Supporting Siblings of Children with Disabilities in the School Setting: Implications and Considerations for School Counselors

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Abstract

This conceptual manuscript argues the utility of school counselors developing knowledge of and competencies to respond to the socio-emotional needs of the siblings of children with disabilities. The discussion informs readers of the range and diversity within this population, shares how the ecological contexts shape their experience and identity, and details how school counselors can leverage their skills to meet needs that emerge for this population as a result of their unique experiences.

Keywords: siblings, children with disabilities, school, school counselors

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Fatima is a well-adjusted, high-performing 4th grader at the local, public elementary school. She has several friends and generally enjoys her school experience. However, in the last several weeks, her teacher mentions to you in her referral that Fatima's behavior has become atypically concerning: she has become socially withdrawn, has missed assignments, and has been openly noncompliant. Fatima's teacher has referred her to you out of concern that the behavior is lasting longer than what he would have anticipated just being a "tough stretch". After meeting with Fatima, she reveals to you that her younger brother, Kareem, has autism and you realize that she is extremely frustrated. She is frustrated at her mom for spending more time with Kareem. She is angry at her brother because she feels embarrassed by his behavior and it prevents her from having friends to her house. And, she is angry because even when she does well in school, her mom doesn't celebrate her achievements the way she do when Kareem simply avoids a behavioral meltdown. Is Fatima the only student in your caseload with this narrative? If not, who are the rest and how are they faring socially, emotionally, and academically?

Consideration and support for people with disabilities is an important topic across contexts, including educational settings. The Americans with Disabilities Act (ADA) defines the term *disability* as, "...(A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment (Equal Employment

Opportunity Commission and the U.S. Department of Justice, 1991)." The Individuals with Disabilities Education Act (IDEA) is the federal law that ensures services to children with disabilities in educational settings and provides special education and related services for special needs children and adolescents up to 21 years old. The IDEA website (http://www.idea.ed.gov) indicates that more than 6.5 million infants, toddlers, children, and adolescents are eligible for IDEA services. The range of disabilities varies by district and impacts the school community (e.g., teachers, students, clinicians, administrators, etc.) greatly, but it is also important to for stakeholders to acknowledge how disabilities can, more broadly, impact a disabled child's family.

Influence of Disability on Family

One way counselors can better understand the influence of disability on the family is to study the phenomena through a systems orientation lens. Two theoretical orientations that highlight this complexity are Brofenbrenner's (1979) ecological model of human development and Bowen's (1978) family systems theory. The ecological model of human development theorizes that there is a reciprocal influence families have on the various contexts in which it operates and those various contexts influence families (Brofenbrenner, 1979). Bowen's (1978) family systems theory specifies some of the same central ideas articulated in ecological systems theory but focuses on the family unit. The theory argues that no individual can be understood in isolation from his/her family unit because of the family's emotional interconnectedness and its influence on individual members. It is important for school counselors to be cognizant of how a child's ecological and family influence their day-to-day experiences and the reciprocal nature of that influence. Children with disabilities uniquely influence their

families (Seligman & Darling, 2007) and this phenomenon is worth understanding more deeply when counselors consider the influence children with disabilities have on their siblings without disabilities.

There exists a body of literature that has explored this influence through both qualitative and quantitative methodologies, documenting the influence of childhood disability and families' adaptation and adjustment (Dyson, 2010; Seligman & Darling, 2007; Canary 2008; Riechman, Corman, & Noonan, 2008). Inquiry about the impact of a range of disabilities (developmental, learning, physical, etc.) on parents has been steady and informative (Semke, Garbacz, Kwon, Sheridan, & Woods, 2010; Trute, Hiebert-Murphy, & Levine, 2007; Gerstein, Crnic, Blacher, & Baker, 2009), most consistently reporting higher levels of stress for parents of disabled children compared to parents of nondisabled children. The impact of a child's disability on siblings has also been widely documented (Barr & McLeod, 2010; Iriarte & Ibarrola-Garcia, 2010; Smith & Elder, 2010), yielding a range of findings that are useful in helping school counselors learn about this unique experience.

