

The Institute for Clinical Social Work

Adolescent Siblings Living with Autism and Their Friendships

A Dissertation Submitted to the Faculty of the
Institute for Clinical Social Work in Partial Fulfillment
for the Degree of Doctor of Philosophy

By

Jacqueline M. Duffy-Hook

Chicago, Illinois

February 2018

Copyright © 2018 by Jacqueline M. Duffy-Hook

All rights reserved

Abstract

Having a sibling with severe autism affects adolescent friendships. Previous studies consider the general effect a disability has on siblings, usually from the parents' perceptions. This qualitative study, using a grounded theory design, explores the thoughts, feelings, and perspectives of 14-17 year-olds living at home with a sibling with level-3 severity ASD and how the adolescents view their friendships. Seventeen in-person interviews reveal five findings: living with severe ASD is often difficult; descriptions of friendships are similar to any other adolescent's friendships; the adolescent's sense of self is affected by the sibling with ASD; friendships and thoughts about friendships are emotionally affected by autism; and ASD affects their practical life. Findings are interpreted using developmental and object relations psychoanalytic perspectives.

For my chosen family, Al, Cole, and Evin

And for my parents, Harold and Eileen

The language of friendship is not words but meanings.

-Henry David Thoreau

Acknowledgments

My sincerest gratitude is extended to my dissertation committee: Constance Goldberg, M.S., Denise Duval Tsioles, PhD, Joe Palombo, M.A., and Karen Bloomberg, PhD, for their time, support, and wisdom. It is to my dissertation chairperson, Joan DiLeonardi, PhD, I am indebted. Thank you, Joan, for your encouragement, guidance, and interest in seeing me through to the end.

This research study would have never happened without the earlier efforts of Peter Shaft, M.S.W. and Michelle Sweet, PhD. They worked in tandem getting me over a seemingly unsurmountable hurdle and I am so grateful.

Lastly, I wish to thank my adolescent participants and their parents who opened their home to me despite the disruption a family experiencing severe autism might incur having a stranger present. I am honored to have had the chance to hear their stories.

JDH

Table of Contents

	Page
Abstract	ii
Acknowledgments	vi
Chapter	
I. Introduction	1
General Statement of Purpose	
Significance for Clinical Social Work	
Statement of the Problem and the Specific Objectives	
II. Literature Review	6
Psychiatric Definition of Autism	
Theoretically Understanding Autism and Relating Siblings with Autism	
Psychoanalytic Thought on Sibling Relationships	
Adolescence	
Friendship in Adolescence	
Theoretical and Conceptual Framework	
Questions Explored	
Theoretical and Operational Definitions of Major Concepts	
Statement of Assumptions	
III. Methodology	32
Research Strategy and Design	
Scope of Study, Setting, Population, and Sampling	
Data Collection Methods and Instruments	
Plan for Data Analysis	
Statement on Protecting Human Rights	

Table of Contents---Continued

Chapter	Page
IV. Introduction to the Results.....	39
Participants	
Categories	
V. Living with My Sibling.....	42
Defining Autism	
Experiencing Behaviors	
Being Responsible	
Sharing Space	
Evoking Emotions	
VI. Becoming Me While Living with You.....	56
Who I Am	
Actions Speak Louder	
“I Have (Other) Feelings, Too.”	
If Only the World Knew	
VII. Friending.....	68
Friends by Number	
Defining Friend	
Where We Met	
Qualities of a Friend	
“My Friends Shape Me.”	
Hanging Out	
VIII. My Brother and My Friends.....	82
This Much Is Known	
The Benefit or Burden	

Table of Contents---Continued

Chapter	Page
IX. Findings	87
Finding 1: Living with severe autism is often difficult for adolescent siblings.	
Finding 2: The adolescent’s sense of self is affected by their sibling with severe autism.	
Finding 3: Adolescents with siblings affected by severe autism describe friendships similarly to descriptions given by other adolescents.	
Finding 4: A sibling with severe autism affects the physical space and practical experience that their adolescent brother or sister shares with friends.	
Finding 5: Living with a sibling with severe autism emotionally affects adolescent friendships and the thoughts given to friendships.	
X. Theoretical Discussion and Clinical Implications	100
Theoretical Discussion	
Clinical Implications	
Study Limitations	
Further Research	
Appendixes	
A. Recruitment Flyer	117
B. Consent Forms	119
References	128

Chapter 1

Introduction

General Statement of Purpose

Studying the perspectives held by adolescents who have a sibling with severe autism especially regarding friendships came from a curiosity. I noticed an eighth grade student whom I had known to have only one sibling, a younger brother with severe autism, and he was always alone at school. Despite attending the same school district with the same classmates his entire school career and his repeated involvement in cross country and track, this eighth grade boy was always by himself. He did not seem to have any friends. Even though there could be any number of reasons a young adolescent might be socially withdrawn, this boy had the added dynamic of growing up and living with a sibling with severe autism. Questions emerged whether living with autism affected his ability to be social, to have friends. Does his lack of interaction with peers at school have anything to do with having a sibling with autism? What might other teenager's perspectives be about social interactions, friendships and having a brother with autism? Is there a connection?

Sibling relationships are known to provide opportunities for developing social competency by learning to compete fairly, to negotiate and compromise, and to

understand ambivalent feelings within relationships. The quality of this relationship varies but is additionally diverse and potentially challenging when the sibling has a disability like autism. For example, there is ample research on the effects on children, adolescents, and adults who have a brother or sister with autism spectrum disorder (Beyer, 2009; Meadan, Stoner, & Angell, 2010; Orsmond & Seltzer, 2007; Smith & Elder, 2010). Parents and teachers have been the primary study participants in the previous research, not the brothers or sisters. “There are little data from children themselves regarding daily coping responses related to living with a brother or sister with disabilities” (Cox, Marshall, Mandelco, & Olsen, 2003, p. 397). This current research study explored friendships from the perspectives of the adolescents who have a sibling with severe autism rather than from their parents and teachers reporting on the adolescents’ perspectives.

People with autism spectrum disorder (ASD) have deficiencies in social interaction and delays in language development (American Psychiatric Association [APA], 2013). Symptoms of severe autism include fleeting to no eye contact, resistance to physical contact, unresponsiveness to verbal communication, negligible verbal and non-verbal communication, repetitive movements, aggression, sensory issues, set routines and rituals, and lack of play skills. Relationships, including sibling relationships, appear one-sided with limited to no give-and-take from the person with severe ASD.

The participants in this study were adolescents because during this stage of development, relationships expand beyond the bounds of the family. Non-familial

relationships hold more significance for the teenager. Developmentally, adolescents are also acquiring a personal sense of identity, are adopting a personal value system, and can provide a more cohesive narrative. The person they are becoming has been affected by their past and the people in their life including their sibling. Their interest in relationships outside their home and their ability to articulate their personal story made them the best population for this study.

