INTRODUCTION

Research literature related to the intersection of work, family, community, and disability care for children or youth with disabilities has grown significantly over the past two decades. The development of this body of knowledge stems primarily from the fields of psychology, nursing, social work, sociology, health and social policy, medicine, and more recently occupational health and safety. Each field has had different foci of interest that contribute to the deepening understanding of the challenges experienced by parents of children and youth with disabilities. This entry identifies key concepts, definitions, and research literatures related to caring for a child or youth with a disability and the challenges and supports they have in finding fit and achieving work-family-community integration.

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 (UNICEF 2013). Using data from the National Health Interview Study, the proportion of families in the U.S. including at least one member under the age of 18 with a disability has been estimated as 13% (Altman and Blackwell 2014). Of the parents responding to the most recent National Survey of Children’s Health, 19% reported that they had a child or youth in their household with special health care needs, including conditions that might be classified as disabling (Abdi, Seok, and Murphy 2020). Clearly many U.S. families include young people who may be struggling with disabling health conditions that require their parents to provide special care and assistance.

Employed parents caring for children with disabilities often find the integration of work and family responsibilities very challenging (Brown and Clark 2017; Kagan, Lewis, and Heaton 1998; Rosenzweig, Brennan, and Ogilvie 2002; Rosenzweig et al. 2011). 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 (Brown and Clark 2017; Earle and Heymann 2011). Necessary supportive community resources that help facilitate work-life integration are usually tailored for families of children with typical development (Brennan et al. 2016; Rosenzweig and 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 (Brannan et al. 2018; Brown and Clark 2017; Powers 2003; Rosenzweig and Huffstutter 2004).

BASIC CONCEPTS AND DEFINITIONS

In the U.S., children with disabilities have been identified through the Americans with Disabilities Act of 1990 as having “a physical or mental impairment that substantially limits one or more major life activities” (29 U.S.C. 705(20)(B)). Alternatively, the term children with special needs, may be applied to children with developmental delays or one or more of a specific set of disabilities that may affect their ability to obtain an education, and require the public school system to provide special education and related services. The Individuals with Disabilities Education Act (IDEA) of 2004 (20 U.S.C. 1401 and 34 C.F.R. 300.8) applies to children with a physical or mental impairment that limits their ability to participate in general education and affects major life activities, and who are entitled to receive special education services (USDOE 2015). Disabilities can also be viewed in a wider social context, and recognized as a function of the fit between a person and their environment (Pledger 2003), and as a distinguishing category of one’s social identity (Dirth and Branscombe 2018).

Because of the intensive demands of time and energy needed to provide care for children with disabilities, parents engage in exceptional caregiving, which is more intense and varied than the caregiving required for children developing typically (Stewart, Stutz, and Lile 2018). Due to the special needs of the young people in their family, parents may spend significant time arranging and coordinating health care for their children, making sure they receive the special education services that are appropriate for their needs, and dealing with social issues that might arise (Abdi et al. 2020; National Academies of Sciences, Engineering, and Medicine 2018). Exceptional care responsibilities are often more intense and pervasive than care given to children and youth with typical development, and may continue beyond childhood into the transition to young adulthood and adult life. (Brennan et al. 2016; Lewis, Kagan, and Heaton 2000a).

Key for children and youth with disabilities is their need for community integration, which provides the opportunity to live as part of a community, and take advantage of the housing, education, recreation, employment, spiritual and religious experiences, and social roles that are available (Salzer 2006). The capacity of the local community to welcome and support children
with special needs and their families will strongly affect both their children’s community integration and the family’s quality of life since parents may be shut out of networks of families supporting the activities of young people that do not include their children (Algood and Davis 2019; Jivanjee, Kruzich, and Gordon 2007; Summers et al. 2005).

Unfortunately stigmatization is frequently experienced by both persons who have disabilities and their family members. Both adults and children with disabilities experience prejudice, stereotyping, and discrimination that can affect all areas of their lives, resulting in physical and social isolation, and limiting their capacity to be fully integrated into their communities (Goffman 1963; Moses 2010, 2015; Sachs and Schreuer 2011). Additionally, their family members may also experience courtesy stigmatization (stigmatization by association) and find themselves excluded from community settings where their children might be involved, and even feel blamed for their child’s disability (Ali et al. 2012; Corrigan et al. 2003).