Unique Experiences of Typically Developing Siblings of Children With Disabilities

The nature of sibling relationships has been studied widely. Recent work has included, but is not limited to how sibling relationships affect interpersonal identity development (Watzlawik & Clodius, 2011), power and conflict negotiations (Recchia, Ross, & Vickar, 2010), and parenting practices (Karande & Kuril, 2011). Studies exploring the relationship experiences between typically developing children and their siblings with disabilities have been used to inform healthcare providers in various settings on interventions for this particular population. Little research discussing how

this phenomenon might look within the context of the school has been done, but much can be learned from what is available.

There appear to be at least four relational domains of influence in the discussion on how a child's disability affects his or her typically developing sibling: (a) the internal influence, (b) the relational influence with peers and adults outside of the family unit, (c) the relational influence on primary caregivers, and (d) the relational influence on the sibling with the disability.

Internal Influence

The most common finding in much of the empirical literature on the influence of a child's disability on his/her typically developing sibling is the experience of increased stress in comparison to children who do not siblings with disabilities (Barr, McLeod, & Daniel, 2008). Intensity and frequency of the stress associated with having a sibling with a disability varies. However, school counselors realize that the ability to healthily manage stress is critical for school-aged children because of how it can impact student performance and success. Additional internal challenges for the typically developing sibling are the potential for low self-esteem (Atkins, 1991), increased risk of internalized behavioral problems (Ross & Cuskelley, 2006), and a heightened sensitivity to typical family stressors (Nixon & Cummings, 1999). The negative outcomes sometimes associated with this lived experience have significant implications for the school experience.

Relationships With People Outside of the Family

School-aged children are expected to navigate relationships within their various ecological contexts that generally include their neighborhood, school setting, and

community setting. Typically-developing children with a sibling with a disability may confront unique challenges in these navigation processes. One of these challenges is experiencing stigmatizing peer interactions in neighborhoods (Green, 2003). Counselors can easily interpret these types of interactions carrying out in the school setting, as well. Another challenge typically developing siblings confront is role assumption or assignment by caregivers or other authority figures in relationship to their brother or sister with a disability. Barr, McLeod, & Daniel (2008) found that the typically developing child generally took on the role of *interpreter* or *protector* with outsiders unaware of or insensitive to the child with a disability and in many cases this role was implicitly or explicitly expressed. There is additional research that highlights how typically developing children benefit from having a sibling with a disability. Macks and Reeve (2007) found that children with a disabled sibling generally demonstrated higher levels of empathy compared to children with typically developing siblings.

Relational Experiences With Caregivers

Among the most glaring realities with this phenomenon is how caregivers must differentiate their parenting styles between children with and without disabilities, depending on the type and severity of the disability. In their qualitative study, Barr, McLeod, & Daniel (2008) documented how typically-developing children related to their parents. They described receiving less parental attention and feeling concern and sympathy for their parents. The study also documented that due to their parental sympathy, the typically developing child might assume a *parentified* role for the parent by attempting to relieve them of typical parental responsibilities. This phenomenon may

present as a strong leadership trait in the school setting but counselors must be mindful of how this conditioned behavior may be a source of tremendous stress.

Relational Experiences on the Sibling With the Disability

Research has also documented how typically-developing siblings interpret and make meaning of their relationship with a brother or sister with a disability. Ross and Cuskelley (2006) found that typically developing siblings can very easily experience anger toward their sibling with a disability and discussed importance of finding appropriate coping techniques to address such feelings. One study of 22 sisters and 11 brothers of siblings with disabilities found that typically developing siblings articulated varying emotions about their mentally disabled sibling where among them, worry and unease was the most frequently occurring emotion because of the nondisabled siblings' perceptions about their sibling's future, differential treatment in the home, and conflicts due to discrimination and insults toward the sibling at school and other social contexts (Iriarte & Ibaroola-Garcia, 2010). Not only might typically developing children assume a parentified role for their parent, but research has documented how they can assume that role for their sibling with a disability (Barr, McLeod, & Daniel, 2008; Barr & McLeod, 2010). Further complexities in understanding this experience are highlighted by Nixon and Cummings (1999) who reported how typically developing children can also feel great admiration for their sibling.

