Slide 1

Parents As Navigators: How Caregivers of Children with Mental Health Difficulties Find Supports in the Workplace

Portland, Oregon

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

www.rtc.pdx.edu

Presented February 23, 2006 at:
19th Annual Research Conference – A System of Care for Children's Mental Health: Expanding the Research Base, Tampa, FL

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Having your email lets us…

- Keep you updated on the progress of the work we're presenting today (and related news). We do this through monthly *rtcUpdates*.
- Evaluate our work and show our funders that what we do has an impact. We do this using very brief internet surveys.

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Slide 4

Work-Life Issues

- Employed parents having children with mental health difficulties must respond to the needs of the 24/7 workplace while also:
  – Arranging for and participating in planning their children's treatment;
  – Seeing that their educational needs are met; and
  – Providing nurturing child care.
- In a recent survey, 48% of parents of children with emotional or behavioral disorders had quit work, and 27% had been terminated due to work disruptions due to care responsibilities (Rosenzweig & Huffstutter, 2004).

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Family Support is Often Lacking

- Because of caregiving and employment demands, parents need to seek support to meet their responsibilities (Brennan, Rosenzweig, Ogilvie, Wuest, & Shindo, in press).
- In many communities there is a serious gap between what families need and the services and resources provided (Heymann, 2000).
- Today's presentation focuses on the ways in which parents function as navigators, using strategies to gain the supports that they need in challenging environments.

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Slide 6

Parents' Experiences of Work-Life Integration

Marlene Penn

A plea from one of our parents: Please do not call these tough life experiences that we have had "stories"

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Building a New Dream

- As we move through our journey and come to believe that the care our child needs is a long term and spiraling process….career plans are dashed, some never begun.

- We build a new dream for our child and hope he'll just be OK, but perhaps not the happy successful child of our fantasies…We rebuild our career path with the same strength and determination

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Karen
School Board Administrative Assistant

- "They knew I depended on this job"

- "My daughter was getting sicker and sicker"

- "I needed 12 weeks family leave"

- "I did get that leave but then they didn't renew my contract…they said my problems were affecting the team.."

- "I took a temp job after that and spent much of the day e-mailing and instant messaging my daughter – She was unsafe – I would pretend I wasn't talking to her"

- "I have no confidence anymore I've never recovered"

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Susan
Career Journalist

- Single parent with 2 sons
- Impossible to meet the demands of the job, the mental health needs of her sons, and the real work of negotiating with the system parts
- Susan was hospitalized due to emotional stress
- Ultimately had 14 successful years in a "safe" work environment with a manager who himself was one of "our" parents – She credits the Management for the success and survival of her family

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Work-Life Integration Project

- Seeks to identify levers of change in the workplace and community:
  - Workplace Awareness. Increased awareness and knowledge of the experiences of employed parents of children with emotional or behavioral disorders for HR professionals and co-workers.
  - Workplace Supports. Improvement in the capacity of the workplace to support work-life integration of these parents.
  - Family Access to Support. Greater awareness of and access to employment-based supports for families that promote participation in the workplace and community life.

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Work-Life Integration Project

- Project components:
  - Caregiver workforce participation study (Brennan & Brannan, in press)
  - Focus groups
    - Parents
    - Human Resource (HR) professionals
  - National HR survey
  - Pilot training
  - Resources for families and employers

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Key Concepts

- *Work-life integration*
- *Flexibility*
- *Disclosure*
- *Stigma*

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Work-life Integration

- 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 at times the amount of time spent in either domain will be different across different stages over the life span

— Rapoport, Bailyn, Fletcher, & Pruitt, 2002

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Flexibility

- Flexibility is a cross-domain concept: workplace flexibility, family flexibility, and childcare flexibility are necessary to maximize work-life integration (Emlen, 1999).
- Employee-driven workplace flexibility permits family members to have a degree of autonomy to control work location, timing, and/or process (Kossek, Lautsch, & Eaton, 2005).
- Workplace flexibility can be either formal and informal (Eaton, 2003):
  - Formal flexibility is approved by HR professionals and written into organizational policy
  - Informal flexibility is not documented as policy, but available to some employees based on supervisory discretion

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Disclosure

- Disclosure of child's mental health status at work comes with risks and benefits.
- Benefits include greater support, such as social support or formal supports such as flexibility, and in some cases protection from job loss.
- Risks include negative reactions from supervisors or co-workers and the potential of job insecurity or job loss.

