

Parenting Success and Challenges for Families of Children with Disabilities: An Ecological Systems Analysis

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This article examines factors that are associated with parenting success for caregivers of children with disabilities using Bronfenbrenner's ecological systems framework. Although numerous studies have investigated risk factors for negative parenting among caregivers of children with disabilities, there are relatively few research findings on parenting success. More specifically, we examine factors for parenting success within the context of micro- (parenting practices, parent-child relations), meso- (caregivers' marital relations, religious social support), and macro-systems (cultural variations, racial and ethnic disparities, health care delivery system), which is then followed by implications for social work practice.

Keywords: Caregivers, children, parenting, ecological systems theory, disabilities, special health care needs

INTRODUCTION

Children with disabilities require much parental attention, which can increase parental stressors. Several researchers have focused on negative adjustment for caregivers raising children with disabilities and special health care needs (Gerstein, Crnic, Blacher, & Baker, 2009; Knestrict & Kuchey, 2009; Parish, Rose, & Andrews, 2010). Findings from these studies suggest that multiple-level factors such as internalized parental stress; socioeconomic status; family rules, rituals, and routines; lack of adequate insurance coverage; and inaccessible community resources can compromise quality of parenting for caregivers of children with disabilities or who have special health care needs. While past studies have examined the negative impact of child's disability on parenting (Olshansky, 1962; Winkler, 1981), researchers more recently have examined the positive aspect on parenting and the family system (Blacher & Baker, 2007; Trute, Hiebert-Murph, & Levine, 2007). For the purpose of this article, children with disabilities are inclusive of children with special health care needs, and the terms will be used interchangeably.

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A growing body of research findings also suggest that parenting style, family dynamics, and environmental factors are important for understanding, assessing, and managing children's disabilities and/or special health care needs (Bitter, 2009; Gfroerer, Kern, Curlette, White, & Jonyniene, 2011; Johnson, Liu, & Cohen, 2011; Middlebrooks & Audage, 2008; Oyserman, Bybee, Mowbray, & MacFarlane, 2002; Whiteside-Mansell, Bradley, & McKelvey, 2009; Zlotnick, Wright, Sanchez, Kusnir, & Te'o-Bennett, 2010). A number of studies have shown that poor parenting quality has consistently been found to be associated with negative outcomes of children with disabilities and special health care needs such as behavior problems (Drotar, 1997; Hastings, 2002; Herring, Gray, Taffe, Sweeney, & Einfeld, 2006). Although much of the research findings provide data on risk factors for negative parenting among caregivers of children with disabilities, there is a major dearth of literature on factors for parenting success.

Progress is needed, both in the understanding of the factors that contribute to or mitigate parenting success of caregivers of children with disabilities and in the development of intervention strategies that enhance parenting success. Such progress requires a comprehensive and integrative framework that examines factors for parenting success at various levels of the social ecology. The objective of this review is to examine factors that are associated with parenting success of children with disabilities within multiple contexts. More specifically, we examine these factors within the context of Bronfenbrenner's ecological systems theory, which is then followed by practice implications for social workers working with caregivers of children with disabilities.

DEFINITION AND PREVALENCE OF DISABILITIES

The Federal Developmental Disabilities Assistance and Bill of Rights Acts define *developmental disability* as severe, chronic conditions that (1) are attributable to mental and physical impairments, or both; (2) are manifested prior to age 22; (3) are likely to continue throughout developmental stages; (4) result in limitations in three or more life activities, such as self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency; and (5) necessitate a combination and sequence of special interdisciplinary or generic care treatment or other services that are of extended or lifelong duration and are planned and coordinated (P.L. 106-402, 2000, pp. 7-8). "Developmental disability," however, is not interchangeable with all types of disabilities. As stated by Sullivan (2009), children can have a disability that may not necessarily be a developmental disability.

According to the Individuals with Disabilities Education Act of 2004 (IDEA), a *special needs child* is an infant or toddler (from birth to age 22) who is "developmentally delayed," which is defined as abnormal growth and development as determined by an early intervention interdisciplinary team of two or more professionals from appropriate allied and mental health professions (National Dissemination Center for Children with Disabilities, n.d.). According to McPherson et al. (1998), children with special health care needs are defined as "children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required for children generally" (p. 1).

