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The Sisters' Experience of Having a Sibling with an Autism Spectrum Disorder

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Antioch University - New England

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THE SISTERS' EXPERIENCE OF HAVING A SIBLING WITH AN AUTISM SPECTRUM
DISORDER

A Dissertation Presented to
The Faculty of the Applied Psychology
Antioch University New England

In Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy in Marriage and Family Therapy

By
Melissa L. McVicker, M.S.

May, 2013

Melissa McVicker. *The Sisters' Experience of Having a Sibling with an Autism Spectrum Disorder* (Directed by Amy Blanchard, PhD and Kevin Lyness, PhD). Applied Psychology Department, Spring 2013.

ABSTRACT

This dissertation consists of two articles. This first article is a literature review identifying studies of autism spectrum disorders and sibling relationships published in the past 10 years.

This search strategy identified 16 articles for inclusion in this review and conveyed the following main outcomes: a) parental factors influence sibling relationship and typically developing child,

b) behavioral interactions/problems affect the quality of the sibling relationship, c) genetic factors have varying impact on diagnosis, and d) effects/outcomes for typically developing

sibling are both positive and negative. This review supported the call for a better understanding of the family factors on the sibling relationship, as well as highlighted the absence of qualitative studies that include the voices of children and their siblings regarding their relationship

experience. The second article reports on a qualitative study exploring the experiences of children who have a sibling with an autism spectrum disorder (ASD) using phenomenological methodology. The aim was to develop a better understanding of how the unique experience of having a sibling with ASD may alter, impact and enrich the lives of siblings. Data were collected through participant interviews, photographs, and drawings. The data analysis revealed the

following themes: a) understanding of ASD, b) challenges and benefits of having a sibling with an ASD, c) relationships and interactions with others, d) attunement and unique connection, and e) advocacy and acceptance. The findings have implications for therapeutic practice, education, and research involving families with children when one child is diagnosed with an ASD. The electronic version of this dissertation is available in the open-access OhioLink ETD Center, www.ohiolink.edu/etd.

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Antioch University New England
Keene, New Hampshire
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May 14, 2013

WE HEREBY RECOMMEND THAT THE DISSERTATION BY

Melissa L. McVicker

Entitled

**THE SISTER'S EXPERIENCE OF HAVING A SIBLING WITH AN AUTISM
SPECTRUM DISORDER**

BE ACCEPTED IN PARTIAL FULFILLMENT
OF THE REQUIREMENTS FOR THE DEGREE OF
DOCTOR OF PHILOSOPHY
IN MARRIAGE AND FAMILY THERAPY

APPROVED BY:

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DEDICATION

This dissertation is dedicated to the five children who shared their stories and creations for this study. I am honored to have been given the opportunity to spend time with these children and to hear their voices tell their stories, to literally see their perspectives in photographs, to witness the interactions they had with their siblings, and to gain a glimpse into their lives, hopes, joys, and unique experiences. In addition, I am thankful for the children's families for opening up their homes, and their lives, for this study to occur. In this work, I hope to honor these children's voices and experiences through sharing, and appreciating, their stories.

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Thank you to my family, friends, and MFT community for their continued support, inspiration, and enthusiasm through each stage of this dissertation journey. Thank you for understanding and appreciating the work I feel compelled to do and for encouraging me to continue, especially in the most challenging times. Thank you to my parents for their continued love and support given effortlessly, and in an endless number of ways. Thank you to my partner,

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“To the outside world we all grow old. But not to brothers and sisters. We know each other as we always were. We know each other's hearts. We share private family jokes. We remember family feuds and secrets, family griefs and joys. We live outside the touch of time.” ~C. Ortega

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PREFACE

As a clinician at the Antioch University Couple & Family Therapy Institute in 2010, an Autism Support Group began and in hearing about these groups, my curiosity about the related family dynamics (and interactions between children in the family) started to grow. I attended local Autism Expositions and information sessions about autism, and talked to therapists who participated in the support groups. Coming from an interest in supporting children and siblings, I listened to the shared observations of how many siblings were attending support groups and the challenges that parents expressed about the sibling needs—and an initial research idea was inspired.

In the Spring of 2011, I completed a research project in which my co-investigator and I interviewed a parent of a child with an autism spectrum disorder (ASD) on the needs of her typically developing sibling. On several occasions, the parent identified the sibling relationship as something “special” and “like no other relationship [the child with ASD] had.” This research experience solidified my passion for wanting to expand this neglected area of focus on siblings, and to explore ways to support the sibling relationship, specifically when a child as ASD.

This first article provided in the dissertation is a literature review. The purpose of this article is to identify and review studies of ASD and sibling relationships published in the past 10 years. An electronic database was used to search the key words *autism spectrum disorder*, *siblings*, and *research* and this search strategy identified 16 articles for inclusion in this review. The articles were reviewed and conveyed the following main outcomes: a) parental factors influence sibling relationship and typically developing child, b) behavioral interactions/problems affect the quality of the sibling relationship, c) genetic factors have varying impact on diagnosis, and d) effects/outcomes for typically developing sibling are both positive and negative. This review supported the call for a better understanding of the family factors on the sibling

relationship, as well as highlighted the absence of qualitative studies that include the voices of children and their siblings regarding their relationship experience.

The second article reports on the qualitative study I completed in an effort to explore the sibling experience when child has an autism spectrum disorder. This qualitative study explored the experiences of children who have a sibling with an autism spectrum disorder (ASD) using a phenomenological methodology. The aim was to develop a better understanding of how the unique experience of having a sibling with ASD may alter, impact and enrich the lives of siblings. Data were collected in two interviews with each of the individual participants, in their home environment. Participants were asked to draw pictures and provide photographs. The data analysis revealed the following themes: a) understanding of ASD, b) challenges and benefits of having a sibling with an ASD, c) relationships and interactions with others, d) attunement and unique connection, and e) advocacy and acceptance. The findings have implications for therapeutic practice, to promote the inclusion of sibling interventions and sibling support groups, as well as for education and research involving families with children when one child is diagnosed with an ASD.

Chapter One: Manuscript One

**AUTISM SPECTRUM DISORDERS (ASD) AND SIBLING RELATIONSHIPS:
A LITERATURE REVIEW**

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Abstract

The purpose of this article is to identify and review studies of autism spectrum disorders (ASD) and sibling relationships published in the past 10 years. In 2012, an electronic database was used to search the key words: *autism spectrum disorder*, *siblings*, and *research* and this search strategy identified 16 articles for inclusion in this review. The articles were reviewed and reported the following main outcomes: a) parental factors influence sibling relationship and typically developing child, b) behavioral interactions/problems affect the quality of the sibling relationship, c) genetic factors have varying impact on diagnosis, and d) effects/outcomes for typically developing sibling are both positive and negative. There is a call for researchers to include the interaction of family and environmental risk variables as influential factors on the sibling relationship, as well as a need for qualitative studies to add richness and data in the words of the children who have a sibling with ASD. Additional clinical implications and future directions for research are discussed. The electronic version of this dissertation is available in the open-access OhioLink ETD Center, www.ohiolink.edu/etd.

Keywords: *autism spectrum disorder*, *siblings*, and *research*

Background

Autism spectrum disorders (ASD) are increasingly becoming an area of concern and interest for mental health professionals, educators, and researchers (Rivers & Stoneman, 2008). It has been estimated that that about 1 in 88 children has been identified with an autism spectrum disorder (Centers for Disease Control and Prevention, 2012). The majority of individuals with an autism spectrum disorder have at least one sibling (Allgood, 2010).

Siblings and Autism

Researchers have studied children with autism in relation to a number of factors such as diagnosis and responses to treatment (Brunner & Seung, 2009; Kabot, Masi, & Segal, 2003); early intervention (Towle, Visintainer, O'Sullivan, Bryant, & Bursby, 2009); intelligence (Scheirs & Timmers, 2009); and mother/child relationships (Hoffman et al., 2008). However, there has been little attention given to the typically developing siblings of children with autism. The sibling bond can be a unique and powerful influence on mental, emotional, physical elements of an individual's life (Wolf, Fisman, Ellison & Freeman, 1998). As such, the presence of a disability or illness in one child can affect the individuals in the siblings relationship—perhaps bringing the siblings closer together, or pushing them further apart (Farber, 2010; Tucker, McHale & Crouter, 2001).

Siblings can play a vital role in a child with autism developing social interaction skills (Harris & Glasberg, 2003). A child with autism can benefit from play with siblings, which can provide appropriate play behaviors and modeling. However, ASD diagnoses are characterized by atypical social interaction styles and impairment in non-verbal behaviors, which may affect the developing of sibling and peer relationships (Howard, 2006). Siblings may also have to manage certain behaviors displayed by their sisters and brothers with autism, such as hyperactivity, temper tantrums, self-injury, and aggression (Gray & Holden, 1992; Guzman, 2009). Some other

challenges siblings may face include relationships with parents, relationships with friends, demands to help care for the sibling, as well as having some restrictions or limitations in participating in typical family activities (Allgood, 2010).

Research on Sibling Relationships When One Child has Autism

The few researchers who have attempted to examine the influence of having a brother or sister with autism on an individual, have explored the sibling's reactions to the child with autism (Sullivan, 1979); the impact of having a brother or sister with ASD on the sibling's behavioral adjustment and play interactions (Hassan El-Ghoroury & Romanczyk, 1999); internalizing and externalizing symptomology (Strobel, 2006); the sibling's understanding of the ASD diagnosis (Glasberg, 2000); selected professional career path (Seligman & Darling, 2007); and the presence of anxiety and depression in the typically developing sibling (Gold, 1993). Researchers studying the experience of an individual having a sibling with autism produce mixed results. Some studies indicate that many siblings report positive emotions (tolerance and pride), while others experience emotions such as fear, guilt, depression, and embarrassment (Bagenholm & Gillberg, 1991; Fisman et al., 1996; Gold, 1993; Rodrigue, Geffken, & Morgan, 1993; Ross & Cuskelly, 2006; Strobel, 2006). However, researchers have supported consistent themes of concern for the interpersonal relationship between siblings (Allgood, 2010).

The quality of the sibling relationship has been discussed in some of the research related to autism (Roeyers & Mycke, 1995). Some studies have reported that siblings of brothers and sisters with autism described their relationship as having less competition, conflict, and quarrels than normally developing comparison siblings groups (Kaminsky & Dewey, 2001). Past research has also supported the positive influences of the sibling relationship, such as increased cooperation, nurturance, sensitivity, compassion, and empathy (Kiburz, 1994; Wilkerson, 2001). Furthermore, typically developing siblings express positive feelings about their sibling

relationships, even though brothers or sisters with ASD often demonstrate aggressive or tantrum behavior, have poor communications skills, and engage in fewer positive interactions with their siblings (Guzman, 2009; Kaminsky & Dewey, 2001; Farber, 2010). While siblings of children with autism express less nurturance, prosocial behavior, and intimacy when compared to siblings of children with Down syndrome, the siblings also expressed increased admiration for their brother and sister and a decrease of competition (Kaminsky & Dewey, 2001; Strobel, 2006). Overall studies seem to indicate that the sibling relationship is one that is complex and diverse—some siblings can be affected in a variety of areas to varying degrees, both positively and negatively (Connors & Stalkers, 2003).

The purpose of this article is to identify and review studies of autism spectrum disorders and sibling relationships published in the past 10 years and discuss the related clinical implications and future directions for research.

Method

In 2012, a search of an online library search engine accessed through a university server was carried out in 2012 first using the key words: *autism spectrum disorders*, *sibling*, and *relationship*. The “EBSCOhost Research Databases” was chosen as the search engine. This electronic database is an online reference system that is accessible via the Internet and contains full text databases from leading information providers. This database ranges from general collections to subject-specific databases for a variety of sources (academic, medical, public libraries, etc).

The search strategy in EBSCOhost was limited to the English language and to references that were published in the last 10 years, to produce articles that are reflective of current research interests and methodologies. To be included in this review, the articles needed to meet the

following inclusion criteria: a) Included siblings in the sample b) published between years 2002-2012 and c) related to autism spectrum disorders.

Results of Review

Using the search strategy, the researcher identified 16 articles for inclusion in this review. Although 28 sources were returned from using the key words in the electronic database, 12 were editorials, lit reviews, book reviews, or presentation material. These items were not included in the review because they were not studies. Therefore, the 16 articles were reviewed and reported by the following main outcomes: 1) Parental Factors Influence Sibling Relationship and the Typically Developing Child 2) Behavioral Interactions/Problems Affect the Quality of the Sibling Relationship 3) Genetic Factors Have Varying Impact on Diagnosis and 4) Effects/Outcomes for Typically Developing Sibling are Both Positive and Negative. Some articles fit into more than one of the thematic outcomes, and are referenced as such. Table 1 summarizes the studies and the results are reviewed below.

Parental Factors Influence Sibling Relationship and Typically Developing Child

After using the keywords *autism spectrum disorder*, *siblings*, and *research* to search the electronic database, 9 articles addressed parental factors. This was the most common theme that resulted from the review of the literature. Similar to the studies included in the previous section, most of the articles in this category included studies that focused on the parental perspective in relation to the sibling relationship. Within this theme of parental factors, there were sub-themes that emerged in the articles. One sub-theme was the parental factors that influenced the sibling relationship, and the second was the parental factors that influenced the experience of the typically developing child.

Researchers explored the parental factors that influenced the sibling relationship—including parental support for the sibling relationship, differential interactions with the children,

and personal mental health. Orsmond, Kuo, and Seltzer (2009) found greater parental support predicted greater positive affect in the sibling relationship. The role of parental influence on the sibling relationship is significant in that once the parents are no longer able to be the primary caregiver for the child with ASD; siblings tend to be less emotional close than siblings of individuals with Down Syndrome. Interestingly, greater social support from both parents was reported by adolescent siblings when compared to adult siblings. This difference ties back to the influence of life stages and developmental factors that could influence the sibling relationship, even as it relates to the experience of receiving parental support for that relationship.

Rivers and Stoneman (2008) also offered support for the quality of the sibling relationship being influenced by parental factors. Through the use of questionnaires given to both a parent and the typically developing sibling, these researchers looked at the link between differential parenting and the quality of the relationships between 50 children with an ASD and their typically developing siblings, considering parental characteristics and behaviors. Typically developing children who reported feeling more satisfaction with differential parented rated their sibling relationship as being of higher quality across the relationship dimensions of overall happiness with the relationship, satisfaction with time spent together, caretaking, and how they got along. Related, the sibling relationship was compromised when the children reported dissatisfaction with differential parenting. Differential parenting can be influenced by many factors, one of which includes the parent's ability to manage different needs of children, while also being affected by the stress and related mental health concerns that may be experienced as a result of these demands.

In the study by Petalas et al. (2012), parents provided data on their own mental health and on their children (one diagnosed with an ASD). From this study, siblings with more features of

broad autism phenotype who also had parents with mental health problems reported more sibling relationship conflict. Similarly, Meyer, Ingersoll, and Hambrick (2011) found that the symptom severity of the child with an ASD positively predicted maternal depressive symptoms, which in effect, was an indirect positive predictor of sibling adjustment problems. Parenting a child with severe ASD symptoms may result in significant levels of depressive symptoms for a parent, who is attempting to balance the demands of multiple children with different needs and may be less able to provide emotional support for the typically developing sibling. The results of this study tie to the second sub-theme of parental factors that influence the experience of the typically developing sibling.

Caruz (2006) examined the dyadic relationship of mothers and their typically developing sibling, specifically looking at the effect of childhood parentification of siblings of children with an ASD. A total of 36 pairs of questionnaires were completed by the children and mothers, and the specific maternal qualities of closeness-caregiving, intrusiveness, and openness of communication were assessed. In relation to parentification of the child, a significant negative relationship between the closeness-caregiving domain and a significant positive relationship between the intrusiveness domain were found. The findings suggest that the adaptive type of parentification of the child is associated with moderate levels of maternal qualities. Overall, research has supported the findings that not only are sibling relationships affected when one child has an ASD, but so to are the relationships between parents and the typically developing child (Kent, 2012; Orsmond & Seltzer, 2007). These findings promote the importance of interventions that can build on relationships within the family, including those between parents and children who are/are not diagnosed with an ASD, and siblings (Wright et al., 2011).

Summary. Overall, the studies that are included in this thematic category demonstrate that parental factors influence the sibling relationship. Parental involvement is important in supporting the sibling relationship, and parental factors are influential in how the typically developing child may experience relationships with siblings and parents. The characteristics of the typically developing sibling, the sibling with autism, and the parent may all interact to contribute to the sibling relationship. It would be important to explore not only the importance of parental involvement and factors that can support sibling relationships for children, but also to extend this inquiry to include sibling relationships in adulthood. When interacting with parents, professionals can highlight the on-going nature of sibling relationships, and the varying qualities and dynamics that can be supported and experienced throughout varying life stages and developmental levels of all family members. Furthermore, expanding studies to look at the sibling relationship as influenced by additional parental characteristics would be helpful, such that functioning of parents, parental marital status, and socioeconomic background could be included. Overall, the articles in this literature review suggest that sibling relationships can be affected by family characteristics and parental factors, which offer important implications for treatment and assessment of family members of individuals with ASD to include a family-level approach.

