

SURVIVING OR THRIVING: AN EXPLORATORY ANALYSIS MEASURING THE  
AWARENESS AND PERCEPTIONS OF EDUCATORS TOWARD THE SOCIAL-  
EMOTIONAL NEEDS OF SIBLINGS OF CHILDREN WITH DISABILITIES

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For Jackie. You inspire all of us more than you know.

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**Abstract**

There are approximately 6 million children in the U.S. who receive special education services to address an identified disability. Many of these children live with typically developing siblings (referred to in this study as "Siblings"). Research suggests that although Siblings may be negatively affected by the needs of the disabled child, there is potential for higher levels of positive outcomes in the social and emotional development of Siblings if they are given opportunities to learn about disabilities and develop positive coping skills. Further research determined that Siblings are mainly considered in the context of their homes and families, however there is little information about how Sibling experiences impact their social and emotional functioning in other settings, including school. This study was designed to determine whether educators are aware of Sibling experiences and how they affect their academic and behavioral performances in school, and the level to which they perceive the potential for positive outcomes as a result of Sibling experiences. Lastly, this study purposed to determine whether educators perceived the need for Sibling support to be a school responsibility as well as home. Results suggest a limited awareness of Sibling needs in educators and generally negative perceptions about Sibling experiences and outcomes. Results also suggested that educators may not consider themselves to be catalysts for Sibling outcomes and are not responsible to support their needs in the school setting.

## **Chapter 1**

### **Literature Review**

In 1975, the Individuals with Disabilities Education Act (IDEA) was established to ensure that children with disabilities receive a free and appropriate education that meets their specific needs. This law was revised to the Individuals with Disabilities Education Improvement Act (IDEIA) in 2004 to include early intervention services for children who were diagnosed with disabilities prior to school age. As of 2010, the United States Census Bureau reports that 21 million American families have a family member with a disability. The same database reports that approximately 2.8 million children in the U.S. aged 5-17 have a reported disability that impairs a child's vision, hearing, cognitive, ambulatory, and age-appropriate skills related to independent functioning and self-care.

According to the National Center for Educational Statistics, over 6 million children received services under IDEIA during the 2015-2016 school year. These services include speech therapy, physical therapy and occupational therapy, counseling, and classroom accommodations. School-based interdisciplinary special education teams conduct assessments and collaborate to determine the best course of action to support these students to ensure their success in the academic setting.

In addition to school-based support services, federal and state government assistance programs have been established to support children and adults with disabilities such as Supplemental Security Income (SSI), Social Security Survivor Benefits/Social Security Disability Benefits, Temporary Assistance for Needy Families (TANF), and healthcare provisions through Medicaid and the Children's Health Insurance Program (CHIP). These programs provide resources for individuals with impairments to find jobs,

independent living, and facilitate peer interactions while recipients attend school, and often after they graduate. Many of these programs recognize that the individuals they serve require support and cooperation from their families, and ensure that there are resources available for them, as well.

### **Resources for Family Support**

Although there are resources that directly address the needs of individuals with disabilities, states also provide resources for families of children with disabilities, such as New York State's Office for People with Developmental Disabilities (OPWDD), the Delaware Autism Program (DAP), and Ohio's Opportunities for Ohioans with Disabilities (OOD). These programs often provide workshops such as parent trainings, counseling for parents, and even group family counseling. They often employ social workers, behavior intervention specialists, and group leaders to support families in finding government assistance, manage behavior at home, and identify safe activities for children and adults with disabilities to engage in. Unfortunately, despite the assistance provided by the government and organizations dedicated to helping this population, many families continue to face significant financial and emotional demands when caring for a child with one or more disabilities (Chien & Lee, 2012; Quine & Pahl, 1991; Roberts & Lawton, 2000; Stabile & Allin, 2012).

According to Stabile and Allin (2012), the cost of caring for a child with a disability can total between an additional \$20,000 to \$60,000 of childcare costs per year, when factoring in direct monetary costs and lost wages due to time off for special appointments associated with the disability or staying home to care for the focal child. Additionally, parents are generally required to spend more time and effort providing extra care in the

home, without outside assistance, for the child with the disability (Roberts & Lawton, 2000). Parents of children with disabilities report that their personal time, social life, and family activities are limited at a higher rate than parents of nondisabled children (Chien & Lee, 2012; Quine & Pahl, 1991). According to Quine and Pahl (1991), families that have a higher income and social class are better able to minimize the stress and provide balance for themselves and their families; however, this does not help families that have more financial difficulties (pg. 67).

### **Impact of the focal child's needs on Siblings**

While there are federal and state government programs available to assist families in caring for members with disabilities, researchers have demonstrated a growing awareness of the social-emotional needs of typically developing Siblings of children with disabilities. This population includes those with chronic illnesses and mental disorders, particularly the concern of parents, specialists, and educators regarding the ways in which this population copes with the complications of living with a child with a disability (Tsao, Davenport, & Schmeige, 2011). It has been well documented that typically developing children growing up with a sibling with a disability face unique trials, and experience various feelings and emotions, including jealousy, resentment, confusion, and responsibility for their sibling (Strohm, 2005; Hames & McCaffrey, 2005; Williams, Piamjariyakul, Graff, & Stanton, 2010). Most of the literature, however, focuses on these effects in the home setting, and only briefly approaches the impact these experiences may have in schools (Wolf, Fisman, Ellison, & Freeman, 1998; Williams et al, 2010; Sim & Frydenberg, 2011).

For this study, the term “disability” will be defined as any mental and/or physical disability that manifests itself before the age of 22, will likely continue throughout the person’s life, and significantly impairs the person’s ability to function in one or more daily life activities such as learning, mobility, and/or social interaction (Williams, Piamjariyakul, Graff, & Stanton, 2011). In this body of work, the child with the disability will be referred to as the “focal child,” based on the terminology used by Tsao, Davenport, and Schmeige (2011). Additionally, this study will use the term “Siblings” to refer to children who are the typically developing siblings of the child with a disability (Sim & Frydenberg, 2011).

When seeking to understand the nature of the relationship between Siblings and focal children, it has been found that the topic of Sibling outcomes outside of the home is underexplored and under-addressed (Tsao, Davenport, & Schmeige, 2011; Kresak, Gallagher, & Rhodes 2009; Sim & Frydenburg, 2011), despite evidence of both positive and negative impacts of living with a child with a disability. Because of the variety of factors and effects associated with a given disability, typically developing children (Siblings) have the potential to be exposed to a range of maladaptive behaviors, fluctuating routines and expectations based on the nature of the focal child’s disability, parental stress, and added household responsibility (Naylor & Prescott, 2004; Tsao, Davenport, & Schmeige, 2011; Kao, Romero-Bosch, Plante, & Lobato, 2012; Breslau, Weitzman, & Messenger, 1981). This level of instability can directly influence the behavior of a Sibling, and impact social interactions and relationships with others.

Through various surveys, interviews, books, and anecdotes, Siblings and parents have specifically reported perceptions of decreased parental attention and altered sibling relationships because of the additional needs of the focal child. This population frequently

reported negative behavioral manifestations in Siblings such as defiance, jealousy of the focal child, and frustration toward the needs of the focal child, as well as increased peer aggressions in the school setting (Sim & Frydenburg, 2011; Breslau, Weitzman, & Messenger, 1981; Strohm, 2005; Hames & McCaffrey, 2005; Williams, Piamjariyakul, Graff, & Stanton, 2010). A child's age, birth order, and sex also have the potential to impact the way a Sibling adjusts to the needs of the focal child, as well as the severity of the disability (Sim & Frydenburg, 2011; Kresak, Gallagher, & Rhodes, 2009; Naylor & Prescott, 2004; Breslau, Weitzman, & Messenger, 1981). According to Sim and Freydenburg (2011), Siblings who are younger are more likely to exhibit maladaptive behaviors in response to difficulties related to the focal child, while older Siblings generally demonstrate higher levels of stress related growth.

Breslau, Weitzman, and Messenger (1981), and Lobato and Kao (2005) introduce the concept of "mattering." More specifically, whether or not a child believes that he or she matters to his or her parents, was directly linked to "deviant," or "delinquent" behavior, as well as the Siblings' self-perception of competency as impacted by how well they understand the focal child's disability and associated needs. Breslau, Weitzman, and Messenger (1981) noted that younger Siblings generally have more needs than older children but are expected to assume more domestic responsibilities. Additionally, female children are more expected than males to support with the care of the focal child. Kresak, Gallagher and Rhodes (2009) note that Siblings are often left out of conversations regarding the focal child, and as they get older, they begin to experience more difficulties dealing with the needs of the focal child and their own anxieties.

Researchers have also observed elevated levels of anxiety, withdrawal, aggression, and dominance displayed in Siblings in comparison to same-age peers who do not share their experiences (Naylor & Prescott, 2004; Williams et al., 2010), as well as a higher propensity to develop poor peer relations (Breslau, Weitzman, & Messenger, 1980). For example, Siblings may feel neglected by their parents in favor of the sibling with special needs (Naylor & Prescott, 2004; Breslau, Weitzman, & Messenger, 1980; Wolf et al., 1998). This may lead to feelings of resentment and influence aggressive and withdrawn behaviors. Tasks and responsibilities, such as providing supervision, helping parents with taking care of the focal child, and navigating challenging behaviors associated with the focal child's disabilities have the potential to limit Siblings' social lives and ability to engage in the same activities as their typical peers (Kao et al., 2012). Siblings in these circumstances reported elevated levels of stress, anxiety, and resentment toward the focal child (pg. 548).

Many studies highlight negative aspects of having siblings with disabilities that directly impact social-emotional functioning, academic functioning, and long-term outcomes (Breslau, Weitzman, & Messenger, 1981; Williams, 1997; Wolf, Fisman, Ellison, & Freeman, 1998; Naylor & Prescott, 2004; Giallo & Gavidia-Payne, 2006; Williams, Piamjariyakul, Graff, Stanton, 2010; Meyer, Ingersoll, & Hambrick, 2011; Burke, Taylor, Urbano, & Hodapp, 2012; Sanders & Syzmaski, 2013). Another group of researchers emphasizes the value of growth and positive outcomes that appear to be unique to a child growing up as a Sibling (Sim & Frydenberg, 2011; Manor-Binyamini & Abu-Ajaj, 2012; Sanders & Syzmaski, 2013). These conflicted findings make it difficult to

identify pinpoint Siblings' needs, which makes it difficult to design and create programs and organizations that will effectively address the social emotional needs of Siblings.

**Minimal Sibling Outcomes.** Despite most researchers highlighting positive and negative Sibling outcomes, a small group of experts argues that having a sibling with a disability has little to no impact on a child's social-emotional functioning (Benson & Karlof, 2007; Neely-Barnes & Graff, 2011). Benson and Karlof (2007) conducted a study to compare adjustment between two groups of Siblings of children with Autism Spectrum Disorder (ASD). Because ASD is often hereditary, children who have siblings with ASDs are environmentally and genetically at-risk for being diagnosed as well. Reporting on the results of 72 families of children who were receiving services for ASD from 35 different schools in Massachusetts, this study compared adjustment issues in Siblings who have been diagnosed and those who have not been diagnosed with a disability.

While taking into consideration socioeconomic status, parent education, and other environmental factors, the study compared Sibling adjustment in the areas of Emotional Symptoms, Conduct Problems, Hyperactivity, Peer Problems, and Prosocial Behavior, to typical U.S. children norms. Their findings indicated that, with the exception of Emotional Symptoms, Siblings who had not been diagnosed with a disability did not exhibit more adjustment problems than siblings of children without disabilities (p. 591). Results from the Emotional Symptoms subscale suggested similar levels of difficulty in this area among typical Siblings and siblings who had also been diagnosed. Unsurprisingly, Siblings who were diagnosed with a disability exhibited adjustment problems across all areas.

Neely-Barnes & Graff reported similar findings in a 2011 study of the adverse consequences of being a Sibling of a person with a disability. Using Propensity Score

Matching (PSM), these researchers analyzed data from the 2006 National Health Interview Survey to compare mental health problems, behavioral difficulties, or greater mental health services between Siblings of children with disabilities and siblings of children without disabilities. The results indicated that, with the absence of environmental risk factors such as low socioeconomic status, family dysfunction, and parental marital discord, there was not a significant difference in the mental health of Siblings of children with disabilities and siblings of children without disabilities. Therefore, the researchers concluded that simply being a Sibling does not necessitate intervention without the presence of co-occurring risk factors (p. 338).

Both studies acknowledged research limitations such as methodological design, small sample size, in large part due to the lack of organizations and support groups that are dedicated to Siblings of children with disabilities, and brief measures which require follow-up. In addition, both studies used secondary data, which limits the ability to specifically define parameters when controlling for variables and determining comparison groups.

**Negative Sibling outcomes.** While some researchers suggest that Siblings can function across all settings comparably to peers without their experiences, there is overwhelming evidence that living with a child with a disability can have long-term negative effects on a Sibling's ability to cope, adjust, and build healthy relationships. Researchers commonly recognize sibling relationships as one of the most influential and longstanding relationships children encounter, and therefore significantly impact their social and emotional development across multiple settings (Kresak, Gallagher, & Rhodes, 2009; Breslau, Weitzman, & Messenger, 1981; Manor-Binyamini & Abu-Ajaj, 2012; Williams, Piamjariyakul, Graff, & Stanton, 2010; Kao, Romero-Bosch, Plante, & Lobato,

2011; Meyer, Ingersoll, & Hambrick, 2011; Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996). It is a common belief that chronic or continued behavior of one sibling will impact the behavior of the other long term. Therefore, if a child is diagnosed with a disability that often negatively impacts behavior, such as ASD, Intellectual Developmental Disorder (IDD), Conduct Disorder (CO), Oppositional Defiant Disorder (ODD), Attention Deficit-Hyperactive Disorder (ADHD), Fragile X Syndrome, or an Emotional or Behavioral Disorder (EBD), logic indicates that the associated behaviors will directly influence or impact any same- or similar-aged children (Siblings, cousins, non-related peers) who live with them.

In support of this theory, Williams (1997) conducted a literature review of over 40 studies on the effects that living with children with spina bifida, cerebral palsy, seizure disorder, traumatic brain injury (TBI), Down Syndrome, Fragile X Syndrome, and ASDs had on families and siblings that were conducted between 1970 and 1995. Williams et al. (2010) revisited this review when conducting a study to evaluate parents' descriptions of the way Sibling experiences impact individuals both negatively and positively. The research team also attempted to identify the reasons for the effects. The findings in 1997 were that most of the studies reported negative Sibling outcomes, although there were some findings of low and positive impact.

In the 2010 review, Williams et. al identified three main categories in which Sibling behaviors reflected the impact of their experiences with the focal child: negative effects, positive effects, and no effects (p. 45). Based on the words parents used to describe the manifestations of effects on Siblings, 61.1% indicated negative effects, 1.7% indicated no effect, and 37.2% indicated positive effects. Negative effects included reports of

challenging behaviors such as “unkind remarks,” emotional problems such as anger toward the focal child, loneliness, depression, embarrassment of the focal child, and jealousy toward the focal child (p. 46). Positive effects included reports of elevated levels of sensitivity and caring, and personal growth and maturation (p. 49).

