



Children with Special Needs and the Workplace: What's The Connection?

How Title V Can Help Families Make the Most of Job-Related Benefit Programs

2001 National Survey Findings:

60% of children with special health care needs are covered by health insurance through a parent's work place

43% of parents report that either they or another family member have reduced their work hours or stopped working altogether to care for their child with special health care needs

Data from the National Children with Special Health Care Needs Survey indicate that *60% of children with special health care needs are covered by health insurance through a parent's work place*. In many cases, employees receive, or have access to, a wide variety of additional workplace benefits that have relevance to a parent's role as caregiver to a child with special health care needs.

This brief draws on the experience of a national project that looked at workplace benefits for families caring for a child with special needs. The project was a collaboration between the MassGeneral Hospital for Children in Boston, Massachusetts, Boston University School of Public Health, Family Voices, and New England SERVE and funded by the federal Maternal and Child Health Bureau. The study entailed in-depth interviews with human resource personnel at 41 companies in four cities across the US. Interviews were also conducted with parent groups in those cities.

The brief offers an overview of lessons learned from the project that are most relevant for Title V programs and then suggests three ways Title V programs can help families maximize the value of workplace benefits. Sources for more general information on the project and its findings appear at the end of this document.

What we learned

Human resource managers have little awareness of children with special health care needs

National survey data tell us that 20% of households include a child with special health care needs. Despite that, children with special health care needs are virtually invisible to human resource managers. They know a lot about general childcare and elder care, but very little about what is entailed in raising a child with more than typical health care needs. To some extent this invisibility reflects parents' fear of being labeled if they are open about their children's needs. It also reflects lack of attention to private benefits on the part of the experts and advocates - like Title V program staff - so that families receive little guidance about how to use benefits to maximum effect.

While parents' fears may be well founded in some cases, Title V programs may be able to strategize with parents to address concerns directly with employers, or to work around them to improve benefit use. Secrecy adds to the stress that is a "normal" part of raising a child with special health care needs. Parents told us that a sympathetic environment at work is not just a means of enhancing the material value of benefit programs; it is of substantial psychological value itself.

Many other employment benefits and arrangements help employees who have children with special health care needs

While health care coverage is clearly key to families of children with special health care needs, flexible work arrangements such as flextime and telecommuting are critical as well. Even when a child is well or has a condition that does not entail acute or critical illness, parents need time for medical appointments and for contact with schools and other service systems. When a child's health is unstable, parents may need to be out of work to provide care. Human resource professionals often do not understand these needs, and parents may not understand the options that are available to them in this domain. A wide range of other benefits, some relatively small or low in cost to employers, may reduce stress and enhance work life as well.

Human resource staff has limited knowledge of Title V and other public programs for CSHCN

It is not surprising, given lack of awareness of the population or its needs, that human resource managers are unfamiliar with Title V programs or other potential resources for their employees. Most of those we talked to were fascinated to learn about the public benefits for which employees might be eligible – this was a new world for them and of great interest.

What can you do?

There are some very simple things you can do to begin to make a difference in this area. There are also some more complex activities you may want to undertake once you get your feet wet. What follow are just initial suggestions.

1. Make your program known to human resource staff in your area

Consider targeting both local employers and local and regional employer and human resource groups. Give them brochures or other materials on your program and the services you offer, including those which help families connect to other service programs. You might also consider meeting with them to introduce yourself and provide a little more substantive information about what you do and the population you serve.

Many worksites offer brown bag lunches through their employee assistance programs (EAPs) on topics of interest; you can take the relationship a step further by offering to present at one of these events. This may also be a way to hear from employees about their interests and concerns. You can also do the converse: invite human resource people to attend conferences or other information programs sponsored by Title V or its partners such as Academy of Pediatrics chapters or parent organizations in your area. You may want to target the largest employers in your city or state for this effort. Or you may want to target employers of the families you serve.

2. Enhance your familiarity with private benefits

Most Title V CSHCN staff is extremely knowledgeable about public benefit programs. You can start to learn about private benefits through the kinds of contact with human resource people suggested above. You can also begin to query families. Some of the things you may want to ask them about are:

- The nature and extent of their employers' health benefits.
- The kinds of flexible work arrangements their employer may offer: are flextime, floating holidays, option to work from home, or sick time used to care for a sick child offered?
- Access to flexible spending accounts for health care expenses. Do they use them?
- On-site childcare (including sick-care, after-school care and/or school holiday programs) at the workplace – is it offered, and if so, does it welcome children with special health care needs?
- Information and referral, concierge services or lunchtime education programs – are they provided through the workplace? If so, are the resources appropriate for the family's needs?
- Work-Life Program or Employee Assistance Program (EAP) – is it offered and if so, are services such as stress reduction, wellness programs, or other relevant services available?

As you get answers to these questions, you will begin to learn about prevailing practice in your state or region. And the process of asking may encourage families to look for resources they had previously ignored. Ultimately, however, you may want to invest more effort in developing expertise in this area; learning to help individual families integrate and optimize their use of public and private benefits, including private health insurance, public wrap-around insurance (as available) and flexible spending funds.

3. Reach out to employers on a more intensive level

As you get to know human resource people in a few companies, you may find some open to a more expansive approach to addressing these needs. Invite them to work with you on strategies to improve quality of work-life for families of children with special needs. The best ways to do this will vary from site to site. Some of the things we heard about from families include:

- Ensure that there is **private space** available for employees who may need to make phone calls to a child's school or health care provider
- **Display materials** on programs and resources related to special health needs, both to relay information and to create an accepting environment.
- Create and prominently display **web links** to relevant programs and agencies.
- Establish **employee support groups** for parents and other caregivers of children with special health care needs.
- **Educate front-line supervisors** about the legitimacy of care giving for CSHCN as grounds for granting flextime, job-sharing or other discretionary work-life benefits.

Our experience suggests that employers' response to preliminary contacts on this topic vary greatly. Some are immediately eager to learn and do more, while others display little or no interest at all. Some employers will assume that improving benefits for families of children with special needs will be costly, and are therefore hesitant to explore the topic. Some families are justifiably hesitant about letting employers know they have children with special needs. The most effective approach is one that makes no assumptions about what employers can or will do, and that ensures employee anonymity when a particular family is involved. However, within these respectful parameters, there is room for Title V programs to explore a new direction in building partnerships and promoting family-centered service systems.

For more information, go to www.massgeneral.org/ebs or contact:

Deborah Allen, ScD
Department of Maternal and Child Health
Boston University School of Public Health
715 Albany St., Boston, MA 02118
617 414-1416 ~ dallen@bu.edu

Christina Fluet
Center for Child and Adolescent Health Policy
MassGeneral Hospital for Children
50 Staniford Street, Suite 901
Boston, MA 02114
617-724-3392 ~ cfluet@partners.org

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