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Experiences of Parents of Children with Mental Health Disabilities

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Families in Context: Work-life Integration Experiences of Parents of Children with Mental Health Disabilities

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Problem Statement

- It is estimated that 20% of US households have a child with special health care needs (Child and Adolescent Health Initiative, 2003).
- Despite these numbers, few studies examine the work-life integration experiences—challenges & strategies—of families with children who have special needs (Lewis, Kagan, & Heaton, 2000) particularly children with mental health disabilities.
Children’s Mental Health Disabilities

- About 20% of children & adolescents experience the signs and symptoms of a mental health disorder during the course of a year, while 5% of all children have what is called a serious emotional disturbance (US Department of Health & Human Services, 1999).

- Serious emotional disturbances are “diagnosable disorders in children and adolescents that severely disrupt daily functioning in the home, school, or community. Some of these disorders are depression, attention-deficit/hyperactivity, anxiety, conduct, and eating disorders” (Substance Abuse and Mental Health Services Administration).
Children’s Mental Health Disabilities: What does it mean for a parent’s work-life?

Tamara is a single mother of two children: Shandra age 10 and Maliq age 6. She recently obtained full-time work at a childcare center. Tamara has been receiving frequent calls from Maliq’s teacher & after-school daycare requesting that she pick him up for disruptive behavior. Tamara has not told anyone at work about her child’s mental health condition; yet, she is needing more time off in order to attend school meetings and doctor’s appointments held during regular business hours to get support for his condition.
Major Research Questions

- What are the challenges experienced by employed parents of children with mental health disorders and how do they achieve a fit between their work and family responsibilities?
- What do these employed parents identify as workplace supports and barriers to obtaining and maintaining adequate employment?
- How can children with mental health disorders be successfully cared for in child care settings, and to what extent does child care serve as a support for their employed parents?
Research Program

- **Support for Working Caregivers Project** (1996-1999)
  - 5 Focus groups with parents (N=41)
  - In-depth interviews with parents (N=60)

- **Models of Inclusion in Child Care** (1999-2004)
  - Intensive interviews with staff and center directors at inclusive centers (N=49)
  - Intensive interviews with parents of children at inclusive centers (N=40)
  - Intensive interviews of state administrators of child care (N=24)
Research Program

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

- **Work-Life Integration for Families With Children and Adolescents Who Have Emotional or Behavioral Disorders** (2004-2009)
  - Secondary analysis of data from the National Evaluation of the Comprehensive Community Mental Health Services for Children and their Families Program
  - Focus groups: parents employed in Fortune 1,000 organizations, HR professionals located in Fortune 1,000 organizations
  - Survey using a random sample of 5000 members of a human resource professional organization
  - Training for HR professionals to increase capacity to assist parents in work-life integration
Research Model
Key Concepts in Today’s Presentation

- Family Support
- Work-Family Fit
- Flexibility
- Community Integration
Family Support

- Federation of Families for Children’s Mental Health (1992) defines family support as a constellation of formal and informal services and tangible goods that are determined by families.
- The design and delivery of these services is intended to support family members to lead healthy, balanced lives that are not burdened by the child with a disability or the requirements of services designed to help (Friesen, 1996).
- Family-defined, family driven, and individualized to the unique needs of the family
Work-Family Fit

- According to Rosalind Barnett (1998), fit is “the extent to which the worker realizes the various components of her or his work/family adaptive strategy” (p.61).
- Encompasses the multiple tasks and decisions executed by the employed parent in relation to personal, community, and societal variables to achieve a sense of accomplishment and meaning in blending work and family life.
- For parents caring for children with mental health disabilities, the adaptive strategy is a fluid process, modified, sometimes daily, in relation to the child’s mental health needs, availability of community resources, and the prevailing attitudes in service and employing organizations.
Flexibility

- Flexibility is a cross-domain concept: work-flexibility, family flexibility, and childcare flexibility are necessary to maximize work-family fit (Emlen, 1999).
- Traditional flex-work arrangements are only one resource in the family/work/childcare system for families caring for children with special needs.
- A lack of community supports, such as childcare and education, force parents of children with emotional or behavioral disorders to accommodate their child’s needs through employment adjustments.
- Additional flexibility within community-based resources: schools, transportation, human services, are necessary to facilitate family development and functioning.
Community Integration

- Encompasses physical space in which families are located as well as relationships and resource accessibility which impacts a families ability to participate fully in community life and roles.

