Parents as Navigators: How Caregivers of Children with Mental Health Difficulties find Supports in the Workplace

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Introduction

For some parents, the gap between the demands of work and family and the resources they have available to meet these responsibilities is too great, particularly for employed parents of children with emotional or behavioral disorders (Brennan & Brannan, 2005). While responding to the increasing demands of the workplace for dedicated performance and significant face-time, parents must also arrange for their children’s treatment, see that their educational needs are met, and provide enrichment opportunities in the community (Huang et al., 2005). Despite challenges, these parents have used creative approaches to “cobble together” flexible arrangements that work for both their families and employers (Rosenzweig, Brennan, & Ogilvie 2002). We report the results of six focus groups of employed parents of children with mental health difficulties. This research was conducted as part of a federally funded five-year research project investigating work-life integration for this group of families. Two major research questions guided our analyses of focus group transcripts:

1. 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?
2. How do family members collaborate with supervisors and human resources professionals in their workplace to combat barriers, and to secure the resources and benefits they need?

Method

Purposive sampling (Patton, 1990) was used with the goal of reaching employed family members from different employment settings and with varied experience. Participants were recruited through parent support and advocacy networks, and through the Research and Training Center on Family Support and Children’s Mental Health website. Information was distributed with an invitation to contact the research team with questions and to sign up for the study.

Twenty-eight female family members, with a mean age of 41.5 years (SD = 9.1), and a median family income between $30,000 and $39,000, participated in the research. Family members cared for a total of 59 dependents, of whom 43 (75%) had emotional or behavioral disorders. Approximately half (54%) shared parenting duties with another adult. Participants were generally European American (68%), and had a high school diploma as their highest level of education (57%). Other ethnic groups represented were African-Americans (15%), and Hispanics (7%). Parents reported spending between 5 and 83 hours per week in care activities, and between 7 and 60 hours in paid work. Of those who reported a job with benefits (68%), most had flexibility (79%), sick leave (75%), vacation time (71%), medical leave (64%), and health insurance (61%).

The selection of topics for discussion in the focus group was informed by the results of the project team’s previous research, and a review of the literature. Topics addressed were availability and use of formal and informal workplace support, dealing with crises related to their child during work hours, communication in the workplace about family needs, and suggestions to improve work-based support for parents.

A focus group script prepared in consultation with project advisors, was used to guide the discussion in each of the six groups that were held in the same city in the Pacific Northwest. Researchers welcomed participants, introduced the study, addressed participant questions, and followed procedures for informed consent. Prior to the focus group discussion, participants completed a short questionnaire to collect demographic, job-related, and caregiving information. During the 60-minute audio-recorded focus
groups, participants were encouraged to share their individual experience and to build on the discussion of the other family members. The focus group moderators supported the discussion and used probes to clarify responses as appropriate (Krueger, 1998).

Transcripts were prepared from the taped focus group discussions, and the text was entered into NUD*IST (Qualitative Solutions and Research Pty. Ltd., 1993) to manage the qualitative coding and analysis. Qualitative data were coded systematically using an iterative approach, beginning with a careful reading of each transcript by two or more researchers working independently. The identification of preliminary codes was followed by meetings of the research team to discuss and compare interpretations of the first level of data coding, and to develop more substantive coding based on themes.

Results

Five major themes emerged from our analysis of focus group transcripts: (a) communicating at the boundaries of work and family, (b) managing flexible work arrangements, (c) developing and carrying out crisis plans, (d) attaining informal workplace supports, and (e) navigating the formal benefit system.

A primary issue for participants was how much they should communicate to their supervisors and co-workers regarding their children's mental health difficulties. Some decided on full disclosure, even in the initial job interview, so their need for flexible work arrangements would be well known. Other participants practiced self-censorship, disclosing only what supervisors or co-workers needed to know at a particular time. "I try to limit what I tell people in the workplace, mostly for self-preservation." Repeatedly, parents spoke of the stigma they encountered in the workplace, reporting worries about the workplace chill that could result from full disclosure, and their fear of negative evaluations.

Parents discussed disclosing enough about their situation to obtain workplace flexibility: "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, working from home, telecommuting, and shifting job duties. For some flexibility came with a price: exhaustion after working for extended hours to compensate for work interruptions the previous day, being taken advantage of by school personnel who called on them to manage their children's problems, and reducing work hours to the point that they lost benefits.

Flexibility was made necessary for many of the participants by the crises brought about by their children's acute emotional or behavioral difficulties in childcare or school settings. "That...was the most difficult thing, because when a crisis does come up, it is hard to leave [work]." Crisis plans involved: having school personnel lined up to step in when other staff could not manage, having the other parent respond if the participant could not leave work, and obtaining coverage from co-workers so that the parent could take care of the child's immediate needs.

Informal workplace supports made it possible for some to hold paid employment. Understanding co-workers gave moral support, covered for each other in times of greatest need, and even let the parent bring the child to work. Supervisors also provided support through flexibility, arranging coverage, and allowing the parent to respond to crises. "[My boss said]...Any time you need to take time off, we understand." In a few cases, participants mentioned that they faced backlash from co-workers who resented providing coverage.

Finally, the parents discussed their search for formal supports, sometimes through human resources professionals. They took advantage of sick leave to care for children with short-term problems, the Family Medical Leave Act to assist their children in extended crises, and when acute episodes went on for a period of months, used intermittent leave. Employee Assistance Programs were used for counseling or referrals, and insurance was used to provide access to treatment for their child for a limited time. Participants spoke about their gratitude to other parents who helped them use formal work supports to their greatest advantage, and one mother labeled this assistance as "peer advocacy for navigation."
Conclusion

The results of this research make an important contribution to our understanding of parents’ experiences of work-life integration when they care for children with mental health needs. These data indicate that the stigma associated with mental illness in the family (Hinshaw, 2005) has a profound effect on the experiences of employed family members. Stigma leads to communication barriers and reduced access to resources and support. It is clear that in addition to redesigning workplace supports to meet dynamic needs of families, other changes are necessary. Stigma reduction efforts are required to increase understanding of how children’s mental health affects family and work life. It is also important to examine ways in which schools and employers might collaborate to create more supportive arrangements for families, and new ways in which service providers in systems of care can support families in their efforts to engage in paid employment.

References


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