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Laura Nordone  
Sibling Relationships: Growing up  
with a sibling diagnosed with Autism  
Spectrum Disorder and its influence  
on perceived family cohesion,  
attachment, and current life  
satisfaction

## **ABSTRACT**

When there is a child with Autism Spectrum Disorder (ASD) in a family, the whole system is profoundly impacted. Little is known about the impact having a sibling with ASD has on the typically developing siblings within a family, as the research that exists on the topic has typically been conducted using parent-impressions of the sibling dyads, making it difficult to infer how the typically developing children themselves make meaning of their internal experiences (Petlas, Hastings, Nash, Hall, Joannidi, & Dowey, 2012; Tomney, et al., 2012). In a sample of 67 adult siblings of individuals with ASD, perceived attention in childhood, attachment to caretaker, current quality of life, and the desire for their sibling with ASD to be typically developing are examined through the use of an online questionnaire. Subjects that reported an unequal amount of attention in childhood had less secure attachments to their caregivers and a poorer current quality of life in comparison to those subjects that reported an equal amount of attention from caregivers in childhood. Subjects that reported a poorer current quality of life were more likely to wish that their sibling with ASD had been typically developing during childhood. Results support the importance of the typically developing siblings to perceive similar amounts of attention as well as the importance for mental health practitioners to provide these siblings with support.

**SIBLING RELATIONSHIPS: GROWING UP WITH A SIBLING DIAGNOSED WITH  
AUTISM SPECTRUM DISORDER AND ITS INFLUENCE ON PERCEIVED FAMILY  
COHESION, ATTACHMENT, AND CURRENT LIFE SATISFACTION**

A project based upon an independent investigation,  
submitted in partial fulfillment of the requirements  
for the degree of Masters of Social Work.

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2014

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## **CHAPTER I**

### **Introduction**

In 2013, the prevalence of Autism Spectrum Disorder (ASD) was 1 in 88 among 8-year-old children (Center for Disease Control and Prevention, 2013). According to the *Diagnostic and Statistical Manual of Mental Disorders* (5<sup>th</sup> ed.; *DSM-V*; American Psychiatric Association, 2013), behavioral markers of a child with an ASD diagnosis include ongoing struggles in social communication and interactions, and repetitive and restricted behaviors and interests. Symptoms begin in early development and result in a general impairment of functioning in social or occupational areas, such as deficits in skills needed to make, develop, and maintain relationships. Since the introduction of ASD to the original *DSM*, in 1940, negotiating the needs of those with ASD has impacted many facets of society, notably the fields of mental health and education (Jones & Schwartz, 2004; Thompson, 2013). In addition to those diagnosed with ASD, the families and caretakers of the children who receive this diagnosis are profoundly affected by ASD, as the atypical needs and communication styles associated with ASD present unique challenges for many families. Service plans and treatment modalities created for children with ASD often include parents as participants in treatment with their ASD children. However, although researchers are increasingly noting the importance of including siblings in treatment (Cebula, 2011; Ferraioli, Hansford, & Harris, 2012; Tsao, Davenport, & Schmiege, 2011), similar services are not typically extended to the siblings of children with ASD.

Sibling relationships are instrumental to social development during early developmental years (Brewton, Nowell, Lasala & Goin-Kochel, 2012; Tsao et al., 2011). As infants and children learn to navigate the world and begin to understand social cues, they often turn to siblings for assistance and for behaviors to mirror (Oppenheim-Leaf, Leaf, Dozier, Shaldon, & Sherman, 2012). This process of teaching, learning, and mirroring behaviors has a profound effect on sibling relationships, as well as family cohesion, attachment, and socio-emotional functioning (Oppenheim-Leaf et al., 2012; Pulakos, 1990; Richmond & Stocker, 2006). Attachment style, family cohesion, and sibling relationships are all related in that the attachment style a child has with their caregiver impacts sibling relationships in addition to the overall cohesion of the family (Fortuna, Holland, Roisman, Haydon, & Groh, 2011).

In a family where there is a child with ASD, siblings who do not display any symptoms or traits of ASD are commonly referred to as *typically developing* siblings, or TD (Brewton et al., 2012; Rivers and Stoneman, 2003; Tomeny, Barry, & Bader, 2012; Tsao et al., 2011). For typically developing siblings, the process of teaching, learning, and mirroring behaviors from a sibling with ASD is atypical, as ASD is marked by a profound impairment in social development, including: reading social cues, having back-and-forth conversations, using words to describe feelings, inflexibility of routines, and repetitive habits of behavior (American Psychiatric Association, 2013). Given the disruption of the natural sibling learning process in a family where there is a child with an ASD diagnosis, is it possible that family cohesion and attachment are also affected more generally?

Having a child with ASD in the family not only impacts the ASD child and his or her parents, but also the other children in the family. Despite this, little research has been conducted on the impact of the presence of a sibling with ASD among typically developing siblings.



Researchers have suggested that typically developing siblings are sometimes *parentified* in their roles, meaning that they take on more caretaking roles in the family, thereby increasing the potential of their feeling neglected by parents (Bauminger & Yirmiya, 2001). Others have suggested that families in which there is both a child with ASD and a typically developing sibling show discrepancies in how parents treat each child in a family, thus increasing the likelihood for sibling tension and decreasing family cohesion (Brody, Stoneman, & McCoy, 1994). However, little is known about the impact this has on the typically developing sibling, as the little research that exists on the topic has typically been conducted using parent-impressions of the sibling dyads, making it difficult to infer how the children themselves make meaning of their internal experiences (Petlas, Hastings, Nash, Hall, Joannidi, & Dowey, 2012; Tomney, et al., 2012). When siblings and parents have both participated in a study, researchers have found that parents reported less positive impressions about their children's sibling relationships than the siblings themselves reported (Rivers & Stoneman, 2003). Therefore, to better understand the typically developing sibling experience within families who have a child with ASD, more research is needed on the typically developing siblings. The purpose of the current study is to advance the field by conducting a series of analyses to address two specific aims:

1. Explore the recalled childhood experience of family cohesion among adults raised as siblings of an ASD child.
2. Evaluate the relationship between family cohesion in childhood and current life satisfaction.

My research questions are: Among adults who grew up as the sibling of a child with ASD, is there a relationship between the perceived attention received from one's caretaker(s) and

one's memory of family cohesion and attachment? Is there a relationship between one's memory of family cohesion and current life satisfaction?

## **CHAPTER II**

### **Literature Review**

This literature review focuses on both theoretical and empirical research that was used to articulate the current study. Peer Modeling, Family Systems Theory, and Attachment Theory will be used to frame the experiences and outcomes of typically developing siblings in families with ASD children. Findings from empirical research will be used to illuminate the importance of sibling relationships in social learning, family cohesion, and attachment. Specific attention will be given to sibling relationships and family functioning when at least one child in the family is disabled and at least one is not. To better understand the potential impact that a child with ASD might have on a typically developing sibling, it is first important to understand how ASD is defined.

#### **Understanding Autism Spectrum Disorder**

Autism Spectrum Disorder (ASD) is a life-long, neurodevelopmental disability characterized by “deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships” (American Psychiatric Association, 2013, p. 31). Although the most recent version of the *DSM-V* labels all subtypes as Autism Disorder (American Psychiatric Association, 2013), ASD commonly takes three subtypes among mental health professionals: Autistic Disorder,

Asperger's syndrome, and Pervasive Developmental Disorder- Not Otherwise Specified. While symptoms vary depending on the individual, they typically fall into three categories: social impairment (e.g. little eye contact, unable to make and/or maintain relationships with peers), communication difficulties, and repetitive and stereotyped behaviors (e.g. the need to have a rigid routine; McLuckey, 2013).

There are many proposed ways to best work with a child who has ASD, including Behavioral Therapy and Family Therapy (Locke, Rotheram-Fuller, & Kasari, 2012; Sears, Blair, Iovannone, & Crosland, 2012). For example, the Prevent-Teach-Reinforce Model is a family therapy model that stresses family collaboration in conjunction with positive behavioral support with the child with ASD. Alternatively, peer-mediated interventions are based on behavioral models which stress the importance of having peers intervene with a child with ASD in the school system, as this can be an important and less stigmatizing way to intervene with a child with ASD. (Locke et al., 2012; Sears et al., 2012). Regardless of treatment modality, McLuckey (2013) suggests using a traditional social work model, which stresses the importance of families, teachers, and siblings in treatment:

[An] ecological perspective focuses on coping tasks of the client and the coping supports that must be provided. This perspective looks at the environment, home, and community.

The social worker should include parents, siblings, and teachers in the assessment process because they are a valuable source of information about the child's development. (p.3)

Therefore, to best serve youths with ASD, it is important for researchers to explore ways of better understanding ASD individuals in their ecological spheres, including their typically developing siblings.

## **Theoretical Research**

**Peer Modeling Theory.** Peer Modeling Theory stems from the idea that much of one's own behavior is learned through the observation and imitation of others; the learning of a behavior is strengthened or learned for the first time by modeling another's behavior (Richards, Heathfield & Jenson, 2010). Many researchers have framed their study of social learning on Peer Modeling Theory. For example, peer modeling in the academic setting has been used to explore how children learn from peers both in the schoolyard and in the classroom (Jones & Schwartz, 2004; Locke et al., 2012; Richards et al., 2010). Using Peer Modeling Theory, researchers have suggested that students learn social cues from observing peers, and that students with disabilities would be better served by integrating among their typically developing peers (Jones & Schwartz, 2004). Jones and Schwartz (2004) also explored the effectiveness of peer modeling in multiple domains, including peers, siblings, and parents. Their research was one of the first to consider how modeling in the home affects both typically developing siblings as well as disabled youths. They argued that children with ASD might learn the most from their siblings, instead of peers and adults. Thus, the importance of the sibling relationship and the effect that one sibling can have on the other is important to keep in mind.

**Family Systems Theory.** Family Systems Theory influences research in which investigators explore the impact of family on individual development. The importance of family rules and family roles are stressed in order for the family to define its relationships with one another and carry out everyday tasks (Goldenberg & Goldenberg, 2013). For example, Family Systems Theory has been used to frame the idea that parents will not respond in the same manner to each child. The way in which a parent responds to each child, and the way in which each

sibling may respond to the differences in the way each sibling is treated will impact how each child functions in the family and in the greater society (Goldenberg & Goldenberg, 2013).

In each family system there are independent subsystems. Examples of subsystems may include: a parental subsystem, a parent and child subsystem, and a sibling subsystem. It is through the lens of the sibling subsystem that one can begin to better understand the importance of sibling interactions (Goldenberg & Goldenberg, 2013; Ferraioli et al., 2012). For example, McHale, Updegraff, and Whiteman (2012) explain that, “sibling influences emerge not only in the context of siblings’ frequent and often emotionally intense interactions but also by virtue of siblings’ roles in larger family system dynamics” (p. 913). Certainly, siblings who live in the same home represent a subsystem which offer opportunities for learning that cannot occur anywhere else, and have direct impact on one another’s development in the forming of relationships outside of the house (McHale et al., 2012).

