Parents of Children with Disabilities and Work-Life Challenges

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Basic Concepts and Definitions

The proportion of U.S. families raising children who have at least one child with a disability has been estimated by the U.S. Census Bureau (Wang, 2005), using a conservative definition of disability, at 9.2% and by the U.S. Department of Health and Human Services ([HHS], 2008), through questions identifying children with special health care needs, at 21.8%. Clearly, the actual percentage of families having children with disabilities is substantial.

Employed parents caring for children with disabilities often find the integration of work and family responsibilities very challenging (Kagan, Lewis, & Heaton, 1998; Rosenzweig, Brennan, & Ogilvie, 2002). Child care arrangements are hard to find and maintain, routine health care appointments must often be scheduled during parents’ workdays, children’s health or mental health crises can disrupt working hours in unpredictable ways, and special education arrangements must be established and updated. However, the necessary supportive community resources that help facilitate integration are usually tailored for families of children with typical development (Rosenzweig & Brennan, 2008). As a result, employers may lose the benefit of these parents’ valuable experience, knowledge, and skills when families cannot marshal the supports they need to take care of their children with disabilities while maintaining their employment (Powers, 2003; Rosenzweig & Huffstutter, 2004).

The terms *children with special needs* and *children with disabilities* are often used interchangeably. Historically, the concept of special needs has been associated with federal mandates regarding special education in public schools, especially the Individuals with Disabilities Education Act (IDEA). 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 that affect their learning and require special education and related services (20 U.S.C. 1401 and 34 C.F.R. §300.8). On the other hand, disability is a broader term more frequently associated with the Americans with Disabilities Act of 1990 (ADA). The legal definition in ADA of an individual with a disability covers adults or children with “a physical or mental impairment that substantially limits one or more major life activities” or who have a “record of” or are “regarded as” having such an impairment (29 U.S.C. § 705(20)(B)). Children with disabilities are alternatively served in the school setting by the development of a Section 504 plan provided through the Rehabilitation Act of 1973. Section 504 plans use a definition of disability similar to the ADA, because the children being covered have a condition that affects their ability to access learning (Holler & Zirkel, 2008). Disabilities can also be viewed in their social context 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). This definition is increasingly being embraced across the world through the conceptualization...
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of disability and health adopted by the World Health Organization (resolution WHA 54.21).

Parents of children with disabilities engage in *exceptional caregiving* responsibilities, which differ from typical caregiving responsibilities on several dimensions. Most importantly, family members spend a significant amount of time arranging care for their children with disabilities (HHS, 2008). Exceptional care needs of children with disabilities are ongoing, can persist throughout childhood into young adulthood or beyond, and are more frequent and intense than the care needs of children developing typically (Lewis, Kagan, & Heaton, 2000b; Porterfield, 2002; Roundtree & Lynch, 2006).

Paramount for children with disabilities is their right to *community integration*, the opportunity to live in the community, to be a full participant in education, recreation, housing, citizenship, and religion/spirituality, and to take on meaningful social roles (Salzer, 2006). The extent to which community integration is realized for individual children reflects the capacity of their social environments to support and sustain them physically, socially, and psychologically (Aubry & Myner, 1996; Jivanjee, Kruzich, & Gordon, 2007; Pledger, 2003; Salzer, 2006). Families may also face serious barriers to community integration, even experiencing exclusion from community-based activities due to their children’s disabilities. When their children are refused entrance to, or are asked to leave, community-based activities such as child care, 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* is a commonplace experience for persons with disabilities and their families. Due to stigmatization, adults and children with disabilities experience prejudice, stereotyping, and discrimination that affect all areas of their lives, creating physical and social isolation, and limiting opportunities to live fully integrated lives in the community (Goffman, 1963). As well, their family members face *courtesy stigmatization* (stigmatization by association) in many domains of their life, especially those where their children are involved, such as community settings, mental health systems, and schools. Family members have often reported being subjected to discrimination and exclusion due to their association with the child with a disability (Corrigan, Markowitz, Watson, Rowan & Kubiak, 2003).

Despite possible stigmatization, there are some parents who opt for *disclosure* and choose to discuss their child’s disability status within the work domain. Indeed, disclosure of a child’s mental health status within the workplace was identified by Rosenzweig and Huffstutter (2004) as an employment-based strategy to enhance work-life integration, particularly the fit between parents’ work and exceptional caregiving responsibilities. Parents may choose to disclose as a means to increase access to much needed workplace adaptations and to enhance organizational and interpersonal support, but the disclosure may not be risk-free and may heighten stigmatization and job insecurity (Ellison, Russinova, MacDonald-Wilson & Lyass, 2003; Huffstutter, et al., 2007; Rosenzweig & Huffstutter, 2004).
Families of children with disabilities function more successfully with effective family support. Family support is a constellation of formal and informal services and tangible goods that are defined and determined by families. Indeed, family support encompasses “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 another form of 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, p. 34).

