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Parents of Young People with Disabilities and their Work-Life Challenges

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Work-life challenges specific to families having children with mental health and other disabilities include:

- *Exceptional caregiving* responsibilities, which differ from typical caregiving responsibilities on several dimensions: time spent arranging care (13.5% of parents caring for children with special health care needs spent 11 or more hours per week coordinating care for their children), ongoing parental responsibilities which can persist throughout childhood into young adulthood or beyond, and more frequent, intense, and crisis-driven care needs (Child & Adolescent Health Measurement Initiative, 2012; Porterfield, 2002; Stewart, 2013).

- *Community integration,* reflecting the capacity of the family's social environment to support and sustain them physically, socially, and psychologically (Aubry & Myner, 1996; Jivanjee, Kruzich, & Gordon, 2007; Pledger, 2003; Salzer, 2006). When their children with mental health disabilities are refused entrance to, or are asked to leave, community-based activities, such as childcare, sports clubs, or church gatherings, parents also are excluded from the adult social networks that support these opportunities for community integration, clearly affecting the family's quality of life (Summers et al., 2005).

- *Stigmatization* based on a personal attribute that is culturally devalued or deemed inferior in comparison with social norms (Link & Phelan, 2001). Adults and children with disabilities experience prejudice, stereotyping, and discrimination that affect all areas of their lives, creating physical and social isolation, limiting opportunities to live fully integrated lives in the community. As well, their family members face *courtesy stigmatization* in many domains of their life, especially those where their children are involved such as community settings, mental health systems, and schools.

- *Disclosure,* revealing a child's mental health disability or special needs outside the family, is used by parents in the work domain as an employment-based strategy to enhance work-life integration, particularly the fit between their work and exceptional caregiving responsibilities (Rosenzweig & Huffstutter, 2004; Rosenzweig, Brennan & Malsch, 2009). Parents may choose to disclose as a means to increase access to much needed workplace support and enhance organizational and interpersonal support, but the disclosure may not be risk-free and may heighten stigmatization and job insecurity (Ellison, Russinova, Mac Donald-Wilson & Lyass, 2003; Huffstutter, et al., 2007).

- *Family support* is enlisted by parents: a constellation of formal and informal services and tangible goods that are defined and determined by families. It is "whatever it takes" for a family to care for and live with a child or adolescent who has an emotional, behavioral, or mental disorder. (Federation of Families for Children's Mental Health, 1992, p. 1), or more broadly a physical, sensory or developmental disability. For employed parents, Friesen has identified another goal of family support: to provide "comprehensive care for a child with a disability and assistance to the entire family, while helping parents and other caregivers function as productive and responsible employees" (Friesen, Brennan, & Penn, 2008).

Need for policy supports for families raising children with disabilities

- It is estimated that approximately 9% of employees in any given company are caring for a child with special needs (Center for Child & Adolescent Health Policy, 2004)

- The exceptional caregiving responsibilities and complexities of work-life challenges that are experienced by a significant number of working families of children with mental health disabilities are not recognized in major discussions of work and family conflicts.

- These families are often under intense stress and *caregiving strain*, as they adapt to their child's mental health care needs and disabilities (Brannan & Heflinger, 2001, 2006; Kendall & Shelton, 2003); the child's disability has been linked to marital distress and higher likelihood of divorce (Risdal & Singer, 2004, Rosenzweig & Kendall, 2008). Also, families may experience both *direct* and *indirect economic consequences*, often related to their opportunity to work (Brennan, Rosenzweig, Jivanjee, & Stewart, 2016).

- Comparisons of workforce participation rates for mothers of children with a variety of disabilities to mothers of children with typical development demonstrate the effects of exceptional caregiving demands on employment. Mothers of children with disabilities, including emotional and behavioral disorders, frequently report quitting their jobs, reducing the number of hours worked, or changing jobs to accommodate care demands (Brennan & Brannan, 2005; Freedman, Litchfield, & Warfield, 1995; Porterfield, 2002; Rosenzweig et al., 2002; Rosenzweig & Huffstutter, 2004; Brannan, Brennan, & Rosenzweig, 2016).

- Holden et al. (2002) also found that parents of children with mental health problems reported missing work or ignoring other activities because of their children's emotional or behavioral challenges. Qualitative studies of dual-earner families found that although most relied on two incomes, mothers typically adapted their work schedules in response to the care needs of their children with disabilities (Lewis, Kagan, & Heaton, 2000). The nature of the child's disability was a major factor influencing whether both parents could engage in full-time employment, particularly in families of children with emotional or behavioral disorders (Lewis, Kagan, & Heaton, 2000). Diminished maternal employment is more prevalent for single mothers of children with disabilities who must assume full responsibility for care, household chores, and paid work (Powers, 2003).

- Parents of children with mental health disabilities require *optimal flexibility solutions* (Emlen, 2010) that include flexibility from the multiple domains in the work-life equation. Policy change is needed to provide access of families raising children with disabilities to flexible work arrangements (Brennan et al., 2016).

- Workforce participation requires exploring flexible work options which may necessitate disclosing information about the child's mental health status (Rosenzweig & Huffstutter, 2004). Disclosing within the workplace places parents of children with mental health problems at risk for experiencing *double stigmatization*---professional competence discredited and parenting skills judged harshly (Rosenzweig et al., 2007).

- When parents of children with mental health disabilities disclose information to supervisors, they may be passed over for promotions, denied flexibility, or forced out of a position, triggering legal action on the basis of *family responsibilities discrimination* (Williams & Calvert, 2006).

- Community supports involving *inclusion* in child care, educational, transportation, recreational, and respite care arrangements and effective health and mental health treatment have implications for the ability of parents to engage in the workforce (Gilliam & Shahar, 2006; Rosenzweig & Brennan, 2008; Warfield 2005). However, family members may also have great rewards from parenting the child and have enrichment to their lives as they participate in community-based *peer support networks* (Kagan et al., in press).

- When *work-family-community fit* is not achievable through formal supports (including family-friendly policies), and informal supports (e.g., co-worker coverage at times of crisis), and sufficient community resources (Barnett & Gareis, in press), parents may become underemployed or exit the workforce (Brennan & Brannan, 2005; Brannan et al., 2016).

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