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# A Professional's Guide to Supporting Families of Children with Mental Health Disorders

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Portland, OR

# A Professional's Guide to Supporting Families of Children with Mental Health Disorders

Presented at:

The Building on Family Strengths Conference: Research and Services in Support of Children and their Families

June 24, 2009

Portland, OR



[www.rtc.pdx.edu](http://www.rtc.pdx.edu)

# Part Two: Strategies Used by Parents to meet their Caregiving Needs and Employment Responsibilities

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Work-Life Integration Project--Research and Training Center on Family Support & Children's Mental Health; Portland State University.

- ✎ Eileen M. Brennan and Julie M. Rosenzweig, Co-principal Investigators,
- ✎ Anna Malsch, Project Manager,
- ✎ Lisa Stewart, Graduate Research Assistant, and
- ✎ Kayti Mills, Undergraduate Research Assistant.

# 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)

# Work-Life Integration for Families with Children and 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 Human Resource (HR) Professionals; Parents: 5 groups, N = 28, HR: 3 groups, N = 17

**Phase III:** Work-Life Flexibility and Dependent Care Survey, N = 551; In partnership with WorldatWork

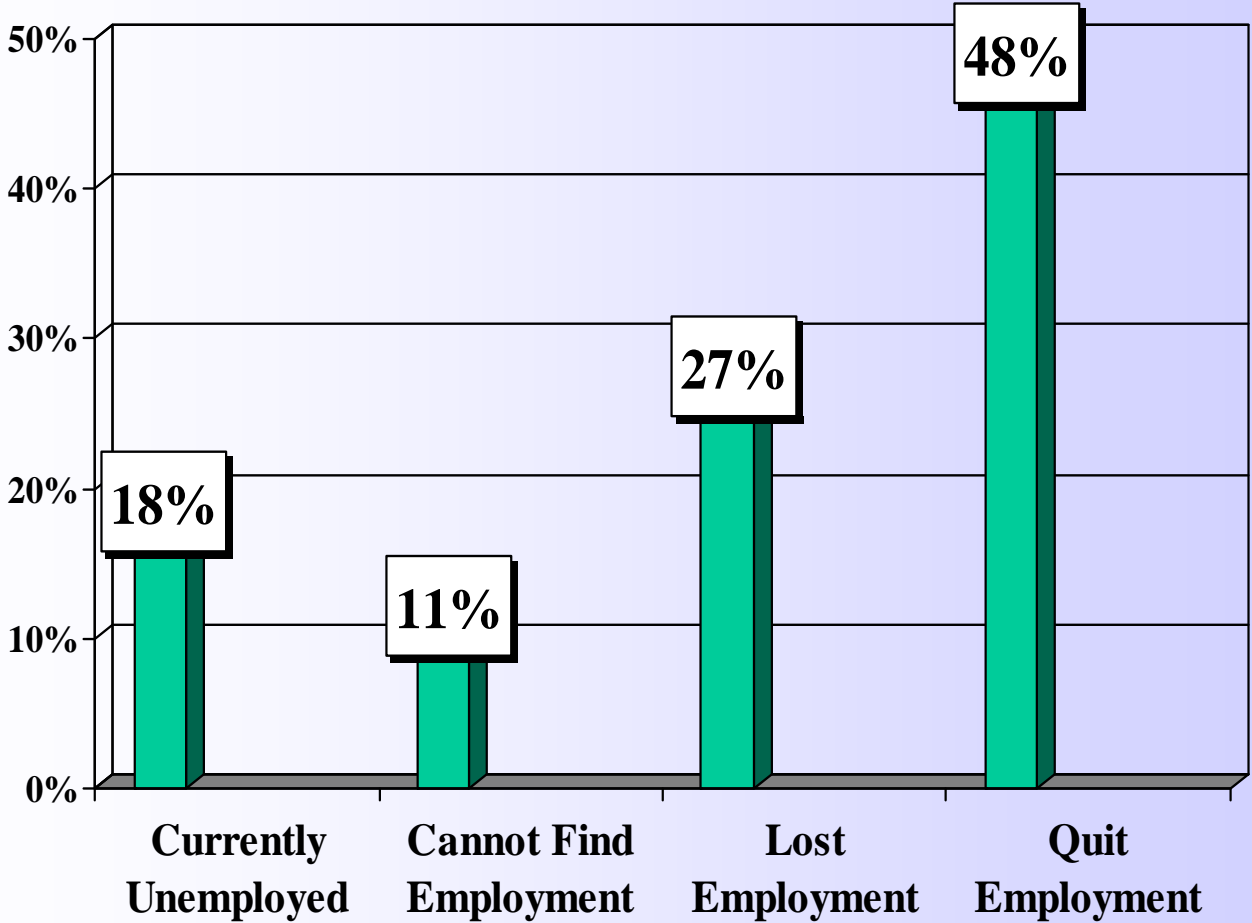
**Phase IV:** Design and offer training to HR professionals