Significance for Clinical Social Work

Gaining an understanding through an adolescent's narrative about the added dynamics of living with a sibling affected by severe autism enhances clinical social work practice in three ways. First, the practitioner benefits from knowing how brothers or sisters developing neurotypically understand the effect living with a sibling with severe ASD has on their friendships. Does the adolescent feel that having a sibling with autism hurts or helps their relationship with friends? What are the effects on an adolescent's friendships when their sibling has severe ASD? The results from this study provide social workers explanations about clients' relationships with friends, how they engage with them, the roles they might ascribe to themselves within their friendships, and how their personal stories include their sibling relationship and their friendships. Social workers learn how their client has been relationally affected by having a sibling who lacks social give and take.

Second, during adolescence, thoughts about the future and consideration about desirable societal roles are forming (Erickson, 1963). Friends become increasingly important as the adolescent becomes more observant of the social environment beyond the family. Living with a sibling affected by autism is a factor with potential lifelong implications for the sibling without ASD. The possibility of assuming guardianship for a sibling and how this will affect long term friendships may become a conscious thought during this stage of development. Social workers would benefit from knowing how the adolescent client thinks about their future with friends and their future obligation to their sibling with severe autism. The practitioner may learn from this study how the client contemplates the future, how the client handles the desire for more independence from the family, and what questions the client has about forming and keeping current and future friendships. Wanting, needing, and having more independence from the family could raise “why me” questions.

Lastly, respect and consideration must be given to siblings living with autism as a professional and ethical value. The National Association of Social Workers (NASW) Code of Ethics states, “Social workers should obtain education about and seek to understand the nature of social diversity...with respect to...mental or physical disability” (2008). This research study adds to social workers’ understanding of the social diversity severe autism adds to the friendships of teenagers’ developing neurotypically.

Statement of the Problem and the Specific Objectives

The impact on adolescent friendships when a sibling has severe autism was studied. The objectives of this project were to learn from siblings without autism what views they hold regarding friendships and how having a sibling with autism has or has not affected these views.

Chapter II

Literature Review

Psychiatric Definition of Autism

Autism is a neurodevelopmental disorder affecting social communication and social interaction. Repetitive and restrictive patterns of behaviors are also present (National Institute of Neurological Disorders and Stroke, 2009). The Diagnostic and Statistical Manual of Mental Disorders, 5th edition, (DSM-5) uses the term Autism Spectrum Disorder (ASD) to include disorders once categorized as Pervasive Developmental Disorders (APA, 2000). A person affected with ASD may have deficits with social and emotional reciprocity, nonverbal communication deficits, and/or deficiencies in “developing, maintaining, and understanding relationships” (APA, 2013, p. 50). Severity specifiers are given in the DSM-5. Of interest for this study, severity level 3 “requiring very substantial support” (APA, 2013, p. 52) is considered.

The American Psychiatric Association defines social communication and restricted, repetitive behaviors, severity level 3 as:

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social interactions, and

minimal response to social overtures from others. Inflexibility of behavior, extreme difficulty coping with change, or other restricted/repetitive behaviors markedly interfere with functioning in all spheres. Great distress/difficulty changing focus or action. (p. 52)

Theoretically Understanding Autism and Relating

Autism significantly impacts the how-to of relating with others. Children with autism appear to lack aspects of ‘knowing’ they “live within a social context” (Palombo, 2010, lecture). Several psychodynamic theories provide a framework explaining the development of understanding the self and the other in relationship. These theories may clarify how a sibling with a brother or sister with severe autism develops object relations but there is no psychodynamic theory to explain the apparent object relations difficulty experienced by people with autism.

Autism is a neurologically based disorder and neurobiology is missing in most psychodynamic theories. The perspectives that include neurobiology may offer some understanding of autism or, in the least; help discover which psychodynamic processes happen for people with autism. These theories include the psychodynamic approaches of attachment and object relations, and the developmental psychology concept of theory of mind.

Attachment emerged from Freud, who believed infants attach to the primary care person because they are motivated by the desire for food. However, Bowlby’s theory of

attachment provides a more personal understanding of relationship, by giving an infant a secure base to a caregiver (Bowlby, 1969). The infant's interest in being close to the primary care person is not desire driven but prewired within him (Palombo, 2010). As Bowlby and neuropsychologists see it, attachment is biologically-based.

Then Bowlby's colleague, Mary Ainsworth, contributes to attachment theory by developing a research procedure called Strange-Situation resulting in three types of attachment: "anxious/avoidant," "securely attached," and "anxious/resistant." These attachment types are not a predictor for psychopathology but describe the behaviors seen when an infant is reunited with the caregiver. Mary Main, who worked for Ainsworth, adds a fourth type called "disorganized/ disoriented" (Main & Solomon, 1986). The children having this type of attachment are described as being in trance-like states, crying for their parent while also moving away from the parent when picked up. This is similar to some of the behaviors of autism but not all. In addition, children with this form of attachment have been maltreated or neglected by their caregivers. Autism is currently thought to result from genetic and environmental factors and decisively not caused by ill-treating adults (National Institute of Mental Health, 2009).

The function of attachment is to regulate the child's affective state. Schore (2000) holds as Bowlby does that attachment is instinctive but he is additionally interested in understanding the neurobiology involved in the "affect-regulating functions that are central" (p. 31) to attachment. The interchanges between the caregiver and the infant allow the infant's brain the capability to self-regulate. The caregiver's receptiveness

determines whether a secure or an insecure attachment results (Schoore, 1994). A person's psyche and neuropsychology allow attachment to develop unless one is compromised. Shapiro, Sherman, Calamari, and Koch (1987) studied the attachment in autism and other developmental disorders and found children with autism demonstrate attachment behaviors "not significantly different from the attachment behaviors of (younger) normal children...but they make attachments variably in accordance with their capacity for affective display and understanding" (p. 483). Despite the presence of attachment behaviors, the neurobiological systems necessary for affect regulating functions are compromised when autism exists (Hirstein, Iversen, & Ramachandran, 2001).

Fonagy's conceptual framework provides another idea about attachment and the neurobiology involved. Understanding the 'how-to' of a child acquiring self and object representations and the functions those serve throughout development is integral to understanding the establishment of a child's thoughts, emotions, and behaviors (Fonagy, 1999). Severe autism leads to difficulty developing self and object representations. When thoughts, emotions, and behaviors are not established psychological discontinuities occur affecting the ability to establish relationships and the need for relationship. Although people with autism are affected relationally, their sibling, who is developing neurotypically, would be expected to establish and desire relationships.

