

**Workplace
Benefits
for Families
of Children with
Special Needs**



A GUIDE FOR EMPLOYEES



Executive Summary

For working parents caring for a child with a special need, balancing the needs of their child with the demands of their work life can be challenging. Taking full advantage of all services and supports available to them and their family is crucial. One potential source of benefits and services is a parent's employer. Many worksites offer benefits and work-family supports that parents may find helpful. So it is important to understand and consider what may be available through the workplace.

This guide is designed to help working parents think about employer-sponsored benefits and supports. It addresses the kinds of benefits and policies that may be available and describes ways to access these benefits, in particular:

Health Care Benefits, including dental benefits, prescription drug plans, catastrophic funds, public benefits that may be available (such as SSI/Medicaid and SCHIP), and employer advocacy with health plans on behalf of employees

Work-Life and Employee Assistance Programs that may offer information and referral to child-care providers, stress-management seminars, flexible work arrangements, and legal counseling, in addition to many other types of services

Flexible Spending Accounts for dependent care and medical expenses

Employer Assistance in determining whether and how an employee can access and use benefits that are offered through the workplace

Disclosure as an important and personal issue to consider when evaluating use of employer-sponsored benefits and supports

This information can help employees optimize the use of benefits provided through their workplace. Resources are also provided that can help parents make more informed choices about both public and private benefits and support programs.

Why Consider Workplace Benefits?

These days working families live complicated lives. Employees want to do their best at work and be good parents, too. If you are the parent of a child with special needs, balancing your responsibilities as a parent and those as an employee can be especially difficult.

This guide is designed to help you think about benefits available in your workplace that may be helpful to you in balancing the special needs of your child with the demands of your work life. It addresses the kinds of benefits or policies that may be available in your place of work and also will help you to think about how to access these benefits. Your employer has ample information about benefits available to you. Your union, if you belong to one, is also an excellent source of information about benefits within your workplace.

We hope you will share with your employer and other families some of the specific information in this guide concerning benefits or practices that are supportive of families with children who have special needs (also referred to as children with special health care needs).

Whether you're looking for a new job or interested in starting a discussion at your present workplace about improving benefits and thereby contributing to improved morale and work quality, we hope the ideas discussed here will be helpful.

Who Are Children With Special Health Care Needs?

“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

According to a national household survey of children with special health care needs conducted by the federal Maternal and Child Health Bureau and the Centers for Disease Control, there are more than 9 million children with special health care needs in the United States. These children have conditions such as asthma, seizures, childhood diabetes, attention deficit hyperactivity disorder (ADHD), cerebral palsy, mental retardation, leukemia, mental health issues, and obesity, to name a few. Older children are more likely to have been diagnosed with special needs than younger ones.

Between 1960 and 1980, the number of children with special needs, particularly children whose special needs limited their activities or caused a disability, grew rapidly because of improved treatments and medical advances. These children survived diseases that had almost always been fatal in the past and were left with lingering chronic conditions. Since 1980, some of these conditions have grown more common, notably asthma, obesity, ADHD, depression, and autism.

This means that in a great many households, one of every five in fact, a family is caring for a child with special needs. Since the majority of parents work either full or part time, this obviously has an impact in the workplace as well as on the families' lifestyles. All parents occasionally need time off to take their children to appointments or to deal with school issues. Parents of children with special needs may have more frequent and more intense needs for such time off; they may also find themselves under stress periodically, particularly at times when their child's needs are changing or unsettled.

What Should You Tell Your Employer about Your Family's Needs?

Does your employer know that you have a child with special needs?

Is this something you want your employer to know?

What you think about these two issues affects your view of and approach to workplace benefits. You may be comfortable openly discussing your child's and family's needs with your employer. Or you may prefer not to share information about your family life in your workplace. Whatever you decide would be best for you, it's important to clarify to yourself how much information about your family you want to share with your employer.

If your child has extensive medical needs and costs, you may worry that discussing these factors with your employer will endanger your job by pointing up limits to your flexibility and commitment. On the other hand, letting your employer know about your child's medical needs could in some cases give the employer an opportunity to respond sensitively and helpfully—while allowing you as an employee to avail yourself of the relevant benefits. Your knowledge of the situation at your workplace will help you to decide what is best for you.

One advantage to discussing your child's specific needs with your employer is that the employer can then consider these needs when negotiating contracts for health insurance coverage.

It's important to clarify to yourself how much information about your family you want to share with your employer.