Breslau, Weitzman, and Messenger (1981) and Meyer, Ingersoll, and Hambrick (2011) examined the psychological response and adjustment of Siblings over an extended period of time. Breslau, Weitzman, and Messenger interviewed 370 families with children diagnosed with cystic fibrosis, cerebral palsy, myelodysplasia (bone marrow failure disorder), and multiple disabilities to determine whether Siblings exhibited psychological impairments and elevated levels of aggressive behavior when compared to siblings of typically developing children. They also examined the level at which the type and severity of the focal child’s disability impacted the psychological functioning of the Sibling, as well as whether age and birth order were related to psychological functioning.

The research team determined that Siblings generally did not exhibit elevated levels of psychological impairment, and that there was no difference based on the type and severity of the disability. They did find, however, that Siblings exhibit higher levels of interpersonal aggression with peers and within the school setting (pg. 350). The study also found that, as individual factors, age and sex did not affect psychological functioning in Siblings; however, male Siblings who were younger than the focal child experienced greater psychological impairment, and female Siblings who were older than the focal child exhibited difficulties as well, including deprivation of parental attention, premature obligations, and maladjustment in challenging situations (pg. 344). The highest correlations in this study were identified between Siblings and school problems, which

could indicate further complications later, such as dropping out of school, drug abuse, and trouble with the law.

Although Breslau, Weitzman, and Messenger (1981) determined that the type of disability of the focal child had little to no impact on Sibling development, Meyer, Ingersoll, and Hambrick (2011) found that Siblings of children with ASDs were more likely to struggle with developing positive coping skills. This research team used a research data base to contact 90 families and had them complete a depression scale to measure depression in mothers, a social responsiveness scale to measure behaviors observed in the Sibling when compared to the focal child, and a behavioral scale to study the behavior of Siblings of children with ASD. According to the results of this work, Siblings of children with ASDs likely have an increased risk of experiencing difficulties with adjustment, and that mothers of children with ASD reported higher symptoms of depression, which in turn negatively impacts the children in the home (p. 1418). The researchers hypothesized that a mother who is experiencing depressive symptoms will likely have more difficulties maintaining balance between caring for the focal child and adequately attending to the Sibling, which will directly impact the way the Sibling copes.

The research has been consistent in revealing the likelihood of Siblings exhibiting elevated negative emotional outcomes as a result of being a Sibling. Multiple studies have cited parent and sibling reports that Siblings experience feelings of embarrassment, anger, and sadness due to the circumstances and events that occur within the sibling relationship (Kao et al., 2011; Williams et al., 2010; Strohm, 2005). These feelings tend to be elevated when Siblings do not understand the focal child's disabilities or are unable to establish their own identities outside of the care of the focal child.

In addition to the internalizing and externalizing difficulties exhibited among siblings, researchers found an initial reluctance of the Sibling to address their own discomfort in relation to their siblings (Naylor & Prescott, 2004; Kao et al., 2011). When interviewed in a hospital research study, Siblings often reported concern and worry for their sibling, including the desire for better companionship or care for the focal child (Kao et al., 2011). Also, while responding to questionnaires about their experiences, children were found more likely to give avoidant responses such as "I don't know," or "nothing" when directly asked to discuss challenges related to their sibling (Naylor & Prescott, 2004).

One hypothesis for this phenomenon is that Siblings are conditioned to refrain from complaining about their personal discomfort regarding their sibling (Naylor & Prescott, 2004). It is common knowledge that suppressing emotions and failure to process feelings in a healthy manner can lead to unhealthy coping skills, which can lead to maladaptive behaviors and habits long term. As such, logic suggests that Siblings may not have the skills to identify when they are experiencing emotional crisis and seek help. This could potentially impact other areas of functioning, including learning in the classroom and developing outside peer relationships.

**Positive Sibling outcomes.** In the face of discrepant arguments that Siblings are relatively unaffected or are negatively affected by their experiences, there is yet another group of researchers who believe that being a Sibling can influence positive outcomes in social emotional development (Sim & Frydenburg, 2011; Manor-Binyamini & Abu-Ajaj, 2012; Sanders & Syzmanski, 2013). These researchers have identified methods in which Siblings have overcome the complications of living with a child with special needs, and incorporated them into skills that propelled their success across multiple domains.

Sim and Frydenburg (2011) conducted a study to explore the connection between stress, coping, and stress-related growth. The researchers stated interest in the extent to which Siblings reported stress-related growth (SRG), external factors that contribute to SRG, and the family factors associated with SRG in Siblings. Through a quantitative study in which 25 families responded to an online questionnaire regarding sibling experiences, the research team found both positive and negative changes related to SRG. The researchers identified problem-solving, the ability to focus on the positive, being physically active, and making social connections as effective strategies for positive growth in Siblings.

Moreover, the results of this study indicated that positive SRG is directly related to strong family relationships between parents and children, and between siblings. Open communication and problem-solving as a family were also factors that directly impacted positive changes. In direct contrast, negative SRG changes were affected by difficulties with communication between family members and ambivalent relationships between siblings. Finally, the researchers found that as the age of the children with disabilities increased, there were higher reports of SRG from the Siblings. This was interpreted as possibly indicating a higher level of development of communication and adaptive skills in the children with disabilities, generally putting less pressure on their Siblings (p. 161). Limitations to this particular study included a small sample size (n = 25 families), which limited the number of robust statistical analyses that could be conducted to explore different variables.

The findings of Sim and Frydenberg (2011) are supported by the research conducted by Mayor-Binyamini and Abu-Ajaj (2012), along with Sanders and Syzmanski

(2013), who each found that Siblings who were able to establish an identity outside of being a Sibling developed healthier coping skills. Mayo-Binyamini and Abu-Ajaj (2012) administered questionnaires to approximately 200 pre-adolescent students and found that Siblings who were active in a religion or cultural traditions displayed lower levels of stress when compared to siblings of typically developing children. Sanders and Syzmanski (2013) interviewed approximately 35 children and found that Siblings who were not heavily depended on to help take care of the focal child also exhibited healthier coping skills than those who were given caretaker responsibilities. The consistency of these results indicate that it is important for Siblings to find interests outside of the focal child to maintain a healthy balance in their own social and emotional development.

**Family interventions.** Although this work focuses on Sibling needs, it is important to consider them within the context of the entire family. A common method that families use to address issues in the home is to attend family therapy. It gives all members of the family the opportunity to gain the perspective of other family members, and ideally provides a safe space to identify family dynamics and address unhealthy behaviors. According to Sayger (1996), multi-family group therapy has the potential to create resilient children, as it provides children with the opportunity to receive attention and affection from other adults and exposes them to other children who have similar experiences.

Perlick et al. (2013) conducted a clinical study in which 14 families of veterans with a Traumatic Brain Injury (TBI) participated in multi-family group therapy. This study took place over multiple phases in which the veterans were assessed individually, then with their families, who were given pre- and post-intervention assessments. Afterward, all families participated in educational workshops about TBI before participating in group

therapy for six months. The results of this study found a significant decrease in caregiver burden and an increase in family empowerment.

Ziffer, Crawford, and Penney-Wietor (2010) conducted a school-based family intervention for children of divorce. At the time of the intervention, there was no existing option for group therapy for children of divorce (pg. 158). Under the supervision of licensed family therapists, school counselors conducted multi-family counseling with five participating families. The intervention took place over the course of eight weeks. Pre- and post-intervention interviews were conducted, and the families reported stronger relationships with their children in the home and strengthened their relationships with other adults. A three-year follow up was conducted in which the families requested a reunion of the group, as they felt their time together was effective. The researchers also noted this study indicates that school professionals can provide effective mental health services to the children and families they serve in schools.

Although these studies do not specifically highlight the Sibling experience, they reinforce the need to address overlooked populations, such as children of divorced parents, relatives of TBI victims, and Siblings of children with disabilities. Specific multi-family group counseling exposes whole families to others who are experiencing the same things and empowers them to build healthier relationships with their own families. Perhaps the most relevant perspective that these studies provide is that these interventions build resilience and strength in the children who are often not otherwise given the opportunity to explore their own development in the context of the events taking place around them (Sayger, 1996; Ziffer, Crawford, & Penney-Wietor, 2010).

**Sibling interventions.** Despite limited documentation regarding available resources providing Sibling support groups, trainings, and social-emotional interventions (Tsao, Davenport, & Schmeige, 2011), several researchers have launched and evaluated the outcomes of support groups and other interventions to encourage and promote positive social-emotional outcomes in Siblings (Naylor & Prescott, 2004; Hartling, Milne, Tjosvold, Wrightson, Gallivan, & Newton, 2010; Lobato & Kao, 2005; Kresak, Gallagher, & Rhodes, 2009; McConkey, Gent, & Scowcroft, 2013). Some groups implemented interventions using a model that centered on educating the Sibling of the focal child's disabilities, separate from their families (Granat, Nordgren, Rein, & Sonnander, 2012; Lobato & Kao, 2005). The purposes of these models were to empower Siblings to learn about the focal child's disabilities and foster positive sibling relationships.

Lobato and Kao (2005), Granat, Nordgren, and Sonnander (2012), and Naylor and Prescott (2004) experimented with Sibling interventions that focused on group treatments with Siblings and parents, with the intention of educating Siblings on disabilities, and supporting parents in finding effective ways to educate the typically developing child on the needs of the focal child. Each study conducted pre- and post-treatment interviews with participants to determine the effectiveness of their interventions. Lobato and Kao (2005) worked with 15 families and found that, while parents did not report observing visual improvements in sibling relationships, the children who participated reported feeling more competent within themselves regarding their abilities to adapt to their siblings' needs. Granat, Nordgren, and Sonnander (2012) similarly found that, at the end of their study with 54 participants, Siblings reported having more fun with the focal child as a result of spending less time in their presence while participating in the Sibling group.

Finally, Naylor and Prescott implemented a Sibling support group comprised of 55 Siblings total, that lasted for approximately 5 months and met biweekly. At its conclusion, parents commented on the advantages of their typically developing children being able to associate with other children who had similar issues and experiences as them. Parents also stated that their children exhibited elevated levels of self-esteem and positivity regarding their situations. Children reported feeling "less annoyed" with their siblings and reductions in negative feelings in general, particularly when the focal child engaged in a behavior that was particularly unpleasant for the Sibling. This indicates that the participants were able to develop or strengthen coping skills which enabled them to handle their siblings in a more positive manner.

**Future implications for Siblings.** The research that was previously discussed provides implications that highlight the need for additional emotional support for Siblings, as well as educational resources to help them better understand the needs of the focal child in the home. Williams et al. (2010) stated that there was a need to build on positive attributes of the Sibling experience and to limit the negative risks associated with being a Sibling, and for practitioners in family-centered care to address Sibling experiences and well-being (p. 52). Most of the published research on this subject emphasize the importance of providing education and information to the Sibling about their sibling's disability, as well as adopting and maintaining positive attitudes and perspectives (Sim & Frydenburg, 2011; Williams et al., 2010; Kresak, Gallagher, & Rhodes, 2009; Naylor & Prescott, 2004; Kao et al., 2011; Manor-Binyamini & Abu-Ajaj, 2012; Tsao, Davenport, & Schmiede, 2011).

Other key elements of the social emotional development of Siblings included cultural and environmental factors. Researchers consistently highlighted that having a child with a disability often correlates with living in a single-parent household, low socioeconomic status, a parent or another sibling having a disability or chronic illness, and overall family dysfunction (Benson & Karlof, 2007; Neely-Barnes & Graff, 2011). It is arguable that Siblings need additional support when considering children who are exposed to similar challenges but do not have siblings with disabilities. Kao et al. (2011) also noted that some cultural traits could serve as supports for Siblings. Siblings from Latino backgrounds (e.g., Puerto Rico, the Dominican Republic, Panama, Costa Rica, etc.) who were encouraged to partake in the care of siblings with developmental delays developed positive relationships with the child. Although there were still issues of negative feelings and interactions, these siblings exhibited compassion and a greater level of understanding of their siblings than other ethnic groups (p. 550).

Another study demonstrated that Siblings who were expected to care for children with mental disorders experienced less positive growth than Siblings who did not participate in caring for children with mental disorders (Sanders & Syzmanski, 2013). Some of the contrast may be attributed to the nature of the disabilities included in each study. Kao et al. (2011) studied siblings of children with developmental delays, while Sanders and Syzmanski (2013) conducted a study involving mental illness; both types of disabilities presented challenges, but the circumstances presented different outcomes. This further supports the argument that Siblings require unique interventions to address a wide variety of outcomes due to the wide variety of challenges associated with each disability or illness.

In addition to information derived from studies that identify Sibling needs, it should be noted that Siblings often have a clear understanding of their own challenges and needs (Tsao, Davenport, & Schmiede, 2011; Arnold, Heller, & Kramer, 2012; Strohm, 2004; Hames, 2005). According to anecdotes from Strohm's (2004) book, *Siblings*, adults and children often recalled feelings of irritation, embarrassment, abandonment, and loneliness. Hames (2005) featured anecdotes from children, aged 4 through 12, who expressed desires to interact with their siblings like "normal" children, including the freedom or permission to retaliate to the challenging behaviors the focal child exhibits (i.e., making hurtful comments, breaking the Sibling's personal items, hitting) and engaging in social activities with their siblings (e.g., going to the mall together, physical play, etc.).

Most Siblings expressed a desire to complain about their experiences without feeling guilty, and to be understood. The main theme identified through these anecdotes was a need for Siblings' feelings to be validated and adequately processed in a healthy manner. Hames (2005) used each anecdote as an opportunity to explore healthy coping strategies, including relaxation exercises (deep breathing, counting backward from ten, finding an outlet to release the stress, etc.). Based on this information, Siblings who are provided with an opportunity to discuss their true feelings without fear of guilt or reprimand would more likely thrive than those who are made to suppress their feelings in favor of the focal child.

**Siblings across domains.** Much of the research targeting Siblings used anecdotal information, through semi-structured interviews (Naylor & Prescott, 2004; Williams & Piamjariyakul, 2010; Kao et al., 2012), analyses and meta-analyses of previously conducted research (Kresak, Gallagher, & Rhodes, 2009; Sim & Frydenberg, 2011), and

controlled clinical studies (Breslau, Weitzman, & Messenger, 1981; Granat, Nordgren, Rein, & Sonnander, 2012) to measure predictors of social-emotional outcomes and identify needs for social-emotional intervention and supports. Additionally, while many researchers compared the social-emotional outcomes of Siblings to those of their same-age peers, including the ability to socialize with children who did not have siblings with disabilities, none of the present research measured these outcomes specifically within the school setting, or from the viewpoint of educators who spend a considerable amount of time with students throughout the week. While parents and certainly the Siblings themselves provide important insight on the impact of Sibling experiences on long-term outcomes, teachers often serve as great resources for predictors of outcomes through their observations of behavior in the classroom setting among same-age peers. To ignore this aspect of Siblings' experiences would be to ignore a major component of their development.