— Rosenzweig & Huffstutter, 2004

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Stigma

- Mental health stigma refers to, "a cluster of negative attitudes and beliefs that motivate the general public to fear, reject, avoid and discriminate against people with mental illness" (President's New Freedom Commission on Mental Health, 2003).
- Courtesy stigma (Goffman, 1963) refers to mental health stigma applied to family members and others associated with the person with mental illness (Corrigan & Kleinlein, 2005).

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Research Questions

- *What are the employment based strategies used by family members of children who have emotional disorders that increase work-life integration and reduce workplace barriers?*
- *How do family members collaborate with supervisors and human resources professionals in their workplace to combat barriers, and to secure resources and benefits they need?*

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Methods: Sampling

- Purposive sampling (Patton, 1990)
- Goal to reach employed family members from a variety of employment contexts and varied experiences
- Recruitment through parent support and advocacy networks and RTC website
- Information provided about study and invitation to contact research team with questions or to sign up for study

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Methods: Procedures

- Focus group discussion topics derived through prior research and literature reviews.
- Prior to start of group, informed consent collected and demographic questionnaire administered; permission to tape session obtained.
- Protocol began with more general questions to familiarize participants with the topic, then proceeded to more specific questions (Kreuger, 1997).
- Moderators supported discussion and probed to clarify information or deepen the conversation (Kreuger, 1998).

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Methods: Analysis

- Systematic coding process using grounded theory approaches
- Open coding by three researchers working independently
- Preliminary coding and agreement established through meetings of research team to discuss and compare interpretations
- Secondary/axial coding focused on establishing substantive themes and relationships among them (Strauss & Corbin, 1998)

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Results: Participants

- 5 groups of female caregivers (N = 28).
- Mean age = 41.5 (SD = 9.1)
- Median family income between $30,000 and $39,000; 57% high school diploma.
- 59 dependents, 43 (75%) w/EBD
- 54% shared parenting duties w/partner
- 54% White, 15% African-American, 7% Hispanic
- Hours per week spent in care = 5-83; in work =7-60
- 68% had benefits, mostly flex (79%), sick leave (75%), vacation (71%), medical leave (64%), and health insurance (61%)

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Results: Themes

- Five themes emerged from analysis of focus group data:
  - Communicating at the boundaries of work and family
  - Managing flexible work arrangements
  - Handling crises
  - Negotiating informal work supports
  - Navigating the formal benefit system

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Communicating at the Boundaries of Work and Family

- **Disclosure was used to obtain supports and manage expectations. Family members carefully, intentionally managed the communication about their caregiving.**

  One parent explained that, "*I think one of the most important things was when we get to a place where we understand what our needs are and before we jump to a new job, that we are able to clearly put out on the table what our limitations are, or what considerations and flexibility we need.*"

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Communicating at the Boundaries of Work and Family

- Some parents practiced self-censorship, and disclosed only what supervisors and co-workers needed to know at a certain time.

  A mother said: "*I try to limit what I tell people in the workplace, mostly for self preservation.*"
- Several parents discussed the workplace chill that could result from full disclosure, and their experience of courtesy stigma.

  "*When my problems kind of first started with my boys, my boss was good about letting me off, but they always made me feel like they were looking down on me….They didn't have problems like that in their family, and I think they really frowned on me… They would say, here she is, having trouble with these kids again.*"

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Managing Flexible Work Arrangements

Flexibility was necessary to meet care needs and work responsibilities.
- Parents valued "*being able to take the time off to do whatever it is I am needing to do for my child.*"
- They reported flexible work scheduling, being allowed to work from home, telecommuting, and shifting job duties.

