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# **Caring for a Child with a Disability: Dilemmas of Disclosure for Parents and Human Resource Professionals**

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# Introductions

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## ☞ Julie Rosenzweig, Ph.D.

- Principal Investigator, Work-Life Integration Project
- Research Team Members
  - Eileen Brennan, Ph.D., Co-Principal Investigator
  - Anna Malsch, Ph.D., Project Manager
  - Kitty Huffstutter, M.A., M.S.W., Doctoral Student Collaborator
  - Lisa Stewart, M.S.W., Graduate Research Assistant

## ☞ Linda Roundtree

- President, Roundtree Consulting, Advisory Board, Work-Life Integration Project

# Over a Decade of Work-Life Integration Research on Families of Children with Mental Health Disabilities

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## ☞ **Support for Working Caregivers Project (1996-1999)**

- Secondary analysis of data from North Carolina caregivers survey (N = 243)
- 5 focus groups with parents (N = 41)
- In-depth interviews with parents (N = 60)

## ☞ **Models of Inclusion in Child Care (1999-2004)**

- Interviews with staff and center directors at 9 inclusive centers (N = 49)
- Interviews with parents at 9 inclusive centers (N = 25)
- Interviews with state child care administrators (N = 24).

## ☞ **Common Ground? Families & Employers (2000-2004)**

- Parent Employment Experiences Survey (N = 349)
- Workplace Support for Parents of Children with Mental Health Disorders Survey: mailed surveys (N = 31), interviews with supervisors (N = 27)

# Current Research Project

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## *Work-Life Integration for Families with Children & Adolescents Who Have Emotional or Behavioral Disorders (2004-2009)*

- ☞ Phase I: Caregiver workforce participation study, N=2,585  
*Secondary analysis of data from the national evaluation of the Comprehensive Community Mental Health Services for Children and Their Families Program*
- ☞ Phase II: Focus groups: Parents and HR Professionals  
Parents: 3 groups N= 17 HR: 5 groups N=28
- ☞ Phase III: Work-Life Flexibility and Dependent Care Survey N=551  
in partnership with WorldatWork
- ☞ Phase IV: Design and offer training to human resource professionals
- ☞ Phase V: Resource development for families and businesses

# Work-Life Integration Project Goals and Objectives

**Overall Goal:** *To improve awareness and access for families with dependent care needs to employment based supports that promote work-life integration--participation in the workplace while permitting them to take part in family and community life and roles.*

## Objectives:

- ✎ To identify HR policies & practices that support employees with dependent care responsibilities, particularly children with special needs.
- ✎ To provide information & resources to HR professionals about best practices that support employees caring for children with mental health disabilities.

# Work-Life Integration Defined

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- Refers to the degree to which people are able to find a functional and satisfactory level of assimilation in their work and personal lives.
- Acknowledges that the amount of time spent in either domain will vary over one's life span (Rapoport, Bailyn, Fletcher, & Pruitt, 2002).
- Is affected by disclosure, stigmatization, and flexibility arrangements experienced by the parents (Brennan et al., 2005).
- Impacted by the availability of community resources and demands for both families *and* workplaces (Voydanoff, 2002).



# **WHO ARE CHILDREN WITH SPECIAL NEEDS?**

# Types of Disabilities

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- ☞ Physical
- ☞ Chronic Illness
- ☞ Developmental
- ☞ Cognitive
- ☞ Emotional

# Children with Special Needs: The Numbers

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- ✎ 20% of U.S. households care for children with special needs (Child & Adolescent Health Initiative, 2004).
- ✎ Nearly 20% of children experience symptoms of a mental health disorder over the course of a year.
  - 5% are considered to have serious emotional disorders (U.S. Department of Health & Human Services, 1999).
- ✎ In any given company about 9% of employees have children with special needs (Center for Child & Adolescent Health Policy, 2004).

