

Supports for Families of Children with Disabilities

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- I. **Prevalence. Estimates of prevalence of children with disabilities in the U. S. vary by definition and source, but substantial numbers of children and families are affected.**
 - The U.S. Census Bureau estimates 9.2% of households are caring for a child with a disability (U.S. Census Bureau, 2005).
 - According to the 2005-06 CSHCN survey (U.S. Department of Health and Human Services [DHHS], 2008), 13.9 % of children under 18 years of age, or approximately 10.2 million children in the U.S. have special health care needs.
 - *Special needs* have generally been identified through the Individuals with Disabilities Education Act. Children who have been diagnosed as having developmental delays, or any child who has been evaluated as having one of a limited list of disabilities specified in IDEA are considered as having special needs when they require special education and related services (20 U.S.C. 1401 and 34 C.F.R. §300.8). In 2006-2007 approximately 8.6% of children/youth ages 3-21 (6.7 million children) received services and the rate is increasing (U.S. Department of Education, 2007).
 - Drawing on national estimates of children with disabilities and chronic conditions and the employment rate among parents of children/youth the Center for Child and Adolescent Health Care Policy (2004) estimates that in any given company there are approximately 9% of employees with children/youth with disabilities.
- II. **Community Resources. When children have disabilities, supports available in communities may not meet the needs of working families, and they struggle to find solutions promoting work-life integration.**
 - *Exceptional caregiving* responsibilities differ from typical caregiving responsibilities on several dimensions: time spent arranging care (15.5% of parents caring for children with emotional, behavioral, or developmental disorders spent 11 or more hours per week coordinating care for their children; DHHS, 2008); ongoing parental responsibilities which can persist throughout childhood into young adulthood or beyond; and more frequent, intense, and crisis-driven care needs (Lewis, Kagan, & Heaton, 2000a; Porterfield, 2002; Roundtree & Lynch, 2006).
 - Parents of children with mental health and substance abuse difficulties require *optimal flexibility solutions* (Emlen, 2010) that include flexibility from the multiple domains in the work-life equation: education and child care, family care arrangements, and work arrangements (Rosenzweig & Brennan, 2008).
 - Most children with disabilities are guaranteed the right to *special educational* services; parents are expected to participate in planning these services, with planning sessions occurring during their working hours. (U.S. Department of Education, 2007). Even with special supports in schools, parents have reported being called during the workday to assist school staff when they cannot cope with children's behavior (Rosenzweig, Brennan, & Ogilvie, 2002).
 - While finding childcare that is reliable, affordable, and flexible is a concern for all employed parents, parents raising children with disabilities report finding and maintaining childcare is a difficult challenge (Emlen, 1997). This is due to the fact that their children often require specially trained child care providers or inclusive child care centers. Both are uncommon and often unaffordable (Brennan, Bradley, Ama, & Cawood, 2003).
 - Given the challenges in finding and maintaining child care, families may arrange to care for their children at home, using non-overlapping shifts, having siblings caring for each other, or leaving the child or youth in self-care (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008).

- Given the lack of community supports, the flexibility solutions for working parents of children with mental health disorders often involve making adjustments to their *work arrangements* (Parish, Seltzer, Greenberg, & Floyd, 2004; Warfield, 2005).

III. Negotiation for Workplace Flexibility. New research reveals challenges encountered by parents and human resource professionals as they negotiate flexible work arrangements.

- *Disclosure*, revealing a child's mental health disability or special needs outside the family, is used by parents as an employment-based strategy to enhance work-life integration (National Business Group, 2009; Rosenzweig & Huffstutter, 2004).
- Disclosure at work may trigger *courtesy stigmatization*. Courtesy stigmatization refers to the stigmatization projected toward family members and friends associated with a person with a disability. Family members often report being subjected to discrimination and exclusion due to their association with the child/youth with the disability (Rosenzweig, Malsch, Brennan, Mills, & Stewart, 2010).
- Human resource professionals are knowledgeable about some of the challenges faced by employees with exceptional care responsibilities but many are unsure of how to best balance the business goals with the needs of the individual requesting flexibility (Rosenzweig et al., 2011).
- A training partnership between KPMG and Portland State University demonstrates how organizational commitment to understanding disabilities can positively affect the awareness and knowledge of human resource professionals regarding the needs of employed parents of children with disabilities (Wankoff, Rosenzweig, & Brennan, 2011).
- Human resource professionals can support the needs of working parents of children with disabilities through their ability to provide layers of organizational support. Three layers of support are needed:
 - an *organizational policies and practices layer* which builds supportive workplace policies and programs that target employees with exceptional care responsibilities;
 - a *workplace culture layer* which promotes awareness and education about disabilities and stamps out stigmatization; and
 - a *collaborative communication layer* involving a three step circular process that employs empathy without promise, partnering for solutions, re-connecting, re-evaluation and re-committing (Rosenzweig et al., 2010).