Even though courtesy stigmatization is a possibility in the workplace, some parents use careful disclosure of their child’s disability to negotiate the changes they need to manage both their work and the exceptional care they provide (Rosenzweig and Huffstutter 2004; Rosenzweig et al. 2011; Stewart and Charles 2019). However, such disclosure of private family information can be risky, and may increase their stigmatization, isolate them from their co-workers, contribute to feelings of stress, and add to job insecurity (Ellison et al. 2003; Hays and Butauski 2018; Huffstutter et al. 2007; Stewart and Charles 2019).

Family support is of crucial importance to parents raising children with disabilities (Vanegas and Abdelrahim 2016). Family support is delivered through a constellation of formal and informal services and tangible goods defined and determined by families, and increasingly the young people with disabilities themselves (Friesen et al. 2011). Considering employed parents, family support also provides “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 et al. 2008:34). Increasingly families have received crucial assistance from peer support providers, parents raising children with similar disabilities, who share their own experiences, offer emotional support, and help parents access needed resources and navigate service systems (Gopalan et al. 2017; Hoagwood et al. 2010).

**IMPORTANCE TO WORK-FAMILY STUDIES**

A growing body of knowledge demonstrates that the challenges these parents raising children with special health care needs or disabilities face integrating work and family responsibilities can differ in important ways from those of families that do not have members with disabilities (see Brown and Clark 2017). Despite this evidence, their situations remain relatively invisible in major discussions of work-life integration and organizational health interventions.
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 (Brown and Clark 2017; Kagan et al. 1998; Kagan, Lewis, and Brennan 2008; Roundtree and 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 et al. 1996; Rosenzweig et al. 2011; Roundtree and Lynch 2006; Stewart 2014).

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 et al. 2007; Brennan et al. 2016; Stewart et al. 2018). Emlen (2010) has identified their search as the quest for optimal flexibility solutions with parents using adaptive strategies within the family, workplace, and community to manage their caregiving demands. Community resource ecologies influence strategic choices available to parents of children with mental health conditions through the provision of adaptive strategies that can enhance fit (Sellmaier 2019b; Stewart et al. 2018). 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 and Burris 2003). Although most employers have both formal policies and informal practices allowing flexible work arrangements (Goshe, Huffstutter, and Rosenzweig 2006; Ireson, Sethi, and Williams 2018), many workers do not make use of them due to an organizational culture that deters them from asking for, and receiving these accommodations (Sellmaier 2019a). 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 et al. 2007; Rosenzweig et al. 2011; Stewart and Charles 2019). 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. Understanding these complex processes is important given evidence suggesting that parents of children with disabilities are more likely to face retaliation and dismissal from work (Rosenzweig and Huffstutter 2004; Stewart 2014). It is also
important given a developing body of biomedical research which is finding longitudinal biomedical impacts among mothers of children with disabilities compared to those of typically developing children (DePascale et al. 2019; Seltzer et al. 2010; Witt et al. 2010).

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. In child care settings, support for care providers from disability consultants may stabilize care arrangements (Gilliam, Maupin, and Reyes 2016). If the supports such as consultants 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 and Shahar 2006; Warfield 2005; Gilliam et al. 2016). 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 (Brannan et al. 2018; DeRigne and Porterfield 2017). 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 responsibilities discrimination it is crucial to gain accurate knowledge about the lived experiences of employed parents with exceptional caregiving commitments (Calvert 2016; Henle et al. 2020; O’Connor, Kmec, and Harris 2015; Williams and Calvert 2006).

BODY OF KNOWLEDGE
Research examining the experiences of working families caring for children with disabilities has grown over the past 25 years encompassing studies from across the world. This area of research has not just become increasingly international, but has also included a wide variety of disability types, expanded research beyond a focus on primary care providers, and been enriched by inclusion of community resources in addition to workplace and family supports. This 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 children with disabilities in U.S. families

Because of variations in the definition of disability, and the differing methods and measures used in national surveys, a consistent and comprehensive determination of the prevalence of disabilities of children in the U.S. is not available. Recently, the 2016 National Survey of Children’s Health (NSCH) included questions designed to gather information on children and youth with special health care needs (CYSHCN) in terms of specific diagnoses reported by the parent participants, and the services that they accessed. Mattson et al. (2019) reported that 19.4% of young people were identified as CYSHCN through having “…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. 1998:138). This indicates a notable increase from the 15.1% of CYSHCN that were found in the 2009-2010 National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, HHS 2013). In the 2016 survey, parents in families including CYSHCN reported greater financial demands and caregiving responsibilities than parents with children developing typically (Mattson et al. 2019).

