



Employees Raising Children with Disabilities: Work-life Experiences and Strategies for Success

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November 7, 2008

Work-Life Integration Project Team

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Your Experiences

- ✎ What have been your experiences in the workplace with families having children with disabilities?
- ✎ Have you had employees ask for workplace flexibility to manage their children's care?
- ✎ How have their co-workers responded to their requests for flexibility?

One Family's Story



- ✎ Taken from Rosenzweig & Brennan (2008). *Work, Life, and the Mental Health System of Care: A Guide for Professionals Supporting Families of Children with Emotional or Behavioral Disorders*. Baltimore: Paul H. Brookes.

Prevalence of Families having Children with Disabilities in the U.S.

- ✎ Estimates vary by definition and source.
- ✎ According to the 2005-06 CSHCN survey, 13.9% of children under 18 years of age in the United States have special health care needs. This number represents 21.8% of U.S. households with children (HHS, 2008).
- ✎ Using strict criteria, the U.S. Bureau of the Census (2000) has estimated that 9.2% of households raising children had at least one child with a sensory, physical, or mental disability.

Definitions





Special Health Care Needs

-  Physical, developmental, behavioral, emotional
-  Requiring more health services

Special Needs

-  Legal (Individuals with Disabilities Education Act)
-  Special Education

Disability

-  Legal (Americans with Disabilities Act)
 -  Limiting major life activities
-  Theoretical
 -  A function of the person in the environment

Impact on the Family

- ☞ Caregiver strain due to unusual demands
 - ☞ Disrupted family and social relationships
 - ☞ Exhaustion
 - ☞ Financial difficulties
 - ☞ Guilt
 - ☞ Parenting distress
- ☞ Caregiver strain experienced at work → lessened workforce participation
- ☞ The positive side...
 - ☞ Families reach out for and receive helpful social support
 - ☞ Have greater appreciation for diversity
 - ☞ Learn about human disabilities
 - ☞ May even use new knowledge in their work

Impact on the Workplace

- ✎ In any given company in the United States, approximately 8.6% of employees are caring for a child under the age of 18 years with special needs (Center for Child and Adolescent Health Policy, 2001).
- ✎ Effects of caregiver strain on employment
 - ✎ Workforce participation rates
 - ✎ Retention (quitting, changing jobs)
 - ✎ Reduction of hours
 - ✎ Absenteeism

Work-life Challenges Specific to Families having Children with Disabilities

- ✎ Exceptional caregiving responsibilities
- ✎ Community integration
- ✎ Stigmatization
- ✎ Disclosure
- ✎ Family support

Exceptional Caregiving Responsibilities

Child with Typical Development

- ✎ Constant care that diminishes
- ✎ Major input of time and energy
- ✎ Easier as time goes by
- ✎ Few interruptions are emergency-driven
- ✎ Child grows increasingly independent
- ✎ Requires some lifestyle adjustments
- ✎ Challenges and successes are easily shared

Child with a Disability

- ✎ Constant care that often escalates
- ✎ Extraordinary input of time and energy
- ✎ Often harder as time goes by
- ✎ Many interruptions are emergency-driven
- ✎ Child may grow increasingly dependent
- ✎ Requires numerous lifestyle adjustments
- ✎ Challenges are rarely shared; successes are fewer

Community Integration

- ✎ Reflects the capacity of the family's social environment to support and sustain them physically, socially, and psychologically
- ✎ Children with disabilities are often excluded from community-based activities such as child care, sports clubs, or church gatherings
- ✎ Parents are also excluded from the adult social networks that support these opportunities

Stigmatization

- ✎ Based on a personal attribute that is culturally devalued or deemed inferior in comparison with social norms
- ✎ Adults and children with disabilities experience prejudice, stereotyping, and discrimination
 - ✎ Creates physical and social isolation, limits community integration
- ✎ Family members face *Courtesy Stigmatization*
 - ✎ Discrimination and exclusion due to their association with the person with a disability

Disclosure

- ✎ Revealing a child's disability outside the family
- ✎ Used by parents in the work domain as a strategy to enhance work-life integration
- ✎ Parents may chose to disclose as a means to access workplace supports
- ✎ Disclosure may be not be risk-free; may heighten stigmatization and job insecurity

Family Support

- ✎ A constellation of formal and informal services and tangible goods that are defined and determined by families
- ✎ “Whatever it takes” for a family to care for and live with a child with a disability
- ✎ Comprehensive care for a child with a disability and assistance to the entire family, while helping parents and other caregivers function as productive and responsible employees

Workplace Supports for Parents of Children with Disabilities

- ✎ Workplace culture
- ✎ Workplace policies
- ✎ Workplace flexibility
- ✎ Workplace reciprocity