**Importance of Topic for Work Family Studies**

Although the number of families having children with special health care needs or disabilities is substantial in the United States and other developed and developing countries (Heymann, 2000, 2006), comparatively few studies have directly addressed work-family issues for this group of employed parents. The challenges these parents face integrating work and family responsibilities can differ in important ways from those of families that do not have members with disabilities, yet their situations remain relatively invisible in major discussions of work-life integration.

In contrast to caregiving responsibilities for children with typical development, exceptional caregiving responsibilities for children with disabilities can increase rather than decrease as children become older, and care needs frequently rather than occasionally create disruptions at work. (Kagan, et al. 1998; Kagan, Lewis, & Brennan, 2008; Roundtree & Lynch, 2006). Many rather than few work disruptions are crisis-driven for these parents, and require them to make substantial rather than minor family and work adjustments (Gallimore, Coots, Weisner, Garnier, & Guthrie, 1996; Roundtree & Lynch, 2006).

Perhaps more than other employees, parents of children with disabilities require flexibility in their family schedules, their child care arrangements, and their work lives (Brennan, Rosenzweig, Ogilvie, Wuest, & Shindo, 2007). Emlen (2008) has identified their search as the quest for optimal flexibility solutions. Work-family researchers who address the struggles of all employed parents to build flexibility into their lives can learn from those parents with special challenges in their caregiving situations who are able to maintain employment by piecing together flexibility in the domains of their lives.

The successful workforce participation of families of children with disabilities has been linked to the flexibility they have found in their workplaces (Rosenzweig, Huffstutter & Burris, 2003). Although most employers have both formal policies and informal practices allowing flexible work arrangements (Goshe, Huffstutter, & Rosenzweig, 2006), many workers do not make use of them due to an organizational culture that deters asking for, and receiving these accommodations. When seeking out support in the
workplace, employed parents are faced with a decision about whether or not to share information about their child’s special needs. Parents engage in an assessment of the costs and benefits of their disclosure. In the process of potentially gaining the beneficial accommodations, parents also face significant emotional costs. They often are targets of courtesy stigmatization by their supervisors and co-workers who may have negative attitudes and beliefs about disabilities and illness. In fact, they may experience “double jeopardy” stigmatization in which their professional competence is discredited and their parenting skills are judged critically (Rosenzweig, Brennan, Malsch, Stewart, & Conley, 2007). Employed parents of children with disabilities have compelling reasons for asking for flexibility, particularly in times of health or mental health crisis. The study of parents’ processes and strategies allows work-family researchers to explore the intense interplay between disclosure of the employee’s family situation and the response of the supervisor to requests for flexibility and workplace adjustments.

Flexibility required in the area of caregiving is also of particular interest to the work-family field. Child care arrangements, educational settings, and out-of-school care programs are developed for and focused on children with typical developmental needs, and parents with more common work schedules. In order for flexibility to be maintained in these settings, supports must be developed for many children with health, sensory, developmental, emotional, or behavioral challenges; some children may even require a behavioral aide. If the supports are not available and flexibility is not present, children may be asked to leave care and education settings, adding stress to already burdened families and forcing them to find ways of caring for the child using other family members, if the parents are to maintain employment (Gilliam & Shahar, 2006; Warfield, 2005). The care strategies that have evolved in families having children with disabilities are of particular interest, since they point to the importance of developing a rich array of community-based supports.

From the perspective of the employer, the examination of work-life integration for employed parents of children with disabilities may focus on the decisions pertaining to valued workers’ entry and exit decisions from the workforce due to a lack of understanding, flexibility, and other supports. As they struggle with their children’s disabilities and health care needs, parents frequently reduce their work hours or leave the workplace altogether. Employers need to be made aware of strategies they can use to recruit and retain talented employees, and the policy and practice shifts that will make their workforce participation possible. As some employers are learning through the increasing prevalence of successful lawsuits based on family responsibility discrimination (Williams & Calvert, 2006), it is crucial to gain accurate knowledge about the lived experiences of employed parents with exceptional caregiving commitments.