### **Siblings in Schools**

When addressing the needs of Siblings in the learning environment, it is important to identify the needs highlighted in available literature regarding Sibling needs. The issues that researchers continually discuss include the presence of stress and how Siblings generally cope with the needs of the focal child (Sim & Frydenberg, 2011; Giallo & Gavidia-Payne, 2006; Kao et al., 2012; Williams et al., 2010; Manyor-Binyamini & Abu-Ajaj, 2012; Naylor & Prescott, 2004; Granat et al., 2012), difficulties that Siblings have expressing their own dissatisfaction and needs (Kao et al., 2012; Lobato & Kao, 2005; Strohm, 2005; Wolf et al., 1998), maladaptive externalizing and internalizing behaviors (Wolf et al., 1996; Williams et al., 2010; Manyor-Binyamini & Abu-Ajaj, 2012; Hastings,

2007), and finally, the impact of knowledge about the focal child's disability and associated needs have on the Sibling in all the aforementioned areas.

**Stress and coping.** Researchers have found that parents who possess effective coping skills when caring for the focal child are generally better equipped to support the typically developing Sibling (Sim & Frydenberg, 2011; Giallo & Gavidia-Payne, 2006; Lobato & Kao, 2005). Using scales that were developed to measure caregiver burden and Sibling behaviors, Roper, Allred, Mandleco, Freeborn, and Dyches (2014) surveyed 136 families consisting of children with disabilities to study the connection between the types of disability, caregiver burden, and sibling relationships. They found that families who do not have positive coping skills, however, are more likely to experience stress as a unit, and more specifically, cause the Sibling stress. The results of this study are consistent with reports that Siblings who are required to participate in the caregiving process at the expense of their own individual and social needs feel stressed and resentful toward the focal child (Kao et al., 2012; Strohm, 2005; Hames & McAffrey, 2005).

When considering Sibling stress, one must also acknowledge the impact that stress has on learning. Siblings have reported feeling that they need to be perfect in order to offset the limitations of their siblings with disabilities (Strohm, 2005; Hames & McAffrey, 2005). These statements indicate self-imposed pressures are likely not prevalent in children with typical siblings, but creates additional stress for Siblings, which can ultimately impact their learning and behavior in school.

Yang & Chen (2016) highlighted the correlation between stress and learning burnout. According to their research, students who attempted to live up to others' perceived standards experienced higher levels of stress than students who set their own learning

goals, which led to exhaustion in learning. Vogel and Schwabe (2016) studied the neurological impact that stress has on learning in the classroom and found that although stress does not impact children's ability to understand new information, it does interfere with the ability to retrieve and build on information that has been learned prior. Willis and Nagel (2013) interviewed 16 educators (i.e., teachers and school administrators) in Uganda and found that student learning was negatively impacted due to exposure to trauma and stress. Students who experienced trauma displayed "gaps" in their learning, indicating that they were unable to fully retain information (pg. 44). The research team also found that their students responded positively to educators taking additional steps to provide emotional and instructional supports during the school day to help them overcome their difficulties, such as modeling appropriate social interactions, provide safe learning environments, and exhibit integrity in their instruction (pg. 49).

Siblings who are experiencing stress related to their siblings' disabilities need to learn how to cope with their feelings while using tools to ensure that their needs are met. If their parents are unequipped to address needs related to stress and coping, it is a logical expectation that their learning in school will be impacted. Additionally, Siblings may require supports to generalize these skills across domains. Without the perspective of those who work with and observe them in the school setting, it is difficult to ascertain the depth of needs in this area within the learning environment.

In addition to stress related difficulties, another area of need for Siblings is that of self-advocacy. According to the research of Lobato and Kao (2005), Siblings are often reluctant to express their own discomfort and needs. This study theorized that Siblings have been conditioned to defer their own needs to those of the focal child, and therefore have

not developed the skills to express their own needs. Kao et al. (2012) noted that Siblings did not want to discuss their dissatisfaction outside of hopes related to their siblings (e.g., wishing that their sibling could have friends of their own, go out and play, etc.). This difficulty can also extend to the ability to request help when needed. Siblings who are experiencing difficulties in school may be reluctant to ask for help when struggling because they have been conditioned to figure things out for themselves. As a result, they leave themselves vulnerable to misunderstanding material or struggling unnecessarily because they did not request assistance or express their own needs for learning.

**Behavior.** Another aspect of Sibling needs that directly impacts learning is that of internalizing and externalizing behaviors. Williams et al. (2010) conducted a study surveying 151 parents who reported negative manifestations in Siblings, such as anger, jealousy, anxiety, worry, depression, and low self-esteem. Meyer, Ingersoll, and Hambrick (2011) interviewed 90 mothers of children with ASD, who were also raising at least one typically developing child via questionnaires. They noted that Siblings of individuals with Autism experienced difficulties with adjustment. Giallo and Gavidia-Payne (2006) used a scale to measure parent stress, Sibling adjustment, parenting and family functioning, and Sibling stress and coping in 49 families. The results indicated elevated levels of adjustment problems and difficulties relating to peers in Siblings.

Like stress related struggles, behavioral and adjustment difficulties can severely impact learning. Students are expected to make multiple transitions throughout the school day and year, which requires constant adjustment and adaptability. Additionally, they are expected to coexist with peers and interact in a healthy manner, including using problem

solving and conflict resolution skills. Difficulties in these areas will make it hard for learning throughout the school day and have the potential to disrupt the learning of others.

**Educator Knowledge and Response.** Finally, researchers note that the amount of knowledge that Siblings have directly impacts their perceptions of themselves, their siblings with disabilities, and their overall abilities to cope with the needs associated with the focal child (Sim & Frydenberg, 2011; Lobato & Kao, 2005; Kresak & Gallagher, 2009). The more Siblings and families in general understand the focal child's disability and specific needs, the easier it is for them to accept their circumstances and communicate with one another, fostering healthy coping skills and problem-solving strategies. Unfortunately, parents are not always able to take on the responsibilities of the caregiver and learn enough to educate the Sibling (Stabile & Allin, 2012; Roberts & Lawton, 2000). Additionally, parents do not always possess the pedagogical competency that a teacher or school related service provider may have to adequately educate the Sibling on the focal child's disability or monitor Sibling adjustment to the needs of the focal child. As such, the Sibling would likely benefit from a collaboration between home and school to identify their level of knowledge and understanding and how they are affected across settings.

**Support for Siblings.** Given the universal supports that are available to focal children, parents, and families as a unit and the lack of a general model designed specifically for Siblings, there is a strong likelihood that Siblings do not receive the necessary tools to learn about their siblings' disabilities, or their own abilities to cope and advocate for themselves outside of the home. This may not pose an issue for children whose parents have the time, education, and emotional resilience to provide healthy outlets for their children (Sim & Frydenberg, 2011; Kresak, Gallagher, & Rhodes, 2009), but for many

families, these resources are not available. According to Sim & Frydenberg (2011), families that are unable to understand or explain the nature of the focal child's disability to the typically developing Sibling are more likely to experience family stress and long-term negative Sibling outcomes (pg. 154). In other words, individual members of the family, namely Siblings, are likely to experience higher stress levels due to a lack of understanding, information, and healthy coping methods.

As researchers report that stress impacts learning (Willis & Nagel, 2013; Vogel & Schwabe, 2016), and Siblings are likely to experience stress and trauma while navigating the needs of the focal child (particularly if there are significant health and behavioral concerns), it would be negligent of researchers to ignore the possibility of stressors negatively impacting Siblings' behavioral and academic performance in the school setting. It is arguable that this population would benefit from additional opportunities to learn strategies for coping and self-advocacy from professionals (e.g., counselors, speech therapists, etc.) who are trained and able to provide the support needed.

### **Approaches to Measuring Educator Awareness and Perceptions**

Researchers have measured the attitudes of educators regarding various topics by gathering data from participating principals, teachers, and school guidance counselors. Cook, Semmel, and Gerber (1999), and Praisner (2003) conducted studies to observe teacher and principal attitudes toward the inclusion of children with disabilities. They each used surveys to measure the opinions of 115 teachers and principals (Cook, Semmel, & Gerber, 1999), and 408 principals (Praisner, 2003) regarding their attitudes and intentions toward including students with special needs in general education classroom. Wood, Evans, and Spandagou (2014) used a Principals and Behavior survey to analyze the

attitudes of 340 principals toward including students with behavioral and mental health problems in mainstream schools. Finally, Levins, Bornholt, and Lennon (2005) measured teachers' attitudes, experiences, feelings, and behavioral intentions toward children who have special education needs.

Bryan and Holcomb-McCoy (2007) surveyed 205 school counselors to measure their involvement in school-family-community partnerships to compare to respondents' general attitudes about their roles and abilities as counselors to foster positive relationships between the school and outside entities. Parkinson (2006) conducted a qualitative study in which 25 counselors were interviewed via email and subsequently a group discussion regarding their attitudes toward the need for more extensive education on disability awareness and equality. Surprisingly, there was little documentation that focused on the attitudes of school psychologists and social workers within the school setting on any given subject. Most researchers contacted schools directly to recruit participants and distribute surveys (Praisner, 2003; Levins, Bornholt, & Lennon, 2005; Cook, Semmel, & Gerber, 1999). One group used a stratified, random sample that did not yield a large enough sample size; as an alternative, the researchers accessed the database of a local principals' professional organization and recruited participants through email (Wood, Evans, & Spandagou, 2014).

Because of the lack of representation of school clinicians, related service providers, and even building administrators on a given topic related to student issues, this study presents a unique opportunity to identify the awareness and perceptions of these professional groups toward the needs of an underrepresented population of students (Siblings). This work is also important as it is intended to provide comprehensive insights

regarding the needs of Siblings by drawing from a multidisciplinary target base. By nature of their positions, although teachers may be the first to recognize and report difficulties in the classroom, related service providers and administrators are generally called upon to provide the supports and education needed for classroom teachers and students to identify solutions and appropriate supports. Despite their very necessary roles, these groups have the least amount of representation when studying attitudes toward students with disabilities and their families.

Based on the most popular mode of sample gathering, the most effective way to reach the target group is to approach potential participants within the school setting or by making direct contact through various modes of communication, including email, phone calls, and post mail. Walsh, Rassiafani, Mathews, Farrell, and Butler (2010) point out, however, that relying on the school staff throughout the process of scale development and validity testing can be burdensome to the participants, who are already under pressure due to intense work-related demands (p. 329). As such, it would be beneficial to find ways to maximize participation without taxing participants. This may include pinpointing specific times of the school or calendar year when educators are not as busy, such as summer vacations or days when schools are closed.

### **Need for the Educator Perspective**

Considering the underrepresentation of specific educator groups in overall research and the limited amount of information on Sibling adjustment and performance in schools suggests that the level of awareness among school professionals, specifically school administrators (e.g., principals, vice principals, etc.), teachers, and related service providers (e.g., school guidance counselors, social workers, psychologists, etc.) regarding the social-

emotional needs of Siblings, is less than what is necessary to adequately identify these needs in the school setting. Additionally, it is uncertain whether educators would identify the unique needs of Siblings as a school issue or as a matter best handled in the home or by outside professionals. More research in this area is needed to further identify implications for long-term social-emotional functioning and academic performance among Siblings in the educational environment.

### **Purpose of Study and Research Questions**

The purpose of the proposed study is twofold: first, to explore the perceptions and awareness of educators toward Siblings, and second to encourage professionals to be more conscious of the needs and experiences of a population that is largely overlooked. Although there is a lot of information about Siblings in the home and in relation to their families, the amount of information available regarding Siblings in schools and interacting with unrelated peers is severely limited. It is important to include educators when studying Sibling outcomes to give researchers a more well-rounded view of the impact that Sibling experiences have on their academic and behavioral performance in the school setting.

To achieve this purpose, this study will distribute a survey to educators to address the following research questions:

1. To what extent are teachers, administrators, and related service providers aware of the challenges that the typically developing siblings of children with disabilities face?
2. Do educators' perceptions of the social-emotional functioning of typically developing siblings of children with disabilities differ based on their specific roles in the school?

3. Do educators perceive that the possible impact of the needs of siblings of children with disabilities on their social-emotional development requires in-school supports and education for Siblings?
4. Do most educators have generally negative or positive perceptions of Sibling outcomes and experiences?

## **Chapter 2**

### **Methods**

#### **Participant Characteristics**

The New York State Education Department Reference File contains a public directory that provides access to the telephone and email information of over 7,000 school administrators throughout the state. These administrators represent schools in rural, suburban, and urban areas. This wide range of geographical diversity suggests that there is a high variety of ethnic, socioeconomic, and cultural backgrounds in the schools represented in this directory. The participants of this survey consisted of three groups: building administrators (principals, assistant principals, supervisors), classroom instructors (general education teachers, special education teachers, specialist teachers), and related service providers and building clinicians (speech providers, guidance counselors, occupational therapists, physical therapists, school psychologists, school social workers, etc.) who are currently employed in these schools throughout the state of New York.

A total of 110 individuals consented for the researcher to use their responses for the purpose of this study. When asked to respond to the statement, "I have worked with Siblings of children with disabilities," 89 respondents selected "Yes"; 13 selected "No"; and 4 selected the "I Don't Know" response. Of the 89 respondents who indicated having worked with Siblings, 67 completed the first five sections of the survey. 75 (68%) of all respondents completed the demographic portion which identified their positions as teachers, related service providers, or school administrators (N=75). Most respondents identified as related service providers (45.3%). Specific job titles included classroom teachers, special education coordinators, principals, superintendents, occupational

therapists, guidance counselors, school psychologists, speech therapists, and school social workers.

Most participants identified as female and were 41 years of age and older. 73.3% percent have worked in 3 or more schools. 52% have worked in their respective positions for 10 years or more, and 53% reported having obtained a Master's Degree as their highest level of education (see Table 1).

### **Procedures**

**Sampling methods.** The researcher used random sampling to select specific districts from the New York State Education Department Reference File. With a list of approximately 734 schools, the list was separated into seven (7) sections consisting of 104 schools per section. The researcher then chose numbers from a bag to determine which district to target. A second number was chosen to determine a counting interval to select 20 districts per section. The researcher then accessed school district public websites to directly email school staff in the district, including teachers, related service providers, and school administrators (Wood, Evans, & Spandagou, 2014).

The email consisted of a brief description of the study, as well as a link to the survey measuring educator perceptions and awareness of Siblings. The email also stated that participants had the option to participate in a lottery in which they could win a gift card to a popular retailer, such as Amazon, Target, or Walmart (See Appendix C).

In addition to accessing official district websites, the researcher accessed professional groups on social media, specifically educator groups on Facebook and LinkedIn for additional opportunities to reach school educators outside of the school setting. This was a moderately successful effort, particularly during the summer months

when school faculty were generally not working. Ultimately, the majority of survey responses came from emailing staff members directly through their district email addresses.

**Survey design.** The survey consisted of six (6) sections that were designed to briefly measure different aspects of educator awareness and perceptions toward Sibling needs in the school setting. Survey sections were as follows: Stress and Coping, Behavior, Knowledge and Response, Support, Open-Ended Questions, and Demographics (See Appendix D). Prior to the start of the survey, the researcher presented a question asking respondents whether they have worked with Siblings in the school setting. Response options were “Yes,” “No,” and “I Don’t Know.” Only respondents who answered “Yes” were invited to take the entire survey. Those who responded “No” and “I Don’t Know” were immediately directed to the Open-Ended Questions section.