Kaminsky and Dewey (2001) have written that social support from family members is very important to the development of siblings and sibling adjustment. Indeed, siblings contribute to learning skills that work on social, emotional, and cognitive development (Cox, 2010; Davies & Cicchetti, 2004; Rivers & Stoneman, 2003). According to Cox (2010) “the sibling relationship is especially well suited for learning to stay involved in the face of emotional conflict. And because siblings are not usually the same age, the sibling relationship is also a context for practicing leadership as well as following” (p.95). Thus, this theory is well suited to frame the exploration of sibling relationships and their effects on the typically developing siblings in families that have a child with ASD.

Finally, Family Systems Theory gives one potential explanation for how siblings adjust to having a child with an ASD diagnosis in the family. As Bauminger and Yirmiya (2001)

explain, “Problems in adjustment are more likely to occur in families in which the nondisabled children take over parental duties for the child with a disability, with older girls in the family at greater risk to experience ‘role tension’” (p. 74). The need for clear role definition in a family with a higher needs child is a family systems issue because without it, there is an increased likelihood for the typically developing child to take on a parentified role, in which a child is asked to play the role of another parent. This behavior has the potential to put increased stress on both the child and the entire system. Additionally, parents can be overprotective of a child with a handicap, thereby creating the potential to intensify sibling rivalry (Kennedy, 1985). It is more than likely that a family that includes a child with ASD will have different sets of roles and rules within the family and while the subject of the parentified child is supported in theoretical research, there is a lack of empirical research. To address this gap in existing literature, the present study will consider the idea of parentification among typically developing siblings.

**Attachment Theory.** Siegel (1999) explains attachment as “an inborn system in the brain that evolves in ways that influence and organize motivational, emotional, and memory processes with respect to significant caregiving figures” (p.67). According to attachment theorist, John Bowlby, the four different forms of attachment seen in childhood are secure, avoidant, ambivalent, and disorganized (Shillkret & Shillkret, 2011). In a broader context, attachment styles can be seen as “secure” or “insecure” (Siegel, 1999).

One way of measuring attachment is by looking at the parent-infant dyad. Specifically, by looking at how the mother attunes to the infant and assists the infant in regulation of the arousal system (Schoore, 2005). Siegel (1999) explains, “the emotional transaction of secure attachment involve a parent’s emotionally sensitive responses to a child’s signals, which can serve to amplify the child’s positive emotional states and to modulate negative states” (p.67). For

example, a securely attached infant is able to use the mother (or primary caregiver) as a safe base and will explore new surroundings, fully knowing that the infant can return to the mother when distressed (Shillkret & Shillkret, 2011).

The initial attachment to one's caregiver provides a working model for attachment relationships throughout life that assist with interpreting, regulating, and understanding different environmental and relational events (Schoore, 2005). A child with a secure attachment to one's parents is able to explore the world and develop relationships with others. These children are able to seek proximity with their attachment figures when feeling upset, as the attachment figure provides them with a sense of security. As these children get older, they are able to internalize their attachment figure and the feeling of being safe (Siegel, 1999).

An "insecure" attachment can be broken up into three categories: avoidant, ambivalent, and disorganized (Siegel, 1999). When a parent is emotionally unavailable, inconsistently available, or shows frightening communications to the infant, an insecure attachment to caregiver is formed (Siegel, 1999). When an insecure attachment relationship is formed, the infant will not have a sense of a secure base, and thus "the development of normal behaviors (such as play, exploration, and social interactions) will be impaired" (Siegel, 1999, p. 72). While an individual's attachment style can fluctuate throughout one's life, as attachment in general is on a spectrum, often the attachment style seen in infancy and childhood persists through adulthood (Shillkret & Shillkret, 2011).

If one child in a family is securely attached to the main caregiver, this does not necessarily mean that another child in the same family will also be securely attached. Kennedy (1985) suggests that when the first child in a family has a disability, that when a second child is born, it can impact the mother's ability to appropriately relate to and attach to the second child.



The mother is preoccupied with the firstborn child. Understanding attachment in regards to sibling relationships is important to the current study because, “attachment to parents has been shown to play a role in sibling relationships in early years” (Fortuna et al., 2011, p. 1367). Additionally, it has been suggested that how an individual perceives their attachment style as a child can also impact their relationships as an adult (Fortuna et al., 2011). Studying sibling relationships provides valuable insight into the importance of family cohesion and attachment style.

**Integrated perspectives.** Family Systems Theory and Peer Modeling help explain the importance of sibling relationships within a family. Family Systems Theory explains role tension and typical family roles in helping to further explain sibling development in relation to other siblings in a family. A potential limitation with Family Systems Theory is the emphasis on the whole family and not just sibling interactions. Peer modeling theory resolves this by conceptualizing siblings as peers who learn from one another (Jones & Schwartz, 2004). Attachment theory provides a bridge to frame family systems and peer modeling. According to Fortuna et al. (2011), “family systems research in particular suggests that parental behaviors and the emotional tone of parent-child interactions are transferred into the sibling system” (p. 1367). In consideration of later outcomes for typically developing siblings, attachment theory also emphasizes how early childhood attachment influence life satisfaction in adulthood.

### **Empirical Research**

**Impacts of the whole family.** Working with individuals should also involve conceptualizing their role in their larger family system. Family cohesion and the family environment have the ability to impact, not only sibling relationships and externalizing behaviors, but also the closeness of relationships with adult siblings. (Brody et al., 1994;

Pulakos, 1990; Richmond & Stocker, 2006). The more cohesive the family, the closer sibling relationships tend to be (Pulakos, 1990). For example, Richmond & Stocker (2006) demonstrated that whole family functioning can both impact an adolescent's behavioral problems and influence a child's adjustment by showing that adolescents whose families are more cohesive tend to reach out to multiple family members for support and are more apt to discuss personal matters within the family than are those whose families are less cohesive. They also found that more communication was correlated with a more cohesive family, as well as less externalizing behaviors for the adolescent (Richmond & Stocker, 2006). Their research suggests that an emphasis on the whole family might be useful when a child or adolescent is in therapy, as an individual is influenced by the whole. Cohesive families tend to demonstrate "emotional connectedness, openness, and flexibility" (Richmond & Stocker, 2006, p. 667), while less cohesive families tend to demonstrate more emotional distance. Family cohesion is also related to how close one feels to other siblings, as when a family is more cohesive, siblings tend to be closer and more open with each other.

It is also important to consider the implications of differential parental treatments. Perceived parental favoritism can be correlated with an increase in sibling rivalry and overarching themes of conflict and competition that may persist over the lifespan (Kennedy, 1985). If an individual believes that they are the disfavored one in the family, they tend to show higher family disengagement and a perception of lower family cohesion (Brody, Copeland, Sutton, Richardson, & Guyer, 1998). The perception of parental differential treatment can also be attributed to negativity within a sibling dyad, and more feelings of anger and rivalry (Brody et al., 1994). However, when positive parent-child relationships are present, there is a tendency for more prosocial behaviors between siblings (Brody et al., 1994). While sibling dyads tend to be

the focus in primary literature, the recurring theme is the importance of parent-child relationships on sibling dyads, and the importance of family cohesion.

**Sibling relationships.** Early perceptions of sibling and family relationships have the potential to influence adult sibling relationships. In a study of 60 sibling pairs, ages 18-25 years, Fortuna et al. (2011) found that individuals who dismissed the importance of early attachment needs and early relational experiences tended to also report less warmth in their current sibling relationships (Fortuna et al., 2011). This illuminates the importance of young adult's perception of their childhood attachment relationships and its influence on the quality of adult relationships. This suggests that attachment styles in childhood influence sibling interactions in adulthood.

Siblings can have profound effects on one another, as they often serve as not only role models, but social partners. For example, McHale and colleagues (2012) found that sibling dyads have the ability to influence the larger family dynamics, as they hold a specific role within a family, and therefore they have the ability to impact family structure as well as dilute resources. The authors discussed the importance of working with and interviewing the sibling dyad, as it provides an easier way to form a connection with the ASD individual and enter into a working family system. Working with the siblings of an individual with ASD can be less stigmatizing for the ASD individual than only working with the parents (McHale et al., 2012). Finally, while much of the research dealing with ASD siblings tends to rely on parent interviews alone, McHale et al. (2012) stressed the importance of interviewing the siblings of those in treatment. This is an important step forward in ASD research, as it makes sense that parents cannot possibly know what goes on in a sibling dyad as well as the siblings themselves.

The importance and impact of sibling relationships is a theme well supported throughout existing literature. Gamble, Jeong, and Kuehn (2011) studied the effects of trustworthiness and

modeling on adolescent siblings' adjustment to environmental and social situations outside of the home and found that sibling relationships tend to have two types of interactions: positivity (such as warmth and affection) and negativity (such as conflict, rivalry, and aggression). They found that sibling positivity assists in the development of pro-social behaviors, which assists in protecting against problem behaviors throughout childhood. Conversely, sibling negativity, such as controversy between siblings was correlated with poor adjustment among siblings (Gamble et al., 2011). Those siblings who displayed poor adjustment tended to display more internalizing and externalizing behaviors outside of the home. Sibling trustworthiness and the trusting of one another is also illuminated, and correlated to the positive adjustment of both siblings to larger social situations and the trusting of others outside of the sibling dyad. In addition to the potential effect on later adjustment, the authors found that siblings can take the peer modeling that they learn at home from siblings and apply this to other relationships outside of the home (Gamble et al., 2011).

**Birth order.** Implications of birth order and its effects are a contentious topic. While popular media may often state that birth order has direct impacts on personality type, research tends to show only weak to moderate effects on personality (Bleske-Rechek & Kelley, 2014). Even if it may be beneficial for the oldest sibling to be dominant in the home, this does not necessarily transition to that child's behavior outside of the home or on the playground (Bleske-Rechek & Kelley, 2014). However, there is a correlation between birth order and perceived family roles. In a study of 200 undergraduate students, participants reported that the oldest child tended to have the responsible role in the family, the middle child filled the popular role within a family, and the youngest held the spoiled role (Pulakos, 1987). In families with only two children, there tended to be little role differentiation, whereas when there were three siblings,

there was a stronger differentiation between perceived roles. Additionally, it is important to note that males tended to be seen in the irresponsible role more often than females (Pulakos, 1987). To date, there is very limited research on the impact of birth order on ASD sibling relationships. However, this is important to consider in the current study, as the addition of a sibling with ASD to the family changes the roles within the system (Bauminger & Yirmiya, 2001). Thus, it may be important to see if birth order makes a difference to the family roles, which could thereby assist practitioners when working with a family where there is a child with ASD.

**Siblings with ASD.** There is little research on the experience of growing up with an ASD sibling among typically developing individuals, and among the studies that have been completed, results are mixed. Interestingly while researchers have found that typically developing individuals tend to report the experience has having been positive or negative, it is rarely reported as neutral.

Some studies suggest that the severity of behavioral problems in children with ASD is directly related to increased behavioral problems in their typically developing siblings (Gold & McCabe, 2012; Tomnety et al., 2011; Petalas, et al., 2011). Petlas and colleagues (2011) found that typically developing sibling adjustment is related to externalizing behavioral problems in their ASD sibling. Meaning, if a sibling with ASD has a behavior problem, there is a greater likelihood for the typically developing sibling to have a behavioral problem. Meyer, Ingersoll, and Hambrick (2011) examined possible predictors of adjustment difficulties in TD individuals who have a sibling with an ASD diagnosis and found that symptom severity in the child with ASD had a positive correlation to the adjustment difficulties that their typically developing siblings had (Meyer et al., 2011).