State of the Body of Knowledge

Although a large number of families include children with disabilities, the study of their work-life-community integration is in its early stages. This review draws primarily from studies conducted within the past 15 years by researchers in Canada, the United
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It features groundbreaking work by Jody Heymann of McGill University in Canada; by Carolyn Kagan, Suzan Lewis, and their co-workers at Manchester Metropolitan University in England; and by U.S. researchers studying families of children with developmental disabilities (Penny Hauser-Cram of Boston College and Marji Warfield of the Starr Center for Mental Retardation at Brandeis University); and families of children with emotional and behavioral disorders (Julie Rosenzweig, Eileen Brennan, and their collaborators at the Research and Training Center on Family Support and Children’s Mental Health at Portland State University). The review will first address the prevalence of families having disabilities in one country, the United States; will next summarize the theoretical approaches that may be applied to the study of these families; and then will move on to consider the literature that has been developed in key domains affecting these families.

Prevalence of families having children with disabilities. The range of disabilities and different survey methodologies make it difficult to obtain accurate and comprehensive statistics on the number of families with children experiencing disabilities or having special needs in the United States. The criteria used by the National Survey of Children with Special Health Needs (CSHCN) for identifying 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, a slight increase over the number of households (20%) identified in the 2001 survey (HHS, 2001). In the 2006 CSHCN survey (HHS, 2008), the prevalence of special health care needs varied by the child’s race/ethnicity and sex, and increased with age of the child. Special health care needs were reported as highest among children with multiracial ethnicity (18%) and lowest among children of Asian ethnicity (6.3%). Males (16.1%) were also more likely to experience special health care needs compared with females (11.6%). Because some disabilities or special health care needs are either not diagnosed in the youngest age group (0-5 years of age) or do not develop until in later ages, the highest prevalence of disabilities was reported in school-aged children: 16% in children ages 6-11 years and 16.8% in children ages 12-17 years.

In the 2000 census, the U.S. Census Bureau (Wang, 2005) determined that 9.2% of households raising children had at least one child meeting strict criteria for a sensory, physical, or mental disability. The presence of a child with a disability was linked in this study to family poverty. Among families in which no member had a disability, 7.7% were below the poverty line. The poverty rate increased to 17.0% for families having a child with a disability. For families with both adults and children with disabilities the poverty rate increased even more dramatically to 28.9%.

The 2006 National Health Interview Survey examined the incidence of the specific diagnoses of asthma, allergies, and Attention Deficit Hyperactivity Disorder (ADHD; Bloom & Cohen, 2007). Findings indicate that in children under the age of 18 years of
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age, 9.4% have asthma and 11.8% have respiratory allergies. For children 3-17 years of age, 7.4% have ADHD.

Recently, it has been estimated that nationally 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). Young children receive services through the development of an Individualized Family Service Plan (IFSP) and older children receive accommodations through an Individualized Education Plan (IEP). Also, a national survey of U.S. public schools has estimated that an additional 1.2% of children, who are not served through IDEA, receive individually-designed school-based accommodations through a 504 plan (Holler & Zirkel, 2008). Children served through Section 504-only plans, most of whom have been diagnosed as having ADHD, are given services in order to promote their learning which has been negatively affected by a disability (Betz, 2001; Holler & Zirkel, 2008). Finally, according to the Surgeon General’s Report (2001), the nation is facing a public crisis in mental health care for children and adolescents. Approximately 11% of children and adolescents in the United States suffer from mental health disorders severe enough to cause significant impairment, yet only 20% of those receive the treatment they need.

Theoretical approaches to exceptional caregiving. For families with children who have disabilities, the challenges and barriers to work-life integration can be overwhelming and the solutions elusive. The concept of work-life integration emerged largely as a result of continuous change in workforce demographics, the changing nature of paid work, and concomitant changes in the structure of the family. The challenge of combining paid work and family life initially was framed as an issue of “work and family balance,” with the primary focus on working mothers. Work-life integration is a more inclusive idea, encompassing not only the domains of workplace and family, but additional life domains, roles, and responsibilities within the community for both men and women (Lewis, Rapoport, & Gambles, 2003).

Work-life integration for families of children with disabilities is highly dependent upon community resource fit with the demands exceptional care creates for a family. Recent theoretical analyses, such as border theory, suggest that individuals have preferences about the extent of integration they desire, but may have differing degrees of control over the level of integration they can obtain (Clark, 2001, 2002). Employed parents bridge the gap between the desired level of integration and that which is obtainable through a strategic process of adaptation or accommodation, or fit (Barnett, Gareis, & Brennan, 1999). Fit is not a static outcome achieved by the individual; rather it is an ongoing process, constantly responding to personal, community, and societal conditions and resources (Rosenzweig, Barnett, Huffstutter, & Stewart, 2008).