The U.S. Census Bureau uses the Survey of Income and Program Participation (SIPP) to determine whether the civilian population living in the community rather than institutional settings has difficulty performing certain common activities, and if so, the extent of their limitations (Briault 2012). Most recently, the 2014 SIPP results estimated that 17.1% percent of children in the U.S. had a disability, with 9.8% having a disability that was severe enough to limit their functioning. The most common condition reported was Attention Deficit Hyperactivity Disorder (ADHD), which affected 8.6% of school aged children and youth, 4.5% had a developmental disability, and 2.8% were reported to have a mental illness (Taylor 2018).

The National Health Interview Survey examines the incidence of specific diagnoses such as ADHD and developmental disabilities in children and youth. Studies based on this national survey have found that 13.8% of children between the ages of 3-17 years had received a diagnosis of ADHD or a learning disability (Zablotsky and Alford 2020), and that the incidence of any developmental disability had increased from 16.2% in 2011 to 17.8% in 2017 (Zablotsky et al. 2019).

In the most recent report released by the U.S. Department of Education, 7 million children and youth ages 3-21, 14% of public school students, received services through the Individuals with Disabilities Education Act of 1975, (20 U.S.C. 1401, 34 C.F.R. 300.8) in 2017-18 (McFarland et al. 2019). Having a specific learning disability was the basis of service for 34% of students who received accommodations through an Individualized Education Plan (IEP), with other major
disabilities including speech or language impairment (19%), health impairment (14%), autism (10%), development delay (7%), intellectual disability (6%), and emotional disturbance (5%). Younger children receive early intervention services through the development of an Individualized Family Service Plan (IFSP). Screening and monitoring can begin as early as 10 months and may continue through the toddler years, as health care providers work with families of children showing developmental delays to provide the supports and interventions they need; a recent study found 3.3% of children under 4 years of age had an IFSP (Barger et al. 2018). Also, a national Civil Rights Data collection survey of U.S. public schools determined that an additional 1.5% of children who were not being served through IDEA, instead received a 504 Plan (Zirkel and Weathers 2016). Section 504 of the Rehabilitation Act (Americans with Disabilities Act, 42 U.S.C 12101-12213 2012) provides individually-designed school-based accommodations to children and youth because they have a mental or physical impairment that affects their ability to participate in major life activities, including education (U.S. Department of Education 2015; Zirkel 2011).

Theoretical approaches to exceptional caregiving

Theoretical approaches to integrating work and family obligations changed and evolved over the last 20 years, starting with a focus on conflict and strain associated with meeting the demands in competing roles (Bianchi and Milkie 2010; Brown and Clark 2017; Perry-Jenkins, Repetti, and Crouter 2000). This was expanded to include positive spillover or facilitation acknowledging that participation in different roles cannot only create conflict but enhance functioning. The challenge of combining paid work and family life was then framed as an issue of “work and family balance,” with the primary focus on working mothers. Acknowledging that balance assumes an equal weight between different roles, the field moved to framing the issues as work-life integration 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, and Gambles 2003). Most recently the concept of work life fit has been expanded and developed to include different systems (work, family, and community), and a life course perspective. This perspective states that employed parents bridge the gap between the demands and the resources available in these systems through a strategic process of adaptation or accommodation, or fit (Barnett, Gareis, and Brennan, 1999; Moen 2011; Voydanoff 2005). 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 et al. 2008). Theoretical and empirical developments have paid greater attention to community demands and resources in addition to workplace and family demands/resources (Gareis and Barnett 2008; Sellmaier 2019b; Voydanoff 2005). Voydanoff (2005) expanded on her model of the work family interface including both community demands and resources, which can either exacerbate work family conflict or support work family facilitation. Similarly, Gareis and Barnett (2008) further developed their 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 (Gareis and Barnett 2008). In addition, it was proposed that the different resources and demands are considered complex ecologies instead of single measures of a resource or a demand (Moen, Kelly, and Huang 2008). Families experience work-family fit within a complex web of resources and demands, and it is therefore necessary to assess overall fit of different resource ecologies (Sellmaier 2019b).