What Benefits Helpful to Parents are Offered in Your Workplace?

Changes in health benefits can occur annually as a result of negotiations between the employer and insurance providers.

Health Benefits

Health Care Benefits: In many places of employment, provided that you work the required number of hours, you may enroll in a health insurance plan to help you pay for your own and, with a family plan, your family's medical care. Most commonly, such health insurance plans include well and sick doctor visits, hospital care, tests, durable medical equipment and, in some cases, prescription medicines. Health insurance plans vary in the amount charged for premiums, amount of co-payment, and list of participating doctors, hospitals, and other providers. Often your employer will pay a portion of the monthly costs of your health insurance plan.

Health benefits are usually the most important benefits workers and their families receive, particularly families of children with special needs. Perhaps because health benefits matter to employees as much as they do, employers tend to make frequent changes in the definition of these benefits in response to employee concerns. Changes may even come about annually as a result of negotiations between the employer and insurance providers.

Health insurance benefits are based on a contract between your employer and a health insurance company. This contract represents an agreement to cover certain health costs of employees who enroll. The specific medical expenses that are included and the amounts of care covered are, in most cases, specifically spelled out in the contract. Your employer may offer more than one health plan and may allow you to choose the one that best suits your family's needs. You are usually offered health insurance benefits when you first begin a job and then allowed to switch plans once a year, during a scheduled "open enrollment" period.

When choosing a plan, you will want to identify the benefits you think your family will need during the coming year, then compare these with the benefits offered. Although your employer will give you information (either web-based on your company's Intranet or in print form) that explains the benefits of each health plan offered, you may find that you need more specific information than what these company resources offer. To find answers to your specific questions about benefits your child might need, ask the plan representatives directly before signing up for a plan. Many families of children with special health care needs wish to know specifically what doctors and other providers they may use within a given plan, and what flexibility they will have to see a provider outside the plan network if needed.

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Other features to check when comparing plans include:

- ◆ **costs** of co-payments and deductibles
- ◆ **waiting** periods and preexisting conditions
- ◆ **out-of-pocket** expenses and lifetime maximums
- ◆ **prior-approval** requirements
- ◆ **appeal procedures** (in case you disagree with a decision about coverage)
- ◆ **any differences in coverage** for therapies provided in hospital and out of hospital.

Specific features ought to be clear to you before you select a health plan, such as:

- ◆ **how much flexibility** your doctor will have in making decisions about your care
- ◆ **whether case-management programs** will be available to you
- ◆ **what special programs** the plan offers to help families of children with special needs.

You may become aware of options such as these by reading plan materials carefully and by questioning plan representatives.

When health care expenses are denied, some employees have found that their employer will help them negotiate with the insurance carrier to get the needed services or treatment covered.

Dental Plans: These plans provide benefits that typically cover preventive oral care, such as teeth cleaning on a periodic basis and restorative dental care (fillings). Some plans may also cover orthodontic care, at least partially. You may need to pay co-payments for treatment. As with health benefits, if a dental plan is offered, you will be allowed to sign up when you begin working, or later during a yearly “open enrollment” period.

Prescription Drug Plans: Some employers offer prescription drug plans in which you enroll separately from health insurance; with others, the health insurance premium includes prescription drug coverage.

Catastrophic Funds: An unusual but interesting option some companies make available to their employees is access to emergency or catastrophic funds that come into play when employees face unexpected or very costly expenses not covered by their regular health plan. Check to see if your employer offers such a benefit.

Health Benefit Strategies: When insurance underwriters deny health care expenses that an employee expected to be covered by his/her health plan, some employees have found that their employer will help them negotiate with the insurance carrier to get the requested services or treatment covered. Consider asking your employer for this kind of help if you feel you've been treated unfairly by your health insurance plan.

If you feel comfortable discussing your child's needs, it will help your employer to know about any benefits that have been denied or insufficiently covered for your child. This knowledge will aid your employer in evaluating the quality of competing health insurance options.

In some places of employment, you may elect to have your portion of the cost of any of the above health benefit options deducted directly from your paycheck, and paid for with pre-tax dollars, which is a financial advantage to you.

Public Benefits: Every state and the federal government offer a variety of public benefit programs that may supplement your employer-sponsored health insurance. In some instances your income will determine your eligibility; in others, your child's special need will. The following paragraphs describe briefly some of these resources. See the Additional Resources section for further information.