IV. Effects on Workforce Participation. When community supports or workplace flexibility are not available, parents may scale back work hours or even leave the workforce altogether.

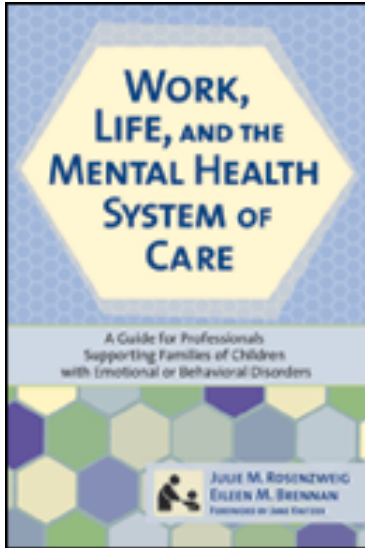
- Parents of children with disabilities frequently report quitting their jobs, reducing the number of hours worked, or changing jobs to accommodate care demands (Brennan & Brannan, 2005; Porterfield, 2002; Rosenzweig et al., 2002; Rosenzweig & Huffstutter, 2004; Thyen, Kuhlthau, & Perrin, 1999). In a 2006 survey, 38.5% of parents of children with emotional, behavioral, or developmental issues cut back or stopped working due to their child's special health care needs (DHHS, 2008).
 - Qualitative studies of dual-earner families found that although most relied on two incomes, mothers typically adapted their work schedules in response to the care needs of their children with disabilities (Lewis, Kagan, & Heaton, 2000b). Diminished maternal employment is even more prevalent for single mothers of children with disabilities who must assume full responsibility for care, household chores, and paid work (Powers, 2003).
 - When *work-family-community fit* is not achievable through formal supports (including family-friendly policies), and informal supports (e.g., co-worker coverage at times of crisis), and sufficient community resources (Barnett & Gareis, 2008), parents of children with disabilities may become underemployed or exit the workforce (Brennan & Brannan, 2005; Powers, 2003; Rosenzweig & Huffstutter, 2004).
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Work, Life, and the Mental Health System of Care: A Guide for Professionals Supporting Families of Children with Emotional or Behavioral Disorders



By Julie M. Rosenzweig, Ph.D., & Eileen M. Brennan, Ph.D., *with invited contributors*

When a child has an emotional or behavior disorder, parents experience a host of extra challenges as they attempt to meet their caregiving and employment responsibilities: stigma, increased stress, child care difficulties, lack of workplace supports. Professionals need to know how to help parents address these critical issues—and now there's a book that shows the way. Expertly researched and enhanced with actual strategies used by parents, this accessible resource gives professionals the up-to-date knowledge they need to support entire families, ease the pressures they face, and connect them with the best help and services.

2008, Paul H. Brooks Publishing Company

Children/Youth with Disabilities: Their Parents are Your Employees: Training Manual and Workbook



By Julie M. Rosenzweig, Ph.D., Anna M. Malsch, Ph.D., Eileen M. Brennan, Ph.D., Kathryn L. Mills, and Lisa Stewart, Ph.D.

This training manual and workbook helps human resource professionals and managers:

- Examine the work experience and coping strategies of working parents of children with disabilities;
- Select successful intervention strategies to reduce liability and cost while avoiding misunderstanding and conflict;
- Influence managers on legal and policy issues impacting employers of parents of children with disabilities;
- Assist employees and managers in developing actionable solutions; and
- Present the business case for change.

2010, Portland State University, Research and Training Center on Family Support and Children's Mental Health. <http://www.pathwaysrtc.pdx.edu/pdf/pbWorkLifeTrainingManual.pdf>



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