Strategies conceptualized by the parent or parenting couple can only be operationalized with adequate resources. Resources, both tangible and intangible, are located at the individual, couple, family, workplace, community, and societal levels. A contextualized perspective of work-life integration is of increasing interest to work-family researchers
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(Barnett & Gareis, in press; Bookman, 2004; Voydanoff, 2001). The most immediate context of the work-family interface is that of the community. Barnett and Gareis (in press) expand the model of work-family fit to include the community context in which adaptive strategies emerge. Central to their community-families-work model is the availability of community resources, ranging from caring neighbors to accessible health care. Availability alone however, is not enough to serve as a supportive function to work-family fit; families must also perceive resources as accessible. The match between the availability and accessibility of resources, and between the family’s needs and responsibilities, is what determines community resource fit (Barnett & Gareis).

The workplace. The Center for Child and Adolescent Health Care Policy has estimated that in any given company in the United States, approximately 8.6% of employees are caring for a child under the age of 18 years with special needs (Center for Child and Adolescent Health Policy, n.d). 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 care demands on employment. Mothers of children with disabilities 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 & Huffstutte, 2004; Thyen, Kuhlthau, & Perrin, 1999). 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 revealed 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, 2000a). 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, 2000a). Diminished maternal employment is more prevalent among single mothers of children with disabilities who must assume full responsibility for care, household chores, and paid work (Powers, 2003).

Formal and informal workplace support is critical for parents of children with disabilities to sustain adequate employment and fulfill work obligations while being available to meet ongoing and unpredictable demands of exceptional caregiving. Unfortunately, parents of children with disabilities—particularly mental health disorders—may experience a lack of understanding in regard to their family situations due to a lack of knowledge about unique care needs on the part of their supervisors and co-workers. Additionally, these parents face inadequate workplace policies to support combining work and family (Rosenzweig, et al, 2003). For example, parents, especially mothers, are often blamed by extended family members and professionals for causing their children’s mental health disorders through poor parenting practices (Harden, 2005; Norvilitis, Scime, & Lee, 2002) and report experiencing courtesy stigmatization in the workplace as well (Angermeyer, Schulze, & Dietrich, 2003; Rosenzweig et al., 2007).

Workplace flexibility is essential for parents of children with disabilities to support adjustments in the timing and the physical location of work tasks. For parents of children with
exceptional care needs, flexibility provides time off to attend doctor and school appointments, scaled-back hours to allow more time to care for their child, adjustable hours to accommodate school and child care schedules, options to deal with emergency situations, and extended leaves. Availability of formal policies on flexible work arrangements or informal supervisor support does not necessarily encourage or promote employee utilization of flexibility. Research indicates that is the not the availability of flexibility that makes the organization family-friendly, but rather the workplace culture (Thompson, Beauvais, & Lyness, 1999). Studies have found that benefit availability is much more common among organizations than actual benefit usage among employees, and that utilization of flexibility benefits is associated strongly with the organizational culture (Hammer, Neal, Newsom, Brockwood, & Colton, 2005; Secret, 2000; Thompson et al., 1999). An important consideration for parents seeking family-friendly employment is the extent to which employees in the organization feel supported to use benefits. In their study of employed family members of children with disabilities, Lewis et al. (2000b) found that employees were reluctant to utilize available benefits fearing that their loyalty and commitment to the organization would be questioned.

In a national study of over 500 human resources (HR) professionals employed in Fortune 1,000 companies, 34% of respondents indicated that, despite the availability of leave or flexibility in hours, employee utilization of such benefits was not supported by the culture of the organization (Goshe, Huffstutter, & Rosenzweig, 2006; WorldatWork, 2005). Indeed, the study found remarkably low utilization rates compared to availability across all job classifications. Even among employees in the professional job classification, who were reported to have the highest level of availability (84%), respondents indicated only a 15% utilization rate by more than 50% of those employees. The study also reported that availability of flexible work arrangements was more restricted for hourly wage-earner employees compared to salaried employees. This finding is particularly concerning in relation to working class families of children with disabilities. The survey findings suggest that families with the highest rates of children with exceptional care needs would be least likely to have access to flexibility.

