

Caregiving & Employment: Workplace Challenges and Strategies for Parents of Children with Serious Emotional or Behavioral Disorders

Julie M. Rosenzweig, Principal Investigator

Kitty Huffstutter, Research Assistant

Common Ground? Families & Employers

Doctoral Seminar Presentation

Graduate School of Social Work

Portland State University

April 6, 2004



Research & Training Center on Family Support and Children's Mental Health

Portland State University, Portland, Oregon

Supported by:

National Institute on Disability and
Rehabilitation Research (grant # H133B990025),
United States Department of Education, and the

Center for Mental Health Services,
Substance Abuse and Mental Health Services
Administration.

Common Ground? Families & Employers

Project Goals:

- ✿ To understand and describe how parents' employment is affected when caring for a child with a mental health disorder.
- ✿ To identify employment strategies used by parents to manage employment and family responsibilities.
- ✿ To identify workplace practices and policies that support employees who are caring for children with special mental health needs.

Research Questions

- ✿ What are the employment characteristics from parents' perspectives that maximize work/life integration for employed parents of children with serious emotional and behavioral disorders?
- ✿ What do parents who are caring for children with serious emotional or behavioral disorders identify as workplace supports and barriers to obtaining and maintaining adequate employment?

Methodology

- ✿ Parent Employment Experiences Survey
- ✿ Participant recruitment and eligibility
- ✿ Qualitative analysis methods

The Parent Employment Experiences Survey

- ✿ Web-Based Survey
- ✿ 30 questions
 - ✿ 27 quantitative
 - ✿ 3 qualitative
- ✿ Participant recruitment through national family support organizations, two national conferences, & RTC National Advisory Committee members

Participant Eligibility

- ✿ Self- identified parents of children with emotional and behavioral disorders
- ✿ Currently caring for children in the home
- ✿ Employed, seeking employment, or unemployed by choice to care for their children with emotional or behavioral disorders

Participant Characteristics

N=349

- ✿ 322 women (94%)
- ✿ 83% European-American, 10% African-American
- ✿ Average age = 42.93, range 22-73
- ✿ Education: 34% “some college”, 25% “college degree”, 27% “graduate study or degree”
- ✿ 60% full time, 21% part-time, 19% unemployed
- ✿ 40% professional/technical, 16% executive/managerial, 12% administrative support
- ✿ Median income range = \$30,000-34,999

Family Characteristics

- Partner status: 61% partnered, 39% single
- 80% biological parent, 13% adoptive parent
- 95% caring for child 7 days per week
- 766 total children
- Mean number per family= 2.2
- Mean age of total children=12.46
- 60% of total children have serious emotional or behavioral disorder
 - 27% girls, Mean age= 13.1
 - 73% boys, Mean age=12.51

Problem Statement: Caregiving & Employment

- ✿ With child disability rates growing considerably, it is timely to examine the effect of caregiving on labor force participation (Powers, 2003).
- ✿ Parents caring for children with mental health disabilities experience unique challenges to obtaining and maintaining employment.
- ✿ Despite these difficulties, this population of parents have developed successful adaptive strategies to facilitate greater integration of work and family .