# Special Needs Increasing

*Children receiving early intervention services under IDEA\* in 2000:*

- ☞ 2% of children birth through 2 years of age.
- ☞ 5% of preschool-aged children.
- ☞ Number receiving services increase (1992/93 to 2000/01).
  - 3 year-olds, up 44%
  - 4-year olds, up 37.6%
  - 5-year-olds, up 22.4%
  - 6-11year-olds, up 19.3%

\*IDEA: Individuals With Disabilities Education Act

# Special Needs Reach the Workplace

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- ☞ Ceridian LifeWorks Services reports that 10-15% of all requests involve some aspect of raising a child with special needs.
- ☞ LifeCare® has seen a 25% increase in special needs cases since 2003 when they provided 23,000 special needs referrals.
- ☞ This year, the Working Mother “100 Beat” application includes a special section of questions about support for children with special needs.



# **PARENTING A CHILD WITH SPECIAL NEEDS**

# In Addition to Typical Parenting

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- ✎ In addition to typical parenting activities, parents of children with disabilities frequently:
  - Arrange for and participate in their children's ongoing physical and mental health treatment.
  - Provide consultation to school personnel about their children's special educational needs.
  - Face significant obstacles in locating and sustaining adequate child care.
  - Are the primary, if not the only, source of their children's transportation.
  - Respond to frequent health or mental health crises, sometimes requiring hospitalization of the child.



# **THE CHALLENGE: WORK-LIFE INTEGRATION**

# The Challenge of Work-Life Integration

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## Workplace Support

- Typically intended for women of child bearing age
- Assumes need will be relatively short-term

## Community-based Support

- Child care and school programs designed for typically developing children
- Health and mental health services offered only or primarily during day hours

## Stigmatization

- Assumption by supervisors and co-workers that you are not doing your job or that you are an inadequate parent

# Barriers to Work-Life Integration

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- ✎ Employees who have children with disabilities are reluctant to ask for flexibility, fearing negative job consequences (Lewis, Kagan, & Heaton, 2000).
- ✎ 37% of employees say it is hard to take time off during work when personal or family issues arise and 39% report that using flexibility jeopardizes their advancement (Families & Work Institute, 2004).
- ✎ 54% of employed parents say they cannot take time off for sick children without losing pay, using vacation days, or making up an excuse (Families & Work Institute, 2004).

# Caring for a Child with Special Needs: Effects on Employment are Significant

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## ☞ **According to the Parent Employment Experiences Survey:**

- 17% currently unemployed to care for child with serious emotional or behavioral disorder
- 11% unable to find work due to caregiving responsibilities for child with serious emotional or behavioral disorder
- 27% (of total) have had employment terminated because of work disruptions due to care responsibilities
- 48% (of total) have quit work to care for child with serious emotional or behavioral disorder

Rosenzweig & Huffstutter, 2004

# Work-Life Integration Challenges: Parents' Comments

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## ✎ **Difficulty with community supports**

- *“Difficulty with school. They are not supportive and always calling about problems with school and do not follow through with handling or they do not notify me right away when something happens.”*

## ✎ **Regarding the workplace response**

- *“This company was not flexible as a whole. I did have a supervisor who covered for me regularly and most of my co-workers were very supportive. However, before I left the company my supervisor was getting an enormous amount of pressure from higher-up. I felt his job may be threatened because of my performance and the amount he covered for me.”*

## ✎ **Personal impact**

- *“...the mental, emotional, and physical exhaustion I must continually deal with and still try to work.”*

# Work-Life Integration Challenges: Parents' Comments


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## ☞ On stigmatization

- *“I also get a lot of people who don't understand a lot, or who say, ‘Oh, it is just one day, what is the big deal?’ Or who say, ‘I had ADHD. That is just baloney. Everybody is overmedicated. Nobody needs Zoloft’ ...I think that is the difficulty, but it usually just comes out because of necessity, just having to say something because you have to maneuver and manage things, and don't have any other choice.”*

## ☞ On necessity of disclosure

- *“But you still have to let people know what is going on, because it is impacting your ability to do your job and do it well, and to keep up with the things that are at the highest priority.”*



# **WORK-LIFE INTEGRATION: LEGAL CONSIDERATIONS**

# Recent Legal Challenges

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## ✎ Family Responsibilities Discrimination (FRD)