The Stress and Coping section measured educators’ perceptions about the way Siblings handle stress. Respondents were asked to report on the way Siblings use coping skills, advocate for themselves during stressful situations, and ask for help with difficult tasks. Items in this section included: “When compared to typical peers, Siblings complain a lot,” “When compared to typical peers, Siblings put a lot of pressure on themselves to do well,” and “When compared to typical peers, Siblings ask for help when they need it.” There were eight (8) items in this section.

The Behavior section of the survey analyzed educator perceptions of Siblings’ ability to adjust to changes in their environment, resolve conflicts with others, and exhibit self-control. Respondents were asked to report on whether Siblings display behaviors related to anxiety, depression, or low self-esteem. Items in this section include: “Siblings

follow the rules,” “Siblings are disruptive in class,” and “Siblings are off-task.” There were eight (8) items in this section.

The Knowledge and Response section reviewed the educators' efforts to learn as well as teach students about disabilities. Responses to these items suggested the level of consciousness educators have toward Siblings in their general practice. Items in this section included: “I have attempted to speak with a Sibling of a child with a disability about his or her experiences,” “I actively provide lessons to help children understand disabilities and special needs,” and “I actively attempt to learn about disabilities and how they affect children and their Siblings in school.” There were four (4) items in this section.

The Support for Siblings section reviewed educators' efforts to provide support to Siblings in the school setting. Responses to these items suggested educators' likelihood to encourage Siblings to advocate for themselves, understand the focal child's disability, and provide tools to help them navigate difficult situations. Items in this section included: “I actively seek ways to support Siblings in the school environment,” “I try to help Siblings identify healthy coping skills when things are difficult,” and “I work to ensure that Siblings have access to resources and people they can consult to help them understand their siblings' disability.” There were five (5) items in this section.

The Open Ended section gave respondents the opportunity to express their perceptions of Sibling development in their own words. Participants were requested to identify some experiences that Siblings may encounter, and how these experiences may impact their growth. There was one question in this section; however, in which participants were given room to expound on their responses if they so choose.

Finally, the Demographics section provided the background information of respondents to determine the levels of awareness and perceptions of Sibling needs between professional groups. Participants were asked to report their racial ethnicity, age, sex, length and depth of experiences in their fields, and their specific job titles. Responses were analyzed based on participants' professional groups, age, ethnicity, and level of education, and other present variables.

**Participant Safeguards.** The risks regarding participants' privacy and safety were minimal. Participants are informed of the purpose of the survey and asked to respond to questions based on their professional experiences. Participants were given the option to decline or rescind their participation at any time without questions or threat of consequences. Additionally, the survey was distributed through a link for interested participants to access at their convenience and designed to consume as little time as possible to ensure that there were no major interruptions to participants' time or responsibilities.

**Care and use of results.** Apart from those choosing to enter the lottery, participants were not asked for identifying information, such as names, addresses, or the locations of the schools that employ them. All individual contact information was kept on a separate encrypted USB flash drive which was only be used to complete survey procedures. When the study was completed and accepted, all information on the flash drive was deleted.

Participants who chose to enroll in the offered lottery was given the choice to provide a personal or professional email to receive their gift cards. Five (5) persons were randomly selected and provided an "egift" card to Amazon. Once the link was sent with confirmation of receipt, the person's email address was discarded. Email addresses not

chosen for the lottery were discarded immediately. When the study was completed, the survey link was destroyed, as well as all individual responses to the survey. The researcher retained personal notes gathered during data analysis for future research.

### **Data Analysis**

**Likert responses and section scoring.** Survey responses were assigned coded numbers ranging from zero to three (Wood, Evans, and Spandagou, 2014). Each number corresponded with a specific response. For Likert scale responses, the number “4” represents the responses “Strongly Agree/Always/Extremely Likely,” while the number “1” represents the responses “Strongly Disagree/Never/Not Likely” in answer to item statements. The researcher added the value of item responses per section. Sections with high sums indicate higher levels of awareness, positive perceptions of Siblings, and increased feelings of responsibility on the school’s behalf to support Siblings.

The researcher added the sums of participant responses across the four identified survey sections. Response sums from the Stress and Coping section ranged between 8 and 32 when totaled; sums from the Behavior section ranged between 8 and 32; sums from the Knowledge and Response section ranged from 4 to 16; and sums from the Support for Siblings section will range from 5 to 20.

The items in these categories were designed to respond to research questions 1 and 2, comparing educator roles to their awareness and perceptions of Sibling needs. Section totals were added to reveal a Total Perceptions and Awareness score for the Likert style section of the survey. The researcher determined category ratings of *positive*, *neutral*, or *negative* by dividing the highest possible section total by 3. Total section responses were then ranked by section score sums (Gosavi, 2015). For the “Stress and Coping” and

“Behavior” sections, scores ranging from 8 to 16 were considered to be in the *negative* range, scores ranging from 17 to 24 were in the neutral range, and scores from 25 to 32 were in the *positive* range. For the “Knowledge” section, scores ranging from 4 to 7 were considered *negative*, scores from 8 to 11 were *neutral*, and scores ranging from 12 to 16 were considered *positive*. Finally, scores from the “Behavior” section ranging from 5 to 10 were considered *negative*, scores from 11 to 15 were *neutral*, and scores from 16 to 20 were *positive*. The researcher compared means and frequencies between groups using chi squared tests and descriptive statistics.

**Open ended response coding and theme development.** A form of qualitative content analysis was conducted to code responses to the open-ended question (Mayring, 2000; Ciao, Ohls, & Pringle, 2017; Vaismoradi, Turunen, & Bondas, 2013). As defined by Mayring (2000), qualitative content analysis is the use of various techniques for analyzing text. Because the researcher also sought to identify, define, and name themes, the most accurate description of the measures used to analyze responses to the open ended question is called thematic qualitative content analysis (Filia, Cotton, Jackson, Gardner, & Killacky, 2018). After the distribution of the survey, the researcher met with two professionals in the field of education: one classroom teacher, and one guidance counselor. These individuals were selected through recommendations from local school professionals.

The researcher provided a brief synopsis of the study to co-readers, requesting their assistance in coding qualitative responses to survey items. Group members were then asked to sign a confidentiality and ethics statement with the understanding that they had the option to recuse themselves from participating in the study at any time. The researcher

explained the process of coding write-in responses and discussed sample words and phrases to ensure that everyone in the group understood the instructions. The group then individually coded open ended responses and discussed differing ratings to come to a consensus.

Open-ended questions were coded based on the level of perception as interpreted by the researcher and independent co-readers. Responses were initially read by each individual and then rated between 0 and 3 using the following criteria. A person who indicated only negative aspects of Sibling experiences and coping abilities obtained a "0" rating, meaning the research team found the response to be "negative." For example, persons who stated "Siblings are overwhelmed" would likely obtain a "0" rating because of the negative connotation of the word, "overwhelmed."

Participants who expressed neither positive nor negative views of Sibling experiences obtained a of "1," meaning the team found their responses to be "neutral." For example, an individual who states, "Siblings have more responsibility" does not carry a specifically negative or positive connotation; therefore, the statement would be considered neutral.

Respondents who were able to identify both positive and negative aspects of Sibling experiences obtained a rating of "2," as the response was found to be "ambivalent." Examples for this rating included, "Siblings may be resentful, but they can also be more compassionate and patient," due the negative connotation of the word "resentful" and positive connotation of the words, "compassionate" and "patient." Finally, participants who expressed only positive views of Sibling experiences were given a "3" rating, for "positive." Examples included "Siblings are very helpful," or "independent."

After coding overall responses, the co-reading group then identified and listed key words and phrases that described Siblings and their experiences. The words were then grouped into subcategories. For example, if the phrase "left out" was found frequently, the group listed "Left Out" as a subcategory. If the word "friends" was observed to occur frequently among respondents, the group listed "Friendship" as a subcategory. Once all possible subcategories were listed, the researcher and independent readers searched for relationships between subcategories and grouped them into broader themes. The group then connected subcategories into four broad themes: 1) "Time and Attention," 2) "Social-Emotional," 3) "Caregiver/Advocate", and 4) "Resources and Finance."

Finally, descriptive statistics were employed to provide a summary of those participating in the survey. The researcher used central tendency measures to determine the frequencies, range, mean, median, and mode of respondents' age, sex, years of experience, number of schools they worked in, and level of education. The researcher determined the mean, median and mode of represented professional groups. Measures of dispersion were used to identify the variance, standard deviations, and range of participants' ages, profession, and gender. All statistical tests were used with IBM Statistical Package for Social Science (SPSS) Version 25.0.

## Chapter 3

### Results

#### Likert Style Results

Of the 75 participants who completed the demographic portion of the survey, 66 acknowledged having worked with Siblings, making them eligible to complete the Likert-style portion of the survey (N=66). Sections in this part of the survey include: Stress and Coping, Behavior, Knowledge, and Support. See Appendix D for the survey and response options.

**Stress and Coping.** The Stress and Coping section was designed to measure the perceptions of educators about the level of stress that Siblings experience, and how well they cope with stress and pressure. See Table 5 in Appendix C for participant responses to individual survey items. Most respondents indicated viewing Siblings as stressed but capable of managing their stress in healthy ways. 71% of all respondents indicated that they *agree* or *strongly agree* with the perception that Siblings are more stressed out than their peers, and 67% of respondents indicated that they *agree* or *strongly agree* that Siblings put pressure on themselves to do well in school.

Despite these responses, 75% of participants replied *disagree* or *strongly disagree* to the perception that Siblings have more learning problems than peers; 89% *disagree* or *strongly disagree* that Siblings complain a lot, and more than 70% *disagree* or *strongly disagree* that Siblings are more withdrawn than their peers or have trouble focusing in class. Finally, 51% of respondents indicated that they *disagree* with the perception that Siblings are strong self-advocates, while 64% indicated that they *agree* or *strongly agree* that Siblings ask for help when they need it.

Based on the responses in this section, although educators view Siblings as experiencing higher levels of stress when compared to typical peers, they perceive that instead of stress causing a hindrance to the ability to learn, it serves as a possible source of motivation for Siblings to do well in school. Respondents also indicate perceptions that while Siblings are less likely to engage in negative outlets such as complaining or withdrawing from others, they are also less likely to seek help or speak up for themselves when they are uncomfortable. These responses indicate that while educators acknowledge the stress and pressure that Siblings may experience, many perceive that Siblings have learned to handle it on their own.

**Behavior.** The Behavior section measures educators' perceptions of Siblings' abilities to engage with peers and the school community appropriately. See Table 6 in Appendix C for responses to survey items. Most respondents indicated more conservative views on either end of the spectrum in this section of the survey. However, some educator groups gave stronger responses of *never* or *always* to specific statements. For example, 19.5% of all participants replied that Siblings are *never* bossy toward other students. 18.5% replied that Siblings are *never* disruptive in class, and 24% replied that Siblings *never* have trouble keeping friends. 9% of participants replied that Siblings *Always* follow the rules, and 10.5% replied that Siblings *always* get along well with their peers. Among the milder responses, 83.6% of respondents replied that Siblings are *sometimes* off-task, and 71% indicated that Siblings are *sometimes* disruptive in class.

Participant responses indicate educator perceptions that Siblings are able to maintain age appropriate social skills and behaviors despite perceiving higher levels of stress in this population. Based on participant responses, educators find that Siblings follow

rules, participate in routines, and establish and maintain friendships with their peers. If Siblings engage in behaviors that are off-task or disruptive, these behaviors are not considered to be more frequent or significant than those of typical peers.

**Knowledge.** The Knowledge section of the survey was intended to determine educators' perceptions of their own awareness toward Sibling experiences through their own observations and proactiveness in seeking information regarding Sibling experiences. See Table 7 in Appendix C for responses to survey items. More than 90% of all participants replied *agree* or *strongly agree* to statements that they are considerate and conscious of the effects of childhood disabilities affect Siblings in school. 70% of all participants *agree* or *strongly agree* that they actively work to ensure children understand disabilities and special needs. Over 85% of educators *agree* or *strongly agree* that they have attempted to speak with Siblings about their relationships with the focal child. 52% of all participants replied *disagree* to the statement, "I actively attempt to learn about disabilities and how they affect Siblings in school."

Participant responses indicate that most educators hold Siblings in their awareness when addressing students or planning lessons and encourage Siblings to share their experiences with others. Educators also indicate perceptions at raising awareness and education in children to learn about disabilities. Finally, educators indicate perceptions that they seek ways to learn about Sibling experiences on their own, albeit at a lower rate.

**Support.** The Support section measures educators' perceptions of the level of supports they provide to Siblings in school. See Table 8 in Appendix C for responses to individual survey items. 75% of all participants replied that they *often* or *always* try to help Siblings identify healthy coping skills in difficult situations, and 80% replied that they *often*

or *always* encourage Siblings to speak up when they are uncomfortable. Additionally, 40% of all participants replied *always* to the statement, "I encourage Siblings to find someone to talk to about their problems." 46% of participants replied that they *often* actively seek ways to support Siblings in the school environment; 6% replied that they *never* seek ways to support Siblings in the school environment.

With the exception of a small group, participant responses indicate that educators view themselves as encouraging and supportive toward Siblings learning healthy and positive coping skills in the school setting. Most educators indicate that they push Siblings to communicate their feelings and seek help from others who are able to provide supports. Finally, overall participant responses indicate that educators are more likely to proactively assist Siblings to utilize strategies to help them deal with negative experiences.

### **Open Ended Responses**

72 participants completed the open ended question: "What are some experiences Siblings may encounter when living with a child with a disability, and how can these experiences impact their social-emotional development?" (N=72). 24% of respondents were teachers, 48% were related service providers, and 28% were school administrators.

**Identified themes.** The interdisciplinary co-reading team read through responses and, based on frequently used key words and phrases, identified four (4) main themes that educators believe affect Sibling development. The identified themes were as follows: 1) Time and Attention, 2) Social-Emotional, 3) Caregiver/Advocate, and 4) Finances and Resources. See Table 3 in Appendix C for identified themes by educator group.

**Time and attention.** The researcher and independent co-readers observed that 48% of all participants referred to the amount of time or attention given to Siblings from their

parents or other adults in their responses to the open-ended question. Key words and phrases related to this theme included: "neglect," "left out," and "less attention." Related Service Providers were the most represented educator group in this theme (54%).

68.6% of all responses related to this theme were rated as negative and indicated participant beliefs that Siblings do not receive the attention or care they need, which in turn causes them to feel left out and possibly neglected. One respondent indicated that Siblings may receive too much attention from adults in school, making them more vulnerable for unnecessary special education referrals. Two respondents stated that less attention for Siblings is a positive thing, as it gives them opportunities to explore their individuality, including their own interests and goals.

**Social-Emotional.** 78% of all participants responding to the Open Ended question referred to an aspect of Siblings' social and emotional development and functioning in the school setting. 20% of respondents stated Siblings may experience negative emotions or engage in attention-seeking behaviors as a result of receiving little or less attention from parents. Based on these responses, many educators perceive that the social-emotional development of Siblings is closely related to time and attention received from parents. Related service providers were the most represented group for responses related to this theme (41%).

Key words and phrases identified in the Social-Emotional theme included: "jealous," "resentful," "withdrawn," "peers won't play with them," and Siblings not being "interested in socializing with peers." 68.9% of all educator groups indicated negative perceptions of Sibling social-emotional development. Many participants stated that

Siblings can feel stressed out. Respondents also expressed that Siblings may perceive themselves as less important or less of a priority at home and in school.

