

Running head: SIBLING RELATIONSHIPS WITH ASD

A GROUNDED THEORY APPROACH TO INVESTIGATING THE SIBLING
RELATIONSHIPS OF INDIVIDUALS WITH AUTISM SPECTRUM DISORDERS AND
THEIR TYPICALLY DEVELOPING SIBLINGS

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Abstract

The relationships between individuals with autism spectrum disorders (ASD) and their typically developing siblings were explored using the qualitative methods derived from grounded theory. Ten typically developing siblings between the ages of eleven and sixteen were interviewed regarding their experiences as a sibling of an individual with ASD. An interview protocol of fourteen open ended questions was developed and participants were encouraged to share any additional information which might not have been discussed in response to the interview questions. A grounded theory approach was used to analyze the interview data. As such, the principal investigator conducted several readings of the complete transcripts and refrained from developing any prior hypotheses and allowed the participants' responses to guide the analysis. The principal investigator first engaged in open coding in which memo-writing and in-vivo codes were used, with an emphasis on using the participants' own words to describe their experiences. Then, the principal investigator engaged in the focused coding phase in which categories and sub-categories emerged. The development of categories and sub-categories was derived from the data and not in an attempt to confirm initial codes established in the open coding phase. Several categories which describe the experiences of typically developing siblings of individuals with ASD emerged: responsibilities of the typically developing sibling, challenging behavior, positive attributes, frustration/anger, fears, not a normal sibling experience, and autism definition. Within these main categories, many sub-categories were identified. Other findings included a summary of participants' ratings of their experience as a typically developing sibling of an individual with ASD and the propensity of participants to express a desire to pursue a career in a helping profession. Additionally, many participants provided valuable advice for parents and siblings of individuals with ASD as well as

practitioners working with individuals with ASD and their families. Recommendations for future research were provided.

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CHAPTER I

Introduction and Rationale for the Dissertation

Autism Spectrum Disorder

According to the US Centers for Disease Control and Prevention (CDC), Autism Spectrum Disorder (ASD) is a serious developmental disability that presents with impairments in social, communication, and behavioral functioning (CDC, 2017). Individuals with ASD are expected to have lifelong symptoms and impairments and there is currently no cure (CDC, 2017). The exact cause or causes of ASD is unknown, but there is agreement among researchers that there is a genetic component to the manifestation of ASD. However, the genetic component of ASD is believed to be unlocked by certain environmental factors to result in the development of the disorder (CDC, 2017). For example, it has been suggested that prenatal exposure to certain drugs is associated with ASD diagnoses. Although the cause of ASD is unknown, there are many treatments available for ASD which can remediate some of the difficulties experienced by individuals with ASD (CDC, 2017).

Diagnosis and characteristics. There have been recent changes in the diagnosis and classification of ASD. There were previously several distinct/separate diagnoses for related disorders that are now all included under the diagnosis of ASD (CDC, 2017). These include Asperger syndrome, pervasive developmental disorder, not otherwise specified (PDD-NOS), and autistic disorder (CDC, 2017). Individuals must meet diagnostic criteria to receive a diagnosis of ASD. Some of the criteria include impairments in social interaction and/or communication and restricted patterns of behavior (CDC, 2017). Individuals with ASD often experience delays in language acquisition, fail to make eye contact, and might exhibit inappropriate, aggressive, or challenging behavior (CDC, 2017).

Additionally, many individuals with ASD also have co-morbid diagnoses with associated symptoms/impairments that impact functioning in different ways. Examples include intellectual impairments, neurodevelopmental disorders, behavior disorders, and genetic or medical conditions (CDC, 2017). There is a wide range of functioning and presentation possible with the diagnosis of ASD. Many factors impact the severity of certain diagnostic criteria. For example, the existence of additional diagnoses and their associated symptoms impacts the functioning of individuals with ASD.

Prevalence. According to the CDC (2017), approximately 1.5% of children in the United States have a diagnosis of ASD. Put differently, approximately one in every sixty-eight children is diagnosed with ASD. In recent years, there has been a documented increase in the number of children diagnosed with ASD, but there is evidence to suggest that it has plateaued (CDC, 2017). There are certain populations who are more likely to receive a diagnosis of ASD. For example, male children are significantly more likely to have ASD and are diagnosed 4.5 times more than female children (CDC, 2017). Similarly, white children are more likely to be diagnosed when compared to black and Hispanic children (CDC, 2017).

It is also important to note that ASD rates vary based on location, with New Jersey having the highest number of children diagnosed with ASD. More specifically, one in every forty-one children in New Jersey is diagnosed, as compared to the national average of one in sixty-eight (CDC, 2017). According to these estimates, approximately 2.5% of children in New Jersey are diagnosed with ASD. There are a variety of factors which are believed to contribute to the increase, including environmental factors, higher quality services, greater awareness, and school-lead diagnoses (CDC, 2017). Regardless of the reason, the increased prevalence of individuals diagnosed with ASD requires attention from researchers and practitioners alike to

ensure that individuals with ASD and their families receive the supports and resources necessary to meet their needs.

Impact of ASD on Families

In addition to the impact that ASD has on the individual's functioning, there are financial, emotional, practical, and educational impacts on the family as well. These impacts should be considered because family factors can impact how well an individual with autism responds to interventions as well as what services they are able to obtain. The financial impact of having a child with ASD can be debilitating and it is reported that parents spend significantly more on children with ASD than typically developing children (CDC, 2017). These costs include bills for medical treatments, appointments, prescriptions, school, and therapies (CDC, 2017). Financial burdens are often exacerbated by parents opting to leave their job to stay home with their child with ASD (CDC, 2017).

Additionally, research suggests that parents of children with ASD are at a higher risk for experiencing stress and poor psychological outcomes (Hastings & Brown, 2002; Woodman, Mailick, & Greenberg, 2016). This, in turn, impacts the entire family, including the child with ASD and any other siblings or parents living in the home. It has also been suggested by practitioners and researchers that individuals with ASD would be expected to experience difficulties in their sibling relationship due to their impairments in emotional understanding, communication, and behavioral characteristics (Orsmond, 2007).

Researchers have also investigated the impact of having a sibling with ASD. Some research suggests that siblings of individuals with ASD are negatively impacted by having a sibling with ASD, but the impact is not clearly understood (Orsmond & Seltzer, 2007). However, there is also evidence to suggest that typically developing individuals are impacted positively by

having a sibling with ASD (Orsmond & Seltzer, 2007). More research is needed to fully understand the impact of having a sibling with ASD and to address the existing inconsistencies in the literature.

ASD Sibling Services

A cursory internet search of ASD sibling services yields several results. Sibling support groups, sibling toolkits, and sibling training are all available, among other services. Also available are tips for parents in supporting their typically developing child and facilitating a positive sibling relationship between their typically developing child and their child with ASD. There is extensive research on the involvement of typically developing siblings participating in interventions for their sibling with ASD, and some anecdotal evidence that participation in interventions inherently improves the sibling relationship (Banda, 2015; Shivers & Plavnick, 2015). However, there is significantly less research examining the need for and effectiveness of interventions targeting typically developing siblings of individuals with ASD (Tsao, Davenport, & Schmiede, 2011). Given the anecdotal reports and some research suggesting adjustment difficulties for siblings of individuals with ASD, it is possible that this population would benefit from targeted interventions.

There is some research which supports the effectiveness of sibling support groups. Typically developing siblings who participated in sibling groups learned coping techniques and were able to speak more positively about their sibling with ASD after participation (Tsao et al., 2011). Additionally, parent training has been shown to be effective in improving sibling interactions when one child has ASD (Tsao et al., 2011). There is also some evidence that play interventions involving both the typically developing sibling and the sibling with ASD can improve the sibling relationship and the social and play skills of the sibling with ASD (Tsao et

al., 2011). However, more evidence is needed to thoroughly evaluate the need for and effectiveness of these interventions.

Purpose of Study

Inherent in all of the services and supports provided for typically developing siblings is the assumption that their experience as a sibling of an individual with ASD is negative. Although researchers and practitioners alike are attempting to provide a service they perceive to be needed, there is not enough evidence to suggest that the sibling experience is fundamentally different when one sibling has ASD. Several research studies have begun with the hypothesis that typically developing individuals might experience poor outcomes and relationships when their sibling has ASD (Orsmond & Seltzer, 2007). It is possible that this assumption has impacted the results and contributed to the conflicting findings.

The purpose of this dissertation was to interview ten typically developing siblings of individuals with ASD. The interview questions were designed without making any assumptions regarding the participants' experiences, thoughts, or sibling relationships. Grounded Theory was used to ensure that the study design, analysis, and interpretation of results were not impacted by pre-existing hypotheses or assumptions. As such, the purpose of this dissertation was to give typically developing siblings of individuals with ASD the opportunity to share about their experience and sibling relationships in their own words, since they are the most reliable reporter of this information.

The present study has the potential to improve understanding of sibling relationships in which one individual has ASD by allowing typically developing siblings to describe their subjective experience. Understanding of sibling relationships and how they might change over time is crucial to creating supports and services which might be necessary for individuals with

autism and their typically developing siblings throughout the lifespan (Mailick, Seltzer, Greenberg, Orsmond, & Lounds, 2005). In addition to the benefits to research, practitioners, and society in general, the current study also offers benefits to the participants. Participants might benefit from being given the opportunity to have their experiences and thoughts validated. Also, it is possible that participants are not frequently able to speak candidly regarding their sibling and/or their sibling relationship.

The present study may provide insight regarding the experiences of typically developing siblings between the ages of 10 and 17. Furthermore, the results of the present study can also inform the development and implementation of services and supports for typically developing siblings of individuals with ASD. For example, there has been a recent emergence of sibling support groups and other services which are designed without a thorough understanding of the experiences, needs, or characteristics of the populations for whom they are serving. The current study, and similar designs, can inform the future development of services to ensure that they are relevant and appropriate for the population.

CHAPTER II

Review of the Literature

Typical Sibling Relationships

Sibling relationships are often defined as the longest lasting relationships many individuals will ever experience. Siblings serve as teachers, confidantes, competitors, and much more. According to results from the 2011 United States Census, 78% of children lived with a sibling. As such, a large majority of American children experience sibling relationships and research has attempted to investigate the nature of these relationships and different factors which might impact both the relationships and the siblings themselves.

Sibling Relationships Across the Lifespan

Since sibling relationships typically span multiple generations, it can be assumed that some aspects of the relationship will remain stable and that some will be dynamic. As such, researchers investigate the sibling relationship at different age groups to draw conclusions regarding how sibling relationships evolve in general as the siblings age. Typically, early childhood, middle childhood, adolescence, and adulthood are seen as different populations, but are sometimes researched together (McHale, Updegraff, & Whiteman, 2012).

Early childhood. Most of the information available regarding sibling relationships in early childhood is limited by several factors. The most salient is that a majority of research conclusions with this population has been drawn from data sources other than the participants themselves (Dunn, 1983). Since very young children are often unable to express themselves and articulate their perceptions of their sibling relationships, researchers have relied on other measures, such as parent report, observation, time spent playing together, and time spent in

conflict with each other (Aksan, Goldsmith, Essex, & Vandell, 2013; Dunn, 1983; Howe & Recchia, 2005; Pike, Coldwell, & Dunn, 2005).

Reciprocity and agonistic interactions. The early sibling relationship is defined by both reciprocity, which is seen as positive, and agonistic interactions, which are more negative and involve conflict (Dunn, 1983). According to Dunn (1983), interactions in which siblings “tease, annoy, and compete” are classified as agonistic. This relationship also involves a lot of imitation, teaching, and caretaking, in which younger siblings imitate behavior and language modeled by their older siblings and older siblings engage in teaching and caregiving activities for their younger siblings (Dunn, 1983). Siblings also become emotionally attached to their siblings at a young age, which could be due to the time spent with each other. Once both siblings reach their first birthday, siblings are reported to spend as much time interacting with their sibling as they spend interacting with their mother and this intimacy is important to the development of their relationship (Dunn, 1983; Howe & Recchia, 2014).

Reciprocal and complementary interactions. Siblings in early childhood engage in both reciprocal and complementary interactions as they develop social cognitive skills (Howe & Recchia, 2005). Reciprocal interactions are typically seen during play and conflict and involve siblings interacting as equals and are very common in early childhood. Complementary interactions involve siblings taking on certain leadership role and responsibilities like teaching and caretaking (Howe & Recchia, 2005; Howe & Recchia, 2014). More specifically, siblings who participate in complementary interactions characterized by positivity and collaboration are likely to be more engaged as learners during complementary teaching interactions (Howe & Recchia, 2005).

Conflict. Conflict is a hallmark of the sibling relationship across the lifespan, but it is especially relevant to early childhood in which siblings experience conflict approximately eight times per hour (Aksan et al., 2013; Howe, Ross, & Recchia, 2010). Siblings in early childhood are in the process of developing skills related to social interactions, communication, emotion recognition/regulation, and conflict resolution which impact family dynamics and relationships. Many siblings participate in experiential learning of these skills as they navigate the conflict-rich sibling relationship (Aksan et al., 2013; Howe & Recchia, 2014).

Individuals in early childhood also begin to develop the ability to discern emotion based on verbal tone and use that information to respond during conflict. For example, siblings are more likely to respond to agonistically when their sibling uses a negative emotional tone during a conflict (Aksan et al., 2013). Although very young children are impacted by emotional tone, this skill is usually refined during middle childhood. As such, individuals in early childhood are typically responsive to obviously negative or positive emotional tones, but might not be able to distinguish between more subtle tones (Aksan et al., 2013). The sibling relationship in early childhood serves a very important function in the development of social cognitive skills.

Middle childhood. Individuals between the ages of approximately seven and thirteen are typically considered to be in middle childhood. This time period is often characterized by the emergence of social and emotional connections sustained independently by children (Edwards, Hadfield, & Mauthner, 2005). Prior to this time, parents and other adults intervene and scaffold these interactions. Individuals in middle childhood are generally able to articulate their own experiences, thoughts, and emotions to others, so they can participate in research without relying exclusively on parent report measures (Edwards et al., 2005).

Emotional connection. When asked to describe their sibling relationship, individuals in middle childhood provided information regarding the emotional connection, their relationships over time, problems in the relationship, and coping strategies (Edwards et al., 2005). Children in middle childhood describe their siblings as being emotionally connected to them and articulated a sense of mutual love and caring (Edwards et al., 2005). They also felt protected by their siblings and benefited from a sense of security in their relationship (Edwards et al., 2005). The emotional closeness experienced by siblings in middle childhood was discussed in contrast to the existence of conflict in this stage of the sibling relationship (Edwards et al., 2005).

Conflict. Conflict is a theme which continues in the sibling relationship throughout middle childhood (Edwards et al., 2005; McGuire, Manke, Eftekhari, & Dunn, 2000). As siblings enter middle childhood, conflict typically becomes less physical and more verbal, which is likely due to the fact that social, communication, language, and interpersonal skills have developed (McGuire et al., 2000). Despite the improvements in communication and social emotional skills, parents often solve conflicts in middle childhood, suggesting that siblings do not apply these skills automatically to the sibling relationship (McGuire et al., 2000).

Conflicts in middle childhood are most likely to arise when siblings need to share belongings or when one sibling takes something from another sibling. Additionally, individuals in middle childhood reported that both siblings typically start a conflict, but that the older sibling usually “wins” (Edwards et al., 2005; McGuire et al., 2000). This is what might be expected, since the older sibling typically has more power in the relationship. Conflicts during this stage in development are often seen as “normal” by the siblings and are not always perceived to be problematic or to have a negative impact on the quality of the relationship (Edwards et al., 2005).

“Annoying” is a word frequently used by individuals in middle childhood to describe their siblings and their sibling relationships (Edwards et al., 2005). Older siblings are more likely to refer to their younger siblings as annoying. Actions which elicit this description often include perceived immaturity, inappropriate behavior, and repetitive behaviors and sometimes take place in the presence of the older siblings friends (Edwards et al., 2005). Annoying behaviors are likely to result in sibling conflicts in middle childhood and children often rely on parents or other adults to address annoying sibling behavior. Other solutions include walking away, ignoring the annoying behavior, or asking his/her sibling to stop (Edwards et al., 2005).

The selection of coping strategy and/or solution is thought to be related to the responsibility assigned for the sibling argument. More specifically, some individuals in middle childhood avoid conflict because their parents do not want them to fight with their sibling, and thus, are likely to assign their parents with the responsibility of solving the problem. Alternatively, individuals who attempt to avoid conflict because they care about their sibling and their sibling relationship are likely to assume responsibility for solving their own sibling conflicts (Edwards et al., 2005). The selection process might also be impacted by the parents willingness to engage in conflict resolution with the siblings.

Shared activities and conversations. Individuals in middle childhood define their sibling relationship, in part, by the conversations and activities they share with their sibling (Edwards et al., 2005). Activities in middle childhood are heavily influenced by sibling gender in that female siblings are more likely to engage in conversations and male siblings are more likely to engage in activities (Edwards et al., 2005). These activities and conversations are impacted by the developing competence of the siblings. Individuals in middle childhood explain that they are able to engage in more activities and conversation as the younger sibling ages and develops additional

skills (Edwards et al., 2005). As such, middle childhood is a transition for the sibling relationship and siblings are able to engage in new activities and have conversations of greater depth and breadth (Edwards et al., 2005). However, individuals in middle childhood still experience conflict and their relationship is often defined by ambivalence (Edwards et al., 2005; McGuire et al., 2000).

Adolescence. Individuals between the ages of thirteen and twenty are typically considered to be adolescents, but there is some degree of variation in ages included in research studies. In general, adolescence is defined as a transitional period between childhood and adulthood. Individuals are developing their own identity and are exposed to new situations and environments. Additionally, adolescents are typically focused on peer relationships outside of the family, which might impact how they interact with and perceive their siblings (Bascoe, Davies, & Cummings, 2012).

Empathy and warmth. Individuals also develop and refine their ability to experience empathy in adolescence, which has an impact on their sibling relationships (Lam, Solmeyer, & McHale, 2012). Individuals who have empathy are able to take the perspective of others, which requires advanced development of social cognition (Lam et al. 2012). Empathy development is related to the amount of warmth in the sibling relationship in that siblings with higher levels of warmth in their relationship are more likely to exhibit higher levels of empathy (Lam et al., 2012). This correlation extends to empathy for other people, not just empathy for one's sibling and suggests that adolescent social cognitive development is impacted by sibling relationships (Lam et al., 2012).

