provide and learn from them.

Additional Resources

Alliance for Work-Life Progress – a membership organization committed to the development and advancement of the field of work-life effectiveness
www.awlp.org

The Arc - a national organization of and for people with mental retardation and related developmental disabilities and their families (301) 565-3842
www.thearc.org

Children's Public Health Insurance - information on children's public health insurance (877) 543-7669
www.insurekidsnow.gov

DisabilityInfo.gov - information on federal government resources relating to disabilities
www.disabilityinfo.gov

Employee Benefit Research Institute (EBRI) - nonprofit, nonpartisan organization committed exclusively to data dissemination, policy research, and education on economic security and employee benefits.
www.ebri.org

Family Village - information on a wide range of disability topics relevant to families
www.familyvillage.wisc.edu

Family Voices - national grassroots organization of families and friends of children with special needs (888) 835-5669
www.familyvoices.org

Federation for Children with Special Needs - provides advocacy and support for families in the areas of health, education, early childhood, and transition for children and young adults with special needs (617) 236-7210
www.fcsn.org

Federation of Families for Children's Mental Health - a national organization with state chapters, provides families with support, information, and resources for children with mental, emotional, or behavioral needs (703) 684-7710

www.ffcmh.org

Genetic Alliance - an international coalition of individuals, families, professionals, and genetic support organizations (202) 966-5557

www.geneticalliance.org

Exceptional Parent - a monthly publication and library for families compiled by the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services

www.eparent.com

Maternal and Child Health Bureau (MCHB) of the Department of Health and Human Services – the nation's oldest federal program serving mothers and children

www.mchb.hrsa.gov

National Information Center for Children and Youth with Disabilities
(800) 695-0285

www.nichcy.org

Parent-to-Parent Programs – information, links, and supports for parents and families of children with special needs (785) 864-7600

www.beachcenter.org

Learning Disabilities Association of America - provides information, resources, and support to families about learning disabilities (412) 341-1515

www.Ldanatl.org

National Fiesta Educativa Inc. - helps Latino families care for their children with special needs through information, education, training, and referral (323) 221-6696

www.fiestaeducativa.org

State Title V Programs - list of all state Title V program directors and how to contact them

<http://cshcnleaders.ichp.edu/TitleVDirectory/PDF-Files-2003/CSHCNDIR%2010-1-03.pdf>

Technical Assistance Alliance for Parent Centers - a national network of state parent centers providing information and training for families of children with disabilities (952) 838-9000

www.taalliance.org

Project and Contact Information

This information is copyright free. Readers are encouraged to copy and share it. However, please credit the Center for Child and Adolescent Health Policy at the MassGeneral Hospital for Children.

www.massgeneral.org/children/ccahp

This guide was developed in collaboration with Linda Roundtree of Roundtree Consulting, LLC as part of the Employee Benefits Study for Children with Special Health Care Needs, a joint effort of:

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The study was supported through a Cooperative Agreement (1U93MCO0183) with the Health Resources and Services Administration, Maternal and Child Health Bureau and the Center for Child and Adolescent Health Policy at MassGeneral Hospital for Children.

Additional information about the study can be found at www.massgeneral.org/ebs, including a PDF version of this guide.

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