

## Parents of Children with Disabilities and Work-Life Challenges—Presentation Summary

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### **Prevalence of families having children with disabilities in US: Estimates vary by definition and source:**

- *Special health care needs* are broad and include children with "...a chronic physical, developmental, behavioral or emotional condition who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998, p. 138). According to the 2005-06 CSHCN survey (HHS, 2008), 13.9 % of children under 18 years of age, or approximately 10.2 million children in the United States have special health care needs. This number represents 21.8% of U.S. households with children. Prevalence estimates vary by race, gender, and age group.
- *Special needs* have generally been identified through the Individuals with Disabilities Education Act. Young children who have been diagnosed as having developmental delays, or any child who has been evaluated as having one of a limited list of disabilities specified in IDEA are considered as having special needs when they require special education and related services (20 U.S.C. 1401 and 34 C.F.R. §300.8). Nearly 7 million children with disabilities receive special education services under IDEA, including 270,000 infants and toddlers, 715,000 preschool-age children, and 6 million students from ages 6 through 21 (U.S. Department of Education, 2007).
- *Disability* is legally defined for an individual in the Americans with Disabilities Act of 1990 as a person having "a physical or mental impairment that substantially limits one or more major life activities" or who has a "record of" or is "regarded as" having such an impairment (29 U.S.C. § 705(2)(B)). Using a similar functional definition of disability, the U.S. Bureau of the Census (2000) estimated that 9.2% of households raising children had at least one child with a sensory, physical, or mental disability using strict criteria. Approximately 11% of children under 18 have mental health disorders severe enough to cause significant difficulty, yet only 20% of those receive the treatment they need (U.S. Surgeon General's Report, 2001).
- *Disability* can also be viewed theoretically as a function of the person in the environment (Brandt & Pope, 1997; Pledger, 2003) and as the "expression of a physical or mental limitation in a social context, the gap between a person's capabilities and the demands of the environment" (Pope & Tarlov, 1991, p. 1).

### **Work-life challenges that are specific to families having children with 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 (Lewis, Kagan, & Heaton, 2000; Porterfield, 2002; Roundtree & Lynch, 2006).
- *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 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. Family members may be subjected to discrimination and exclusion due to their association with the child with a disability (Corrigan, Markowitz, Watson, Rowan & Kubiak, 2003; Goffman, 1963).

- *Disclosure*, revealing a child's 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). 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; Rosenzweig & Huffstutter, 2004).
- *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, in press).

### Importance of Topic for Work Family Studies

- A large proportion of parents of working age have children with disabilities, and experience unique and intense work-life challenges, but are relatively *invisible* in major discussions of work-life integration.
- These families are often under intense stress and *caregiving strain*, as they adapt to their child's health care needs and disabilities (Brannan & Heflinger, 2001, 2006; Kendall & Shelton, 2003); the child's disability has been linked to higher rates of divorce (Risdal & Singer, 2004). Also, families may experience both *direct* and *indirect economic consequences*, often related to their opportunity to work (Lynch, 2007).
- Parents of children with disabilities require *optimal flexibility solutions* (Emlen, 2008) that should be of empirical and theoretical significance to work family studies, since they have cobbled together strategies at the limit of what can be done while maintaining employment (Brennan et al., 2007).
- Workforce participation requires obtaining flexibility through disclosing information that may trigger stigmatization and scrutiny. Possible *double stigmatization* may result from disclosure, when workers have professional competence discredited and parenting skills judged harshly (Rosenzweig et al., 2007).
- When parents of a child with 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, recreation, 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, in press; 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 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).