Trustworthiness and warmth. As siblings grow together and individually, a sense of trustworthiness develops. Trustworthiness is understood as the extent to which an individual can

depend on their sibling to care for them, remain loyal, keep secrets, and be sincere and honest (Gamble, Yu, & Kuehn, 2011). Adolescents who reported high levels of trustworthiness in their siblings experienced significantly more positive psychological outcomes and adjustment (Gamble et al., 2011). For the adolescent population, trustworthiness appears to be more correlated with sibling adjustment than warmth (Gamble et al., 2011). More research is needed to examine the mechanism for this change.

Trustworthiness is also correlated with adolescent sibling relationship quality in that adolescents who report high levels of trustworthiness in their sibling are more likely to experience a high-quality sibling relationship (Gamble et al., 2011). The correlations are stronger for older adolescents, suggesting that there is a developmental aspect to the importance of trustworthiness to the sibling relationship. Adolescent gender differences have been reported regarding the levels of trustworthiness. Adolescent male sibling pairs report higher levels of trustworthiness than mixed gender dyads or female sibling pairs (Gamble et al., 2011). This gender difference is especially important when considering trustworthiness as similar to warmth, because female sibling dyads in other age groups typically have the highest levels of warmth.

Conflict. Despite the developments in social cognition during this period, adolescents have reported that they engage in conflict with their siblings more than anyone else in their lives (Campione-Barr & Smetana, 2010). This increase in sibling conflict is most often seen in early adolescence and not necessarily endure throughout the entire period (Campione-Barr & Smetana, 2010). Similar to individuals in middle childhood, adolescent sibling conflict is most likely to arise when siblings invade each other's personal domain or take belongings. Also similar is the impact of conflict on the quality of the adolescent sibling relationship (Campione-Barr & Smetana, 2010; Gamble et al., 2011). Although conflict is an enduring characteristic of sibling

relationships, there are aspects of conflict that are unique and relevant to adolescence (Campione-Barr & Smetana, 2010). Self-report measures indicate that adolescent sibling conflicts occur with a higher frequency than conflicts in other age groups and are also reported to be higher in intensity (Campione-Barr & Smetana, 2010). However, these measures do not involve direct observation and rely instead on the participants' perceptions of their sibling conflict (Campione-Barr & Smetana, 2010).

Adulthood. Adulthood differs from the other stages of life in that siblings are typically not living in the same house and instead live as independent adults who choose when and how to interact with one another. As such, it can be assumed that some of the common dimensions of sibling relationships might differ for adults (Stocker, Lanthier & Furman, 1997). However, the dimensions of warmth, conflict, and rivalry remain in the sibling relationship through adulthood (Stocker et al., 1997). The way in which these dimensions manifest in sibling relationships differs in adulthood, however. Adults also report more positive sibling relationships overall, compared to individuals in other age groups (Myers & Bryant, 2008).

Commitment and warmth. Sibling warmth in adulthood is related to levels of commitment present in the relationship (Myers & Bryant, 2008). There are a variety of ways in which adult siblings demonstrate their commitment to one another, including providing support, engaging in shared activities, and communication (Myers & Bryant, 2008). Some of these behaviors are unique to the sibling relationship, while others are common in all close relationships. Demonstration of the behavioral indicators of commitment is thought to be important in the adult sibling relationship because it reaffirms the stability of the lifelong bond siblings share. This is especially important given the life changes which occur during this time period for individuals (Myers & Bryant, 2008).

Factors Impacting Sibling Relationships

Sibling relationships have been investigated by several different researchers who have attempted to identify factors which impact the nature of sibling relationships. A recent literature review has summarized these findings (McHale et al., 2012). Initial research focused on personality differences and other individual factors which were related to the siblings themselves. From an ecological perspective, researchers have suggested that sibling relationships are not only impacted by factors within the siblings themselves, but by larger factors out of their control (McHale et al., 2012). Some of these factors include family characteristics, culture, socioeconomic status, and the beliefs of society at large (McHale et al., 2012).

Individual factors impacting sibling relationships. Temperament, gender, and age have been identified as individual characteristics shown to impact the quality of sibling relationships (McHale et al., 2012). Individuals who have a difficult temperament are more likely to experience low-quality sibling relationships. Research also supports the theory that siblings who share a gender are likely to have closer relationships than sibling pairs of opposite gender (McGuire & Shanahan, 2010; Mchale et al., 2012). Furthermore, age of siblings has been shown to have a high correlation with the quality of the relationship. This correlation is most often described in terms of age-spacing, or the age difference between the sibling pairs. More specifically, there is evidence to support that sibling pairs who are closer in age will likely have closer relationships (McHale et al., 2012; McGuire & Shanahan, 2010; Breslau, 1982).

Van Volkum and Beaudoin (2016) recently examined the impact of a variety of individual and contextual factors on the sibling relationship reported by college students. Participants completed a questionnaire to provide demographic information regarding their family as well as information related to their sibling relationship(s). The researchers found that

males and females did not significantly differ in their reports of sibling relationship quality (Van Volkum & Beaudoin 2016). This is different from what has been found by other researchers, but the gender of the siblings was not taken into consideration, which could explain the conflicting findings.

Contextual factors impacting the sibling relationship. In addition to the individual characteristics which impact the sibling relationship, there is evidence to suggest that these relationships are also impacted by the contexts in which they exist (McGuire & Shanahan, 2010). For siblings, many of these contexts are related to the structure and composition of the family. For example, birth order, parental factors, family stressors, and family financial status can impact the sibling relationship.

Birth order is a contextual factor which can impact an individual's perception of his/her sibling relationship. College-aged middle siblings differed from both younger and older siblings when reporting on the quality of their sibling relationships (Van Volkum & Beaudoin, 2016). More specifically, middle children were significantly more likely to perceive that they had a close relationship with their siblings (Van Volkum & Beaudoin, 2016). Birth order is also impactful in the way it shapes each individual's experience in the same family. For example, there are different roles, parental expectations, and levels of power given to individuals based largely on their birth order (Howe & Recchia, 2014).

Parental marital status has been shown to impact the quality of the sibling relationship throughout the lifespan. In general, individuals from cohesive family units report closer and more satisfying sibling relationships (Deater-Deckard, Dunn, & Lussier, 2002; Rocca, Martin & Dunleavy, 2010; Van Volkum & Beaudoin, 2016). Young children with single mothers are found to have higher levels of sibling conflict when compared to children with married parents (Deater-

Deckard et al., 2002). Similarly, college-aged individuals with married parents are more likely to depend on their siblings for support and assistance (Van Volkum & Beaudoin, 2016). This finding has also extended into adulthood, in that adults with married parents are more likely to report having positive sibling relationships (Rocca et al., 2010).

Perhaps more influential than parental marriage status, are the interactions between family members (McHale et al., 2012). Children who witness high levels of parental arguments are more likely to experience poor sibling relationship quality. This is possibly due to the fact that spousal conflict is often correlated with negative interactions between parents and children (McHale et al., 2012). Family systems theory suggests that patterns of negative family interactions often impact all relationships (McHale et al., 2012).

One of the most commonly researched themes is the impact that differential parental attention and treatment, or favoritism, might have on sibling adjustment and relationships (Coldwell, Pike, & Dunn, 2008; Jensen, Whiteman, Fingerman, & Birditt, 2013). It has been found that maternal differential treatment is related moderately to child adjustment (Coldwell et al., 2008). Additionally, it has been reported that the child's perception of differential treatment might be more impactful than actual differential treatment (Coldwell et al., 2008). These results suggest that children who perceive that their siblings receive more attention might be at risk for poorer adjustment and might also have hostile feelings towards their sibling.

Cultural and religious practices are also likely to have a large impact on sibling relationships (Lobato et al., 2011; McGuire & Shanahan, 2010; Tarakeshwar & Pargament, 2001). McGuire & Shanahan (2010) have attempted to analyze the experience and relationships of siblings using an ecological framework. This framework facilitates the investigation of the dynamic influence that a variety of factors might have on sibling relationships. Using this

framework is also especially important because of the emphasis placed on the macrosystem, or the broader cultural and societal beliefs (McGuire & Shanahan, 2010). In the United States, there are several different ethnicities, races, and family structures. Therefore, it might not be possible to apply all research findings to all families and individuals. Using an ecological approach takes all of these differences into account (McGuire & Shanahan, 2010).

The Impact of the Sibling Relationship on Individuals

There are many ways in which individual and contextual factors impact sibling relationship quality. There is also evidence to suggest that the nature of the sibling relationship can have impacts on the siblings themselves (Buist & Vermande, 2014; Dirks, Persram, Recchia, & Howe, 2015; Gass, Jenkins, & Dunn, 2007; Kim, McHale, Crouter, & Osgood, 2007; Stocker, Burwell, & Briggs, 2002). Researchers have established sibling relationship classifications, which largely depend on the amount of warmth and conflict present (Buist & Vermande, 2014). Although some slight differences in the classifications exist, there are three common types of sibling relationships. Some sibling relationships are characterized by very high levels of warmth and very low levels of conflict and are often labeled as “harmonious.” Other sibling relationships are the exact opposite; they are characterized by very high levels of conflict and very low levels of warmth. These relationships are often referred to as “conflictual.” Lastly, some sibling relationships are high in both warmth and conflict, and are categorized as “affect-intense” (Buist & Vermande, 2014).

It should be noted that there are several factors which can impact the classification of the sibling relationship. For example, gender has been identified as a factor which correlates with the different relationship classifications. More specifically, sister pairs are most likely to be categorized as harmonious and least likely to be categorized as conflictual (Buist & Vermande,

2014). Additionally, Buist & Vermande (2014) found that relationships in which there is an older brother are more likely to be categorized as conflictual. However, gender did not solely determine classification in any category.

Impact of conflict. In general, research has supported the theory that siblings with conflictual relationships are more likely to experience poor psychosocial adjustment and that siblings with harmonious relationships are more likely to experience positive psychosocial adjustment (Buist & Vermande, 2014; Dirks et al., 2015; Kim et al., 2007; Stocker et al., 2002). Buist & Vermande (2014) also found that siblings in middle childhood who have a harmonious sibling relationship are more likely to report higher levels of perceived self-competence and self-esteem. Furthermore, individuals who have an affect-intense sibling relationship are also at risk for poor psychosocial outcomes (Buist & Vermande, 2014). These findings suggest that high levels of sibling conflict are strongly associated with a variety of undesirable psychosocial outcomes.

Although all sibling relationships are defined by some level of conflict, the impact of conflict on individuals becomes pathological when it is aggressive, destructive, and revolves around a variety of issues (Dirks et al., 2015). Sibling relationships with high levels of destructive conflicts pose the greatest risk for the development of individual internalizing and externalizing behavior problems across age groups (Dirks et al., 2015). Destructive conflicts are characterized by high levels of negative emotions and often become aggressive and differ from normal sibling conflicts. Physical aggression among siblings is not uncommon, but when it becomes a repetitive part of conflicts, it can result in poor psychological outcomes for the victim (Dirks et al., 2015). It can be hypothesized that the development of psychological symptoms and

disorders further worsens the sibling relationship, thus contributing to a cycle of continued destructive conflict and poor psychological adjustment.

Sibling conflict not only impacts the current psychological adjustment of individuals, but has been shown to have a predictive influence on later psychological adjustment (Kim et al., 2007; Stocker et al., 2002). Individuals who reported high levels of sibling conflict in middle childhood are significantly more likely to develop internalizing and externalizing psychological problems in adolescence (Kim et al., 2007; Stocker et al., 2002). More specifically, siblings with high levels of conflict in middle childhood are at risk for both depression and anxiety in adolescence (Kim et al., 2007; Stocker et al., 2002). Additionally, their parents are more likely to report that they engage in delinquent behaviors as adolescents (Stocker et al., 2002).

Impact of warmth. Just as high levels of sibling conflict have been shown to impact individual outcomes, researchers have documented the impact of high levels of warmth on individual outcomes (Gass et al., 2007; Kim et al., 2007). Individuals who reported that they often depend on their sibling for emotional support in middle childhood had more positive individual outcomes in early adolescence (Kim et al., 2007). More specifically, siblings who had a more intimate and warm sibling relationship had higher levels of social competence, which is a measure of adjustment and social cognitive thinking (Kim et al., 2007). Additionally, positive sibling relationships serves as a protection for girls against the development of depressive symptoms in adolescence (Kim et al., 2007). However, high levels of sibling intimacy and warmth is not believed to protect boys against depressive symptoms (Kim et al., 2007). In general, the positive impacts of warmth and intimacy are not as strong as the negative impacts of conflict (Kim et al., 2007).

It has been theorized that sibling warmth can protect individuals who are experiencing a stressful life event (Gass et al., 2007). Stressful life events include, but are not limited to, changes in family structure, accidents, relocation, and death. Children who experienced a stressful life event were indeed protected by a sibling relationship characterized by affection and warmth. In the years following a stressful life event, children with warm sibling relationships were less likely to experience internalizing problems (Gass et al., 2007). This interaction was maintained even when children did not have affectionate relationships with their parents, suggesting that warm sibling relationships alone can offer security and protection against stressful life events (Gass et al., 2007).

Mechanisms for individual impacts. Individuals impact the quality of their sibling relationships and vice versa. Additionally, there are a variety of contextual factors which are also related to both the quality of the relationship and the individuals themselves. There are likely several complex processes intertwined in all of these factors, but researchers have attempted to identify and explain some mechanisms and processes, such as behavioral modeling, emotion, social cognition, and family relationships (Dirks et al., 2015).

Younger siblings often rely on their older siblings as models and teachers. As such, it is expected that younger siblings would model both functional and dysfunctional behaviors displayed by older siblings. It is possible that behavioral modeling impacts the interplay between sibling relationships and individual psychological outcomes in that younger siblings respond to hostile or aggressive behavior from their older sibling with equally hostile and aggressive behavior (Dirks et al., 2015). The siblings then adopt a pattern of aggressive behavior which characterizes their sibling relationship as well as other important relationships in their lives (Dirks et al., 2015).

As young children develop social cognitive and emotion regulation skills, they depend on their family to scaffold interactions and provide assistance when necessary. As such, if there are high levels of emotional instability or inappropriate social cognition is modeled by family, individuals will be at risk for not mastering these skills (Dirks et al., 2015). Relatedly, the development of social cognition and emotion regulation skills positively impact future relationship quality and individual outcomes (Dirks et al., 2015). More research is needed to fully understand the interconnectivity of all of these variables.

Sibling Relationships with a Disability

One salient factor which has been hypothesized to impact the sibling relationship is the presence of a disability. It can be assumed that these relationships are impacted by factors specific to the presence of the disability, in addition to all of the same factors which impact the relationships of typical sibling pairs. Furthermore, the presence of the disability can make other factors, such as birth order, spacing-effects, and differential parental treatment more salient to the quality of the relationship (Breslau, 1982; Levy-Wasser & Katz, 2004; Coldwell et al., 2008). Due to the distinctive qualities of these relationships, research has also focused on investigating potential psychological and behavioral outcomes that are associated with having a sibling with a disability (Bischoff & Tingstrom, 1991; Dew, Balandin, & Llewellyn, 2008; Gallo, Breitmayer, Knafl, & Zoeller, 1992; Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Schuntermann, 2007; Schuntermann, 2009; Sharpe & Rossiter, 2002; Stoneman, 2005).

Parent Outcomes

When a child has a disability, it can impact the family in several ways. One of the most meaningful is the documented increase in parental stress associated with childhood disabilities (Hastings, 2002; Hayes & Watson, 2013; Woodman, Mawdsley, Hauser-Cram, 2015). Parental

stress becomes dysfunctional when it impacts the parent-child relationship (e.g., limits the parents ability to emotionally connect with the child) and when it impacts the parents themselves (e.g., development of depressive symptoms). Parents of children with developmental disabilities are significantly more likely than their peers to develop dysfunctional parental stress and its associated impacts (Hastings, 2002; Woodman et al., 2015). More specifically, parents of children with developmental disabilities are more likely to report symptoms of depression and anxiety as well as low levels of self-competence (Hastings, 2002; Woodman et al., 2015).

Researchers have proposed transactional models to explain the connection between the existence of stress in parents of children with developmental disabilities (Hastings, 2002; Woodman et al., 2015). These models largely focus on the presence of behavior problems common in individuals with developmental disabilities. There is a reciprocal connection between child behavior problems, parental response, and the existence of parental stress (Hastings, 2002; Woodman et al., 2015). All three of these factors continue to exacerbate each other and ultimately have negative impacts on the family system (Hastings, 2002; Woodman et al., 2015).

Psychological/Behavioral Outcomes for Typically-Developing Siblings

Due to the documented impact that having a child with a disability has on parents, it has been assumed by many practitioners and researchers that individuals who are raised with a sibling who has a disability will be more likely than the general population to experience psychological or behavioral difficulties (Stoneman, 2005). More specifically, it was speculated that these siblings would experience more loneliness, depression, anxiety, and stress as a result of their sibling having a disability. Additionally, siblings of individuals with disabilities were predicted to have lower levels of self-esteem and self-concept and exhibit more problematic

externalizing behaviors, as compared to their same-age peers with typically-developing siblings (Stoneman, 2005; Dew et al., 2008).

Despite the theory, there is little research to support that simply having a sibling with a disability results in negative psychological or behavioral outcomes. Most of the literature has found that, in general, siblings of individuals with disabilities are just as well-adjusted as their peers (Bischoff & Tingstrom, 1991; Gallo et al., 1992; Pilowsky et al., 2004). There is also evidence which suggests that having a sibling with a disability might result in more positive adjustment and outcomes (Cox, Marshall, Mandelco, & Olsen, 2003).

Although the research in general suggests that these individuals are well-adjusted, there have been a few negative themes noted across different studies. Typically-developing siblings have reported feeling more socially-isolated than their peers (Dew et al., 2008). Also, many typically-developing siblings have reported that they feel their parent(s) provide higher levels of attention to their sibling with the disability, which has been shown to negatively impact adjustment and relationships for typically-developing sibling pairs across different age groups (Coldwell et al., 2008; Jensen et al., 2013). However, differential parental attention has not been consistently shown to be related to psychological or behavioral outcomes for siblings of individuals with disabilities (Pilowsky et al., 2004).