There is a metacognitive process Fonagy terms mentalization which integrates attachment, psychoanalysis, and neurobiology and appears to be negatively impacted by

autism. Mentalization is “the capacity to make use of an awareness of [a child’s] own and other people's thoughts and feelings” (Fonagy & Target, 1998, p. 92). This process allows a reflective capacity. “By attributing mental states to others, children make people's behavior meaningful and predictable (Fonagy & Target, 1998, p. 92).” Autism seems to inhibit this capacity.

Researchers are finding that mentalization develops when other cognitive capacities are available. These include effortful control, theory of mind, inhibitory control, and attentional control (Fonagy & Target, 2002). Theory of mind, from developmental psychology, is the cognitive ability to evaluate and predict the behavior of other people based on knowing their intentions, goals, and beliefs (Baron-Cohen, Leslie, & Frith, 1985; Tager-Flusberg, 2007). Theory of mind is a deficit for most people with autism but does not address the affective-awareness and affective-regulatory or other social cognition issues of autism.

Recent neuroimaging studies on social cognition have discovered the mentalizing system and “the mirror [neuron] system...[which] has been associated with several emotional and cognitive functions central to social interaction, ranging from empathy to gestural communication and imitation” (Sperduti, Guionnet, Fossati, & Nadel, 2014, abstract). The role of the mirror neuron system is being considered in current research to account for the various social cognition deficits in autism (Tager-Flusberg, 2007).

Mentalization, attachment, and theory of mind are becoming more than theoretical

perspectives to explain the processes of social cognition and possibly the deficits of autism. They are now being understood neurobiologically.

Siblings with Autism

The effects of having a sibling with a disability have been assumed if not studied for 85 years (Martz, 1930) and studies abound with conflicting conclusions. Research specific to ASD is increasing exponentially just as the prevalence of the disability is increasing (Centers for Disease Control and Prevention, 2014). Four literature reviews have been published specific to siblings with a brother or sister with autism. Orsmond and Seltzer (2007) review articles examining the sibling relationship and sibling well-being. They find brothers and sisters of children with ASD “describe positive aspects of their sibling relationship” (Orsmond & Seltzer, 2007, p. 316). However, the literature also indicates less closeness in the sibship (Orsmond & Seltzer, 2007). In the Beyer (2009) review, attention is given to “the impact of having a sibling with ASD as compared to one with other disabilities” (p. 444). The results are mixed. There are findings for positive and negative sibling relationships and no difference in contrast to sibling relationships when one sibling has a non-ASD disability.

The Smith and Elder (2010) review considers “sibling characteristics, relationships, and adjustment” (p. 190) in siblings with ASD, typically developing siblings, and siblings with other disabilities. ASD is an inconsistent factor regarding “self-competence, social competence, and experiences of living” (Smith & Elder, 2010,

p. 191) for the sibling developing neurotypically. Inconsistency in the research is found for the adaptability of the sibling with a brother or sister with ASD. The quality of the sibling relationship is affected by the responsiveness of the brother or sister with autism (Smith & Elder, 2010). In the fourth literature review, Meadan, Stoner, and Angell (2010) consider “the social, emotional, and behavioral adjustment of siblings of individuals with ASD” (p. 83). The reviewed studies lead to limited generalization due to the variety of methodologies used, the small number of qualified studies available, and the range and severity of ASD symptoms examined.

Research considering children in a sibling relationship when the brother or sister has severe ASD is sparse. Some studies use Pervasive Developmental Disorder (PDD) which includes all levels of severity while other studies include both Asperger’s syndrome and autism. “Asperger syndrome is considered by many to be the mildest form of ASD” (National Institute of Neurological Disorders and Stroke, 2012). Two studies specify ASD severity and the effects on siblings. Macks and Reeves (2007) include children with “a diagnosis of autism as opposed to other autism spectrum disorders such as Asperger’s syndrome, Pervasive Developmental Disorder, or high functioning autism” (p. 1062). The sibling of the child who has a diagnosis of autism is found to have a more positive self-concept than siblings of children with no diagnosis. Siblings are impacted negatively when demographic risk factors are present, such as being male, living with a low socioeconomic status, having only the one sibling, and being older than the brother or sister with autism (Macks & Reeves, 2007). Hastings (2003b) determines the severity

of the disability by using the Autism Behavior Checklist from Krug, Arick, and Almond (1980). When the severity level is high and the sibling participates in a level of formal social support, the sibling's behavioral adjustment improves as the support level increases. No behavior adjustment concerns are found when a high level of social support is provided (Hastings, 2003b).

Other studies examine the sibling relationship or the adjustment of siblings typically developing but do not define the severity of ASD. One study by Ross and Cuskelly (2006) recognizes aggression as the most reported interaction problem by siblings in their relationship with a brother or sister with a non-specified severity level of ASD. These siblings with typical neurology, who are aggressed against by their sibling with ASD, are at increased risk for internalizing problems.

As the symptoms of autism distinguish it from other disabilities questions have been raised comparing the effects various disabilities have on a sibship. Roeyers and Myche (1995) studied siblings of children with autism, with mental retardation, and with no disability. All the siblings had similar stress, however, siblings of a brother or sister with a disability rated a more positive relationship than sibships having no disability. The relationship quality for autism was better when the sibling with neurotypically development was informed about ASD (Roeyers & Myche, 1995). McHale, Sloan, and Simeonsson (1986) found when ratings were averaged, children of siblings with autism, mental retardation, and no disability had similar positive qualities within the relationship. However, a wider variability in the sibling relationship existed when only siblings of

children with disabilities were considered. Only one factor contributed to a better sibling relationship, when parents coped well having a child with a disability, (McHale, Sloan, & Simeonsson, 1986).

Sibling relationships with sibships including Down syndrome, autism, and children developing typically were compared by Kaminsky and Dewey (2001). When autism is a factor in a sibling relationship less intimacy, prosocial behavior, and nurturance was found between the siblings. However, in sibships with autism and sibships with Down syndrome, there was greater admiration toward the sibling affected by a disability compared to the admiration level in sibships with typical development. There was also less quarreling and competition (Kaminsky & Dewey, 2001).

Bågenholm and Gillberg (1991) found “siblings of children with autism, on the whole, were somewhat more negative in their views concerning their sibling relationship than siblings of mentally retarded and healthy children” (p. 304) and siblings of a brother or sister with mental retardation played together much more than sibships with autism or with no disability. In Hodapp and Urbano’s (2007) study comparing the relationships of adult siblings of individuals with Down syndrome or autism, warmer and closer relationships were found in sibships with Down syndrome. However, when there was frequent and lengthier contact, lower levels of behavior problems, and an ability to maintain better friendships by the individuals with disabilities, the sibling relationship was closer.