Respondents indicated that Siblings may engage in unexpected or disruptive behaviors in the school setting as a result of these emotions. Another common belief expressed is that Siblings may have difficulty relating to their peers and advocating for themselves when they are uncomfortable. Finally, a common perception found in these responses is that Siblings may be affected by a stigma resulting from having a sibling with a disability. Educators noted that Siblings may feel the need to outperform or overachieve to make up for any belief that they may share the focal child's disability.

Finally, 16% of participants responding to the Open Ended question indicated positive or ambivalent perceptions of social-emotional development in Siblings. These respondents stated perceptions that Siblings are more mature and responsible, as well as compassionate and tolerant of differences in others. They also stated perceptions that Siblings may be more patient, and more independent than their peers in general.

**Caregiver/Advocate role.** A third theme found in responses is one related to the Sibling being placed in the role of a caregiver or advocate for the focal child. 25% of participants used words and phrases such as Siblings fillings roles as a "second parent," "care-taker responsibilities," having "too many responsibilities," and placed in a position of having to advocate on behalf of the focal child. Teachers and Related Service Providers were equally represented in this group at 44% each, while administrators were in the minority (11%).

50% of the terms related to this theme were rated as negative. Educators expressed perceptions that Siblings are often relied upon too heavily to assist in caring for the focal

child. One participant stated that Siblings are not allowed to be children, while others noted that Siblings may miss out on common childhood experiences, such as going on certain vacations.

39% of participants stated positive aspects of Siblings having added responsibilities. Participants expressed perceptions that Siblings are more helpful and mature than their peers. Many of their answers overlapped with the Social-Emotional theme, in that respondents noted that taking care of the focal child causes them to be more patient and compassionate.

**Resources and financial strain.** A small percentage of participants identified hardships associated with Sibling experiences, such as lack of resources and finances. 9.8% of respondents used terms related to this theme, including: "poverty," financial "difficulties," "financial strain," "financial constraints," and "lack of resources." 100% of the responses relating to this theme were rated negative. Based on responses related to this theme, educators largely believe that Siblings may not be able to access all the opportunities and activities their peers enjoy because the family is financially affected by the focal child's disability. Teachers provided the highest percentage of responses relating to this theme (57%).

### **Awareness of Sibling Experiences by Educator Group**

The first research question of this study seeks to determine the level of awareness educators have of the challenges typically developing Siblings experience when living with a child with disabilities. Based on responses to the confirmation question (i.e., "Have you worked with a Sibling of a child with a disability?"), as well as Knowledge section responses, educators exhibit moderate to low levels of awareness (refer to Table 7 in

Appendix C). Most participants demonstrated an awareness of their proximity and exposure to Siblings. 81% of all individuals who consented to the survey indicated that they have worked with Siblings. 12% indicated never having worked with Siblings, and 4% indicated that they did not know whether or not they have worked with Siblings.

Of the individuals who confirmed that they have worked with Siblings, most indicated some attempts to learn about Sibling needs by engaging with Siblings directly. This group also indicated that they consider ways that Sibling experiences impact them in school; however, more than 50% indicated that they do not attempt to learn about disabilities and their effects on Siblings on their own. Despite reports of most individuals not attempting to learn about disabilities, 70% of all participants indicated that they make conscious efforts to help children understand disabilities and special needs.

### **Perceptions of Sibling Outcomes by Educator Group**

Question 2 of this study seeks to determine whether educator perceptions of potential Sibling outcomes vary based on their specific roles in the school building. Most participants exhibited generally neutral perceptions of Sibling outcomes across Likert-style questions (Refer to Table 2 in Appendix C). 73% of all participants obtained scores in the *neutral* range. 27% obtained scores in the *positive* range, and 0% obtained scores in the *negative* range. Related service providers obtained the highest percentage of scores in the *positive* range (13%).

To determine the rate in which individual groups obtained scores in a given category, the researcher reviewed the rate of perception within each group by calculating the percentage of scores within the group. See Figure 3.1 in Appendix C for the overall Rates of Perceptions and Awareness within Educator Groups.

Chi squared tests showed that School Administrators obtained the highest rate of scores in the *neutral* range across all Likert style responses. Related service providers obtained the highest rate of *positive* range scores on the overall survey, and specifically in the areas of Knowledge and Stress and Coping. Responses indicate that related service providers are more likely to seek information regarding Sibling experiences and needs. Related service providers also exhibited more positive perceptions regarding Siblings' abilities to manage stress and develop healthy coping skills than other educator groups.

Related service providers replied *Agree* or *Strongly Agree* to the perception that Siblings are strong self-advocates at a higher rate than other educator groups and indicated lower rates of belief that Siblings have trouble with focusing and learning in class. Additionally, this group indicated lower levels of belief that Siblings are more withdrawn than peers or complain more than peers. In contrast, related service providers indicated higher levels of perceptions that Siblings put more pressure on themselves to do well in school than other groups.

Related service providers indicated higher levels of consideration given to Sibling needs and experiences and how these factors impact Sibling performance in school. Related service providers also indicated that they provide lessons and tools to teach children about disabilities and special needs at a higher rate than the other groups, and that they make more attempts to learn about disabilities and their effects on Siblings in school.

Teachers obtained the highest rate of scores in the *positive* range in the Behavior and Support sections. Responses from this sample indicated that teachers seek ways to provide emotional support in the school building at a higher rate than other groups but are

less likely than other groups to seek information regarding Sibling experiences or teach other children about disabilities. Finally, participant responses indicate that teachers perceive Siblings as more stressed than typical children.

### **Overall Perceptions and Awareness of Sibling Experiences and Outcomes**

Based on the results of the survey, educators generally indicated *neutral to negative* perceptions of Siblings responses to stress and coping abilities (See Figure 3.2 in Appendix C), however, Sibling behavior is viewed in a more positive, albeit neutral position when compared to typical peers (See Figure 3.3 in Appendix C). Educators reported making minimal to moderate efforts to learn and teach children about disabilities, giving specific attention to Sibling experiences; however, many respondents indicated the belief that they are highly supportive of Siblings in the school setting.

Based on their ratings, participants overall held neutral to positive views regarding the social-emotional development of Siblings, as well as their own awareness and sense of responsibility to support Siblings in the school setting. 73% of all participants obtained scores in the *neutral* range throughout the entire survey, while 27% obtained scores in the *positive* range. 0% of all participants obtained scores in the *negative* range. Related service providers presented the highest percentage of respondents who obtained scores in the *positive* range.

Related service providers generally responded to Likert style and open ended questions more positively than teachers and school administrators, although there was no statistical significance found between groups. School administrator and teacher responses leaned toward more negative responses and expressed perceptions of Sibling experiences and social-emotional functioning in the school setting.

Of all the participant responses in the Stress and Coping section, one respondent who identified as a related service provider obtained a score in the *positive* range for the section. Respondents overall exhibited neutral to negative views of Siblings' ability to manage and cope with stress. Most respondents indicated positive views of Siblings' abilities to focus in class, and interact with others; however, respondents indicated perceptions that Siblings appear more stressed than typical peers, and that they advocate for themselves less than their peers.

Responses to items in the Behavior section indicate that educators hold neutral to positive perceptions of Sibling behavior in schools. 76% of participants obtained section scores in the *neutral* range, indicating that educators do not generally perceive Sibling behaviors to be noticeably more positive or negative than their typical peers. 22% obtained scores in the *positive* range, and 2% obtained scores in the *negative* range of this section.

Teachers represented the highest percentage of views in the positive range in the Behavior section of the survey at 10.4% of all participant responses. They were also the only group to obtain scores in the negative range in this section. 9% of scores in the *positive* range were from related service providers, while 3% were from school administrators. Neither related service providers nor school administrators obtained scores in the *negative* range regarding Sibling behavior.

Responses to the Knowledge section indicate that educators have neutral to positive views toward their responsibilities in developing their own awareness about disabilities as well as helping Siblings learn about their siblings' challenges. 85% of participants obtained scores in the *neutral* category of this section, which indicated that respondents made conservative attempts to learn and teach others about children with disabilities, and the

effects that Siblings may experience. 5% obtained scores in the *positive* category, indicating that respondents actively or consistently attempt to learn and teach about children with disabilities and their Siblings. 10% of participants obtained scores in the *negative* category, indicating little to no attempts made to learn or teach about children with disabilities and Sibling experiences.

Related service providers reported higher levels of attempts to learn about children with disabilities, and how their experiences impact them and their Siblings in the school setting (See Figure 3.4 in Appendix C). 10% of related service providers obtained scores in the *positive* category of the Knowledge section in the survey, while 0% of teachers and 0% of school administrators obtained scores in this range. 8% of all teachers and 7% of all school administrators obtained scores in the *negative* category, while 7% of related service providers obtained a *negative* response score.

Educators' overall reported attempts to provide supports to Siblings in school were *neutral* (See Figure 3.5 in Appendix C). 49% of participants obtained scores in the *neutral* range for this section, indicating that educators generally make conservative efforts to support Siblings specifically in the school setting. 43% of respondents obtained scores in the *positive* range, and 8% obtained scores in the *negative* range.

46% of all teachers responding to the Support section obtained scores in the *positive* range, indicating that teachers have a higher sense of responsibility or interest in supporting Siblings in the school setting. 45% of related service providers and 36% of school administrators obtained scores in the *positive* range. 8% of all teachers indicated little to no interest in providing in-school supports to Siblings, while 7% of related service

providers and 7% of school administrators demonstrated low levels of support attempts for Siblings in the school setting.

When answering the open ended question, all groups expressed a strong focus on Siblings' social-emotional functioning, specifically internal feelings such as stress, jealousy and resentment, however teachers discussed the financial strain on families more than related service providers and school administrators. Participants also gave a high level of attention to Siblings being placed in a caregiver role, or given responsibilities that are not commonly assigned to children. Teachers and related service providers indicated an equal awareness level of Siblings being placed in the role of a caregiver or advocate for the focal child. Related service providers placed a higher focus on Siblings receiving the appropriate amount of time and attention than teachers and school administrators. See Figure 3.6 in Appendix C for identified themes by educator group.

Based on participant responses, school administrators expressed the most neutral perceptions toward Siblings than other educator groups throughout the Likert-style and open ended sections of the survey. Administrators obtained the lowest means in overall Perceptions and Awareness, Behavior, and Support, as well as in response to the open ended question. These responses indicate that administrators perceive Sibling behaviors in a less positive light than other groups.

For example, administrators disagreed that Siblings participate in class and are more responsible than their peers with their belongings. Administrators also indicated the lowest level of willingness to provide supports and encouragement in the school building. Finally, the majority of administrators expressed negative perceptions related to social-emotional functioning in response to the open-ended question.

Related service providers obtained the highest means in the overall Perceptions and Awareness and Knowledge sections, and open-ended question. Based on their responses, related service providers make the most effort to seek information regarding Sibling experiences by engaging Siblings in conversation about their feelings.

Finally, related service providers and school administrators obtained equal means in the area of Stress and Coping. Based on their responses, related service providers equally view Siblings as stressed out, yet having positive coping skills. Related service providers and teachers obtained equal means in the Support section. Based on their responses, teachers and related service providers view themselves as encouraging of Siblings finding supports and resources, as well as teaching strategies and healthy coping skills to Siblings.

## **Chapter 4**

### **Discussion**

The literature reviewed for this study revealed a wealth of research on Siblings and their behaviors at home and with their families (Sim & Frydenberg, 2011; Giallo & Gavidia-Payne, 2006; Kao et al., 2012; Williams et al., 2010; Manyor-Binyamini & Abu-Ajaj, 2012; Naylor & Prescott, 2004; Granat et al., 2012). Available research highlighted the likelihood of Siblings experiencing stress and variant coping abilities based on the level of education and coping mechanisms of the family unit overall (Sim & Frydenberg, 2011; Giallo & Gavidia-Payne, 2006; Lobato & Kao, 2005). The studies relevant to this research allowed gave parents and Siblings voice to advocate for supports and interventions (Arnold, Heller, & Kramer, 2012; Strohm, 2004; Hames, 2005). In contrast, there is little representation of teachers, related service providers, and school administrators who also impact the social and emotional growth of children, and Siblings in particular.

The purpose of this study was to determine the perceptions and awareness of educators, specifically teachers, related service providers, and school administrators toward the social-emotional needs of siblings of children with disabilities. The researcher attempted to measure this by conducting a survey with the following purposes: 1) to determine the extent to which teachers, related service providers, and school administrators are aware of the challenges siblings of children with disabilities experience; 2) to determine whether educator perceptions of Siblings differ by role or discipline; 3) to determine the extent to which educators believe schools are responsible for support the social-emotional needs of Siblings; and 4) to determine whether educators hold generally positive or negative views of Siblings' experiences and outcomes.

### **Educator Response to Research**

The first indicator of educator perceptions and awareness regarding Sibling experiences was determined by the participant characteristics. Responses to recruitment for participants were slower and less sizable than originally expected. The researcher made the survey accessible to eligible participants on a broad scale by accessing public directories and contacting individuals with public email addresses (Praisner, 2003; Levins, Bornholt, & Lennon, 2005; Cook, Semmel, & Gerber, 1999; Wood, Evans, & Spandagou, 2014). As there are generally more teachers in a school building than related service providers and administrators, this approach resulted in the researcher reaching out to more teachers than related service providers and administrators overall.

Of the 110 participants who consented to participate in the survey, only 89 respondents confirmed whether or not they worked with Siblings, and 75 completed the survey, regardless of whether they worked with Siblings or not. Response rates averaged one completed survey per day, although the survey was accessed an average of 13 times per week during the time period in which the survey was open. While more teachers were contacted during participant recruitment, related service providers were the highest represented group of participants in this study.

One of the possible reasons for the higher volume of related service providers as participants can be credited to the specialized trainings that related service providers may receive to equip them to consider and support not only students with disabilities, but those who specifically support and instruct them, such as parents and teachers. Another consideration might be that related service providers have more flexibility and autonomy in scheduling than teachers, who traditionally spend much of the school day engaging in

instruction. Finally, this response pattern suggests that related service providers may identify more with topics concerning special education and children with disabilities.

As many providers, specifically clinicians including school psychologists, social workers, counselors, and speech pathologists, are required to consider external factors, such as family history and educational background when conducting evaluations and preparing individual treatment plans, Siblings may come into consideration with this educator group due to their training and specific job responsibilities.

Teachers are generally expected to instruct larger groups and consider individual student needs as they relate to school and classroom measures of success. Administrators are generally tasked with ensuring the general function of the school at large, including monitoring finances, maintaining the school social-emotional climate and academic performance, and ensuring the safety of all persons who operate within the school building. As survey responses indicate that Siblings overall are not perceived to noticeably disrupt the school or classroom atmosphere or perform at a significantly lower academic level than their peers, this population may be less likely to capture the attention of teachers or school administrators when planning lessons or school policies.