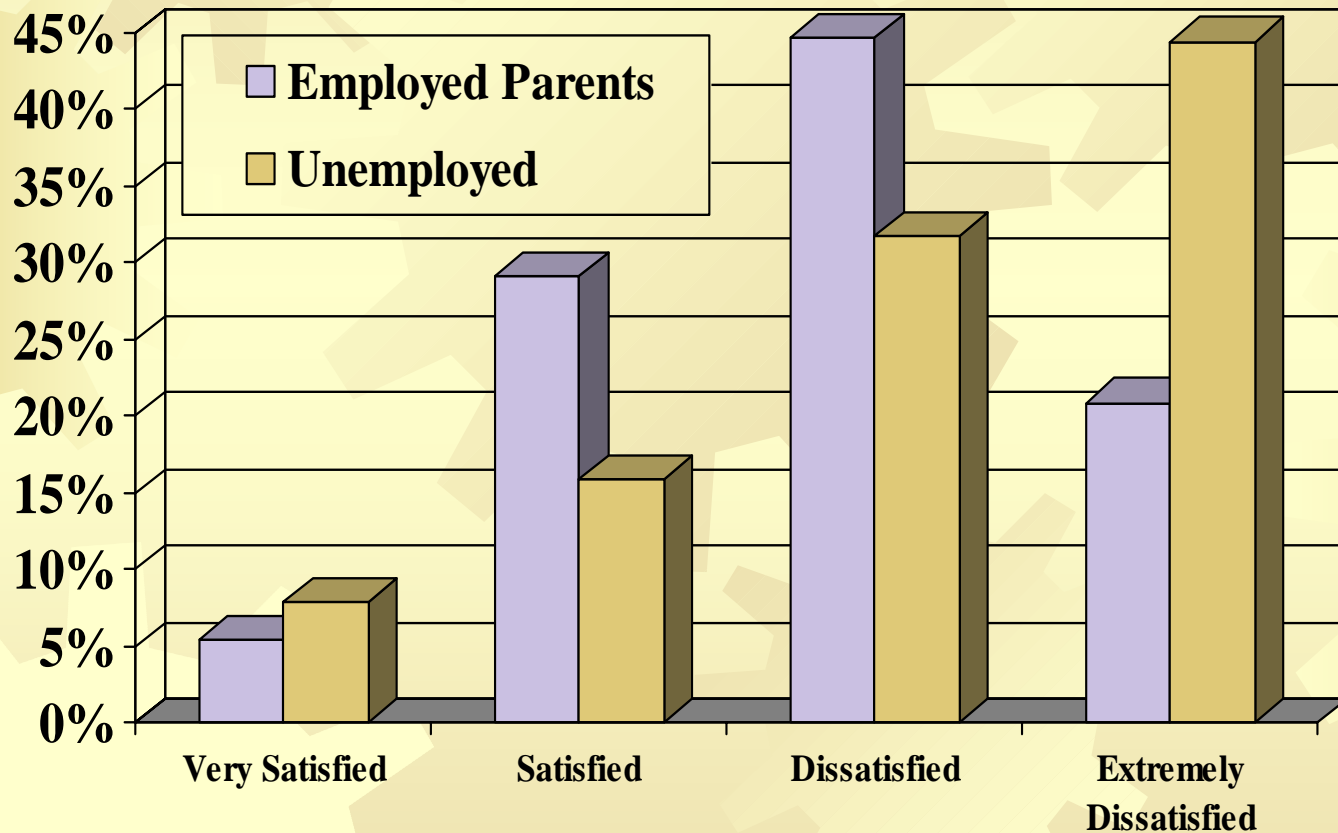
Effects on Employment

- ✿ 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

Participant Ratings: Work-Family Fit

- ✿ We asked, “How satisfied are you with your ability to meet both work and family responsibilities?”
- ✿ Overwhelmingly, parents reported dissatisfaction with the degree of work-family fit.
- ✿ Overall, 67% dissatisfied, 33% satisfied

How Parents Feel About Work-Family Fit



Qualitative Analysis Methods

- Thematic analysis- a process for encoding qualitative information according to patterns, or themes, found in the data that describe, organize or interpret observations (Boyatzis, 1998).
 - Two researchers generated codes based on themes emerging from individual responses to each question
 - Reviewed and revised codes
 - Defined and categorized codes

Employment Barriers

Parents were asked, “What have you personally found to be the most significant challenges/barriers to finding and keeping employment because you are caring for a child with emotional or behavioral disorders?”

✿ Four Categories:

- ✿ Inadequate Workplace Support
- ✿ Lacking Community Resources
- ✿ Limited Workplace Flexibility
- ✿ High-level Stress

Workplace Support

Workplace support incorporates flexibility in work arrangements, supervisor support, supportive workplace culture, positive coworker relations, respect in the workplace, and equal opportunity for workers of all backgrounds (Bond, Galinsky, & Swanberg, 1998).

What Parents Say About the Inadequate Workplace Support

- ✿ In general, parents surveyed noted a lack of “understanding” by their supervisors and co-workers about their family situation.
- ✿ Respondents also reported that traditional workplace culture and insufficient work/life policies deterred the necessary latitude needed to care for their children while meeting work responsibilities.

What Parents Say About Inadequate Workplace Support

- ✿ One parent explains that, *“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.”*
- ✿ Another parent states, *“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.”*

Lacking Community Resources

- ✿ The ***community context***, including both resources and demands, is a factor that assists or detracts from the efforts of workplaces, families, and individuals to support work/personal-life integration (Voydanoff, 2002).
- ✿ Respondents reported inadequate support from their children's school and a deficit in appropriate child care settings.

What Parents Say About Lacking Community Resources

- ✿ This parent asserts, *“Finding sources to help care for your child that are qualified, dependable, and affordable is difficult. Without those services, one cannot work.”*
- ✿ Another parent voices: *“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. Also finding child care with someone who can handle his severe rage outbursts and unpredictable behavior.”*
- ✿ One parent writes, *“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.”*

Flexibility

- ✿ **Flexibility** is the latitude to adapt working times and place to respond to family needs (Lewis, Kagan, & Heaton, 2000).
- ✿ A lack of community supports, such as child care & education, force parents to seek flexibility to accommodate their child's needs through employment adjustments (Rosenzweig, Brennan, & Ogilvie, 2002).
- ✿ The implementation of flexibility in the workplace largely depends upon the discretion of line managers (Yeandle, Wigfield, Crompton, & Dennett, 2002).