Conflicting Findings

The existing research provides conflicting conclusions regarding the psychological and behavioral outcomes of typically-developing individuals who have a sibling with a disability, as well as the quality of the sibling relationships (Dew et al., 2008). The differences in findings might be due, in part, to differences in the research designs themselves, or differences in the participation inclusion criteria (Dew et al., 2008). For example, many studies rely on parents as

the sole reporter of sibling relationships and experiences (Begum & Blacher, 2011; Benson & Karlof, 2007; Macks & Reeve, 2007; Meyer, Ingersoll, & Hambrick, 2011; Taunt & Hastings, 2002). Although the results from parent report measures do give some information about the nature of the sibling relationship, many practitioners and researchers agree that individuals are the best reporters of their own subjective experience (Patton, 2002).

Additionally, the conflicting results might be due to the broad definition of “disability” used as inclusion criteria for the studies. This factor can further be defined in terms of the classification or label of the disability as well as the nature or severity of the symptoms of the disability. The severity of the disability is important in terms of the parental and family resources necessary to care for the child with the disability. The severity of the disability is also related to the amount of stress experienced by the family, which has been shown to impact the adjustment of typically-developing siblings in undesirable ways (Giallo & Gavidia-Payne, 2006; Kilmer, Cook, & Munsell, 2010; Williams et al., 2002).

The findings suggest that having a sibling with a disability can mean many different things and that using a global definition of “disability” when conducting research might not be the most appropriate course of action. Instead, researchers should use diagnostic classifications or measures which assess severity of disability symptoms (e.g., time spent caring for the child) as inclusion criteria for studies. This is especially important when considering the sibling relationship when one sibling has an autism spectrum disorder (ASD). It can be assumed that the sibling relationship is impacted or changed by the social and communicative deficits and behavioral difficulties characteristic of ASD.

Sibling Relationships with ASD

With the documented increase in the amount of autism diagnoses, researchers and practitioners in several fields have focused on potential causes, impacts, treatments, and risk factors. Siblings of individuals with autism have participated in interventions as both targets and administrators (Tsao et al., 2011). Based on results from previous studies involving siblings of individuals with disabilities, researchers had cause to believe that siblings of individuals with ASD might experience different sibling relationships and personal adjustment when compared to peers with typically developing siblings. Given the established methodological concerns mentioned previously, researchers have begun to adjust inclusion criteria to focus on just ASD. The body of research has grown to include both quantitative and qualitative studies examining the sibling relationship with ASD as well as the individual adjustment and psychological outcomes for typically developing siblings of individuals with ASD.

Impact of ASD on Adjustment of Typically Developing Siblings

Many early research studies involving siblings of individuals with ASD also recruited participants who had a sibling with Down syndrome (Fisman et al., 1996; Foden, 2007; Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001; Knott, Lewis, & Williams, 1995; Mascha & Boucher, 2006; Orsmond & Seltzer, 2007; Roeyers & Mycke, 1995). The two groups were often compared in an attempt to see how their experiences, outcomes, and relationships were similar and how they might be different. It was thought that siblings of individuals with ASD and siblings of individuals with DS would both have sibling relationships and outcomes which differed from the general population. Research on outcomes suggests that typically developing siblings of individuals with ASD might be at a higher risk for poor psychological adjustment,

when compared to typically developing siblings of individuals with DS and other disabilities (Beyer, 2009).

In a 3-year longitudinal study, Fisman et al. (1996) compared siblings of children with pervasive developmental disorder, siblings of children with Down syndrome, and a control group of siblings of typically-developing children. The goal of the study was to identify potential risk and protective factors which might impact psychological adjustment and outcomes for these siblings (Fisman et al., 1996). Both experimental groups (i.e., siblings of individuals with pervasive developmental disorder and siblings of individuals with Down syndrome) differed from the control group in terms of overall adjustment. However, the researchers also commented that siblings of individuals with pervasive developmental disorder had significantly more adjustment difficulties than the siblings of individuals with Down syndrome (Fisman et al., 1996). These findings are supported by a recent review of the literature regarding siblings of individuals with ASD (Beyer, 2009).

Despite the evidence supporting negative outcomes, a review of the literature suggests that siblings of individuals with ASD might benefit from their experience (Mandleco & Webb, 2015). When compared to siblings of typically developing individuals, siblings of individuals with ASD scored higher on measures of self-concept, suggesting that their experience contributed to their thoughts about themselves and their capabilities (Mandleco & Webb, 2015). Additionally, siblings of individuals with ASD have higher levels of certain positive character traits including kindness, patience, acceptance, responsibility, and caring (Mandleco & Webb, 2015). Although the findings are mixed regarding outcomes, there is slightly more evidence to suggest negative adjustment and psychological outcomes for typically developing siblings of individuals with ASD (Beyer, 2009).

Factors impacting adjustment. Despite the increased specificity of research inclusion criteria, there have still been conflicting findings regarding the psychological outcomes for typically developing siblings of individuals with ASD (Meadan, Stoner, & Angell, 2010; Tomeny, Barry, & Bader, 2012; Walton & Ingersoll, 2015). There is some evidence to suggest that typically developing siblings are at-risk for maladjustment and the development of psychological symptoms and disorders, but there is also research which supports that they do not experience adjustment difficulties (Tomeny et al, 2012). In an attempt to understand the conflicting findings, researchers have proposed theoretical hypotheses for investigating the multidimensional processes which impact both the sibling relationship and individual adjustment when one sibling has ASD (McHale, Updegraff, & Feinberg, 2016). Additionally, models including risk and protective factors have been proposed to explain the differences in outcomes (Walton & Ingersoll, 2015). Factors impacting typical sibling relationships and sibling adjustment are also believed to apply to siblings of individuals with ASD.

Factors related to the sibling with ASD. Individuals with ASD present with a variety of symptoms and characteristics which can impact their family in different ways. For example, individuals with severe ASD symptoms are more likely to have typically developing siblings with adjustment difficulties (Meyer et al., 2011). There is evidence to suggest that this might not be a direct relationship and that other individual and contextual factors contribute to this correlation (Meyer et al., 2011).

Factors related to the typically developing sibling. Although methodological concerns have been considered in explaining the conflicting findings, it is also possible that individual differences exist which impact the results. More specifically, researchers have identified different characteristics of the typically developing sibling which could contribute to the impact

of ASD on their adjustment (Meyer et al., 2011; Petalas, Hastings, Nash, Hall, Joannidi, & Dowey, 2012; Walton & Ingersoll, 2015). Gender appears to have a unique impact on adjustment, but the relationship is not fully understood. There is evidence to suggest that typically developing older siblings of individuals with ASD are more likely to experience adjustment difficulties (Walton & Ingersoll, 2015). Additionally, male siblings are also more likely to experience adjustment difficulties, thus suggesting that older male siblings of individuals with ASD are at highest risk (Walton & Ingersoll, 2015). However, other researchers have found adolescent female siblings of individuals with ASD to report the highest level of depressive symptoms, so more information is needed to fully understand how gender is related (Bitsika, Sharpley, & Mailli, 2015).

Given the genetic component of autism, it has been hypothesized that varying degrees of the symptoms and characteristics might be present in other family members who do not qualify for a diagnosis of ASD. This sub-clinical presentation of symptomatology is referred to as the Broad Autism Phenotype (Meyer et al., 2011; Petalas et al., 2012; Walton & Ingersoll, 2015). Individuals impacted by the BAP might exhibit subtle behaviors or actions which suggest impairments in social thinking, language, and emotional understanding. Siblings who present with BAP behaviors appear to be more likely to experience poor adjustment and psychological difficulties than siblings of individuals with ASD who do not possess BAP markers. However, this relationship is thought to be impacted by other factors as well and is not to be understood as a causal link between the presence of BAP and sibling adjustment (Meyer et al., 2011; Orsmond & Seltzer, 2009; Petalas et al., 2012; Walton & Ingersoll, 2015).

The concept of resilience as a protective factor for typically developing siblings has also been explored (Bitsika et al., 2015). Resilience is understood as an individual's capacity to

endure stressful situations without experiencing expected negative outcomes (Bitsika et al., 2015). Resilience can protect against the development of psychological symptoms related to depression and anxiety and include coping skills and strategies used when facing a difficult situation. For children who have siblings with ASD, high resilience scores were associated with lower levels of anxiety (Bitsika et al., 2015). However, resilience was not found to be a protective factor for typically developing adolescent siblings of individuals with ASD (Bitsika et al., 2015).

Family factors. The presence of maternal depression is associated with poor adjustment and psychological outcomes for typically developing siblings of individuals with ASD (Meyer et al., 2011). More specifically, maternal depression is thought to mediate the relationship between ASD severity and typical sibling outcomes (Meyer et al., 2011). The impact of maternal depression on typical sibling adjustment is especially salient because of the prevalence of depressive symptoms in parents of children with ASD (Hayes & Watson, 2013). Families and parents of children with ASD experience high levels of stress which contribute to maternal depression and anxiety (Hayes & Watson, 2013). Even when compared to parents of children with other disabilities, parents of individuals with ASD report higher levels of stress, anxiety, and depression (Hayes & Watson, 2013). It is hypothesized that the behavioral symptoms of ASD contribute to the increases in psychological difficulties for parents, which has important implications for understanding how those behaviors impact the psychological functioning of siblings.

The way in which a family discusses ASD and the impact it has on individual members and the family as a unit has been shown to impact outcomes (Mandleco & Webb, 2015). A recent review of the literature suggests that typically developing siblings adjust better when

parents are open and honest regarding their sibling's ASD diagnosis (Mandleco & Webb, 2015). Typically developing siblings receive most of their information about ASD from their parents, so it is important that parents are providing accurate facts. This allows typically developing siblings to fully understand and accept the impact that ASD will have on their sibling, themselves, and their family (Mandleco & Webb, 2015). The type of information shared by parents with typically developing siblings has been shown to vary based on ethnicity and other factors (Mandleco & Webb, 2015). The frequency and depth of conversations regarding ASD between typically developing siblings and parents also vary based on other factors. There is evidence to suggest that the more frequent, honest, and supportive the conversations are, the better the outcomes will be for the typically developing siblings (Mandleco & Webb, 2015).

Diathesis-stress model. It is widely accepted that there are many complex individual and contextual factors which impact families of individuals with ASD. A diathesis-stress model has been proposed to understand the way in which these factors are related (Orsmond & Seltzer, 2009; Petalas et al., 2012; Walton & Ingersoll, 2015). It is believed that BAP, the genetic component of the model, predisposes some typically developing siblings to experiencing certain adjustment difficulties and psychological symptoms/disorders. The existence of other risk factors related to the typically developing sibling, the sibling with ASD, and the family converge and result in poor adjustment for typically developing siblings (Orsmond & Seltzer, 2009; Petalas et al., 2012; Walton & Ingersoll, 2015).

Impact of ASD on Sibling Relationships

Just as ASD is believed to impact typically developing siblings in unique ways, researchers were interested in investigating the ways in which sibling relationships might differ when one sibling has ASD. Individuals with ASD often have difficulty with communication,

emotion, social cognition, and play skills, all which are integral skills for relationship development. Additionally, the presence of challenging behaviors and aggression common in individuals with ASD has also been thought to impact the sibling bond (Beyer, 2009).

In addition to providing the aforementioned review of the literature regarding outcomes of typically developing siblings, Beyer (2009) provided a review of the literature addressing relationship quality indicators for individuals with ASD and their typically developing siblings (Fisman et al., 1996; Foden, 2007; Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001; Knott et al., 1995; Mascha & Boucher, 2006; Roeyers & Mycke, 1995). The results from these studies are conflicting at times. Some researchers found that siblings of individuals with ASD reported more positive sibling relationship indicators when compared to siblings of individuals with DS (Fisman et al., 1996; Foden, 2007; Knott et al., 1995). More specifically, some researchers found that siblings of individuals with ASD experienced less sibling conflict and felt proud when they were able to take responsibility for their sibling (Fisman et al., 1996; Foden, 2007; Knott et al., 1995). Other findings suggested poorer sibling relationships and included less warmth, a lack of intimacy in the relationship (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001).

Tomeny, Ellis, Rankin, & Barry (2017) utilized a quantitative approach to investigate both relationship quality and psychosocial outcomes for typically-developing adults who either had a sibling with ASD or a sibling with Intellectual Disability (ID). When compared to siblings of individuals with ID, adult siblings of individuals with ASD were less likely to report positive sibling relationships (Tomeny et al., 2017). Furthermore, typically-developing siblings who reported lower quality relationships were more likely to experience stress and anxiety. Additionally, low quality sibling relationships were shown to be related to the amount of aid or support the typically-developing sibling gives to his/her sibling with ASD. More specifically, the

researchers found that participants who reported more positive sibling relationships were more likely to provide aid and support to their sibling with ASD (Tomeny et al., 201). These results support the notion that typically-developing siblings of individuals with ASD have unique experiences and needs across the lifespan, which last well into adulthood.

Use of Grounded Theory

Researchers have recently made use of qualitative research and Grounded Theory in particular to investigate sibling relationships when one individual has ASD or another disability (Angell, Meadan, & Stoner, 2012; Moyson & Roeyers, 2011; Petalas, Hastings, Nash, Downey & Reilly, 2009; Ward, Tanner, Mandleco, Dyches, & Freeborn, 2016). Grounded Theory was selected because of the aforementioned inconsistencies in the literature regarding sibling relationships when one sibling has ASD. It was presumed that the inconsistencies were also a result of researcher bias impacting the development of hypotheses and study designs which might not reflect the subjective reality of participants (Petalas et al., 2009). Grounded Theory gives the participants the opportunity to guide the research and development of conclusions without making any assumptions about the nature of their experience or their relationship with their siblings (Kao, Romero-Bosch, Plante, & Lobato, 2011).

Grounded Theory differs from other qualitative approaches in a variety of ways. Most notably, Grounded Theory investigations do not begin with a hypothesis (Glasser & Strauss, 1967). Instead, researchers rely on the data to form all conclusions and are not biased by preconceived notions regarding what the data might show (Glasser & Strauss, 1967). This is especially relevant to sibling studies because it is possible that assumptions regarding the sibling experience has contributed to the inconsistencies found in the research (Kao et al., 2011). Grounded Theory research can be more exploratory since it is not restricted by a specific

hypothesis or research question (Glasser & Strauss, 1967). Other qualitative approaches might be more useful following Grounded Theory studies.

Petalas et al. (2009) interviewed eight siblings of individuals with ASD who were between the ages of nine and twelve. The interviews were designed to gather more information regarding the participants' experiences and sibling relationships. Five main themes emerged from the interview data including the impact of having a sibling with ASD, reactions of others, acceptance/wanting change, positive aspects, and support (Petalas et al., 2009). All participants were recruited through a specialized school for children with ASD, so it is important to note that their experiences might not be representative of all children who have siblings with ASD.

Several participants discussed the negative impact that their sibling with ASD has on their family as well as themselves. Incidents of challenging behavior were often discussed as evidence for how their sibling's ASD impacts their family life and relationship (Petalas et al., 2009). Participants also discussed the additional responsibilities they were given for their sibling with ASD (Petalas et al., 2009). In addition to discussing the negative impact of having a sibling with ASD, participants shared how public reactions impact their experience as a sibling of an individual with ASD. The theme of reactions from others was explained in the context of a lack of public understanding of ASD as well as feelings of embarrassment and shame when their sibling with ASD exhibits challenging behaviors (Petalas et al., 2009). These results confirm existing research regarding the sibling experience.

Although most participants discussed the negative impact of ASD, every participant shared positive attributes about their sibling with ASD (Petalas et al., 2009). Some participants characterized their sibling relationship as fun while describing shared activities (Petalas et al., 2009). Additionally, many participants recalled feeling excited for their sibling's

accomplishments and proud of what they have accomplished (Petalas et al., 2009). Furthermore, some participants felt that their experience as a sibling to an individual with ASD has made them a better person (Petalas et al., 2009). These results suggest that the experience of having a sibling with ASD can be very rewarding.

In addition to sharing positive aspects, siblings in middle childhood expressed an acceptance of their sibling as well as their sibling's ASD (Petalas et al., 2009). Many siblings displayed an understanding that their sibling would have ASD for their duration of his/her life and had come to accept this fact (Petalas et al., 2009). However, many also shared that there were certain things they longed to change about their sibling and his diagnosis which caused feelings of frustration (Petalas et al., 2009). More specifically, siblings often wished that their sibling with ASD would display less challenging behavior (Petalas et al., 2009). Similarly, participants discussed a desire to improve their sibling's ability to interact socially (Petalas et al., 2009). Overall, participants appeared to accept their sibling with ASD, while still maintaining a desire to change some of the more difficult aspects of their sibling's diagnosis.

Many siblings of individuals with ASD discussed supports that assist them in navigating their sibling relationship. Some participants relied on family members, while others received more formal supports (Petalas et al., 2009). Participants benefited from informal supports such as honest communication with parents regarding their sibling's ASD. Similarly, some participants in middle childhood felt supported if they had another typically developing sibling to talk to about their sibling's ASD (Petalas et al., 2009). Other participants benefited from more formal supports like respite programs (Petalas et al., 2009). These supports appeared to be very important to siblings of individuals with ASD.

All sibling relationships are characterized by both positive and negative attributes, but these results suggest that sibling relationships are somewhat different when one sibling has ASD. For example, the existence of challenging behaviors and the added responsibilities mentioned by participants would not necessarily exist in typical sibling relationships. Participants also discussed the negative impact they felt that ASD had on their life, their sibling's life, and on the functioning of their family (Petalas et al., 2009). Furthermore, many participants described ASD symptoms when discussing what they wished they could change about their sibling with ASD (Petalas et al., 2009). These results support existing conclusions regarding the sibling relationship when one sibling has ASD.

Angell et al. (2012) used Grounded Theory to investigate the experiences of typically-developing siblings of individuals with ASD in middle childhood. The researchers were also interested in obtaining more information about the need for sibling supports (Angell et al., 2012). Although Grounded Theory was used, Angell et al., (2012) presented the findings in the context of family systems theory instead of stating the categories discovered from the data alone. The two main pillars of this theory are cohesion and adaptability (Angell et al., 2012). Cohesion is similar to the concept of warmth used by other researchers in that it refers to the emotional connection between the siblings (Angell et al., 2012). Warmth and cohesion are thought to be especially relevant to sibling relationships involving an individual with ASD because of the social and communication impairments characteristic of the diagnosis. Adaptability is relevant to this population as well, because of the documented impact the presence of a disability can have on the amount and intensity of stressful events.

