



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

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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.

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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