Supportive work environments inevitably foster attitudes of reciprocity, where employees will give back to their employers because they were given the latitude to address their family needs. Workplace reciprocity is a relational process of mutual exchange between the parent and the immediate supervisor or co-workers resulting in costs and benefits to both the parent and the workplace (Rosenzweig, et al 2003). Fundamentally, the best workplace cultures for parents of children with special needs are those that promote diversity and inclusion, support and train their management team to consider employees as whole people with lives outside of work, and understand the mutual advantages gained by providing supportive benefits, policies, and practices. For leading family-friendly companies, support for work-life integration has evolved from perks and programs to an everyday business strategy. Companies are realizing that when work-family support systems are in place, there is a significant “bottom line” impact evidenced by improved productivity, increased job satisfaction, enhanced commitment, and retention (Bond, Galinsky, Kim, & Brownfield, 2005). In fact, one study found that shareholder value increased after public acknowledgements of a company’s family-friendly practices (Arthur & Cook, 2004).
Community supports. Studies conducted in the U.S. and the U.K. have substantiated the lack of fit between work and exceptional care responsibilities, and the importance of having community resources and supports in place if parents are to maintain employment in the face of high demands in the domains of their lives. Domains that have received attention from researchers include child care, education, the health care system, and support through community networks. As Heymann (2000) has pointed out, however, there is a “widening gap” between what families need and the supports that are actually available in the community.

Interviews of parents of children with disabilities revealed that they are often unable to manage both employment and caregiving due to lack of adequate child care options and inadequate leave time permitted by their employers to meet episodic care needs (Lewis et al., 2000b; Rosenzweig, et al., 2002). Unlike families of children with typical development, who often rely upon extended family members or child care and out-of-school programs to care for their children (Sonenstein, Gates, Schmidt, & Bolshun, 2002), families of children with disabilities must often make complex and flexible arrangements for their care (Heymann, 2000). Extended family members are often not available to care for children with intense needs, particularly those with behavioral challenges (Rosenzweig, Brennan, Huffstutter, & Bradley, 2008). Instead some parents work at home, bring the child to the workplace, or engage in tag-team parenting with adults in the family working at different times of day so care of the child with disabilities is covered (Boushey, 2006; Rosenzweig et al., 2008). Other families may choose to have their child cared for in community-based programs or with unrelated care providers in the community, but may have great difficulty finding or maintaining these child care arrangements. Even preschool-aged children are frequently expelled from child care settings when care providers cannot manage their challenging behavior or provide for their special needs (Gilliam & Shahar, 2006; Warfield & Hauser-Cram, 1995). When child care or out-of-school programs successfully include children with disabilities, they provide great support for working parents (Brennan, Bradley, Ama, & Cawood, 2003). However, providers of inclusive child care often require both specialized training and consultation with inclusion specialists or mental health consultants to design and provide the supports needed by children and families (Cohen & Kaufmann 2005).

For parents of school-age children, the school can be an important setting in which children receive support and services, and where parents can find assistance in their efforts to provide care and opportunities for their children with special needs. Ideally the school partners with parents and other professionals in developing plans for the child’s education and care, and for specific procedures for handling possible crises. In this sense, the school system can be integral to parents’ ability to fit together their work and life responsibilities. Unfortunately, many overburdened and underfunded schools may not have the capacity to meet this need, and therefore may not act in accordance with federal mandates to provide these additional services (Kauffman, 1997 in Epstein et al., 2005). In this case, parents may go without this additional source of support and consequently face significant difficulties with employment. When schools are unable or unwilling to manage a child’s special needs, their first line of action is to contact the parent during the school/work day (Rosenzweig et al., 2002). This is especially the case...
in times of crisis and particularly affects parents of children with emotional or behavioral disorders, which are often unpredictable in nature. If parents are frequently contacted at work and asked to come to the school, their work schedule and performance will likely suffer, adding an additional layer of strain to an already stressful situation. For example, among employed parents of children with emotional or behavioral disorders, contact with school personnel predicted parents’ work absences and interruptions, which in turn increased parents’ level of stress (Brennan, Rosenzweig, Bradley, & Huffstutter, 2003). Further, children with behavioral challenges are often suspended from school, and school absences are correlated with less caregiver participation in the workforce (Brennan & Brannan, 2005). Even the more routine obligations of attending scheduled school special education meetings can result in a parent’s need to take time away from work—often necessitating either a flexible work schedule or access to leave benefits. School personnel often perceive a parent’s difficulty in attending meetings as a lack of caring or involvement, rather than considering the impact of the parent’s employment.