Research analyzing the impact of having a sibling with autism for the brother or sister developing typically has included psychosocial difficulties, social adjustment, behavioral or prosocial behavior, and emotions. Results range from a positive impact to no impact to a negative impact in the domains considered.

Benson and Karlof (2008) found no increased risk of psychosocial difficulties including conduct problems, hyperactivity or inattention, and peer problems for siblings with neurotypical development in a sibship with ASD. Others reported social adjustment was successful when siblings with a brother or sister affected by ASD were specifically asked (Gold, 1993; Macks & Reeves, 2007; Verté, Roeyers, & Buysse, 2003). For example, Kaminsky and Dewey (2002) found “siblings of children with autism are not at inflated risk for adjustment difficulties or loneliness” (p. 231) due in part to the children and/or parents’ participation in support groups. In contrast, when parents reported the significance of having a child with ASD on the social and emotional adjustment of that child’s siblings the impact was described as unfavorable (Macks & Reeves, 2007) and 35% of the siblings developing neurotypically felt lonely (Bågenholm & Gillberg, 1991).

The sibling developing neurotypically does not have an increase in behavioral adjustment problems related to having a sibling with ASD compared to a normative sample (Hastings, 2003b). In contrast, when the sibling with autism is nonverbal, the brother or sister studied “has more behavior problems and lower socialization skills” (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004, p. 860). Brothers of siblings

with autism engaged less in prosocial behaviors than sisters of siblings with autism (Hastings, 2003a).

Internalizing difficulties of depression, distress, and/or anxiety were present in children having a sibling with autism (Fisman, Wolf, Ellison, & Freeman, 2000; Gold, 1993; Ross & Cuskelly, 2006) with sisters reporting more depression and anxiety than brothers (Orsmond & Seltzer, 2009). Despite, Rodrigue, Geffken, and Morgan (1993) finding more internalizing problems in siblings with a brother or sister with autism than the comparison groups, the mean scores fell in the normative range of the Child Behavior Checklist.

The results are contradictory and for many reasons: different methodologies were used; the reporters (parents or the sibling without ASD) were different and may have had differing perspectives; demographic considerations may have been included; or cultural effects of sibling relationship and disability could play a role, as discussed in studies done internationally. What is known is that psychosocial difficulties, social adjustment, prosocial behavior, and/or emotions impact relationships and that people with ASD face some of these obstacles. Despite the varied conclusions, these studies are still valuable because they identify factors that influence a sibling's relationship with their sibling who has ASD as well as the factors that influence success in friendships beyond the sibship. These factors are crucial for this study. Perhaps some consistency will be discovered.

One last area needing attention is the fact that a person appears to be at a higher risk for autism when there is a sibling with ASD. In a study using a large, population-

based sample it was found that the recurrence risk for ASD was about 7% (Grønberg, Schendel, & Parner, 2013). The Centers for Disease Control and Prevention (2014) estimate the risk for autism in the general population to be 1.47%. Numerous research studies have been conducted about siblings with a brother or sister with ASD and phenotypic characteristics the sibling may exhibit. Pisula and Ziegart-Sadowska (2015) offered a review of those studies completed between 1993 and 2014. Similar to the sibling adjustment studies, contradictory results were found. Some researchers have posited various phenotypic traits of autism in siblings of individuals with ASD while others found no differences between siblings of individuals with ASD and comparison groups with respect to the phenotypic characteristics. For this current study, participants with a diagnosis of any level of autism will not be included.

Psychoanalytic Thought on Sibling Relationships

This research focuses on the perception one sibling has of their brother or sister who has a diagnosis of severe autism, and learning the impact, if any, on the social life and friendships of the reporting sibling. Although the focus of this study includes a sibling with a specific disability some understanding of the experience of typically developing siblings must be provided. Mitchell (2003) considers siblings to be “essential in any social structure and psychically in all social relationships” (p. 1). The sibling relationship is dynamic and adds to the psychodynamics of any person whether the sibling is typical, neuro-atypical, disabled, ill, adopted, stepped, deceased, or fantasized.

“Clinical experience with children repeatedly reveals the vital significance of real, lost and imagined siblings” (Rustin, 2009, p. 149). Sisters and brothers have a very important role in early development and the relevant effect of the relationship continues throughout their lives.

Knowing the significance sibling relationships have throughout a person’s life, it may be surprising to learn little attention was given to the sibling relationship in early psychodynamic thinking. Even though Freud and psychoanalytic theorists after him regularly mentioned if not discussed siblings and sibling relationships in their written texts, psychoanalytic consideration of this relationship was limited. Only 212 results were found in the Psychoanalytic Electronic Publishing database that covers the period of 1918 to the present and half were published since 2000. However, Morley (2013) in a review of Joyce Edwards’ book, *The Sibling Relationship-A Force for Growth and Conflict*, states that, “The stream of articles and books on the subject [of siblings] then accelerated until, between 2000 and 2010, there were over 5000 listed by [PsychInfo], of which more than 800 were from the American Psychoanalytic Association” (p. 109).

Psychoanalytic texts reference the hostility and rivalry existing between brothers and sisters and/or their role as parent substitutes (Colonna, 1983; Colonna & Newman, 1983; Kris & Ritvo, 1983; Rosner, 1985). Freud (1909) provides an infamous example when he reports Little Hans’s protest of not wanting his baby sister. Freud (1918) also describes the unfortunate experiences The Wolf Man endured with his rivaled and older sister, including sexual stimulation and exposure to frightening pictures of wolves. Banks

and Kahn (1980-81) consider Freud's personal sibling experience to explain his perspective. Freud gives attention to sibling relationships, but he takes a primarily bleak view of the role siblings have.

More recent psychoanalytical examination is expanding the understanding of the sibling relationship and the impact it has. Neubauer (1983) and others (Coles, 2009 [in Lewin & Sharp, eds.], A. Freud, 1951; Klein, 1932) find sibling relationships affect both character formation during childhood and object choice in adult life through the experiences and modifications of rivalry, envy, and jealousy. Parens (1988) conceptualizes the roles a sibling has in a person's psychic experience. A sibling can be an object of libidinal attachment despite the parent's preeminent place in classical theory. A sibling can be an erotic object, a hostile/hated object, and an object of the displacement of hostility. A new sibling can be the "wished-for baby" (Parens, p. 38), an auxiliary ego, and a facilitator of socialization.