Another possible reason for the disparity between educator groups responding to the survey is that teachers and administrators may not feel equipped to discuss Sibling experiences, as indicated by survey response patterns. Because disabilities manifest in many forms and levels of intensity, the amount of possible effects on Siblings are endless. Respondents may have not been comfortable reporting on particular aspects of Sibling behaviors because there are so many variations in presentation. It is also important to note that many of the individuals who consented for the researcher to use their responses did

not respond to any items after confirming that they did not know whether they had worked with Siblings, or that they had *not* worked with Siblings. Although these individuals were invited to respond to the open ended question, respondents may not have been comfortable commenting on Sibling experiences and outcomes because of a lack of awareness or exposure to Siblings.

### **Educator Awareness and Perceptions of Sibling Experiences and Outcomes**

**Levels of awareness.** Prior research revealed limited evidence of awareness about Sibling behavior outside of the home (Tsao, Davenport, & Schmeige, 2011). Most respondents demonstrated a basic awareness of Sibling experiences and challenges. While most educators replied that they consider Siblings and attempt to engage them in discussions about their experiences, they also indicated that they do not independently attempt to learn or educate children about Siblings, or disabilities in general. This response pattern indicates that while educators are willing to acknowledge that Siblings may experience different challenges than their peers, many individuals may not consider these challenges to be impactful enough to make additional efforts to learn more.

**Educator roles and perceptions.** Questions 2 and 4 of this study sought to determine whether educators' perceptions and beliefs about Siblings varied based on their specific field, and whether educators generally held positive or negative perceptions toward Siblings. The researcher hypothesized that, despite exhibiting lower levels of awareness, when asked to consider this population, educators would likely identify more negative than positive facets of Siblings' experiences and social and emotional development. When responding to both the Likert-style and open ended sections of the survey into account, educators exhibited conflicting perceptions and beliefs regarding Sibling experiences and

outcomes. Likert-style outcomes indicated that most educators have neutral to positive perceptions of Siblings. While most respondents indicated that they perceive Siblings as stressed and under more pressure than peers, they also indicated perceptions that Sibling experiences do not significantly impact their academic performance or social-emotional functioning.

Respondents generally chose more conservative responses such as “agree/disagree” instead of “strongly disagree/strongly agree.” When including responses to items regarding educators’ approaches to expanding their knowledge about Siblings, responses suggest that educators may not have definite opinions or views about their experiences and how they impact their abilities in school. As disabilities present in many different forms and levels of intensity, the amount of possible effects on Siblings are endless. Respondents may have not been comfortable reporting on Sibling behaviors because there are so many variations in presentation. However, it is important to note that, while most leaned toward neutral perceptions, participants who indicated stronger opinions were generally more positive than negative.

In contrast, when asked to provide their own perceptions of Sibling experiences and their effects in school through the open-ended question, educator responses were more negative than positive or even ambivalent. Many respondents expressed beliefs that Siblings are “neglected, “overlooked, and “left out.” They also indicated beliefs that Siblings are expected to take on more responsibility than they should as children and often miss out on positive experiences with other children their age.

The negative nature of open ended responses reflects traditional views of Sibling outcomes and experiences. Studies dating back to the 1980s and 1990s generally addressed

negative aspects of Sibling experiences (Williams, 1997; Breslau, Weitzman, & Messenger, 1981; Fisman, Wolf, Ellison, Gillis, Freeman, & Szatmari, 1996). In more recent years, the focuses of many studies have addressed the possibilities of positive outcomes and thriving in Siblings (Manor-Binyamini & Abu-Ajaj, 2012; Sim & Frydenburg, 2011; Sanders & Syzmanski, 2013). The changing trends suggest that, as researchers continue to study Siblings, the focus will likely become more solution focused than problem focused.

In response to the open ended question, educators expressed perceptions that Sibling experiences may negatively impact their social-emotional functioning. This view consistent with pervious findings related to Sibling social and emotional development, and the researcher's original hypothesis (Wolf et al., 1996; Williams et al., 2010; Manyor-Binyamini & Abu-Ajaj, 2012; Hastings, 2007). Generally, educators expressed beliefs that Siblings may struggle to make friends, engage in disruptive behaviors, or emulate the characteristics of the focal child for attention. Participants also noted that Siblings may experience the effects of financial hardships as many of the family's resources may be dedicated to care of the focal child.

Although the majority of open-ended responses were generally negative, a small group of participants indicated ambivalent or positive perceptions of Sibling experiences. Respondents in this group consistently acknowledged the imbalance of parental attention and caregiver responsibilities, however these individuals also cited potentially positive outcomes and characteristics of Siblings. This group of participants noted that Siblings can be more "mature," "helpful," and "compassionate" than other children as a result of their experiences. They also noted that Siblings develop more independence and freedom to

explore their own desires as a result of not receiving a typical amount of parent attention. This outlook supports prior studies in which researchers concluded that educating Siblings on the nature of the focal child's disabilities and healthy coping strategies are likely to foster "thriving" outcomes (Sim & Frydenberg, 2011; Lobato & Kao, 2005; Kresak & Gallagher, 2009) rather than negative outcomes.

Based on participant responses, educators hold dissonant beliefs about Sibling experiences. Of those who indicated neutral or strong positive views of Siblings when presented with a choice, many could only identify negative aspects of Sibling experiences when presenting their views on their own. These responses support the researcher's hypothesis that, while many educators would like to view themselves as knowledgeable and perceptive of Sibling experiences, they do not know enough to form realistic and well-rounded ideas of Siblings, which directly impacts their ability to support them in the school setting.

**School based supports and responsibility.** Educator responses to the "Support" section of the Likert-style survey indicate the general perception that they are supportive of Siblings in the school setting. Survey respondents largely acknowledged that Siblings experience stress and more responsibilities than other children. Additionally, educators acknowledged that Siblings can be overlooked and lack parental attention, as well as may experience financial hardships directly related to the needs of the focal child. When responding to the open-ended question, most participants focused on the lack of support from parents and alienation from same-age peers. They also noted the possibility that Siblings out their frustration in class. In contrast, most respondents did not discuss possible responses or interventions from school faculty to address these behaviors.

One participant acknowledged that Siblings “need a safe place to be heard.” Another respondent noted that Siblings may lack academic support, and a third noted that they lacked the self-awareness to encourage Siblings to seek guidance. Overall, however, educators indicated that Sibling outcomes are mainly impacted by parental attention and support, without mentioning ways that school faculty can positively or negatively impact Siblings.

These results indicate that while educators may agree with the concept of providing informal emotional supports for Siblings during the school day, they may not perceive themselves as major catalysts for Sibling outcomes, and may not have beliefs that they are responsible to intentionally provide supports in the school setting. They may also believe that Sibling experiences are too various to adequately address them through groups and general strategies. Finally, educators may perceive that Siblings need support on a case-by-case basis, which does not require routine check-ins for the entire population.

### **Implications for Progress and Future Research**

**Bridging the gap.** Raw data from responses to Likert style and open ended survey items indicated higher levels of interest, perceptiveness, and awareness in related service providers over teachers and school administrators. When responding to the open-ended question, related service providers gave the highest rate of positive responses and acknowledged the impact that educators can have on Siblings. Although related service providers also demonstrated conflicting views of Sibling experiences, outcomes, and educator support, they demonstrated a higher likelihood to be more receptive to learning more about Siblings and distributing information to other groups, as well as planning and implementing interventions to support Siblings in the school setting. One step in this

direction is to take advantage of in-service trainings and professional development programs to provide more in-depth information to other educational groups.

Prior studies have developed methods for group family interventions that target various issues that affect families that yielded promising results (Perlick et. al., 2013; Ziffer, Crawford, & Penney-Wietor, 2010; Granat, Nordgren, Rein, & Sonnander, 2012; Lobato & Kao, 2005). Many schools currently provide parent trainings and workshops to teach strategies to help manage behaviors and learning skills when addressing the focal child's specific needs. In some cases, parent trainings may be included in a student's individualized education program (IEP) as required or mandated services. As related service providers are generally responsible for conducting these trainings, it may be beneficial to also provide strategies to support Siblings, as well as consult with classroom teachers and administrators to generalize these supports across home and school settings.

Another way to provide supports to Siblings is to increase awareness of children's disabilities and their effects universally. Siblings would benefit from not only emotional support, but generalized education of disabilities, specifically those that affect their siblings with disabilities (.Naylor & Prescott, 2004; Hartling, Milne, Tjosvold, Wrightson, Gallivan, & Newton, 2010; Lobato & Kao, 2005; Kresak, Gallagher, & Rhodes, 2009; McConkey, Gent, & Scowcroft, 2013). Additionally, regularly providing information about disabilities will increase overall awareness in across educator groups, and perhaps close the gaps in perceptions between groups.

**Thriving over surviving.** Many educators indicated perceptions that Siblings are simply "surviving": coping with negative aspects of living with a child with a disability, and handling things on their own, which is consistent with findings from previously

conducted studies on Sibling behavior (Naylor & Prescott, 2004; Kao et al., 2011). Educators expressed beliefs that Siblings do not have “safe spaces” or a community that understands their unique experiences. A small group expressed beliefs that Siblings can develop positive traits and outcomes as a result of their experiences with the focal child, otherwise known as “thriving.”

As educators develop more awareness of Sibling experiences and outcomes, including positive traits, the researcher is hopeful that they will begin to see their importance in encouraging Siblings to develop positive traits, such as resiliency, compassion, patience, and responsibility (Sim & Frydenburg, 2011; Manor-Binyamini & Abu-Ajaj, 2012; Sanders & Syzmanski, 2013). Another intention of this study was to aid in preventing Siblings from “slipping through the cracks,” as educator responses indicated that the academic and social functioning of Siblings are largely unremarkable, despite evidence to the contrary (Sim & Frydenburg, 2011; Breslau, Weitzman, & Messenger, 1981; Strohm, 2005; Hames & McCaffrey, 2005; Williams, Piamjariyakul, Graff, & Stanton, 2010). Overall responses indicate beliefs that Siblings can manage their challenges on their own without additional support. As such, educators are less likely to engage in proactive approaches to ensure that Siblings are engaging in healthy coping and communication skills on a regular basis.

**Qualitative research.** It may be beneficial to conduct qualitative studies in the future to identify more nuanced aspects of educator perceptions about Siblings. Rather than a general survey, researchers may find more in-depth understandings of the factors that impact educators' perceptions and desire to learn about the effects of children's disabilities on Siblings through interviews and other forms of anecdotal information (Chislom, 2014).

The original research questions can be used as discussion prompts during in-person interviews, and the responses to individual survey questions can be used to probe further consideration. It is hopeful that as more educators are challenged to consider their views regarding this population, their willingness to participate in research in this area will increase.

### **Study Limitations**

**Sample size and profile.** The final sample size of educators who completed the survey was 75 (N=75). This is a significantly small number given the amount of people who fit the participant criteria in the state of New York. As such, the final response pool cannot be generalized to represent all teachers, related service providers, and school administrators in New York.

One possible cause of the small sample size can be attributed to the timing of data collection (Walsh et. al., 2010). The researcher initially distributed the survey toward the end of the 10-month school year when school staff are typically focused on end-of-year tasks, such as final exams, completing reports of student progress, and preparing the building and classrooms for the summer. The researcher continued to collect data through the summer months when school-based educators are off duty and do not access their professional emails or wish to discuss work-related topics. It is possible that if the survey had been conducted throughout the entire 10-month school year, there would have been a higher response rate.

Another limitation of the sample included the lack of equity among educator groups. 45% of all respondents to the survey identified as related service providers, making them the highest represented group in the study. 35% of respondents were teachers, and

20% were school administrators. Related service providers exhibited higher levels of awareness and positive perceptions of Sibling outcomes than other educator groups. It is possible that these levels are inflated because there are simply more participants in this group, rather than suggest the belief that related service providers view siblings more positively than other educator groups. If future research ensures more equity in sample sizes between groups, those response patterns may confirm or contradict the one reflected in this study.

**Survey structure.** Finally, the survey itself proved to be a limitation for several reasons. First, to encourage respondents to choose a “side,” avoiding overwhelming ambiguous results, the researcher did not include truly neutral responses, or another option for respondents to indicate that they were not sure of their responses to a statement. While this helped to answer the question of whether Siblings were viewed more positively or negatively by educators, such an option may have helped to further inform levels of awareness between educator groups.

Another limitation of the survey was the vagueness of the item statements. The researcher included items that were intended to encourage critical thinking in respondents and avoided obvious statements that may have helped to more definitively answer research questions. One example of a vague statement includes, “Siblings get along well with peers.” Although this is a direct statement, it is also very broad. Positive responses to this question do not answer more specific aspect of Siblings’ interpersonal skills. For example, this statement does not address nuances such as whether Siblings initiate peer interactions, how they respond to conflicts or perceived offenses, or whether Siblings are seen as leaders or followers.

Additionally, the survey reviewed voluntary efforts made by educators to provide supports to Siblings in school (i.e., "I actively encourage Siblings to find resources or someone to talk to about their problems"). However, it would have been beneficial to also include statements that challenged respondents' actual beliefs on whether these practices should be mandated or included in school policy (i.e., "I believe educators are responsible for help Siblings learn about their siblings' disabilities"). Instead, the researcher had to interpret educator perceptions based on the responses to the statements included in the survey.

### **Conclusion**

In the United States of America, approximately 21 million families are impacted by disabilities (United States Census Bureau, 2010). Over 6 million children reportedly receive special education services to address specific disabilities in the school setting (National Center for Education Statistics, 2017). Parents reported that raising children with disabilities impacts their financial, emotional, and social well-being (Chien & Lee, 2012; Quine & Pahl, 1991). Additionally, studies have shown that Siblings are affected by the needs of the focal child, particularly if they are younger and the focal child's needs are severe or chronic (Strohm, 2005; Hames & McCaffrey, 2005; Williams, Piamjariyakul, Graff, & Stanton, 2010).

While there are government funded services to provide financial and educational supports to parents, research shows that these services are not often supportive enough (Roberts & Lawton, 2000; Stabile & Allin, 2012). There is even less evidence of support provided to the typically developing Siblings of children with disabilities, despite evidence that Sibling outcomes are often impacted by parental and family communication and stress.

It is probable that Siblings are not as highly considered on a global scale because most studies addressing Sibling development focus on the home environment and their relationships with the focal child. There is little information regarding Siblings in other environments, such as schools (Wolf, Fisman, Ellison, & Freeman, 1998; Williams et al, 2010; Sim & Frydenberg, 2011).

The purpose of this study was to provide insight to educator's perceptions and awareness toward the social-emotional needs of Siblings, as well as expected outcomes of Sibling experiences. The objectives of this study were to identify educators' awareness of Sibling experiences by determining the level of efforts they made to engage with and learn about Siblings; to determine whether educators held positive or negative perceptions of Siblings' abilities to handle stress and exhibit age-appropriate social skills and behaviors in the school setting; and to determine whether educators felt a duty or responsibility to provide supports to Siblings in schools.

Based on the results of this study, educators hold a general awareness that Siblings are emotionally and socially affected by the needs of the focal child. They did not exhibit beliefs that these effects significantly impact learning or the ability to function appropriately in the school setting. While educators exhibited some willingness to engage with Siblings and encourage them to advocate for themselves, they did not demonstrate significant efforts to formally educate themselves or students about disabilities and how they affect others, including Siblings.