- When employees are discriminated against as caregivers
  - e.g., when an employee's caregiving responsibilities cause job loss or affect promotion
- Lawsuits have increased by 400% in the last 10 years
- These cases have twice the success as other employment discriminations cases (Center for WorkLife Law)



# **WORKPLACE DISCLOSURE DILEMMAS**



# **PARENTS: TO TELL OR NOT TO TELL?**

# Disclosure as a Work-Life Integration Strategy

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## *According to the Parent Employment Experiences Survey:*

- ✎ **Parents of children with mental health disabilities identify four primary strategies to locating and sustaining employment:**
  - Finding a job in a family-friendly workplace
  - Restructuring of employment
  - **Disclosure in the workplace about child's mental health status**
  - Reciprocity and negotiation
  
- ✎ **Disclosure levels were high among respondents:**
  - 83.2% of the sample disclosed their child's mental health status to the supervisor.
  - 86.2% of the sample disclosed their child's mental health status to coworkers.

(Rosenzweig & Huffstutter, 2004)

# Costs and Benefits of Disclosure

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- Disclosure is very individual and personal. Only the parent knows the scope of the family situation and the job situation.
- Disclosure may be made by choice or out of necessity.
- A parent's decision about whether or not to tell the supervisor or co-workers about a child's mental health status is complicated and has associated risks and benefits.
- Benefits include: increased support, improved work-life integration, increased access and utilization of benefits.
- Risks include: stigmatization, job insecurity or job loss.

# Disclosure Considerations

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- ✎ Disclosure is a process that requires careful consideration of several factors such as:
  - To whom to disclose and how — supervisor, coworkers, human resources staff, EAP?
  - Timing of disclosure — during hiring process, when child situation arises?
  - Amount and type of information disclosed — nature of disability, behaviors involved, anticipated frequency of interruptions?
  - Issues of confidentiality

# Parents on Disclosure

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- ✎ “Honesty with my employer. That has been the main strategy and working very, very hard when life is going well to make up for the times when I have to be out from work.”
- ✎ “I do try to be up front with selective people about this. Some people I tell about my son’s emotional disorder; to others I just say that my son has a chronic illness that sometimes requires hospitalization.”
- ✎ “All I’ve been able to do is explain to my employer the reality of my life with an autistic child. Some have understood and others have absolutely not!”

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**PROFESSIONALS:**

**TO KNOW OR NOT TO KNOW?**

# Professionals' Dilemmas

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- Needs of the individual vs. needs of the work group.
- Is the business case strong enough?
- Concerned about knowing too much information.
- Breaches of confidentiality.
- Feeding the rumor mill.
- Employee taking advantage of accommodations.

# Disclosure: Policy vs. Practice

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- How comfortable are you with an employees disclosure of personal information?
- Does the reason for a request for flexibility or accommodation make a difference in your decision?

# Disclosure: Policy vs. Practice

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- ✎ According to the Work-Life Flexibility & Dependent Care Survey:
  - 9% of respondents indicated that disclosure is discouraged due to potential privacy/legal reasons.
  - 77% reported that employee disclosure of personal circumstances can help in obtaining flexibility.

# HR Professionals' on Disclosure Dilemmas

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- ✎ “When the other employees don’t know and don’t understand the circumstance, then the rumor mill gets cranked up, and then the peer pressure and the backbiting and the whining and moaning goes on. This person is put into a really tight position and the company is sitting there saying, well, I can’t say how come she is not showing up for work...the government says you can’t do it anywhere.”
- ✎ “It seems that there are issues out there that you really don’t, from a professional standpoint always acknowledge that exist. Part of that may be motivated by the fear that in a situation that is highly personal like this, you have conflicts with confidentiality issues and you have how much [as an employer] should I know, and how much do I dare ask.”



# WHERE IS THE COMMON GROUND?

# Parents and HR Professionals Agree

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*According to focus group results:*

- ✎ Both parents and HR professionals stated that being granted accommodations resulted in employee loyalty and retention, and competent, if not superior, performance.