Typically developing siblings reported both positive and negative themes related to cohesion (Angell et al., 2012). Positive themes included reduced sibling conflict, existence of

sibling friendships, pride in sibling with ASD, and love for sibling (Angell et al., 2012).

Typically developing siblings also discussed the responsibilities they have for their sibling with ASD which has been found in other studies (Angell et al., 2012; Petalas et al., 2009). Negative themes included fears for sibling with ASD, frustration, and feelings of embarrassment at times (Angell et al., 2012). Other researchers have documented that typically developing siblings of individuals with ASD often report feeling embarrassed when their sibling engages in inappropriate behavior (Angell et al., 2012; Petalas et al., 2009).

Typically developing siblings discussed adaptability in terms of coping strategies they employ for themselves when they experience frustration. This frustration felt towards the sibling with ASD is often the result of challenging behavior. Additionally, typically developing siblings report that they frequently manage the behavior and emotions of their sibling with ASD (Angell et al., 2012). Adaptability is necessary to preserve the quality of the sibling relationship as well as the psychological adjustment and well-being of the typically developing sibling (Angell et al., 2012). Participant responses suggest that typically developing siblings benefit from learning coping strategies, having time to use the strategies when upset, and having a confidante with whom they can share their feelings of frustration (Angell et al., 2012).

Researchers have found contradictory sibling reports when investigating the relationships of individuals with ASD and their typically developing siblings (Angell et al., 2012; Petalas et al., 2009). Recently, Ward, Tanner, Mandleco, Dyches, & Freeborn (2016) utilized a grounded theory approach to gather more information regarding these relationships. Twenty-two typically-developing siblings between the ages of seven and eighteen participated and shared their experiences (Ward et al., 2016). The researchers identified “contradiction” as the overall theme to describe the sibling relationships and noted that participants assigned both positive and

negative attributes to describe their relationship with their sibling with ASD (Ward et al., 2016). These results confirm the existing conclusions regarding contradictory sibling reports (Angell et al., 2012; Petalas et al., 2009; Ward et al., 2016).

Typically-developing siblings commonly reported many positive aspects of their sibling relationship. Many participants shared that their sibling with ASD had personality characteristics which contributed in a positive way to the relationship (Ward et al., 2016). Other researchers have documented that typically-developing siblings commonly note positive characteristics of their sibling with ASD (Angell et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2012; Sage & Jegatheesan, 2010). Additionally, participants discussed how being a sibling to an individual with ASD had a positive impact on their lives. More specifically, participants shared that they had a lot of patience, were understanding of differences, and loved unconditionally (Ward et al., 2016). Negative aspects of the sibling experience confirmed existing research and included the presence of challenging behaviors, additional responsibilities, and difficulties communicating with their sibling with ASD (Ward et al., 2016).

In general, much of the qualitative research has yielded similar findings regarding the experiences and sibling relationships of this population. Across studies, participants share both positive and negative aspects of their sibling relationship which has been characterized as contradictory (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016). Many participants have shared positive aspects regarding their sibling with ASD. More specifically, participants have reported that their sibling with ASD is fun and that they have pride and love for their sibling with ASD (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016). Regarding the sibling relationship, participants often experience reduced sibling conflicts and enjoy participating in shared activities with their sibling with ASD

(Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016).

Participants have also shared that their experience as a sibling to an individual with ASD has been beneficial to them. These participants attribute increased patience and a tendency to be understanding of differences to their experience as a sibling to an individual with ASD (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016).

Although participants are quick to share positive aspects of their experience, several common negative themes have been identified in the Grounded Theory literature. Some negative aspects are related to ASD symptoms and include the existence of challenging behavior and difficulties communicating (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016). Additionally, many typically developing siblings have shared that they feel they have additional responsibilities for the sibling with ASD. Some of these responsibilities are related to fears for their sibling with ASD and a desire to protect their sibling (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016). Other negative themes are related to emotions felt by typically developing siblings of individuals with ASD. The most commonly reported negative emotions are embarrassment, frustration, and anger (Angell et al., 2012; Moyson & Roeyers, 2011; Petalas et al., 2009; Ward et al., 2016). The existing Grounded Theory results propose an overall theme of “contradiction” with typically developing siblings reporting both positive and negative aspects of their relationship with their sibling with ASD.

CHAPTER III

Method of Investigation

Study Rationale

The purpose of this dissertation was to obtain information about the relationships between individuals with autism spectrum disorders (ASD) and their typically developing siblings by asking open-ended questions to typically developing siblings. Grounded Theory was used for this study, which means that the Principal Investigator refrained from developing hypotheses regarding the perspectives and responses of the participants (Patton, 2002). As such, the desired objective of the current study was to derive meaning from the subjective experiences of the participants. Common themes from the interviews can assist professionals in understanding the unique perspectives and needs of this population and inform the development of services for families of individuals with autism spectrum disorders.

Researchers have recently made use of qualitative research and Grounded Theory in particular to investigate sibling relationships when one individual has ASD or another disability (Angell et al., 2012; Moyson & Roeyers, 2012; Petalas et al., 2009). Grounded Theory was selected because of the documented inconsistencies in the literature regarding sibling relationships when one sibling has ASD. It was presumed that the inconsistencies were also a result of researcher bias impacting the development of hypotheses and study designs which might not reflect the subjective reality of participants (Petalas et al., 2009). Grounded Theory gives the participants the opportunity to guide the research and development of conclusions without making any assumptions about the nature of their experience or their relationship with their siblings (Kao et al., 2011).

The exclusivity of the factors to ASD (e.g., challenging behaviors, communication difficulties, etc.) have led to the assumption that the experiences and relationships of typically developing siblings of individuals with ASD is different in some way. The existing literature suggests an overall theme of contradiction (Angell et al., 2012; Moyson & Roeyers, 2012; Petalas et al., 2009). As such, there is still not a clear and consistent description of sibling relationships of individuals with ASD and their typically developing siblings. Collecting more first-person accounts using Grounded Theory will assist researchers and practitioners in truly understanding the experiences and relationships of individuals who have siblings with ASD.

The current study design provides a unique contribution to the existing literature using Grounded Theory to explore the relationships between individuals with ASD and their typically developing siblings. The current study focused broadly on understanding the sibling relationship, whereas other studies have used Grounded Theory to understand specific aspects of the relationship (Angell et al., 2012). For example, Angell et al. (2012) gathered information regarding self-reported support needs of typically developing siblings. Furthermore, other studies using Grounded Theory were conducted outside of the United States (Moyson & Roeyers, 2012; Petalas et al., 2009) and it is unclear how the findings might reflect the relationships of American sibling dyads.

The current dissertation seeks to expand understanding and address some of the methodological issues with previous studies. For example, some of the Grounded Theory studies investigating the relationships between individuals with ASD and their typically developing siblings has taken place in other countries. It is possible that the results gathered in those studies might not apply to individuals in the United States, given the potential differences in cultural understanding and acceptance of disabilities as well as available programs. Additionally, some of

the existing studies had very large participant age ranges. It is possible that these results were impacted by the researchers combining different populations, given the documented changes in cognition and emotion that exists between children and adolescents. Other researchers used Grounded Theory to focus on specific domains, such as perceived support needs. Although this research is helpful for practitioners, it might not be as unbiased as other studies which attempt to gather information about the entire sibling experience. The current dissertation is exploratory in nature and attempts to gather information regarding the sibling relationships of individuals with ASD and their typically developing siblings.

Study Methods

Research Design

Due to the exploratory nature of the current study, Grounded Theory was used to investigate the relationships between individuals with ASD and their typically developing siblings.

Sample

The inclusion criteria for participation in this study were that all participants must be typically developing (without an autism spectrum disorder diagnosis) children between the ages of 10 and 17. All participants have a siblings with a diagnosis of an autism spectrum disorder. Children from families for whom the principal investigator is currently providing behavioral consultation were excluded from participation.

Participant demographics. The ten participants came from seven families. Half of the participants ($n=5$) were male and half ($n=5$) were female. Participants ranged in age from 11 to 16-years-old. All participants ($n=10$) were Caucasian/White. A majority of the participants ($n=9$) were older than his/her sibling with ASD and one participant ($n=1$) was a twin to his/her sibling with ASD. *See Table 1.*

Sibling demographics. Information was also obtained from participants' parents/guardians regarding the sibling with ASD. Each parent/guardian was asked to complete a demographic questionnaire. If more than one typically developing sibling participated in the study, demographic information for the sibling with ASD was only collected once. As such, the following sibling demographic information is for the seven siblings with ASD.

The siblings with ASD ranged in age from 8 to 15-years-old. A majority ($n=6$) of the siblings with ASD were male and one was female. More than half ($n=4$) of the siblings were given an initial diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified. The remaining siblings ($n=3$) were given an initial diagnosis of Autistic Disorder (Autism). More than half of siblings with ASD ($n=4$) engaged in challenging or aggressive behaviors. The remaining siblings ($n=3$) did not engage in these behaviors. All siblings with ASD ($n=7$) lived in the same home as his/her participant sibling(s). *See Table 2.*

Recruitment. A convenience sample was employed, in which the first ten individuals to volunteer who met the criteria for participation were interviewed and given the opportunity to participate in the study.

Subjects were recruited through two affiliated northeast university institutions that service children and families and facilitate social skills groups for individuals with autism. Recruitment flyers were displayed at both sites and given to parents of children participating in the social skills groups. Additionally, subjects were recruited through a local special education parent group based out of New Jersey. Members of the group are parents of children with autism and other disabilities. Lastly, in an effort to recruit enough participants, a private agency was secured as a third recruitment site. This agency provides social skills and enrichment activities to individuals with autism.

Measures

The following measures were designed for use in the current study to gather in-depth meaning regarding the relationships of participants with his/her sibling who has ASD.

Interview Protocol. An interview protocol was used with all participants. The protocol was written by the Principal Investigator and consists of 14 open-ended questions. Consistent with Grounded Theory, the questions were designed without any prior assumptions regarding the responses of the participants (Patton, 2002). Also consistent with Grounded Theory, the participant responses guided the interview, and participants were given the opportunity to share any additional information with the Principal Investigator (Patton, 2002). The design of the interview protocol was also influenced by the interview protocols used in similar studies (Angell et al., 2012; Moyson & Roeyers, 2012; Petalas et al., 2009), but the specific protocol is unique to the present study. The questions were designed to be balanced and allow the participants to guide the interview without impacting how they should respond. *See Appendix A.*

Demographic Questionnaire. A short demographic questionnaire completed by the parent/guardian of each participant was created by the Principal Investigator. The questionnaire was designed to gather information regarding the demographic characteristics of the participant, his/her sibling with ASD, and his/her family in general. *See Appendix B.*

Procedures

Overview of Procedures. Participation in the current study included parental completion of a demographic questionnaire and one interview with the child. The interviews were audio recorded and transcribed for analysis. All interviews were conducted at the participant's home or another location of convenience. All participants received a \$10 Amazon Gift Card for his/her involvement in the research.

Each interview was expected to last approximately one hour, but many interviews were much shorter. Interviews ranged from approximately fifteen minutes to approximately forty minutes. As such, the duration of subject participation in the project was approximately one hour or less. Interview length depended on participant characteristics, such as depth and breadth of responses. Participants were encouraged to discuss their experiences in their own words. At the end of the interview, the Principal Investigator asked the participant if he/she had anything else to share regarding his/her experience and relationship with his/her sibling with an ASD. This approach is consistent with Grounded Theory in that the Principal Investigator does not hold assumptions regarding potential hypotheses and allows the participants to guide the research.

Consent Procedures. Due to the age of the participants, both parental consent and child assent were needed for participation in the current study. Prior to conducting the interviews or speaking with the potential participants, the Principal Investigator first obtained parental consent for participation in the study (*See Appendix C*). The study procedures and purpose were explained to the subject's parent/guardian by the Principal Investigator, the consent form was read, and the parent/guardian's questions answered. The parent/guardian was asked to initial all pages, then sign the consent form. Next, the Principal Investigator introduced and explained the audio recording consent form and answered any questions. The parent/guardian then was asked to sign the audio recording addition to the consent form. A dated and signed copy of both forms were given to the subject and another dated and signed copy was retained by the Principal Investigator.

After obtaining parental consent, the Principal Investigator then obtained assent from the child. The study was explained to the child using developmentally appropriate language and terms. The Principal Investigator emphasized that participation is voluntary and even though

parental consent was given, the child had the right to refuse to participate. Any potential questions were answered by the Principal Investigator. If the child agreed to participate, they were asked to sign and date the assent form (*see Appendix D*). If the Principal Investigator determined that the child was participating in the study knowingly and willingly, she also signed and dated the assent form. One signed and dated copy of the assent form was given to the child and parent/guardian and another signed and dated copy was retained by the Principal Investigator.

Confidentiality and Record Retention. The data obtained from the interviews were treated as confidential. Some of the information collected about the participants included demographic information, and interview responses. The principal investigator will keep this information confidential by limiting individuals' access to the research data and keeping it in a secure location. Consent forms, assent forms, demographic forms, and other relevant paper documents will be stored in a separate locked cabinet to ensure confidentiality.

Permitting parental consent and child assent, all interviews were audio recorded and transcribed. The recordings and transcriptions were used for analysis by the Principal Investigator. More specifically, the Principal Investigator identified common themes across all interviews. Furthermore, specific quotes from transcripts were used to exemplify the themes and use the participants' own words when describing their experiences, but the quotes are not associated with the child's name.

Due to the conversational nature of the interview, the audio recording might include the names of the participants or their family members. However, pseudonyms were used when the interviews were transcribed to ensure confidentiality. If the participant said anything that she/he or his/her parent/guardian believed at a later point may be hurtful and/or damage his/her

reputation, then he/she or his/her parent/guardian could ask that certain text be removed from the transcript.

Audio files and transcribed interview documents have been saved on a password protected memory key and stored in a second locked cabinet, apart from the demographic forms, consent forms, and assent forms. The transcribed interview documents and audio files are labeled with the child's pseudonym. A master list with corresponding names and pseudonyms is stored in a third locked cabinet.

All study data will be kept for at least three years following completion of the research. Three years after completion of the research, all of the above mentioned data will be destroyed. Digital documents and audio files will be permanently deleted and all paper documents will be shredded. At no time will the data be available for public viewing or listening.

Data Analysis

Overview. In general, the Principal Investigator used a Grounded Theory Method to approach the transcribed interviews. The Principal Investigator loosely followed the phases of analysis proposed by Glaser & Strauss (1967), with some changes. This began by performing three readings of the transcripts and then coding the data to identify common themes. Then, the Principal Investigator engaged in the open coding phase which involved memo-writing and generating a list of in-vivo codes, which will be explained below. Next, the Principal Investigator initiated the focused coding phase with consideration given to internal and external validity of results.

The changes made to the Grounded Theory Method used in the current dissertation were based on practical constraints. For example, Grounded Theory studies typically employ more than one person to code the data. However, the Principal Investigator was the sole coder of the current dissertation, due to the feasibility of obtaining a second person. The use of one coder also resulted in

the lack of core category development, which is understood as the final step in Grounded Theory Methodology (Glaser & Strauss, 1967). Additionally, Grounded Theorists usually alter the interview protocol after each participant to allow the protocol to be dynamic and guided by participants (Glaser & Strauss, 1967). However, the interview protocol in the current dissertation remained the same in accordance with the Institutional Review Board approval. Lastly, it is standard in Grounded Theory Method to continue to interview participants to obtain more information and meaning (Glaser & Strauss, 1967). In the interest of practicality, participants were only interviewed once for the current dissertation.

Open coding. First, the Principal Investigator engaged in the initial open coding phase. Once all of the interviews were transcribed, the Principal Investigator began by doing several complete readings of the transcripts. Since the Principal Investigator also conducted and transcribed the interviews, she was already familiar with the content. During this time, the Principal Investigator was still refraining from making any specific assumptions about the data (Glaser & Strauss, 1967). The Principal Investigator relied on memo-writing and the use of in vivo codes to perform the initial open coding phase of analysis.

Memo-writing. After conducting several readings of the complete transcript, the Principal Investigator initiated the memo-writing process. Memo-writing is typically used in Grounded Theory and is essential to the development of emerging themes. During this process, the investigator writes notes regarding his/her thoughts on the data, meaning, and possible theoretical relationships (Glaser, 1978). Memos are meant to be quick and capture the investigators current thoughts on the data. As such, the process is dynamic and should evolve based on the data (Glaser, 1978).

For the purpose of this dissertation, the Principal Investigator employed a detailed color-coded system for organizing memos. More specifically, the Principal Investigator assigned pen and

highlighter colors for each reading of the complete transcript. Memos were written in pen and the Principal Investigator highlighted quotes that she felt were particularly salient and/or meaningful at the time. This system allowed the Principal Investigator to see the evolution of her thoughts about the data and the possible relationships between codes, while being grounded in the transcripts and the words of the participants.

In vivo codes. During open coding, the Principal Investigator frequently used in vivo codes, in which the participants' own words were used to identify and name codes (Charmaz, 2006; Saldana, 2008). This type of coding is especially relevant to Grounded Theory and the open coding phase, because it allows the Principal Investigator to maintain the participant's' perspective and meaning of their own experiences as siblings of individuals with ASD without the initial interpretation of the analyst (Charmaz, 2006; Saldana, 2008). All in vivo codes were given the same consideration and analysis as other codes in the second phase of data analysis (Charmaz, 2006; Saldana, 2008).

Focused coding. After establishing a list of initial open codes, the Principal Investigator moved on to a higher level of analysis in which categories and themes emerged (Glaser & Strauss, 1967). During this phase, the Principal Investigator developed a deeper understanding of the meaning of the data (Glaser & Strauss, 1967). For the purpose of this dissertation, focused coding was selected because it is appropriate for Grounded Theory and emphasizes the participants' experiences in that categories are developed strictly based on the data (Saldana, 2008). The Principal Investigator made a master list of codes derived from the memo writing process and began to sort them into more meaningful categories and subcategories. Then, these categories and subcategories were compared with the data to ensure that they were accurately representing the experiences of the participants, in accordance with Grounded Theory (Charmaz, 2006; Glaser, 1978; Saldana, 2008).