Based on the U.S. Census Bureau (2005), more than 9% of families had a child with a disability in 2004. According to the U.S. Department of Health and Human Services (2008), 13.9% of children require special health care, and 21.8% of American households have at least one child with a special health care need. Children from birth to age 5 have the lowest prevalence rates (8.8%) compared to children 6 to 11 years of age (16.0%). The highest prevalence rates are among those 12 to 17 years old (18.8%). In terms of gender, boys are more likely to have a special health care need (16.7%) compared to girls (11.6%). With regard to race and ethnicity, multiracial children have the highest prevalence rates (18.0%), while children of Asian descent

have the lowest (6.3%). Among children with special health care needs in poverty, 38% of low-income parents reported emotional, behavioral, or developmental problems compared to 22% of high-income parents (U.S. Department of Health and Human Services, 2008).

These children experience a wide range of physical, emotional, and behavioral health challenges such as allergies (53.0%); asthma (38.8%); ADHD (29.8%); depression, anxiety, or other emotional problems (21.1%); mental retardation (11.4%); autism or autism spectrum disorder (5.4%); seizure disorder (3.5%); and juvenile-onset diabetes (1.9%). As these prevalence rates indicate, these children require parental obligations, attention, skills, or financial support.

Ecological Systems Review

The ecological framework facilitates organizing information about people and their environment in order to understand their interconnectedness. Individuals move through a series of life transitions, all of which necessitate environmental support and coping skills. Social problems involving health care, family relations, inadequate income, mental health difficulties, conflicts with law enforcement agencies, unemployment, educational difficulties, and so on can all be subsumed under the ecological model, which would enable practitioners to assess factors that are relevant to such problems (Hepworth, Rooney, Rooney, Strom-Gottfried, & Larsen, 2010, p. 16). Thus, examining the ecological contexts of parenting success of children with disabilities is particularly important. Utilizing Bronfenbrenner's (1977, 1979) ecological framework, this article explores parenting success factors at the micro- (i.e., parenting practice, parent-child relations), meso- (i.e., caregivers' marital relations, religious social support), and macro-system levels (i.e., cultural variations, racial and ethnic disparities, and health care delivery system) of practice.

Micro-System

Bronfenbrenner (1977) described the micro-system as a pattern of activities, social roles, and interpersonal relations experienced by the individual or a group of individuals in a direct setting (e.g., family, school). Factors at the micro-system level can directly affect caregiving for children with disabilities, such as *parenting practices* and *parent-child relations*.

Parenting practices. While there is limited research on micro-level parenting success factors for the broad category of children with disabilities, the literature provided some evidence for specific categories of disabilities. According to McDonald and Hastings (2010), fathers who were more attentive of their parenting role would be highly involved in their parenting tasks and were more likely to provide support and care to their child with a disability. Positive family support has also been demonstrated as an essential success factor (Boyd-Franklin, 2003; Perry & Henry, 2009).

African American children reportedly have greater levels of disability compared with other racial and ethnic groups due to low socioeconomic background (Newacheck, Stein, Bauman, & Hung, 2003). However, several studies also found that African American families experience greater success than other racial/ethnic groups in their adaptation and adjustment in raising a child with a disability (Daly, Jennings, Beckett, & Leashore, 1995; Dunlap & Hollingsworth, 1977; Neely-Barnes & Marcenko, 2004; Valentine, McDermott, & Anderson, 1998). As theorized by Ha, Greensberg, and Seltzer (2010), positive family support is especially important among African American families. Extended family support and kinship networks are ongoing mechanisms of physical, social, and psychological support for African American families (Crewe & Wilson, 2007; Gourdine, 2007; Taylor, Seaton, & Dominguez, 2008). For instance, a study by Ferguson (2002) found that a large number of caregivers experienced successful parenting while raising a child with a disability. Caregivers in the study received a considerable amount of support from other

family members. Successful parenting necessitates strong social support systems (Freedman & Boyer, 2000).

Other authors have identified the following resiliency factors as being successful in parenting of children with disabilities: parental psychological well-being or health, caregivers' tolerance and understanding of disabilities, a supportive partner or intimate relationship, and a positive parent-child relationship (e.g., Dyken, 2005; Heiman, 2002). For instance, Heiman reported that the caregivers of children with disabilities had positive experiences in parenting because the parent-child bond was strong. In contrast, Gerstein et al. (2009) found that parental stress in raising a child with a disability differs in mothers and fathers, with fathers experiencing less stress perhaps due to less time spent in parenting than mothers. This finding supports the McDonald and Hastings (2010) findings that indicate that parent mindfulness was greater in fathers who were stay-at-home dads. Gerstein et al found that the crossover effect of both parent's psychological well-being was a significant factor in reducing stress associated with raising a child with a disability. In addition, a positive father-child relationship was significant, but a positive mother-child relationship was not, for reducing stress associated with having a child with a disability. This difference may in part be explained by an earlier study that found that mother's over-involvement in the life of a child with a disability may increase her stress (Button, Pianta, & Marcin, 2001).