Both Rivers and Stoneman (2003) and Kaminsky and Dewey (2001) note that family context is important when assessing the quality of a sibling relationship. Rivers and Stoneman (2003) looked at marital stress in a study of 50 families and found that when marital stress was high, the quality of relationship between the TD sibling and child with ASD was compromised. The authors highlight the importance of family cohesion and family dynamics on sibling relationships (Rivers & Stoneman, 2003). Similarly, Kelley, Garnett, Attwood and Peterson (2008) demonstrated families with a high level of stress, family conflict, and lack of cohesion showed an increase in anxiety and depression within members of the family.

Kaminsky and Dewey (2001) investigated sibling relationships of children with ASD and compared them to children with Downs Syndrome, as well as siblings of typically developing children. Ninety subjects were used in this study, 30 per group. Results showed that sibling relationships in families where there is a child with ASD had less intimacy and nurturance, and fewer pro-social behaviors than the other groups (Kaminsky & Dewey, 2001).

While the above studies suggest that there may be negative effects to having a sibling with ASD, Dempsey, Llorens, Brewton, Mulchandani, and Goin-Kochel (2012), suggest that TD siblings are not necessarily at risk for more severe externalizing behaviors. In their study, they questioned 486 families, divided into two groups. One group had a sibling identified with ASD, and the other control group did not. In a survey of parents and teachers, the researchers did not find significant differences in internalizing or externalizing behaviors between groups. In another study, Macks and Reeve (2007) show that the presence of a sibling with ASD can enhance the psychosocial and emotional development of TD siblings. However, a caveat existed in their research and as demographic risk factors increased, there were more negative impacts on the TD sibling's relationship with their ASD sibling. Additionally, Tomney et al., (2011) found that

there was less conflict between siblings the longer that time had passed since the child with ASD was diagnosed (Tomney et al., 2012).

While much of previous research shows that having a child with ASD in a family impacts the TD sibling in some way, Petlas, Hastings, Nash and Duffs (2013) disagree, as they found that sibling dyads between ASD and TD siblings have typical sibling interactions. In their study, 12 adolescents with ASD were interviewed and reported that overall these sibling dyads were beneficial and these siblings had positive relationships with one another. While researchers did not interview TD siblings, they suggested that the results from the adolescents with ASD were typical and positive in comparison with sibling relationships where there is not someone in the family with ASD, although no control group was used in this study. Petlas et al. (2013) explain that, “despite the social context reinforcing views that autism impacts the sibling relationship in an atypical way, the overwhelming sense from participants was of typical siblings relationships” (p.1). While this research provides different insight into the sibling dyad where there is a sibling with an ASD diagnosis, it is important to note that only 12 adolescents were used in this study, and the findings have not been replicated.

It is worth noting that the majority of studies who claim to be investigating sibling relationships in this population chose to survey the parents, rather than members of the dyad itself (Gold & McCabe, 2012; Macks & Reeve, 2007; Tomney et al., 2011; Petalas et al., 2011). This is important, as siblings’ and parents’ views tend to be incongruent in studies of family dynamics. For example, Ohannessian, Lerner, Lerner, and vonEye (2012) discuss the discrepancies in adolescents’ and parents’ perceptions of family functioning. In this study, adolescents viewed family relationships more negatively than parents. Conversely, Rivers and Stoneman (2003) suggest that when parents are reporting on their children’s relationship, they

tend to state that the relationship is less positive than when asking siblings' perspectives on their relationships. Additionally, a common theme noted was the need for more attention and research on sibling adjustment as well as sibling relationships in families where there is a child with a diagnosis of ASD (Gold & McCabe, 2012; Tomney et al., 2011; Petalas et al., 2012). Due to the discrepancies between siblings' and parents' reporting of the sibling relationship, and the overarching practice of researchers primarily interviewing parents, it is this author's intent to question only siblings for the purpose of this current study.

**Overarching methodological issues.** Research in the field of ASD- TD sibling relationships has been conducted using Quantitative Methods, specifically Cross-Sectional Design or Case Control Study. When a Case Control Study is used, surveys are typically given to both a control group (where there is no sibling with ASD) and the test group (where there is a sibling with ASD) (Cebula, 2011; Tomney et al., 2011). The typical goals of these studies are to compare the control group with the test group and see if the group with a sibling with ASD is higher or lower on the given scales. Those that do not use a control group, and utilize a Cross-Sectional Design looking specifically at using rating scales and self-report inventories to see what data can be gathered to further the research in siblings of a child with ASD (Rivers & Stoneman, 2003). Surveys were the most common instrument used, and were typically given to adults (specifically the parents), even when assessing sibling relationships. This demonstrates the need to tap into the population of the siblings themselves, because they have not been commonly given a voice.

### **Synopsis of literature and statement of implication**

Current literature suggests ASD has the potential to impact sibling dyads and the family system as a whole in many ways. Identifying these positive and/or negative aspects of the sibling



dyad can be helpful to families when there is an identified child with ASD. Kaminsky and Dewey (2001) suggest that sibling relationships where there is a sibling with ASD have less intimacy, while Dempsey and colleagues (2011) suggest that there is no extra risk factor to TD children when there is a sibling with ASD in the home. Meyer et al. (2011) and Petlas et al. (2011) suggest that a TD siblings' adjustment can be directly correlated to the outward behaviors of the child with ASD. Some studies indicate that there are positive relations between siblings when one is identified with ASD, potentially showing more warmth, care, and protective factors. Other studies state the importance of including siblings in the actual treatment of children with ASD and the importance that a typically developing sibling may have on teaching their sibling with ASD specific skills (Brewton et al., 2011; Ferraioli et al, 2012; Oppenheim-Leaf et al., 2011). Finally, parental marital stressors, and family cohesion can affect sibling relationships, especially in those relationships where one sibling is diagnosed with ASD (Kelley et al., 2008; Rivers & Stoneman, 2003). Theoretically, through the use of Family Systems Theory in conjunction with Attachment Theory, it is important to look at family dynamics and family cohesion when looking at sibling relationships (Cox, 2010). Under the theory of Peer Modeling, the importance of siblings on a child's development and learning prosocial skills is illuminated (Jones & Schwartz, 2004).

### **Purpose of the current study**

It is through the lens of Attachment Theory and Family Systems Theory that the importance of early childhood relationships is stressed. By using Peer Modeling Theory, one is able to better understand the impact that siblings can have on one another in development. These three theories together provide the groundwork for understanding the importance of a family system and family cohesiveness on the development of children. When a child with ASD is a

part of this family, adjustments within the family need to be made in order to best serve the child with ASD's needs. The previous research demonstrates that there is an effect, either positive or negative, on having a sibling with ASD in the family. Having a child with ASD can impact not only the parents and TD siblings, but the family structure as a whole. Little research has been conducted looking at adult siblings, and what they felt when growing up in a household with a sibling with ASD. Is there a perception of family cohesiveness? Does one's perception of family cohesion also impact that individual's current life satisfaction? It is the hope that this current research can shine a light onto the impacts of having a sibling with ASD can have not only on a family, but on quality of life for those TD siblings. In turn, perhaps providers can be given suggestions in order to work toward making the addition of a child with ASD in a family be a more positive experience.

## **CHAPTER III**

### **Methodology**

This study is an investigation into the relationship between perceived family cohesion in childhood in relation to current life satisfaction of typically developing individuals who grew up with a sibling diagnosed with Autism Spectrum Disorder (ASD). The research question for this study is: Among adults who grew up as the sibling of a child with ASD, is there a relationship between the perceived attention received from one's caretaker(s) and one's memory of family cohesion and attachment? Is there a relationship between one's memory of family cohesion and current life satisfaction?

#### **Research Design**

The current study uses Quantitative Methods. Data for the current study was collected confidentially using a cross-sectional, nonrandomized, convenience sample. The current study was designed with the intention of exploring individuals' experiences of having a sibling with ASD, which will, in turn, help social workers better understand and work with this population. A self-administered online survey was used in order to seek out a large participant pool and maximize effort for the sample.

## **Sampling**

**Selection criteria.** Nonprobability convenience sampling and snowball sampling were used to gather participants. Adult sibling participants were defined as individuals being 18 or older and needed to have a sibling that had been diagnosed with Autism Spectrum Disorder.

**Sampling Techniques.** Nonprobability convenience sampling and snowball sampling were used to gather participants. Data were collected via Survey Monkey, an online survey tool, from January 31<sup>st</sup>, 2014 through March 7<sup>th</sup>, 2014. Following approval from the Human Subjects Review Committee (HSRC) at Smith College School for Social Work (see Appendix A for approval letter), contact with different agencies that may have communication with the target population was established. Emails were sent out to the Disability Rights New Mexico (DRNM), Youth Advocates of Sitka, INC. (YAS), Collage, Sibling Support Project, and MD Junction: Siblings of Children Support Group (see Appendix B). These letters described the current study and the selection criteria for those that may participate in the study. This author had previous connections with DRNM, Youth Advocates of Sitka, INC., and Collage. This author had previously worked at both YAS and DRNM, and had a family member that was affiliated with Collage, which is located in Philadelphia, PA. In an attempt to gain as wide and diverse a sample as possible, two online sibling support groups were found through a Google search and contacted as well: Sibling Support Project and MD Junction: Siblings of Children Support Group. A sample letter and criteria needed to participate in my survey was posted to both of these support groups' online discussion boards.

Additionally, a message was posted on Facebook and Reddit (see Appendix C) asking the Facebook and Reddit community if they, or anyone they knew, had grown up with a sibling that had been diagnosed with ASD, and if so asking them to consider participating in the current

study. The message on Facebook was posted through this author's personal page, with the option for others to share the post to reach a larger target audience.

### **Data Collection Methods**

**Informed consent procedures.** Before participants began the questionnaire, they were provided with an informed consent letter (see Appendix D). This letter explained the purpose of the current study, eligibility criteria, a description of the study procedures, any potential risks or discomforts, an explanation of benefits of the current study, confidentiality, payments, the right to refuse or withdraw, and the right to ask questions. Participants were then able to electronically indicate whether they consented to participate in the study or not. They were asked to select either "I agree to participate" or "I do not agree to participate." If participants did not agree, they were directed to the final page of the survey. This page provided resources for counseling in the event that the current study caused any discomfort. For those who agreed to participate in the study, when they hit the "next" button, they were directed to the demographic data questions.

Participants were given the option of remaining anonymous in the survey. Anonymity would be maintained unless one of two things occurred: One way for anonymity to be broken was if participants chose to participate in the Amazon Gift Card Drawing. If participants wanted to be entered into this drawing, they were asked to provide their email addresses. The second way for anonymity to be broken was if participants chose to contact this author with an interest in obtaining a copy of the summary of results. However, it was made explicitly clear to participants that, if they chose to make their identities known, it would not be possible to link their name to the survey they completed. Participants were also assured that confidentiality would be upheld, as no participant names or identifying data would be shared in any written reports or findings.