Siblings become objects of attachment and help organize the self. They become a "bridging or connecting object" (Parens, 1988, p. 34) acting as a parent substitute at times and a peer at other times. Siblings are used to impact psychic and social experiences. The effects can include becoming parental objects when gaps exist in parental care and also becoming "bridging objects to neutralize aggression, displace hostility, and transform incestuous fantasies toward more age-appropriate peer fantasies" (Charles, 1999, p. 880). Over the course of a person's life, sibling attachments affect the quality of other object relationships. Siblings provide a stage for interpersonal and intrapersonal development.

Kernberg and Richards (1988) delineate some interpersonal consequences of having a sibling. Brothers or sisters as hostile objects and erotic objects are available for play where affect discharge is accepted and expected. This play allows for a growth in fantasy. Sibling play provides the opportunity to model different social behaviors and to witness and negotiate character differences. Play helps children “develop the tools to make sense of things, to link experiences together, and to unravel the tangle of feeling and impulses” (Slade, 1994, p. 91).

Another interpersonal consequence occurs when a parent’s pathology interferes in the relationship between siblings, adding to sibling rivalry or role confusion. When a parent’s developmental issues have not been resolved, intergenerational transmission of pathology results, creating developmental impediments for the child and the siblings (Houzel, 1996; Silverstone, 2006). These impediments can alter the building blocks necessary for understanding the self and the self within the family. Interpersonal and intrapersonal development of a sibling will vary when parental pathology exists.

When a family member has had difficulties generating a sense of self and others, the related family members might adapt and remain successful developmentally (Silverstone, 2006) or problems may develop leading to their own pathology (Houzel, 1996). Siblings can be a benefit or hindrance toward successful development despite the existence of pathology. As children must manage and contain opposing feelings regarding their relationship with parents and other family members, the sibling relationship can be a safer avenue for having and acting on existing conflicting emotions.

Anxiety and regulation concerns can occur with a sibling if the parent is not “good-enough” (Winnicott, 1953) resulting in the child’s inability to develop a capacity for attending to and finding meaning from self experience. Having the capacity to think about one’s own experience is essential for healthy psychological development (Winnicott, 1971/2006) and for realizing both affectionate and object relationships (Winnicott, 1963). When a child’s psychic developmental need is not met by the parents, a sibling can meet it. “Each sibling plays out various roles or functions of the parents” (Charles, 1999, p. 893). Each child and each sibling dyad develop particular unconscious roles within the family. As each person’s defenses and understanding of the world evolve, these prohibited or appointed roles help the person manage and function in the familial environment.

However, a sibling can also interfere with the development of ego functions resulting in various consequences. Overidentification with a sibling can interfere with the establishment of a separate identity (Sharpe & Rosenblatt, 1994). Idealization of a sibling can lead to “devalued self-images” (Sharpe & Rosenblatt, 1994, p. 508) while devaluation of a sibling can lead to grandiosity. Each sibling also identifies with particular aspects of the other sibling. A sibling can counteridentify, splitting off those aspects of the brother or sister that are unbearable. This ‘process’ develops a self or other who can endure reality. Nonetheless, it is an adequately developed brother /sister relationship where a resolution of sibling conflict and ambivalence plus an attainment of

a unique individual identity allow the person to find “a love object outside the family” (Sharpe & Rosenblatt, 1994, p. 508).

Attachment theory has also been considered in sibling relationships and the potential influence on social facilitation and friendship. The significance of attachment came from Bowlby’s experience with children who were separated from their mothers which caused some children to develop psychopathology and “affectionless personalities” (Sanders, 2004, p. 177).

Sanders writes:

Attachment is defined in terms of parental and child behaviour – in the proximity-seeking behaviour of the young child during separations. The complement of attachment is the contribution of the primary carer to the relationship, which is usually described as ‘bonding’. Thus, the child attaches to the parent; the parent bonds with the child. These dual processes are mutually reinforcing in a cycle of dependency, need-arousal and need-fulfillment, described by Fahlberg (1994).
(p.178)

Rutter (1972) suggests the separation a child experiences is not only from the mother but also the father, the siblings, and the home environment. This gives importance to everyone in the home where bonds are forged. Thus siblings may have a “moderating” influence on the impact of separation experiences for young children (Sanders, 2004, p. 178) and siblings are inevitably bound together by the family narrative they share (Silverstone, 2006).

The sibling relationship is the first peer relationship a child knows. It holds significance in the psychic, social, and emotional development of a person. Character is enhanced or complicated. Roles are defined and future relationships are affected.

Adolescence

The stage of development called adolescence has a biological beginning with personal and psychological implications and a relatively recent history in our culture. Biology marks the start of adolescence with the onset of puberty. This first occurs when the body releases sex hormones causing the reproductive organs to mature (Merriam-Webster's collegiate dictionary, 2014).

However, adolescence is often defined culturally as a period of transition from childhood to adulthood. A cultural example of the move from childhood to adolescence to adulthood in the United States can be found in the public educational system. Over 100 years ago, teenagers would have followed in the footsteps of their parents taking over the farm or family business (Nasaw, 1981). There was no adolescence. When it became necessary in the US during the industrial revolution to have a more educated population institutionalized secondary school began (Nasaw, 1981). The task of secondary education is evolutionary, molding a young adolescent into a contributing adult member of society by preparing them to succeed in a career and postsecondary education (ISBE, mission statement, n.d.). Culturally, adolescence ends when there is minimal parental dependency and entry into the work force (Sisler & Ittel, 2015). A cultural definition of adolescence is

“the period from puberty to maturity terminating legally at the age of majority”

(Merriam-Webster’s collegiate dictionary, 2014).

In addition, adolescence is marked by intrapsychic development. “The psychic achievement of...adolescence [lies] in the mastery of emotions” (Blos, 1962, p. 174).

“Adaptive or defensive mechanisms” (Blos, 1962, p. 172) should be the result of balanced integrated ego development however; adolescence is a time of balance disturbances (Blos, 1962). For an adolescent to become an adult with an organized personality, individuation must occur, again. The first individuation process happens around three years of age and results in object constancy. Adolescent individuation results in stable and “firm boundaries” (Blos, 1967, p. 163) of self and object representation.

The transition from adolescence and adulthood also results in other psychological changes. Sharpe and Rosenblatt (1994) consider the change of the oedipal relationships and wishes that lead an adolescent to adulthood. They write:

In normal development, the aims of oedipal sibling relationships are gradually given up during adolescence, along with oedipal wishes toward parents. The processes involved in this more definitive resolution would appear to be similar and can be schematized as follows: (1) deidealization of self, parents, and siblings, with the attainment of more realistic representations; (2) selective identification with parents and siblings; (3) formation of the mature ego ideal (Blos, 1979). These achievements result in the late adolescent’s development of a

unique identity and the ability to relinquish any family member as a primary love object or as an infantile object of rivalrous hate and revenge, with the ensuing freedom to pursue and commit to a love object outside the family, and to pursue realistic career goals. (pp. 507-508)

Ammaniti and Sergi (2003) give a detailed summary of the changes occurring during adolescence through the lens of developmental and attachment theory.