The Principal Investigator defined each of the categories and subcategories which emerged during focused coding. Then, the Principal Investigator conducted several additional readings of the complete transcript, adjusting the categories and subcategories based on the data, and not with an intent to maintain previously established initial codes (Saldana, 2008). Memo-writing continued throughout the focused coding phase. Additionally, some of the in vivo codes were maintained and later became category or subcategory names. This process was stopped once no new meaning or categories emerged from the transcripts, which is known as theoretical saturation (Strauss & Corbin, 1998). Then, the Principal Investigator identified example quotations for each category and subcategory to maintain the emphasis on the participants' words and experiences.

Internal validity. Throughout the data analysis, consideration was given to internal and external validity. Considerations regarding internal and external validity in qualitative research are different from those used in quantitative research (Mertens, 2010; Patton, 2002). The Principal Investigator established "credibility" (internal validity) by using negative case analysis and triangulation (Mertens, 2010). Generally gathering convergent evidence from multiple sources using various methods, also known as triangulation, has been shown to improve the validity of empirical conclusions (Mertens, 2010). For the purposes of this dissertation, the Principal Investigator looked for consistencies across interviews to establish credibility. More specifically, the Principal Investigator created a table to track which categories and subcategories were discussed by each participant. Additionally, for each category and subcategory, the Principal Investigator reported the percentage of interviews in which that category or sub-category appeared to ensure that the category development was grounded in the interview transcripts and not the preconceived ideas of the Principal Investigator,

The Principal Investigator also compared interview responses to information provided by parents on the demographic questionnaire when applicable. For example, the number of participants who discussed challenging or aggressive behaviors in interviews was compared to the number of parents who endorsed those behaviors on the demographic form. However, this type of triangulation was not possible for other categories.

Some believe that the process of triangulation potentially discounts the personal experiences or opinions of the subjects or that it is too narrow in its focus on a single or representative perspective across subjects (Mertens, 2010). For the purposes of this analysis, triangulation across interviewees was used with consideration of alternate realities and explanations to best assess convergent and divergent information (Mertens, 2010; Patton, 2002). More specifically, the Principal Investigator would define the category/theme, state the number of participants who discussed the category/theme, and provide example quotations from the interviews which best represent that category/theme. Then, the Principal Investigator acknowledged any outlying cases by including quotations which contradicted the category/theme. Being cognizant of outlying cases allows researchers to implement negative case analysis to promote credibility in the formulated hypotheses (Mertens, 2010).

External validity. The Principal Investigator established “transferability” (external validity) by using thick description and multiple cases (Mertens, 2010). The Principal Investigator used thick description by providing sufficient details regarding the context of the participant responses to allow for appropriate conclusions. For example, when introducing a quote, the Principal Investigator would often describe what was being discussed when the participant said that statement and possibly additional information about his/her relationship with his/her sibling.

Principal investigator's involvement. It is essential that all conclusions are a result of the data and not external factors related to the Principal Investigator. As such, to the extent possible, all personal thoughts, biases, and experiences did not impact the development of interview questions or study conclusions. It should be noted that the Principal Investigator refrained from reading findings of studies which used Grounded Theory to investigate the relationships of siblings when one individual has an ASD. Reading findings from similar studies could have impacted the coding process of the current study.

It should also be noted that the Principal Investigator has a sibling with a disability. However, the Principal Investigator's sibling has Epilepsy, not ASD. As a result, the Principal Investigator's experiences as a sibling of an individual with Epilepsy are not likely to impact conclusions regarding the sibling relationships of individuals with ASD. Furthermore, using the aforementioned structured data analysis has reduced or eliminated any potential personal biases when coding the transcripts and ensured "pure" conclusions were made, based solely on participant responses and experiences.

CHAPTER IV

Results and Analysis

Responsibilities of Typically Developing Sibling

All participants (100%) discussed having some type of responsibility for their sibling with ASD. For the purpose of this dissertation, “responsibility” was defined as an obligation or any duty carried out by participants to care for, control, or assist their sibling with autism. Mention of potential future responsibilities, such as being an adult caregiver for their sibling with autism, were also included in this category. It should be noted that none of the interview questions asked explicitly about responsibilities and that all of these participant responses were given when discussing other topics, such as shared activities and plans for the future. Additionally, since all participants are older siblings, some degree of responsibility is to be expected. Within the category of responsibilities of typically developing sibling, seven sub-categories were identified: helping, teaching, pushing, calming down, adult caretaker, advocacy, and protection.

Helping

The majority of participants (80%) spoke about helping their sibling with ASD. Helping was defined as assisting with or making a task easier for their sibling with ASD. Many participants explained how they help their sibling with ASD in the context of shared activities. For example, when asked about what activities she does with her brother, one 13-year-old participant noted “We don’t really do much. It’s mostly that I help with some things.”

However, the topic of helping also surfaced in other contexts. For instance, an 11-year-old participant discussed helping when asked to identify the best part about being a sister to her brother with ASD by saying “It can be really fun to help him do things.” After being prompted

for more detail, she further explained, “I’d be watching him when my parents or brother aren’t home or I’d be helping him get something or make something and help him with his homework.”

Teaching

Teaching was introduced by 40% of participants. For the purpose of this dissertation, teaching was defined as taking the responsibility for showing his/her sibling with ASD how to do something. This differs from helping in that teaching implies a new skill and an intention for the sibling with ASD to acquire the skill and independently apply it in the future.

One 16-year-old participant introduced the topic of teaching when asked to tell the interviewer more about his brother with ASD. He first discussed his brother’s independence and then said “I recently taught him how to shower by himself...so now we don’t have to watch him when he showers and tell him what to do.” This participant then provided a detailed account of the teaching process.

Another 16-year-old participant replied by saying “We just tried to teach him like how to behave as well.” when asked to tell the interviewer about some of the things she does with her sibling with ASD. This participant explained her involvement in behavior management and skills that she learned from practitioners of her brother’s social skills class.

Pushing

Across interviews, many participants (40%) expressed a desire and/or responsibility to “push” his/her sibling with ASD. For the purpose of this dissertation, “pushing” was defined as encouraging or pressing his/her sibling with ASD to achieve more and become more successful. For example, when asked what he thought his brother with ASD would do when he grew up, one 13-year-old participant stated, “I really want to push him, so he gets like, so he gets far in life.”

Calming Down

Several participants (70%) explained how they are often responsible for helping their sibling with ASD calm down when he/she is upset or agitated. Many participants were able to provide details regarding what strategies they have found to be most successful for calming their sibling down. Participants typically explained that there was a process of trial-and-error in which they learned through experience which strategies are successful in calming their sibling with ASD down. For example, an 11-year-old participant explained that “Sometimes giving him a drink or letting him lay down and calm down for a minute or 2” works best for her brother with ASD. A 12-year-old participant stated, “I try to calm him down...I try to talk to him and like say he’s my best friend and stuff, cause usually that just helps.”

However, some siblings have been explicitly taught strategies to utilize when attempting to help their sibling with ASD calm down. For example, one 16-year-old participant explained, “We have like little signals for him because at the social skills place, they said there’s like one for behavior, three is odd, and four is like annoying, and five is scary. So, whenever he starts to act out, we show him a number and he understands and gets calm.”

Adult Caretaker

All participants were asked what they want to do when they grow up and what they thought their sibling with ASD would want to do when he/she grew up. When responding to this question, 50% of participants discussed the potential responsibility of being an adult caretaker for their sibling with autism. For the purpose of this dissertation, “adult caretaker” was defined as any mention of caring or providing for his/her sibling with ASD as an adult.

One 13-year-old participant explained his plans for caring for his brother with ASD in the future by saying, “I want to stay really close to him and if he can’t find somewhere to live or

can't live on his own, I want to live with him." A 16-year-old participant who had recently been struggling with his sibling relationship discussed the possibility of being an adult caretaker for his sibling with ASD: "I'd get Franklin like a, an extension onto my house maybe. Or like, this is a, this is a pipe dream, but like, get like an extension to say like a really nice house and have him live with me and have somebody to like take care of him. Given that my parents wouldn't be around, uh, cause I wouldn't want that to fall on them. My mom always says that she wants to, that she's going to be ending up taking care of Franklin and sometimes, like when I'm mad and having an argument with her, I'm like, "go ahead, take him. Please. I'm leaving." But like, I really don't want that to be laid on her."

Another 16-year-old participant discussed the possibility of caretaking, but also mentioned the potential difficulties by stating, "When I get older, if there's no place for him, I want to take care of him....Because, I mean, he's my brother and I don't want him to be with just anybody, especially since when kids are put in foster homes, you never know if the parents are going to be loving and like really accepting, or if they just want it because of the money...So, I would like to take him when I get older, but I don't know if that's going to happen in reality, because it's a lot of work." Similarly, a 15-year-old participant mentioned taking care of her brother with ASD as an adult and continued by saying "I wouldn't mind, but I feel like it could be a struggle with like career things and like college and stuff like that."

Advocacy

The theme of advocacy was present in 30% of participant interviews. For the purpose of this dissertation, advocacy was defined as the responsibility to advocate for their siblings with ASD. One 16-year-old participant explained that she felt it was her responsibility to "Make people aware that there is such a thing as a spectrum." This participant felt that when people

heard her brother's diagnosis, they often made judgements regarding his abilities. Similarly, a 13-year-old participant discussed people making fun of individuals with ASD or other disabilities by saying, "I'd probably just say 'don't do that; you don't know what he's thinking. It's not like they don't have a brain, cause they do.'"

Protection

Another responsibility mentioned by 40% of participants was protection. For the purpose of this dissertation, protection was defined as guarding or defending his/her sibling with ASD from any type of physical or emotional harm or attack. One 16-year-old participant discussed her responsibility to protect her brother with ASD by explaining, "If someone comes at him, he knows I will be in that kid's face, no matter how old they are." She continued by saying, "My friends used to kind of make fun of him so I took a lot of action and I think I pushed someone and I was like "if you come at him again, it's going to be 10 times worse."

Another 16-year-old participant discussed a similar desire to protect his sibling with ASD from verbal attacks, but also mentioned that he felt it was his responsibility to protect his brother from getting hurt by stating "I have to be watching him."

Challenging Behavior

Several participants (80%) discussed their sibling with ASD displaying challenging behavior and how that impacts their sibling relationship. For the purpose of this dissertation, challenging behavior was defined as any aggressive (e.g. hitting, punching, property destruction, et.) or socially inappropriate behavior (e.g., screaming, "tantrum" behavior, excessive crying, etc.). It should be noted that none of the interview questions asked about challenging or aggressive behavior. Participants often discussed this topic when asked about the worst part of being a sibling to an individual with ASD, but it was also discussed at different points in the

interviews. Within the category of challenging behavior, three related sub-categories were identified: embarrassing, sibling's wants/needs come first, and restricted family activities.

For example, one 11-year-old participant discussed her brother with ASD exhibiting challenging behavior and her feelings of inadequacy by saying, "He gets frustrated really easily, so it could like, he could just be doing something and start screaming and just be really hard to calm down. I can't like do it right." Another participant shared a similar thought about how challenging behaviors are sometimes unexpected by saying, "He'll have like a mental breakdown and start yelling and stuff."

One 16-year-old participant reflected on the duality of her brother's behavior and stated that "He's fun to play with, but at the same time, he like hits a lot and pulls hair and throws things at you and stuff like that." Not all of the participants had been the target of their sibling's challenging behaviors, but most had witnessed it several times.

In addition to the interview questions, parents of participants were asked to fill out a demographic questionnaire to provide information about the participant, his/her sibling with ASD, and other family characteristics. According to parent report, 70% of participants' siblings with ASD exhibit challenging or aggressive behaviors. Of the 7 parents who endorsed challenging behavior, 3 reported that it was exhibited weekly, 1 reported that it was exhibited daily, and 3 reported that it was exhibited several times a day.

Wants/Needs Come First

Several participants (60%) expressed that the wants and needs of their sibling with ASD often took priority over their own. Responses related to the sibling with ASD being demanding or "getting what they want" were included in this category for the purpose of this dissertation. Participants sometimes described their sibling with ASD as being selfish. For example, one 13-

year-old participant stated, “He always thinks about himself and he thinks that it’s all about him.”

However, this category was often discussed in the context of avoiding potential challenging behaviors. For example, one 12-year-old participant explained that “If he doesn’t get his way, he’s just like, he just turns into a different person where he starts hitting and stuff.” Many participants explained that when their sibling with ASD does not get his way, he is likely to exhibit challenging behaviors.

Embarrassing

Many participants (40%) reported feeling embarrassed specifically when their sibling with ASD exhibits challenging behaviors. Most participants used the word “embarrassed” when discussing this feeling, but responses related to shame, self-consciousness, and similar emotions were also included in the definition for the purpose of this dissertation.

One 13-year-old participant discussed her brother with ASD exhibiting problem behaviors in public: “It is very frustrating because I get mad at him and I get self-conscious of him cause he always, he doesn’t really act appropriate in public. He just, he sometimes has these breakdowns and I’m just scared that people are going to look at me.” She later continued by explaining that “I can’t get it through my brain that we can’t change how embarrassing he is.”

Restricted Activities

Some participants (30%) mentioned not being able to engage in certain activities with their family because of their sibling’s challenging behaviors. These responses were defined as “restricted activities” for the purpose of this dissertation. For example, when asked to discuss the hardest part of having a sibling with ASD, one 16-year-old participant explained, “Just the fact that we can’t get up and go whenever. Like, vacations, like we can’t really go on a lot of

vacations.” She provided detail regarding her brother’s challenging behaviors and how it makes it difficult for the family to go out together.

Another participant discussed choosing to not participate in family activities because of her brother’s challenging behavior by stating, “I usually don’t like to go out with my mom and my brother when they go out places, because it’s, he just is so difficult and if they go into a store, then Kurt would get like mad...” This participant explained that her brother’s challenging behaviors do not stop her mom from going out in public, but that she just found it to be too embarrassing.

Positive Attributes

Throughout the interviews, 80% of participants were able to identify at least one positive attribute of their sibling with autism. For the purpose of this dissertation, positive attributes were defined as any characteristic that is generally seen to be positive. Examples include, being loving, funny, happy, smart, creative, and fun. Some of the following responses were given when participants were asked to identify the best part of being a sibling to their brother with ASD. However, some of the positive attributes were given spontaneously. Within the category of positive attributes, three sub-categories were identified: funny, loving, and fun.

Fun

Half of participants (50%) reported that their sibling with ASD is fun. Many of these responses came when participants were asked to identify the best part of being a brother or sister to their sibling with autism. For example, one 11-year-old participant explained, “He can also be fun to hang out with” to describe the best part of her sibling experience.

Some participants described their sibling with ASD as fun after providing a rating for how much they enjoy being a sibling to their brother or sister with ASD. For example, a 12-year-

old participant said, “I really like love my sister. She’s really fun” when asked why he chose his rating.

Funny

Many participants (40%) described their sibling with ASD as funny. Participants often referred to laughter and jokes when describing their sibling’s sense of humor. For example, one participant first said “Sam is kind of like my best friend. He can always like, make me happy whenever I’m having a bad day.” When asked what his brother does to make him happy, the participant clarified that, “He can always make me laugh.”

One participant, who discussed often feeling negative about his relationship with his brother with ASD was able to identify a positive attribute by saying “He’s funny, he has a sense of humor.” This participant went on to discuss how humor helps him to connect with his brother with ASD.

Loving

Some participants (30%) described their sibling as being very loving and affectionate. Responses which used the word “loving” or described siblings as frequently displaying affection were included in this category. For example, one 13-year-old participant described his brother with ASD by saying, “He’s just amazing and I wouldn’t want anyone else. He’s just, he’s so nice and he’s kind and he’s loving.”

Frustration/Anger

Several participants (60%) referred to feelings of anger or frustration toward their sibling with ASD. For the purposes of this dissertation, participant reports of feeling “annoyed” or “embarrassed” by their brother or sister with ASD were not included in this category. This distinction was made because responses in this category are more emotionally intense and are

thought to be different from typical feelings of embarrassment or annoyance. Often, feelings of frustration/anger were discussed in connection with remaining patient, regardless of the participant's own feelings. Participants described feelings of frustration/anger as momentary and also as a lingering overarching emotion felt towards their sibling with autism.

One participant explained that, as a typically developing sibling of an individual with autism, "You feel much more angrier at them than you think you should." She further expressed her frustration by saying "he's just so difficult and it makes me so angry sometimes. And sometimes, I think it would be easier if he was just normal." A second participant described a recent increase in the amount of time he spent with his sibling with autism. He explained that the increase in time had negatively impacted his patience and said that "I'll start getting angry and it's not right, I know, but I can't really help it sometimes." Within the category of frustration/anger, three sub-categories were identified: patience, acceptance/understanding, and walk away.

Patience

Nearly all participants (90%) identified patience as an integral part of their relationship with their brother or sister who has ASD. For the purpose of this dissertation, patience was defined as the ability to control one's emotions or temper, even when angry or frustrated. Several participants referred to patience when asked to give advice to other individuals who have a brother or sister with autism, but it should be noted that the theme of patience was also mentioned at several other junctures throughout the interviews.

When giving advice to other typically developing siblings, one participant noted that "It's always going to be the other sibling's responsibility to be like overly patient" to explain that the burden of patience often falls on the typically developing sibling. Other participants referred to

patience in connection with their sibling's diagnosis of autism and the associated challenges. One participant reported that "I have to like control myself and be like "she has autism, I have to stop and be more nice." Another participant similarly noted that "I have a short temper, but I always manage to try and keep the fuse a little longer with him."

Acceptance/Understanding

Some participants (30%) talked about accepting or understanding their sibling with autism and how that might or might not contribute to their patience. One participant advised other siblings that "You shouldn't openly say you dislike them, you should try to like accept and try to figure out how to be a good sister or brother to them." She continued by saying "I don't expect you to understand them completely." Another participant similarly stated that "you really have to be patient and you have to like understand that this isn't just any kid, like he's different and you can't, you can't treat him the same way you would treat another kid."