In addition, Moen (2011) integrated a life course perspective with the concept of fit. She also defines fit as the match or mismatch between resources and demands across different resource ecologies including the workplace, the family, and the community. This individual experience of fit is assumed to shift across the lifespan depending on current family conditions such as caring for a young child. For parents of children with disabilities, the fit between resources and demands across different ecologies is also determined by the intensity, the typology, and the complexity of care demands (Stewart et al. 2018). These factors of care are conceptualized as the continuum of care with typical care on one end and exceptional care on the other end (Stewart et al. 2018). Work life fit for parents of children with disabilities therefore changes across the life course and the continuum of care.

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 (Perrin et al. 2007). 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 (Brannan et al. 2018; Brennan and Brannan 2005; Freedman, Litchfield, and Warfield 1995; Porterfield 2002; Rosenzweig et al. 2002; Rosenzweig and Huffstutter 2004; Sellmaier et al. 2016; Thyen, Kuhlthau, and Perrin 1999). Related research also shows that employment outcomes might not only be influenced by severity of a child's symptomology (Okumura et al 2009; Sellmaier et al. 2016), but also by the caregiver's subjective experience of the care demands (Brannan et al. 2018). Support provided through informal and formal networks might therefore play an especially critical role for the employment outcomes of parents for children with disabilities. 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, and 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 et al. 2000a; Sellmaier et al. 2016). 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 (DeRigne and Porterfield 2010; Powers 2003). Parents of children with disabilities are also more likely to experience work family conflict in addition to experiencing disruptions to employment (Brown and Clark 2017; Stewart 2013). Severity of the disability and the number of children with disabilities in the home also heightened work-family conflict (Brown 2014). Families with exceptional care demands were found to have low levels of home control and high levels of home demands, which negatively affected their sense of conflict and spillover (Moen et al. 2008).

Research about the role of gender in the experience of work-family conflict is still limited but increasing. For example, one Australian study reported that 52% of the participating fathers felt that family demands affected their work performance sometimes, often, or, always (Wright, Crettenden, and Skinner 2016). Additionally a U.S. study compared work-family and family work spillover scores from 122 employed fathers who cared for a child with special health care needs to scores of men who participated in the nationally representative MIDUS study (Grzywacz and Marks 2000) and found that fathers caring for children with special health care needs (SHCN) scored significantly higher on positive work family spillover, and on both negative spillover scales, and significantly lower on positive family work spillover compared to men in the MIDUS sample (Sellmaier 2019a). There is also a growing body of research examining differences in employment for fathers and mothers of children with disabilities. For example, mothers of children with special health care needs seem to be more likely to experience employment disruptions (DeRigne and Porterfield 2017), and are more likely to lose wages (Earle and Heymann 2012) compared to fathers of children with special health care needs. One national survey of British fathers raising children with learning disabilities examined fathers’ workplace and employment adjustments and found that a majority took leave for more than one month (80.7%), reduced their work hours (67%), changed their type of work (58.7%), or changed their workplace responsibilities (57.3%; Towers 2009). Most also identified their work responsibilities as one of the main reasons for why they could not spend more time with their children. More research is needed to better understand the gendered nature of work life fit for these families.

Formal and informal workplace support is critical for parents of children with disabilities to sustain adequate employment, fulfill work obligations while being available to meet ongoing and unpredictable demands of exceptional caregiving, and experience better work-life fit. Unfortunately, parents of children with disabilities—particularly mental health disorders—may experience a lack of understanding in regard to their family situations due to minimal 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 (Lero et al. 2012; Principi et al. 2014;
Work and Family
Encyclopedia

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, and Lee 2002) and report experiencing courtesy stigmatization in the workplace as well (Angermeyer, Schulze, and Dietrich 2003; Rosenzweig et al. 2007; Stewart and Charles 2019).

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 looking into the gendered nature of work and family roles, introduced the concept of flexibility stigma, which is especially prevalent for men and fathers in the workplace (Berdahl and Moon 2013). Flexibility stigma refers to stigmatization experienced by men and fathers in the workplace when they use flexibility options to meet family demands. Using workplace flexibility for family reasons contradicts prevailing gender norms of men being solely dedicated to work and work responsibilities. With increased family demands related to exceptional care responsibilities, flexibility stigma could be especially relevant for fathers of children with disabilities, and fathers might be more reluctant to access workplace flexibility fearing repercussions since they violate male gender norms (Sellmaier 2019a; Venter 2011).