**Demographic Data.** The demographic questions were used with the hope to gather specific information on participants, such as: geographical location, age, race, ethnicity, class, and job status. Additionally, under this section, specific questions were asked regarding birth order for both the current participant and their sibling with ASD (to see a full copy of the survey used for this study, see Appendix E).

**Quantitative Data.** The parent subscale of the Inventory of Parent and Peer Attachment (IPPA) was used to measure the attachment each respondent remembered feeling towards his or her caretaker growing up (Armsden & Greenberg, 1987). See Attachment F for the letter asking for permission and for the response when permission was granted. Twenty-five questions were asked that explored parental attachment. Participants were asked to answer the questions using a 5-point Likert Scale ranging from 1: “Almost Never or never true,” to 5: “Almost always or always true”. Questions ranged from, “My caregiver respected my feelings” to “my caretaker expected too much from me” to “I didn’t get much attention from my caretaker.” The measure had acceptable inter-item reliability of ( $\alpha = .96$ ).

The Quality of Life Enjoyment and Satisfaction Questionnaire-short form (Q-LES-Q-SF) was used to measure current satisfaction with life (Endicott, Nee, Harrison, & Blumenthal, 1993). See Attachment G for the letter asking for permission and for the response when permission was granted. The Q-LES-Q-SF is a 16-item scale, which asked questions such as, “taking everything into consideration, during the past week how satisfied have you been with your physical health?” and “taking everything into consideration, during the past week how satisfied have you been with your mood?” Respondents used a 5-point Likert Scale which ranged from 1= “Very Poor,” to 5= “Very good.” This measure had an acceptable inter-item reliability ( $\alpha = .87$ ).

To understand what participants perceived what life might have been like if their sibling with ASD had been typically developing, a theoretically informed scale was created using the IPPA questions as a guide. For this scale, participants were prompted to imagine that their childhoods were exactly the same in every respect *except* that their sibling with ASD *did not have* ASD and had been typically developing. They were then asked to respond to 7 items that used the same 5-point Likert Scale as the IPPA. Prompts included, “I would have felt closer to my caregiver as a child” and “My role in the family would have been different.” The measure had acceptable inter-item reliability ( $\alpha=.89$ ).

**Qualitative data.** At the end of the survey, participants were given a space to free-write in response to this question, “Finally, is there anything else that you feel would be beneficial for this researcher to know about your experience growing up with a sibling with Autism Spectrum Disorder?” These responses were all coded to look for common themes that may be beneficial to include in the overall results (see Attachment H for all qualitative responses).

### **Data Analysis**

Descriptive statistics were used to analyze and assess the overall age, race, gender, geographical location, class, job status, and birth order of the participants. Pearson correlations and Levene’s tests were used to assess the equality of variances calculated for the IPPA, Q-LES-Q-SF, and the theoretically informed scale created to assess the hypothesized quality of life without an ASD sibling.

### **Researcher Biases**

It is important for this researcher to discuss personal biases heading into the data collection portion of this project. This author has a younger sibling that was diagnosed with ASD at a young age. This author notes this bias, and has depended on the thesis advisor to help hold

this author accountable, to think critically, and to step back at times throughout the process in order to remain critical of the study at hand.



## CHAPTER IV

### Findings

The purpose of this study was to look at perceived family cohesion in childhood in relation to current life satisfaction of typically developing (TD) individuals who grew up with a sibling diagnosed with Autism Spectrum Disorder (ASD). Among adults who grew up as the sibling of a child with ASD, is there is a relationship between the perceived attention received from one's caretaker, one's memory of family cohesion, and one's attachment to the caretaker? Is there a relationship between one's perception of family cohesion in youth and one's current life satisfaction?

#### **Descriptive Statistics and Quantitative Data**

Sixty-seven siblings participated in this study, and 45 completed the survey in its entirety. Two participants were disqualified from analysis, as one was under 18, and the other did not have a sibling with ASD. Ages of participants ranged from 18 to 63 years of age, with a mean age of 29.25 ( $SD = 9.44$ ). Twenty seven percent identified as male ( $n = 17$ ) and 73.0% identified as female ( $n = 46$ ). On the question of race and ethnicity, 79.7% identified as Caucasian ( $n = 51$ ), 1.6% identified as Black of African American ( $n = 1$ ), 3.1% identified as Asian or Pacific Islander ( $n = 2$ ), 3.1% identified as Hispanic or Latino ( $n = 2$ ), and 12.5% identified as Mixed Race/Other ( $n = 8$ ).

Table 1

*Demographic Characteristics of Participants*

Variable	<i>n</i>	%
Male	17	26.9%
Female	46	73.0%
White or Caucasian	51	79.7%
Black or African American	1	1.6%
Asian or Pacific Islander	2	3.1%
Hispanic or Latino	2	3.1%
Mixed Race/Other	8	12.5%
Gender of Siblings with ASD	<i>n</i>	%
Male	47	27.7%
Female	7	13.0%
Birth Order	<i>n</i>	%
Sibling with ASD is Older	21	32.3%
Sibling with ASD is Younger	62	61.8%

Consistent with other studies, the sex of the sibling with ASD was overwhelmingly male (87.0%,  $n=47$ ). Sixty two percent of the respondents were older than their sibling with ASD (61.8%,  $n=34$ ), while 32.3% responded that their sibling with ASD was older ( $n=21$ ).

Table 2

*I felt that my caretaker treated me like an adult growing up*

My caretaker treated me like an adult growing up	<i>n</i>	%
No	13	27.7%
Yes	34	73.2%
My caretaker paid an equal amount of attention to my sibling and myself	<i>n</i>	%
False	28	57.1%
True	21	42.9%

To assess for the parentification of typically developing siblings in childhood, the participants were asked to respond true or false to the following statement, “I felt that my caretaker treated me like an adult growing up.” Nearly three quarters of respondents felt that their caretakers treated them as an adult growing up (73.23%,  $n=34$ ), while 27% did not feel as though their caretaker treated them like an adult ( $n=13$ ). Due to the lack of variance among respondents, and the low number reported in the “No” cell, this question was not used in subsequent analyses for testing group difference. To assess for family cohesion, respondents were asked to respond true or false to the following statement, “My caretaker paid an equal amount of attention to my siblings and myself.” Respondents were nearly evenly split on the issue as a little more than half reported this to be a false statement (57.7%,  $n = 28$ ), while 42.9% answered this question as true ( $n = 21$ ).

Table 3

*Is the perception of the amount of attention received from parents affected by the birth order of the sibling with ASD relative to the respondent?*

Variable		Is your sibling with ASD older or younger than you?	My caretaker paid an equal amount of attention to my siblings and myself.
Is your sibling with ASD older or younger than you?	Pearson Correlation	1	-.163
	Sig. (2-tailed)		.269
	<i>n</i>	55	48
My caretaker paid an equal amount of attention to my sibling and myself.	Pearson Correlation	-.163	1
	Sig. (2-tailed)	.269	
	<i>n</i>	48	49

The possibility that birth order might confound the amount of attention received and lead to a possible misinterpretation of subsequent testing, the correlation of these variables was tested. No relationship was found,  $r = -.16$ , ( $p = .269$ ).

**Attachment.** Those reporting an unequal amount of attention from caregivers directed at themselves and their siblings reported a less secure attachment to their caregivers as children ( $M= 83.07$ ,  $SD= 19.99$ ) than those who reported equal amounts of attention from caregivers as their siblings ( $M= 100.57$ ,  $SD= 11.04$ ).

**Current quality of life.** Those reporting an unequal amount of attention from caregivers directed at themselves and their siblings reported a poorer quality of life currently ( $M= 49.42$ ,

$SD=7.89$ ) than those who reported equal amounts of attention from caregivers directed at themselves and their siblings ( $M = 54.95, SD = 7.06$ ).

**If my sibling with ASD had been typically developing.** Those reporting an unequal amount of attention from caregivers directed at themselves reported they would have had a more positive experience during childhood if their sibling with ASD had been typically developing ( $M = 24.30, SD = 7.75$ ) than those who reported equal amounts of attention from caregivers as their siblings ( $M = 18.79, SD = 4.96$ ).

A Levene's test was used to assess the equality of variances calculated for the IPPA, Q-LES-SF-Q, and if the sibling with ASD had been typically developing (If not ASD sib) total between those who responded True and those who responded False to the question, "My caretaker paid an equal amount of attention to my siblings and myself." In all cases, we were able to reject the null hypothesis of equal variances (Attachment  $t(43.682) = -3.906, p < 0.01$ ; Quality of life:  $t(41.165) = -2.466, p < 0.05$ ; If no ASD sib:  $t(43.696) = 2.935, p < 0.01$ ).

To measure the impact of the amount of attention received relative to one's ASD sibling on attachment to caregiver as a child, correlations were run to measure the relationship between current quality of life and whether or not life might have been different if their sibling had been born without ASD.

Table 4

*My caretaker DID NOT pay an equal amount of attention to my siblings and myself*

Variable		IPPA	Q-LES	If no ASD
IPPA	Pearson Correlation	1	.466*	-.593
	Sig. (2-tailed)		.016	.001
	<i>n</i>	28	26	27
Q-LES	Pearson Correlation	.466*	1	-.465
	Sig. (2-tailed)	.016		.017
	<i>n</i>	26	26	26
If no ASD	Pearson Correlation	-.593**	-.465*	1
	Sig. (2-tailed)	.001	.017	
	<i>n</i>	27	26	27

\* Correlation is significant at the 0.05 level (2-tailed).

\*\* Correlation is significant at the 0.01 level (2-tailed).

Among those who reported an unequal amount of attention paid to them by their primary caretakers when compared to their siblings, there was a significant correlation between childhood attachment to caretaker and current quality of life ( $r = .466, p < 0.05$ ), as well as a significant inverse relationship between childhood attachment and a hypothesized better childhood if the sibling with ASD had been TD growing up ( $r = -.593, p < 0.01$ ). Similarly, there was also a significant inverse relationship between current quality of life and a hypothesized better childhood if the sibling with ASD had been TD growing up ( $r = -.465, p < 0.05$ ).

Table 5

*My caretaker DID pay an equal amount of attention to my siblings and myself*

Variable		IPPA	Q-LES	If no ASD
IPPA	Pearson Correlation	1	.477	-.452
	Sig. (2-tailed)		.055	.052
	<i>n</i>	21	19	19
Q-LES	Pearson Correlation	.447	1	-.662**
	Sig. (2-tailed)	.055		.002
	<i>n</i>	19	19	19
If no ASD	Pearson Correlation	-.452	.662**	1
	Sig. (2-tailed)	.052	.002	
	<i>n</i>	19	19	19

\*. Correlation is significant at the 0.05 level (2-tailed).

\*\*. Correlation is significant at the 0.01 level (2-tailed).

Among those who reported an equal amount of attention paid to them by their primary caretakers when compared to their siblings, there was no correlation between childhood attachment to primary caretaker and current quality of life ( $r = .447, p = 0.055$ ). Similarly, there was no significant relationship between childhood attachment and a hypothesized better childhood if the sibling with ASD had been TD growing up ( $r = -.452, p = 0.052$ ). However, there was a significant inverse relationship observed between current quality of life and a hypothesized better childhood if the sibling with ASD had been TD growing up ( $r = -.662, p < 0.01$ ).