Behavioral Interactions/Problems Affect the Quality of the Sibling Relationship

A total of six articles reflected this theme. Articles in this category examined behavioral interactions between a child diagnosed with an autism spectrum disorder and the typically developing sibling, which included behaviors and characteristics of the child with ASD that influenced the quality of the sibling relationships. One study by Orsmond et al. (2009) investigated the sibling relationship in a cross sectional study of adolescents and adults with a

sibling with an autism spectrum disorder (ASD). Participants were siblings from families of 406 adolescents and adults diagnosed with ASD who were participating in a longitudinal study. Data was collected from adult siblings at the second point of the ongoing study through completion of a packet of questionnaires, and from adolescent siblings during the fourth time point via phone interview and a packet of questionnaires. Half of the participants lived in Wisconsin and half lived in Massachusetts. Engagement in shared sibling activities and positive affect in the sibling relationship were measured using various assessment scales. These scales explored coping strategies of the typically developing sibling, behavioral problems of the sibling with ASD, and the influence of support systems on the sibling interactions. The results of this study supported that when the sibling with an ASD had fewer behavior problems the sibling relationships were more positive for both adult and adolescent siblings, and more shared activities and positive affect in the relationship occurred (Orsmond et al., 2009). Behavior problems and the characteristics of the brother or sister with an ASD were deemed as the most influential factors for the sibling relationship (Orsmond et al., 2009).

Behavioral problems of a child with an ASD and the related influence on the sibling relationship were also explored in a study by Petalas et al. (2012). This researchers in this study asked parents from 166 families to report on the child with an ASD and their sibling using depression a scale, a sibling relationship questionnaire, and a strengths and difficulties questionnaire, among additional measures. The goal of this study was to explore the quality of the sibling relationship, as well as the adjustment of siblings of individuals with an ASD, as predicted by environmental stressors and genetics. Results were that sibling relationships were more negative when the child with an ASD had more behavior problems and when there was evidence of critical expressed emotion in the family environment (Petalas et al., 2012). Although

the results of this study highlight that behavioral problems of a child with an ASD can influence the sibling relationship, this study relied on parental report on the sibling relationship and the child with an ASD, making the source variance a potential problem.

Another study by Orsmond and Seltzer (2007) also found that the sibling relationship was associated with characteristics of the brother or sister with an ASD—specifically with having higher levels of independence and living closer to the sibling. This study also included adults with a brother or sister with ASD who completed questionnaires (including various scales and subscales) to measure their coping strategies, feelings, and activities with siblings. In this study 154 adults siblings in two associated longitudinal studies participated, with 77 siblings with a brother or sister with ASD being matched by age and gender to 77 siblings with a brother or sister with Down syndrome (DS). Although the design of the study does not allow causal or directional inferences, the siblings of adults with DS were compared to siblings of adults with ASD and reflected that siblings of adults with ASD had less contact and lower levels of positive affect with their sibling. However, when the sibling with an ASD had higher levels of functional independence and siblings were in closer in living proximity, a closer sibling relationship was observed—consistent with the previous study (Orsmond et al., 2009).

In addition, researchers have examined temperament of children and the effects on sibling interactions, as well as the role of interventions in decreasing tension and facilitating quality time in sibling relationships. From questionnaires completed by one parent and the typically developing children in 50 families, the temperament dimension of persistence, but not activity level or emotional intensity, was found to relate to the quality of the sibling relationship (Rivers & Stoneman, 2008). In a qualitative design looking at social engagement among families (including the sibling dyad), focus groups examined social interactions and relationships.

Following a computer program intervention, there was a theme of facilitating friendships, less tension at home between siblings after intervention, and an increase in spending time together and sharing interests (Wright et al., 2011). This was one of the rare studies that included sibling pairs, parents, and grandparents in the focus groups to examine interactions and sibling relationships after an intervention.

Summary. The studies in this cluster demonstrate that the quality of the sibling relationship is influenced by a variety of factors, such as siblings living in proximity, utilizing coping strategies, and sharing activities. Additional factors would be worthy of further exploration, such that there could be consideration for developmental changes that might occur over time that may influence the individuals' behaviors and sibling interaction. Impairments in social interaction, behavior, and communication that are common for individuals with ASD may become less severe over time (CDC, 2012), and alter the sibling relationship according to the life stage (and age) of both siblings.

Considering that coping strategies of the typically developing sibling were found to promote positive sibling relationships (buffering the effects of the challenging behaviors of the child with an ASD), it could be beneficial to look at the sibling's exposure to resources that could promote coping skills, such as education about diagnosis and related behaviors, involvement in support groups, or even membership in organizations that provide information about strategies to improve problem solving and communication in the family. The results from this literature review also have implications for interventions that can focus on supporting emotional closeness of siblings through use of problem-focused coping strategies in managing interactions between siblings, especially when the sibling with an ASD has increased behavioral problems.

While behaviors and characteristics of the individual with an ASD were identified as influencing the quality of the sibling relationship, a dominant trend in these articles was the use of parental response to questionnaires about the sibling relationship and individual characteristics of the children. The majority of the studies that included the perspective of the typically developing sibling used questionnaires and scales, or were combined with parental responses and experiences. This dominant methodology highlights the need for research to include the experiences of the typically developing children beyond quantitative measures, and separately from the parental responses about their sibling relationship.

Genetic Factors Have Varying Effect on Diagnosis

The review of the literature resulted in finding six articles that reflected the theme of genetic factors having varying affects on having an autism spectrum disorder. This theme includes studies that examined the genetic basis of ASDs, the etiology of autism, and the physiological and biological differences in children diagnosed with ASDs and possible dysfunctions related to the diagnosis. In this category siblings were included in most of the studies as a comparison group. Looking at diagnostic boundaries, several studies attempted to look at communication and cognitive domains to gain information about how criteria are met for some children in the family and ways to build on early detection (and diagnostic tools) to assess if siblings (other children in the family) are also at risk for ASDs.

Sepata (2011) examined the relationship between atypical facial fixation pattern and autism symptom severity through the use of multiple studies. In one of the quantitative studies in particular, the participants were 36-month old siblings of children with autism who were used as a comparison group to explore the relationship between social impairment and facial fixation behavior. Although quantitative, this study included different means of data collection and

participant involvement, using photographs and direct interactions to gain information. In using photographs, the children were asked to observe or imitate the five different emotions that were expressed. Using eye tracking technology and live face-to-face peek a boo interactions, the study demonstrated that aberrant facial fixation in autism occurs across development (beginning as young as 36 months). This study represented a common way siblings are involved in the research in the field of autism—as a comparison group. In addition, this study also explored the risk of siblings being diagnosed with autism (and emphasizing early detection), which is also a trend in research examining genetic or biological influences on an ASD diagnosis.

A study including 52 children with autism and 36 children with specific language impairment (SLI) and their parents and siblings, looked at reading abilities, language and IQ to better understand the overlap of autism and broader phenotypes (Lindgren, Folstein, Tomblin, & Tager-Flusberg, 2009). Children and their families participated in a family and personal history interview, including such assessments as the Peabody Picture Vocabulary Test, The Woodcocks-Johnson Psycho-Educational Battery, and the frequently used Wechsler Intelligence Scales CELF-III and Autism Diagnostic Interview. The results of the study show that genetic loading for language is not shared by ASD and SLI families. The participants in this study included siblings who were six years or older, which could mean that the children could have outgrown the language impairments, or managed to compensate for them. Extending this research longitudinally could allow the inclusion of younger siblings, which could offer an exploration of the changes in language as a result of growth and development over time. This article is part of the trend of siblings as comparison groups for risk factors and genetic differences of children with ASD, and also the interest of exploring differences in intelligence and language abilities.

Lerer's study (2008) also had a sibling comparison group to examine possible genetic contributions shaping cognition, daily living skills, and communication sub-domains of children meeting the diagnostic criteria for ASD. Working with 133 families, a parent interview and family-based association tests assessed areas of child functioning, including communication and language, social interaction, and stereotyped behavior. The results suggest that IQ and communication are shaped by partially by genes, which presents a risk for children in the same family being diagnosed with ASD. Researchers in the ASD field continue to explore genetic influences, particularly as related to the risks for ASD. One study by Puleo, Reichenberg, Smith, Kryzak, & Silverman (2008) looked at paternal age as a potential parental factor for the risk of genetic autism. However, the results suggest that the two concepts were unrelated (Puleo et al., 2008).

The risk factors for ASD diagnosis were also explored in a study looking at the relationship between birth and pregnancy complications and genetic factors in autism (Zwaigenbaum et al., 2002). Again with typically developing siblings as a comparison group, standardized interviews were used to ask mothers about the pregnancy and birth of each child (78 children with an ASD and 88 typically developing siblings). The findings from this study argue against complications being a direct cause of autism. However, it is important to note that the sample size and power in this study may not be sufficient to explain the associations with genetics and complication-free experiences, especially considering missing data was an issue, with only 43 of 60 families having family history information data available. Also, the study heavily relied on the recall of participants, which could easily be affected by information about the diagnosis gathered over time.

Lastly, using quantitative and qualitative methodologies, Campbell et al. (2006) compared the brain morphometry of 39 children and adolescents in an effort to study the neuroanatomy, specifically structural brain anomalies. Semi-structured interviews were conducted to gather past medical history, as well as the use of scales and questionnaires to obtain information on intelligence, strengths and difficulties, and behaviors associated with autism. The results from this study suggest that there is evidence of brain differences related to individuals with ASDs when compared to control groups, such that there are reductions in cerebella grey matter (which may be associated with behavioral problems), and differences in the frontostriatal regions (related to emotional problems and social behavioral difficulties).

Summary. This theme in the literature offers findings consistent in the autism spectrum disorder field, specifically that the genetic influence on ASD diagnoses is supported in some ways, and not in others. This variation speaks to the need for continued research in this area to explore the contribution of genetics in children being diagnosed with ASD, and using siblings as comparison groups. In addition, these studies also included information on early detection for ASD, and diagnostic tools to assess if other children in the family are also at risk for an ASD diagnosis. The interest in brain anatomy is also reflected in this collection of articles, again looking to identify genetic differences/risk factors of and ASD diagnosis on children within the same family.

Some challenges in these articles appear to be the design of studies—specifically cross-sectional designs and lack of matched control groups. In addition, carrying out multiple comparisons also creates some limitations. Another challenge is the common one of having a heterogeneous sample, in addition to some individuals having specific “autism” diagnosis, and other research participants having “Asperger’s” diagnosis. Researchers have defined the

variation of specific ASDs as an influential factor needing to be further explored in future research studies.

Effects/Outcomes for Typically Developing Sibling are both Positive and Negative

From the collection of articles on siblings, research, and autism, six articles emerged demonstrating that the effects of, and outcome for, the typically developing sibling are both positive and negative. Researching how children with a sibling with an ASD have been affected has been common in the field—this research looks at both positive and negative influences and outcomes. Orsmond and Seltzer (2007) (mentioned previous in this article) investigated the sibling relationship in adolescents and adults with a sibling with an ASD through the use of questionnaires and a brief telephone interview. Results from this study showed that siblings of adults with ASD (compared to those who had a sibling with Down syndrome) had less contact with their brother or sister, felt more pessimistic about the brother or sister's future, and also were more likely to report that their relationship with their parents had been affected by having a sibling with an ASD (Orsmond & Seltzer, 2007). This study reflects the significance of the typically developing sibling's feelings and experiences of having a brother or sister with an ASD, and the factors that have influenced that relationship and the sibling's experiences. This ties into additional ways researchers have looked at the way siblings have been affected by a diagnosis of ASD in the family—the behavior outcomes for the typically developing siblings.

Behavioral problems and adjustments for the typically developing sibling were researched by Meyer, Ingersoll, and Hambrick (2011) and also by Petalas et al. (2012). These studies produced similar results—that the sibling's behavioral problems were associated with the behavioral problems of the child with an ASD. Specifically, the quality of the sibling relationship was found to be moderated by the severity of autism in the child with ASD, which includes the

child having general behavior problems such as tantrums and aggression (Meyer et al., 2011). These behaviors may serve as stressors for siblings of children with an ASD, which may increase the risk of that sibling having adjustment problems. When the diagnosed child is low-functioning, the sibling may have difficulties with empathy, social relatedness, and emotional awareness, which may increase the likelihood of that sibling developing depression and anxiety in response to stressful life events (especially when the sibling also has broad autism phenotype characteristics). The study by Petalas et al. (2012) also supported the influence of behavioral problems of a child with an ASD on predicting increased behavioral problems in siblings.

Characteristics of the typically developing sibling were also explored in other studies that explored the themes of families who had a child with an ASD. One study supported that siblings of a child with an ASD would have a pattern of defending their brother and sister in social settings, as well as increasing caretaking responsibilities for them (Kent, 2012). Even when the diagnosed sibling was older, age role reversal was a common theme that emerged from the data, as well as the general idea of siblings (and the sibling relationship) being affected by the diagnosis of a brother or sister.

The benefits of having a sibling with an ASD was also investigated, including the impact of siblings characteristics on the social-skill functioning of the diagnosed child. Such sibling characteristics that were highlighted were having an increased empathetic ability, well-rounded character, and maturity—which were seen as benefits that resulted from having a sibling with an ASD (Brewton, Nowell, Lasala, & Goin-Kochel, 2012). Furthermore, results from qualitative studies that included the perspective of the sibling without an ASD included both themes of

“Having a sibling with ASD has actually impacted my life for the better” and “It’s a blessing and a curse” (Henderson, 2011, p. 4).

Summary. These studies support the idea that siblings can influence each other in various ways—behaviorally, emotionally, and in building personal characteristics and social skills. There is variation in the affect on each other, which includes additional individual and family factors. It would be interesting to do studies that include attention to the age and gender of the siblings, socioeconomic factors of the family, as well as number of children in the family to explore different effects and outcomes for siblings within the same family. In addition, these articles draw attention to the need for specialized interventions for siblings of children with ASD, as they are affected in different ways than parents or other family members. This also speaks to the need for family-focused interventions that can assist with communication techniques to enhance the relationships and empower families to support individual members, included the typically developing sibling.

The limitations of these articles are consistent with challenges in previous research, in that parental interview and reports are the common method of obtaining information. Interviews with adult parents were used to obtain information about the effects and outcomes for the typically developing sibling, although this resulted in small sample sizes and excluding the first hand experience of the siblings themselves. It would be helpful to invite the voices of children, adolescents, and adults who have a sibling with an ASD and hear their stories, experiences, and ways they (and their family) have been affected by the diagnosis. It would also be interesting to conduct longitudinal studies with these siblings, to assess any changes that occur as a result of aging, changes in life stage, services received (such as therapy or psycho education), etc.

Discussion

Research on siblings of children with an ASD has produced an inconsistency of results—which may be reflective of the means of data collection and methodology (Hannah & Midlarsky, 1999). To collect data, many researchers have used questionnaires, surveys, observation and behavioral measures, and paper assessments (Hannah & Midlarsky, 1999; Pilowsky et al., 2004; Strobel, 2006). Also, while typically developing siblings have been assessed at different ages, most studies have focused on adolescents, young adults, and adults from the parental perspective, with a parental comparison, or with the typically developing siblings as a comparison group (Farber, 2010; Gold 1993). The majority of researchers have used quantitative methods, included the typically developing child as a sibling comparison or control group, have used the mother as the source of data, and included concepts that can be limiting, such as focusing on social and psychological adaptation and behavioral problems (Wilkerson, 2001). These methods may not have permitted fully exploring the richness of the experience of the sibling relationship (Wilkerson, 2001). While some studies and publications have focused on the unique conditions of the sibling relationship when one child has an autism spectrum disorder, few studies have examined the relationship between children diagnosed with ASD and their siblings, and of those, even fewer include the perspectives of the siblings themselves (Allgood, 2010).

Though identifying the risk factors for siblings with ASD is necessary in order to ensure their well-being, there is also the need to honor the unique perspectives of children with autism and to acknowledge the ways in which they and their siblings support each other, even if these forms of support differ from those commonly found in typical sibling relationships (Sirota, 2010). The voices of children in general and those with ASD in particular have often been marginalized or ignored, and the majority of existing studies of this population have relied on quantitative measures that fail to capture the richness of their lived experiences (Neuman, 2003;

Sirota, 2010). Qualitative researchers tend to be aware of this marginalization and aim to employ methodologies that minimize the power differential between researchers and participants (Creswell, 2007). There is a need for qualitative studies to add richness and data in the words of the children who have a sibling with ASD (Wilkerson, 2001).

Furthermore, one of the consistent problems that researchers face in this area is with sampling and lack of generalizability. A vast majority of participants identified as Caucasian and did vary greatly in demographic variables (age of parents, age difference of siblings, SES). It might be helpful to include attention to the interaction of family and environmental risk variables (such as lack of access to resources or having a child with an ASD who is lower functioning). Lastly, it would be beneficial to gain more information on the processes and interventions that can promote supportive, positive relationships between children with ASD and their siblings. In doing so, meaningful information can be provided about how to further enhance and strengthen these relationships in the family, through extending resources, inclusion in therapy, and variety of family-focused interventions. There is a call for strength-based approaches that focus on children's abilities and creativity, rather than maintaining attention on risk-factors, problem-focused conversations, and their limitations.

This literature review has implications not only for interventions and supports for sibling subsystems, but could also promote the inclusion of siblings in support groups or family therapy in relation to the experienced stress, and resilience, in the family system. Furthermore, hearing the unique experiences and insights of siblings of children with ASD can facilitate a greater understand of interactions within the family, which can promote mental health and education professionals expanding the family context to include the sibling relationships as a possible strength, intervention, or resource.

Educating parents about the children's experience of the sibling relationship may increase the family's psychological resources, and in turn, may increase positive sibling interactions and experiences (Guzman, 2009). As previously mentioned, the sibling bond can have a unique and powerful influence on the mental, physical, and emotional aspects of a person's life. With a better understanding of this relationship (and its possible strengths and influences) parents, mental health professionals, and supporting organizations can work together to create greater supports and outcomes not only for children diagnosed with an ASD, but also for their siblings and their families.