The conflicting views of participants supports the hypothesis that educators are not very aware of Sibling experiences and potential positive outcomes. Most respondents perceived the negative aspects of Sibling needs without considering that Siblings could

possibly “thrive,” as well. As such, it is probable that educators are not giving this population much thought or attention when planning lessons or making decisions for the school. This provides greater potential for Sibling needs to go unnoticed in schools; while they may “survive,” and adequately participate in the flow of the school day, there are missed opportunities for both educators and Siblings to develop more positive traits, such as higher levels of compassion toward others, patience, and mindfulness.

It is hopeful that this study will be one of many to be conducted in the future and will encourage the development of programs and policies to include Siblings when supporting families of children with disabilities. There is also potential for Siblings who have learned to overcome their challenges to support other students who may experience different struggles, if they are receiving ongoing supports from their teachers and school staff. Finally, the researcher hopes to encourage educators to support one another in learning and teaching others about disabilities in general, keeping Siblings in mind, as they can provide insights on how disabilities manifested in children can impact those around them, as well as develop universal strategies to support all children in the school setting.

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### **Appendix A: Email to Potential Survey Participants**

**Subject Line:** Request for Participation – Dissertation Research on Educator Awareness and Perceptions of Siblings

**Message Text:**

My name is Jalisa Barnes, and I am a graduate student for Alfred University. I am currently conducting research on the awareness and perceptions of educators about the social-emotional needs of the typically developing siblings of children with disabilities (Siblings, for short). I have created a short survey to help me understand the views of school professionals toward Sibling behavior and adjustment in schools, and I am requesting the participation of school principals and administrators, teachers, and related service providers including speech therapists, occupational therapists, school psychologists, guidance counselors, and social workers. The survey takes approximately 10 minutes to complete, and participants will have the option to enter a lottery and win a \$20 gift card to Amazon, Target, or Walmart.

Participation in this survey is completely voluntary. Participants may discontinue the survey at any time with no threat of repercussions or negative consequences. Your personal information will not be shared with anyone besides the research team. Once the survey is completed, all personal information will be destroyed.

To participate in this survey and give consent for me to use your responses for my research, please [click here](#) (*hyperlink*).

If there are any additional questions or concerns, you may contact the following persons:

Running head: EDUCATORS' AWARENESS AND PERCEPTIONS OF SIBLINGS

Jalisa Barnes, MA/CAS (Principal Researcher) – [jab22@alfred.edu](mailto:jab22@alfred.edu)

Mark Fugate, PhD (Dissertation Chair) [ffugate@alfred.edu](mailto:ffugate@alfred.edu)

Thank you for your time and attention!

Sincerely,

Jalisa A. Barnes, MA/CAS, NCSP

**Appendix B: Telephone Script for Requesting School Participation**

Hello, my name is \_\_\_\_\_. I am a graduate student from Alfred University, and I am conducting a survey measuring school faculty perceptions about the needs of students who have siblings with disabilities. I would like to distribute the survey to the teachers, related service providers, and building administrators in your school. It is an online survey, which can be done at participants' convenience, and should take no more than 10 minutes to complete. Would you be open to distributing the survey to your colleagues if I send you the email?

## Appendix C: Tables and Figures

## Tables

Table 1

*Characteristics of Survey Participants*

<b>Participant Characteristics</b>	<b>N</b>	<b>%</b>
<i>Total Sample</i>	75	
Gender (1 missing case)		
Male	9	12.2
Female	65	87.8
Age Range (years)		
22-30	7	9.3
31-40	16	21.3
41-50	28	37.3
50+	24	32.0
Years Experience		
1-2	10	13.3
3-5	11	14.7
6-9	15	20.0
10-20	17	22.7
20+	22	29.3
Highest Education Level		
Bachelor's Degree	12	16.0
Master's Degree	53	70.7
Doctoral Degree	10	13.3
Educator Category		
Teacher	26	34.7
Related Service Provider	34	45.3
School Administrator	15	20.0

Table 2

*Perceptions and Awareness of Sibling Needs Between Educator Groups by Mean*

	<b>M</b>	<b>SD</b>
<i>Total Perceptions and Awareness</i>	2.27	.447
Teacher	2.25	.442
Related Service Provider	2.31	.471
School Administrator	2.21	.426
<i>Total Stress and Coping</i>	1.97	.244
Teacher	1.92	.282
Related Service Provider	2.00	.267
School Administrator	2.00	.000
<i>Total Behavior</i>	2.21	.445
Teacher	2.25	.532
Related Service Provider	2.21	.412
School Administrator	2.14	.363

<i>Total Knowledge</i>	1.94	.385
Teacher	1.83	.381
Related Service Provider	2.03	.421
School Administrator	1.93	.267
<i>Total Support</i>	2.36	.620
Teacher	2.38	.647
Related Service Provider	2.38	.622
School Administrator	2.29	.611

Table 3  
*Identified Themes in Open Ended Responses*

	N	Teachers (%)	Related Service Providers (%)	School Administrators (%)
Time and Attention	35	34.3	54.3	11.4
Social and Emotional	56	37.5	41.1	21.4
Caregiver/Advocacy	18	44.4	44.4	11.1
Finance and Resources	7	57.1	14.3	28.6

Table 4  
*Open Ended Response Means Between Educator Groups*

	N	Mean	SD
Teachers	26	1.46	.859
Related Service Providers	32	1.59	.837
School Administrators	13	1.38	.650
Total	71	1.51	.808

Table 5  
*Stress and Coping Survey Question Responses by Educator Group*

Survey Questions	Educator Group	N	% (N)	% (N)	% (N)	% (N)
			Strongly Disagree	Disagree	Agree	Strongly Agree
When compared to typical peers, Siblings put a lot of pressure on themselves to do well in school.	Teachers	24	0.0 (0)	10.5 (7)	20.9 (14)	4.4 (3)
	Related Service Providers	29	0.0 (0)	14.9 (10)	25.3 (17)	3.0 (2)
	School Administrators	14	0.0 (0)	7.5 (5)	10.5 (7)	3.0 (2)
	<i>Total</i>	67	0.0 (0)	32.9 (22)	56.7 (38)	10.4 (7)
When compared to typical peers, Siblings are often stressed out.	Teachers	24	0.0 (0)	11.9 (8)	23.9 (16)	0.0 (0)
	Related Service Providers	29	0.0 (0)	4.5 (3)	37.3 (25)	1.5 (1)
	School Administrators	14	0.0 (0)	11.9 (8)	9.0 (6)	0.0 (0)
	<i>Total</i>	67	0.0 (0)	28.3 (19)	70.2 (47)	1.5 (1)

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When compared to typical peers, Siblings have a lot of learning problems.	Teachers	24	0.0 (0)	28.4 (19)	7.5 (5)	0.0 (0)
	Related Service Providers	29	0.0 (0)	32.8 (22)	10.4 (7)	0.0 (0)
	School Administrators	14	1.5 (1)	13.4 (9)	6.0 (4)	0.0 (0)
	<i>Total</i>	67	1.5 (1)	74.6 (50)	23.9 (16)	0.0 (0)
When compared to typical peers, Siblings are strong self-advocates.	Teachers	24	0.0 (0)	19.4 (13)	14.9 (10)	1.5 (1)
	Related Service Providers	29	0.0 (0)	19.4 (13)	17.9 (12)	6.0 (4)
	School Administrators	14	0.0 (0)	11.9 (8)	7.5 (5)	1.5 (1)
	<i>Total</i>	67	0.0 (0)	50.7 (34)	40.3 (27)	9.0 (6)
When compared to typical peers, Siblings complain a lot.	Teachers	24	4.5 (3)	28.3 (19)	3.0 (2)	0.0 (0)
	Related Service Providers	29	7.5 (5)	31.3 (21)	4.5 (3)	0.0 (0)
	School Administrators	14	0.0 (0)	17.9 (12)	3.0 (2)	0.0 (0)
	<i>Total</i>	67	12.0 (8)	77.5 (42)	10.5 (7)	0.0 (0)
When compared to typical peers, Siblings are withdrawn.	Teachers	24	1.5 (1)	23.9 (16)	7.5 (5)	3.0 (2)
	Related Service Providers	29	0.0 (0)	31.3 (21)	11.9 (8)	0.0 (0)
	School Administrators	14	0.0 (0)	17.9 (12)	3.0 (2)	0.0 (0)
	<i>Total</i>	67	1.5 (1)	73.1 (49)	22.4 (15)	3.0 (2)
Siblings ask for help when they need it.	Teachers	24	0.0 (0)	11.9 (8)	22.4 (15)	1.5 (1)
	Related Service Providers	29	1.5 (1)	19.4 (13)	22.4 (15)	0.0 (0)
	School Administrators	14	0.0 (0)	3.0 (2)	17.9 (12)	0.0 (0)
	<i>Total</i>	67	1	23	42	1
When compared to typical peers, Siblings have trouble focusing in class.	Teachers	24	1.5 (1)	25.4 (17)	9.0 (6)	0.0 (0)
	Related Service Providers	29	1.5 (1)	32.8 (22)	9.0 (6)	0.0 (0)
	School Administrators	14	0.0 (0)	11.9 (8)	9.0 (6)	0.0 (0)
	<i>Total</i>	67	3.0 (2)	70.1 (47)	27.0 (18)	0.0 (0)

Table 6  
*Behavior Survey Question Responses by Educator Group*

	N	% (N) Never	% (N) Sometimes	% (N) Often	% (N) Always
Teachers					
Siblings follow the rules	24	0.0 (0)	13.4 (9)	17.9 (12)	4.5 (3)

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	Related Service Providers	29	0.0 (0)	14.9 (10)	23.9 (16)	4.5 (3)
	School Administrators	14	0.0 (0)	4.5 (3)	16.4 (11)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>0.0</i>	<i>32.8 (22)</i>	<i>58.2 (39)</i>	<i>9.0 (6)</i>
Siblings are bossy toward other students	Teachers	24	9.0 (6)	22.4 (15)	4.5 (3)	0.0 (0)
	Related Service Providers	29	7.5 (5)	32.8 (22)	1.5 (1)	1.5 (1)
	School Administrators	14	3.0 (2)	13.4 (9)	4.5 (3)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>19.5 (13)</i>	<i>68.6 (46)</i>	<i>10.5 (7)</i>	<i>1.5 (1)</i>
Siblings participate in group discussions	Teachers	24	0.0 (0)	14.9 (10)	17.9 (12)	3.0 (2)
	Related Service Providers	29	0.0 (0)	25.4 (17)	17.9 (12)	0.0 (0)
	School Administrators	14	0.0 (0)	13.4 (9)	7.5 (5)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>0.0 (0)</i>	<i>53.7 (36)</i>	<i>43.3 (29)</i>	<i>3.0 (2)</i>
Siblings are disruptive in class	Teachers	24	10.5 (7)	22.4 (15)	3.0 (2)	0.0 (0)
	Related Service Providers	29	7.5 (5)	35.8 (24)	0.0 (0)	0.0 (0)
	School Administrators	14	1.5 (1)	17.9 (12)	1.5 (1)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>18.5 (13)</i>	<i>76.1 (51)</i>	<i>4.5 (3)</i>	<i>0.0 (0)</i>
Siblings are more responsible with their belongings than their peers	Teachers	24	6.0 (4)	20.8 (14)	7.5 (5)	1.5 (1)
	Related Service Providers	29	3.0 (2)	19.4 (13)	16.4 (11)	4.5 (3)
	School Administrators	14	0.0 (0)	14.9 (10)	6.0 (4)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>9.0 (6)</i>	<i>55.1 (37)</i>	<i>29.9 (20)</i>	<i>6.0 (4)</i>
Siblings have trouble keeping friends	Teachers	24	10.5 (7)	20.8 (14)	4.5 (3)	0.0 (0)
	Related Service Providers	29	10.5 (7)	31.3 (21)	1.5 (1)	0.0 (0)
	School Administrators	14	3.0 (2)	16.4 (11)	1.5 (1)	0.0 (0)
	<i>Total</i>	<i>67</i>	<i>24.0 (16)</i>	<i>68.5 (46)</i>	<i>7.5 (5)</i>	<i>0.0 (0)</i>
Siblings get along well with their peers	Teachers	24	0.0 (0)	7.5 (5)	23.8 (16)	4.5 (3)
	Related Service Providers	29	1.5 (1)	11.9 (8)	25.4 (17)	4.5 (3)
	School Administrators	14	(0)	7.5 (5)	11.9 (8)	1.5 (1)
	<i>Total</i>	<i>67</i>	<i>1.5 (1)</i>	<i>26.9 (18)</i>	<i>61.1 (41)</i>	<i>10.5 (7)</i>
Siblings are off-task	Teachers	24	4.5 (3)	28.4 (19)	3.0 (2)	0.0 (0)
	Related Service Providers	29	6.0 (4)	35.8 (24)	1.5 (1)	0.0 (0)

School Administrators	14	0.0 (0)	19.4 (13)	1.5 (1)	0.0 (0)
<i>Total</i>	67	10.5 (7)	83.6 (56)	6.0 (4)	0.0 (0)

Table 7  
*Knowledge Survey Question Responses by Educator Group*

		N	% (N) Strongly Disagree	% (N) Disagree	% (N) Agree	% (N) Strongly Agree
	Teachers	24	1.5 (1)	1.5 (1)	28.4 (19)	4.4 (3)
I have attempted to engage a Sibling in conversation about his or her relationship with their sibling with a disability	Related Service Providers	29	0.0 (0)	6.0 (4)	29.8 (20)	7.5 (5)
	School Administrators	14	1.5 (1)	3.0 (2)	14.9 (10)	1.5 (1)
	<i>Total</i>	67	3.0 (2)	10.5 (7)	73.1 (49)	13.4 (9)
	Teachers	24	1.5 (1)	4.5 (3)	22.4 (15)	7.5 (5)
I am often considerate and conscious of the impact that Siblings' experiences may have on their behavior and academic performance.	Related Service Providers	29	0.0 (0)	0.0 (0)	29.9 (20)	13.4 (9)
	School Administrators	14	0.0 (0)	1.5 (1)	13.4 (9)	6.0 (4)
	<i>Total</i>	67	1.5 (1)	6.9 (4)	65.7 (44)	26.9 (18)
	Teachers	24	3.0 (2)	10.4 (7)	19.4 (13)	3.0 (2)
I actively provide tools and lessons to help children understand disabilities and special needs	Related Service Providers	29	1.5 (1)	6.0 (4)	25.3 (17)	10.5 (7)
	School Administrators	14	3.0 (2)	6.0 (4)	10.4 (7)	1.5 (1)
	<i>Total</i>	67	7.5 (5)	22.4 (15)	55.1 (37)	15.0 (10)
	Teachers	24	0.0 (0)	17.9 (12)	9.0 (6)	9.0 (6)
I actively attempt to learn about disabilities and how they affect children and their Siblings in school.	Related Service Providers	29	0.0 (0)	22.4 (15)	14.9 (10)	6.0 (4)
	School Administrators	14	0.0 (0)	11.9 (8)	4.5 (3)	4.5 (3)
	<i>Total</i>	67	0.0 (0)	52.2 (35)	28.4 (19)	19.5 (13)