**Phase V:** Resource development for families and businesses

## How Many Families are Affected?

- 11% of children under 18 have mental health disorders severe enough to cause significant difficulty (Surgeon General, 2001).
- 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).

# Job Insecurity and Job Loss for Employed Parents of Children with Mental Health Disorders



Rosenzweig & Huffstutter, 2004

# Current Work-Life Integration Project

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**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 learn from family members the ways in which they have worked with HR professionals to assure their ability to participate in employment.
- ✎ To identify policies and practices that support employees with dependent care responsibilities, particularly children with special needs.
- ✎ To provide information and resources to professionals and family members about best practices that support employees caring for children with mental health difficulties.



# WORK-LIFE INTEGRATION—A SYSTEMIC CONCEPT



- ✎ Refers to the degree to which people are able to find a functional and satisfactory level of accommodation in their work and personal lives (Rapoport, Bailyn, Fletcher, & Pruitt, 2002).
- ✎ Affected by the availability of community resources and the level of demands for both families and workplaces (Voydanoff, 2002).
- ✎ All families seek greater work-life integration through an optimal flexibility solution combining flexibility in the work, family, and/or child care system (Emlen, 2008).

## Work-Life Integration Barriers

- Stigmatization of children with mental health difficulties and **courtesy stigmatization** of their family members.
- Inadequate community-based **child care** arrangements.
- Lack of support in the **schools** for children and youth with mental health difficulties.
- Inadequate formal and informal **workplace** supports.

# Courtesy Stigmatization Barriers:

## PARENTS BLAMED FOR CHILD'S DIFFICULTIES


- ✎ Parents of children and adolescents with serious emotional or behavioral disorders experience **courtesy stigmatization** associated with their children's behaviors related to the mental health disorder.
- ✎ **Courtesy stigmatization** is based on assignment of responsibility for children's private and public behavior to successful or deficient parenting.
  - Mothers compared to fathers are held more responsible for the behavior and mental health of children.
  - Stigmatization experiences by vary by cultural identity.
- ✎ Success of parenting is culturally evaluated by the youth's successful attainment of adult roles and responsibilities, as signified by the diminishment of the active parenting.

(Gray, 2002; Fernandez & Arcia, 2004; Harden, 2005).

# Managing Courtesy Stigmatization

- Management strategies used by parents related to associated stigma focus largely on controlling the spread of information regarding their child's mental health disorder (Gray, 2002).
  - Concealment and secrecy
  - Passing: "normal appearing round of family life" (Birenbaum, 1970).
  - Limiting exposure to stigmatizing reactions of others, including limiting public outings, selective disclosure, and restricting socializing to others who would understand (Gray, 2002).
  - Levels of **disclosure** differ from across domains, roles, and relationships (home, school, work, child care, and community activities).

## Child Care Barriers: DIFFICULT TO FIND AND MAINTAIN CARE

-  Parents of children with emotional or behavioral disorders report:
  - Significant difficulty obtaining and maintaining child care (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008; Rosenzweig, et al., 2002).
  - Lower quality and less stability of care than parents of children with typical development; children often expelled from care (Emlen, 1997; Gilliam & Shahar, 2005).
  - Settling for whatever child care arrangement could accommodate their children with mental health difficulties (Brennan, Bradley, Ama, & Cawood, 2003).