Research indicates that it is not the availability of flexibility that makes the organization family-friendly, but rather the workplace culture (Thompson, Beauvais, and 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 et al. 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, Kagan, and Heaton. (2000b) found that employees were reluctant to utilize available benefits fearing that their loyalty and commitment to the organization would be questioned. Supervisors and co-workers can play a critical role in establishing a positive and supportive environment, which reduces work-family conflict for parents raising children with disabilities (Brown 2014; Stefanidis, Strogilos, and Kyriakidou 2020; Stewart 2013). Supervisor support might not only positively affect work-life fit but possibly also reduce the risk of wage loss, at least for fathers (Earle and Heymann 2012).

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 et al. 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. In addition to the need to differentiate between access to and use of workplace flexibility, research also demonstrates that flexibility could be experienced as stressful. The availability of workplace flexibility can lead to blurring of boundaries between work, family, and community, which can actually increase a sense of work stress for individual parents (Kossek, Lautsch, and Eaton 2006, Sellmaier 2019a). Depending on family demands, parents of children with disabilities might also be forced to seek greater workplace flexibility. For example, one study of fathers who reported using more workplace flexibility reported higher levels of negative family to work spillover (Sellmaier 2019a).

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 (Stefanidis et al. 2020; 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, et al. 2005; Ronda, Ollo-López, and Goñi-Legaz 2016). In fact, one study found that shareholder value increased after public acknowledgements of a company’s family-friendly practices (Arthur and 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 to maintain employment and improve work-family fit (Emlen 2010; Kagan et al. 2008; Sellmaier 2019b; Stewart 2013). 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 et al. 2002), families of children with disabilities must often make complex and flexible arrangements for their care (Ceglowski et al. 2009; Heymann 2000; Weglarz-Ward and Santos 2018). Extended family members are often not available to care for children with intense needs, particularly those with behavioral challenges (Rosenzweig, Brennan et al. 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, Brennan 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 et al. 2016; Gilliam and Shahar 2006; Warfield and Hauser-Cram 1995). Parents might also be concerned about safety factors of child care programs that were willing to take their children with disabilities or even forced to terminate care arrangements because of safety concerns (Glenn-Applegate, Pentimonti, and Justice 2011; Jinnah and Stoneman 2007). When child care or out-of-school programs successfully include children with disabilities, they provide great support for working parents (Brennan et al. 2003). However, providers of inclusive child care and early childhood programs often require both specialized training and consultation with inclusion specialists or mental health consultants to design and provide the supports needed by children with disabilities and their families (Gilliam et al. 2016; Wiart et al. 2014).

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 government mandates to provide these additional services (Ceglowski et al. 2009; 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 et al. 2003). Further, children with behavioral challenges are often suspended from school, and school absences are correlated with less caregiver participation in the workforce (Brennan and 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. Certain school–based programs such as after-school care or summer programs are also geared towards the needs of older children with typical development, leaving parents of older children with disabilities struggling to find care for their children while they are not in school (Jinnah and Stoneman 2007; Meade and O’Brien 2018).

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 15% of families having children with special health care needs spent 11 or more hours a week in these health care activities, and 25.2% spent between 1 and 4 hours a week coordinating care (NSCH 2016). Receiving family centered care, care coordination, and needed referrals appear to be critical factors for reducing this time burden (Miller, Nugent, and Russell 2015), but the National Survey of Children’s Health (2016-2018) also reported that 7.8% of children with SHCN did not receive needed health care in the last 12 months compared to 2.1% of children without special health care needs (NSCH 2016-2018). Children of poorer households appear to be even more likely to experience unmet health care needs (McCabe et al. 2003). 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 (2004:249) describes community as “the connective tissue that makes [peoples’] work and family lives possible. It is the invisible framework that
connects families to the people and institutions that provide care, services, and support.” 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. Research has also demonstrated 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 (Kagan et al. 1998; Sellmaier 2019a; Stewart 2013). 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). Peer support providers raising children with special needs also can offer other parents emotional support and help with navigating the complex systems of health and special education services and finding other needed resources (Anthony et al. 2019; Gopalan et al. 2017; Kagan et al. 1998).