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Managing Flexible Work Arrangements

Flexibility can come with a downside
- One parent noted, "*I found you do the flex-time…being able to flex your hours. The downside is that you have to leave so often that you are flexing time enough that you are starting at 6:00 in the morning and finishing at midnight. Sometimes that part is really difficult. At the same time, it allows the time to be able to address things like children's therapy sessions or even for school.*"
- "*If I would have accepted the half-time position, it would have cut my benefits in half, so I would have had half as much vacation, half as much sick, qualify for less FMLA.*"

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Handling Crises

Parents managed crises utilizing problem-solving: drawing on resources from work, family members, and schools.
- One parent described her crisis plan: "*When my son's school calls, they, of course, say who they are and whoever answers the phone gets me immediately, because they know my situation. Typically I assess what's happening. I find out what the problem is, find out why my options are with the school—whether he is suspended, restrained, what the situation is. Then I go from there.*"

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Handling Crises

- Disclosure was used to let employers know the need for flexibility in crises:
  "*Before I became employed in this last job, I just let them know right up front that I was on a one-to-one basis with the police, one-to-one basis with the emergency room, one-to-one basis with almost anybody who would be emergency personnel, the principal also.*"
- Crisis plans involved having school personnel step in when other staff couldn't manage, having the other parent respond, and obtaining coverage from co-workers.

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Negotiating Informal Work Supports

Informal supports are negotiated with understanding supervisors and co-workers, through arranging **coverage** when needed, allowing the parent to respond to crisis.
  "*If I have to leave work immediately, there are designated people that I talk to and that I trust, that I know will inform the other people that need to know, like my supervisor. I can tell my desk partner and she will sign me out and then she will talk to a couple of other people just to make [sure] that the key staff that is affiliated with my job know that I am on my cell phone right now.*"

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Negotiating Informal Work Supports

- Being a valued employee with a history of high levels of performance helped establish **worthiness**:
  "*When I get back to business, I am going to get the job done…and I give it everything I can.*"
- A few participants also mentioned facing **backlash** from resentful co-workers who were unhappy about the employee's absences and having to cover for them.
  "*I feel like I've already asked for too much and don't want to keep pushing it.*"

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Navigating the Formal Benefit System

Employee Assistance Programs (EAP) helped access community supports and insurance helped in accessing treatment.

- One parent commented on the benefit of EAP: *"I worked for government, so I had the advantage of an employee assistance program, that actually helped us initially try to sort out between behavior and a mental health issue, which was real helpful."*
- Another parent stressed the help of insurance: *"I think that probably the benefit of finally getting him on the insurance is a huge benefit to us, being able to access medical and psychiatric care through my health insurance through my employer has been a great benefit."*

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Navigating the Formal Benefit System

Formal benefits included sick leave for short-term issues, FMLA for extended crises, and intermittent leave through FMLA.

"When I had to tell my supervisor we all gathered and we went to human resources and they did support me. They gave me, instead of giving me family leave, they gave me leave whenever I can or whenever I wanted to, when the school called."

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Conclusions

- Parents navigate the boundaries of work and family (Kossek et al, 1999) through using specific strategies:
  - disclosing their child's emotional or behavioral challenges to achieve necessary supports, and
  - managing crisis through specific steps, with associated costs and benefits
  - Seeking out formal and informal supports
- Managing communication boundaries by disclosure led both to experiences of
  - co-worker and supervisor support and
  - courtesy stigma (Corrigan & Kleinlein, 2005)
- Stigma reduction efforts are needed in society in general (President's New Freedom Commission on Mental Health, 2003), but specifically in the workplace.

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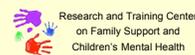Support and Children's Mental Health

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Conclusions

- Flexibility, while needed by families, can also come with the price of long days and associated exhaustion, and reducing hours to the point of benefit loss. Paid leave could help to alleviate some of the downside of flexibility.
- Further support is needed—through collaboration between schools, employers, and systems of care—in order for employed family members to achieve a functional level of work-life integration.

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A final word from a family member

- *"I would like for employers* [to know]*… that most caregivers that have children with special needs…because they have to navigate through so many things in life, they are the hard workers. They are the ones that know how to pick up and carry on and make sure that things get done…so they are a valuable employee for companies."*
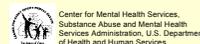
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NIDRR National Institute on Disability and Rehabilitation Research, U.S. Department of Education