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Table 1

Literature Review

APA Citation	Participants	Study Information	Theme(s) of Article
1. Brewton, C. M., Nowell, K. P., Lasala, M. W., & Goin-Kochel, R. P. (2012). Relationship between the social functioning of children with autism spectrum disorders and their siblings' competencies/problem behaviors. <i>Research in Autism Spectrum Disorders, 6</i> , 646-653. doi:10.1016/j.rasd.2011.10.004	1355 children with ASD 1351 siblings	Explored possible relationships between sibling characteristics (social competencies and problem behaviors) and the social functioning of children with ASD.	Theme: Effects/Outcomes for Typically developing sibling are both positive and negative
2. Kent, M. (2012). Autism spectrum disorders and the family: A qualitative study. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering, 72</i> , 5573.	8 biological parents (7 mothers, 1 father) Children 5-13 years old, 2 girls and 5 boys, non ASD were 6-11 yrs	Focused on parental experience of being of a parent of ASD child and the impact an ASD diagnosis has on different family dynamics	Themes: Parental factors influence sibling relationship and the experience of typically developing child; Effects/Outcomes for Typically developing sibling are both positive and negative
3. Petalas, M. A., Hastings, R. P., Nash, S., Hall, L. M., Joannidi, H., & Dowey, A. (2012). Psychological adjustment and sibling relationships in siblings of children with autism spectrum disorders: Environmental stressors and the broad autism phenotype. <i>Research In Autism Spectrum Disorders, 6</i> , 546-555. doi:10.1016/j.rasd.2011.07.015.	166 families The children with an ASD were 137 boys and 29 girls; mean age of 10.46 years (SD = 2.73)	Goal was to explore the interactions between genetic liability and environmental stressors in predicting the adjustment of siblings of individuals with an ASD and the quality of their sibling relationships.	Themes: Behavioral interactions/problems affect the quality of the sibling relationship; Parental factors influence sibling relationship and the experience of typically developing child; Effects/Outcomes for Typically developing sibling are both positive and negative

APA Citation	Participants	Study Information	Theme(s) of Article
4. Wright, C., Diener, M. L., Dunn, L., Wright, S. D., Linnell, L., Newbold, K., & Rafferty, D. (2011). SketchUp™: A technology tool to facilitate intergenerational family relationships for children with autism spectrum disorders (ASD). <i>Family and Consumer Sciences Research Journal</i> , 40, 135-149. doi:10.1111/j.1552-3934.2011.02100.x.	Seven high-functioning boys (ages 8–17) with ASD; parents; siblings ages 8-12, (4 sister 2 brothers)	Qualitative design to examine intergenerational relationships—facilitate computer skill development and social interaction	Theme: Behavioral interactions/problems affect the quality of the sibling relationship
5. Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. <i>Research in Autism Spectrum Disorders</i> , 5, 1413-1420. doi:10.1016/j.rasd.2011.01.027.	70 mothers Biological child aged 2–18 with an ASD and at least one typically developing child aged 6–18	Examine possible predictors of adjustment difficulties in siblings	Theme: Effects/Outcomes for Typically developing sibling are both positive and negative
6. Henderson, D. L. (2011). A phenomenological case study of the impact of autism spectrum disorders on the sibling relationship. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> , 71, 5425.	Five adolescent participants ranging from 11-18 years of age; urban and rural settings and were within close age proximity (5 years) of their sibling	Examines the perspectives of siblings of children with ASD.	Theme: Effects/Outcomes for Typically developing sibling are both positive and negative
7. Sepeta, L. (2011). An examination of the social deficit of autism: A comprehensive study of facial fixation behavior throughout development. <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> 72, 3740.	24 (1 female) ASD and 15 (1 female) typically developing child (age 8-18) 53 children (36months of age)	Examined the relationship between autism symptom severity and atypical facial fixation pattern	Theme: Genetic factors have varying impact on diagnosis
8. Lindgren, K. A., Folstein, S. E., Tomblin, J., & Tager-Flusberg, H. (2009). Language and reading abilities of children with autism spectrum disorders and specific language impairment and their first-degree relatives. <i>Autism Research</i> , 2, 22-38. doi:10.1002/aur.63	52 autistic children, 36 children with SLI ,their siblings, and their parents. Siblings and children between age 6-16.	Looked at IQ, language, and reading abilities of ASD and SLI (specific language impairment)	Theme: Genetic factors have varying impact on diagnosis

APA Citation	Participants	Study Information	Theme(s) of Article
<p>9. Orsmond, G. I., Kuo, H., & Seltzer, M. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. <i>Autism, 13</i>, 59-80. doi: 10.1177/1362361308097119.</p>	<p>406 adolescents and adults with an ASD; ongoing longitudinal study</p> <p>Data were collected from adult siblings and from the adolescent siblings.</p>	<p>Investigated sibling relationships and wellbeing in adolescents and adults with a sibling with an autism spectrum disorder (ASD).</p>	<p>Theme: Behavioral interactions/problems affect the quality of the sibling relationship</p>
<p>10. Rivers, J. W., & Stoneman, Z. (2008). Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorder. <i>Journal of Autism and Developmental Disorders, 38</i>, 1740-1750. doi: 10.1007/s10803-008-0560-z.</p>	<p>50 children with autism spectrum disorder (ASD) and their typically developing siblings</p> <p>One parent per family</p>	<p>Examined links between sibling temperaments, differential parenting, and the quality of the relationships between children with (ASD) and siblings.</p>	<p>Theme: Behavioral interactions/problems affect the quality of the sibling relationship</p>
<p>11. Lerer, E. E., Levi, S. S., Salomon, S. S., Darvasi, A. A., Yirmiya, N. N., & Ebstein, R. P. (2008). Association between the oxytocin receptor (OXTR) gene and autism: Relationship to Vineland Adaptive Behavior Scales and cognition. <i>Molecular Psychiatry, 13</i>, 980-988. doi:10.1038/sj.mp.4002087.</p>	<p>152 subjects diagnosed with ASDs</p>	<p>Examined the association with IQ and daily living skills and socialization sub-domains to see if a gene shapes both cognition and daily living skills that may cross diagnostic boundaries.</p>	<p>Theme: Genetic factors have varying impact on diagnosis</p>
<p>12. Puleo, C. M., Reichenberg, A. A., Smith, C. J., Kryzak, L. A., & Silverman, J. M. (2008). Do autism-related personality traits explain higher paternal age in autism? <i>Molecular Psychiatry, 13</i>, 243-244. doi:10.1038/sj.mp.4002102.</p>	<p>131 fathers and mothers of autistic children.</p> <p>6 families participating in ongoing study</p>	<p>Assessed the relationship between BAP traits and age at first procreation, regardless of affected status</p>	<p>Theme: Genetic factors have varying impact on diagnosis</p>

APA Citation	Participants	Study Information	Theme(s) of Article
13. Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism or Down syndrome: Effects on adult lives. <i>Journal of Intellectual Disability Research</i> , 51, 682-696. doi:10.1111/j.1365-2788.2007.00954.x.	154 adult siblings in two linked longitudinal studies; matched by age and gender to 77 siblings with a brother or sister with DS.	Examined instrumental and affective involvement in the sibling relationship for adults who have a sibling with an autism spectrum disorder or Down syndrome .	Theme: Behavioral interactions/problems affect the quality of the sibling relationship; Effects/Outcomes for Typically developing sibling are both positive and negative
14. Campbell, L. E., Daly, E., Toal, F., Stevens, A., Azuma, R., Catani, M., & Murphy, K. C. (2006). Brain and behavior in children with 22q11.2 deletion syndrome: A volumetric and voxel-based morphometry MRI study. <i>Brain: A Journal of Neurology</i> , 129, 1218-1228. doi:10.1093/brain/awl066.	Compared the brain morphometry of 39 children and adolescents with 22qDS and 26 sibling controls	Studied the neuroanatomy of 22qDS children using fully automated voxel-based morphometry (VBM) and manually traced single region-of-interest (ROI) analysis	Theme: Genetic factors have varying impact on diagnosis
15. Caruz, L. (2006). Dyadic relationship and parentification in siblings of children with autism spectrum disorder. (Unpublished doctoral dissertation) Alliant International University, California School of Professional Psychology, Los Angeles.	Consisted of 36 typically developing children and 33 mothers between the ages of 26 and 55 years	Examined the dyadic relationship of mothers and their typically developing children; and childhood parentification in siblings of children with autism and PDD-NOS.	Theme: Parental factors influence sibling relationship and the experience of typically developing child
16. Zwaigenbaum, L., Szatmari, P., Jones, M. B., Bryson, S. E., MacLean, J. E., Mahoney, W. J., & Tuff, L. (2002). Pregnancy and birth complications in autism and liability to the broader autism phenotype. <i>Journal of the American Academy of Child & Adolescent Psychiatry</i> , 41, 572-579. doi: 10.1097/00004583-200205000-00015.	Included 78 children with an autism spectrum disorder and 88 unaffected siblings.	Studied the relationship between pregnancy and birth complications and genetic factors in autism.	Theme: Genetic factors have varying impact on diagnosis

Chapter Two: Manuscript Two

**THE SISTERS' EXPERIENCE OF HAVING A SIBLING WITH AN AUTISM
SPECTRUM DISORDER**

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Abstract

This qualitative study explored the experiences of children who have a sibling with an autism spectrum disorder (ASD) using a phenomenological approach. Participants were recruited from local autism community and support groups in New England and were between the ages of 8-12 with a brother or sister with ASD. Data were collected in two interviews with each of the individual participants. Participants were asked to draw pictures and provide photographs. IPA data analysis was used and revealed the following themes: a) understanding of ASD, b) challenges and benefits of having a sibling with an ASD, c) relationships and interactions with others, d) attunement and unique connection, and e) advocacy and acceptance. The findings have implications for therapeutic practice and for education and research involving families with children when one child is diagnosed with an ASD. The electronic version of this dissertation is available in the open-access OhioLink ETD Center, www.ohiolink.edu/etd.

Background

Sibling Relationships

Interactions among siblings have been characterized as intense, unrestrained expressions of human emotion, ranging from love and affection to hatred and hostility (Lobato, 1983).

Sibling relationships can be distinguished from other interpersonal relationships because of unique characteristics such as sharing common genetics, cultural background, experiences, and living space (Wilkerson, 2001). Sibling relationships often have a longer duration than any other relationship in one's life, making the sibling relationship a unique type of experience (Cirirelli, 1995). And with an increasing life span, the sibling relationship has the potential to be longer and affected by more changes in family life than in previous times (Wilkerson, 2001). Specifically, the increase of single-parent families and two-parent working families; time constraints and parental stress; mobility of the family; and families having only two children may create greater intensity and increase emotional interdependence between siblings (Bank & Kahn, 1982; Wilkerson, 2001).

Emotional Influence. Siblings can mutually trigger emotional responses, and their relationships are often characterized by a combination of love and hate. Emotional support or rivalry may be elements of the sibling relationship, along with helping, sharing, fighting and playing (Strobel, 2006). Siblings endure developmental stages together, creating opportunities for unique experiences, while also sharing common experiences. These experiences and interactions can give children in sibling relationships opportunities to learn conflict management, emotion regulation, adaptation to the needs of others, and self-soothing (Bedford, 1998; Desautels, 2008; Kitzmann, Cohen, & Lockwood, 2002). In addition, through imitating,

reinforcing positive and negative behaviors, and modeling, siblings tend to learn social communication skills that carry over into other social environments (Farber, 2010).

Developmental Influence. Throughout their entire life cycle siblings serve social-development functions for each other (Bank & Kahn, 1982; Minuchin, Montalvo, Guernsey, Jr., Rosman, & Schumer, 1967; Seltzer & Krauss, 1993). Siblings can directly influence each other's development in a variety of ways, including the naturally occurring caregiving and teaching experiences facilitating psychosocial and cognitive development (Guzman, 2009). Researchers have suggested that early sibling experiences have a long-term effect on individual well-being, since the interactions between siblings shape the context in which they develop (Delve, Cernerud, & Hallberg, 2000; Desautels, 2008). Additionally, researchers have found that when children have at least one sibling, they have better social and interpersonal skills (Downey & Condon, 2004). These skills can encourage effective interactions within the family and can also be transferred to other relationships (Desautels, 2008).

Siblings and Autism

Demographic surveys estimate that 1 in 88 8-year old children the United States have ASDs and at least 1 to 1.5 million Americans may be diagnosed with some type of autism spectrum disorder (Centers for Disease Control and Prevention, 2010), and the majority of individuals with an autism spectrum disorder have at least one sibling (Allgood, 2010). When a child in the family is diagnosed with a disability such as having an ASD, the development of the sibling relationship may differ from a normal development of sibling interaction (Guzman, 2009).

ASD Risk Factors and Characteristics. The *Diagnostic and Statistical Manual of Mental Disorders: DSM-V* specifies that the diagnosis of ASD captures four separate disorders:

autistic disorder, Asperger's disorder, childhood disintegrative disorder, or pervasive developmental disorder not otherwise specified (APA, 2013). ASDs can be diagnosed before the age of 3 and last a lifetime, although symptoms may improve or change over time (CDC, 2012). Each child with an ASD will have a different combination of characteristics that occur on a continuum from mild to severe and changing over time (Simpson, 2005; Whittinghill, 2011). A person diagnosed with an ASD might have trouble understanding other people's feelings or talking about their own feelings; have delayed speech and language skills; avoid eye contact and want to be alone; overly dependent on routines; and/or get upset by minor changes (APA, 2013; CDC, 2012). ASDs occur in all "all racial, ethnic, and socioeconomic groups and are 5 times more likely to occur in boys than in girls" (CDC, 2012). The IQs of children with ASD can range from above average to severe cognitive development (Whittinghill, 2011).

The cause of ASDs is not known for most people, although it is believed that genes and the environment both play a role (CDC, 2012). Through family studies, scientists have provided evidence that there is a genetic contribution to autism, indicating that if a child has autism, there is a 60%-90% chance that identical twins will also be affected (CDC, 2012). In addition, parents who have a child with ASD also have a 2%-19% chance of having a second child who is also affected (CDC, 2012). Children who have a parent or a sibling with an ASD are also at a higher risk of having an ASD (CDC, 2012).

Sibling Dynamics. A typically developing sibling may become resentful or cease trying to engage in activities if play is not age appropriate, if restricted by the interests of the child with autism, or if attempts to connect are consistently unsuccessful (Guzman, 2009; Harris & Glasberg, 2003; Strobel, 2006). Researchers have reported that children with autism often have difficulty initiating and maintaining friendships, and prefer structured activities that require low

levels of social exchange (Bauminger & Shulman, 2003; Howard, 2006). Siblings of individuals with ASDs may have to face such challenges as resentment, embarrassment, misunderstanding of the diagnosis, jealousy or problem behaviors (Glasberg, 2000; Harris & Glasberg, 2003; Hastings, 2003; Matthew, Leong, & White, 2002; Sullivan, 1979). Siblings of children with autism may express less nurturance, prosocial behavior, and intimacy when compared to siblings of children with Down syndrome, siblings may also have admiration for their brother and sister and a decrease of competition (Kaminsky & Dewey, 2001; Strobel, 2006). A child with autism can benefit from play with siblings, which can provide appropriate play behaviors and modeling. Overall, the sibling relationship is one that is complex and diverse—some siblings can be affected in a variety of areas to varying degrees, both positively and negatively (Connors & Stalkers, 2003).

Purpose of Study

The purpose of this qualitative study was to explore the experience of having a sibling with an ASD and to develop an understanding of the relationship experience from the typically developing siblings' perspective. This study honored the sibling perspective through various types of data consistent with phenomenology—interview data, photographs, and art. Specifically, this study included photographs to move beyond traditional research methods, allowing the children to express themselves symbolically and in ways that are not entirely language-based (Wilkerson, 2001). The overarching goal of this study was to represent a group of voices (shared experience) that has commonalities as well as variations, providing a rare opportunity for siblings of children with ASD to share their experiences.

Significance of the Study

This study was designed to develop a better understanding of how the unique experience of having a sibling with ASD may alter, impact and enrich the lives of siblings. It is expected

that a deeper understanding will be gained in order to better support the sibling relationship where one child has an ASD diagnosis. This study emphasized the needed attention on sibling coping systems and aimed to add richness and data in the words of the children who have a sibling with ASD, honoring their unique perspectives which to date have been left unheard. This study provided a rare opportunity for these siblings to tell their stories, and acknowledge both the positive and negative aspects of their sibling relationship. It is important to shed light on the experience and create potential interventions that could optimize the strengths of the sibling relationship and positive outcomes in this population.

The following was the primary, overarching research question, and the 2 sub-questions in the study:

- What is the child's experience of having a sibling with ASD?
 - What influences the child's experience of having a sibling with ASD?
 - How is the sibling relationship influenced by having a brother or sister with ASD?

Theoretical Framework

The epistemological framework that guided this study is constructionism. The Constructionist Perspective contends that through past and present interactions in the world people assign meanings to their experiences (Crotty, 1998). From this perspective objective knowledge is considered to not exist (Anderson, 1997; Crotty, 1998). Different people may define truth in very different ways, based on individual constructions. The experience of having a sibling diagnosed with ASD may carry very different meanings for different children. From a constructionist perspective, all individuals' interpretations should be considered valid (Crotty, 1998). The meanings that children assign to the experience of having a sibling diagnosed with ASD may be influenced by many past and present circumstances, including age of children

in the family, the number of siblings in a family system, understanding of an ASD diagnosis, available social support, parental interactions, and other factors. Under this constructionist idea, even when individual interpretations may vary considerably from each other, all should be considered valid (Crotty, 1998). Guided by the constructionist perspective, I selected a methodology that would allow the voices of the participants to be heard, while having the researcher become conscious of biases—which is well aligned with the phenomenological approach.