Parent resolution to and acceptance of the child's disability need is also a success factor. These parents are able to move on with their lives incorporating the child's challenges into their daily routines and lives. These parents do not focus on the causes of the disability but have realistic viewpoints about the challenge and expectations (Milshtein, Yirmiya, Oppenheim, Kroen-Karie, & Levi, 2010). According to Perry and Henry (2009), parental coping and problem-solving skills contribute to future success in parenting a child with a disability.

Parent-child relations. Child characteristics associated with the type of disability may influence the responsiveness of parents. Communication challenges found in children with autistic spectrum disorders may decrease the responsiveness and mindfulness of parents. As a result, the child with the disability may become distressed, leading to insecure or disorganized attachment (Howe, 2006). According to Howe,

sound socio-economic circumstances, good family harmony, reliable social support, and improved and better coordinated services by key agencies appear to reduce maternal stress, increase sensitivity and improve children's feelings of security. . . . Key to success is the ability of parent and child to communicate effectively and reciprocally. (p. 103)

Meso-system

Understanding factors associated with caregiving for children with disabilities necessitates an examination of the interactions at the meso-system level. A meso-system comprises the interactions or interrelations among two or more micro-systems, each of which can affect the individual (Bronfenbrenner, 1977, 1979; Compton, Galaway, & Cournoyer, 2005; Magnusson & Allen, 1983). Experiences involving one micro-system (e.g., caregivers' marital relationship, religious social support) may influence another micro-system (e.g., caregiver-child relations).

Caregivers' marital relations. A caregiver's marital relation is a meso-system-level factor that has been frequently examined in research (Parish et al., 2008). However, findings from a number of research studies have produced mixed results. For instance, Friedrich and Friedrich (1981) found that mothers of children with developmental disabilities reported less satisfaction with their marital relationship than those of normative children. Other researchers also suggest that the quality of marital relationship of caregivers of children with disabilities and special health care needs are lower than marital relationship of caregivers of children without disabilities due

to parental distress (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006) and marital violence (see Algood, Hong, Gourdine, & Williams, 2001). Kersh and colleagues reported that parents in their study appear to have lower-quality marriage than couples in the general population, and about one-fourth of parents in their sample characterized their marital relationship as 'distressed'

Other studies report no difference in the association between children's disability and parents' marital relations. A study by Seltzer, Greenberg, Floyd, Pettee, and Hong (2001) found from a large sample of parents in Wisconsin that marital status of parents of children with a developmental disability were similar to parents of children without a developmental disability. A meta-analytic study by Risdal and Singer (2004), which examined a body of research on marital satisfaction/discord in parents of children with and without developmental disabilities, found a much smaller effect of children's disability on parents' marital relationships.

Religious social support. Religion is another meso-system-level factor relevant to caregiving for children with disabilities. Religion as a social support utilized by caregivers of children with disabilities has received considerable research attention (Bennett, DeLuca, & Allen, 1995; Coulthard & Fitzgerald, 1999; Poston & Turnbull, 2004; Skinner, Correa, Skinner, & Bailey, 2001). Caregivers of children with disabilities experience high level of stress (Dyson, 1991), and the quality of caregivers' social support network can influence the quality of parent-child relations (Green & Rodgers, 2001). Findings from studies suggest that religion as social support is related to positive outcomes (Coulthard & Fitzgerald, 1999; Rogers-Dulan, 1998). A study by Bennett and colleagues (1995), which consisted of in-depth interviews with 12 parents of children with disabilities, reported that prayer, church attendance, and religious beliefs were identified as sources of social support. Coulthard and Fitzgerald, conversely, found from a sample of 60 families who had a child with autistic spectrum disorder that participants reported receiving considerably less social support from their religion, although support from personal beliefs were associated with better health.