Participants that reported an unequal amount of attention from caregivers directed at themselves and their siblings reported less secure attachment to their caregivers as children ( $M = 83.07$ ,  $SD = 19.99$ ) than participants who reported equal amounts of attention from their caregivers for both themselves and their siblings, who also had a more secure attachment to said caregiver ( $M = 100.57$ ,  $SD = 11.04$ ). Participants that reported an unequal amount of attention from caregivers during childhood reported a poorer quality of life currently ( $M = 49.42$ ,  $SD = 7.89$ ) than those that reported equal amount of attention from caregivers during childhood ( $M = 54.95$ ,  $SD = 7.06$ ). Additionally, participants that reported an unequal amount of attention from caregivers in childhood reported that childhood would have been a more positive experience if their sibling had not had ASD ( $M = 24.30$ ,  $SD = 7.75$ ) compared to those who reported equal amounts of attention from caregivers ( $M = 18.79$ ,  $SD = 4.96$ ).

It was important to look at if there was a difference between the 61.8% of participants who marked that they had an ASD sibling that was younger and the 38.2% of participants that reported that their sibling with ASD was older, as Bleske-Rechek & Kelley (2014) discussed the correlation between birth order and perceived family roles. To date, there are very few studies that look at the difference between having a sibling with ASD is older or younger and see if there is a difference. A *t*-test was run to see if there was a difference between the groups in regards to attachment style to caregiver (IPPA), current quality of life (Q-LES-SF-Q), and contemplating what it may have been like had the sibling with ASD been typically developing (if no ASD). There was no statistical significance between these groups.

### **Qualitative Data**

To learn additional information about the respondents, the final question was open-ended: “Finally, is there anything else that you feel would be beneficial for this researcher to know



about your experience growing up with a sibling with Autism Spectrum Disorder?” Twenty-nine participants answered this question (see Appendix H for a full list of answers). All responses were read and general themes were coded. It is important to note that this section does not specifically answer the research questions asked in this study, but can help strengthen this study by providing further clarification and opinions surrounding questions asked, as well as provide ideas for areas of future research. While there were many themes in the responses, three major themes were present. First, feelings of parentification among typically developing (TD) siblings were abundant. Secondly, TD siblings expressed strong love for their sibling with ASD. Finally, it was clear that TD siblings witnessed a plethora of tantrums from their ASD siblings during childhood, as well as family traumas including abuse. Other less frequently reported themes noted were the need to look at family socioeconomic status growing up, as well as TD siblings wondering what would have been different if their ASD sibling had been “normal” or typically developing. These responses will be further analyzed in the discussion section.

### **Limitations**

It is important to note that this data is not largely generalizable, as using an Internet study immediately leaves out those individuals that are unable to use a computer or have access to Internet. In addition, snowball and nonprobability convenience samplings were utilized, meaning that potential agencies and support groups that may have been important to survey were not utilized for the purpose of this study. While many agencies and support groups were contacted, there is no way to know if the agencies passed along the recruitment letter that was sent. Additionally, the researcher bias is important to continue to address, since this researcher is also a typically developing individual who has a sibling with ASD. Because of this, this author was able to utilize online support groups that perhaps other researchers who did not have a sibling

with ASD would not be able to use. While specific participants that were collected from sibling support groups were unaware that this researcher has a sibling with ASD, this researcher was able to join some of these groups because of having a sibling with ASD. Additionally, since this author used her personal Facebook account to post a message about this study, there is the potential that some of the participants knew of the family dynamics and the sibling with ASD in this researcher's family. Due to this, it has remained important that this author continue to discuss this with one's thesis advisor and the HSR committee in order to make sure that data collection remained ethical and fair.

## **CHAPTER V**

### **Discussion**

The purpose of the current study was to further expand and compliment previous research by looking at perceived family cohesion in childhood in relation to current life satisfaction of typically developing (TD) individuals who grew up with a sibling diagnosed with Autism Spectrum Disorder (ASD). More specifically, the current study aimed to address the question: Among typically developing siblings of individuals with ASD, is there a relationship between the perceived attention that was received from one's parents, one's memory of family cohesion, and attachment to one's caretaker? Additionally, is there a relationship between one's perceived family cohesion in youth and current life satisfaction?

Results from the current study suggest that participants who felt that they received an unequal amount of attention from caregivers growing up also reported a less secure attachment to their caregivers as well as a poorer current quality of life compared to participants who felt that they received an equal amount of attention from their caregivers. Regardless of attention received in childhood, there was a significant relationship between current quality of life and a hypothesized better childhood if the participant's sibling with ASD had been TD growing up.

The results from the current study suggest that when siblings perceived that they received equal amounts of attention from their caregiver during childhood in comparison to their sibling with ASD, that there was no significant correlation to wishing that their sibling with ASD had

been typically developing. This is important for researchers and mental health practitioners moving forward, for it speaks to the need for TD children to perceive equal amounts of attention. Although, it is important to note that this does not necessarily mean the *same* type of attention. Interestingly, regardless of perception of attention received in childhood, happiness and current quality of life interacted to affect the likelihood that participants wished their siblings were TD. This suggests that the less content an individual is with their current life, the more likely they are to wish that their childhood had been different and contemplate what childhood may have been like if the sibling with ASD had been TD. It therefore can also be suggested that perhaps one's opinions on childhood may change depending on current quality of life and that, in future studies, this should be a longitudinal study in order to better assess this. Finally, it is interesting to note that for those who reported unequal amounts of attention, there was a correlation between attachment to caretaker and current quality of life. Meaning that, when looking at those who reported they received unequal amounts of attention in childhood, it is critical to understand the importance of attachment to primary caregivers, as the more secure the attachment to the caretaker and the more able that the caregiver was to be in tune with the TD siblings needs, the less likely the sibling was to wish that their sibling with ASD had been TD.

While the current study produced significant findings, it is also important to note the non-significant findings. When looking at the difference in birth order in comparison to the participant's quality of life, attachment to caretaker, and contemplating what it may have been like if the sibling with ASD had in fact been TD, there was no statistically significant difference between the participant being the older or younger sibling in relation to the sibling with ASD. Additionally, the perception of the amount of attention received from parents was not impacted on the birth order of the sibling with ASD relative to the participant. This is interesting to note

because birth order did not impact a TD sibling's likelihood to be parentified, which goes against the typical roles in a family, as often the oldest sibling in the family takes on the responsible role (Pulakos, 1987). The current results suggest that when there is a sibling with ASD in the family, that perhaps typical family roles are nonexistent, or not as well defined.

It is also important to further look at the qualitative data gathered at the end of the survey. The question, "Finally, is there anything else that you feel would be beneficial for this researcher to know about your experience growing up with a sibling with Autism Spectrum Disorder?" was asked. As this question was optional, twenty-nine out of the 67 participants answered. The common themes were: negative thoughts surrounding the questions that asked the participant to consider if their sibling with ASD had been TD, parentification of the participant, love of their sibling with ASD, embarrassment by their sibling with ASD, violence and trauma in the household, feeling that everyone in the family was treated the same, tantrums that the ASD sibling had and the potential of hurting other siblings in the house, wishing that the survey had asked about socioeconomic status growing up, answering what might have been different if the sibling with ASD had been TD, that some of the TD siblings had some of their own mental health concerns, and participants who wished they had known there were other siblings out there. The themes here varied, emphasizing that every ASD child, their sibling(s), and the family system as a whole is varied. While it is important for practitioners to find better ways to work with the family system, it is still crucial for these practitioners to look at the family system as a whole and bear in mind that each family is different. This suggests that the needs of the family will vary slightly from family to family.

Results from this section rarely seemed neutral, and if anything appeared polarizing. For example, "...she was IMPOSSIBLE. She destroyed my things. I could never express like for

anything or she would destroy it. I wanted real siblings” or “[t]he violence growing up, and it was tolerated, dismissed, excused, or my parents didn’t know how to handle it even when they wanted to. Parents had a serious conflict of interest between the ‘Special’ boy and the well-being and safety of the rest of the family, including themselves...” Conversely, many responses followed this theme, “We are extremely close” to “My brother and I are pretty close. When I found out about his Aspergers it probably only made me a bit more protective of him!” to “You love the person, but bearing the responsibility of taking care of not only your parents but your sibling as you get older is a hard hit as an adult especially in this economical climate.” As mentioned, a very strong theme, regardless of the closeness or distance to the sibling with ASD was that many of the participants wrote about their parentification in the family system. These responses suggest that having a sibling with ASD definitely impacts the TD sibling and the family system as a whole, and reemphasizes the need for siblings to be able to express themselves and discuss how it feels to grow up with a sibling with ASD. It is important for families and mental health practitioners to allow for siblings to have a voice and put words to their experience, as this was also an important theme from siblings in the current study.

### **Findings compared to previous literature**

The literature to date on sibling relationships and family cohesion differs depending on the article. Some research states that having a sibling with ASD can impact family cohesion and dramatically impact sibling relationships in a positive or negative manner, while others state that there is no difference in sibling relationships (Brewton et al., 2011; Ferraioli et al., 2012; Meyer et al., 2011; Oppenheim-Leaf et al., 2011; Petalas et al., 2012; Petlas et al., 2013). However, one overarching theme amongst previous literature was that most of the research on sibling relationships has been conducted using teacher and parent data. There has not been much

research done asking the sibling's perspectives and experience growing up with a sibling with ASD, which is something that the current study achieved.

Previous literature suggests that when there appears to be more parental favoritism, there is a tendency for an increase in sibling rivalry and lifelong themes of conflict (Kennedy, 1985). If the individual believes to be disfavored, they tend to shower higher disengagement from the family and have a perception of lower family cohesion (Brody et al., 1998). The current study compliments current literature by suggesting that there is a correlation between the perception of not receiving equal attention and having a lower view of attachment and family cohesion.

Mack and Reeve (2007) show in their study that the presence of a sibling with ASD can enhance the psychosocial and emotion development of TD siblings. The caveat to this is that there can be a negative impact on the TD siblings as demographic risks increase. This is interesting to note, because in the current study, when analyzing and coding the qualitative data, there appeared to be a few participants who noted severe demographic risk factors and how they believe that impacted their relationship with their sibling. Those that reported severe demographic risk factors, such as the socio-economic status of their family growing up, also reported a strained relationship with both parents and siblings. While this partially supports Mack and Reeve's study, it is also important to note that this could not be fully analyzed as not all participants answered the open-ended question and demographic risk factors such as socio-economic status during childhood were not explicitly asked in the current study.

In contrast to previous research, Pulakos (1987) reported that often the oldest child in a family tends to take on the responsible role in the family. This is not necessarily the case in the current study, as birth order did not impact the overall results, and there was no significance between feeling parentified in the family and birth order of the TD sibling. The current research

assists in complimenting and building upon previous research by continuing research on individuals with ASD, their families, and their siblings, most specifically through the use of questioning the siblings.