1. Body and sexual puberty transformations that deeply influence the perception of the self and of the others.
2. Affective changes due to the progressive detachment from the attachment figures.
3. Cognitive changes with the advent of more mature functioning, such as the formal operations, the ability to reflect on one's own cognitive processes (i.e., metacognition, self-reflective function, and the ability to understand and explain ambivalence).
4. Joining the peer group, which has a decisive role especially in the first phase of adolescence. (p. 59)

Psychosocially, adolescence affords opportunities and experiences in the wider society allowing non-familial relationships to develop. During this stage of life, youth are “concerned with what they appear to be in the eyes of others as compared with what they feel they are” (Erikson, 1950, p. 261) and relationships are given principal consideration (Blos, 1967). Ego identity occurs through integrating experiences, aptitudes, and

opportunities in the wider world, enabling end-stage adolescents' sexual identity, occupational identity, and social identity (Erikson, 1950).

Blos (1979) summarizes the adolescent stage of development by stating, "with the advent of sexual maturation, cognitive leaps to higher levels, and new physical capabilities, a thrust away from infantile family dependencies into the wider social milieu becomes not only feasible but mandatory" (p. 5).

Friendship in Adolescence

Friendships in adolescence are essential and aid in development of the self and with ego identity. These relationships provide an opportunity for teenagers to "learn of an extrafamilial reality" (Savin-Williams & Berndt, 1990, p. 278) away from parents and siblings and experience a life uniquely theirs (Savin-Williams & Berndt, 1990).

Friendships are defined as the state of being in relation with a non-biologically related person by feelings of affection, personal regard, and interest. Rangell (1963) provides a psychoanalytic definition.

Friendship: Mutual regard cherished by kindred minds. Friendship is a deep, kind, enduring affection, founded on mutual respect and esteem. Friendship is always mutual. Friendliness is the quality of friendly feeling without the deep and settled attachment implied in the state of friendship. Affection may be purely natural; friendship is a growth. Friendship is more intellectual and less emotional than love. Friendship is more calm and quiet, love more fervent, often rising to

intensest passion. Friendship implies some degree of equality, while love does not. (p.11)

The evolution of friendships starts with playmates to companions to intimate friends to love interests. At the start, a child has to have specific skills to have successful friendships such as communicating clearly, delaying wishes, attending to the other's perspective, and managing disappointments (Dunn, 1993). During adolescence, socioemotional development affords interpersonal intimacy (warmth, closeness, love) in friendships. Sullivan (1953) theorizes there is a need for intimacy, for satisfaction and security, with at least one other person. Intimacy occurs in adolescent friend relations.

Teenaged friendships can develop because the time spent with friends for most adolescents is greater than time spent with parents and siblings. The older the adolescent the more time spent with friends. This leads to the development of "a sense of connectedness with others and individuating the self" (Savin-Williams & Berndt, 1990, p. 279). These relationships form when there is loyalty and intimacy between the two friends. Loyalty is the "commitment and genuineness in attitudes, values, and interests" (Savin-Williams & Bernt, 1990, p. 278) and intimacy is "the ability to share one's thoughts and feelings" (Savin-Williams & Berndt, 1990, p. 278).

Adolescent friendships like friendships at any age are voluntary and fulfill various interdependency needs. These social needs include security and affection, playful involvement, acceptance and status, and consensual validation (Buhrmester, 1992; Sullivan, 1953). Security is defined as personal worth and self-esteem. Companionship

with one's experiences, interests, recreation, or sport is playful involvement. Affirmation of one's value and competence is acceptance (Buhrmester, 1992) and consensual validation happens when collaboration is possible. Collaboration means "clearly formulated adjustments of one's behavior to the expressed needs of the other person in the pursuit of increasingly identical (or) nearly mutual satisfactions" (Sullivan, 1953, p. 246). A friend "becomes practically of equal importance in all fields of value" (Sullivan, 1953, p. 245) thus meeting social interdependency needs.

In the research on friendship, various relationship dimensions and social contextual factors have been considered and examined. Emotional intimacy, control, conflict, guidance, conflict resolution, and exclusivity are some of the relationship dimensions studied (Buhrmester, 1992; Furman, 1996; Cleary, Ray, LoBello, & Zachar, 2002; Updegraff, McHale, & Crouter, 2002). Several social contextual factors such as frequency of interaction, proximity, family circumstance and stress, parent-child interaction and relationship, and early attachment behaviors have been researched (Cohn, Patterson, & Christopoulos, 1991; Dishion, 1990; Henggeler, Edwards, Cohen, & Summerville, 1991). Most studies, similar to sibling relationship studies, are quantitative and use parents as the data source.

However, empirical studies allowing adolescents to share their personal experiences with friends rather than their parents' perceptions would best derive a theory to guide the selection of features of adolescent friendship research (Furman, 1996).

Empirical study is necessary as “adolescents may be the most accurate reporters of the affective nature of their friend relationship” (Updegraff, et al., 2002, p. 186).

Theoretical and Conceptual Framework

Relating holds significance for humans. The infant’s dependency on the parent for care and provision is obvious. The beginnings of relating with the caregiver lead to the development and capacity for intimate relationships throughout life. Also stated, the development of an internalized object allows for later formation of interpersonal relations. “Fairbairn, as Sullivan, felt that there is a naturally unfolding, maturational sequence of needs for various kinds of relatedness with others, from infantile dependence to the mature intimacy of adult love” (Mitchell, 1981, p. 386). This study concerns the relationship an adolescent has with friends which is minimally two steps away from the caregiving bond but is one step away from the person’s first lateral relationship, the relationship with a sibling (Mitchell, 2003). The adolescents in this study have a different experience of sibling relationships because severe autism is affecting a brother or sister.

A psychoanalytic theoretical framework will be used to discuss and evaluate the analysis of the data. This framework will be Winnicott’s object relations theory regarding the development of self-formation, which is “ultimately dependent on an interpersonal dynamic,” (Kirshner, 1991, p. 169) initially occurring through “affective exchanges communicated by facial expressions” (p. 170) seen by the infant from the mother. In this study, the then-infant is now an adolescent, who continues his development of selfhood

through interpersonal relations with perhaps his sibling with autism and friends. Object relations theory regards relatedness as the primary motive for psychic development (Ainsworth, 1969), interpersonal relations, and mental health.