Phenomenological Research

Qualitative inquiry was used in this study, as it fit with the purpose to explore the phenomenon from the perspective of this group of participants. The selection of qualitative rather than quantitative methods was guided by the research question, which was to understand the experience of the child with a sibling diagnosed with ASD. Qualitative research aims to include the generation of insight and understanding of a phenomenon or experience (Powers & Knapp, 1995; Wilkerson, 2001). Qualitative research is an approach to understand the qualities of a phenomenon within a particular context (Brantlinger, Jimenez, Klinger, Pugach, & Richardson, 2005; Whittinghill, 2011). Rather than predicting outcomes or finding causal factors in quantitative research, this study focused on studying the phenomena in depth.

To gain an understanding of the shared aspects of people's experiences, the sibling perspective is represented as a group voice—a shared experience that has commonalities as well as variation. The common story of this group of participants is meant to honor and appreciate the experiences of those children that may often feel unheard, or unrecognized. It is important to understand the potential implications of their unique contexts and experiences in order to develop an empathetic understanding of their sibling experience and relationship, and perhaps to

inspire therapeutic interventions to strengthen or appreciate the sibling dyad. Various types of data which describe the experience were studied—including interview data, photographs, and drawings.

Phenomenology was selected because of the interest and intent to understand the phenomenon from the participants' point of view through the collection of data from interviews, drawings, and photographs. Phenomenology is a way of thinking about what life experiences are like for people (Whittinghill, 2011). The reality is defined by the perceptions of the individual in the experience (Munhall, 1994). Phenomenological research inquires about the meaning of an experience, giving a description of the experience as it is lived in everyday existence (van Manen, 1990; Wilkerson, 2001).

Consistent with phenomenological research, this study included several participants to arrive at an understanding of the phenomenon. Although photography and art were used to elicit stories, analysis was not used to explain or interpret them (Giorgi, 1997; Whittinghill, 2011). The purpose of the phenomenological research procedure was to illuminate similar and divergent themes in the descriptions of the sibling experience. This method provided in-depth information regarding the lived experience of the participants with respect to the sibling relationship. The primary data for phenomenological studies is the first-person account of the individuals who have lived through the experience (Moustakas, 1994). The role of the researcher is to describe the essence, the shared meaning, of the phenomenon (Merriam, 1998). As such, the goal of this study was to explore the phenomenon from the perspective of this group of participants, in this case children.

Researching Children

Historically, there has been a commonly held view of children as incomplete or developmentally immature and not being seen as active constructors of social meaning (Freeman, 2009). In this way, children's lived experiences were not always of interest to researchers. However, interviewing children allows them to voice their own thoughts and experiences, rather than rely on adult interpretations of their lives (Eder & Fingerson, 2002). In addition, interviewing children allows for the discussion of topics that are salient in their lives but may not be present in daily conversations and interactions (such as family relationships).

Children's everyday experiences shape their sense of self and their views of others; hence each individual's knowledge is seen as legitimate. Researchers can treat children in such a way that they receive something from participating in the study—whether it is a greater understanding of their own life experience or a sense of empowerment (Eder & Fingerson, 2002). Even just having “someone to talk to” can be meaningful and empowering to young people (Freeman, 2009, p 83). Researchers should create conditions that promote the child's meaningful and informed participation (Freeman, 2009). This could include having child-centered ways of working together, including child-friendly spaces and language; assurances that participation is voluntary; and giving a genuine commitment to listen to and take the child seriously. In addition, the researcher should be aware of the burden of adult-centrality; the exercise of power and winning trust; and the equality of the dialogue between a child and adult (Freeman, 2009). It is essential that researchers examine the power dynamics between adults and youth (Eder & Fingerson, 2002).

Use of Photographs and Drawings in Research.

To move beyond traditional research methods, this study included photographs—allowing the children to express themselves symbolically and in ways that are not entirely language-based (Wilkerson, 2001). Photographs can serve to facilitate discussions of an experience, and can provide insights into an individual’s experience—allowing one to sense the experience of others (Hagedorn, 1996; Wilkerson, 2001). Consistent with the phenomenological approach, I elicited the participants’ own meanings and experiences and focused on using photographs and drawings in the face-to-face interview to bring forth further the children’s experiences and stories.

Hagedorn (1996) describes the three important functions of photography in phenomenology: (a) the photographs are symbols of the experience; (b) the photographs are taken by the participant and then interpreted by the participant during interviews; and (c) analysis of the interviews reveals the meaning of the experience as illustrated in the photographs. Using child-produced photography can give children the flexibility and freedom to select what to depict and what is important to them (Freeman, 2009). Having the children participate in taking, selecting, and talking about their photographs is a way to promote empowerment, decision making, and dialogue among the participants (Freeman, 2009; Hurworth, 2003).

In addition to photography, the use of drawing in research can also reveal the emotions and feelings of participants (Freeman, 2009). Participants can use drawings and photography to capture meanings beyond words, with images conveying meaning in powerful, accessible, and direct ways (Freeman, 2009). Rather than the researcher constructs dictating communication, the limited structure in the drawing activity can allow for, and honor, the participants’ unique experiences. In addition, when combined with additional meanings and interpretation given by

the participants, drawings can become even more valuable to the understanding of the participant experience (Freeman, 2009).

Method

Participants and Setting

Participants were five children ages 8-11 who have a biological brother or sister with ASD. The age range of 8-11 was selected because it could be expected that the children should be at a cognitive level to be able to articulate and comprehend their childhood experiences and relationships. As children develop, they will be able to understand their brother or sister's disability from a more sophisticated perspective. All children were at least 8 years old since it was expected that younger children would be less likely to be able to sustain the attention necessary to participate in the study. Including children twelve years and younger attempted to honor the neglected age group in this area of research, which most often includes the focus on adolescents and young adult siblings.

Following approval from Antioch University New England's Institutional Review Board (Appendix B), participants were recruited through electronic communication and re-postings (see Appendix C) sent to the members and community of the Friends and Family of Individuals with Autism; Asperger's Association of New England; Massachusetts Sibling Support Network; Advocates for Autism of Massachusetts; and additional supporting organizations and mental health professionals working with families and children with ASDs in the New England area. For practical reasons, the participants were limited to the first five respondents.

Data Collection

Data was obtained from the children through interviews, photographs, and drawings. Two interviews took place face-to-face with each of the participants in their home environment. Each interview lasted for no more than an hour. Interviews were conducted individually with each

child, although the parent was in proximity (in the home) to provide consent, receive information from the researcher, and to ensure the comfort of children and family members. Requests were made by the researcher to the guardian to have privacy for the interview within the home, to facilitate an open conversation between child and researcher without child's concerns about what other family members may hear in the conversation.

The interviews were voice recorded. The participants were informed of the recording equipment prior to the interview. The questions were developed based on a pilot study I (as the principal investigator) completed in the Spring of 2011. The interviews were guided by standardized, open-ended interview questions and the same open-ended questions were asked to all participants to facilitate more expedient interviews that can be easily compared and analyzed. I used an interviewing guide to facilitate the interviews (see Appendix H). The grand tour question was "What is it like having a brother/sister with ASD?" Follow-up questions were used to assist with seeking richer data.

During the first interview, parents of participants were first informed about the study, and then asked to give written consent for children to participate in an interview (see Appendix D). The researcher then informed the participating child of all features of the research that may affect her willingness to participate and answered the child's questions in terms appropriate to the child's comprehension. Participants were then asked to agree to being interviewed and provided written assent (Appendix F). The researcher orally covered the content of the assent form and offered to read it to the children and/or have them read it. The parents also completed a demographic information sheet (Appendix G).

Each child was interviewed based on questions from the interviewing guide, and was also asked to draw a picture of herself with her sibling and to talk about the drawing. Furthermore,

during the interview process, I monitored signs of discomfort and stress and when detected, I provided the participant an opportunity to pause the interview. At the end of the first interview, each child was provided a disposable camera to take with them to capture photographs related to their experience of having a sibling with ASD. Each participant was given written instructions regarding the purpose of the camera, which was reviewed with parent and child. Participants were given a pre-paid postage envelope to mail the camera back to the researcher, to allow for the film to be developed prior to the second interviewing session.

In the time between the first and second interview, participants were encouraged to reflect on their experiences and take photographs related to the experience of having a sibling with ASD. The second interviewing session included the photographs as tools to continue the interviewing questions and follow up with previous statements from the first interview. The researcher reviewed the photographs with each child and asked her to describe the photographs. Each child selected her “favorite 3” photographs that best represented the sibling relationship, and then gave permission for the photographs and drawing (from the first interview) to be shown to the parent to provide consent for use in presentations or publications. After the participants and parents saw the actual drawings and photographs, consents were obtained for the use of photographs for publication and presentation (Appendix E). The children were provided copies of their photographs to keep. To honor their contributions, the children each received a \$25 gift card to a business in their community, selected by the child and approved by the parent. I also provided the parents with a resource list that included books, community supports, and websites related to siblings and autism (Appendix I).

Verification Strategies and Trustworthiness

Particularly important to phenomenological research, self-reflection was used to manage the risk of clouding the data with the researcher’s affective reactions or bias (Gilbert, 2001;

Whittinghill, 2011). To better understand the information, I attempted to be conscious of preexisting ideas or biases and I reflected on these biases prior to data collection (see Appendix A), as well as continued to recognize biases through the analysis process (Giorgi, 2006). I also deliberately did not look at the children's photographs before meeting with them (beyond confirming photographs were developed and images visible), to provide the children the opportunity to share their photographs and stories on their own terms, without my having preconceived ideas about the meanings or items captured in film.

I engaged in epoche and bracketing to control for bias (Creswell, 2007), and reflected on my emotional reactions related to the research process and interviews. I used a field journal to record reflections related to the process and experience as researcher (see Appendix A for excerpt), and field notes were used to include a description of key words and statements made during interview and my reactions to the interview (Merriam, 1998). To ensure the quality of the information gathered, and to strive to keep the memories of the interview more vivid (and have the reactions be less contaminated by later information), I reflected on the experience immediately following an interview or observation (Patton, 1990). In addition to journaling, I also took my own photographs of my experiences throughout the research process and images representing my emotional process. After the research was completed, I organized my photographs and notes in an album and shared it with my committee members, triangulated investigator, and peer debriefer to have transparency and honor the self-as-researcher in the process of this study. Consistent with phenomenology, I also used various types of data collection methods to capture information beyond the interview data, which included the children's photographs and drawings. I discussed the study with colleagues and mentors (peer review) to gain external perspectives concerning the meanings, interpretations, and methodology

(Merriam, 1998). A triangulated investigator participated and contributed as a partner throughout the entire data analysis, and a peer debriefer added to the trustworthiness of the study through reviewing the data analysis process and interpretations and challenging researcher bias in the resulting themes. In addition, an audit trail was used to capture each step of the decision making procedures, the process of data analysis, peer-debriefing conversations, and triangulated investigator interactions. The final results were confirmed and agreed upon by both investigators, and reviewed by the peer debriefer.

Data Analysis

Interpretative phenomenological analysis (IPA) was the approach used to analyze the data (Smith & Osborn, 2003). Consistent with its phenomenological origins, IPA is concerned with trying to understand what an experience is like from the point of view of the participants, and emphasizes the role of the interviewer as a facilitator and guide. In addition, the small sample size, homogeneous sample, and emphasis on participants as story tellers (rather than respondents) solidified IPA as the most fitting analytical approach for this study.

The method used, adopted from IPA, was a cyclical process adopted as follows:

a) Transcripts were read and the most exhaustive transcript was selected to analyze first; b) notes of any thoughts or observations were written in the margin of the transcript, as well as emerging theme titles; c) both investigators discussed their emergent themes and looked for repeated or similar themes; d) emergent themes were printed on strips of paper and moved into clusters, with each cluster being confirmed by checking direct quotations from the transcript; e) each cluster was given a main theme title and a master list of themes was created, which included the subthemes and supporting quotations; f) the themes from the first transcript were used to orient the other transcripts, specifically to identify repeating themes and new emerging themes; g) after all the transcripts were analyzed, the main themes and subthemes were reviewed, confirmed, and re-organized based on

quotations and meanings; and, h) the final main themes, subthemes, and evidence were confirmed by both investigators and reviewed by the peer debriefer.

Findings

Appropriate for the Interpretative Phenomenological Analysis, this study included a small sample size and homogenous sample, with participants being very similar in demography and family structure. All of the participants were female, with an average of 9.8 years of age. Four out of the five children had a brother with an ASD, and one child had a sister. ASDs are five times more common in among boys (1 in 54) than among girls (1 in 252), therefore this study is representative of the prevalence of ASD in the general population (CDC, 2012). The average age of the siblings was 9.6 years, and four out of the five siblings were diagnosed with autism, and one with Asperger's. Additionally, all of the participants and siblings were identified as Caucasian, with one child and sibling also being identified as Hispanic. All of the participating families had only two children in the family—one diagnosed with an ASD and one typically developing child (See Table 1 for demographic information of participants and siblings).

Following data collection and analysis, 5 major themes, or essences, of the 5 participants' experiences emerged, with 17 subthemes. The five thematic clusters and subthemes (Table 2) are described below, and are not presented in a hierarchical arrangement. Quotations are used to illustrate the richness of the children's experiences. For clarity, the quotes are labeled C1, S2, where the letter identifies the Child/Sibling and the number identifies the interview order (first child interviewed is C1 and her sibling is S1). Additionally, since the participants are all female, gender-specific language (the use of "she" or "her") is used to refer to the children in the study. The exhaustive description is also presented.

While photographs and drawings were used to elicit stories and not analyzed, items captured by the children (and offered further support for the themes) included the following:

siblings' favorite toys, things they built together, games played together, sports equipment, art work, bedrooms, family pets, furniture in the house, favorite plants, books, CDs and music players shared with siblings, images of computer screens with favorite games or television shows, backyards, memorabilia from sports teams/games, autism speaks magnets, collectables, favorite hide and seek locations, sentimental toys, snowman, favorite snacks, images of favorite television or movie characters, and photos of parent, self, and brother/sister.

Thematic Cluster #1: Understanding of ASD

This thematic cluster includes the children's understanding of ASD, as it relates to the subthemes of *having a general knowledge of the diagnosis*, *as the understanding of ASD changed over time* and *recognizing how the diagnosis affected their siblings*. All children shared things that they knew about ASD in general, not specifically tied to their sibling. One child (C1) shared that she understood ASD to be a "disorder where some children, when they're born with it, they can't speak. And there's times where a child will be three and act like two, or a child will be ten and act like 9." *General knowledge of ASD* seemed to come from experience, books, as well as parents educating the child about ASD. C5 said of how she learned about ASD, "My mom came home one day and she told me about it."

Most of the children shared that they started to *understand the ASD diagnosis more as they got older*. C3 shared, "I'm 2 and a half years older than [S3]...I was around 4 when he got diagnosed and I didn't really understand it. When I was 5 or 6 I kind of started to understand it." Part of understanding of ASD was the child starting to recognize her sibling was "different," and starting to recognize the sibling's behaviors were related to the diagnosis. One child, C5, said "When we were kids we played all the time. But when we started realizing he wasn't the same as other kids, it was kind of difficult." C4 also shares her understanding changed over time, to not

noticing anything different about her sibling to recognizing and understanding the diagnosis—“It just went from thinking that [S4] was perfectly normal to knowing that [S4] had a disability.”

The most influential way the child came to understand ASD was *recognizing the effect the diagnosis had on her sibling*. All of the stories told by the children included experiencing the sibling’s copying behaviors, routines, and habits. C4 said of the copying behavior, “Sometimes it can get a little bit annoying, but sometimes I feel proud because sometimes it's sort of flattering that [S4] wants to do what I do.” Regarding the adherence to strict routines and habits, C1 said, “My brother's routine, he listens to his routine, and every single day he does it because of the autism when they tell him to do that, wake up...he sort of gets used to that, he won't do anything else.” And while only two of the five children were the oldest children in the family, most reported feeling like they were the oldest child, with the diagnosed sibling acting or appearing younger than them, regardless of the birth order. C5 says of her older sibling, “I think of him as a little brother” and “Sometimes he kind of acts like a little kid.” C4 also tells a similar perception about her sibling, “[S4] has the mind of a like 5 year old ‘cause [C4] still likes barney and Dora and Angelina ballerina and all those little shows.”

Recognizing the impact the ASD diagnosis has on the sibling also came from recognizing the disruptive behaviors or social challenges faced by the sibling. C3 describes her sibling in the following ways:

Sometimes he's in a great mood and it's like quiet, but sometimes he just like gets up in the middle of the night and starts crying and screaming...He tries to get out and run away, because if he sees something he likes, he wants to get it, he doesn't care whose it is, he just wants it. He thinks everything is his basically.

C1 also described her sibling being upset as “when he gets upset it’s not more that he's getting upset normally, but it's more of that the autism kicking in.”

In all interviews there seemed to recurrent statements of recognizing the sibling did not always understand things, including interactions or their own sensations. C5 said of her brother, “He doesn't really know how to communicate well, like sometimes he doesn't get some sarcasm or something ...he's not that social.” C1 also shared, “I mean he can feel and develop pain and feel it and hear it in every single way, but there's sometimes he just doesn't get it right off the bat.” C4 demonstrated her understanding of ASD as it applied to her brother in the following way: “It's a disability and her brain works differently than ours. So she thinks differently and she acts differently.”

Most of the children reported instances of recognizing sibling limitations and the need for the sibling to have new ways to connect and communicate with others. C1 shared that her sibling learned to communicate through music, with her parents first noticing that when playing music, her brother, “could hear the words. That's sort of what helped him vocally develop noise and talking to people.” She identifies music as being “one of the first things that made him able to talk and actually interact with other people.” Regarding her brother’s communication, C3 shared the following:

Well, I can talk to him, but he understands most things that you say, but it's just that he can't respond really. But he knows a few signs, just a few that are like important that he can use a lot. He knows like food, drink, hungry. He loves, his favorite one's candy, he loves candy, and that's what he uses all the time, is candy... he knows “help” and “more” and “all done” so he just knows ones that he uses a lot so and um, you can sometimes tell like what he's doing, if he has to, if he wants to do something.