Walk Away

Half of participants (50%) mentioned "walking away" when discussing what they do when they become angry or frustrated with their sibling who has autism. One participant stated that "If I get like really aggravated by him, I'll just walk away." A second participant said he will "Just walk away" if he is unable to diffuse a situation with his sibling who has autism.

Fears

More than half of participants (60%) discussed being fearful or worried for their sibling with ASD. For the purpose of this dissertation, responses related to fears, concerns, or being scared/nervous for their sibling with ASD were included in this category. Responses in this category were given at different points in the interview. For example, one 16-year-old participant discussed his fear when asked what it was like being a sibling to his brother with ASD by saying,

“It’s fun, but sometimes it’s concerning.” This participant continued to discuss how he is frequently afraid for his sibling with ASD. Within this category, two sub-categories were identified: fears for sibling and fears for sibling’s future.

Fears for Sibling

Half of participants (50%) expressed being fearful or worried for their sibling with ASD in the past or present. Some fears were related to physical safety and their sibling with ASD not understanding rules and expectations for behavior. One participant explained this by saying “It scares me, once again, him doing something that will get him in trouble or hurt.”

Other responses were related to possible emotional harm or social rejection by peers. One 13-year-old participant stated, “There’s always going to be people who make fun of him and like he gets bullied at school, so I’m always like nervous for him.” These responses were often discussed in connection with responsibilities of protection and advocacy.

Participants were also likely to discuss a lack of public understanding in connection with fears. One participant discussed his fears related to his brother’s behavior in public and possible reactions by stating, “It scares me, the things he does. Like, in public I mean.” He continued by saying, “so, like an angry parent or just adult in general is always a concern.” Similarly, another participant shared, “Anyone could get insulted easily, like not realizing he’s different and stuff. And there’s like a lot of things I hear on the news where people have beaten up like kids like him and that just scares me.”

Fears for Sibling’s Future

Half of participants expressed fears related to their sibling’s future. Some of these fears were connected to the possibility of serving as an adult caretaker for their sibling with ASD. However, others were discussed with what might be possible for their sibling with ASD in the

future. For example, one participant said, “I feel like it would be a little difficult for Conor to find like work or something or like if he wants to do something, I don’t really know how he would handle it.”

One 12-year-old participant shared many feelings related to his sibling’s future. At first, when asked what his sibling with ASD would do when she grew up, he expressed hope for the future by saying, “I think she’s going to be okay, cause she’s getting better. Like, every year, she’s getting better.” This participant then discussed his plans to be an adult caretaker for his sibling with ASD. Finally, this participant expressed his fear and concerns by saying, “I feel kind of sad, because I want her to like move on in life and have a family, but I’ve realized, um, that it’s going to be hard.”

Not a Normal Sibling Experience

Many participants (40%) spoke explicitly about how they did not have a “normal” sibling relationship. Statements regarding missing out on perceived “normal” sibling experiences or differences between participant sibling experiences and typical sibling experiences were included in this category. It should be noted that participants were not asked how their sibling relationships might differ from other, more typical sibling relationships. Of the four participants who spoke about not having a “normal” sibling experience, two (50%) have other, typically-developing siblings and two (50%) only have his/her sibling with ASD.

At the end of each interview, participants were asked if there was anything else they might like to share. One 13-year-old participant took advantage of that opportunity by saying, “It’s different, with, um, a sibling with like autism, because it’s not like, like normal siblings are usually there for you and you don’t fight all the time and you understand each other, cause you’re like brothers and sisters. But, it just, you don’t feel as brother and sister. Like, you still

feel protective over them, but it's just different." Similarly, a 16-year-old participant, who only has one sibling, stated "He lacks what I wish I had as a brother. Like, a normal brother...cause I don't really have another one" when asked what it was like being his sibling's brother. This participant frequently returned to this theme throughout his interview.

While many of the responses in this category were negative or related to the participants feeling sadness or grief over the loss of his/her expected sibling experience, some emphasized the positive aspects. For example, one participant said that the best part of being a brother to his sibling with autism was that "It's relaxing sometimes instead of having a brother that is on top of you all the time, or crazy, you know, younger or older...he stays in his own world a lot of the time, like I said, on the iPad and the computer and the Wii and xBox, but sometimes it's good to just be left alone."

Within the category of not a normal sibling experience, four sub-categories were identified: communication difficulties, can't argue, shared activities, and worldview. These categories are thought to be unique to the experience of having a sibling with ASD, and how that experience is felt to be abnormal at times.

Communication Difficulties

Siblings often serve as lifelong confidants and there is a widely held perception that siblings are frequently talking and communicating. Many participants (40%) expressed communication difficulties they experienced with their sibling with ASD, which could be related to the social, emotional, and communication deficits experienced by many individuals with ASD. Communication difficulties were defined as a lack of or difficulty having conversations or talking to his/her sibling with ASD for the purpose of this dissertation.

One 16-year-old participant explained that he felt he was missing out on “normal” sibling experiences with his brother. When asked to provide detail, he said “Like talking and having someone to like share secrets with.” Similarly, another 16-year-old participant discussed communication difficulties with his brother by saying, “We don’t really get to talk about things that I want to talk about because it’s, it’s different.” He later continued by clarifying that “It usually has to be about what he wants to talk about for me to get any reaction out of him.”

Although 40% of participants discussed communication difficulties, there was also mention of positive conversations with siblings. For example, when discussing what she likes to do with her brother with ASD, one 11-year-old participant said “We could just be like playing a game or talking.” When asked what she talks about with her brother, she responded by saying “just like anything.”

Can’t Argue

Several participants (70%) discussed how they cannot argue with their sibling with ASD. Many of these responses were discussed in the context of how typical sibling relationships involve frequent arguments. For example, one 16-year-old participant explained, “It’s really weird because I’ve never had a comparison. Like, sometimes on TVs and movies, I’ll see like how siblings interact. Like, they wrestle, they fight, obviously, and I can’t really do that with Tyrion.” Another 16-year-old participant expressed a similar sentiment by saying, “Not having somebody to like, I guess you could say argue and fight with, in like a, a more, I don’t, a more normal way.” Although many participants felt that it was difficult to not be able to argue with their siblings, one participant explained that the best part of having a sibling with autism is “Not fighting like constantly with a brother and sister.” He continued by saying, “if she didn’t have autism, we’d probably like fight every single day.”

Other participants discussed this topic when asked to provide advice to siblings of individuals with ASD. For example, one 11-year-old participant shared, “I argue with him and act as if he was someone that acts like his age, but the way he functions, he acts like a younger person....you can’t really argue with him.”

Different Worldview

Half of participants (50%) explained that they had a changed worldview as a result of being a sibling to an individual with ASD. For the purpose of this dissertation, statements related to seeing the world and/or people differently because of the participant’s relationship with his/her sibling with autism were categorized as different worldview. Many of these statements were positively phrased and expressed that the participants felt better for having a sibling with ASD.

For example, one participant said “I believe I’m less bigoted and ignorant. Because certainly, having the experiences, it opens me up to a lot of different people and backgrounds.” Similarly, when asked to identify the best part of having a sibling with ASD, one 13-year-old participant explained that “It just makes you realize like a lot more to life.”

All participants were asked to provide advice to other individuals who have a sibling with ASD. One 16-year-old participant suggested that other siblings “Take as much from it as you can because it not only helps you better your relationship with your, your sibling, but it helps you with other people, because you get to understand and come across things that you wouldn’t necessarily have to deal with if you had a typical brother or sister. Uh. You get different perspectives on things and although your patience will go up and down with it, you’ll learn to deal with more things, like, that normal, more typical people wouldn’t have.”

Shared Interests/Activities

All participants were asked about shared activities or things they do with their sibling with ASD. Sibling relationships often involve many shared activities, especially in childhood when siblings are usually the primary playmates most children have. A lot of answers were related to helping or teaching his/her sibling with ASD instead of shared activities like playing or engaging in a hobby.. Some participants (40%) took this opportunity to discuss a lack of shared interests or activities and how that felt different from typical sibling relationships. For example, one 16-year-old participant shared, “There are certainly things that I can’t do with Tyrion that a lot of other siblings can do.”

A 13-year-old participant discussed how it is harder for her to do things with her brother with ASD now that she is older: “I think it was more when we were younger and we used to lay a lot outside, cause he has such a big imagination, and he still does. But, I can’t really support that anymore, because I don’t really like to play games that much. But, I think it was more when we were younger, we used to do a lot of like hanging out and playing with toys and stuff.”

Autism Definition

All participants were asked how they would explain their sibling’s diagnosis. All (100%) of participants described the diagnosis in terms of a deficit. Half (50%) of participants mentioned a deficit in comprehension and/or understanding. For example, one participant stated, “He’s on the spectrum, like he’s like a little different, he can’t comprehend things as well as other people...he doesn’t have a mind of his own.” Many participants (40%) referred specifically to a disability or disease. One 16-year-old participant partially described ASD as “A disability that impairs learning and/or social interactions.” This participant also referred to the autism spectrum and provided additional details.

Some participants (30%) referred to communication when explaining ASD. For example, one 13-year-old participant explained that “It’s like somebody doesn’t really recognize what somebody else is feeling and they don’t know how to explain what they’re feeling at some point and they don’t know how to communicate like what they need or like what they want and why they want it. And they can’t like communicate with people because they aren’t thinking alike.”

Although all participants described ASD in terms of deficits, one 16-year-old participant discussed the strengths of her brother with ASD. She began by discussing his deficits:

“Sometimes he struggles with like reading comprehension and like not speech as much, but like some of the words, he doesn’t really know like where or how to use them sometimes. Sometimes he uses the wrong words and sometimes his social skills are off.” She then continued by saying, “His brain works differently. He’s still breathing, he’s still eating, you know? He can still play sports, he can still have friends and stuff like that. I guess god just had a different plan for him. The fact that he has some weaknesses that everyone’s focusing on, you can’t forget that he’s so smart, he’s so friendly.” Finally, she added “watching him grow up and become such a little man, it has been awesome to just watch him do that.” It should be noted that other participants provided positive descriptions of their siblings with ASD throughout the interviews.

Within the category of autism definition, two sub-categories were identified: difficult for sibling with ASD and limits of disability. The responses in the two sub-categories were not typically given during the question related to defining ASD. However, they were included as sub-categories because they represent the meaning assigned to ASD by the participants.

Difficult for Sibling with ASD

Half (50%) of participants referred to the difficulties that ASD presents for their sibling. For example, one 11-year-old participant described ASD by saying that it “Can be very difficult

for the people who have it.” Similarly, a 16-year-old participant stated that “It’s hard for them because their brain works differently” when discussing the impact of ASD and how difficult it can be for those who are diagnosed.

Some participants discussed this difficulty in connection with perspective taking. For example, one 13-year-old participant advised that typically developing siblings of individuals with ASD “should try and put themselves in their sibling’s shoes.” When asked for clarification, he said “Just like think about it. How hard it is for them and like how difficult things can be for them.”

Limits of Disability

More than half (60%) of participants referred to the limits of their sibling’s ASD at some point in the interview. This category consists of responses related to their sibling with ASD not being able to do certain activities. For example, a 12-year-old participant stated, “He can’t do everything that a normal person could” when describing what it was like to be a sibling to his brother with ASD.

Other responses were related to “pushing” their sibling with ASD and how that relates to the limits of their diagnosis. For example, one 16-year-old participant stated, “You can’t really push him past his disability. It just doesn’t work and I’m still learning that.” This participant was discussing his desire to have his sibling with ASD engage in reciprocal conversation. Similarly, another participant said, “You have to push him, but you have to know that after a certain point, they can’t be pushed any more, because they can’t do it.”

Responses related to the perceived permanency of ASD and its associated symptoms were also included in this category. For example, a 13-year-old participant said “We can’t change him, so it’s really hard” when explaining how she feels about her brother’s ASD

symptoms, specifically challenging behaviors. Other participants referred to not being able to change or control the behavior or functioning of their sibling with ASD.

Other Findings

Rating

Each participant was asked to rate on a scale of 10-0 (a score of 10 is highest) how much he/she liked being a sibling to her/his brother/sister with ASD. Participants were asked to explain why they picked that number. The average rating was 7.6 out of 10. The lowest rating given was a 6 and the highest was a 10. It should be noted that one participant responded with a rating of 11, but a 10 was used to keep the scale consistent. Similarly, one 16-year-old participant said “It’s probably been like a 5 or 6, but overall, when we do have good times together, a 7 maybe.” A rating of 6 was used for this participant since it was the average of the range provided by the participant.

The average rating of 7.6 suggests that, overall, participants enjoy their experience as a sibling to an individual with ASD. Similarly, the cluster of ratings on the higher end of the spectrum suggest that the experience is more positive than negative. However, the ratings should be interpreted in conjunction with the additional information and perspectives shared by the participants during their interviews.

Helping Profession

Each participant was asked what they think they will do when they grow up. Some participants took this opportunity to discuss their future relationship and involvement with their sibling with ASD. All participants commented on their future career plans. Half of the participants (50%) discussed plans to go into a helping profession. For the purpose of this

dissertation, helping professions were defined as occupations focused on solving a problem, meeting a need, and caring for someone. Examples include education, medicine, and psychology.

Some of the participants explicitly discussed a desire to help people. For example, one 16-year-old participant said that she wanted to pursue a career in the criminal justice field. When asked why, she said “just me wanting to help...maybe try to fix things to make people happier.” Similarly, another 16-year-old participant said he wanted to be a psychiatrist because “I wanna help people other people say can’t be helped.”

Advice for Parents and Practitioners

Throughout some of the interviews, participants discussed advice that they would give to adults regarding their experience as a sibling of an individual with ASD. Although this was not an interview question, and was not a category discussed by many participants, the PI determined that the advice could be invaluable to parents and practitioners attempting to understand the potential needs of this population. As such, the following pieces of advice should be viewed in the context of individual experiences instead of group themes.

One 16-year-old participant who shared many positive aspects of being a sibling to an individual with ASD shared advice for practitioners. She stated, “A lot of people are always focusing on how to help the kid themselves, which is very important, but that’s not, well, not that it’s a problem, but that’s the fundamental issue that we need to fix. So, a lot of people don’t think about the parents and the siblings. I watch the toll it takes on my mom and her always being out of the house, always taking him to something. I guess just like try to think of the family too.” It should be noted that this participant rated her sibling experience initially as an 11 and overall presented a very positive experience as a sibling to her brother with ASD.

The same participant also shared advice for parents. She stated, “I always used to get really mad at my parents. It’s not like they were giving him more attention, because it wasn’t like that, but it was just that they always gave him an excuse. So, I guess just try to treat your kid as normal as you possibly can and then that actually helps.” She went on to explain that since her parents have begun to treat her brother more “normally,” things have improved for the sibling pair. More specifically, she said, “Now with Bill that mom was [*sic*] finally like ‘oh, maybe if I treat him like every other kid like he’ll be better, and he’s like leaps and bounds...no matter what part of the spectrum they’re on, if you treat them like more of a normal kid, it makes them feel less different.”

Another 16-year-old participant discussed past participation in a counseling group for siblings of individuals with ASD. He mentioned being unhappy with the experience and did not find it to be helpful. When asked what he thought would be helpful, he shared advice for practitioners by saying, “I would feel that if the person directing the group would get to know the siblings really well, that it would probably give them a little more insight into how the siblings would deal with things.” He continued by explaining, “Or where their life is at and how they choose to do things. Because like, I feel if somebody were to meet me and just talk about Franklin and myself, it wouldn’t give them the full, I don’t know, background. Like, if they knew my family and the situations that we’re put in, or I don’t know, our background, it would help.”

One 13-year-old participant who discussed the difficulties she is having in her sibling relationship stated, “I think adults should know that it’s normal to be like mad at your siblings or hate your siblings.” This participant then discussed how she attempts to explain this to her

mother, but it is not always successful. She continued by saying, “I don’t think she understands completely how it feels to have him as my brother.”

CHAPTER V

Discussion

Interpretation of Findings

Responsibilities of typically developing sibling. The most common theme discussed by all participants (100%) was a sense of responsibility for their sibling with ASD. Sub-categories include helping, teaching, pushing, calming down, adult caretaker, advocacy, and protection. Of these sub-categories, helping and calming down were the most commonly discussed. A majority of participants (80%) discussed helping their sibling with ASD engage in a task. It is interesting to note that none of the questions asked about helping and that participants generally referred to helping their sibling with ASD when they were asked about shared sibling activities. It is possible that the tendency of participants to talk about helping their sibling when asked about shared activities suggests that the participants do not experience shared activities such as playing with their sibling with ASD. One participant explicitly stated this by saying “we don’t really do much. It’s mostly that I help with some things.” A tendency for siblings of individuals with ASD to be helpful and caring has been documented by researchers, so these results provide additional evidence (Mandleco & Webb, 2015).

A majority of participants (70%) discussed their responsibility to calm their sibling with ASD down when they become upset and/or engage in challenging or aggressive behaviors. This is another responsibility which is most likely a result of participant siblings having ASD. Participants were able to describe situations in which their sibling with ASD is likely to become upset and/or engage in challenging behaviors. They also usually provided details regarding how they attempt to avoid high-risk situations. Additionally, participants explained how they typically calm themselves down when frustrated so that they are able to assist their sibling in calming

down. Participants benefited from the use of coping strategies to manage both their own unpleasant emotions as well as those of their sibling with ASD, which has been suggested by researchers and practitioners alike (Tsao et al., 2011).

Half of participants (50%) mentioned the possibility of being a caretaker for their sibling with ASD when they grow up. It is important to note that none of the questions asked siblings about this prospect. All participants were simply asked about future plans for themselves and then the same for their sibling with ASD. This suggests that typically developing siblings in middle childhood and adolescence are already pondering the idea of caring for their sibling into adulthood. It can be assumed that this is not a consideration for typically developing sibling pairs and that it is a responsibility unique to siblings of individuals with ASD and other disabilities which might impact their ability to care for themselves. Given that ASD is a lifelong disability, it is logical that typically developing siblings would feel the need to involve themselves in future plans.

Some participants (40%) discussed teaching their sibling with ASD. However, this topic is prevalent in the existing research, so it would have been expected that more participants would mention teaching (Banda, 2015; Shivers & Plavnick, 2015). It is possible that it was not discussed by more participants because it was not a direct question, but rather came up organically during the interviews.