Macro-system

The macro-system level of Bronfenbrenner's (1977) ecological framework is depicted as culture in which the individual is embedded. More specifically, Bronfenbrenner conceived the macro-system layer as a larger society, which consists of cultural values, laws, and customs, which influences the micro-, meso-, and exo-systems. Three examples of macro-system-level factor that are relevant to caregiving for children with disabilities are cultural variations, racial and ethnic disparities, and the health care delivery system.

Cultural variations. Culture affects the individual child as well as his or her relations with the caregivers and the larger community (Banks, 2003). Moreover, the effectiveness of intervention and services available and the types of support the child and family receives may depend on the culture and lifestyle of the family (Hanline & Daley, 1992). Hruschka (2009) contends that variations in culture, such as language and value, might impact daily functioning and health of children with special health care needs. Further, the author states that behaviors of those seeking care and their health risk might be influenced by culture, and the effectiveness of intervention strategies and treatment outcomes depends on whether they are consistent with the culture and lifestyle with the family.

Racial and ethnic minorities are more likely than Whites to report feeling that their cultural values are not considered and their concerns are not met by practitioners (Sorkin, Ngo-Metzger, & Alba, 2010; Substance Abuse and Mental Health Services Administration, 2001). Racial and ethnic minority families of children with disabilities do not receive adequate support and services due to disparities in the health care system. Despite the lack of adequate services, African American

families experience greater adjustment and satisfactions while raising a child with a disability. Taylor and Chatters (1986) argued that African American families have developed strong coping capacities due to a long history of overcoming many financial, educational, and social barriers.

Racial and ethnic disparities. Many researchers have documented that there are major disparities in the health care system between Whites and racial and ethnic minorities. Newacheck, Kim, Blumberg, and Rising (2008) found that gender, age, and ethnicity were major predictors of children's disabilities. African American children had a greater likelihood of being identified as having disabilities as opposed to non-Hispanic White children. Similarly, Newacheck, Hung, and Wright (2002) reported that disparities exist in regard to access and the use of services for children with disabilities. Van Dyck, Kogan, McPherson, Weisman, and Newacheck (2004) also argued that racial and ethnic minority children with disabilities do not receive services that are on par with White children with disabilities due to lack of services and dissatisfaction with the availability of services. Racial and ethnic disparities might occur due to cultural differences in the treatment outlook by racial and ethnic minority caregivers and the health care providers (Flores, Olson, & Tomany-Korman, 2005). These differences might be related to the needs of the child, how the child's health care needs are met, and the parents' ways of raising their children. Additionally, there is a major disparity between racial and ethnic minority children and White children in terms of health status, health insurance, and level of discussions by pediatricians during their visits, health care services, parental satisfactions, and links to other medical specialist (Flores et al., 2005).

Another area where major disparities exist is respite care, a support service for caregivers of children with disabilities. According to Nageswaran (2009), respite care needs for parents of children who experience disabilities have not been fully considered, despite the improvement in the availability of respite care since the passage of the Life Span Respite Act (2006) by the Congress. Although there have been improvements in services and support for families of children with disabilities, research has focused more on the deficits of the families rather than their strengths. For instance, findings from Kalyanpur and Rao's (1991) research on low-income mothers of children with developmental disabilities indicated that service agencies and professionals have the tendency to focus on deficits rather than their strengths. However, Mullins, Aniol, Page, and Chaney's (2002) longitudinal study on the effect of respite care on caregivers with developmental disabilities revealed that the impact of respite care on the families was very positive on their psychological functioning and well-being.

Health care delivery system. Access to health care services, such as equipment and counseling, is critical for children with disabilities or special health care needs. However, studies consistently find that low-income and racial and ethnic minority children are least likely to receive needed services (U.S. Department of Health and Human Services, 2008), such as primary care (Starfield, Shi, & Macinko, 2005). Ngui and Flores (2006) examined disparities in health care services for racial and ethnic children and their parents. Findings revealed that among Hispanic and African American parents of children with disabilities, 13% to 16% reported dissatisfaction with the health care services for their children. One-third reported difficulty in access to services due to less than adequate facilities and the care systems. Ngui and Flores suggested removing the existing language barriers between the caregiver and service providers, along with expanding insurance coverage for these families.

According to the American Academy of Pediatrics, Council on Children with Disabilities (2005), health care systems that coordinate care across several systems, educate and utilize families to coordinate their child's care, provide access to care based on the concept of a medical home, have adequate reimbursement rates for health care, and provide interdisciplinary training opportunities are all factors that will assist families in successfully raising a child with a disability.