Thematic Cluster #2: Challenges and Benefits of Having a Sibling with an ASD

This thematic cluster includes the children recognizing the experience of having a sibling with ASD as being *positive*, *challenging*, and including making *accommodations and sacrifice* for their sibling. Many of the children described their experience as being *positive*—sometimes due to benefits and rewards, and other times for learning something that other children may not have the opportunity to learn. C1 says of her experience, “It's actually kinda cool having a brother that's autistic because you get to experience stuff that other people won't.” C5 also shared this sentiment in saying, “I think my experience is kind of cool. I mean not everybody gets to have a brother or a sibling or something with autism or something. It's actually kind of nice and you learn something every day.” In addition, C5 shares that sometimes she gets to share in the benefit of her sibling’s successes, such as when her sibling “has 5 perfect nights. It's good because we get to go to the bookstore or out to ice cream or out to dinner. So it's exciting.”

As for the *challenges* of having a sibling with an ASD, some of the children described instances of having personal property destroyed or having an invasion of privacy or personal space. C3 described her brother destroying her homework and worrying about getting in trouble. She stated, “Once, he's like ripped up my homework before I had to turn it in, so I had to get a new one like the day it was supposed to be turned in...he saw it and started ripping it up. I got kinda mad at him.” Another child, C4, shared examples of how she manages her sibling’s tantrums, which sometimes results in her things being destroyed or having to leave her room. She states, “Sometimes if [S4] is having a fit we need to run up to my babysitter's room and lock doors since my door doesn't have locks. And then [S4] usually pounds on the door.” Another child, C4, also described having her physical space invaded, saying “it will be like 3'oclock in

the morning and he'll come jump on me. Once he started jumping on my bed and I told him to get down, so he got down, but he got down on top of me.”

Some of the children also recognized that their sibling relationships were unlike the sibling interactions their friends experienced and were aware of some limitations or things they missed out on. C3 stated, “It's hard for us...just ‘cause we can't do some normal stuff... like some of my friends say fun stuff that they do with their siblings, but I can't do some of that stuff.” C4 also seemed to resonate with recognizing that things can be hard, and feeling as though people don't always understand her experience. “I just want them to know that it's actually sort of hard having a sister with autism...Sometimes I just wish that [S4] was an average kid. Like without any disabilities.”

The children also acknowledged their own willingness to make *sacrifices and accommodations* for their sibling's needs. For example, C5 talked about recognizing her sibling didn't have very many friends and so agreeing to play certain games or join in activities she didn't really enjoy, just so her brother wouldn't be alone. She stated, “He doesn't have like many friends that like the same things he likes, so when I can tell he really wants to do something and he asks me to do it, then I say ok.” This same child also talked about how she would try to help her brother interact with her friends, recognizing he had challenges with social relationships. “Whenever I have a friend over I always introduce them and I always, like, try and get them to talk so he won't just be weirded out if they come over all the time.”

Also included in this subtheme of *accommodation* is the child's attempt to modify and learn communication in ways that she could interact with and understand her sibling. C3 described her efforts to learn how to communicate with her brother by taking initiative to watch and learn from a teacher that came to the house to work with her brother:

When he had the home services, I would like to help a lot with the teacher. She needed help with him... And I would like to watch and see what they were doing with him so I could know how to do stuff when they weren't here.

C3 also shared that although sometimes she may not understand her brother's behavior, she attempts to understand and support him, as evidenced in her stating, "I spend a lot of time with him, and like if he's upset, I'll just sit with him."

Thematic Cluster #3: Relationships and Interactions with Others

All children interviewed shared stories of how their relationships and interactions with others are affected by having a sibling with ASD. This category includes the subthemes of *emotional experiences and challenges to public reactions*; *peer consequences*; recognizing the *presence of a supportive community* for her, her brother, and her family; and lastly, how the *parent/child relationship* was influenced by having a sibling with ASD.

The majority of data fell under the subtheme of *emotional experiences and challenges to public reactions*. Included in this category are statements related to people staring at her sibling; being mean to her, her sibling, and to her family; and not understanding, or seeming to care about, the ASD diagnosis. Many of the children experienced strangers coming up to their families and remarking about the sibling's poor behavior, or threatening to have them kicked out of restaurants if the sibling continued to be disruptive. One child, C3, described an interaction she experienced with a stranger on an airplane in the following way:

When we go on a plane, once, he was kinda kicking the seat in front of us a little bit and she turned around and started yelling at him, at my brother... so my mom told her, "Sorry, he has autism, I'll try and keep him..." and she's like, "I don't care if he has autism."

Not only did some of the children report witnessing how their parents respond to the public, but they also shared having to deal with public reactions to their sibling as well. C3 shares the following:

A lot of people like, like almost everywhere we go, people stare at him and I don't like when they do because then they stare at me too...like if I tell them to get up or stop something they'll start staring at me too... Some people just think since he's weird, they call me 'weird' too sometimes.

Feeling angry, embarrassed, and hurt were common experiences of the children in this study, as evidenced by C3 stating, "Sometimes I get sad when people call names or be mean to him... 'cause a lot of people do." C1 also shared her feeling so angry at the staring and comments by people that she, "wanted to walk up to them, and I wanted to punch them in the face!" Related to some of the public reactions, some children also reported wanting to defend and protect their sibling, and sometimes just not being sure what to do or feeling powerless, especially when an adult is the one yelling at her parent or sibling. The following is described by C3:

I don't like when they [stare] but it's usually adults that don't know...if I say he has autism and they still just start yelling at him, I don't know what to do really... like I wanna stand up for my brother but I don't wanna sound rude.

In addition to dealing with the responses from strangers in public, many children spoke of having *peer consequences*, which included discussing interactions they had with friends or peers in school that were affected by other children knowing they had a sibling with an ASD diagnosis. Such interactions included having friends feel afraid or be distressed by the sibling's behavior, peers thinking the sibling is weird, and even refusing to be friends with the child because of the

sibling's diagnosis and behavior. One child, C1, describes her response to peers who said they could not be friends with her because of her brother:

They're like "Ew. You have a brother with a learning disability? I can't be friends with you". [I said] "He's a person! And, how do you feel if I said that to you, if I was friends with your big sister and you were standing right there...and I said to your sister 'I can't be friends with you because your sister has a learning disability?'"

Navigating new friendships appeared to be a challenge to some of the children, as well as maintaining friendships once established, due to embarrassment about friends witnessing sibling tantrums or behaviors. C4 describes the following as a common occurrence, and a reason why friends do not come to the house very often:

One time I had a slumber party for my birthday and like seven girls came. [S4] started hugging, kissing them pretty much immediately...she embarrasses me in front of my friends...and after [S4] had the tantrum, me and [friend], we were not that much close.

Another child describes how her friends don't always understand her brother or the diagnosis:

My friends didn't really understand what he had, so my friend, whenever [S5] would say like "Hi," she'd be kind of weirded out 'cause you know he would do stuff not normal.

And she would say stuff that was mean about him...I would always tell her like, "Stop.

It doesn't matter if he's a little bit different. I mean everyone is different than everybody."

However, while some relationships with peers were halted or negatively affected, most children also recognized the *presence of a supportive community*, which included friends who were understanding and supportive of their siblings. C1 describes having friends that not only understand her experience, but also include her brother:

One of my best friends that actually came over to my house, she's so kind and she includes my brother and does stuff with my brother.... it's good to know that there are some best friends that you can count on that are nice to you and your brother or your sibling.

The community of people that were described as supportive to the sibling, the child, and the family included a teacher, grandma, bus driver, waitress, other children with a sibling with autism, external agencies that came to the home to assist the family, and members of ASD organizations. C3 describes an upsetting experience in a restaurant where a stranger started yelling at her brother and threatened to have the family thrown out, and her feeling relieved by the waitress' response to witnessing the interaction:

[The waitress] said "Don't even bother." She's like, "I don't care. It's fine. And we wouldn't kick you out just because he has autism and he's kicking." She was really nice.

As mentioned previously, many children reported learning about ASD from their parents, and also shared witnessing how their parents responded to public reactions to their children. Many children also shared feeling, and recognizing, that their relationships with their parents were affected by having a sibling with ASD. This effect on the *parent/child relationship* includes recognizing times when the focus moved towards the sibling and, consequently, resulted in the child feeling left out. One child, C1, describes her experience:

And I remember as a little kid, where I had been the only child and I'd always been revolved around, that I was kind of like, "Why you hanging out with him so much?!" Even when I was 8 and 9, I didn't get it a lot because they would be sort of just like reading with him, doing stuff with him... I think that was a tough time, when I was 4 and 5 and 6 when [S1] sort of got revolved around, like it was this big *Star Trek* force field

not letting me get in... That [feeling left out] was probably the toughest time for me with having a brother with autism.

In addition to recognizing times when the parental focus shifted to the sibling, some children described trying to help their parents out with their siblings, as well as being given more responsibility from the parents. C5 states, “It was like we just found this shocking thing about [S5] and my mom was like worried that he was gonna feel different and stuff, but I was just like ‘My mom needs to help him so I'm gonna help too.’” Another child, C4, describes her experience of recognizing that although she was the younger sibling, she was given more responsibilities, which included caring for her sibling. She shares:

[S4] says that she's younger, so I'm the older one. So I have a little bit more responsibility than [S4]. Mom has trusted me with a lot of things that [S4] doesn't...[Mom] just depends on me to make sure the [S4] stays out of trouble while she's in the shower.

Thematic Cluster #4: Attunement and Unique Connection

In addition to most data supporting the challenges of public reactions to the sibling, the cluster of attunement and unique connection in the sibling relationship also had extensive support from the children’s stories. This category includes the subthemes of the child *recognizing the successes, interests, and positive attributes of the sibling, togetherness*, as well as *fondness and closeness* between siblings. The majority of the data provided evidence for the child being very attuned to the sibling, as evidence by knowing the things that the sibling enjoyed and the skills and positive attributes of the sibling. All the children easily described extensive details about their siblings’ interests and joys. Many children listed their siblings’ favorite games, music, activities, animals, foods, and colors. One child, C1, says of her sibling’s strengths, “He's really good with choosing the right thing to do. And I think, that's the, a great

thing about him...My brother is pretty awesome for an autistic kid and he's really imaginative and fun.” This subtheme also captures the hopes that some of the children had for their siblings. One child, C5, says of her brother, “I think he could be an astronomer ‘cause he's really good... I just want him to know that I believe that he can do great things.” Another, child, C4, says of her sibling, “[S4] has a really good memory. So [S4] can look at a book for the first time, remember it for like 20 years probably...like she has memorized every state and every country in the world.” All of the children interviewed talked about the shared interests and activities they had with their siblings, and told of the many ways they played and experienced *togetherness*. C3 smiled as she told of the many recreational activities that she does with her brother in various seasons:

I play with him a lot ‘cause we both have basketballs and we like to go outside and just run up and down the driveway together, dribbling the ball... I'm happy about the stuff that me and my brother get to do together and that we like a lot of the same things.

Other children also tell similar stories of creating games together, sharing hobbies and liking the same movies and music. C2 describes how often she and her brother spend time together creating and building things. She says, “We've actually made a sundial out of wood ...we created castles together. [S2] and I worked on it a lot, it's really nice...it was great.” In addition to spending time together, all children also shared many examples of really enjoying having/being a sibling, genuinely liking each other, and marked by *fondness and closeness*. One child, C1, described her close relationship with her brother in the following way:

My brother and I are really close...Two peas in a pod. We stick together every single day...We go to bed at the same time. We brush our teeth at the same time. We stay together. We go outside together. We play together. We do almost everything together.

We go on car rides together. We watch movies together. We do all this stuff together, and it's like we never separate. It's like there's glue between us.

Another child, C2, repeatedly described her relationship with her sibling with a simple phrase, “We just like each other!” She also said, “We always do things together...It's great to be a sister. It's great to have a brother...Together forever. Ever.” Not only did all of the children share that they liked their sibling, but they all acknowledge how good it was to have a sibling. Child 4 says:

It's also good to have a sister. To just have someone to hang out with. She's always in the other room, stomping or laughing...she's always there for you. And I can talk to her while she's sleeping and she won't talk back or yell and sometimes we can get along really well.

When describing her relationship with her brother as very close and connected, one child, C1, shared the tradition that she and her brother do every night, and her expectations for the future:

He says, “Goodnight.” I say, “Goodnight.” “I love you.” “I love you.” “See you in the morning.” “See you in the morning.” “Goodnight!” “Goodnight!” And we do it every single night. I don't know who made it up, him or me, I really have no clue...but all I know is that was a really special thing to us to do.... Me and my brother, even after I go to college or he goes to college, there will be a tight relationship...Every single weekend we're free in college or when we grow up, we will see each other. So we're never ever ever ever going to let go of each other because we're going to be two peas in a pod.

Thematic Cluster #5: Advocacy and Acceptance

This theme captures the many ways the children told of methods they have tried to get other people to understand ASD, to accept their sibling, and to be accepting of other people's differences. The subthemes in this thematic cluster include perceiving the *sibling as “normal kid”*; *educating others about ASD*; *trying to promote acceptance and empathy in others*; and

wanting to have *support for other children*. All five children told of ways they felt their *siblings were “normal,”* regardless of having an ASD diagnosis. Related to previous thematic clusters of understanding ASD and recognizing challenges with the public and peers because of her sibling’s diagnosis, one child, C1, told how she views her brother as “normal,” and how she tries to explain this to others in the following way:

I would like others to know that he's a normal kid! And he's no different from you! He has a face, he smiles, he has eyes, and he can talk! He's not any different from you...he's normal, he's just like us, he's a human! What do you guys think he is an alien? I wanted to say, “You know what? It's not any different than living with a kid in a wheelchair. It's not any different with living with another brother or sister. It's not any different because he's one of you.”

Other children also described feeling like their siblings were just like other people, but with a diagnosis. This idea was expressed by other siblings, such as C5 stating, “It's not like a big shocking thing like finding out someone has cancer. It's just like they just got a title and they work a tiny bit different. It's not like a big deal.” Another child, C4, also stated “It's just a disability and they’re still the same as us, it's just that their brains work differently.” With an understanding of ASD, most of the children also shared stories of attempting to *educate others about ASD* while in school or with friends. Many of the children shared that they recognized that many people, both children and adults, do not know what autism is, and even after talking to them about it, people still don’t really understand. C3 states the following:

Sometimes we go to places, like if a little kid comes up and says hi to [S3] and they'll be like, “Why is he being mean to us, why doesn't [S3] talk to me? Does he not like me?”

And so they just think he doesn't like him—he just really can't talk. Like younger kids, I'll

say, “He has autism.” And they’re like, “What's autism?”...I'll explain it, but they'll be like, “I still don't understand why he's not talking to me.”

And while many of the children described attempts to *educate others about ASD*, some of the children also had ideas of what could help people better understand the diagnosis, such as C3 sharing her ideas for how ASD can be better understood:

A lot of people don't understand what autism is, so I think a lot of people should learn about autism and like, what it's about and how it can be different for everyone. Because a lot of people just think he's being rude or something...they've heard of Down syndrome and stuff like that, but they've never heard of autism...I think they should put some stuff, like make some book for kids to learn about it...some for adults too ‘cause they still yell at him and don't understand...I think they should mention some things about autism on the news a little, because you don't hear many things about autism or disabilities, even on the news.

Related to trying to educate others about ASD, most of the children also told stories of *trying to promote acceptance and empathy in others*. C5 shares, “It doesn't matter if he's a little bit different. I mean everyone is different than everybody. No one looks exactly alike, even identical twins.” Another child, C3, returns the stares of strangers, with the idea that “When they stare at him I just either stare back at them and like show them ‘How do you think he feels?’ or something, because like, how would they feel if someone kept staring at them almost everywhere they went?” Some of the children also stated that they have come to recognize that not everyone will be as accepting or understanding of differences in others. One child, C1, shares her experience the following way:

When I try and talk to people, when I try to be their friends, there are these crabby mean people that don't get the world, and they don't get people. They only think that there's one type of person—a normal person with brown or blue or green or blue or brown eyes, or brown or black or blonde or red hair, that have light skin or dark skin. They think there's only one type of person.

Lastly, most of the children promoted stories of advocating for acceptance of others and for an increased understanding of ASD by others. In addition, most of the children also shared stories of *support for other children* with a brother or sister with a diagnosis, and how their experiences can make them more understanding of others' experiences (see Appendix J for their advice for other siblings). One child, C4, says the following:

It's also really interesting 'cause if I become like a scientist or a therapist when I grow up, I know firsthand how people's sisters or brothers of autism would feel, and I could ask my Mom how it felt to have a daughter with autism.

Another child, C3, shared many ideas she had that could support and connect children with similar experiences. She shared, "You could find someone who has a sibling with autism and either write each other or have certain times where you can get together and talk." Many of the children shared how talking about their experiences, specifically what it's like having a sibling with ASD, can be helpful. One child, C1, said, "Sometimes there's nobody really to let your feelings out about an experience living in a household with another child that has a learning disability... It was nice to let my feelings out and talk about my brother." Another child, C5, shared that talking could be helpful for other children, too, especially when learning about their sibling having a diagnosis of ASD. She states, "Sometimes kids can be shocked and they maybe they want to talk about it." Additionally, another child, C4, recognizes that some children may

not want to talk about what it's like for them, stating that children should talk, "only if they want to. I mean, seriously, if they want to keep it secret, they can." The idea of promoting a space for children to talk about their experiences, and helping them feel as though someone else can understand their experiences was also discussed by C3:

And I wanna kinda help other kids understand he's not just weird. And I wanna help maybe some kids that do have siblings with autism that kinda feel like people make fun of them...and they just think they're weird because they can't talk or do stuff like some stuff that we can do...some kids who have siblings with autism or parents who have kids with autism should be write books or do something. I think they should have one that has some stories that kids have told, not just the ones about the parents...like, how all of it's different but kinda some stories about me and [S3] um, how's it hard for us...I wanna help families and kids who have siblings with autism, and kids with autism—'cause I wanna help, like kind of have something for them.