◆ **State Programs for Children with Special Health Care Needs**

These programs, which have state-specific names, are funded with federal as well as state dollars and provide varying services from state to state. The program in your state may help you find community resources or coordinate your child's care. In some states, the program will provide or pay for care.

◆ **SSI/Medicaid**

If your child has significant special needs and you are eligible by income, Supplemental Security Income (SSI) can help you with expenses. In most states SSI also allows your child access to Medicaid, a public insurance program that offers a broad spectrum of health benefits for children when a doctor prescribes these benefits as medically necessary. Your state may also have a specific Medicaid program for children with severe special needs, such as a Home and Community-Based Services Waiver Program or Katie Beckett Waiver, that provides an eligible child access to Medicaid regardless of his/her parents' income. Eligibility for waiver programs is determined by state-specific requirements based on a child's special need.

◆ **State Children's Health Insurance Program (SCHIP)**

If your employer does not offer health insurance or if you lose your family health coverage for any reason, this program provides at least basic health coverage (and sometimes more) for children. Refer to the Additional Resources section for more information.

◆ **Special Education**

Your child may be eligible for special education benefits that could cover not only classes, but also related services such as therapies, counseling, and assistive technology if they are deemed necessary for your child to succeed in school. Special education is available for children from birth through age 21. Talk to your local school or to the Parent Training and Information Center in your state about special education benefits, and refer to the Additional Resources section for more information.

Additional Workplace Benefits

EAP and Work-Life programs may provide services within the workplace or by contracting with outside providers. Either way, you should expect complete confidentiality when you use such services.

Employee Assistance and Work-Life Programs (EAP, W-L): These days most employers recognize that everyone needs help sometimes to manage the complexities in their lives – a new baby, a move, a divorce, or caring for an elderly parent or a child with special needs. Employers benefit when their employees feel supported and are able to contribute their best efforts at work. A variety of benefits and services may be offered at your workplace to help you balance work and family needs. The names of these services will vary, but generally they are called Employee Assistance Programs (EAP) or Work-Life (W-L) Programs. If your company does not have a formal EAP or W-L office, as may be the case for small organizations especially, you may still discuss work-life problems informally with your employer and perhaps negotiate some of the help you need.

EAP/W-L programs may provide services within the workplace or by contracting with outside providers. Either way, you should expect complete confidentiality when you use such services. Examples of specific benefits offered are flexible work arrangements, counseling, information about and referral to a variety of services and providers, wellness programs (for employees and sometimes for family members also) and child care or elder care services or information about such services.

Families of children with special needs will want to know whether information about child care or camps is provided and whether there is information about programs that welcome children with special needs. If your employer offers child care, is the staff trained, or can they be trained, to care for your child? Is the child care site accessible? If your child needs more specialized or expensive care than is normally available through the child care program, you can ask specifically how the needs of your child might be met. For example, your company may have extra funds available to cover the services your child needs.

Talking with EAP and Work-Life staff may give you ideas for configuring existing benefits in ways that address your specific needs. Such conversations may also lead you to relevant workplace or community resources. Even before approaching a staff member, you could learn a great deal about the EAP/W-L resources in your company by reading informational materials available at work either in printed form or on the organization's Web site.

When you do make an appointment to talk with an EAP/W-L representative, bear in mind that this person has been designated to think about your needs, to suggest ways to meet them, and to maintain confidentiality. You should feel free to propose solutions that make sense to you. Many employers are willing to be flexible if they believe that adaptations will help you to do your job well.

Some EAP/W-L programs help families work with schools to meet their children's needs. They may also help them locate educational testing and assessments that will help identify special education needs.

Ironically, it is often the case that employees do not turn to company EAP/W-L programs even though these resources could be very helpful. This has led some employers to underestimate the need for and importance of these benefits. So when you have the opportunity, tell your employer what services and benefits will help you be a more productive employee; for example, when completing an employee survey or workplace needs assessment. Offer your ideas about how to make benefits more understandable to employees. In this way you can influence policy in your organization and perhaps safeguard the availability of benefits that have improved many employees' quality of life.

What About Flexible Work Arrangements?

The ability to create a flexible work schedule is critically important to working parents of children with special needs. Accordingly this work-life benefit merits particular attention.

In many places of work, there are opportunities to set up your schedule so that you regularly work some of the time at home, perhaps to accommodate your child's schedule. This will depend on the kind of work you do, of course, and your access to the equipment and resources you need at home that would allow you to carry out your work efficiently. Your workplace may have a specific policy to allow employees to set up flexible schedules, including paperwork that outlines the boundaries, or this may be arranged in a more informal way through your supervisor.