Implications and Considerations for School Counselors School Context for Psychosocial Development

Developmental theorists (Erikson, 1963; Havighurst 1972; Bandura, 1977) have provided evidence to support the notion that school aged children (6-18 years old) are

confronted with developmental tasks to achieve during this important time in their lives. The school, with all of its complex parts, functions as a laboratory for children to ideally accomplish developmental tasks in a highly social context. Erikson (1963) argued that children between 6 and 12 years old have the capacity to develop a sense of industry, by learning and acquiring new skills. A sense of inferiority can develop if children feel unsuccessful in acquiring such skills. Between 12 and 18 children are confronted with opportunities to become confident in their identity within a broader context of family and school, based on how they interpret and approach new learning opportunities. Children unable to engage in experiences that facilitate this development are at risk for what Erikson (1963) described as role confusion.

Bandura's (1977) social learning theory is useful in the discussion of how the school setting influences children's social development. He wrote, "most human behavior is learned observationally through modeling: from observing others one forms an idea of how new behaviors are performed, and on later occasions this coded information serves as a guide for action" (p. 22). Children in the school setting are consistently challenged with the choice to model what is considered appropriate or inappropriate behavior and, consequently, influence the meaning derived from such behavior. Havighurst (1972) similarly argued that mastery of age-appropriate tasks fosters a healthy sense of identity in school-aged children between 6 and 18 years old. The tasks Havighurst (1972) identified within this time frame included: developing physical skills for games, learning to get along with peers, developing a positive view of self, developing a sense of conscience (i.e., morality), and achieving personal independence. Considering the extent to which schools support, or hinder, a child's

development, it behooves counselors to be keenly aware of how the school context might impact children in their work.

The American School Counselors Association (ASCA) developed the ASCA National Standards (2004) to inform and structure how school counselors help meet the needs of school children by framing counselor support along three domains: Academic Development, Career Development, and Personal/Social Development. These domains provide school counselors a roadmap to create and implement programs, interventions, and support systems to assist students in developing and meeting goals. The domains further substantiate the important role school counselors assume in helping holistically nurture children. The respective standards within each domain are intended to be inclusive to support children from diverse backgrounds. Among those diverse backgrounds exists a population of children whose lives are impacted by a brother or sister with a diagnosed disability (i.e., students eligible for an Individualized Educational Plan and/or 504 Plan). These students, as discussed earlier, share some common and complex experiences that can benefit from specific school counselor practices.

Counselor Self-Awareness

Counselor education literature has appropriately identified self-awareness as one ingredient for success in any counseling context, particularly in diverse school settings (Evans, Zambrano, Cook, Moyer, & Duffey, 2011; Margolis, 1986; Niles, Akos, & Cutler, 2001; Lawson, 2007; Henricksen & Watts, 1999). And while much of counseling scholarship points to the importance of self-awareness in working in racially and ethnically diverse clients, it is equally important for counselors to be aware of their cultural identity, biases, and assumptions when it comes to disabilities. Counselors'

ability to work with students whose families are affected by disabilities certainly falls within the scope of multicultural competence. ASCA (2004) addressed multiculturalism by noting that multicultural competency was demonstrated by school counselors' awareness of how their own cultural identity impacted the counseling process.

Moreover, the Council for the Accreditation for Counseling and Related Educational Programs (CACREP, 2009) specifically addressed the role of school counselors by requiring foundational knowledge in issues of advocacy, diversity, equity, and barriers that impede student success. As school counselors take inventory and become aware of their "blindspots" to avoid projecting negative or assuming attitudes to students who have siblings with disabilities, they position themselves to provide a more empathic and effective scope of services.

Interventions and Support

School counselors are challenged to meet the needs of large numbers of students over the course of an academic year. According to the National Center for Education Statistics (NCES) Common Core Data (CCD), the national average student to counselor ratio during academic year 2008-09 was 459 to 1 (2010), although ASCA recommends the student to counselor ratio be 250 to 1. This average varies from state to state, but the reality is that school counselors have to balance providing contextually appropriate services to as many students as possible.

Group counseling. Group counseling in the school setting continues to be an effective method to reach larger numbers of students with impactful programming and outreach (Newsome & Gladding, 2007). For this specific population it is useful to consider psychoeducational groups to begin the process of meeting needs. Bergin

(2004) informs readers that psychoeducational groups use educational methods to help students gain knowledge and skills in several domains, such as personal identity and interpersonal interaction and tend to focus on central themes that correspond with students' developmental levels. Group work for siblings of disabled children has provided a fruitful way to reach this population in both elementary and secondary levels.