### **Strengths and limitations**

The research questions for the current study looked at attachment, family cohesion, and current life satisfaction. The tools used in this research study were useful, straightforward, were accessible to this researcher, and for the most part aligned with the research questions. It appears as though the tools implemented provided results to answer the given research questions. One limitation was that while attachment was assessed and that was used to help discuss family cohesion, family cohesion itself was not explicitly tested. Instead, attachment to the caretaker was more explicitly looked at, as well as perceived amount of attention received from the primary caregiver. These tools and questions were put together in order to assess family cohesion, but perhaps a specific test that looked at family cohesion may have been more beneficial.

Nonprobability convenience sampling and snowball sampling were used to gather participants through the use of a self-administered online survey. A potential limitation with the use of an online study is leaving out those individuals that do not have access to a computer, or are unable to navigate an online survey. While the goal of this research project was to obtain a diverse sample, across differing classes and races, by using an internet study, a specific population was automatically left out: those that are unable to have access to the internet. The sample size was adequate for the research at hand, however due to the use of nonprobability convenience sampling and snowball sampling, the results are not generalizable.



Reliability and reproduction of these results in another survey is unknown, as it has not been tested. Since the participants were gathered in a wide array of places online, it can be suggested that the test-retest reliability may be high, yet this was not tested. However, the reliability between questions, and making sure that all of the questions were pertinent to the current study was assessed by one's advisor and the HSR committee, thus it can be suggested that the reliability of the questionnaire is high.

It is important to note validity of the current study. The face validity of the current study is high, in that the questionnaire tested what it stated it would test. Content validity for this study could have been stronger, in that there was no sample group or experts that looked over the questionnaire before it was distributed, aside from one's thesis advisor and the HSR committee. If time had not been a factor, it may have been interesting to speak with experts in the field, or a small sample of individuals who have a sibling with ASD and ask for their feedback on the survey.

### **Implications for practice and research**

One purpose of the current study was to provide families and providers who work with individuals diagnosed with ASD suggestions for how to best account for the siblings of those individuals with ASD. The results from the current study suggest that the perception of attention received from caretakers in childhood in comparison with their sibling with ASD is correlated to current quality of life and attachment to caregivers. It suggests that those who felt they received an unequal amount of attention had less secure attachments to one's caregiver, a poorer current quality of life, and thought more often about what their childhood may have been like if their sibling with ASD had been typically developing. There was not a correlation between those that received equal attention in childhood, attachment to caregiver, and current quality of life. These

results suggest that it is important for the typically developing sibling and the sibling with ASD to perceive similar amounts of attention. This survey looked at siblings' *perceptions* of the amount of attention that they received in childhood, suggesting that this could be a dialogue for TD children and their parents to check in about at different points throughout childhood. Perhaps this may even mean including the typically developing sibling in treatment/family treatment when working with a sibling with ASD, as has been suggested by previous researchers (Brewton et al., 2011; Ferraioli et al., 2012; Oppenheim-Leaf et al., 2011). Additionally, when the question, "Finally, is there anything else that you feel would be beneficial for this researcher to know about your experience growing up with a sibling with Autism Spectrum Disorder?" was asked, a few participants wrote that they wished that they had known there were other siblings out there.

One thing that this author has learned from this research is that there are quite a few support groups out there for siblings of someone diagnosed with ASD. It is important for mental health providers, when working with a family where someone is diagnosed with ASD, to also provide the sibling(s) with support, and to let that sibling know that they are not alone. One participant put it well saying, "I wish I knew that there were other people like me who were going through the things I was going through; I wish I could have gotten away, been able to talk or be angry...I wish I had language then to describe my situation and ask for what I needed."

### **Recommendations for the future**

It would be interesting to conduct this survey again, but to a wider sample range, perhaps even looking to tap into different support networks that are not solely located on the Internet. This could help with addressing test-retest reliability. Additionally, it might be useful to ask a question surrounding current feelings of closeness to their sibling with ASD, as this could help

expand the knowledge base and see if and how family cohesion and attention received growing up may impact the current relationship between the typically developing sibling and the sibling with ASD.

During the open-ended question at the end of the current study, results varied between a strong bond with current siblings including the sibling with ASD and a tumultuous relationship with the sibling with ASD. As not everyone answered this question, it was not possible to analyze if there was a correlation between family cohesion and current state of sibling relationship. Participants also made a number of suggestions about the methodology of the current study that could be used to inform future research. Some participants pointed out that their sibling with ASD often had tantrums growing up and that they wished this had been accounted for in the survey. This may be an important path for researchers to delve into in the future, and see if there is any relationship between tantrums growing up and family cohesion.

Having a sibling diagnosed with Autism Spectrum Disorder impacts all members in the family, including other siblings in the family system. It is imperative that these typically developing siblings are not ignored in the process of working with someone with ASD. Results from the current study illuminate this by demonstrating the correlation between attention received from primary caregivers in relation to attachment to the caregiver, current life satisfaction, and the musings of what life may have been like if the sibling with ASD had been TD during childhood. While having someone in the family diagnosed with ASD can be distressing and alter the family system, it continues to remain evident that the sibling perspective is an important one, one that should not be ignored, and one that should be continued to be discussed and researched in the future.

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## Appendix A

### HSR Approval Letter



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**School for Social Work**  
Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950 F (413) 585-7994

January 15, 2014

Laura Nordone

Dear Laura,

You did a very nice job on your revisions. Your project is now approved by the Human Subjects Review Committee.

*Please note the following requirements:*

**Consent Forms:** All subjects should be given a copy of the consent form.

**Maintaining Data:** You must retain all data and other documents for at least three (3) years past completion of the research activity.

*In addition, these requirements may also be applicable:*

**Amendments:** If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

**Renewal:** You are required to apply for renewal of approval every year for as long as the study is active.

**Completion:** You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Congratulations and our best wishes on your interesting study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten'.

Elaine Kersten, Ed.D.  
Co-Chair, Human Subjects Review Committee

CC: Adam Brown, Research Advisor



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**School for Social Work**  
Smith College  
Northampton, Massachusetts 01063  
T (413) 585-7950 F (413) 585-7994

February 6, 2014

Laura Nordone

Dear Laura,

I have reviewed your amendment and it looks fine. This amendment to your study is therefore approved. Thank you and best of luck with your project.

Sincerely,

A handwritten signature in black ink, appearing to read 'Elaine Kersten', written over a light grey rectangular background.

Elaine Kersten, Ed.D.  
Co-Chair, Human Subjects Review Committee

CC: Adam Brown, Research Advisor

## Appendix B

### Letter to Agencies

Dear Agency (DRNM, Youth Advocates of Sitka, INC., Collage, Sibling Support Project, and MD Junction: Siblings of Children Support Group),

My name is Laura Nordone, and I am a graduate student at the Smith College School for Social Work. Because of your agency's commitment to serving siblings, family members, and those with Autism Spectrum Disorder, I am writing to ask for your help in completing my Master's thesis by promoting my brief (20 minute) anonymous electronic survey on growing up with a sibling with an Autism Spectrum Disorder Diagnosis, and how this may impact perception on family cohesion and current life satisfaction. By promoting this research to siblings of individuals with Autism Spectrum Disorder, you are helping to determine what the impacts of growing up with a sibling with ASD can have on the rest of the family. Their responses could give insight as to how professionals and agencies like you can effectively support and empower families when there is a sibling with an ASD diagnosis in the family.

Siblings are eligible to participate in my study if they are over 18 years of age, and have a sibling that is diagnosed with ASD, whether that be Autism Disorder, Asperger's Disorder, or PDD—NOS. Participation is anonymous, so I will have no way of knowing who participated. Please share this survey link with your clients by posting the link where siblings can easily see the link, share the link with other siblings, and/ or allow siblings access to computers to take this short survey.

Below is a link to the website containing my thesis questionnaire.

Please follow this link to the survey:

If you have any questions about my research or the nature of participation, please feel free to reply to this email (XXXXXXXX@smith.edu).

Thank you for your time and interest in sibling interactions and family cohesion when there is a sibling with ASD in the family!

Laura Nordone  
MSW Candidate 2014

## Appendix C

### Online Recruitment Letter

My name is Laura Nordone, and I am a graduate student at the Smith College School for Social Work. I am writing to ask for your help in completing my Master's thesis by promoting my brief (20 minute) electronic survey on growing up with a sibling with an Autism Spectrum Disorder Diagnosis, and how this may impact perception on family cohesion and current life satisfaction. By participating, you are helping to determine what the impacts of growing up with a sibling with ASD can have on the rest of the family. Your responses could give insight as to how professionals and agencies can effectively support and empower families when there is a sibling with an ASD diagnosis in the family.

Siblings are eligible to participate in my study if they are over 18 years of age, and have a sibling that is diagnosed with ASD, whether that be Autism Disorder, Asperger's Disorder, or PDD—NOS. Participation is anonymous, so I will have no way of knowing who participated. If you would like, you have the option of entering your name into a drawing to win a gift card to Amazon. However, I will still not be able to tie your name to the survey that you filled out.

Below is a link to the website containing my thesis questionnaire.

Please follow this link to the survey:

If you have any questions about my research or the nature of participation, please feel free to reply to this email (XXXXXXXXX@smith.edu).

Thank you for your time and interest in sibling interactions and family cohesion when there is a sibling with ASD in the family!

Laura Nordone  
MSW Candidate 2014

**Appendix D**

Consent Form

**Consent to Participate in a Research Study  
Smith College • Northampton, MA**



.....  
**Title of Study:** Sibling Relationships: Growing up with a sibling diagnosed with Autism Spectrum Disorder and its influence on perceived family cohesion and current life satisfaction

**Investigator(s):** Laura Nordone

Smith College School for Social Work

MSW Candidate

XXXXXXXXXX@smith.edu

XXX-XXX-XXXX

.....

**Introduction**

- You are being asked to be in a research study that looks at siblings’ perspectives in regards to what these siblings felt their adjustment was like and what impact there may have been (if any) of growing up with a sibling with an Autism Spectrum Disorder Diagnosis. Autism Spectrum Disorder can include those individuals diagnosed with Autism Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS).
- You were selected as a possible participant because you have identified yourself as having a sibling that has an Autism Spectrum Disorder Diagnosis.
- I ask that you read this form and ask any questions that you may have before agreeing to be in the study.

**Purpose of Study**

- The purpose of the study is to look at the impacts on the sibling of a child with an Autism Spectrum Disorder Diagnosis. Previous research tends to focus on parents’ perspectives on sibling relationships. Therefore, the purpose of this study is to survey 18+ siblings about your perceptions of family cohesion and growing up with a sibling with a diagnosis of Autism Spectrum Disorder. The survey also inquires about your current satisfaction with life now. It is

also intended to get your perspective on if there could have been more resources provided to them when they were less than 18 years.

- This study is being conducted as a thesis requirement for my master's in social work degree.
- Ultimately, this research may be published or presented at professional conferences.

### **Description of the Study Procedures**

- If you agree to be in this study, you will be asked to do the following things: You will be asked to complete the following questionnaire. The first section asks general demographic questions, such as your age, birth order, etc. The second section will involve questions where you will be asked to pick a number that most describes how you relate to the question. The questionnaire in its entirety should take no more than 15-20 minutes. After you complete this, you will click on "submit" and the anonymous questionnaire will be complete. At this time, a closing section will be provided, with resources if so desired and a way to contact me if you are interested in receiving the results of this study after it is completed.