Families, while maintaining their own employment, must also provide for the special health care or mental health treatment requirements of their children in addition to making sure their children are well cared for and educated. The National Survey of Children with Special Health Care Needs found that many parents spent substantial time arranging for, and participating in, the treatment needed by their children (HHS, 2008). These activities may include transporting children to care, participating in treatment, administering medication, and maintaining assistive devices. Fully 9.7% of families having children with special health care needs spent 11 or more hours a week in these health care activities, and another 8.9% spent between 5 and 10 hours a week engaging in health-related care. Kagan et al. (1998) make the case that health care providers often expect mothers to be available for care of their children with disabilities during the day, and provide no opportunities for appointments outside of parents’ usual working hours. It is not surprising that service providers can become frustrated with families who fail to keep health care or mental health appointments. Harrison, McKay, and Bannon (2004) surveyed families who failed to keep their children’s mental health treatment appointments and found that nearly half failed to bring their children to the appointment because they were overwhelmed with other responsibilities, or were expected to be somewhere else; more than likely, their workplace.

Other sources of formal and informal support for families of children with disabilities can be found in community networks. Bookman (2004) describes community as “the connective tissue that makes [people’s] work and family lives possible. It is the invisible framework that connects families to the people and institutions that provide care, services, and support” (p. 249). Community can be viewed through the lens of an ecological systems theory framework (Voydanoff, 2001), with the family being part of a social ecology which includes social networks of formal and informal groups, supplying help and resources to their members in a spirit of mutuality. Formal supports can be obtained from community child care and education providers, health and human service agencies, transportation services, and the workplace. Kagan, Lewis, and their co-workers (Kagan et al., 1998) have found that informal support obtained from family, friends, neighbors, and peer support and volunteer groups can also be of great assistance to families struggling with the demands of work and exceptional caregiving. These informal
networks can be sources of information and of instrumental support through exchanges of respite care, emergency coverage, and help in the home (Kagan et al., 2008). In their interviews of families of children with disabilities in the U.K., Kagan et al. (1998) also found that community members provided emotional support for each other as they faced the challenges of raising a child with a disability. Churches, cultural groups, and family networks also supplied opportunities for spiritual renewal, family recreation, and giving back to the community that were important to achieving a stable and happy family life.

**Impact on Family Members.** Having a child with a disability can have profound effects on the family, many of which affect the ability of parents to achieve work-life integration (Rosenzweig & Kendall, 2008). Much of the research on the family impact of having a child with a disability has focused on the family stress, strain, and burden that are experienced by the adults caring for the child. In an extensive study of children with ADHD, Kendall and her colleagues have chronicled the evolution of the stress experienced by parents as they struggled with getting a diagnosis, learned to cope with the disruptions that resulted from the disorder, and moved on to recast their family life and family management style (Kendall, 1998; Kendall & Shelton, 2003). For some families, although parenting a child with a disability may test their relationships, it can serve to draw couples closer together as they work to adapt their family life to the needs of the child (Heiman, 2002). However, a review of 13 published studies by Risdal and Singer (2004) found a small negative effect on marital discord of parenting a child with a disability, and also revealed an average increase of 5.97% in the number of divorces of parents who cared for children with a disability, compared to parents who had only children with typical development.

Family members giving care to the child with special needs may experience particular caregiver strain due to unusual demands including disrupted family and social relationships, exhaustion, financial difficulties, guilt, and parenting distress (Angold et al., 1998; Brannan, Heffinger, & Bickman, 1997; McDonald, Poertner, & Pierpont, 1999; Yatchmenoff, Koren, Friesen, Gordon, & Kinney, 1998). In research with parents of children with mental health difficulties, both objective (observable events in family life such as financial hardship) and subjective (internal states such as sadness, guilt or stress) dimensions have been investigated and shown to have different correlates (Brannan & Heflinger, 2006). Caregiver strain is predicted by the severity of the child’s mental health symptoms (Brannan & Heflinger, 2001, 2006), and is buffered by family strengths such as financial resources and social support (Brannan, Manteuffel, Holden, & Helfinger, 2006; Yatchmenoff, et al.,1998). Caregiver strain experienced at work, in conjunction with inadequate child care arrangements, has been found to predict lessened workforce participation of parents of children with mental health problems (Brennan & Brannan, 2005).