Exhaustive Description

The children interviewed in this study shared expressive and rich descriptions of what it is like to have a brother or sister with an autism spectrum disorder. While all the children reported feeling as though their sibling was "normal" regardless of having a diagnosis, most of the children also shared that they started to understand the ASD diagnosis as they grew older and started to see the sibling as "different" when compared to themselves, or compared to their siblings in earlier years. Many children described their experience as starting to recognize how their siblings were affected by the diagnosis, mostly through noticing the siblings' strict adherence to routines, disruptive behaviors that were not easily understood, and from recognizing the social limitations or challenges experienced by their brother or sister.

Not only did most of the children report that their sibling's behavior resulted in people sometimes staring, yelling, or being mean to their brothers or sister, the children also described experiencing their own challenges with people because of their siblings' diagnoses. These responses could include strangers staring at them, or being mean to the child and the family (in addition to the sibling), but also applied to their own friendships and peer interactions. Several of the children described not being able to have friends over to the house because of the sibling's behaviors, or having other children refuse to be their friend because of the sibling's diagnosis. The children often described feeling a range of emotions about these relational experiences—angry, mad, sad, and embarrassed—and wanting to defend their sibling, even if it meant standing up to strangers or their own friends. The responses of the public to their siblings, themselves, or their families appeared to be the most distressing experiences described by the children, who often felt confused, hurt, and helpless in knowing how to respond, especially if the stranger was an adult.

However, while the children experienced unsupportive and upsetting interactions with people, most also reported having a supportive community, which included extended family members, friends, school professionals, health care providers, babysitters, waitresses, and members of ASD organizations (which included other children who had a family member with an ASD diagnosis). This experience of knowing there are people who can, and/or try, to understand the child, her sibling, and the family appeared to also facilitate an understanding that some people may be more understanding and more supportive than others. Related, most children's stories included attempts to educate others about the ASD diagnosis, while also promoting understanding and acceptance of differences in others, as it related to their own siblings, as well as to the idea of empathy and acceptance in general.

While most of the children's experiences included dealing with challenges related to their siblings, such as having personal property destroyed or having to manage and witness sibling tantrums, all of the children also acknowledged the positive experiences that came from having a sibling, and specifically having a sibling with an ASD diagnosis. A lot of the children described feeling lucky or thankful to have unique experiences because of their siblings' diagnoses, getting to learn new things, and being able to experience things that other people may not have the chance to experience. In addition, although some of the children described their experience of having a brother or sister with ASD as difficult, and sometimes wishing their sibling did not have a diagnosis, all the children described enjoying having a sibling. They all described feeling close and connected to their siblings, and demonstrating attunement to their sibling's words, interests, strengths, and joys. Most children even described their sibling relationship as marked by fondness, togetherness, and with a bond unique between them and their siblings.

Discussion

This study provides a phenomenological view of the sibling relationship from the perspective of 5 children who have a sibling with an ASD. While not generalizable to all siblings, or to all children with a sibling with an ASD, the data are consistent with the relevant literature. Each thematic cluster will be discussed and compared to the available literature in this area.

Thematic Cluster #1: Understanding of ASD

The development of the sibling relationship may differ from the normal development of sibling interaction when a child in a family is diagnosed with a disability, such as autism (Guzman, 2009). Researchers have examined the influence of having a sibling with autism on an individual, to include exploring how the typically developing sibling reacts to the diagnosed sibling (Sullivan, 1979); plays with the sibling (Hassan El-Ghoroury & Romanczyk, 1999); and

how the child understands the ASD diagnosis (Glasberg, 2000). Most of the children in this study shared that when they were younger they did not have the awareness that something was “different” with their siblings. It wasn’t until the children started to notice differences between the siblings and themselves that the diagnosis of ASD started to “make sense.” Although children described remembering when their sibling received a diagnosis, and could describe how the family reacted and adjusted, most of the children remarked that looking back at their siblings’ behaviors the diagnosis explained things, yet they could not comprehend or understand the diagnosis initially. This change in understanding is consistent with research on child development, with middle to late childhood (age 6 to 12 years) being characterized by change and growth in interpersonal skills and the quality of children’s peer relationships and self-understanding (Parker, Rubin, Erath, Wojslawowicz, & Buskirk, 2006). Many of the children tell of recognizing that they passed developmental markers while their siblings did not, and also noticing that the siblings’ responses to social interactions varied from their own. Comparison of the siblings to themselves, and to the siblings when they were younger, seemed to influence the changing understanding of ASD and the affect it had on their siblings.

Thematic Cluster #2: Challenges and Benefits of Having a Sibling with an ASD

The children’s stories of recognizing positive experiences, as well as challenges, in having a sibling with ASD are consistent with previous research in this area. As described by many of the children in this study, typically developing child in other studies shared their experience of having to manage certain behaviors displayed by their siblings—including temper tantrums, hyperactivity, and aggression (Gray & Holden, 1992; Guzman, 2009). In addition, the children in this study also shared recognizing that they could not do things they witnessed friends doing with their siblings, and also experienced some limitations in activities because of their

siblings' diagnoses (Allgood, 2010). In addition, previous researchers have also highlighted some of the subthemes from this study, including the children's experience of feeling angry or resentful at their siblings' behaviors related to ASD, and as also describing experiences common of siblings, with or without diagnoses.

Sibling relationships, in general, have been studied by researchers and have promoted sibling interactions as giving children opportunities to learn emotional regulation, adaptation to the needs of others, and conflict management (Bedford, 1998; Desautels, 2008; Kitzmann et al., 2002). The adaptation to their sibling was described by children in this study, and interpreted as *accommodation* by this researcher. While it is unclear if these children had different, or even more, instances of accommodating to situations to help their siblings, adapting to meet the needs of a sibling is common in sibling relationships. Furthermore, the stories in this study also included recognizing the experience of having a sibling with ASD as a positive experience. This experience is consistent with previous research on siblings of children with autism as well as siblings of children with Down Syndrome, which highlighted the typically developing sibling reported having admiration for their sibling and a decrease of competition (Kaminsky & Dewey, 2001; Strobel, 2006).

Having a sibling with ASD is also like having a sibling without a diagnosis, in which the sibling interactions can promote opportunities to self-soothe and to learn social communication skills that can transfer to other social environments (Farber, 2010). Learning to appreciate their sibling's successes and perceiving having a sibling with ASD as presenting benefits and unique ways of learning may be ways in which the child is self-soothing, attempting to regulate emotions, and also adapting to the needs of the family and sibling. Overall, some children can be

affected to varying degrees in both positive and negative ways (Connors & Stalkers, 2003), which is reflected in the stories of these children.

Thematic Cluster #3: Relationships and Interactions with Others

As expected, the stories in this study included experiencing challenges in relationships with friends and parents. These interactions may happen as the children experience restrictions in participating in activities, or when they attempt to manage, or shield, the behaviors of their siblings towards their own friends (Allgood, 2010). Children with ASDs are characterized by atypical social interactions styles and impairment in non-verbal behaviors (Howard, 2006), which may affect their development of peer, as well as their typically developing sibling, who may become associated with the atypical behaviors or interactions of the diagnosed sibling.

The parental relationship with the typically developing child can also be influenced when there are expectations or requests to help care for their siblings (Allgood, 2010). Some of the children in this study shared having more responsibility and expectations to care for the diagnosed sibling when parent(s) were not present. At times helping the parent was done voluntarily, while at other times it seemed to be an expectation, or need, of the family system that developed over time. Regardless, assisting the parent and having responsibility can affect the child's relationship with her parent in various ways, as can the experience of sharing parental attention with another child. The children in this study shared feeling left out at times, or recognizing times when parental focus shifted to the sibling. This dynamic is common in most sibling experiences, as well as in families during the time a child receives a diagnosis and the family attempts to meet the needs of the child and to adapt to new information.

The stories of the children also provide richer descriptions of the affect a siblings' diagnoses may have on their social/peer relationships. Because I wanted to focus on a neglected population in research, children between the ages of 8-12, the emphasis on social relationships

was evident in the stories more than reported by other researchers. Specifically, this age is characterized by children defining themselves in terms of appearance and activities, with peer groups becoming more important than at previous ages (Parker et al., 2006). This could offer some understanding of why so many of the experiences shared by the children included instances of defending their siblings in front of friends; being rejected by peers at school; or establishing and maintaining friendships with those children who were supportive and understanding of the child and her sibling. In addition, observing and modeling become important ways the children are learning to navigate relationships, so as the children in this study reported, witnessing how their parents respond to strangers who approach the sibling or the family may also produce a similar response in the child when experiencing the same thing, without the parents present.

Likewise, this study provides more details about the ways in which children with a sibling with ASD have to navigate with others in relation to them (specifically with the general public) than in previous research studies. The children told of many instances of witnessing strangers yell at their sibling or parents about the sibling's behaviors, and specifically, experiencing lots of staring at their siblings, them, or their families. Children with a sibling with ASDs may have to face embarrassment, deal with sibling behaviors in public, as well as experience people not understanding, or even knowing, what ASD is and how their sibling may be affected (Glasberg, 2000; Harris & Glasberg, 2003; Hastings, 2003; Matthew et al., 2002; Sullivan, 1979).

Thematic Cluster #4: Attunement and Unique Connection

Sibling relationships, in general, are characterized as ranging from love and affection to hatred and hostility (Lobato, 1983). And because sibling relationships have a longer duration than most relationships on one's life, it is often a very unique type of experience (Cirirelli, 1995). The stories of these children offer support for this idea, and include many examples of ways they

have a unique connection and bond to their siblings, and the many ways that they spend time together, share interests, and genuinely enjoy being together. The sibling relationship has unique characteristics when compared to other interpersonal relationships because of sharing experiences, living space, genetics, and cultural background (Wilkerson, 2001).

When one of the children has a disability or illness, the sibling relationship can be affected—sometimes pushing the siblings apart or bringing them closer together (Farber, 2010; Tucker et al., 2001). Most of the experiences shared by the children promoted a sense of being close to their diagnosed siblings, and recognizing that they had a unique way of communicating and connecting with their sibling, especially when compared to other relationships their siblings experienced. In addition, all of the children shared liking their brother or sister, and valuing having someone to talk to and play with, regardless of the sibling having any diagnosis. This is fitting with previous researchers promoted the sibling bond as a powerful (and unique) influence on an individual's mental, emotional, and physical aspects of life (Wolf, Fisman, Ellison & Freeman, 1998).

Despite the challenges and frustrations reported by most of the children, all of the children shared positive experiences with their diagnosed siblings, and could easily identify unique interests, strengths, and qualities of their brother or sister. Fighting with their sibling was mentioned by the children, yet was always followed up with a positive statement about being able to repair the relationship or that the argument was resolved quickly because of their strong bond. These results are consistent with previous findings in studies on the quality of the sibling relationship related to a brother or sister having autism (Roeyers & Mycke, 1995). Some researchers have reported those relationships as having less conflict and competition than

normally developing comparison sibling groups (Kaminsky & Dewey, 2001), which fit with the descriptions told by the children in this study.

Thematic Cluster #5: Advocacy and Acceptance

Previous researchers have found that children with at least one sibling have better social and interpersonal skills, which can then be transferred to other relationships (Desautels, 2008; Downey & Condrón, 2004). This transfer of skills can apply to family relationships, friends, and to interactions with the general public. Many children in this study shared their attempts to educate others about ASD, and not only to see how their sibling was “normal” and “like us” but also to promote acceptance of anyone else who may have differences. This sense of advocacy and promotion of acceptance of others with a perceived difference ties to research studies in which researchers attempted to examine how having a brother or sister with autism influenced an individual regarding selection of career path and positive characteristics. Researchers have supported the typically developing individual to have increased cooperation, sensitivity, compassion, and empathy (Kiburz, 1994; Wilkerson, 2001). This idea of promoting empathy and demonstrating compassion for others is painted richly in the descriptions of the children in this study. So many of the children told of standing up to others who were judging their sibling based on the diagnosis, and passionately expressing how hurtful it might feel if the roles were reversed. This sense of advocacy, to promote an increased sensitivity and acceptance of ASD or perceived challenges, was evident in many of the children’s stories, as it related to school, strangers, or friends. Lastly, this idea of increased empathy and sensitivity was also evident in the children’s ideas to support other children who had a sibling with an ASD diagnosis, promoting a sense of inclusion and connection for children who may have similar experiences (see Appendix J for the children’s advice for others with a sibling with an ASD).

Exhaustive Description

Overall, the exhaustive description is consistent with the literature and captures the many ways the children experience having a sibling with an ASD. The stories shared by the children fit with previous research studies, while also contributing to the generation of insight and understanding of the phenomenon. The use of photographs and drawings provide further meaning and in-depth information regarding the children's experiences, building on the emerging themes found in the collective stories in this study, as well as those noted in previous research findings on siblings of children with autism.

Limitations

One limitation of the study is that participants were recruited from families connected to supporting networks and organizations for families with a child with an ASD. Families who are connected and involved in supporting organizations may differ from other families that may not have the resources, contacts, or access to internet/technology (where recruitment was done). In addition, families who consented to their children participating in this study may differ from those who did not participate. For instance, some parents of the children participating in the study described themselves as “active” in seeking out additional resources or ways to gain support for their typically developing child, which could influence the child's experiences, stressors, or responsibility in relation to her diagnosed sibling.

Interpretative Phenomenological Analysis was the most appropriate approach because of the small sample size and homogenous sample, and this meant that the participants were very similar in regard to demography and family structure. All of the parents of participants identified themselves and their participating child as Caucasian. All of the families had only two children in the family—one diagnosed with an ASD and one typically developing child. All participating

children were female, and all but one sibling was diagnosed with autism. Having four of the five children be part of a brother-sister dyad may have affected the stories of supportive sibling interactions and experience, especially as girls typically have more home and child care responsibility than boys, whether there is a child with a disability in the home or not (Damiani, 1999). The sister-sister dyad in the study was associated with more stories of conflict and frustration, which could have been further supported as a theme if more same sex dyads were included.

Lastly, four out of the five families in this study had a household income greater than \$100,000. This socioeconomic status not only could have affected who was available for the study (to have a child meet with researcher without a sibling present) and who had access to the modes of recruitment (internet, communication with support groups), but could also be associated with factors that could mediate the sibling relationship. A lot of the children described having community support (which included people coming to the house to help with the sibling), having access to programs, having live-in help, as well as stories of relocating multiple times or having multiple houses so services for the sibling can be easily accessed.

Clinical Implications

This study demonstrated how sibling relationships are complex and diverse, and can be affected in a variety of areas to varying degrees, both positively and negatively. Family and individual characteristics can directly affect sibling relationships (Strobel, 2006), and when a child in a family is given an ASD diagnosis there is a unique family structure that is created, which may affect not only the types of roles taken on by individual family members, but also influence the sibling relationships (Myers, 2004). This study promotes the consideration of the

sibling relationship as an important factor in relation to the experienced stress, and resilience, in the family system when a child is diagnosed with an ASD.

The findings from this study offer a more in-depth understanding of the sibling experience, which, when shared with parents, can increase support and understanding in relational interactions and in the home environment, and in turn, can increase the family's psychological resources. The parents of the children who participated in this study were very supportive of the process and very encouraging of the children having an outlet to share their thoughts and experiences. The parents were willing to step aside for the children to have the focus and opportunity to share their stories, a strength that could continue to be present in clinical settings. Additionally, the parents genuinely appeared interested in gaining insight into their children's experiences of being a sister to a sibling with an ASD, and appeared enthusiastic about seeing the children's photographs and drawings (as directly shared with them by their child). This supportive, curious stance of the parents speaks to the possibilities of therapeutic interventions in facilitating parental insight and family sharing of the child's experience in a family where a sibling has a diagnosis. Through the use of artistic expression (such as drawings or photographs), family members can share their perspective and emotional experiences with one another, building on communication and emotional support and witnessing in the family system.

Importantly, as supported by this study, positive sibling relationships can lead to better adjustment outcomes (Desautels, 2008), which emphasizes the importance of families, mental health professional, and educators working to improve the relationship bond that could potentially affect the entire family system (Barr & McLeod, 2010). To facilitate a positive sibling relationship and offer support for children who have a sibling with a diagnosis, groups for typically developing children can be offered to create a space for those children to share their

thoughts, feelings, and experiences. Such groups could include group therapy sessions to process shared emotions and thoughts; activities to build on group strengths and highlight individual skills; and journal writing (or pen pals within group) for children to communicate and connect with others who can relate to their experiences.

In addition, clinical interventions could also extend to include parents, siblings, and the children with an ASD diagnosis in focusing on strengthening the supportive relationships in the family system at the parent-child and sibling level. Specifically, a focus on sibling dyads in family therapy can serve as opportunities to facilitate change for children who identify as having a challenging or difficult relationship with their sibling. Furthermore, hearing the unique experiences and insights of siblings of children with ASD can facilitate a greater understand of interactions within the family, which can promote mental health and education professionals expanding the family context to include the sibling relationships as a possible strength, intervention, or resource.