### **Risks/Discomforts of Being in this Study**

- The study has the following risks. First, this study has the potential of being emotionally distressing, for it asks you to reflect on your sibling relationships and growing up with a sibling with an Autism Spectrum Disorder Diagnosis. The study also asks for you to reflect on your family relationships growing up. The likelihood of this is dependent on the individual. If you feel distressed please see the list of resources and community sources that can be provided to you, and feel free to skip a question that you find distressing, or stop participating entirely if you find participation emotionally distressing.

### **Benefits of Being in the Study**

Prior research suggests that growing up with a sibling who has been diagnosed with Autism Spectrum Disorder (ASD) can be an isolating experience, so providing you with an outlet to talk about it, even through the use of a survey, may be beneficial. This study also provides you with a unique opportunity especially since little research has been done surrounding adult siblings of individuals with an Autism Spectrum Disorder Diagnosis. If you request a summary of the study's results, you may learn more about what other siblings' perceptions are surrounding growing up with a child with an Autism Spectrum Disorder Diagnosis.

### **Confidentiality**

- This study is anonymous. I will not be collecting or retaining any information about your identity. Records will be kept in a locked file, and all electronic information will be coded and secured using a password-protected file. If you chose to obtain a summary report of my findings, your participation will not longer be anonymous, however I will have no way of being able to link your name back to the survey that you completed.

### **Payments**

- All participants, if they desire, will be entered to be part of a drawing. For about every ten participants, one name will be drawn to win a \$10 gift card to Amazon. A maximum of 15 gift cards will raffled away.

### **Right to Refuse or Withdraw**

- The decision to participate in this study is entirely up to you. You may refuse to take part in the study *at any time* without affecting your relationship with the researchers of this study or Smith College. Your decision to refuse will not result in any loss of benefits (including access to services) to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely at any point during the study, simply by navigating away from the survey site or closing your web browser. If you choose to withdraw before clicking on the “Submit” button SurveyMonkey will not have collected any information. However, once you click on the “submit” button on the last page of the survey, you can no longer withdraw, since I won’t be able to identify the information you submitted.

### **Right to Ask Questions and Report Concerns**

- You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have any further questions about the study, at any time feel free to contact me, Laura Nordone at XXXXXXXXX@smith.edu or by telephone at XXX-XXX-XXXX. If you like, a summary of the results of the study will be sent to you. If you have any other concerns about your rights as a research participant, or if you have any problems as a result of your participation, you may contact the Chair of the Smith College School for Social Work Human Subjects Committee at (413) 585-7974. Please print out a copy for your own records.

### **Consent**

**\*\* I agree**

**\*\* I disagree**

## Appendix E

### Questionnaire

#### Demographic Questions

Q. *What is your sex?*

- Male
- Female

Q. *How old are you?*

Q. *Who do currently you live with? Check all that apply*

- I live by myself
- I live with roommates
- I live with one or more of my parents
- I live with my partner or spouse
- I live with one or more of my children

Q. Marital Status *What is your marital status?*

- Married/ in a domestic partnership
- Widowed
- Divorced
- Separated
- Never married

Q. Education *What is the highest degree or level of school you have completed? If currently enrolled, mark the previous grade or highest degree received.*

- Some high school
- High school graduate - high school diploma or the equivalent (for example: GED)
- Some college credit
- Associate degree (for example: AA, AS)
- Bachelor's degree (for example: BA, AB, BS)
- Post-bachelor's degree (such as Master's degree, Professional Degree, and/or Doctorate degree)

Q. Employment Status *Are you currently...?*

- Employed Full-time (40+ hours per week)
- Employed part time (less than 40 hours per week)
- Unemployed
- Full-time student



- Retired
- Unable to work
- Other: \_\_\_\_\_

Q. Please check all the ethnic or racial groups that you belong to.

- American Indian or Alaska Native
- Asian or Pacific Islander
- Black or African American
- White or Caucasian
- Hispanic or Latino
- Arab American
- Other (please list): \_\_\_\_\_

Now I'm going to ask you about your family of origin.

Q. *How many siblings do you have? Please include all step-siblings/half-siblings, etc.*

Q. *Is your sibling with ASD older or younger than you?*

Q. *If you have more than one sibling, what is your birth order?*

- I am the oldest
- I am the second oldest
- I am the middle child
- I am the second youngest
- I am the youngest

Q. *If you have more than one sibling, what is the birth order for your sibling with Autism Spectrum Disorder?*

- He/she is the oldest
- He/she is the second oldest
- He/she is the middle child
- He/she is the second youngest
- He/she is the youngest

Q. *What is the sex of your sibling with Autism Spectrum Disorder?*

- Male
- Female

Q. *Do you feel as though your sibling with ASD received more attention than you from your caretaker(s) while growing up?*

- Yes
- No

Part I: The following set of questions asks about your relationship with your primary caretaker(s) (the adults who you lived with growing up).

- Q: The caretaker/legal guardian who I felt closest to growing up was:
  - Biological/adopted/foster mom
  - Biological/adopted/foster dad
  - Both parents equally
  - Biological/adopted/foster grandparent
  - Other family member/legal guardian
  - Other (please specify): \_\_\_\_\_

In the following questions, think only about the person to whom you are referring to in the previous question (caretaker you felt closest to) :

Response categories:

- 1= Almost never or never true
- 2 = Not very true
- 3 = Sometimes True
- 4 = Often True
- 5 = Almost always or always true

1. My caregiver respected my feelings.
2. I felt my caregiver did a good job as my caregiver.
3. I wish I had a different caregiver.
4. My caregiver accepted me as I was growing up.
5. I liked to get my caretaker's point of view on things I was concerned about.
6. I felt it was no use letting my feelings show around my caretaker.
7. My caretaker could tell when I was upset about something.
8. Taking over my problems with my caretaker made me feel ashamed or foolish.
9. My caretaker expected too much from me.
10. I got upset easily around my caretaker.
11. I got upset a lot more than my caretaker knew about.
12. When we would discuss things, my caretaker would care about my point of view.
13. My caretaker trusted my judgment.
14. My caretaker had her own problems, so I didn't bother him/her with mine.
15. My caretaker helped me to understand myself better.
16. I told my caretaker about my problems and troubles.
17. I felt angry with my caretaker.
18. I didn't get much attention from my caretaker.
19. My caretaker helped me to talk about my difficulties.
20. My caretaker understood me.
21. When I was angry about something, my caretaker tried to be understanding.
22. I trusted my caretaker.
23. My caretaker didn't understand what I was going through.
24. I could count on my caretaker when I needed to get something off my chest.

25. If my caretaker knew something was bothering me, he/she would ask me about it.

Please Answer the following questions by marking True/False

1. My caretaker paid an equal amount of attention to my siblings and myself.
2. I felt like my caretaker treated me like an adult growing up.

For the next series of questions, imagine that your childhood was exactly the same in every respect *except* that your sibling with ASD *did not have ASD* and had been typically developing.

Response categories:

- 1= Almost never or never true
- 2 = Not very true
- 3 = Sometimes True
- 4 = Often True
- 5 = Almost always or always true

1. I would have felt closer to my caregiver as a child.
2. I would have felt closer to my sibling(s) as a child.
3. I would have felt more loved by my caregiver as a child.
4. I would have spent more time with my family.
5. I would have enjoyed my childhood more in general.
6. My role in the family would have been different.
7. I would have had fewer responsibilities in the family.

Part II –Taking everything into consideration, during the past week how satisfied have you been with your.....

- 1 = Very poor
- 2= Poor
- 3= Fair
- 4= Good
- 5= Very good

- Physical health?
- Mood?
- Work
- Household activities?
- Social relationships?
- Family relationships?
- Leisure time activities?
- Ability to function in daily life?
- Sexual drive, interest and/or performance?

- Economic status
- Living/household situation?
- Ability to get around physically without feeling dizzy or unsteady or falling?
- Your vision in terms of being able to do work or hobbies?
- Overall sense of wellbeing?
- Medication? (if not taking any check here \_\_\_\_ and leave item blank).
- How would you rate your overall life satisfaction and contentment over the past week?

Finally, is there anything else that you feel would be beneficial for this researcher to know about your experience growing up with a sibling with Autism Spectrum Disorder?

## Appendix F

### Request to use the IPPA

January 10, 2014

Dear Dr. Greenberg, and Dr. Armsden,

Hello, my name is Laura Nordone. I am a current graduate student at Smith College School for Social Work, located in Northampton, MA. I am currently working on my masters' thesis. The working title for my thesis is, Sibling Relationships: Growing up with a sibling diagnosed with Autism Spectrum Disorder and its influence on perceived family cohesion and current life satisfaction. I have been working for the last several months to formulate my topic, collect previous studies, as well as search for research instruments that I may use for my own research. My thesis advisor suggested that I look at the Inventory of Parent and Peer Attachment (IPPA) since it is crucial in my current research to look at attachment styles between the typically developing sibling and their parent/caregiver. I believe that using the IPPA as one of the tests in my own study would be very beneficial for my current research. I am hoping to use your measures in data collection in order to look at quality of attachment between a typically developing sibling and the primary caregiver. I would greatly appreciate if you could assist me with how to move forward on this, and how I can receive your approval to use the IPPA in my own research.

Sincerely,

Laura M. Nordone

Dear Laura

This email grants you official permission to use the IPPA in your research. We would love to see a copy of the finished thesis.

The IPPA manual is attached.

best of luck

Mark

Mark T. Greenberg Ph.D.  
Bennett Chair of Prevention Research  
Biobehavioral Health Bldg Room 306  
Penn State University  
University Park, PA 16802

## Appendix G

### Request to use the Q-LES-Q-SF

Dear Dr. Endicott,

Hello, my name is Laura Nordone. I am a current graduate student at Smith College School for Social Work, located in Northampton, MA. I am currently working on my masters' thesis (that I am not intending to publish- it is a requirement for our graduation). The working title for my thesis is, Sibling Relationships: Growing up with a sibling diagnosed with Autism Spectrum Disorder and its influence on perceived family cohesion, attachment, and current **life** satisfaction. I have been working for the last several months to formulate my topic, collect previous studies, as well as search for research instruments that I may use for my own research. I found your Q-LES-Q-SF survey online (<https://outcometracker.org/library/Q-LES-Q-SF.pdf>) and it mentioned that I may need to get approval to use this survey if it was within the same industry. I am interesting in using your measures in data collection in order to look at participants who have a sibling with ASD and their current quality of life in correlation with perceived childhood attachment. I was curious if you would need to grant me permission, and I would greatly appreciate if you could assist me with how to move forward with this, and how I can receive your approval to use the Q-LES-Q-SF in my own research (and if I need your approval for this). Thank you for your help.

Sincerely,

Laura M. Nordone

Laura,

The following Q-LES-Q materials should be attached...  
a copy of the Full (i.e. longer) version,  
a copy of the Short Form (same content as the General Activities section of the Full version),  
scoring instructions for both,  
a paper based up a prescreened community sample. (The data reported for the General Activities section is applicable to the Short Form.)

