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## **FLEXIBILITY IS PARAMOUNT FOR PARENTS CARING FOR A DISABLED CHILD**

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Coping with an accounting job and caring for the house are only a fraction of Holly Simione's daily routine. The Somerville mother also manages multiple medications, nurses, therapies, doctors' visits, and sometimes unexpected hospitalizations for her disabled daughter, 2-year-old Elizabeth.

"It's a huge juggling act," says Simione, a former IT professional who works at a part-time job with no benefits to get the flexibility she needs to care for Elizabeth, a blind quadriplegic with severe cerebral palsy. Her husband, John, is also careful about budgeting time off from his job managing private trusts at Mellon Financial Corp. to deal with his daughter's medical needs. A hidden but growing sector of the labor force, working parents of the country's 9 million children with special health needs have enormous challenges balancing exhausting home lives with job demands.

As a result, their careers and earnings are often hurt. About a third of such children have a family member who has cut back or stopped working due to the child's condition, according to federal government surveys.

"A lot take marginal employment, with fewer hours, less pay and benefits," says Dr. James Perrin, director of the Center for Child and Adolescent Health Policy at MassGeneral Hospital for Children. "If you have a child whose asthma has gotten worse, and you were up all night, what does that do to your work?"

About 13 percent of US children have a "special healthcare need," defined by the government as a chronic problem that limits activities or demands extra healthcare. Their ranks are growing, due to a rise in childhood obesity and asthma as well as treatments that extend the lives of children with diseases such as leukemia, Perrin says. Children with a disability that limits their activities, for instance, have quadrupled to 8 percent of the youth population since 1960. Flexibility is paramount for parents. Government surveys show that about 9 percent of children with special healthcare needs are hospitalized annually, compared with 3.1 percent of all US children, according to Paul Newacheck, a professor at the University of California at San Francisco. Once admitted, such children spend twice as much time in the hospital as other youngsters.

Yet parents are often reluctant to tell employers their situation. "Not everyone is looking to hire a mother with a kid, much less a mother with a sick kid," says Simione, holding her daughter's hand through a seizure. On this humid day, Simione and her husband rush home from work to relieve a niece who filled in for an absent nurse. Her parents' kisses bring coos and laughter from Elizabeth.

Alarmed by the trends, the Center launched an initiative in 2001 with Boston University and two nonprofits to raise employer awareness of the issue. Over two years, the group surveyed 41 big companies in Boston, Cleveland, Seattle, and Miami and found few specific employer benefits for this population.

Now, the group is working with a handful of employers, including the accounting firm Ernst & Young, to develop guides, seminars, and online tools to teach families about public and corporate resources. The Center will distribute the information nationally.

As part of its efforts, Ernst & Young is planning a virtual support group for the firm's parents with special needs kids. A recent trial conference call opened a flood of emotional sharing. "There was relief that we're all in this together," says David Bruesehoff, a Dallas-based regional human resources director who has an autistic 16-year-old daughter.

Even progressive companies need to do more for workers whose children have special health needs, says Bruesehoff. "We don't need to have this code of silence about it."