Future Directions

A long term goal of mine that evolves from this study is to identify therapeutic programs and family interventions that can encourage positive relationship experiences between children and siblings who have an ASD diagnosis. It is important to shed light on the experience and create potential interventions that could optimize the strengths of the sibling relationship and positive outcomes for this population. Gaining a deeper understanding of the sibling relationship may have implications for therapeutic practice, as well as for education and research involving families with children when one child is diagnosed with ASD.

This study may also contribute to mental health professionals' understanding of children who have a sibling with ASD by presenting an alternative perspective to previous research

findings that focused on quantitative methodology with traditional means of data collection obtained mostly from parents of the children. Future studies would include the voices of both siblings and other family members in this area of research. While this study included all participants as being identified as Caucasian and part of a family with only two children, it would be greatly beneficial for this research study to include a variety of family structures and demographic characteristics. Researchers could explore the similarities and differences of the experiences of multiple children in the same family with a sibling with a diagnosis, acknowledging how they may vary depending on birth order, age, gender, or personality factors.

Also, as previously mentioned, all participants were female and all but one had a brother with an ASD. Expanding the gender combinations of dyads to include brother-brother dyads and brother-sister dyads with the sister having an ASD could offer additional understanding of sibling relationships. In addition, all but one sibling in this study was diagnosed with autism. Further examining how the specific disorders (within the ASD diagnosis) affect the behaviors, perceptions, and interactions of the diagnosed child and the typically developing child, could offer more information on the factors that influence the sibling relational experience.

In addition, most of the participants and their siblings were around 10 years old, and this dominant age could have also affected the experiences reported. Developmentally, peer relationships and self-awareness in relationships become more heightened areas of focus at this age, when compared to younger children who may not relate as strongly to the stories shared by the older children. Including a wider range of ages of children in research studies could capture some of the developmental differences, specifically when the child begins to notice and understand the effects and differences in their sibling with ASD.

Lastly, expanding this research to include the voices of children from various cultural backgrounds, with varying family values and beliefs, and those of the diagnosed children in the sibling dyads, could further add depth and richness to the stories of sibling experiences. The sibling relationship has the potential to affect various aspects of children's development in both negative and positive ways; therefore it is of great interest to families, researchers, and clinicians.

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Table 1

Demographics

Child	Age of Child (years)	Sex of Child	Race of Child	Age of Sibling (years)	Sex of Sibling	Race of Sibling	ASD Diagnosis Given to Sibling	# Children in Family
1	10	Female	Caucasian	7	Male	Caucasian	autism	2
2	8	Female	Caucasian	10	Male	Caucasian	autism PDD-NOS	2
3	11	Female	Caucasian	8	Male	Caucasian	autism	2
4	10	Female	Caucasian & Hispanic	11	Female	Caucasian & Hispanic	autism	2
5	10	Female	Caucasian	12	Male	Caucasian	Aspergers	2

Table 2

Main Findings

Thematic Clusters	Subthemes	Evidence
Understanding of ASD	Understanding Changed Over time	“When we were kids we played all the time. But when we started realizing he wasn't the same as other kids, ah it was kind of difficult.” (C5)
	Recognizes impact diagnosis has on sibling	“My brother's routine, he listens to his routine, and every single day he does it because... because of the autism when they tell him to do that.” (C1)
	General Knowledge of ASD	“It's a disability and her brain works differently than ours. So she thinks differently and she acts differently.” (C4)
Challenges and Benefits of Having a Sibling with an ASD	Recognizes Experience as Positive	“It's actually kinda cool having a brother that's autistic because you get to experience stuff that other people won't.” (C1)
	Recognizes Challenges	“I just want them to know that it's actually sort of hard having a sister with autism... Sometimes I just wish that [S4] was an average kid. Like without any disabilities.” (C4)
	Accommodation and Sacrifice	“He doesn't have, like, many friends that like the same things he likes, so when I can tell he really wants to do something and he asks me to do it, then I say ok.” (C5)
Relationships and Interactions with Others	Emotional Experiences and Challenges to Public Reactions	“A lot of people stare at him, so like I just like stare back at them and they just look away... I don't want them making fun of him or staring at him.” (C3)
	Peer Consequences	“One time I had a slumber party for my birthday and like seven girls came. [S4] started hugging, kissing them pretty much immediately... she embarrasses me in front of my friends... and after [S4] had the tantrum, me and [friend], we were not that much close.” (C4)
	Presence of Supportive Community	“It's good to know that there are some best friends that you can count on that are nice to you and your brother or your sibling.” (C1)
	Parent/Child Relationship	“I think that was a tough time when I was

Thematic Clusters	Subthemes	Evidence
		4 and 5 and 6 when he sort of got revolved around like it was this big <i>Star Trek</i> force field not letting me get in.” (C1)
Attunement and Unique Connection	Can recognize successes, interests, and positive attributes of sibling	“I think he could be an astronomer ‘cause he's really good...I just want him to know that I believe that he can do great things.” (C5)
	Togetherness	“We always do things together. Together forever. Ever.” (C2)
	Fondness and Closeness	“We do almost everything together... like we never separate. It's like there's glue between us... Two peas in a pod.” (C1)
Advocacy and Acceptance	Sibling as “normal kid”	“He's a normal kid! And he's no different from you, he has a face, he smiles, he has eyes, and he can talk! He's not any different from you...he's a human, what do you guys think he is an alien?” (C1)
	Educating Others about ASD	“I think a lot of people should learn about autism and like what it's about and how it can be different for everyone.” (C3)
	Trying to promote acceptance and empathy in others	“It doesn't matter if he's a little bit different. I mean everyone is different than everybody. No one looks exactly alike, even identical twins.” (C5)
	Support for other children	“Sometimes there's nobody really to let your feelings out about an experience living in a household with another child that has a learning disability.” (C1)

APPENDICES

Appendix A: Researcher Positionality

Researcher as Instrument and in Context

In qualitative research, the researcher can be understood as the primary tool—through which the voices of the participants are heard (Ducey, 2010; Merriam, 1998). Phenomenological Inquiry requires that the researcher serves as the primary data collection instrument, and owns her subjectivity (Creswell, 2007). As such, in a phenomenological study the initial stage (the epoche process) involves the researcher reflecting on her own views concerning the topic being explored (Creswell, 2007). For this study, it was necessary for me to examine my own values and biases towards the sibling relationship in general and specifically sibling relationships when one child has ASD. My view of the world and this research study has been shaped by my past experiences and is continually influenced by my ongoing perceptions and interactions. My personal experience, professional background, and education have shaped my perspective as a Marriage and Family Therapist and researcher. My experiences with children, a previous research study that included an interview with a parent of two children (one with autism), and my own sibling relationships have motivated me to pursue this study.

I believe sibling relationships are important. My relationships with my two older sisters are marked by affection, intimacy, and support. Through that bond, I have very strong relationships with my three nephews and niece. I also grew up closely knowing my aunts and uncles and understanding my dad's relationship with his siblings as being very important. The value of sibling relationships was supported directly ("be nice to your sister, she is going to be there the rest of your life") and indirectly (witnessing the practice of my dad having weekly calls with his siblings). The sibling relationships I have experienced, and witnessed, have been a strong foundation to my memories, beliefs, joys, and support—including such traditions as having a sibling in the delivery room when a new child is born. My relationships with my sisters

have greatly impacted my experience in the world, and I feel that there is a unique connection and strength I have within these relationships that is specific to siblings.

In addition, I have witnessed sibling dynamics when a child has particular challenges. In my family I have one aunt with two sons—one of whom has Down Syndrome. I have witnessed how these brothers can amuse and irritate each other, and above all, I have seen the apparent bond they have, in loving and in fighting, and the way they can communicate, share, and play together. I have seen how the non-diagnosed child is sometimes asked to take some responsibility for caring for his brother and seemed to feel a sense of pride, and also at times when he seemed to be annoyed in doing so. There seemed to something about their dynamic that serves as a strength and mediates the challenges. This witnessing seemed to be a theme of the stories I would also hear from parents, strangers, grandparents, friends, etc—remarking that the particular sibling dyad had a “unique” bond, especially when one child had a diagnosis or condition of some kind. On several occasions, I have heard parents express this “unique” relationship between the siblings that is characterized by this mutual affection, support, and understanding.

In addition to personal relationships, my professional background has included a variety of positions and roles working with children—a preschool teacher; an intern at a children’s residential treatment center; a mental health worker at a children’s mental health center; a therapist—to name a few. Children have impacted my world-view, and my appreciation for humor, patience, creativity, and playfulness. My work, and relationships, with children has motivated me to attempt to understand and recognize their voices and experiences, which are not often heard, or appreciated, especially when verbal “adult-like” communication may be more valued.

In my clinical work, I often consider sibling relationships as a point of clinical intervention or recognition, specifically acknowledging it as a possible strength and support that is often overlooked. As a clinician at the Antioch University Couple & Family Therapy Institute, I was part of clinical teams that included working with a client's sibling relationship as a source of strength and support when one child had a diagnosis. In addition, during my time at the clinic, an autism support group began and my curiosity about the family dynamics started to grow. I attended local Autism Expositions and information sessions about autism, and talked to therapists who participated in the support groups. Coming from an interest in supporting children and siblings, I listened to the shared observations of how many siblings were attending support groups and the challenges that parents expressed in their support groups about sibling needs.

In the spring of 2011, I completed a research project in which my co-investigator and I interviewed a parent of a child with an ASD on the needs of her typically developing sibling. On several occasions, the parent identified the sibling relationship as something "special" and "like no other relationship [the child with ASD diagnosis] had." This research experience solidified my passion for continuing to contribute to this research area and explore ways to support the sibling relationship, specifically when a child has ASD. Research of this kind is important in understanding the relationship experience from the typically developing siblings' perspectives, and also representing a group of voices (shared experience) that has commonalities as well as variations. I am passionate about supporting diverse groups and working to amplify their voices, experiences and needs, specifically those of children—easily identifiable as an underprivileged, often powerless, group. This research could provide a rare opportunity for children with ASD to share their experiences.

Knowing there are gaps in literature and research around sibling relationships, it seems helpful to embrace curiosity in exploring these experiences, from multiple voices and perspectives. I also intend on tying my research interest in siblings to extend to clinical practice and interventions. I hope to start sibling groups for children and families who are affected by various issues, including mental health issues— using research to offer justification for such attention and application. In my professional career, I aim to work to promote practices for including sibling dyads in therapy to build on the possible strengths and resources that are often unacknowledged in the field. I am enthusiastic about exploring sibling relationships in various contexts and the possible opportunities to support the children, families and community.

Lastly, as a Marriage and Family Therapist, I believe it is important to contribute actively in the positive development and representations of diverse families, their communities, and needs specifically in honoring the resiliency factors and support systems in families. Among my clinical and research interests are resiliency, positive psychology, and supporting factors in family systems and dyad relationships. I believe that members of a family can directly influence each other's development in a variety of ways, through interactions and relationships, with each having a story that should be honored and appreciated.

Research Bias

My bias is that, as a Marriage and Family Therapist, I tend to be interested in the relationships between siblings, and I prefer to work systemically. I operate from a postmodern worldview, and am interested in multiple perspectives and being non-blaming and non-pathologizing. The assumptions in this study are the result of an accumulation of personal and professional experiences. The inquiry design was also guided by my personal assumptions and world view.

- I hold the following assumptions:
 - No objective reality; reality is the observer’s interpreted experience (Anderson & Goolishian, 1988; Ducey, 2009; Munhall & Boyd, 1993)
 - Disability/Diagnosis in a child has some affect on the members of the family and family as a whole
 - Every family member has own perspective and experience—all should be considered valid
 - Children are competent in sharing their experiences
 - Children have the ability to share their reality through the use of photography, art, and words
 - The children will attempt to be truthful in their interview responses (Ducey, 2009)
 - There may be positive and negative outcomes from the experience of having a child with ASD in the family (Wilkerson, 2001)

Overall, these experiences and beliefs have informed the design of this study.

Excerpt from Researcher’s Field Journal

“I was moved to tears as I was driving home. The story was so powerful and I felt so lucky to have the honor to hear it. When youth began crying, I stopped the recorder; felt the pull to slip into the therapist role (where does the line of researcher and therapist roles overlap?); and validated how hard things can be sometimes, how people can’t always understand what it’s like, and how helpful it can be to have someone to talk to about these feelings. We talked about her wanting someone else to talk to after me, and made a plan to talk to mom about maybe making calls to someone, such as a therapist. After the interview, with youth’s permission, we sat down with mom together and talked about how it might be helpful for the youth to have someone else to talk to (how powerful to help family access mental health resources!). I wanted to do more. I wanted to do family therapy with this youth. I wanted to be her therapist and help support her and the family. Such a loving family, doing the best they can. Stories and emotions are the reason that I wanted to do this...I want to honor the stories and share them. I want to do some of the things the children are asking for...”

Appendix B: IRB Approval

From: <kclarke@antioch.edu>

Date: Mon, Jan 28, 2013 at 5:24 PM

Subject: Online IRB Application Approved: The Sibling Experience When One Child has an Autism Spectrum Disorder January 28, 2013, 5:24 pm

To: mmcvicker@antioch.edu, kclarke@antioch.edu

Dear Melissa McVicker,

As Chair of the Institutional Review Board (IRB) for Antioch University New England, I am letting you know that the committee has reviewed your Ethics Application. Based on the information presented in your Ethics Application, your study has been approved.

Your data collection is approved from 10/01/2012 to 4/30/2012. If your data collection should extend beyond this time period, you are required to submit a Request for Extension Application to the IRB. Any changes in the protocol(s) for this study must be formally requested by submitting a request for amendment from the IRB committee. Any adverse event, should one occur during this study, must be reported immediately to the IRB committee. Please review the IRB forms available for these exceptional circumstances.

Sincerely,
Katherine Clarke

Appendix C: Recruitment Letter

Research Participants Sought: Young Siblings of Individuals with Autism Spectrum Disorders

Volunteer participants are being sought for a research project titled *The Sibling Experience When One Child has an Autism Spectrum Disorder* being conducted by Melissa L. McVicker, a doctoral graduate student at Antioch University New England. The purpose of the study is to explore and describe the experiences of children who have a sibling with an autism spectrum disorder (ASD). The aim is to develop a better understanding how the unique experience of having a sibling with ASD may alter, impact and enrich the lives of siblings.

Study participants must be 8-12 years old and have a brother or sister with an autism spectrum disorder. Volunteer participants will be asked to meet with the researcher for two sessions, for no more than an hour each. Participants will receive a gift card to honor their contribution. The researcher will come to your house, as long as it is within a 1.5hr distance from Keene, New Hampshire.

The first session will involve a series of semi-structured questions. Participant responses will be voice recorded by the researcher for later transcription and analysis. Participants will also be given a disposable camera to complete a photography task between interviews. During the second interview, participants will be asked to complete a drawing activity and discuss it, as well as share the photographs they took between interviews. Participants have the opportunity to contribute to general understanding of the siblings' experience and gain their own insights regarding their personal experience.

Please contact Melissa McVicker, M.S. at mmcvicker@antioch.edu or 219.488.6001 if available and interested in having your child participate in this study. I genuinely thank you for your time and contribution to this important research topic. Thank you!

Appendix D: Research Study – Parental Consent Form

The Sibling Experience When One Child has an Autism Spectrum Disorder
Principal Investigator: Melissa L. McVicker
Antioch University New England
Department of Applied Psychology

This informed consent form is for parents of children participating in the research titled "The Sibling Experience When One Child has an Autism Spectrum Disorder."

You will be given a copy of the full Informed Consent Form.

Introduction

I am a graduate student in the Marriage and Family Therapy Doctoral Program at Antioch University New England. I am doing some research which might help researchers and therapists better understand the sibling relationship so they can help families better.

In this study I will talk to children and ask them a number of questions. Whenever researchers study children, we talk to the parents and ask them for their permission. After you have heard more about the study, and if you agree, then the next thing I will do is ask your daughter/son for their agreement as well.

If you have any questions, please ask me and I will stop to take time to explain. If you have questions later, you can ask them of me at any time.

Purpose

Your child is being asked to participate in an interview to better understand the experience of growing up with a sibling with ASD. This study will provide a rare chance for these children to tell their stories, and share their own experiences of having a sibling with an autism spectrum disorder. By participating in this study the child also may have new feelings and thoughts about his/her relationship with the diagnosed sibling.

Type of Research Intervention

An interview; drawing activity; and use of photography.

Selection of Participants

We would like to ask your daughter/son to participate in this study because she/he is a biological brother or sister between the ages of 8-12, living in the same home with a sibling diagnosed with an autism spectrum disorder, who is identified as healthy, and without a chronic illness or developmental disability.

Voluntary Participation

You can choose to say no and nothing will change. You can ask as many questions as you like and I take the time to answer them.

Procedure

Data will come from the children through interviews, photographs, and drawings. Your daughter/son will participate in two interviews with the researcher in your home. Each interview should not last for more than an hour. Interviews will be held alone with each child, although

you can be close by (outside the interview room). You will also be asked for demographic information prior to your child's first interview.

Interview:

Your child will be asked questions about their sibling relationship and about their ages and birth order. Your daughter/son will be informed that if he/she does not wish to answer any of the questions during the interview, she/he may say so and the interviewer will move on to the next question.

Photos:

At the end of the first interview your child will be given a disposable camera to capture photographs related to the experience of having a sibling with ASD. You will be given a pre-paid postage envelope to mail the camera back to the researcher, to allow for the film to be developed before the second interviewing session. The second interviewing session will include talking about the photographs.

Drawings:

Your daughter/son will also be invited to participate in a drawing activity of him/her and the brother/sister doing something together.

Risks and Discomforts

The risks to the participants are minimal. It is possible that in answering the questions and talking about having a sibling with ASD that negative emotions could be stirred up. During the interview, the researcher will observe signs of discomfort and stress and if detected, the researchers will provide the participant(s) an opportunity to cancel or postpone the interview.