Workplace Culture

- ✎ Family-friendly culture
 - ✎ Promotes diversity and inclusion
 - ✎ Supports and trains management to consider employees as whole people with lives outside work
 - ✎ Understands the mutual advantages gained by providing supportive benefits, policies, and practices
- ✎ Family-friendly culture and “bottom line” impact
 - ✎ Job satisfaction, commitment, retention

Workplace Policies

- ✎ Formal policies
 - ✎ Family Medical Leave,
 - ✎ Vacation/Sick Time
 - ✎ Availability of Flexible Work Arrangements
- ✎ Informal policies
 - ✎ Co-worker coverage in times of crisis
- ✎ Availability of formal policies does not necessarily encourage or promote employee utilization





Workplace Flexibility

- ✎ Essential for parents of children with disabilities to support adjustments in the timing and physical location of work tasks
 - ✎ Time off to attend doctor and school appointments
 - ✎ Scaled-back hours to allow more time to care for child
 - ✎ Adjustable hours to accommodate school and child care
 - ✎ Options to deal with emergency situations
 - ✎ Extended leaves

Workplace Reciprocity

- ✎ A relational process of mutual exchange between employee and supervisor/co-workers
- ✎ Costs and benefits to both
- ✎ Employees will give back to their employer because they were given latitude to address their family needs
- ✎ Part of workplace culture

Community Supports

-  Child care
-  Education
-  Health care system
-  Community networks

Child Care

- ✎ Families must often make complex and flexible child care arrangements
- ✎ Lack of adequate child care, inclusive child care
- ✎ Difficult to find and maintain
- ✎ Children are often expelled from child care due to challenging or troubling behavior.

Education





- ✎ For parents of school-age children, the school can be an important setting
 - ✎ Where children receive support and services
 - ✎ Where parents can find assistance in their efforts to provide care and opportunities for their children
- ✎ Partnership between parent and school (and other professionals)
- ✎ Overburdened and under funded schools may not have the capacity to meet this need

Health Care

- ✎ In addition to maintaining employment, families must provide for the special health care or mental health treatment requirements of their children
- ✎ Parents spend substantial time
 - ✎ Arranging care
 - ✎ Transporting child to care
 - ✎ Participating in treatment
 - ✎ Administering medication
 - ✎ Maintaining assistive devices

Community Networks

Formal supports

-  Community child care and education providers
-  Health and human service agencies
-  Transportation services
-  Workplace

Informal supports

-  Family
-  Friends
-  Neighbors
-  Peer support groups
-  Volunteer groups

Policy Supports

- 👤 American with Disabilities Act
 - 👤 Association provision
- 👤 Individuals with Disabilities Education Act
- 👤 Universal supports for families
 - 👤 Family and Medical Leave Act
 - 👤 Tax credits for child care
 - 👤 Funding for preschools and out-of-school care
- 👤 Targeted supports for families
 - 👤 TANF
 - 👤 Earned Income Tax Credit
 - 👤 Child Care Development Fund

The Employer's Perspective

- ✎ Valued employees may make decisions to leave the organization due to lack of understanding, flexibility, and other supports
- ✎ Increasing prevalence of Family Responsibility Discrimination lawsuits
- ✎ Employers need strategies they can use to recruit and retain talented employees
- ✎ Employers need strategies for policy and practice shifts that will make workforce participation possible
- ✎ Employers need accurate information and knowledge about the lived experiences of employed parents with exceptional caregiving commitments

Future Directions

- ✎ Training for HR professionals and supervisors
 - ✎ Knowledge of exceptional caregiving and children with disabilities
 - ✎ Increased awareness of stigmatization
 - ✎ Communication skills; navigation of dialog with employees
- ✎ Helpful tips for employed caregivers
 - ✎ Picking family-friendly organizations
 - ✎ Knowledge of available supports
 - ✎ Communication skills; navigation of dialog with HR or supervisor

References and Resources

✎ Research and Training Center on Family Support and Children's Mental Health (RTC)

✎ www.rtc.pdx.edu

✎ Sloan Work and Family Research Network

✎ <http://wfnetwork.bc.edu/>

✎ Center for Work Life Policy

✎ <http://www.worklifepolicy.org/>

✎ Berger Institute for Work, Family, and Children

✎ <http://www.claremontmckenna.edu/berger/>



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Funds to support this activity come from The Child, Adolescent and Family Branch, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services; and from

The National Institute on Disability and Rehabilitation Research, U.S. Department of Education (NIDRR Grant H133B990025).



Center for Mental Health Services,
Substance Abuse and Mental Health
Services Administration, U.S. Department
of Health and Human Services



National Institute on Disability and
Rehabilitation Research, U.S.
Department of Education