# Solutions/Strategies

## Maximize Gains & Minimize Risks

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- ✎ Federal Policies
- ✎ Reciprocity Negotiation
- ✎ Make expectations explicit
- ✎ Family-friendly workplace culture
- ✎ Training for HR/work-life professionals & supervisors
- ✎ Survey employees

# Federal Policies

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- ✎ Family Medical Leave Act (FMLA) mention proposed changes
- ✎ Americans with Disabilities Act (ADA)
- ✎ Individuals with Disabilities Education Act (IDEA)



# FEDERAL POLICIES

Family Medical Leave Act

Americans with Disabilities Act

Individuals with Disabilities Education Act

# Family and Medical Leave Act

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- ✎ Major policy passed in 1993 allowing employees to take time off without losing their jobs
- ✎ FMLA allows up to 12 weeks of unpaid leave in four circumstances:
  - For a newly-born child;
  - For a child placed with an employee in adoption or foster care;
  - For the employee's own health condition;
  - For a spouse, child, or parent who has a serious health condition (U.S.C §2612 (a) (1) (A) – (D)).

# Many Families Not Covered by FMLA

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- ✎ Only covers workers in organizations with 50 or more employees within 75 miles of the employee's worksite.
- ✎ Eligible employees must have worked at least 1,250 hours for the employer in the past 12 months; part-time or seasonal workers not covered.
- ✎ Some employers not covered by FMLA will allow workers to take this leave.

## FMLA Often Used for Child Illness

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- ✎ In 18 months prior to a 2000 survey Cantor et al (2001) found 16.5% of all employees took FMLA.
  - 9.8% took longest leave for child illness;
  - 20.1% took second longest leave for to care for ill child.
- ✎ About ¼ of workers take intermittent leave, which allows workers to take leave for a few hours or days at a time, or reduce to part-time.
  - 39.5% of those who cared for a sick child chose intermittent leave (Cantor et al., 2001).

# Why Do Many Employed Parents Not Take FMLA?

- Financial consequences are often serious; workers might have to borrow money or go on public assistance (Gerstel & McGonigle, 1999).
- Some cultural groups need FMLA to care for family members not covered by the law—grandchildren, cousins, siblings— or those accepted as family (Hogan, Eggebeen, & Glogg, 1993; Stack & Burton, 1994).
- FMLA can have negative employment consequences given certain organizational climates or economic downturns.
- Even California paid FMLA not used by all; only replaces 55% of their weekly earnings to a maximum of \$850 per week (Halpern, Tan, & Carsten, 2005).

# Americans with Disabilities Act

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- ✎ Americans with Disabilities Act, passed in 1990 protects the civil rights of individuals with disabilities, including children.
- ✎ Covers persons who suffer from a physical or mental impairment which substantially limits one or more major life activities.
- ✎ ADA prohibits discrimination on the basis of disability and requires places of public accommodation and commercial facilities to be designed, constructed, and altered to make them accessible.

# Inclusion under ADA

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- ✎ In principle, ADA means that children with serious physical or mental health problems should not be excluded from public accommodations, like child care center or before- and after-school programs.
- ✎ In practice, the law is enforced very unevenly; one study found that one third of child care providers being surveyed had refused enrollment to children with disabilities (Eisenman, Shishler, & Healy, 1995).
- ✎ Frequently, children are expelled from child care due to behavior problems (Gilliam & Shahar, 2005)

# Individuals with Disabilities Education Act

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- ✎ IDEA, passed in 1990 mandates that all children with disabilities have free, appropriate public education available to them, including special education and services which can prepare them for employment and independent living.
- ✎ For many children, this means
  - an individual family services plan (IFSP-usually younger children ),
  - individual education plan (IEP—school aged children).
  - 504 plan (children without learning disabilities but with significant other types of impairments).

# Involvement in Special Education through IDEA

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- ✎ Plans can provide families with support for the special educational needs of their children.
- ✎ Also requires significant time to work with school districts to set up the plans and to review them periodically.
- ✎ Since some accommodations are costly, and communities have few resources, families may need assistance and support getting these plans in place.