While interviews will be done in the participating child's home, it is possible that other children may be present. Requests will be made by the researcher to the guardian to have privacy for the interview within the home, to aid an open conversation between child and researcher without child's concerns about what other family members may hear in the conversation. There are minimal expected risks to other children in the family, beyond the possibility that in negative emotions could be stirred up in the participating child.

If answering the questions in this interview brings about negative emotions and you or your child would like to talk to a mental health professional, you can call The Antioch Couple and Family Therapy Institute at 603.283.2156, or the American Psychological Association Psychologist Referral Service at 1-800-964-2000. If this happens (and even if it does not) you must know that your child does not have to answer any question or take part in the discussion/interview/survey if he/she feels the question(s) are too personal or if talking about them makes him/her uncomfortable. Your daughter/son may choose to tell you about the interview and the questionnaire but she/he does not have to do this. We will not be sharing with you either the questions we ask nor the responses given to us by your child.

Benefits

This study will provide a rare chance for these children to tell their stories, and give voice to their own thoughts and experiences of having a sibling with an autism spectrum disorder. In this way, the child may directly benefit from this study. In addition, the child will be providing

important knowledge that can help researchers better understand the sibling relationship, and help create potential interventions that could help support sibling relationships.

Reimbursements

Your child will receive a \$25 gift card to a local establishment, previously agreed upon by guardian. After the interview is completed, she/he will be given a participation certificate. Your child will receive prints of the photographs taken while participating in the study.

Audio Recordings

For data collection purposes, each child's interview will be voice recorded. Voice recordings will be stored on digital media files and marked with a code by the researcher. All files will be stored in a secure location and will be deleted after two years.

Confidentiality

The contact information, demographic questionnaire, and drawings completed by participants will be kept in a locked briefcase but may be used in dissertation presentation to the Antioch community. After the data are collected and participants see the actual drawings and photographs, consent and assent will be obtained for the use of photographs for publication and presentation. To protect privacy, all data—including the media files, photographs, and transcripts—will be kept on an encrypted flash drive (and duplicated on another encrypted flash drive to ensure back up of data) that has password protection. No names or other identifying information will be used in the transcript and the final written report.

Like any professional I am legally required to report the abuse of children. It is my ethical responsibility to report situations of child abuse, child neglect, or any life-threatening situation to appropriate authorities.

Sharing of Research Findings

Researchers plan to present the findings to the families involved in the Support Groups in the New England area and at other community programs of interest. Nothing that your child will tell us today will be attributed to him/her by name. In addition, we will also publish the results in a journal that is read by family therapists, such as *Family Process* or *The Journal of Contemporary Family Therapy*, so that other interested people may learn from our research.

Right to refuse or withdraw

Choosing to participate or not will not affect either your own or your child's participation with any Autism and Asperger's Support Groups or resources in the New England area. Your child may stop participating in the discussion/interview at any time that you or she/he wishes without either of you losing any of your rights here.

Who to Contact

If you, or your child, have any questions you may ask them now or later, even after the study has started. If you wish to ask questions later, you may contact Melissa L. McVicker at 219-488-6001.

This proposal has been reviewed and approved by Antioch University New England Institutional Review Board, which is a committee whose task it is to make sure that research participants are protected from harm. If you have any questions about your rights as a research

participant, you may contact Katherine Clarke, Chair of the Antioch University New England Human Research Committee, (603) 603.283.2162, or Stephen Neun, AUNE Vice President for Academic Affairs, (603) 283-2450.

Certificate of Consent

I have been asked to give consent for my daughter/son to participate in this research study which will involve completing two interviews and one photography task. I have read the information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered. I consent voluntarily for my child to participate as a participant in this study.

In addition, prior to my child being interviewed by the researcher, I have been asked to provide demographic information regarding myself, my child, and my family. I consent voluntarily to participate in this study.

Print Child's Name _____

Print Name of Parent or Guardian _____

Signature of Parent of Guardian _____ **Date:** _____

Print Name of Principal Investigator: _____

Signature of Principal Investigator: _____ **Date:** _____

Appendix E: Research Study – Parental Consent Form for Photography

The Sibling Experience When One Child has an Autism Spectrum Disorder

Principal Investigator: Melissa L. McVicker

Antioch University New England

Department of Applied Psychology

The Use of the Photographs

Photographs will be used as a means to capture the children's perspective of their sibling relationship, and to help facilitate discussion of the sibling experience. The children's names will not be attached to the photographs, and no photos of identifiable people will be published.

After the data are collected and participants see the actual drawings and photographs, consent and assent will be obtained for the use of photographs for publication and presentation added to the consent form (below). Publications may include the use of photographs in journal articles in the field of family therapy (such as "Family Process"). Presentations may include presenting research findings at local and national conferences in the field of Marriage and Family Therapy. Participants (and guardians) can choose to not to have their photographs published or presented.

Certificate of Consent for the Use of Children's Photographs

I have been asked to give consent for my daughter/son to participate in this research study and to have my child's photographs included in publication and presentation material.

I **GIVE PERMISSION** for my child's photographs (with no name or identifiable people attached to photo) to be included in presentations in the field of Marriage and Family Therapy.

I choose to **NOT** to have my child's photographs published or presented in the field of Marriage and Family Therapy.

Print Child's Name _____

Signature of Parent or Guardian _____ Date: _____

Signature of Principal Investigator: _____ Date: _____

Appendix F: Research Study – Certificate of Assent for Minor Child

Principal Investigator: Melissa L. McVicker
 Antioch University New England
 Department of Applied Psychology

This informed assent form is for children between the ages of 8 - 12 who we are inviting to participate in research study about the relationship between siblings when one child has an autism spectrum disorder. A copy of this assent form will be provided to the participant/guardian.

This assent form will be used as a script, but all of the children will be given the option to read the form. The researcher will orally cover the content of the assent form and offer to read it to them and/or have them read it. The researcher will ask questions to make sure the children understand it.

Introduction

My name is Missy and my job is to research families and hear children's stories about their feelings and thoughts about having brothers and sisters with an autism spectrum disorder.

I am going to talk to you about this study, and see if you would be willing to help me with it. We have talked about this research with your parent(s) and they know that we are also talking to you. You may talk about this study with your parents or friends or anyone else you feel comfortable talking to.

There may be some words you don't understand or things that you want me to explain more about because you are interested or concerned. Please ask me to stop at anytime and I will take time to explain.

Purpose: Why are we doing this research?

We want to know what it's like for children who have a brother or sister with an autism spectrum disorder. We want to hear your thoughts and feelings about what it is like for you. This study can help other therapists like me and other people better understand how this may feel, and maybe help us come up with ways to help children and their brothers and sisters feel happier and healthier.

Choice of participants: Why are you asking me?

We would like to ask children questions who are your age—between 8 and 12 years old—who live with a brother or sister with an autism spectrum disorder.

Participation is voluntary: Do I have to do this?

You don't have to be in this research if you don't want to be. It's up to you. If you decide not to be in the research, it's okay and nothing changes. Even if you say "yes" now, you can change your mind later and it's still okay.

Procedures: What is going to happen to me?

If you decide that you want to do this, there will be four things that happen.

- 1) We will meet the first time, and you will be asked questions about your relationship with your brother and sister
- 2) You will be asked to draw a picture of you and your brother and sister and answer some questions about your drawing
- 3) You will be given a disposable camera to take photographs of things that remind you of your relationship with your brother and sister.
- 4) You will meet with me again, and we will look at your photographs and talk about them

Risks: Is this bad or dangerous for me?

This study will not hurt you and will be like talks you may have sometimes with friends, family, or other people. You do not have to answer any questions you don't want to. If talking brings out some negative feelings we can give your parents a phone number to call to get someone you can talk to about your feelings.

Benefits: Is there anything good that happens to me?

Nothing really good might happen to you, but doing this study will give you a chance to tell your story, and share your own thoughts with someone. After talking, you may learn more your own feelings.

Reimbursements: Do I get anything for being in the research?

For helping in this study, you and your family will be given a gift card to a local restaurant. And after talking to me, you will also receive a certificate for your participation. You will receive copies of the photographs that you took with the camera.

Confidentiality: Is everybody going to know about this?

We will not tell other people that you are in this research and we won't share anything about you to anyone who does not work in the research study. Information about you will be put away and no-one but the researchers will be able to see it. Any information about you will have a number on it instead of your name.

Sharing the Findings: Who will hear about this study?

When we are finished with the research, we will be telling more people, therapists and others, about the research and what we found. We will do this by writing and sharing what we learned and by going to meetings with people who are interested in the work we do.

Right to Refuse or Withdraw: Can I choose not to be in the research? Can I change my mind?

You can decide not to do this study at any time, even after we've started.

Who to Contact: Who can I talk to or ask questions to?

You can ask me questions now or later. I have written a number and address where you can reach me. If you want to talk to someone else that you know like your parents or teacher, that's okay too.

You can ask me any more questions about any part of the research study, if you wish to. Do you have any questions?

Certificate of Assent

I understand that the research is about having a brother or sister with an autism spectrum disorder. I understand that I will be asked some questions and will be invited to draw a picture and take photographs with a camera I'm given.

I have read this information (or had the information read to me) I have had my questions answered and know that I can ask questions later if I have them. I agree to take part in the research.

OR

I do not wish to take part in the research and I have not signed the assent below.
 _____ (initialed by child/minor)

Only if child assents:

Print name of child _____

Signature of child: _____

Date: _____

Print Name of Principal Investigator: _____

Signature of Principal Investigator: _____

Date: _____

Appendix G: Demographic Data Sheet

Parent/Guardian Name: _____

Child's Name: _____

Today's Date: _____

1. Total number of children in the family: _____

a. Ages: _____

2. Child Participating

- Date of Birth (mm/dd/yy): _____
- Gender: _____
- Birth Order: _____
- Race: _____

- 1 = Caucasian
- 2 = African American
- 3 = Hispanic
- 4 = Asian/Pacific Islander
- 5 = Native American

3. Sibling diagnosed with ASD

- Date of Birth(mm/dd/yy): _____
- Gender: _____
- Birth Order: _____
- Race: _____

- 1 = Caucasian
- 2 = African American
- 3 = Hispanic
- 4 = Asian/Pacific Islander
- 5 = Native American

- When guardian suspected diagnosis: _____
- Diagnosis given: _____
- Date of autism spectrum disorder diagnosis: _____

4. Marital status of parents: _____

1 = single, never married

2 = married

3 = separated

4 = divorced

5 = widowed

5. Highest Level of Education Completed by Parents: *Parent #1*) _____ #2) _____

1 = Some Grade School

2 = Grade School

3 = Some High School

4 = High School

5 = Some College

6 = College

6. Race of Parents: *Parent #1*) _____ #2) _____

1 = Caucasian

2 = African American

3 = Hispanic

4 = Asian/Pacific Islander

5 = Native American

7. Occupation of parent(s): *Parent #1*) _____ #2) _____

8. Approximate annual family income: _____

Appendix H: Interview Guide

Grand tour question: *What is it like having a brother/sister with ASD?*

Probing questions: The following questions may be offered as probes if needed. The wording of these questions may differ and will be asked in conversational manner.

1. What kinds of things do you do with your sibling?
2. Describe your relationship with your brother/sister.
3. When did you first become aware of your brother/sister's autism?
4. What kinds of symptoms/behaviors did your sibling display when he/she was young?
Now?
5. How would you describe having a sibling with ASD?
6. How are your relationships with your other siblings the same or different from the sibling with ASD?
7. What were you told about autism and ASD? Describe conversations you had and with whom?
8. Other siblings of people with ASD have described feeling other emotions such as embarrassment, anger, love. Have you felt these emotions or others in relation to your sibling? If so, please describe.
9. Tell a story about your brother/sister.
10. What would you want others to know about what it's like to have a sibling with ASD?
11. What message would you give to other siblings of people with ASD?

1. Drawings/Photographs

- a. Draw a picture of you and your brother/sister doing something together.
 - i. Describe your drawing.
 - ii. What feelings come to mind?
- b. Select two photographs that represent the experience of having a sibling with ASD.
 - i. Describe how each photograph represents your experience.
 - ii. What do you want to share about these photos?
 - iii. How do these photos capture your relationship with your brother/sister?

III. Ending the Interview

- a. Allow participant to clarify any doubts or ask questions about the interview.
- b. Provide the interviewer's contact information.

Appendix I: Siblings and Autism Book and Website List for Participants

Autism, the Invisible Cord: a Sibling's Diary. Barbara Cain, \$10.95 (novel, ages 12-18)

Autism and Me: Sibling Stories. Ousie Shapiro, photos by Steven Vote, \$18.99

Autism through a Sister's Eyes: a Young Girl's View of Her Brother's Autism. E. Band & E. Hecht, \$15.95 (ages 10-12)

Brotherly Feelings: Me, My Emotions, and My Brother with Asperger's Syndrome. Sam Frender & Dennis Dittrich, \$17.95

Everybody is Different: a Book for Young People Who Have Brothers or Sisters with Autism. Fiona Bleach, \$9.95

Everybody is a Person: A Book for Brothers & Sisters of Autistic Kids (Syracuse, NY: Jowonio: The Learning Place., 1979). Laura Burns & Melinda Metz. Middle school level. 16 pages.

Ian's Walk: A Story About Autism. Lears, L. Albert Whitman and Company, 1998.

Julie's younger brother has autism and in this story, she tells how his "brain doesn't work like other people's and how she deals with it in certain situations.

My Brother Charlie. Holly Robinson Peete & Ryan Elizabeth Peete, \$21.99 (ages 10-14)

My Brother is Different: a Sibling's Guide to Coping with Autism / a Parent's Guide to Help Children Cope with an Autistic Sibling. Barbara Morvay, \$27.99

My Brother Sammy. Becky Edwards & David Armitage, \$12.95 (autism)

My Holly: a Story of a Brother's Understanding and Acceptance. Julie Leavitt Wolfe, \$16.99

Nobody's Perfect. Marlee Matlin & Doug Cooney, \$6.99 (novel, ages 9 – 12)

Please Don't Say Hello (New York: Human Sciences Press, 1975). Part of the series *New juvenile series on the exceptional* A good resource for kids at junior high level. [ISBN: 0877052115 \(45 pages\)](#).

Poems and Short Stories About My Brother Kevin Who Has Autism: Entertainment for Boys and Girls Ages 6 to 10 (Writers Club Press, 2002). Richard W. Carlson. [ISBN: 0595228453 \(paperback, 128 pages\)](#).

Rules. Cynthia Lord, \$7.99 (ages 10-14)

Siblings and Autism: Stories Spanning Generations and Cultures. Edited by Debra Cumberland & Bruce Mills, \$24.95

Siblings: the Autism Spectrum through Our Eyes. Edited by Jane Johnson & Anne Van Rensselaer, \$15.95

Siblings of Children with Autism: a Guide for Families, 3rd Edition. Sandra Harris, \$27.50
Sometimes My Brother: Helping Kids Understand Autism through a Sibling's Eyes. Angie Healy, \$16.50

This is Asperger Syndrome (Autism Asperger Publishing Company, 1999). Ages 9-12.
<http://www.asperger.net/book2.htm> ISBN: 0967251419 (paperback, 20 pages).

To Oz and Back (Allen A Knoll, 2002). Part of the series *The Bones and the Duchess Mysteries*.
Alexandra Eden. Ages 9-12 reading level. ISBN: 1888310227 (hardcover, 153 pages).

Views from Our Shoes: Growing Up with a Brother or Sister with Special Needs. Donald Meyer (ed), \$18.50 (ages 11 +)

What's Up with Ben? Medikidz Explain AUTISM. Kim Chilman-Blair & Shawn DeLoache, \$11.99 (ages 8-15)

Websites

We the siblings: <http://www.angelfire.com/bc/autism/index.html>
Interactive website with a chat room, pen pals, bulletin boards, etc

Sibling Support Project: <http://www.siblingsupport.org/>

Helping Siblings Understand Autism and Encouraging Positive Relationships:
www.autism.ca/siblings.pdf

Massachusetts Sibling Support Network <http://www.masiblingsupport.org/>

Sibling Leadership Network <http://siblingleadership.org/>

Gateways Community Services' Siblings Groups, New Hampshire
http://www.gatewayscs.org/fs_siblings.htm

Appendix J: Advice for Other Children with a Sibling with an ASD

“Be patient I'd say 'cause you know it takes a little bit to show your appreciation but you always know that they care about you, so, that's my advice that I could give to other people that have brothers or sisters with Asperger's.”

“I would say you know what, your brother or sister is really awesome and they have some great talents and my brother has great talents and you know what, you should embrace that you have a brother or sister with autism because it's pretty cool.”

“I'd say don't give up. If you're thinking of like 'my brother or sister doesn't even care about me' or that 'they won't pay attention when I ask,' I'd say just keep trying...just keep going, I mean honestly, it will pay off. You just need to find something in common and work with that.”

“Always have a closet with a lock on. Like always have a closet handy with books and food, just in case your sibling is totally freaking out and you just need to get away.”

“Don't let them bother you...ignore your sibling, if they're trying to annoy you or get some attention.”

“Don't just sit there and let people yell at your siblings who have autism or just like stand up for them. Don't let someone be mean to them...don't let anyone bother you or be mean to you.”

“Just don't just let people push you and your brother around... just stand up for yourself and your sibling... maybe talk to an adult.”

“There's nothing wrong with him it's just a disability and they're still the same as us, it's just that their brains work differently and don't be afraid if he starts freaking out because he loves you no matter what and sometimes he just wants to be like you.”

“Be patient... If you want to talk about it [diagnosis] you have to be patient because they might want to talk about it, or they might want to wait a little bit. They might want your help with stuff, so just keep an open mind and be nice.”