What Parents Say About Limited Workplace Flexibility

- ✿ A parent comments, *“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.”*
- ✿ Another parent agrees, *“[I] need to have the flexibility of working a different schedule each week without much notification to [the] employer regarding schedule changes. Until recently I had this benefit, but [the] current supervisor does not allow it any more.”*

High-level Stress

Many parents noted that the most significant challenge to work is the difficulty managing the stress of the multiple demands of caregiving while staying focused on the job.

What Parents Say About Stress

- ✿ One parent expresses the stress of *“the mental, emotional, and physical exhaustion I must continually deal with and still try to work.”*
- ✿ Another parent articulates, *“the most significant challenge was maintaining my productivity and concentration at work, while dealing with his often destructive and difficult behavior at home and school.”*

Work/Life Integration Strategies

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.

Employment Strategies To Increase Work/Life Integration

Participants were asked: “What strategies have you used to find and keep employment while you are caring for a child with emotional or behavioral disorders?”

Four major employment strategies identified:

- 1) Finding a job in a family-friendly workplace
- 2) Restructuring of employment
- 3) Disclosure in the workplace about child’s mental health status
- 4) Reciprocity and negotiation

Strategy:

Finding A Family-Friendly Workplace

A ***family-friendly workplace*** is one that acknowledges and responds to the work and family responsibilities of its employees. There are four interrelated components:

- ✿ Benefits, policies, and programs
- ✿ Workplace culture and climate
- ✿ Workplace relationships
- ✿ Work processes, systems, and structures that sustain family-friendly practices

(Pitt-Catsoupes, 2002)

What Parents Say About Finding A Family Friendly Workplace

- ✿ *“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.”*
- ✿ *Another parent explains, “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.”*

Strategy: Restructuring Employment

Faced with inflexibility of job demands or schedules and lack of child care resources, parents frequently must alter their employment or leave the workforce completely. Gaining job flexibility is a central focus in the restructuring strategy.

Restructuring strategies include:

- ✿ Relocation to another community to enhance job opportunities, child care options, or school programs
- ✿ Shift in career focus or type of employment, including self-employment
- ✿ Reduce number of hours employed, full-time to part-time
- ✿ Reschedule when and/or where hours are worked, including: flex-schedule, telecommuting, job sharing

What Parents Say About Restructuring Employment

- ✿ One parent's comments, *"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."*
- ✿ Many parents are forced to alter their careers altogether. This parent states, *"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."*
- ✿ Another parent shares, *"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."*

Strategy:

Disclosure about Child's Mental Health Status

- Disclosure is very individual and personal. Only the parent knows the scope of the family situation and the job situation.
- A parent's decision about whether or not to tell the supervisor or coworkers about a child's mental health disability is complicated and has associated risks and benefits.
- Benefits from disclosing may include increased support, improved work-family fit, increased use of benefits.
- Costs from disclosing may include: stigmatization, job insecurity, or job loss.
- Disclosure may made by choice or by necessity.

The Process of Disclosure

Disclosure is a ***process*** that requires careful consideration of several factors such as:

- ✿ **To whom to disclose** and how--supervisor, coworkers, human resources personnel, 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**

Participants' Disclosure

- ✿ 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

What Parents Say About Disclosure

- ✿ One parent explains, *“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.”*
- ✿ Another parents notes, *“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.”*
- ✿ This parent calls attention to the chance that employers may not understand when she says, *“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!”*

Strategy:

Reciprocity and Negotiation

- ✿ 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.

Workplace Reciprocity: Benefits and Costs

- ✿ 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

What Parents Say About Reciprocity

- ✿ One parent describes reciprocity when she states, *“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.”*
- ✿ Another parent explains the relational process when she says, *“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%.”*
- ✿ With respect to co-workers this parent notes that, *“I also offer to help co-workers in hope they can help when I need it.”*

Conclusions

- ✿ Employment strategies developed by parents are only one component of achieving work/family integration.
- ✿ Workplace supports through family-friendly culture, policies and practices that address the unique needs of parents caring for children with disabilities are essential for work/life integration.
- ✿ Community-based resources including inclusive child care providers and responsive schools are essential to enhance parents' participation in the workplace and the community.

Work/Life Integration for Families Caring for Children Who Have Serious Emotional or Behavioral Disorders

Research Agenda

- ✿ Disclosure decisions and the reciprocity processes in the workplace.
- ✿ Short and long term family adaptation stages in work/life integration.
- ✿ Employer-centered studies including: supervisors, coworkers, human resources, and EAPs.