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Taking it on: Disclosure, Stigmatization, and Self-Esteem

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SESSION 07:

Taking It On: Disclosure, Stigmatization, and Self-Esteem.

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Background and context

Employed parents of children with emotional or behavioral disorders face many potential challenges when striving to find balance between their work and family responsibilities. While responding to the demands of the workplace, they must also attend to the unique caregiving needs of their children such as facilitating on-going treatment, responding to frequent emergencies, and arranging adequate child care (Rosenzweig, Brennan, Huffstutter, & Bradley, in press). These parents often develop strategies to gain the flexibility at work they need in order to care for their child while still maintaining a high level of job performance (Rosenzweig, Brennan, & Ogilvie 2002). Whether parents are successful in achieving this balance often depends on the culture of their workplace, the decisions they make regarding whether and how much to disclose about their child's situation, and the stigmatization they may encounter as a result of this disclosure. In this presentation, we reported 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. Our analysis focused on the parental experiences in the workplace and on the interrelationships between workplace culture, decision-making regarding disclosure, stigmatization, and workplace support. Six research questions guided our analysis.

1. How do parents experience stigmatization in the workplace?
2. Why do parents disclose or conceal their children's mental health challenges?
3. What are the workplace factors that encourage or inhibit parental disclosure of their children's mental health status?
4. What are the stigmatization management strategies used by parents in the workplace?
5. What effect does parental disclosure of children's mental health status in the workplace have on their experience of stigmatization?
6. What effect does parental disclosure have on their experience of workplace support?

Methods

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.

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 held in the same Pacific Northwest city. 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 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.

Findings

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 women in the focus groups shared with us the characteristics of their workplaces and their experiences with disclosure, stigmatization, and workplace supports. From our analysis of the focus group transcripts, we developed a conceptual model that illustrates a possible set of relationships between these themes (see Figure 1).
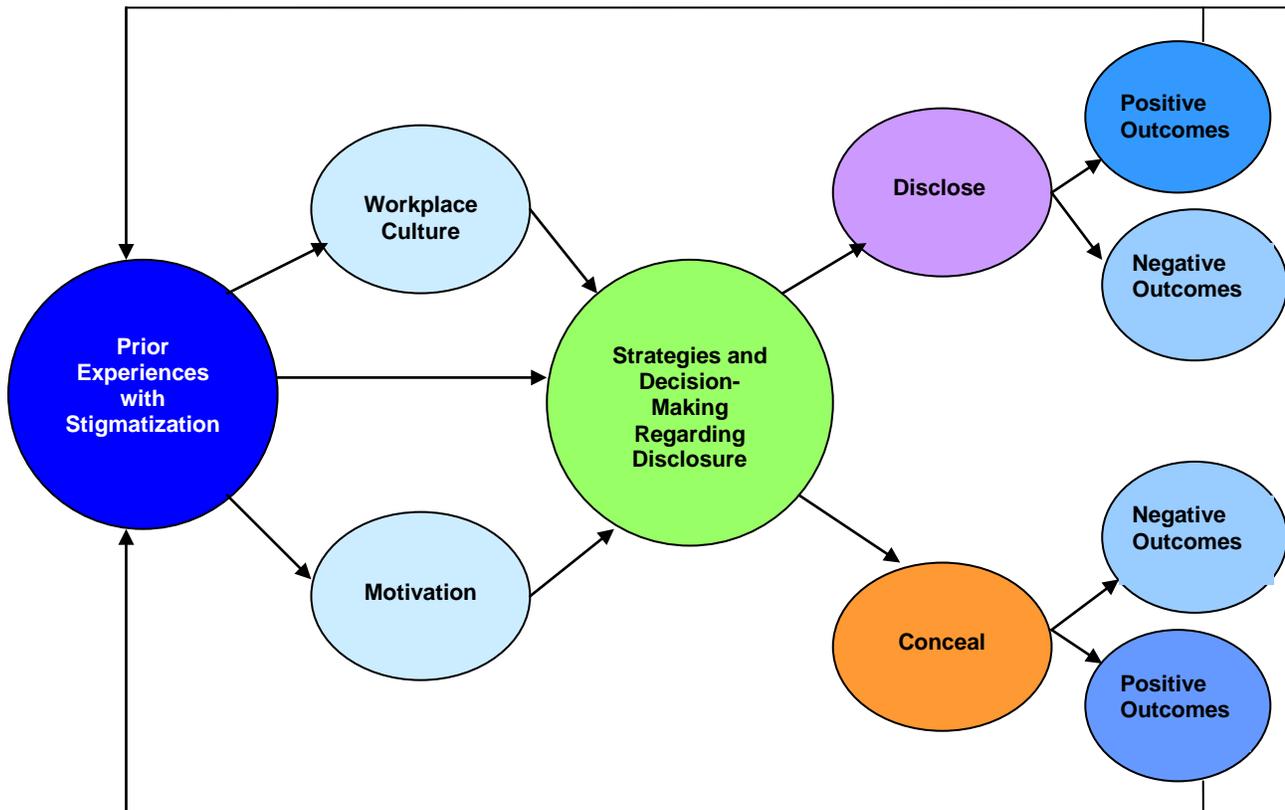
The conceptual model reflects pathways that a parent may navigate when evaluating and choosing certain strategies to manage their work and care giving responsibilities, moving from left to right and starting with a parent's previous experiences with disclosure and stigmatization, the culture of their current workplace, and their own motivation as factors influencing their decision to disclose or conceal their child's mental health status. This decision can result in both positive and negative outcomes.