Although not much research has examined the economic consequences of caring for a child with a disability from the standpoint of the family, the studies that do exist point to both direct costs of care, and the indirect effects on families’ financial position due to inability to fully engage in work. Families affected by children’s mental health problems have substantial costs directly related to treatment (Burns et al., 1995; Ringel & Sturm, 2001). Parents must pay fees
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for treatment and insurance co-payments, purchase medications, spend money to transport children to appointments, and expend resources on child care for the child’s sibling while they participate in treatment or parent education related to the disability (Brennan & Lynch, 2008). The indirect costs can also be substantial in terms of lessened career aspirations, diminished participation in the workforce by one or both parents, and time and money diverted from the ordinary activities of daily living (Lynch, 2007; Scott, Knapp, Henderson, & Maughan, 2001). The indirect costs of diminished workforce participation can be linked to the financial position of families of children with special health care needs, with fully 33% of parents under the poverty level reporting that they had to cut back or quit their work due to the extra care required by their child’s needs, in contrast to 16.8% of more affluent families (HHS, 2008). Single parents living in poverty and receiving Temporary Assistance to Needy Families (TANF) income supports, were two times more likely to obtain jobs and leave TANF if they had children developing typically, than if they were raising a child with a disability (U.S. General Accounting Office, 2002). Diminished workforce participation can be linked to the finding of Porterfield, Sanders, and Rainford (2006) that dual parent households of children with disabilities are less likely to own a house, and more likely to have less valuable assets than those households raising only children without disabilities.

In contrast, some effects of parenting a child with a disability are decidedly positive: family members reach out for and receive helpful social support, learn more about human disabilities, have a greater appreciation for diversity, and may even use their new knowledge about disabilities in their work (Trivette, Dunst, & Hamby, 1996). Participation in community-based peer support networks may also bring enrichment and a sense of psychological belonging to the lives of the parents of the child with disabilities (Kagan et al., 2008). Family members also report that the parenting rewards they experience from caring for a child with a disability (mental health disorder) are similar to those experienced by parents of children developing typically (Brennan et al., 2007; Barnett & Marshall, 1992). Brennan et al. (2007) found that the greater the fit employed parents were able to achieve between their work and family responsibilities, the higher the quality of both their work and parenting roles. With the increased involvement of family members of children who have disabilities in research conducted in the field, Risdal and Singer (2004) have remarked that there has been a shift toward examining the resilience and adaptation of families caring for children with unique needs.

Policy Supports

Families who have children with disabilities are afforded some protection from discrimination and access to public services due to policies enacted in the United States. Individual children and adults are protected from discrimination at the workplace and granted access to public accommodations by the Americans with Disabilities Act (ADA, 1990). As public entities that receive federal financial assistance, schools are required to provide free and appropriate education to students with disabilities (Americans with Disabilities Act of 1990; Individuals with Disabilities Education Act of 1975, 20 U.S.C. 1401, 34 C.F.R. § 300.8). This includes any additional and individualized services that the student may need such as in-school counseling and individualized education plans. Parents are also protected through the “association” provision of the ADA. Employed
parents cannot be discriminated against at their workplaces due to their relationship with their child with a disability. In fact, one of the most quickly growing segments of employment law is the “family responsibilities discrimination” area, with over a 400% increase in lawsuits filed in the last 10 years (Still, 2006, p. 2).

In terms of policies that support families, government investment varies considerably among the developed nations. Unfortunately for families of children with disabilities in the United States, our nation is among the group of nations devoting the lowest proportion of their gross national product to services that support families (Organization for Economic Cooperation and Development [OECD], 2007). However the U.S. does provide universal supports for all families having children, as well as targeted sets of supports which serve to improve the situation of children with disabilities and their employed parents (Fredriksen-Goldsen & Scharlach, 2001).

*Universal supports* open to all families with children include family and medical leave (FMLA), tax credits for child care, and funding in some communities for preschools and out-of-school care programs. One of the most frequent reasons that U.S. workers use FMLA to preserve their jobs while they are on leave is to care for sick children (Cantor et al., 2001). However, the lowest income families cannot afford to take unpaid leave and often make do, taking care of children with acute health or mental health issues while still showing up for work (Cantor et al., 2001; Gerstel & McGonagle, 1999). Tax credits for child care generally end at age 13, but for families having members with disabilities, older dependents requiring care during work hours are also covered (U. S. Internal Revenue Service, 2004). Again, low-income families rarely make use of this policy, because their incomes are too low to receive benefit for a credit when they make too little to pay taxes. Finally, “universal” preschools and out-of-school programs are not necessarily open to children with behavioral difficulties as a recent study by Gilliam and Shahar (2006) of expelled pre-kindergarteners made clear.