You definitely have my permission to use either version of the Q-LES-Q or- as is the case for some investigators--selected sections of the Full version.

Don't hesitate to contact me if you have questions.

Jean



## Appendix H

### Qualitative Responses

Qualitative responses to the question: Finally, is there anything else that you feel would be beneficial for this researcher to know about your experience growing up with a sibling with Autism Spectrum Disorder?

I feel the set of questions related to "how I would have felt had my sibling with ASD not had ASD" are not very scientific. Having only known what it's like to have a sibling with ASD (for most of my life), how could I begin to posit my general sense of being if that were different? That's like asking, "I know you're a duck, but how do you think you would feel if you were a squirrel?"

I grew up in a single parent household from the age of 10 until the age of 18, when my biological father rejoined us (my mother and younger brother) in the States. Because of my father's absence and my brother's condition, I was forced to become an adult (and make many sacrifices) at a young age. For example, beginning to work at the age of 14, attending a local university rather than going away for college in order to keep my mother and brother company, passing up employment offers for opportunities outside of my hometown in order to stay close to the family. My parents made efforts not to burden me with my brother's affairs but because of several factors that may include our cultural background and our own family dynamic, there was still an expectation (even if unsaid) and a strong dependence on my presence. Over time, I translated those expectations into my responsibilities. That said, now that I am older, I can say with sincerity that my parents did the best that they could with what they had, and I love them very much.

I feel an immense amount of jealousy regarding friends with normal siblings. I worry constantly about having to care for my sibling after his primary caretaker passes. I get embarrassed by his actions in public.

I feel that growing we treated my brother the same way as if he didn't have Asperger's he was able to grow up such a way that he often comes across as being completely normal to people who have never met him before. He understands some social cues and is learning to live on his own now. We are all very proud of him and wouldn't want him any other way.

Regarding the attention thing, my brother got more attention, but I understood it wasn't exactly good attention from a relatively early age. Sure my mom was spending more time with him, but it was so that he could go to some specialist and have to work. There should be a question or a focus about tantrums; they were a pretty defining part of my childhood experience.

My younger brother (my only sibling) was only diagnosed with Asperger's as an adult. As a child (in central Pennsylvania in the 70s) he was only diagnosed as having a Learning Disability.

Scary. The violence growing up, and it was tolerated, dismissed, excused, or my parents didn't know how to handle it even when they wanted to. Parents had a serious conflict of interests

between the "Special" boy and the well-being and safety of the rest of the family, including themselves. Nobody wants to admit that some of these kids are sexually inappropriate with siblings. The proper term is incest. Parents can get so focused on how special and "wonderful" the special boy is in spite of his challenges that they tend to jump to his defense at every complaint against him. My father was a passive person who died of cancer when I was 15. My mother allowed my brother to live at home as an adult even though he hated her, was violent to her, tried to molest me, was using drugs, hanging out with thug friends, bringing strange men into the house late every night to do drugs with, creating a generally dangerous environment for me to be living in, and my mother was putting up with being domestically abused because she said he's her son and she loves him. This was a sick, sick situation. I ran away from home in high school for my own safety. Very wise choice. My mother tried to shame me for doing that. She wanted me to be ashamed of the way I felt about my brother. My mother died when I was 19. I notice you don't ask if we have children of our own. I don't. I don't want to risk bringing another of my brother into the world. What a gothic nightmare that was. By the way, my parents grew up in a rarefied world of private schools, international travel, art and culture as a profession, Seven Sisters and Ivy League, and a lack of awareness that there was a Great Depression going on. Are you surprised? Most of my childhood was in the '70s, when people didn't know about autism, aspergers, neuro issues. Based on my class, family, culture, being white, I was treated like the way home life was affecting me was my own fault. My parents wouldn't level with me about my brother's condition--like if it could be genetic or not. You should know that I grew up with 2 parents, though you only ask about one: You ask which one I was CLOSEST to. I grew up in fear for my safety and feared for my future that I wouldn't have the resources or education I needed to be an independent adult. Your survey doesn't account for socio-economic background of parents, nor parental factors such as parents neuro-challenges. The answers I give to some of these questions are not for the reasons you might think. For instance: During the past week, I've had challenges with balance, but that's because it's winter, cold out, snowing a lot, icy, freezing, and we're all bundled up and in stiff snow boots while going about our days. The ERs are full of people who've lost their balance in the past week. How's my vision this week? I started wearing glasses in my 40's. My vision could be fine once I put my glasses on; or my vision's so bad that I need glasses. Or maybe I'm in that phase where I'm starting to need reading glasses but don't realize it yet. Just you wait until you're 40 (if you don't already wear glasses) Get the idea? You don't know where I'm coming from when I give the answers I give. That's why I don't really have much regard for these surveys. Also, there are surveys that hurt the cause, such as that Easter Seals survey that ES themselves proclaimed "Ground Breaking!!!" about siblings of disabled people. Their research survey findings were total junk. The most glaring is when they proclaim or ask the "Better Person" question. Glad you didn't ask that question. These surveys don't seem to be a very scientific way of gathering info. I'm surprised your school accepts them as a research tool. How do you know if people are answering them honestly? How do you know if respondents are who they claim to be? What impressions are you getting from our answers?

My youngest brother seemed to suffer more emotionally and socially than I did, as he was often the victim when my middle brother would get angry. He would bite him.

My adult sibling is my fraternal twin brother! :) I often imagine now (never when growing up) how different life would have been and how different it would be now, if he was a 'normal' brother. I believe my bond with him and my family would be stronger and more like a normal

family.

I wish I knew that there were other people like me who were going through the things I was going through. I wish I could have gotten away, been able to talk or be angry. I wish I could explain to my teachers that it wasn't that I didn't respect them, it's that I wasn't used to having an authority figure because at home, I took care of myself. I wish I had language then to describe my situation and ask for what I needed.

my sibling is extremely high functioning (aspergers), is completing his second advanced degree and has lived independently in several cities away from home. Has also had several romantic relationships. We are extremely close. One issue not reflected in the questionnaire, however, is the lingering anxiety that having a sibling with ASD has caused. I think it is related to worrying about his ability to adjust to life changes as they come, and take care of the practical aspects of life. Best of luck with your research, it is valuable.

Although my brother with ASD received more attention than I did, it was because he needed it. My family worked hard to balance out time with us both.

My brother and I are pretty close. When I found out about his Aspergers it probably only made me a bit more protective of him!

I found it really hard to answer these questions as I remember very little about my childhood and my relationship with my parents. I sometimes wonder if I have pushed a lot of it from my mind as it was so difficult at times.

I have learned to be very independent. I have always felt somewhat protective of my sibling with ADS even though I am the younger sibling.

I am an 18 year old at [REDACTED]. My brother, [REDACTED], has high functioning autism and is 22. As a child he definitely received more attention and my parents were much more invested in [REDACTED] than me or my sister. They wanted to help [REDACTED] do well in school and succeed socially. When my brother began high school, he began attending boarding school / residential treatment programs. Then I received a lot more attention. When my brother came back to live at home (and I was a junior / senior in high school) I was often expected to take on more of a parenting role with [REDACTED]. If you have any questions, feel free to reach me [REDACTED].

There is a difference between living with someone with autism, and embracing someone who has autism. It took me a long time to really embrace my brother's diagnosis, but it did help our relationship once I embraced it instead of neglecting the fact and just pushing on in life.

He is 4 years older than I am.

My family was poor and parents were uneducated. They divorced after I moved away. I was also physically abused by my sibling through middle school. They are now in and out of psych ward and have been to prison. Currently homeless.

My brother is high functioning Asperger's and has/had many more behavioral and school performance problems than I did/do. I feel like we got roughly the same amount of attention, just that more of his was negative, although I did take on a number of the typical "mother" role activities in my early teens when my mother largely withdrew from the family (more about her than my brother). Although both of my parents have speculated that they fall on the Autism spectrum, my father has learned to deal with this through a logical routinizing of parts of social/emotional interaction, and I don't think I agree with my mother's assessment of herself (I think she has some minor mental health-related emotional problems, not ASD, although her brother seems to have ASD).

My PDD-NOS sibling was my twin brother. I was one minute older and so I answered the questions as if he were the younger sibling. He passed away six years ago from leukemia (AML), unrelated to his disabilities.

With parents both long deceased, our family of origin has shattered. I rarely am in contact with my Aspergers brother, and only slightly more with my sister. We hardly see one another. Years can go by. We live far distances from one another geographically, and there is no family center. My answers about this past week were a bit skewed, since I just learned something medical about myself, which actually might have a similarly big impact on my siblings. I am going to have to tell them I've inherited a gene mutation...

You love the person, but bearing the responsibility of taking care of not only your parents but your sibling as you get older is a hard hit as an adult especially in this economical climate. Doing things for yourself is much harder.

With nine kids in my family, and two parents that I suspect are far from neurotypical, it's probable that more than one of us actually has ASD-- but the squeakiest wheel gets the grease. Only the most severe and visible health issue among all the siblings got (received, deserved) parental attention at any one time: boy w/ testicular malformation over girl with "period problems" (that actually became ovarian cysts when she grew up), girl needing stitches over girl with pulled muscle (that were part of a pattern of leg issues leading to physical therapy and surgery when she grew up), boy with a speech impediment over boy with sensory processing problems (which were apparently linked to a psychological problem he was diagnosed with when he got to be a teenager), girl with mononucleosis over boy with infected mosquito bite (that turned out to be a staph infection)... We developed our own shared culture of "making do", trading in a currency of first-aid knowledge and supplies. Since none of us were as "bad" (read: severe) as the one sibling who got a diagnosis, none of the rest of us were ever considered for one. After all, who qualifies for the GATE program and needs tutoring at the same time? (Almost all of us.)

I don't know that my responses are useful, because my brother's ASD was overshadowed by other dramatic issues in my family (trauma, drug addiction, separation, instability). It is hard to know which dynamics were because of his status, and which were because of these other things. Also, in surveys consider asking for gender instead of sex (and even allowing for three options, including "non-binary" or "transgender"). Asking for sex makes responses confusing for transgender people, as we don't know if you want to know legal, current, or original "sex."

Anyone who grew up with a sibling with ASD most likely received less attention at times than their disabled sibling. I personally feel no resentment towards my parents- there are plenty of valid reasons why my sibling needed more attention. At times growing up I felt very different and was not able to do everything my friends did and I grew up very fast but I wouldn't change a thing :) My sibling inspired me to go into special education.

■■■■, my autistic sister, was great growing up. Now that she's in her movie mid twenties she's great. We all love her and value her company. But it's different having a family member or friend that can't speak to you or understand basic concepts like time and danger. I wish she was like my other sister but I'd never wish she wasn't my sister.

My sister is dead now, drug overdose. She was IMPOSSIBLE. She destroyed my things. I could never express like for anything or she would destroy it. I wanted real siblings... I love people. I grew up alone, and a loner. I am now very worried about being left, or losing some one. My mother was fabulous and loved me lots. she made it OK because she was a good friend and mom. But I hated my sister, and I wanted her to be normal so I could love her and have a friend.

I did deal with depression after college for about a year and a half. 22-24 was rough and my autistic brother was living at home. At that age I wrongfully blamed my parents for my transition into working full time.