Although a certain degree of responsibility can be expected, given that a large majority of the participants are older siblings, some of the responsibilities appear to be a result of their sibling's ASD. For example, calming a sibling down when they are exhibiting challenging or aggressive behaviors is likely an experience that happens more often when individuals have ASD. Also, some participants (30%) discussed feeling the need to advocate for their sibling with

ASD, due to a lack of understanding from the public. Similarly, many participants (40%) felt responsible for protecting their sibling with ASD from being made fun of or experiencing physical harm. Other siblings in middle childhood have reported a need to protect their sibling with ASD from experiencing physical harm (Angell et al., 2012). Pushing was a topic discussed by some participants (40%) when expressing that they felt a responsibility to encourage their sibling to succeed.

The existence of increased responsibilities of typically developing siblings of individuals with ASD has previously been documented in the literature (Angell et al., 2012; Mascha & Boucher, 2006; Petalas et al., 2009; Ward et al., 2016). A recent review of the literature reveals that the perception of the increased responsibility is not consistent in that some siblings regard it positively and some resent the additional responsibility (Mandleco & Webb, 2015). It has also been documented that many typically developing siblings of individuals with ASD feel a heightened sense of responsibility even when they are younger than their sibling with ASD (Petalas et al., 2009). This suggests that the responsibilities discussed by the participants in the current study are a result of the ASD symptoms exhibited by symptoms and not simply due to birth order.

Challenging behavior. Nearly all participants (80%) shared about their sibling experiencing challenging or aggressive behavior. Usually, participants discussed challenging behavior in the context of being asked to identify the worst part of being a sibling to their brother or sister with ASD. Challenging behavior, which can be aggressive at times, is characteristic of ASD (CDC, 2017). As such, it is assumed that regular displays of challenging behavior is a result of participant siblings' ASD, and not developmentally typical behavior. This distinction is important given that so many participants discussed their sibling's challenging or aggressive

behaviors without ever being asked, suggesting that it is a topic of paramount importance for this population.

Some participants described acts of physical aggression while others described their siblings becoming incredibly upset and yelling. Additionally, participants shared about displays of challenging behavior in public. Challenging behavior was also often discussed in the context of coping strategies participants used to calm their siblings down. Most participants were able to describe situations in which their sibling with ASD is likely to exhibit problem behavior. Within the category of challenging behavior, the following three sub-categories were identified: embarrassing, sibling's wants/needs come first, and restricted family activities.

A majority of participants (60%) mentioned that the needs of their sibling with ASD often come first. This was usually discussed in terms of siblings with ASD always "getting what they want." This type of behavior is characteristic of ASD and reflects a certain degree of behavioral rigidity (CDC, 2017). However, many participants interpreted it as selfishness rather than a manifestation of his/her sibling's disability. It has commonly been reported by researchers that children with disabilities often get extra attention and privileges. However, this is an important consideration given the fact that differential parental treatment has a negative impact on sibling relationships (Coldwell et al., 2008; Jensen et al., 2013). It has also been shown that the perception of differential treatment puts children at-risk for poor outcomes and the development of negative feelings toward siblings. Thus, this perceived selfishness could possibly impact the quality of the relationship and/or psychological outcomes for typically developing siblings.

Some participants (30%) reported that they often do not engage in family activities due to their sibling's challenging behavior. Some participants shared that it caused them to miss out on

certain family activities and that they wish they could participate in vacations and even shopping trips without being concerned. It is possible that these feelings could impact the quality of the sibling relationship and cause typically developing siblings to feel resentment towards their sibling with ASD.

According to a recent literature review, embarrassment has been repeatedly documented by researchers as a common theme used to describe the experience of siblings of individuals with ASD (Mandleco & Webb, 2015). Many typically developing siblings have reported feeling embarrassed of their sibling with ASD, especially in the context of challenging behaviors (Mandleco & Webb, 2015). Although the results of this dissertation recognize embarrassment as a theme characteristic of the typically developing sibling's experience, it was only discussed by some (40%) of the participants. This could be due to the fact that participants were not directly asked about feelings of embarrassment, or it could be because the remaining participants do not, in fact, feel embarrassed of their sibling with ASD.

It is possible that the results of challenging behavior are somewhat impacted by so many participants coming from the same family and thus having the same sibling with ASD. More specifically, there were ten participants from seven families. It is possible that the existence of severe problem behavior in the siblings with ASD was inflated in this sample and might not be representative of the larger population.

Also worth noting is the discrepancy between parent report and participant report regarding challenging behavior. All parents were asked to report whether or not their child with ASD engages in aggressive or challenging behavior. Parent reports indicate that more than half of siblings with ASD ($n=4$) engaged in challenging or aggressive behaviors. The remaining siblings ($n=3$) did not engage in these behaviors. Overall, 80% of participants mentioned that

their sibling with ASD engaged in challenging behaviors without being asked, but only 70% of participant parents endorsed challenging behavior when asked directly on the demographic form. Although this is only a slight discrepancy, it suggests the possibility that sibling and parent interpretations and perceptions of challenging or aggressive behavior might be different.

Positive attributes. Most of the participants (80%) openly discussed positive attributes of their sibling with ASD. Within this category, the following three sub-categories were identified: funny, loving, and fun. When discussing positive attributes, participants often changed their facial expressions, tone of voice, and sometimes laughed while recalling stories about their sibling with ASD. As a result, the interviewer felt that these disclosures were genuine and rooted in an emotional connection between the participant and his/her sibling with ASD.

Often, these disclosures were given in response to being asked to identify the best part of being a sibling to their brother or sister with ASD. However, many of the positive attributes were mentioned at other points in the interview. For example, participants would discuss a positive attribute just after sharing something negative about their sibling with ASD, in an apparent attempt to offer balance. This pattern of balancing negative disclosures with positive disclosures has been documented previously when investigating the sibling relationships of individuals with ASD (Mandleco & Webb, 2015).

Expressions of positive attributes can be interpreted as an indicator for warmth in the sibling relationship. As previously explained, the concept of warmth is related to the amount of intimacy in a relationship and is crucial for determining the quality of a relationship (Lam et al. 2012). It has been previously documented that individuals with ASD and their typically developing siblings experience less warmth in their relationships (Hodapp & Urbano, 2007; Kaminsky & Dewey, 2001). However, the large majority of participants in this study were able

to speak positively about their sibling with ASD, which suggests some degree of warmth. It is possible that participants were prompted to share their siblings' positive attributes when they were asked to identify the best part of being a sibling to someone with ASD. Other indicators, such as shared activities can provide more information regarding the levels of warmth and conflict in sibling relationships.

Frustration/anger. Many participants (60%) discussed frequently feeling frustration and anger towards their sibling with ASD. Although it is typical for all siblings to become frustrated or angry with one another at times, it seemed that the source of these feelings were related to symptoms and characteristics of ASD. Often, participants would discuss feelings of frustration/anger in the context of challenging behaviors, behavioral rigidity, or other similar characteristics of ASD. One participant poignantly stated “you feel more angrier [*sic*] at them than you think you should...he’s just so difficult and it makes me so angry sometimes. And sometimes, I think it would be easier if he was just normal.” This disclosure clearly connects the participant’s intense feelings of anger with her sibling’s ASD.

It is possible that feelings of frustration and anger can impact participants, siblings with ASD, and their sibling relationship. It is also possible that the documented social and communication impairments inherent in ASD might make it difficult for siblings to discuss these feelings and work together towards achieving a mutually beneficial solution. This could lead to increased feelings of frustration and anger and eventually, resentment.

Siblings often discussed feelings of frustration/anger while discussing their tendency to exercise patience with their sibling with ASD. Nearly all participants (90%) discussed the need for patience in their sibling relationship. Many participants referred to remaining patient because their sibling with ASD cannot always control their own emotions or reactions. Thus, the typically

developing sibling was often expected to put their own emotions and reactions aside. This tendency is well-documented in the literature investigating typically developing siblings of individuals with ASD (Mandleco & Webb, 2015; Orsmond & Seltzer, 2007).

Many participants discussed strategies they used when feeling frustrated with their sibling with ASD. In an attempt to remain patient, nearly half (50%) of participants mentioned that they walk away when they are finding it difficult to stay patient. Although this is an effective strategy, it is possible that typically developing siblings do not know about additional coping strategies and walk away from situations because they are not aware how else to handle difficult emotions. Also, it might not always be possible to walk away. All children and adolescents might benefit from coping strategy instruction, but siblings of individuals with ASD might be particularly appropriate for these interventions (Tsao et al., 2011).

Acceptance/understanding is a sub-category mentioned by some participants (30%). Participants explained that understanding their sibling's limitations often helped them to remain patient. Understanding of ASD and its associated characteristics has been shown to help siblings navigate their experience (Mandleco & Webb, 2015). It has been suggested that typically developing siblings understanding ASD and the meaning of the diagnosis varies from family to family and is often dependent on cultural factors (Mandleco & Webb, 2015).

Fears. More than half of participants (60%) discussed fears they have for their siblings with ASD. Once again, participants were not asked at any point if they fear for their sibling, rather the participants discussed this topic at various points throughout the interviews. Some of the fears involved both physical and emotional security of their siblings with ASD. The existence of fears has been found in other studies investigating the experience of siblings of individuals with ASD (Angell et al., 2012; Mascha & Boucher, 2006; Moyson & Roeyers, 2011; Petalas et

al. 2012; Ward et al., 2016). Other fears involved the future and the possibility of being an adult caretaker.

Many siblings felt a personal responsibility for their sibling's personal safety and security. This was sometimes discussed in terms of protecting their sibling with ASD. Typically, it is not expected for siblings to fear for their own sibling in this way, so it can be assumed that it is a result of their sibling's ASD. Furthermore, many siblings stated that they are afraid because of their sibling's challenging behavior and how it might be interpreted by other unfamiliar individuals. Additionally, siblings discussed fears for their sibling's emotional safety and worried that they might be the target of jokes or misunderstandings. One participant expressed that he is afraid of his sibling with ASD being targeted because she does not look like she has a disability.

Moyson & Roeyers (2011) has documented the impact of ASD's "invisibility" on typically developing siblings. More specifically, they found that sibling's felt that the behavioral expectations for their sibling reflected their "normal" appearance and not the reality of their diagnosis. As a result, participants shared that they felt their sibling with ASD would be unfairly judged (Moyson & Roeyers, 2011). Typically developing siblings of individuals with ASD have shared these fears in other research studies (Angell et al., 2012). The existence of fear is often associated with increased levels of empathy and warmth towards the sibling with ASD (Lam et al., 2012; Pilowsky et al., 2004).

Half of participant siblings (50%) expressed fear over their sibling's future. Some siblings were unsure how they might be able to care for their sibling with ASD. The existence of fear suggests that the siblings are aware of the long-term impacts of ASD on functioning. Other participants, however, expressed hope for the future and believed that their siblings would be

able to have a career and a family. Some participants shared that they have discussed this possibility with their parents, but others had not. It is possible that open communication with parents regarding future expectations might be helpful (Mascha & Boucher, 2006; Petalas et al., 2009).

Not a normal sibling experience. Many participants (40%) clearly stated that they did not have a “normal” sibling experience. None of the participants were asked if they thought they had a normal sibling experience, rather these disclosures were given spontaneously at various points throughout the interviews. Some participants found positive aspects of their abnormal sibling experience, but others shared this sentiment with feelings of grief and loss over what they thought their sibling relationship could be. There is research to support that typically developing siblings often report that they do not have a normal sibling experience (Mandleco & Webb, 2015; Orsmond & Seltzer, 2007).

Within the category of not a normal sibling experience, four sub-categories were identified: communication difficulties, can’t argue, shared activities, and worldview. Many participants (40%) referred to difficulties communicating with their sibling with ASD. Difficulties with communication and social interactions are characteristic of ASD and are somewhat expected to impact the sibling relationship (CDC, 2016). Other researchers have documented difficulties in communication reported by typically developing siblings of individuals with ASD (Ward et al., 2016).

A majority of participants (70%) discussed not being able to argue with their sibling with ASD like normal siblings argue. This is also seemingly a result of the social and communication difficulties of ASD (CDC, 2017). It has been documented that sibling relationships involving ASD are often characterized by less conflict than typical sibling relationships (Fisman et al.,

1996; Kaminsky & Dewey, 2001; Knott et al., 1995). Conflict is seen as an important and necessary component of all intimate relationships (Dunn, 1983). It is possible that the previously mentioned existence of undesirable feelings (frustration/anger and embarrassment) combined with a lack of communication and conflict can lead to reduced levels of intimacy and quality in sibling relationships.

Similarly, sibling relationships are often defined by shared activities and play, especially in early and middle childhood (Dunn, 1983). Many participants were able to list some activities that they engaged in with their sibling with ASD. Some participants discussed behaviors like teaching or helping their sibling with ASD. However, it is concerning that some participants (40%) discussed a lack of shared activities when asked to discuss activities they engage in with their sibling with ASD. Reciprocal and complementary interactions are vital to the development of healthy sibling relationships (Howe & Recchia, 2005; Howe & Recchia, 2014). It can be assumed that a lack of these interactions might lead to less positive sibling relationships which could ultimately have a negative impact on the siblings themselves.

Half of participants (50%) discussed how having a sibling with ASD has impacted their worldview. More specifically, participants shared that they felt the experience of growing up with a sibling who has ASD has impacted them in positive ways. Many participants shared that they felt more understanding of people in general as a result. This is confirmatory evidence for previously established conclusions regarding the positive impact of having a sibling with ASD (Mandleco & Webb, 2015). Many participants also felt that they were made a better person by being a sibling to an individual with ASD. This perception of a positive impact and changed worldview should not be overlooked.

Autism definition. All participants were asked to explain the diagnosis of ASD and each one (100%) explained ASD in terms of deficits or impairments. Using a deficit model to explain ASD is similar to existing findings regarding typically developing siblings understanding of ASD (Mandleco & Webb, 2015). However, the fact that all participants were able to provide an explanation is different from what has been documented previously in which a majority of typically developing siblings were unable to explain ASD (Orsmond & Seltzer, 2007). However, prior research has also suggested that typically developing siblings who are able to explain and understand the ASD diagnosis are more likely to avoid negative outcomes and might even benefit from having a sibling with ASD (Mandleco & Webb, 2015). It was demonstrated that understanding ASD and its associated behaviors facilitated acceptance and positive adjustment. It is important to note that typically developing siblings of individuals with ASD benefit from the ability to discuss the diagnosis with their parents in an honest dialogue (Mandleco & Webb, 2015). It is possible that participants in the current study were able to explain more about ASD because there is more social awareness regarding the diagnosis and presentation; studies in which participants were unable to provide this information were conducted nearly a decade ago.

Within the category of autism definition, two sub-categories were identified: difficult for sibling with ASD and limits of disability. Half of participants (50%) referred to things being difficult for their sibling with ASD and often connected this statement to perspective taking as well as a description of ASD. When siblings shared about perspective taking, they were exercising a degree of empathy for their sibling with ASD and reflecting on how things that are easy for them are often very difficult for their sibling with ASD. Empathy is typically mastered in adolescence, which could explain the amount of siblings in the present study who discussed perspective-taking and empathy (Lam et al., 2012). However, it has also been found that siblings

of individuals with ASD often have “enhanced empathy” for both their siblings and others (Pilowsky et al., 2004). As such, it is possible that the current findings related to empathy provide support for existing conclusions.

Many participants (60%) discussed the limits of ASD in conjunction with an explanation of an ASD diagnosis. Participants also discussed the limits of ASD when expressing frustration over their sibling’s challenging behavior. Siblings were able to articulate that although they might wish differently at times, they understand that there are certain things that they cannot change about their sibling with ASD. This suggests that participants have an understanding of the lifelong implications of ASD, which differs from existing conclusions suggesting otherwise (Mandleco & Webb, 2015). A recent review of the literature found that siblings of individuals with ASD reported that they believe their sibling could be cured and no longer display symptoms of ASD in the future (Mandleco & Webb, 2015). More information is needed regarding the factors which contribute to typically developing siblings’ understanding of ASD and the implication the disability has on their sibling.

Rating. Each participant was asked to rate how much they enjoyed being a brother or sister to their sibling with ASD. This rating serves as a quick indicator of sibling relationship quality. Participants were instructed that a rating of zero meant they did not enjoy their experience at all and a rating of ten indicated that they enjoyed their experience very much. Participants gave an average rating of 7.6. This suggests that, overall, participants regard their experience as a sibling to an individual with ASD positively. However, it is possible that participants felt obligated to respond with a higher number since it was obvious what the Principal Investigator was asking. The results of this dissertation should be interpreted together

to achieve a complete understanding of the experiences and sibling relationships between typically developing participants and their siblings with ASD.

Helping profession. An interesting finding of the current dissertation is related to the participants' future plans. All participants discussed future career plans when asked what they think they will do when they grow up. Half of participants (50%) discussed plans to go into a helping profession. More specifically, participant aspirations included the fields of nursing, special education, and psychiatry. Some of the participants expressed a desire to help others and explained that it was important for them to have a career which afforded them that opportunity. These findings are similar to a recent study which found a connection between some siblings of individuals with mild intellectual impairment being involved in helping professions and volunteer initiatives (Taylor & Shivers, 2011). For siblings of individuals with mild intellectual impairment, certain demographic variables were correlated with participation in volunteer initiatives and helping professions. This correlation was only demonstrated for female siblings and not males (Taylor & Shivers, 2011).

It is possible that participants plan to work in a helping profession because of their experience as a sibling to an individual with ASD. More specifically, it is also possible that the concept of "enhanced" empathy is also a factor in their future plans (Mandleco & Webb, 2015). Many individuals pursue careers in helping professions because of an inherent need and ability to care for others who need assistance. It is possible that the participants' future plans will change as they get older, but longitudinal information regarding careers of typically developing siblings of individuals with ASD would be interesting.

Limitations

The results of this dissertation provide a unique contribution to the existing literature. The results of this dissertation also provide insight to families and practitioners attempting to provide services to individuals with ASD and their families. However, the results and conclusions should be interpreted with the following limitations of this dissertation.

Recruitment Method

The Principal Investigator made several attempts to ensure full participation (10 participants) in the study. Initially, the Principal Investigator began by offering an incentive in exchange for participation in the current dissertation. More specifically, each participant was given a \$10 Amazon gift card at the conclusion of their participation. However, despite this, the Principal Investigator did not initially obtain enough participants. Secondary and tertiary recruitment sites were obtained and eventually resulted in the Principal Investigator securing full participation.