# RECIPROCITY AND NEGOTIATION

# Reciprocity/Negotiation as a Work-Life Integration Strategy

- ✎ Workplace reciprocity refers to the relational process of mutual exchange between the parent/employee and the immediate supervisor or coworkers resulting in costs and benefits to both the parent and the workplace.
- ✎ Reciprocity involves negotiation and accountability from all persons involved.
- ✎ Reciprocity and negotiation may be formal or informal.

# Costs and Benefits of Reciprocity/Negotiation

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- ✎ Potential benefits to the parent/employee
  - Better able to fulfill care responsibilities
  - Reduced stress
- ✎ Potential costs to the parent/employee
  - Overworking to show appreciation for flexibility
  - Coworker resentment
- ✎ Potential benefits to workplace
  - Higher work productivity from the employee
  - Increased commitment and engagement
- ✎ Potential costs to the workplace
  - “Backlash” for instituting family-friendly practices

## Parents on Reciprocity

- ✎ “I have been employed in small, family-owned businesses that understand the need for parents to be accessible to their kids. They have more flexibility to their positions, especially when you prove how valuable you can be to their business and give 150% when you are there.”
- ✎ “It is a give and take relationships with flexibility and understanding during times of crisis and when things even out, I attempt to give back 150%.”
- ✎ “I also offer to help co-workers in hope they can help when I need it.”

# Managing Expectations

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- ✎ 59% of respondents to The Work-Life Flexibility and Dependent Care Survey indicated that the HR department holds primary responsibility for flexibility policies and practices.
- ✎ According to the HR focus groups, managing employee expectations about flexibility and other work supports by being explicit up front was an important strategy related to disclosure dilemmas.
- ✎ *“One situation which I had to do, which was very difficult, but it turned out to be successful, is I had an employee who had a lot of family issues, and wasn’t really dealing with them, and it became a performance problem, where our contract was in jeopardy because this person wasn’t fulfilling the requirements. I had to put him on a performance plan...We want to be supportive, we want to help you, but you have to step up, and this person did.”*

# Family-Friendly Workplace Culture

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- ✎ 40% of respondents of the Work-Life Flexibility & Dependent Care Survey Indicated that the culture in their organization around supportiveness of employees taking time in the workday for routine personal or family issues was highly dependent on individual supervisors.
- ✎ 34% of survey respondents reported that the primary reason employees do not utilize flexible work arrangements is because the culture in their organization does not encourage their use.

# Training for HR Professionals & Supervisors

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- According to the Work-Life Flexibility and Dependent Care Survey:
- Training around children with special needs is needed to help respond to the work-life issues of these employees:
  - About 44% of respondents reported that they were neither “likely” nor “unlikely” to grant flexibility for a parent whose child was acting out at school, with 43% following suit for a parent whose child was expelled from school.
  - While 34% of HR professionals responding to the survey indicated that they had almost no knowledge, or not much knowledge of children’s mental health or child disability, the majority reported (77%) that they had not had training in the last two years on managing work-life issues of employees.
  - Only 17% of respondents reported that supervisors in their organizations had training on managing work-life issues of their employees.

# Employee Surveys

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- ✎ 86% of respondents of the Work-Life Flexibility & Dependent Care Survey reported that they did not regularly survey employees about their work-family needs.
- ✎ Surveys are a “win-win” solution to find out specifics about your employees care responsibilities while avoiding legal risk around personal disclosure.

# Is Your Organization Sensitive to Employees who have Children with Special Needs? A Self-Assessment

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- ✎ What percentage or number of employees in your organization have children with special needs?
- ✎ Does your organization regularly survey employees about their work-life needs?
- ✎ Does your organization have brown-bag lunches addressing parenting children with special needs?
- ✎ Does your organization have support groups for parents who have children with special needs?
- ✎ Does your organization put up resources and information about children's mental health, support groups for working parents of children with special needs, how to contact EAP for extra support, in common employee areas?

## Final Reflections from the Frontline...

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*“You earn a lot of loyalty from your people, as an employer, when you do work through these difficulty times with them. You have had their babies with them, and you have been through their cancer treatments, and that, I think, goes a long way in building loyalty in your employees.”*