Naylor and Prescott (2004) developed a support group for school-aged siblings of children with disabilities, between 8 and 18 years old, with overwhelming success. Outcomes associated with this particular intervention were self-reported increases in: self-esteem, quality of life, social interaction, coping strategies within the family situation, understanding of disability issues. Additional endorsement and support for group work has come via the Sibling Support Project (Meyer & Vadasy, 2008), whose program is broadly designed to provide the brothers and sisters of special needs children with peer support in a highly recreational context. This project has been modeled in over 200 locations, including 8 countries.

Iriarte & Ibaroola-Garcia (2010) reiterate that group-based interventions must be motivated by a need to attend this population's developmental and emotional needs, which for school counselors, directly aligns with facilitating students' healthy emotional development. Specific recommendations for sibling support groups are that they be organized along domains that include, but are not limited to: relationship with parents, understanding disabilities, social life, and/or other personal aspects (Benderix & Sivberg, 2007). It is useful to collaborate with personnel who work directly with special needs students and families (e.g., Child Study Team, Intervention & Referral Services Team, School Psychologist) to effectively coordinate outreach. Counselors can facilitate

students identifying what focus would best help them (coping skills, communication skills with parents, self-awareness, etc.) to confront their respective experiences and challenges related to having a sibling with a disability

Individual counseling. School counselors are aware of the need to work with clients on an individual basis, too. Newsome & Gladding (2007) remind school counselors that providing counseling services to children and adolescents in the school setting must be approached with sensitivity because of several considerations. "What distinguishes individual counseling from other forms of interaction is the close emotional contact between the student and professional school counselor" (p. 170). Brown and Trusty (2005) further clarify individual counseling in the school setting by disclosing that the focus is on the student's problem or concern and the goal is to help the student make positive changes in coping, adapting, or in specific behaviors that are problematic.

Among the most salient of considerations for individual counseling in the school setting are developmental considerations. Knowledge of developmental theories can help school counselors make informed assessment and decisions about whether a particular behavior is developmentally appropriate or not (Vernon, 2004). It is also helpful to acknowledge how multidimensional and complex development can be for school-aged children (Gladding & Newsome, 2004). Should counselors identify a need that requires individual counseling for a student whose sibling has a disability, Orton (1997), outlines a model of the counseling process that generally applies across theoretical orientations and is useful in schools. The phases include: building a counseling relationship, assessing specific counseling needs, designing and implementing interventions, and conducting evaluation and closure.

Leadership development. Leadership skill development is a desired outcome of a strong school counseling program because counselors recognize that students should be empowered to become leaders in their school communities (Bailey, Getch, & Chen-Hayes, 2007). Identifying developmentally appropriate leadership activities for students who have a sibling with a disability can nurture their development in this area. School counselors can identify siblings of disabled children to coordinate service leadership opportunities for special needs populations in an individual school or particular school district. Counselors can also consider engaging siblings of disabled children as "consultants" in helping train their peers, teachers, and administrators to more effectively support special needs students. School counselors at the high school level can also engage their students with disabled siblings in peer mentoring of younger students who have disabled siblings to provide very genuine and empathic support that mentors without this experience might not deliver as effectively.

No matter the form of intervention, the value of a strength-based approach in working with this population can be critical. "School counseling programs that use a strengths-based, 'nondeficient' advocacy model are perceived as educational leaders in schools providing measurable equity, achievement results, and success for all students" (Bailey, et. al, 2007, p. 98). Research reinforces this model for this population by focusing interventions (individually or in group) that draw attention to how living with a disabled sibling has enriched their lives by giving them a strong sense of empathy, love, and social justice (McMillan, 2005; Swenson, 2005). Counselors who acquaint themselves with the needs of this population are better equipped to provide the contextually-based interventions necessary in times of intense stress, which potentially

can lead to diminished academic and social functioning. Interventions framed along any or all of these topics are feasible within the domains of the ASCA National Standards (2004) and can provide support, hope, inclusion, and inspiration for the population of siblings of children with disabilities.

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