



HEALTH Tips

Helping Employees who have Children with Special Health Care Needs: Tips for Employers

Almost 14% of children under age 18 in the U.S. have a special health care need (a chronic or severe health problem that requires more intensive or specialized care than children normally require).¹ The number of children with special health care needs has increased threefold since 1960 due in large part to growth in childhood chronic conditions, such as asthma and obesity.²

The increase in the number of children with special health care needs overlaps with changes in population and workplace demographics - there are now more single parents and working mothers in the United States.² This translates into more individuals in the workforce who provide care to children with special health care needs. A 2009 study found that 70% of caregivers of children with special needs either work or have worked while providing care.³

Children with special health care needs have also become an important part of employers' beneficiary populations, as over 60% of children with special needs are covered by employer sponsored health plans.⁴ And because children with special health care needs require more intensive or specialized care, their medical expenses are over twice the cost of children without chronic problems.⁵

Caregiving May Have a Detrimental Effect on Employee Health

- Caregivers of children with special health care needs are twice as likely as the general adult population to say they are in fair/poor health (26% vs. 13%).³
- Studies show that caregivers have higher rates of anxiety and depression than non-caregivers.⁶ For example, mothers of children with autism are much more likely than other mothers to report being highly stressed and having poor or fair mental health.⁶
- Caregivers are more likely to engage in unhealthy behaviors; they are more likely to be smokers, do less physical activity, use seatbelts less frequently and report fewer hours of sleep.⁶

Caregiving Can Reduce Employee Productivity

- Employees who have children with special health care needs may find that their caregiving responsibilities affect their ability to function effectively at work. A study found that mothers of children who had a developmental delay or disability (e.g., autism) lose around five hours of work weekly, equaling around 250 hours per year.⁷ This results in lost productivity costs of \$3,000 to \$5,000 a year (assuming an hourly employee cost of \$12 to \$20, including fringe benefits).⁷
- Parents of children with special health care needs may be forced to cut back their hours. In one study, three out of four caregivers reported making changes to their work situation due to their caregiving role.³
- Caregivers of children with special health care needs may leave the workforce altogether in order to provide full-time care for their child. In a study of mothers caring for children with serious, chronic conditions, one third said they quit their jobs to take care of their child at home.⁸

What Can Employers Do to Support Caregivers?

Employers have good reason to support employees who serve as caregivers to children with special health care needs. Supporting employees who provide care for children with special health care needs can be accomplished without adding new benefits, and existing programs can be adapted for families at no cost, or very low cost. Employer actions include:

Encourage well-child visits. Well-child visits provide important preventive care, as well as the opportunity for the early detection and management of chronic physical, developmental, behavioral or emotional conditions. Employers can encourage their employees to keep up-to-date on well-child care by offering incentives for the appropriate and timely use of recommended health care services, many of which are provided free of charge through the Affordable Care Act.

Work with your disease management vendor to offer programs that are tailored to children and adolescents. Disease management programs offer an opportunity for coordinated care services, case management and education. Common disease management programs for children include:

- Asthma management
- Autism
- Congenital disorders and disabilities, such as cerebral palsy and muscular dystrophy
- Type I diabetes (also known as juvenile diabetes)
- Mental health disorders
- Obesity or weight management
- Rheumatoid diseases, such as juvenile arthritis

Employers may choose to expand their current disease management programs to make them appropriate for the unique needs of children and adolescents. For example, adult-focused weight management programs can be adapted for children and adolescents.

Ensure access to case management services. Caregivers may have challenges coordinating care, especially if the child receives several different services. Case management services can help caregivers navigate the health system and access appropriate care.

Promote EAP utilization. Caregivers may benefit from support to help cope with the challenges associated with their child's unique health care needs. In fact, a 2009 study revealed that 46% of caregivers of children with special needs feel they need more help or information managing their emotional/physical stress and 40% said they need more help or information balancing work/family responsibilities.³ The EAP can facilitate counseling and/or support services to all employees who have children with special health care needs. Employers should ensure that the EAP has a database of providers with special needs expertise.