Prior experiences with stigmatization and disclosure. Participants spoke of their varied experiences with disclosure and stigmatization, both in previous and current workplaces, as well as in society in general. Participants experienced *direct stigmatization*, in which they were blamed for being a bad parent or were discredited professionally because they were seen as incapable of controlling their child's behavior. They also experienced *indirect stigmatization*, in which they observed differential treatment towards others who also had a child with mental health challenges. In addition, parents spoke of their own *perceived stigmatization*. In this case parents assumed that they were being stigmatized even if it was not explicitly occurring. It reflected feelings, assumptions, and anticipation of stigmatization. Finally, *indirect stigmatization* was expressed by participants through their own feelings of inadequacy related to their professional capacity and parenting skills. Stigmatization that is *indirect* refers to participants' awareness of stigmatizing attitudes and their own application of these negative attitudes to themselves.

Workplace culture. The culture of the workplace played a significant role in how participants experienced stigmatization and whether they decided to tell others about their child's situation. Parents described that their decision to disclose, and the consequences of this disclosure, depended on the level of *family-friendliness* of their workplace. For example, parents felt more comfortable sharing their situation in workplaces which acknowledged and

respected the family roles of their employees, and who had policies in place to help employees balance their work and family responsibilities.

Figure 1: The relationship between stigmatization and parental disclosure of a child's mental health status in the workplace.

Prior Experiences with Stigmatization

Workplace Culture

Motivation

Strategies and Decision-Making Regarding Disclosure

Disclose

Conceal

Positive Outcomes

Negative Outcomes

Negative Outcomes

Positive Outcomes

Motivation. Participants described many different reasons for why they decided to tell or not to tell about their child's mental health challenges. Some parents said they decided to tell their supervisor about their child in order to gain some of the formal supports available such as a flexible work schedule or family medical leave benefits. Other parents decided to disclose because they had no choice: a crisis occurred and they had to leave work. Other times parents chose to tell in order to avoid their co-worker's resentment, reasoning that if co-workers knew *why* they were suddenly leaving work they would be more understanding and less resentful. Parents also expressed many reasons why they chose not to disclose. Two common reasons were the desire to have a normal working life and to escape their problems at home.

Strategies and decision-making regarding disclosure. Parents talked about their disclosure strategies ranging from full disclosure to total concealment (with strategies such as partial disclosure, self-censoring, and bending the truth in-between). They spoke about their decisions around how, when, and to whom to disclose. Some family members decided to tell

everyone at their workplace about their children's challenges. Another parent spoke of her concerns about telling enough to get the accommodation of taking personal phone calls, but not "*pushing the envelope.*"

Outcomes of Disclosure. Parents who chose to disclose their children's mental health status benefited by gaining access to formal supports, obtaining flexible work arrangements, receiving emotional and instrumental (practical) support from supervisors and co-workers, finding others with similar circumstances in the workplace, getting useful advice, and by having greater professional credibility on the job. However, parents also reported the following negative aspects of disclosing their situation at the workplace: suffering the emotional costs associated with being the recipient of stigmatization, getting unhelpful and unsolicited advice, raising equity concerns among co-workers (and consequently bearing the brunt of co-worker's resentment for perceived inequity), prompting scrutiny regarding job performance, and becoming fearful that they may lose their job.

Outcomes of Concealment. Parents spoke of several positive outcomes of their decision to conceal their child's mental health status. For example, by not disclosing at the workplace some felt they were able to have a more "normal" working life and that they were able to escape the challenging realities they faced at home. Deciding to conceal also led to being able to avoid stigmatization from co-workers. And finally, some parents felt that if they did not mention their situation, they would be more likely to gain or maintain employment. As with disclosure, there was a flip-side to concealment. Parents who concealed their situation were unable to access formal supports and workplace accommodations, and often felt isolated and alone in their struggle.

Conclusion and implications

The findings 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 challenges. The experiences of the focus group participants offer wide-spread implications for employers, families, and service providers alike. For employers, understanding that parental disclosure helps an employee set up arrangements to handle family challenges before they cause crises at work is critical. Creating a "family friendly" place of employment includes establishing an environment in which all caregivers are welcome to disclose their family needs and ask for the accommodations they require to be effective employees. To do this, workforces need training regarding diversity in their organizations to combat stigmatization of both adults and children affected by mental health challenges.

The findings of this study have implications for family members as well. First, when a parent of a child with mental health challenges is looking for employment, it is helpful to keep in mind that accommodation for one's care giving needs is most likely to be found in a family-friendly organization which has a supportive workplace culture. Second, when a parent is considering disclosing her child's mental health status (and the impact on her work responsibilities), she should carefully consider why, when, how much, and to whom to disclose.

Finally, there are implications of these findings for service providers. When working with families of children with mental health issues, service providers should ask them about their workplace situations and the types of challenges that they may face there. It is likely that these families would benefit from assistance working through stigmatization caused by disclosure and/or the isolation caused by concealment. Further, they may benefit from assistance with planning for disclosure and seeking the workplace supports they need to be successful in their jobs. Finally, service providers need to combat stigmatization of persons with mental health problems and their families through their professional organizations, and by joining with others who want to end this societal problem.

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