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 and 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 and Shelton 2003). A systematic literature review found similar results for parents caring for children with Cerebral Palsy, reporting that parents in these studies indicated higher levels of stress, and depression, and lower levels of quality of life compared to parents caring for children without Cerebral Palsy (Pousada et al. 2013). These effects appear consistent across different disabilities (Bourke-Taylor et al. 2012; Earle and Heymann 2011; Schuh 2008). 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
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, Heflinger, and Bickman 1997; McDonald, Poertner, and Pierpont 1999; Yatchmenoff et al. 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 and Heflinger 2006). Caregiver strain and parental stress is predicted by the severity of the child’s symptoms (Bourke-Taylor et al. 2012; Brannan and Heflinger 2001, 2006; Pousada et al. 2013), and is buffered by family strengths such as financial resources, social support, and health and social services (Bourke-Taylor et al. 2012; Brannan et al. 2006; Breitkreuz et al. 2014; McManus et al. 2011; Yatchmenoff et al. 1998). Ha et al. (2008) found mothers of children with disabilities had higher levels of stress and strain than did fathers. 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 (Brannan et al. 2018; Brennan and Brannan 2005). In addition, workplace supports such as access to sick leave and family-supportive supervisors can also be resources to improve physical and mental well-being for parents of children with SHCN (Earle and Heymann 2011).

Existing research demonstrates the economic consequences of caring for a child with a disability which includes both direct costs of care, and the indirect effects on families’ financial position due to inability to fully engage in work (DeRigne and Porterfield 2010; Kuhltau et al. 2005; Lynch and Dickerson 2012; Porterfield 2002; Power 2003; Ringel and Sturm 2001). The National Survey of Children’s Health (2016-2018) reported that 42% of parents of children with SHCN incurred costs between $250 and $5,000 in the prior 12 months related to covering medical and health care expenses. In the U. S., parents must pay fees 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 and Lynch 2008). The amount of out-of-pocket costs for families also appears to vary based on state policy provisions such as Medicaid eligibility thresholds (Parish, Shattuck, and Rose 2009). 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 (Ghosh and Parish 2013; Lynch 2007; Scott et al. 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). Families who reported their children’s symptomology as more severe, and families who spent more time providing or managing care were
more likely to change their employment situation (DeRigne & Porterfield 2010). At the same time having a medical home, receiving family centered care, and receiving the needed referrals had a positive impact and protected parents from needing to adjust their work schedules, and reduced the risk of accruing direct costs related to treatment (DeRigne and Porterfield 2010; Kuhltau et al. 2005).

Single parents living in poverty and receiving Temporary Assistance to Needy Families (TANF) income supports, were less likely to leave TANF if they were raising a child with a disability than if their children were developing typically (Parish, Rose, and Andrews 2010). 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.

Families with children with SHCN face specific challenges in maintaining employment, and achieving work life fit. Access and availability of meaningful resources in work, family, and community ecologies can support these families to maintain employment, experience less stress and strain, and achieve better work life fit. Accordingly, family members 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 and 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. Economic stability, relevant health and social services, social support from friends and family, and a sense of neighborhood cohesion are just some of the factors found to strengthen families’ resilience (Breitkreuz et al. 2014; McConnell, Savage, and Breitkreuz 2014; Ungar 2011).

**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. Although the law forbids discrimination against employees due to their care
responsibilities for a family member with a disability, *family responsibilities discrimination* is common, and the crux of an increasing number of lawsuits (Henle et al. 2020, Still 2006).

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] 2019). 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 and 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 and 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 2020). 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 national study by Gilliam and Shahar (2006) of expelled pre-kindergarteners made clear; without help from consultants available, teachers may advocate for permanent removal of children with difficult behaviors (Gilliam et al. 2016).

There are some major monetary *targeted supports* available in the U.S. for children with disabilities, particularly for those from 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 may be eligible for Temporary Assistance to Needy Families (TANF) for a limited period of time under special conditions (Ybarra and Noyes 2019). 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 (Sullivan, Farnsworth, and Susman-Stillman 2018). 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 those near the poverty line may draw payments from the Children’s Health Insurance Program (CHIP; Dreyer 2019). The Affordable Care Act, established in 2010,
provides special assistance through a health care team approach that can help children to avoid developing chronic health conditions (Perrin 2012).