## Parents Speak: LACK OF ADEQUATE CHILD CARE

- ✎ *“Finding sources to help care for your child that are qualified, dependable, and affordable is difficult. Without those services, one cannot work.”*
- ✎ *[My son] got kicked out of normal daycare because of his behavioral issues. He’s aggressive, at times he fights and screams and kicks and cusses. [This center] said that they were used to that, and they can deal with it. I decided to take him here. There’s no one else who would take him (Brennan, Bradley, Ama, & Cawood, 2003, p. 90).*

## School Based Barriers: TIME COMMITMENTS AND CRISIS RESPONSES

- ✎ Family members are often required to spend hours during their work days in school meetings, planning for the educational and support needs of their children and adolescents. (Gopalan, Burton, McKay, & Rosenzweig, 2008).
- ✎ When mental health crises arise at school, parents are often called away from work to manage their children's behavior (Rosenzweig et al., 2002).

## Parents Speak: SCHOOL AND WORK CONFLICT

- ✎ *“Getting and keeping an appropriate educational placement so that he may attend school full time. At this time he is on Independent Study and I can only work 10-15 hours a week.”*
- ✎ *“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.”*
- ✎ *“For me it meant rearranging my work schedule and making the time to meet with school teachers, principals, counselors...So I had to drop things and be able to work with the school people.” (Rosenzweig, Brennan, & Ogilvie, 2002)*



# Workplace Barriers:

## INADEQUATE FORMAL AND INFORMAL SUPPORT

- ✎ Some workplaces and some jobs have little flexibility and few supports.
- ✎ Formal workplace policies on flexible work arrangements and family leave may not be actually usable.
- ✎ Courtesy stigmatization by supervisors and co-workers can make obtaining informal supports difficult.

## Parents Speak: INADEQUATE WORKPLACE SUPPORT

- ✎ *“Supervisors who are unable and unwilling to understand the long term nature of caring for kids with serious mental health problems. [They] think that if you have taken the child to the doctor every week for six months then the child should be OK. Generally, they are less supportive as time goes on.”*
- ✎ *“While officially there are policies like the FMLA, it’s still hard for supervisors and co-workers to deal with my sudden absence. There is resentment, but also the question of whether I can do my job.”*

# Work-life Integration Strategies

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- ✎ *Work/life integration strategies* are ideas, plans, actions, resources, services, programs, or policies that when utilized by parents improve their ability to meet employment and family responsibilities, therefore enhancing satisfaction with multiple roles in the family, workplace, and community.
- ✎ Strategies can include:
  - Appropriate disclosure decisions
  - Finding a family friendly workplace
  - Restructuring employment
  - Negotiating reciprocity.

# To Tell or Not to Tell?

## APPROPRIATE DISCLOSURE DECISIONS

- ✎ Employed parents carefully weigh the risks and benefits of disclosing their children's mental health status at work (Rosenzweig & Huffstutter, 2004).
- ✎ Benefits: Improved access to formal benefits and flexibility, informal support from supervisors and coworkers, reduced stress (Ellison, Russinova, MacDonald-Wilson, & Lyass, 2003; Rosenzweig & Huffstutter, 2004).
- ✎ Risks: Increased courtesy stigmatization, coworker resentment, job insecurity (Rosenzweig, Brennan, Malsch, Stewart, & Conley, 2007).

## Parents Speak: FINDING A FAMILY FRIENDLY WORKPLACE

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- ✎ *“The strategy that I now have is to find an employer who is family friendly. I work for an airline and it provides me with great flexibility. I am able to trade shifts with other people to accommodate my needs. I also communicate more with my supervisor. Also, at the airline I don’t feel stigmatized.”*
  
- ✎ *“Having been in retail for the majority of my career, I mentally kept track of those companies that pay the best and offer the best benefits for the fewest hours.”*

## Parents Speak: RESTRUCTURING EMPLOYMENT

- ✎ *“I have had to leave a 12 month full-time job and take a lower paying position at school to be able to get his hours.”*
- ✎ *“My current strategy has been to quit my job and go back to school for medical transcription so I will increase my odds of being able to have a much more flexible employment situation.”*
- ✎ *“I work in a less demanding job. I work less hours than I otherwise would...at a job that allows me to choose which days I will work.”*

# Parents Speak: NEGOTIATING RECIPROACITY

- ✎ *"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 relationship 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."*

# Where do Professionals Fit in?

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- ✎ Ask questions about employment and work-life integration.
- ✎ Provide information about other parents' work/life experiences.
- ✎ Offer additional resources about work-life.