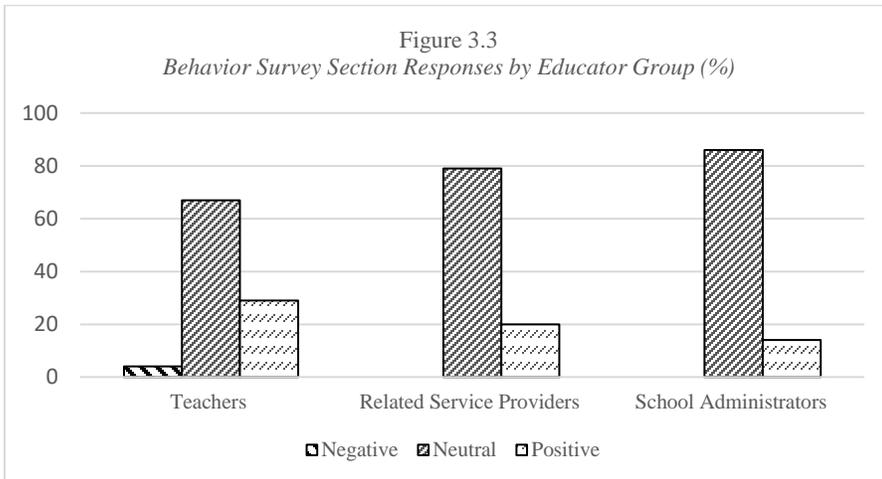
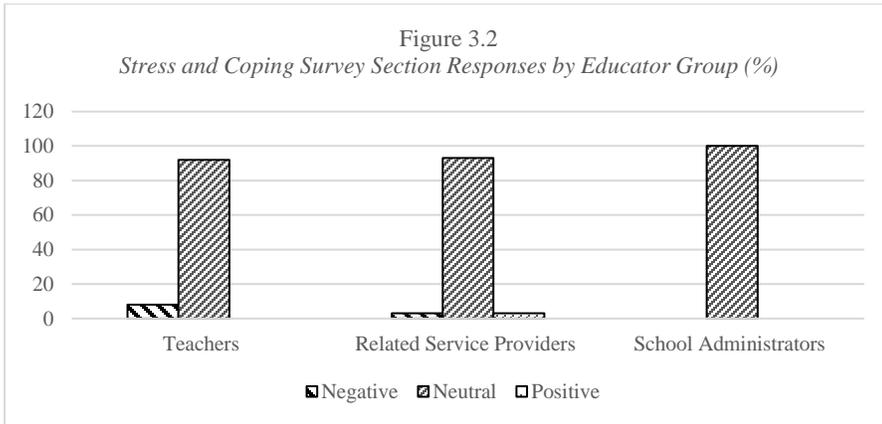
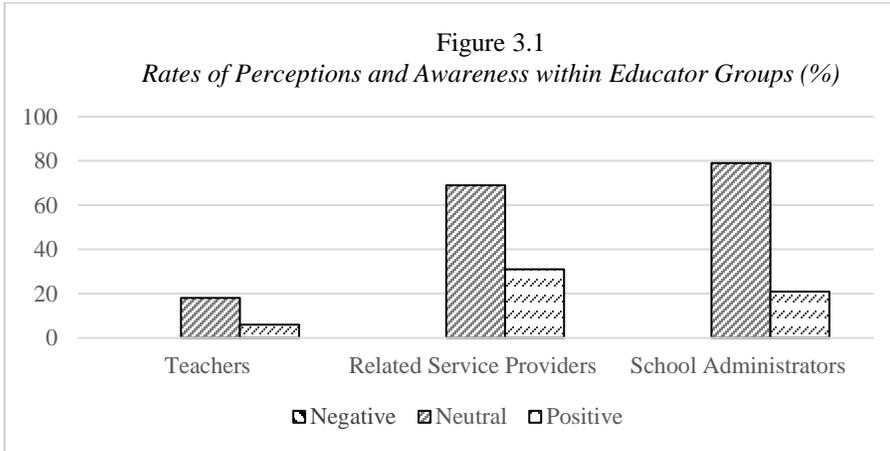
Table 8  
*Support Survey Questions by Educator Group*

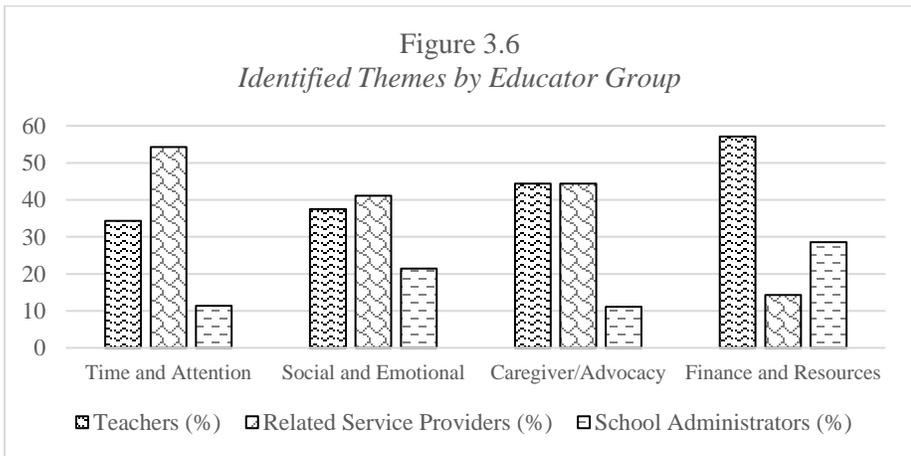
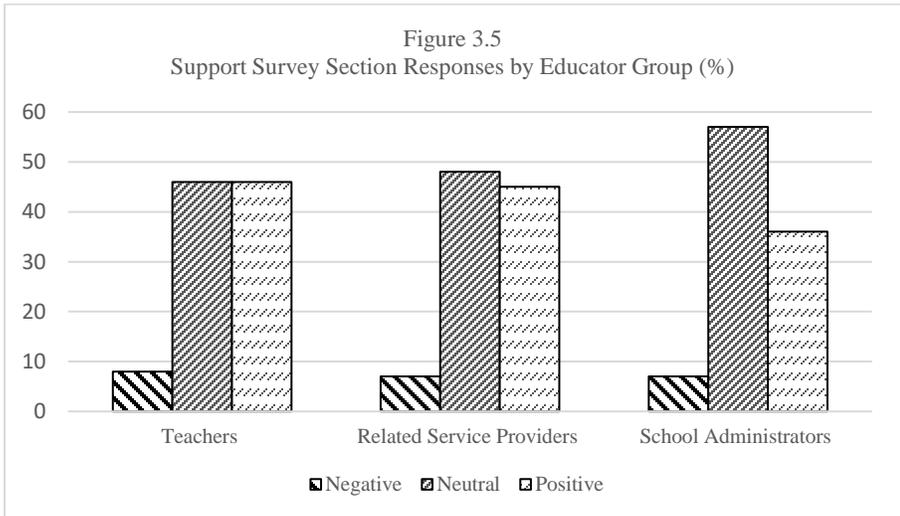
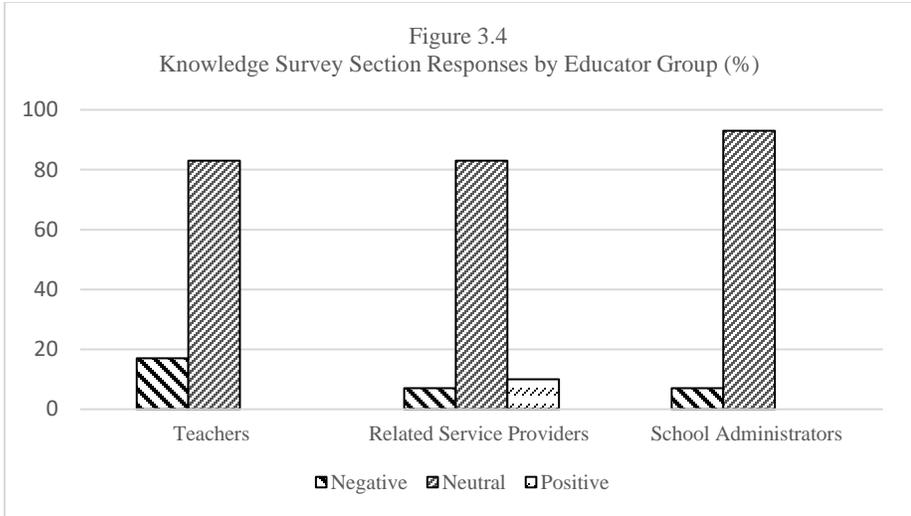
			% (N) Never	% (N) Sometimes	% (N) Often	% (N) Always
	Teachers	24	3.0 (2)	9.0 (6)	16.4 (11)	7.5 (5)
I actively seek ways to support Siblings in the school environment	Related Service Providers	29	3.0 (2)	9.0 (6)	19.4 (13)	11.9 (8)

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	School Administrators	14	0.0 (0)	6.0 (4)	10.5 (7)	4.5 (3)
	<i>Total</i>	<i>67</i>	<i>6.9 (4)</i>	<i>24.0 (16)</i>	<i>46.3 (31)</i>	<i>23.9 (16)</i>
I encourage and give positive reinforcement to Siblings for speaking up when they are uncomfortable.	Teachers	24	0.0 (0)	6.0 (4)	13.4 (9)	16.4 (11)
	Related Service Providers	29	1.5 (1)	6.0 (4)	16.4 (11)	19.4 (13)
	School Administrators	14	0.0 (0)	6.0 (4)	10.4 (7)	4.5 (3)
	<i>Total</i>	<i>67</i>	<i>1.5 (1)</i>	<i>18.0 (12)</i>	<i>40.3 (27)</i>	<i>40.3 (27)</i>
I try to help Siblings identify healthy coping skills when things are difficult	Teachers	24	0.0 (0)	10.5 (7)	10.4 (7)	14.9 (10)
	Related Service Providers	29	1.5 (1)	7.5 (5)	19.4 (13)	14.9 (10)
	School Administrators	14	0.0 (0)	6.0 (4)	10.4(7)	4.5 (3)
	<i>Total</i>	<i>67</i>	<i>1.5 (1)</i>	<i>24.0 (16)</i>	<i>40.2 (27)</i>	<i>34.3 (23)</i>
I encourage Siblings to find someone to talk to about their problems	Teachers	24	1.5 (1)	4.5 (3)	10.5 (7)	19.4 (13)
	Related Service Providers	29	0.0 (0)	10.4 (7)	14.9 (10)	17.9 (12)
	School Administrators	14	0.0 (0)	4.5 (3)	13.4 (9)	3.0 (2)
	<i>Total</i>	<i>67</i>	<i>1.5 (1)</i>	<i>19.5 (13)</i>	<i>38.8 (26)</i>	<i>40.3 (27)</i>
I actively attempt to ensure that Siblings have access to resources and people they can consult to help them understand their siblings' disability.	Teachers	24	3.0 (2)	11.9 (8)	10.4 (7)	10.5 (7)
	Related Service Providers	29	0.0 (0)	16.4 (11)	14.9 (10)	11.9 (8)
	School Administrators	14	0.0 (0)	7.5 (5)	10.5 (7)	3.0 (2)
	<i>Total</i>	<i>67</i>	<i>3.0 (2)</i>	<i>35.8 (24)</i>	<i>35.8 (24)</i>	<i>25.4 (17)</i>

**Figures**





**Appendix D: Educator Perceptions and Awareness Survey**

*Survey Introduction: There are about 6 million children in the U.S. who receive special education services to address a disability. Many of these children live with typically developing siblings (referred to in this survey as "Siblings"). Research shows that although Siblings are affected by living with a child with disabilities at home, they have limited access to resources for social-emotional support. This survey is designed to measure the level of awareness that educators have toward the needs and experiences of Siblings, as well as what educators can do to support Siblings at school.*

**Informed Consent**

**Please check each box to indicate that you understand your rights as a research participant and confirm consent to use your responses as part of the study described above. Failure to check all four boxes will void your responses for this study.**

- I understand that my participation in this survey is voluntary. Check Box
- I understand that any personal information revealed will not be shared with anyone outside of the research team, and will be disposed of immediately upon the completion of this study. Check Box
- I consent to the use of my responses for the research purposes as they were described. Check Box
- I understand that I may withdraw consent and discontinue my participation in this survey without any repercussions. Check Box

**Instructions: Please answer the following questions to the best of your recollection based on your overall experiences working with Siblings in the school setting. If you have not had a lot of experience with this population, please base your answers on your knowledge of Siblings and their experiences.**

Confirm: I have worked with Siblings of children with disabilities	Yes	No	I Know	Don't Know
<b>Stress and Coping</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
When compared to typical peers, Siblings put a lot of pressure on themselves to do well in school.	0	1	2	3
When compared to typical peers, Siblings are often stressed out.	0	1	2	3
When compared to typical peers, Siblings have a lot of learning problems.	0	1	2	3
When compared to typical peers, Siblings are strong self-advocates.	3	2	1	0
When compared to typical peers, Siblings complain a lot.	0	1	2	3
When compared to typical peers, Siblings are withdrawn.	0	1	2	3

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Siblings ask for help when they need it.	3	2	1	0
When compared to typical peers, Siblings have trouble focusing in class.	0	1	2	3
<b>Behavior</b>	<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
Siblings follow the rules	0	1	2	3
Siblings are bossy toward other students	3	2	1	0
Siblings participate in group discussions	0	1	2	3
Siblings are disruptive in class	3	2	1	0
Siblings are more responsible with their belongings than their peers	0	1	2	3
Siblings have trouble keeping friends	3	2	1	0
Siblings get along well with their peers	0	1	2	3
Siblings are off-task	3	2	1	0
<b>Knowledge</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
I have attempted to engage a Sibling in conversation about his or her relationship with their sibling with a disability	3	2	1	0
I am often considerate and conscious of the impact that Siblings' experiences may have on their behavior and academic performance.	3	2	1	0
I actively provide tools and lessons to help children understand disabilities and special needs	3	2	1	0
I actively attempt to learn about disabilities and how they affect children and their Siblings in school.	3	2	1	0
<b>Support</b>	<b>Never</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
I actively seek ways to support Siblings in the school environment	3	2	1	0
I encourage and give positive reinforcement to Siblings for speaking up when they are uncomfortable.	3	2	1	0
I try to help Siblings identify healthy coping skills when things are difficult	3	2	1	0
I encourage Siblings to find someone to talk to about their problems	3	2	1	0
I actively attempt to ensure that Siblings have access to resources	3	2	1	0

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and people they can consult to help them understand their siblings' disability.

<b>Open Ended Question</b>	<b>Negative</b>	<b>Neutral</b>	<b>Ambivalent</b>	<b>Positive</b>
What are some experiences Siblings may encounter when living with a child with a disability, and how can these experiences impact their social-emotional development?	0	1	2	3
<b>Demographics</b>				
What is your age?	22-30	31-40	41-50	50<
What is your sex? (Open Response)				
What is the highest level of education you have completed?	Bachelor's Degree	Master's Degree	Doctoral Degree	
What is your current job title? (Open Response)				
Please select the most appropriate description of your position:	Teacher	Related Provider	Service	School Administrator
How many years have you worked in this position?	1-2	3-5	6-9	10-20 20<
What grades do you work with? Check all that apply.	PreK to 2 <sup>nd</sup>	3 <sup>rd</sup> to 5 <sup>th</sup>	6 <sup>th</sup> to 8 <sup>th</sup>	9 <sup>th</sup> to 12 <sup>th</sup>