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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?
One Family’s Story

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

ไหล 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

<table>
<thead>
<tr>
<th>Child with Typical Development</th>
<th>Child with a Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant care that diminishes</td>
<td>Constant care that often escalates</td>
</tr>
<tr>
<td>Major input of time and energy</td>
<td>Extraordinary input of time and energy</td>
</tr>
<tr>
<td>Easier as time goes by</td>
<td>Often harder as time goes by</td>
</tr>
<tr>
<td>Few interruptions are emergency-driven</td>
<td>Many interruptions are emergency-driven</td>
</tr>
<tr>
<td>Child grows increasingly independent</td>
<td>Child may grow increasingly dependent</td>
</tr>
<tr>
<td>Requires some lifestyle adjustments</td>
<td>Requires numerous lifestyle adjustments</td>
</tr>
<tr>
<td>Challenges and successes are easily shared</td>
<td>Challenges are rarely shared; successes are fewer</td>
</tr>
</tbody>
</table>
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-friend 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
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)
wwwrtc.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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