As the parent of a child with special needs, you might require this kind of flexibility on a regular basis or for specific periods of time—for example, while your child is home recovering from an illness. There is also a federal law, the Family Medical Leave Act (see below) which guarantees you a certain amount of time off to care for a sick child, if your employer is large enough. In some cases this time off may be used in small increments.

Flexible work time may also mean varying the hours you work, for example coming in earlier, or working longer but fewer days, on either a regular or specific time basis.

Flexible Spending Accounts (FSAs): Some workplaces offer the opportunity on a yearly basis for employees to set money aside in one or more Flexible Spending Accounts for certain child care and health care expenses. The advantage is that the money set aside from your paycheck will not be taxed as income. Each of these accounts, for medical/health expenses or child care expenses, is arranged separately.

To set up one of these accounts, you must decide at the beginning of the year how much money you want to set aside, for example, \$3,000. The money is deducted from your wages before taxes on a regular basis over a year's period. You pay the bills for health care and/or child care as you normally would and then submit the appropriate documentation (usually along with copies of the bills) to your employer for reimbursement from this account.

To see how this works, suppose you agree in Year 1 to reduce your income for Year 2 by \$2000 in anticipation of health care expenses in that amount. Suppose further that in Year 2 you actually incur \$2000 in health care expenses not covered by your insurance. When the FSA reimburses you for these expenses with nontaxable income, this is the same as receiving back the money you agreed in the previous year to give up; but then in Year 3 when you file your Year 2 tax return, you pay federal tax on the reduced salary only. Thus you save in federal tax the amount you would have paid on the \$2000; if you are in the 20% bracket, your savings would amount to \$400.

Examples of health care expenses that can be submitted are co-payments, uncovered prescriptions, medical supplies, eyeglasses, Braille books, etc. for you or your dependents. Examples of child care expenses might be the actual costs of a child care or after school program or payments to an individual who cares for your children.

There are advantages and disadvantages to these accounts. They work best when you can predict the expenses you'll incur in each category. The tax bracket you're in will determine the amount you save. At the present time if you don't use all the money you have set aside in your FSA account for the calendar year, you lose it. (Note, however, that efforts are being made to change this.) Check to find out whether your workplace offers FSAs and what the most current rules are.

Legal Service Plans: Some workplaces offer legal information or even legal services, often up to a certain dollar amount, to their employees. Helpful information or services provided might include wills and trusts for children or adults with special needs, guardianship, or help with appeals procedures for special education or health insurance.

Sick Time and Personal Leave: You'll want to read carefully about the sick time and personal leave policies in your workplace. How much of these are available to you and what guidelines are there for using them? Can you use your sick or personal time for your child's special health care needs? Can employees bank sick time in order to share it with other employees who may need it in an emergency?

Your employer may also be willing to make special arrangements for leave time in case of a medical emergency or crisis in your family. The Family and Medical Leave Act offers federal protections provided that you work for a large enough employer (see below).

Family and Medical Leave Act (FMLA): The Family and Medical Leave Act was passed in 1993 and applies to employers with 50 or more employees. It allows eligible employees to take up to 12 weeks of unpaid leave yearly for the adoption or birth of a child, or for the serious illness of an employee or of the employee's parent, spouse, or child. The employee's job is protected for the duration of the leave, and his/her health coverage must be maintained. Employees who have children with special health care needs have expressed the desire to have flexibility in how they use this FMLA benefit, for example, the opportunity to use it a few hours at a time for an appointment. Ask how this benefit can be used in your place of employment.

Conclusion

As a practical matter, you may or may not be able to take advantage of the benefits offered and policies established by your employer. In some offices, it's "just not done" (for example, taking time off) regardless of what's on paper. Many parents say the key factor and most significant person in terms of getting and using benefits and managing stress is their supervisor. If you experience difficulties with your boss in negotiating use of your benefits, contact your Human Resources department. HR managers will often intervene on your behalf and mediate discussions between you and your supervisor.

It's important for parents of children with special needs to understand the benefit programs available through their workplace, and the environment or corporate culture within which they work. Many employers are willing to work with their employees to create an environment that maximizes productivity and satisfaction among employees. We hope this information, along with the following section of additional resources, will help you take full advantage of the benefits available in your workplace.

Additional Resources

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
<http://www.disabilityinfo.gov/>

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 5 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

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www.massgeneral.org/children/ccahp

This guide was developed 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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