There are some major monetary *targeted supports* available in the U.S. for children with disabilities, particularly for those from for low-income families who are out of the job market or in low-wage jobs. Families in poverty, which are very likely to include family members with disabilities (U.S. GAO, 2002), may be eligible for TANF for a limited period of time under special conditions. Low-wage working parents may also receive the Earned Income Tax Credit, which may give them a refund of tax dollars and additional assistance. Low-income families are also eligible for participation in Head Start, a preschool enrichment program which is mandated to reserve at least 10% of enrollment slots for children with disabilities. Finally, low-income families can receive child care subsidies that help them meet the market rates for local child care providers through the Child Care Development Fund. However, most states do not provide subsidies to all eligible families, and some do not prioritize children with disabilities for receipt of subsidies (Child Care Bureau, 2006). Low-income families can also draw upon federal and state programs that offer low-cost or no-cost medical insurance through Medicaid and the State, and may draw payments from the State Children’s Health Insurance Program (SCHIP; Dubay, Haley, & Kenney, 2002).
Perhaps the best known set of supports in the U.S. for those with disabilities is that obtained through the Social Security entitlement programs. Social Security covered almost 800,000 children in the United States in 2001–2002 (Rupp et al., 2005/2006). The Supplemental Security Income (SSI) program is available for those minor children living in low-income families. Youth with disabilities who are over 18 and who have a parent eligible for SSI payments or who is retired or deceased, can also receive cash assistance from the Social Security Disability Insurance (SSDI) program. Both forms of social security payments involve having a health condition or disability that meets strict definitional requirements: the health or mental health condition must seriously limit activities of daily life and must last at least one year or be terminal (U.S. Social Security Administration, 2005).

Although many families of children with disabilities participate in the workforce and draw upon the support afforded by policies in the United States, the serious financial consequences of having a child with a physical, sensory, developmental, emotional, or behavioral disability still may result in a high percentage of these children living in poverty. Policies should be further developed based on firm evidence of need and acceptability to those who will benefit from them (Brennan & Marsh, 2008).

Implications for Research and Policy

Systematic programs of research are necessary to give a more complete and coherent picture of the ways in which families’ work-life integration is affected by their children’s disabilities. Some of the most urgently needed investigations are longitudinal studies that uncover the effects on the workforce participation and the workplace experience of parents having a child with specific types of disability. Investigators need to track the challenges that parents, siblings, and the children with disabilities face at different developmental stages, along with the adjustments that parents make in work and family life along the way. Such detailed research can inform the design of supports, benefits, and services that may improve the life opportunities of all concerned.

One notable example of a longitudinal study that has yielded crucial information is the Early Intervention Collaborative Study [EICS]. This investigation conducted by Hauser-Cram, Warfield and their collaborators (Hauser-Cram, Warfield, Shonkoff, & Krauss, 2001) has followed over 150 families having children who had a diagnosis of developmental disability, and who entered the study when the children were two years of age or younger, until they were age 23. The investigators have tracked the well-being of children and their families, have examined some of the adjustments to work that occurred, the trials of finding suitable child care, and the relationship of marital quality to parental well-being. Similar cohort studies need to focus very directly on the work-family-community interface for other large segments of families affected by their children’s disabilities.

Comparative studies that contrast work-life issues for families having children with disabilities with those experienced by families raising only children with typical development are also warranted. To carry out comparative analyses, large-scale surveys
probing work-life issues of employees should include questions that can capture information on children’s disabilities and special health care needs. In a parallel fashion, surveys investigating the experiences of children with disabilities and their families should also include items on the work experiences of parents, and the community supports, such as child care, that they use.

Finally, specialized studies that examine the effects of specific supports on parental employment can also contribute greatly to our knowledge about this large group of families. Do inclusive child care, early intervention or special education supports, transportation services, or flexible work arrangements enable parents to be more fully employed? Are there other types of supports that parents involved in exceptional caregiving need in order to fully participate in the workforce?

Current and future research might be used to inform policy improvements at the organizational, regional, and national levels. The U.S. has not yet developed a coherent set of policies that support working parents whose children have disabilities or special health care needs. Research currently supports the need for longer and paid family medical leave for those with exceptional caregiving responsibilities, but there are fragmented efforts to achieve more generous coverage. Unlike the U.K., which has policies that recognize the “Right to Request and Duty to Consider” flexible work arrangements from employers (Department for Business Enterprise and Regulatory Reform, 2007), the U.S. has a voluntary system of flexible work policies. Paid sick days are by no means universal, and need not cover employees who stay home to care for sick children or children in crisis. Health insurance is not required to provide parity between health care and mental health care, and does not currently cover caregiving support. Service gaps, fragmentation, and lack of comprehensive planning need to be overcome if families of children with disabilities are to be fully integrated into the workforce and the life of their communities.
References


challenges. Paper presented at the annual meeting of the Western Psychological Association, Vancouver, Canada.


Individuals with Disabilities Education Act of 1975, 34 C.F.R. § 300.8.