# Questions Professionals Can and Should Ask Families

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*Ask questions that encourage parents to discuss their employment situation and how it fits with caregiving for their child with an emotional or behavioral disorder.*

- ☞ Tell me about your job. What kind of work do you do? Hours that you work?
- ☞ How has having a child with an emotional disorder changed the type of job or career you have?
- ☞ How easy or difficult is it to for you to do your job and take care of your child with an emotional disorder?
- ☞ What is most stressful about maintaining employment and taking care of your child?

# Questions Professionals Should Ask About Work-life Integration

- Do you consider your workplace to be family-friendly?
- Does your workplace offer any benefits that help you meet family and work responsibilities?
- How much flexibility do you have at work to respond to the needs of your child during work hours? Could you leave if there was a crisis?
- What type of support do you receive from coworkers that helps you meet both work and family responsibilities?
- What type of support do you receive from your supervisor that helps you meet both work and family responsibilities?
- How much have you told your supervisor or coworkers about your family situation?
- What strategies have you used that are most helpful to fit work and family responsibilities together?

# Offer Guidance on Disclosure Decisions



- ✎ **Why and When?** Identify the goals, benefits, and risks of disclosure. List the pros and cons of different timing options: Never, During the interview process, When the job is secured, When a positive performance pattern is established, When a response to a non-crisis family matter is needed, When a crisis with your child occurs.
- ✎ **Who?** Identify whom you might tell. Think about how you might benefit from a specific person knowing and the possible consequences. Consider your options: No one, your employer, your immediate supervisor, a higher-level manager, one or more coworkers, human resource personnel, employee assistance program staff.

## Offer Guidance on Disclosure Decisions



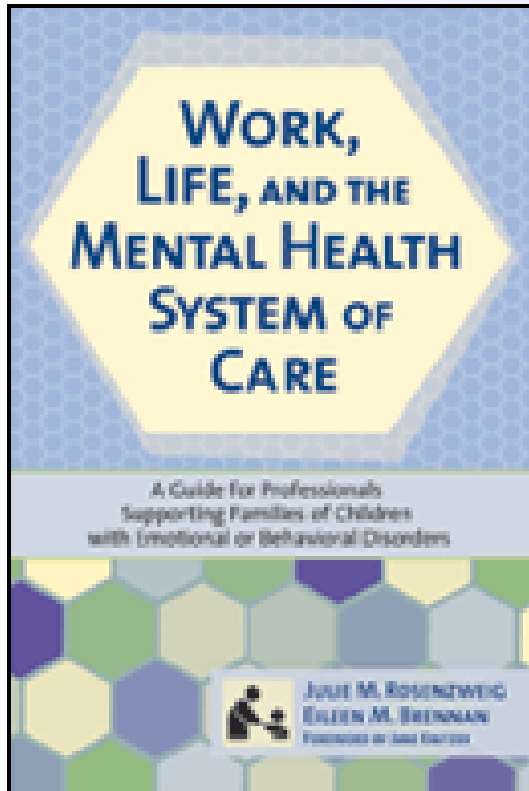
- ✦ **What?** Think about and rehearse what information you want to share. You can be general or specific about your child's situation. For example you might say that your child has a disability, a chronic illness, or a mental health disorder. Perhaps you prefer to name and explain the specific diagnosis, describe the behaviors involved, or identify treatments and supports required.
- ✦ **Confidentiality and Privacy.** Consider issues of confidentiality and privacy. Don't assume that the information will be held in confidence. Ask if the information will need to be shared or if it will be written down. Request that the information be held in confidence.

# Offer Guidance on Reciprocity Negotiation



- **Be Proactive.** Find out what options may be available if you need to flex your work schedule.
- **Offer Win-Win Solutions.** Make suggestions about possible arrangements. Identify benefits to the organization. Think about the unique skills you have to offer to the workplace as a direct result of your experiences as a parent of a child with mental health disabilities. Use them as bargaining power.
- **Demonstrate Commitment.** Follow-through on your agreement. Communicate your appreciation to supervisor and coworkers for their support.
- **Know Your Limits.** Be realistic about what you can and can not do. Reciprocity is mutually beneficial and should reflect equality.

## For More Information



Rosenzweig, J. M., & Brennan, E. M. (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.

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Center for Mental Health Services,  
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