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 nearly 1.3 million children in the United States in 2012 (Fremstad and Vallas 2012). 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. 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 (Kearney 2006).

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 (Ghosh and Parish 2015).

**IMPLICATIONS FOR RESEARCH AND PRACTICE**

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. Time use surveys or dairy studies could be another research tool to increase the understanding of daily requirements for arranging and implementing care. Implementing these types of studies within couples could shed additional light on how couples negotiate family and work responsibilities within the family unit. Such detailed research can inform the design of supports, benefits, and services that may improve the life opportunities of all concerned.

Longitudinal studies have also examined the dynamics over time as families struggle to secure and maintain suitable employment as they simultaneously provide care and manage to obtain supports for their children with special needs or disabilities. 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 et al. 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. More recently, DeRigne and Porterfield (2017), examined data from the Medical Expenditure Panel Survey, and uncovered the complex set of issues faced by parents who disengaged from the workforce while dealing with the special health care needs of their children. Their analysis demonstrated that families who had established a medical home, that provided health care through a stable source, and could count upon assistance managing their children’s services, had parents who maintained more stable work arrangements than parents whose children did not have a medical home. 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 special health care needs or 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. In addition, the experience of parents caring for children with SHCN should be examined across different individual and family situations. For example, additional research should investigate how experiences of work life fit differ or align across gender, or different racial and ethnic groups. How do single parent households, low-income households, or same-sex couples cope with the demands of caring for a child with a disability or special health care need and maintaining employment? This will allow for a better understanding of resilience across a variety of different experiences and for more targeted workplace, community, and policy supports.

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? Issues of stigmatization and disclosure should be included in these studies, since availability of resources cannot be equated with accessibility.

Current and future research might be used to inform policy and practice improvements at the organizational, regional, and national levels. For example, 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 (Bird and Brown 2018), 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. Organizations need to continue to create a family-friendly organizational climate so flexibility policies can be accessed without fearing repercussions. Supervisors are critical to set an example that demonstrates their own commitment to work-life fit. Training for HR professionals can help them better understand certain work-family policies that are especially relevant for families caring for children with disabilities, or counsel employees on disclosure strategies. In addition, investing in teaching and child care personnel to assure that staff are trained to deal with physical disabilities or behavioral issues. This can increase the availability of quality child care, and reduce suspensions for school-aged children, which will allow parents to maintain their employment. After-school programs, and summer programs should be expanded to accommodate children of older age, and should be inclusive of children of all abilities in their programming. Providing specialized services in the school setting can reduce the need to take time off during the work day to transport children to treatment appointments, again allowing families to better align work and family demands. Finally, examining the impact that workplace interventions might have on both psychological and physiological changes could yield compelling evidence supporting the use of targeted healthy workplace approaches to supporting the health of working parents. These are just a few suggestions for policy and practice changes that can support working families of children and youth with disabilities.

REFERENCES


Gopalan, Geetha, Maria Jose Horen, Eric Bruns, Miera Corey, Sarah Meteyer, Morgan Pardue,


*Individuals with Disabilities Education Act*, 34 C.F.R. 300.8 (1975).


Thyen, Ute, Karen Kuhlthau, and James M. Perrin. 1999. “Employment, Child Care, and Mental Health of Mothers Caring for Children Assisted by Technology.” Pediatrics 103(6):1235–42. doi: https://doi.org/10.1542/peds.103.6.1235


U.S. Department of Education. 2015. *Protecting Students with Disabilities: Frequently Asked Questions about Section 504 and the Education of Children with Disabilities.* [https://www2.ed.gov/about/offices/list/ocr/504faq.html](https://www2.ed.gov/about/offices/list/ocr/504faq.html)


**AUTHOR NOTE**

Support for the preparation of this revised manuscript was obtained through the Research and Training Center for Pathways to Positive Futures at Portland State University and funded by both the National Institute of Disability, Independent Living, and Rehabilitation Research and the Center for Substance Abuse and Mental Health Services Administration. (NIDILRR grant 90RT5030). NIDILRR is a Center within the Administration for Community Living (ACL). The content does not necessarily represent the policy of NIDILRR, ACL, HHS, or of SAMHSA, and you should not assume endorsement by the Federal Government. Preparation of the original entry was supported by the Research and Training Center on Family Support and Children’s Mental Health and funded by a National Institute of Disability and Rehabilitation Research Grant (H133B40038).