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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?

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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.

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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

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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

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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

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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

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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-friend culture and "bottom line" impact
  - Job satisfaction, commitment, retention

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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

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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

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Community Supports

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

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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.

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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

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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

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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

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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

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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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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