- Full integration and participation of families in community life is not limited to the role of consumer, but includes decision-maker in the domains of policy and practice.
Major Research Findings

- Work-Life Integration
- Employment Supports
- Child care supports
Work-Life Integration: Challenges

- Major challenges to work-life integration include
  - employment adjustments
  - childcare arrangements
  - inadequate educational resources,
  - inadequate transportation
  - few resources to help with home management
  - lack of community-based supports and services
Work-Life Integration: Supports

- Structural arrangements of parenting and work (full-time vs. part-time) are related to job stress, relationship and work rewards and satisfaction with handling family responsibilities

- Work-family fit is significantly related to family flexibility and family support

- Family flexibility, family support, and work-family fit were predictive of job rewards and family concerns
Employment Barriers

- Barriers to adequate employment include:
  - insufficient workplace support
  - lack of relevant community-based resources
  - limited flexibility
  - personal stress

- Despite high levels of work-based flexibility and workplace support, the majority of parents dissatisfied with their level of work-family fit.
Employment Supports: Strategies

- Work strategies for securing employment to fit with care include
  - seeking jobs in family-friendly organizations
  - restructuring career and employment
  - disclosure about child’s mental health status
  - reciprocity negotiation with supervisors and co-workers
- Supervisor and co-worker relationships were critical to flexibility
Childcare Barriers

- Arrangements are complex and varied
- Rarely provided outside the home or school, or by extended family members
- Costly when available
- Childcare difficulties = limits on work hours = stress in families
Childcare Supports: Inclusive Centers

Inclusive centers share key principles and strategies in how they approached childcare:

- Philosophy of inclusion that informed policies and practices
- Directors and staff demonstrated a continuing commitment to working with children and families to promote success
- Close relationships with local specialists to provide staff with additional services and consultation in support of their inclusive efforts
- Parents reported that inclusive centers supported their ability to work and maintain access to economic resources upon which they depended
Key Conclusions

- Parents of children with emotional or behavioral disorders report significant difficulties in their efforts to combine their work and family responsibilities.
- These parents contend with caring for a child with challenging behaviors in a context of inadequate resources, and paucity of family, workplace, and community supports.
- Although some parents are able to make the accommodations necessary to maintain employment, this may be accompanied by significant loss, and adverse personal and family outcomes.
Key Conclusions

- Community-based inclusive childcare models and best practice principles are possible and need national, state, and local policy support.

- Parents, when provided support, will create innovative and effective strategies that allow them to meet their family’s unique set of needs, participate in the workforce, and fully function as community members.

- More complex theoretical models that recognize the interdependence of work, family, and community, are required to advance our understanding and develop new service approaches in a context of increasingly diverse families and rapidly changing work.
Community Implications

Without support, efforts to combine work and family responsibilities when caring for a child with a mental health disability can produce adverse outcomes for children, families, & communities.

Many parents are forced to reduce work hours, alter careers, or depend on complex and precarious childcare arrangements in order to maintain employment resulting in reduced family income, less access to benefits, lower job satisfaction, and increased family stress.
Community Implications

- Organizations lose valuable employees and experience diminished productivity (Major, Cardenas, & Allard, 2004).
- Families are unable to participate in social, leisure, economic, and community activities that are integral to health and well-being.
- Exclusion of families from full participation contributes to the public remaining unaware of children’s mental health problems (Wahl, 2003), and the stigma experienced by individuals who have mental health disabilities and their families (Corrigan & Miller, 2004).