Screen employees who apply for Family Medical Leave (FML) for depression. Rates of depression are higher among caregivers.⁶ As a result, employers should ensure that Family Medical Leave (FML) programs screen employees who apply for FML using a standardized instrument (e.g., PHQ-9 or PHQ-2). Additionally, FML programs should refer employees who screen positive for depression to appropriate behavioral health specialists or EAP. FML programs should also provide employees with information on caregiving and depression.

Provide flexible schedules and use of leave. Flexibility is essential for employees who have children with special health care needs. Employers should develop policies that allow employees emergency time off and flexible work schedules (e.g., compressed workweeks, telecommuting, flex-time, alternative start and end times, and partial workloads). Furthermore, employers should allow employees to use paid time, paid sick time, or incidental absence days to care for their child. Focus groups of employee caregivers revealed flexible work arrangements in their workplace allowed them to remain employed and without it, they would have to leave the workforce.²

Offer caregivers support when possible. Employers should provide employees with information on local support groups for parents with special needs children. If there is sufficient demand at the work site, employers might consider launching a support group by providing a meeting space at a company location. Additionally, employers may want to conduct seminars in the workplace at lunch or after hours for families of children with special needs on topics such as financial planning, finding appropriate child care services and managing stress.

Train supervisors on the importance of assisting employees with children who have special needs. Supervisors are a critical link to benefit information; their willingness to help employees understand benefits often determines the extent to which employees know about and use their benefits.² However, focus groups of employee caregivers revealed that they are reluctant to disclose information about their family situation to their employer, even when sharing information could help them access available benefits and programs.² Training supervisors to be sensitive to employee caregivers situations may be a promising opportunity to improve the use of benefits and program by employees with children with special needs.

References

1. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2008.
2. Perrin J, Fluet CF, Honberg L, et al. Benefits for employees with children with special needs: Findings from the collaborative employee benefit study. *Health Affairs* 2007;26(4):1096-1103.
3. National Alliance for Caregiving in collaboration with AARP. *Caregivers of children: A focused look at those caring for a child with special needs under the age of 18*. Available at: http://www.caregiving.org/pdf/research/Report_Caregivers_of_Children_11-12-09.pdf. Accessed November 2, 2011.
4. Newacheck PW, Houtrow AJ, Romm DL, et al. The future of health insurance for children with special health care needs. *Pediatrics*. 2009;123(5):e940-947.
5. Chevarley FM. *Utilization and Expenditures for Children with Special Health Care Needs*. Research Findings No. 24. Rockville, MD: Agency for Healthcare Research and Quality; 2006.
6. Burton W, Conti D, Pransky G, Edington D. Caregiving for Ill Dependents and Its Association with Employee Health Risks and Productivity. *JOEM*. 2004;46(10):1048-1056.
7. Powers ET. Children's health and maternal work activity: estimates under alternative disability definitions. *J Hum Resour*. 2004;38(3):522-556.
8. Thyen U, Kuhlthau K, Perrin JM. Employment, childcare, and mental health of mothers caring for children assisted by technology. *Pediatrics*. 1999;103(1235-1242).

Health Tips

November 2011

Helping Employees who have Children with Special Health Care Needs: Tips for Employers

This Tip Sheet was developed by the National Business Group on Health, which should be cited accordingly. Copyright 2011 National Business Group on Health

Written by:

Pamela Rich, M.P.H.

About the National Business Group on Health

The Business Group is the only non-profit organization devoted exclusively to representing large employers' perspectives on national health issues and providing solutions to its members' most important health care and health benefits challenges. The Business Group fosters the development of a safe health care delivery system and treatments based on scientific evidence. Members share strategies for controlling costs, improving patient safety and quality of care, increasing productivity and supporting healthy lifestyles.

National Business Group on Health

20 F Street NW, Suite 200 • Washington, DC 20001

Phone (202) 558-3000 • Fax (202) 628-9244 • www.businessgrouphealth.org

Helen Darling, President, National Business Group on Health

National Committee on Child and Maternal Health

Joseph Hagan Jr, M.D., **American Academy of Pediatrics**; Wayne Burton, M.D., **American Express**; Martín Sepúlveda, M.D., **IBM Corporation**, Daniel Conti, Ph.D., **JPMorgan Chase**; Sharon Adamo, **Maternal and Child Health Bureau**, Isadora Hare, **Maternal and Child Health Bureau**, David Heppel, M.D., **Maternal and Child Health Bureau**