Questions Explored

How do adolescents who have a sibling with severe autism experience their friendships? If living with autism has affected the participants' friendships, how has this affected them?

Theoretical and Operational Definitions of Major Concepts

For the purpose of this study, a person with severe autism will have a medical diagnosis of autism and spend ten percent of the school day or less in general education classrooms indicating an ASD severity level three "requiring very substantial support" (APA, 2013, p. 52).

Siblings are two brothers, two sisters, or a brother and sister, living or having lived in the same household for at least seven years.

Typically developing is defined as never having had a medical or educational diagnosis of any developmental delay.

An adolescent will be defined as anyone between elementary school graduation and the summer following high school graduation.

Statement of Assumptions

Sibling relationships are significant throughout a person's life and in adolescence.

Autism impacts families including siblings.

The ability to form reciprocity in relationships is impacted when someone is affected by severe autism.

Psychodynamic development continues throughout life including for people with autism.

Friendships become more important in the narratives and perspectives of adolescents than during early stages of development.

Having a sibling with severe autism affects social relationships and friendships.

Chapter III

Methodology

Research Strategy and Design

Gaining an understanding of or learning about a perspective someone holds lends itself to qualitative research. This qualitative study uses Charmaz's grounded theory methodology as a means to gain a "theoretical understanding of the studied experience," (Charmaz, 2006, p.4) which in this case are the thoughts, perspectives, and meanings given to friendships when there is the experience of having a sibling with severe autism.

Charmaz (2006) holds a constructivist perspective. Constructivism allows for the epistemological view this researcher has regarding the topic of autism. Constructivists understand there is more than one way to know or develop one's reality. One example of this is the history of the definition and understanding of autism from childhood schizophrenia to autism then to the inclusion of the subcategories of autism to the current autism spectrum disorder. Autism has been known variously through "time, place, culture, and situation" (Charmaz, 2006, p. 131).

The participants of this study know how friendships are impacted by their personal reality of living with a brother or sister with severe autism. The reality and

knowing are the “*how*-and sometimes the *why*-participants construct meanings and actions in (these) specific situations” (Charmaz, 2006, p. 130) of having friends and having a sibling with severe ASD. The purpose of this study is to understand the meaning and effect of the sibling relationship on friendships and to gain greater insight concerning how having a sibling with autism potentially affects friendships during adolescence. Autism and friendships construct multiple realities.

Another aspect of the constructivist perspective in grounded theory is the researcher’s role in the process. By interacting and engaging with the participants; and by having personal views, beliefs, assumptions, and experiences about the topic, the researcher adds to the inevitable subjective nature of the qualitative process and analysis.

Scope of Study, Setting, Population, and Sampling

Purposive sampling was used as the participants had to have a sibling with severe autism. The participants were purposely selected based on this fact. This was a convenience sample as the participants were found in two Midwestern states (Tashakkori & Teddlie, 1998). The study included participants who were high school-aged including those adolescents having just completed the eighth grade through the first summer of high school graduation. The participants did not have a diagnosis of ASD. Their sibling either lived with them at the time of the interview or the two lived jointly for seven years. The sibling with severe autism had to have an Individual Education Plan (IEP) from their school system allowing for, at most, ten percent of their school time to be in the general

education environment. Each participant had to be willing to speak with the researcher about their friendships and assent to the research. Parents had to give consent for under-aged participants as mandated by the Institutional Review Board (IRB) of the Institute for Clinical Social Work (ICSW).

Referrals for this study were obtained through several means. Flyers (Appendix A) were offered to therapeutic day schools who educate children with such severe autism that their home school districts are unable to provide an appropriate education. The Illinois Association of School Social Workers (IASSW) agreed to advertise the study to its membership via emails. IASSW also allowed the researcher to speak briefly and leave flyers at their annual conference attended by more than 500 school social workers. The Autism Speaks Walk at Soldier Field in Chicago was attended and flyers were given to various exhibitors. The study was also posted on Autism Speaks' website under the research tab. A Facebook page was published specifically for the study. Finally, an email was sent to each Director of Special Education in two Midwestern states.

People interested in participating in the study called or emailed. A brief screening was done over the phone to determine if the family met the eligibility criteria. A one-hour in-person interview was then scheduled. After sixteen months of recruiting and interviewing, data saturation was reached with 17 participants. Saturation means the information obtained reaches a point where no new information is heard that would lead to "new theoretical insights" (Charmaz, 2014, p. 213).

Data Collection Methods and Instruments

The in-person interviews were recorded and transcribed. Notes were taken during and after the interview. Brief informational interviewing was used to gather limited demographic data and to build rapport. This information included the participants' age, gender, education level, and the overall family structure. However, the principal method of data collection was through intensive interviews where "the participant can relate his or her experience" (Charmaz, 2014, p. 57). Charmaz suggests this is done by:

- Exploring the participants' experiences of relationships in-depth
- Asking open-ended questions
- Gathering comprehensive responses
- Ascertaining the "participant's perspective, meaning, and experience" (p. 56)
- Investigating unforeseen implications, intimations, and queries.

The open-ended statements used during the interview included the following:

- Tell me about one of your friends.
- Tell me what your friend knows about your sibling with autism.
- Tell me how living with autism has helped/not helped you and your friendships.

Follow-up contact would have been made if clarification was necessary. New open-ended or follow-up questions were added based on the information gathered from the previous interviews.

Plan for Data Analysis

Charmaz's (2014) grounded theory is done systematically without prescribed procedures to structure data analysis while being cognizant that the ultimate goal is to build a theory from the data collected. The process of analyzing the data begins with initial of the transcription from the first interview and continues with every subsequently transcribed interview. All grounded theory coding "fosters studying action and process...to explicate how people enact or respond to events, what meanings they hold, and how and why these actions and meanings evolved" (p. 113). Data analysis in grounded theory is systematic but does not follow a step-by-step process. Each level of analysis is happening as interviewing and transcribing continue. The analysis consists of initial coding, memo writing, and focused coding where categories are discovered and an answer to the research question is found.

Initial coding describes actions per segment of transcription (Charmaz, 2006). It is "categorizing segments of data with a short name that simultaneously summarizes and accounts for each piece of data" (Charmaz, 2014, p.111). Memo writing is used to record the thoughts the researcher has regarding the emerging data. This is another data source and an additional mechanism to analyze data.

The next level of coding called focused coding is "using the most significant and/or frequent early codes to sift through larger amounts of data" (Charmaz, 2006, p. 57). Thus the initial codes are analytically categorized. Once analysis begins and categories are built, follow-up interviews could be been done if necessary. Participants

were also allowed to contact the researcher after the first interview if more thoughts came to mind.