PRACTICE IMPLICATIONS

As evident in this literature review, factors affecting parenting practices for children with disabilities are complex and multi-faceted, which provides a rationale for ecologically based practice implications. Social work and health care practitioners in particular play an important role in working with this population. Waldman, Perlman, and Rader (2010) argued that practitioners need to be sensitive to and have a deep understanding of the struggles that caregivers of children with disabilities face in order to provide appropriate intervention strategies.

Micro-/Meso-system

Considering that parenting practices and parent-child relations are salient factors at the micro-system level, it is important for practitioners to assess parenting practices and parent-child relations. In particular, practitioners need to assess factors that affect parenting practices and parent-child relations. For instance, findings from several research studies (Churchill, Villareale, Monaghan, Sharp, & Kieckhefer, 2010; Kersh et al., 2006; Sharpley, Bitsika, & Efremidis, 1997; Velsson, 1999) indicate that caregivers of children with disabilities are at increased risk of stress, depression, negative emotional state, and marital conflicts, which could undermine parenting practices and parent-child relations. Thus, counseling and intervention strategies that reinforce appropriate coping strategies and self-reliance can foster a sense of empowerment, which can potentially lead to better parenting skills (Churchill et al., 2010). Moreover, services that are family-centered and adequately address parent-related issues, such as family functioning and marital issues, are also most beneficial to caregivers of children with disabilities (King, King, Rosenbaum, & Goffin, 1999).

While it is important for practitioners to recognize the many challenges that parents face in raising children with disabilities, they must also be aware of the strengths of the caregivers. Parental strength can be enhanced when caregivers are provided with an adequate amount of support, as indicated in several research findings (Blacher & Baker, 2007; Ferguson, 2002; Mahoney, O'Sullivan, & Robinson, 1992). As evident in the aforementioned review, religious social support in particular has been found to buffer the negative outcomes associated with parenting for children with disabilities. Thus, it is imperative that practitioners assist caregivers in locating social support and resources that can facilitate parenting practices for caregivers of children with disabilities.

Macro-system

It is evident that there are major health care disparities between racial and ethnic minority and White caregivers. Barriers to health care services for racial and ethnic minority caregivers of children with disabilities may be attributed to lack of culturally relevant practitioners. Thus, practitioners need to bear in mind that intervention programs that are developed to address the needs of parents raising children with disabilities must be culturally congruent with the family (Sanders, 2008; Waldman et al., 2010). Banks (2003) emphasized that caregivers' knowledge of parenting skills is culturally prescribed, which also depends on family makeup and alignment, support from kin, gender roles, and tradition and mores. One of few studies that examined the impact of extended family members, Kelly, Whitley, and Campos (2010) found that intervention that considers kinship family support (e.g., grandparents raising grandchildren) is highly effective in enhancing parenting practices. The program was designed to empower grandparent caregivers by increasing their competency and control over their physical and mental well-being. Components of the program include home visits by nurses and social workers, parenting classes and support

groups, and early intervention services for children with disabilities. Findings from the study also suggest that such program could enhance parenting quality of low-income, racial and ethnic minority caregivers. It is also imperative that a system-wide approach to caring for children and families with children with disabilities is necessary for parental success.

It is critical that researchers and practitioners pay particular attention to the culture and lifestyles of families raising children with disabilities. This is particularly the case for racial and ethnic minority families who are often overburdened and feel helpless because the intervention programs and strategies are not consonant with their culture.

CONCLUSION

As this review suggests, factors associated with parenting success for caregivers of children with disabilities are multifaceted, which necessitates an ecological assessment of the individual (caregivers) and the environment in which the individual is embedded. It is especially important for researchers and practitioners to examine the ecology of parenting success, which must consider the micro-, meso-, exo-, and macro-system levels. We also provide information on assessment, intervention programs, and services that are designed to enhance parenting success for caregivers of children with disabilities. Successful intervention programs and services that enhance parenting success for caregivers of children with disabilities require an assessment at the multiple levels of the social ecology. This article serves as an impetus for understanding parenting success more holistically, which can inform researchers, practitioners, and policymakers in effectively assessing the multiple-level influences. These successes occur when proper supports are in place at the micro-, meso-, and macro-levels and are culturally sensitive to the needs of the child and family members. This article documents that successful parenting does happen when parents have these supports in place.

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