The recruitment sites selected might have impacted the results of this dissertation. The sites were all for individuals with ASD who were experiencing behavioral problems. As such, it is possible that the typically developing siblings might have a sibling experience which is not representative of all siblings of individuals with ASD. Additionally, recruitment was closed once the Principal Investigator received enough participants, which could have excluded other siblings from sharing their experiences. Furthermore, the long duration of data collection impacted by recruitment difficulties could have impacted the interview process and data analysis.

Participant Characteristics

In general, the current study employed a fairly homogeneous sample which should be considered when interpreting the results and applying the conclusions. Although there were even

numbers of males and females, other demographic categories were not represented in the current sample. For example, all of the participants live in New Jersey. Given the documented increase in ASD diagnoses in New Jersey (CDC, 2017), it is reasonable to assume that participants from New Jersey might not be representative of typically developing siblings of individuals with ASD in other states.

Similarly, nine of the participants were older than their sibling with ASD and one participant was a twin. Given the documented differences in the perceptions, outcomes, and relationships of older siblings versus younger siblings, it is possible that the results are not relevant for younger siblings (Mandleco & Webb, 2015). Additionally, all participants (100%) were Caucasian. This is relevant because there is evidence to suggest that culture impacts not only typical sibling relationships, but sibling relationships involving ASD (Lobato et al., 2011; Mandleco & Webb, 2015; McGuire & Shanahan, 2010; Tarakeshwar & Pargament, 2001). More research involving other demographic populations is necessary to understand the typically developing sibling experience.

Sibling Characteristics

In addition to participant characteristics, it is important to consider the characteristics of the sibling with ASD. The ten participants of the current dissertation came from seven families. As such, the characteristics of the seven siblings with ASD are relevant for interpretation. All of the siblings with ASD were also Caucasian which carries the same limitation as the participant siblings. Additionally, only one of the siblings with ASD was female; the remaining six were male. It is possible that the experiences of the participating siblings might differ depending on the gender of their sibling with ASD.

As previously mentioned, more than half ($n=4$) of the siblings were given an initial diagnosis of Pervasive Developmental Disorder-Not Otherwise Specified. Although this diagnosis is now considered a part of ASD, it is possible that differences might exist in the manifestation of ASD (CDC, 2017). The remaining siblings ($n=3$) were given an initial diagnosis of Autistic Disorder (Autism). More than half of siblings with ASD ($n=4$) engaged in challenging or aggressive behaviors. The remaining siblings ($n=3$) did not engage in these behaviors. The presence of challenging behaviors has been shown to be a cause of stress and unfavorable outcomes for typically developing siblings of individuals with ASD. Therefore, it is possible that the results of the present dissertation were impacted by the presence of challenging behaviors.

Interviewer Effects

The Principal Investigator utilized a Grounded Theory approach in an attempt to minimize any potential impact she might have on the results of the current dissertation. However, it is possible that certain interviewer effects exist. For example, it is possible that participants did not feel comfortable disclosing some aspects of their sibling relationship and experience with a stranger. However, there is evidence to suggest that siblings sometimes prefer speaking with unfamiliar individuals regarding their sibling with ASD (Mandleco & Webb, 2015). Additionally, many participants did disclose very personal details and emotions regarding their experience. These disclosures suggest that many participants did, in fact, feel comfortable in the context of the interviews.

One Rater

Due to practical considerations, the Principal Investigator was the sole rater of the transcripts. Typically, researchers attempt to get inter-rater reliability when conducting

qualitative research in an effort to increase the validity of the results. As such, the presence of a one-rater system should be considered when interpreting the results of this current dissertation. However, the Principal Investigator employed a specific data analysis procedure and took precautions to avoid any personal bias impacting the results and conclusions of this dissertation.

Implications and Future Research

The present dissertation provides additional evidence for the growing body of literature investigating the sibling relationships and experiences of typically developing siblings of individuals with ASD. Some of the information from this dissertation combined with previous research is relevant for practitioners and families. Although this dissertation answers questions regarding the typically developing sibling's experience, it also raises additional questions and concerns which should be addressed by future research.

Implications

Participants in the current study shared many important implications for their families as well as other typically developing siblings of individuals with ASD. Some participants provided specific pieces of advice that they thought would be important. One participant shared that she thought more professionals should consider the parents and siblings when designing services. She also spoke of the demands her sibling's diagnosis has placed on her mother. This perspective provides evidence for the implementation of respite programs and sibling support services (Tsao et al., 2011).

Another participant had advice for practitioners as well. He explained his experience in a sibling support group and felt that it was not helpful. The participant explained that he would

have found it more helpful if the facilitators knew his sibling with ASD and his family prior to attempting to intervene. This is an important consideration for practitioners in that all families are different as are all children with ASD. A thorough assessment of the family system might make sibling services more effective.

Participants also gave suggestions for parents of children with ASD. One participant shared that she sometimes noticed differential parental treatment as a child. Given the impact of differential parental treatment, it is important for parents to be aware of the perceptions of their typically developing children. This participant continued to explain that she has noticed an improvement in the functioning of her sibling with ASD as well as her sibling relationship since her parents have changed their expectations. This is relevant for parents who are attempting to navigate parenthood with both typically developing children and children with ASD.

Similarly, a participant discussed a lack of parental understanding regarding her feelings toward her sibling with ASD. This participant felt that her parent did not validate her feelings as “normal” or understand her experience as a typically developing sibling of an individual with ASD. This provides additional support for the suggestion that parents maintain open and honest conversations with all children regarding ASD and the impact it might have on them (Mandleco & Webb, 2015).

In addition to the advice specifically given by participants, there are many other implications for practitioners and families. Given the use of coping skills discussed by participants, it is possible that typically developing siblings of individuals with ASD might benefit from training in additional coping strategies to manage unpleasant emotions which might arise (Tsao et al., 2011). Additionally, typically developing siblings might benefit from honest discussions regarding their sibling’s diagnosis and future plans. Given the lack of shared

activities discussed by participants, it also might be helpful to facilitate interactions between typically developing individuals and their sibling with ASD.

Future Research

The current dissertation provides interesting implications for future research regarding the sibling relationship when an individual has ASD. More specifically, the exploratory nature of the current dissertation provides a basis for the development of a core category to define these sibling relationships. Additionally, the current dissertation confirms the existing themes of “contradiction” found in the research and suggests that typically developing siblings of individuals with ASD between the ages of eleven and sixteen describe their sibling experience in this way. Future research should investigate the contradiction to determine more specifically which aspects are positive and which aspects are negative.

Focusing on sibling perception is important because of the implications perception can have. For example, some typically developing siblings have experienced poor adjustment and relationships when they resented the additional responsibilities placed on them as a result of their sibling’s disability (Petalas et al., 2009). Therefore, the typically developing sibling’s perception of their roles and responsibilities for their sibling with ASD should be investigated and considered. In general, research which allows the participants to share their own thoughts and add additional information will allow for more genuine conclusions regarding sibling perceptions.

Many participants in the current dissertation indicated that they did not have a “normal” sibling experience. This is an important contribution to the research in that it was spontaneously mentioned by participants without prompting as a description of their sibling experience. The use of a Grounded Theory methodology allowed participants the freedom to actively contribute in

this way to the results of the current dissertation. Future research should continue to investigate how siblings define “normal” and whether there is a positive or negative value associated with the perception of being “normal.” The ratings provided by participants in the current dissertation suggest that their experience as a typically developing sibling to an individual with ASD is positive overall. However, more research is needed to confirm this conclusion and investigate perceptions of normality in sibling relationships.

Future research should continue to focus on understanding the experiences and relationships of typically developing siblings of individuals with ASD. Using a Grounded Theory methodology is important to preserve the meaning participants assign to their own relationships and experiences. Additionally, future research should address differences in demographic variables such as race, ethnicity, gender, and the incidence of challenging or aggressive behaviors. Given the existing conflicting findings, more research is needed to determine how sibling relationships might be different when one sibling has ASD.

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Appendix A

Interview Protocol

- 1) Tell me about you and your family
- 2) Tell me (more) about (name of sibling with ASD)
- 3) What is it like being (name of sibling with ASD)'s brother/sister?
- 4) If you had to measure how much you like being a sibling to (name of sibling with ASD), with 0 meaning that you don't really like it at all and 10 meaning that you really like it, what number would you pick? Why? *A visual of a thermometer with numbers will be used for younger participants if necessary.*
- 5) Tell me about some of the things you do with (name of sibling with ASD).
- 6) What is the best part of being a sibling to (name of sibling with ASD)?
- 7) Are there any other really good parts?
- 8) What is the hardest part of being a sibling to (name of sibling with ASD)?
- 9) Are there any other really hard parts?
- 10) How would you explain (sibling's diagnosis) to someone?
- 11) What advice would you give to other kids who have a brother or sister like (name of sibling with ASD)?
- 12) What do you think you will do when you grow up?
- 13) What do you think (name of sibling with ASD) will do when he/she grows up?
- 14) Is there anything else you want me to know?

Appendix B
Demographic Questionnaire

Name of person completing form: _____ Date: _____
Relationship to the participant: _____

Participant Information

Name: _____ Age: _____ Gender: _____

Ethnicity:

- | | | |
|--|--|---|
| <input type="checkbox"/> Asian or Pacific Islander | <input type="checkbox"/> Asian Indian | <input type="checkbox"/> Latino/Hispanic |
| <input type="checkbox"/> Black/African American (non-Hispanic) | <input type="checkbox"/> Caucasian/White | |
| <input type="checkbox"/> Native American | <input type="checkbox"/> Puerto Rican | <input type="checkbox"/> Other (specify): _____ |

Sibling Information (Sibling with ASD)

Name: _____ Age: _____ Gender: _____

Initial Diagnosis:

- | | | |
|--|---|--|
| <input type="checkbox"/> Asperger's Syndrome | <input type="checkbox"/> Autistic Disorder (Autism) | <input type="checkbox"/> Child Disintegrative Disorder |
| <input type="checkbox"/> Pervasive Developmental Disorder, not otherwise specified (PDD-NOS) | <input type="checkbox"/> Rett Syndrome | |

Does the individual have any additional diagnoses? If yes, please list: _____

Does the individual engage in challenging or aggressive behaviors?: ☐ Yes ☐ No

If yes, how often (on average)?: ☐ Rarely ☐ Weekly ☐ Daily ☐ Several times a day

If yes, what is the target of these behaviors? Check all that apply:

- ☐ Self ☐ Others ☐ Objects ☐ Other (specify): _____

Family Information

Are both siblings living in the home? ☐ Yes ☐ No

Please provide the age, gender, and disability status of any additional siblings: _____

Appendix C

Parental Consent

I am Caitlyn Cafferty Mehok and I am a School Psychology doctoral student in the Graduate School of Applied and Professional Psychology at Rutgers University. I am conducting interviews with typically developing siblings of individuals with autism spectrum disorders. The purpose of this research is to gather information about the nature of the sibling relationship when one sibling has an autism spectrum disorder.

Approximately ten subjects will participate in the interviews, and each interview is expected to last approximately one hour. However, the duration of the interview is somewhat determined by the participant and his/her responses to each question. The interviews will consist of a series of open-ended questions regarding your child's experience and relationship with his/her sibling with an autism spectrum disorder. At the end of the interview, your child will be given the opportunity to share any aspects of the sibling relationship that they did not previously discuss. Parents will also be asked to complete a short demographic questionnaire.

This research is confidential. Confidential means that the research records will include some information about you/your child and this information will be stored in such a manner that some linkage between your/your child's identity and the response in the research exists. Some of the information collected about you/your child includes demographic information, and interview responses. Please note that we will keep this information confidential by limiting individual's access to the research data and keeping it in a secure location. Consent forms, assent forms, demographic forms, and other relevant paper documents will be stored in a separate locked cabinet to ensure confidentiality.

The research team and the Institutional Review Board at Rutgers University are the only parties that will be allowed to see the data, except as may be required by law. If a report of this study is published, or the results are presented at a professional conference, pseudonyms will be used to ensure confidentiality. All study data will be kept for at least three years following completion of the research. Three years after completion of the research, all of the above mentioned data will be destroyed. Digital documents and files will be permanently deleted and all paper documents will be shredded. At no time will the data be available for public viewing.

There are no foreseeable risks to participation in this study. You/your child have been told that the benefits of taking part in this study may be: an opportunity to share personal experiences of being a sibling of an individual with an autism spectrum disorder and the ability to learn more about research outcomes if you/your child choose. However, you may receive no direct benefit from taking part in this study. You/your child will receive a \$10 Amazon gift card for completing the entire study.

Participation in this study is voluntary. You may choose for your child not to participate, and you may withdraw your child from participating at any time during the study activities without any penalty to you/your child. In addition, you/your child may choose not to answer any questions with which you/your child are not comfortable.

_____ Parent/Guardian's Initials

If you/your child have any questions about the study or study procedures, you/your child may contact myself at:

Caitlyn Cafferty Mehok
442 Brookside Drive
Roselle, NJ 07203
Tel: 732-439-1349
Email: caitcafferty@gmail.com

If you/your child have any questions about your rights as a research subject, please contact an IRB Administrator at the Rutgers University, Arts and Sciences IRB:
Institutional Review Board

Rutgers University, the State University of New Jersey
Liberty Plaza/Suite 3200
355 George Street, 3rd Floor

New Brunswick, NJ 08901-8559
Email: humansubjects@orsp.rutgers.edu
(732)235-9806

Your child will also be asked if they wish to participate in this study. You will be given a copy of this consent form for your records.

Sign below if you agree to allow your child to participate in this research study:

Name of Child (Print) _____

Name of Parent/Legal Guardian (Print) _____

Parent/Legal Guardian's Signature _____ Date _____

Principal Investigator's Signature _____ Date _____

Audio/Visual Addendum to Consent Form

You have already agreed to allow your child to participate in an interview about his/her relationship with his/her sibling with an autism spectrum disorder conducted by Caitlyn Cafferty Mehok. We are asking for your permission to allow us to audiotape your child as part of that research study. Audio recording is necessary for participation in the interview

All audio recordings will be transcribed. The recordings and transcriptions will be used for analysis by the research team. More specifically, the research team will identify common themes across all interviews. Furthermore, specific quotes from transcripts will be used to exemplify the themes and use the participants' own words when describing their experiences, but the quotes will not be associated with your child's name.

Due to the conversational nature of the interview, the audio recording might include the names of your children or other family members. However, pseudonyms will be used when the interviews are transcribed to ensure confidentiality. If your child says anything that she/he or you believe at a later point may be hurtful and/or damage his/her reputation, then he/she or you can ask that certain text be removed from the transcript.

Audio files and transcribed interview documents will be saved on a password protected memory key and stored in a second locked cabinet, apart from the demographic forms, consent forms, and assent forms. The transcribed interview documents and audio files will be labeled with your child's pseudonym. A master list with corresponding names and pseudonyms will be stored in a third locked cabinet.

All study data will be kept for at least three years following completion of the research. Three years after completion of the research, all of the above mentioned data will be destroyed. Digital documents and audio files will be permanently deleted and all paper documents will be shredded. At no time will the data be available for public viewing or listening.

Your signature on this form grants the investigator named above permission to record your child as described above during participation in the above-referenced study. The investigator will not use the recording(s) for any other reason than that/those stated in the consent form without your written permission.

Name of Child (Print) _____

Name of Parent/Legal Guardian (Print) _____

Parent/Legal Guardian's Signature _____ Date _____

Principal Investigator's Signature _____ Date _____

Appendix D

Child Assent

My name is Caitlyn Mehok. I work with parents and children but I am also a student. Right now, I am researching or trying to learn more about, what it is like to have a brother or sister who has autism. You are being asked to take part in this research since your brother or sister has autism.

If you agree to help with the research, I will ask you some questions about your family and your brother(s) or sister(s). It should take about an hour, but maybe a little shorter or longer. I will be recording what we say on a tape so that I can remember it later, but I will keep all your answers private, and will not show them to your parent(s)/guardian. The only other people who will hear what you say are people who work with me on my research so that we can learn about these relationships.

If you agree to talk with me, you will be helping me understand how it feels to have a brother or sister with autism. If adults understand what it is like, we might be able to help other kids like you and their siblings with autism. If you agree to talk with me and answer all of my questions, you will get a \$10 Amazon gift card as a reward. I don't think that any big problems will happen to you as part of this study, but you might not like talking about some of the things I ask you. That's okay; you can just ask me to skip to the next question.

You should know that:

- **You do not have to be in this study if you do not want to. You won't get into any trouble if you say no.**
- You don't have to answer any questions if you don't want to. You can just ask to "skip" to the next question.
- You can stop being in the study at any time.
- Your parent(s)/guardian(s) said it was okay for you to help with my research, but it is still up to you if you want to talk with me.
- You can ask any questions you have, now or later. If you think of a question later, you or your parents can contact me by phone at 732-439-1349

Do you understand what you will be doing if you help me with my research? ☐ Yes ☐ No

Did I answer all of your questions? ☐ Yes ☐ No

Sign and write your name here if you want to help me with my research AND if it is okay if I record what we say so I can remember later:

Your Name (Print) _____

Your Signature _____ Date _____

Principal Investigator's Signature _____ Date _____

Table 1

Participant Demographics

	<u>Number of Participants</u>	<u>Percent of Participants</u>
<u>Gender</u>		
Male	5	50%
Female	5	50%
<u>Age</u>		
11	1	10%
12	2	20%
13	3	30%
14	0	0%
15	1	10%
16	3	30%
<u>Ethnicity</u>		
Caucasian/White	10	100%
<u>Older or Younger than Sibling with ASD</u>		
Older	9	90%
Twins	1	10%

Table 2

Sibling Demographics

	<u>Number of Siblings</u>	<u>Percent of Siblings</u>
<u>Gender</u>		
Male	9	90%
Female	1	10%
<u>Age</u>		
8	2	20%
9	0	0%
10	4	40%
11	1	10%
12	1	10%
13	0	0%
14	1	10%
15	1	10%
<u>Ethnicity</u>		
Caucasian/White	10	100%
<u>Challenging Behavior</u>		
Yes	7	70%
No	3	30%
<u>Diagnosis</u>		
Autistic Disorder (Autism)	4	40%
PDD-NOS	6	60%