Next, member-checking which allows participants to confirm the analysis of the data or refine the categories was offered to the participants after the categories were determined. An email was sent to the participants for member-checking.

According to Charmaz's (2014) grounded theory methodology, as categories become evident, a strategy called theoretical sampling becomes necessary. "The purpose of theoretical sampling is to obtain data to help explicate categories" (Charmaz, 2014, p. 198). Data can include follow-up interviews, memo-writing, and studying previous data, giving thought to the similarities and differences between categories. Theoretical sampling affords strong categories and an analyzed theory. For a constructivist approach to grounded theory, the process of analyzing the data and generating the theory are interpretive which "calls for the imaginative understanding of the studied phenomenon" (Charmaz, 2006, p. 126). No follow-up interviews were necessary for theoretical sampling but memo-writing, the studying of previous data, and comparing categories were completed.

Statement on Protecting Human Rights

The participants were a vulnerable population because they were adolescents. Informed consent was obtained from the parents and informed assent was obtained from the minor participants (Appendix B). Either parent or participant could withdraw from

the study at any time. The participants were sharing information about their friendships, their family, and having experienced autism in their family. This could cause emotional distress and/or discomfort. The participants were also allowed to refuse to answer questions at any point and could stop the interview at any time. Although risk for severe distress was low, a list of referrals for clinical assistance and support was given to every person who signed a consent/assent form.

Every effort was made to insure participant privacy and confidentiality. The researcher is the only person holding any identifying information. This information will be kept separately from other research materials and kept in a personal, locked drawer for five years. The information will then be destroyed. No other information is included in the study that would identify the participant or any person mentioned during the interview process. All digital recordings and transcripts will be locked in a private filing system and destroyed five years after the completion of the dissertation. If a participant and/or the parent were interested, the dissertation would be shared with them. There was no direct personal benefit for the participants in this study. However, some participants may appreciate talking and being heard as they share their narrative about their friendships and their life with their sibling with severe autism.

Chapter IV

Introduction to the Results

Through data analysis four categories or results were discovered using Charmaz's grounded theory. These results capture a summary of 17 individual voices sharing their unique experience of living with severe autism in their families and how that experience shaped their perspective on friendships. Participants were afforded the opportunity to affirm, discredit, or clarify the findings. The next four chapters categorize the major themes and their descriptive properties. The findings follow in the next chapter.

Participants

Seventeen adolescents from 13 families were interviewed for one-hour each using open-ended questions regarding their friendships, their sibling with severe autism (ASD), and their perspective of the effect having a sibling with severe autism had on their friendships. Four families provided two participants. The participants ranged in age from 14 to 17. There was one participant aged 14. Seven participants were 15 years old. Four were 16 years old and the other five participants were 17. All but one participant's sibling

with ASD lived at home. That sibling resided in a group home but visited the family on weekends.

Most of the families were two-parent households with three children in various life stages. One family included two children. Another family was step-parented with an additional child. A third family was single-parented and the last family had adopted to add a fourth child. There were nine male and eight female participants. Four participants were younger than their sibling with autism. Two were the same age. Of the participants who were older, three years was the largest difference in age between siblings. The siblings with autism included two females and eleven males. For confidentiality purposes, the sibling with autism is identified using male gendered terms throughout this study.

Geographically, the families resided in two Midwestern states living primarily in suburban areas but some also lived in urban and rural areas. Most families appeared to be from the middle socio-economic class. There was some but limited racial diversity. The interviews occurred at the participant's home or in a study room of their local library.

Categories

Each of the four resulting categories includes a minimum of two subcategories or properties. The category "Living with My Sibling" describes more struggles than joys encountered on a regular basis by the participants. As the joys and struggles were shared, they also explained what they thought about their sibling with ASD, themselves, other

siblings, and their parents. Lastly, Living with my Sibling provides a historical perspective from the time they first noticed they were different from their sibling to learning about autism and, for a few participants, consideration about their future with their sibling. The properties of this category are: “Defining Autism,” “Experiencing Behaviors,” “Being Responsible,” “Sharing Space,” and “Evoking Emotions.”

Discerning the day-to-day experiences of the adolescent participants contributed to the second category: “Becoming Me While Living with You.” Already developing a sense of identity, participants were proud, timid, egalitarian, social, or aloof. As with any adolescent growth domain, the participants varied widely in their progress. Some attributed parts of their sense of self to their family, while others denied the influence or never considered their family’s effect. The properties of Becoming Me While Living with You include: “Who I Am,” “Actions Speak Louder,” “I Have (Other) Feelings, Too,” and “If Only the World Knew.”

The third category, “Friending” provides a picture of the participants’ friends from the beginning of the friendships to the influence their friends had on them. “Friends by Number,” “Defining Friend,” “Where We Met,” “Qualities of a Friend,” “My Friends Shape Me,” and “Hanging Out” are the properties.

The last category, “My Brother and My Friends” arrives at the proposed question: if adolescents believe their friendships have been affected by living with a sibling with severe autism, how have they been affected? The two properties for this category are: “This Much is Known” and “The Benefit or Burden.”

Chapter V

Living with My Sibling

As the interviews unfolded in this study, it was evident autism had a role in the life of the participants. The consequences of having a brother with autism provided this chapter's properties. Experiences in everyday life added to new understandings of "normal" and the thought that perhaps their sibling was "not normal." By noticing and questioning the differences from their sibling, the participants learned the definition of autism. This is described in the property, Defining Autism. The next property, Experiencing Behaviors, describes those behaviors witnessed or personally experienced by the adolescent participants. Next, Being Responsible describes the additional responsibilities the participants had as a result of having a brother with severe autism and how those were primarily seen as obligations with little benefit. Sharing Space is the property depicting living and being together as siblings. All of the experiences described in this chapter evoked a plethora of feelings: positive, negative, and ambiguous; and became the last property, Evoking Emotions.

Defining Autism

When younger, some participants held a belief that all families were like theirs. Eventually they realized this was not true. Their family “wasn’t normal.” They realized how hard their parents had caring for their sibling with ASD and how a shift in roles occurred for them from being cared for when small to becoming a caregiver now, as an adolescent. Some participants have begun speculating about long term care plans for their sibling with ASD.

The realization there was a difference between them and with their brother led to learning about ASD. At an early age, the participants noticed evidence that their sibling acted differently or strangely including behaving violently, learning and processing information slowly, and not speaking at three or four years old. Some brothers with ASD needed schedules, remembered word-for-word movie dialogue, responded slowly and with a different cadence, played differently, did not share their interests, were “in their own world,” and did “not care about anybody.” These observations led them to ask their parents questions, but some participants turned to the internet or school resources especially if their parents’ explanations did not feel complete. They received the following answers:

Your brother’s brain just shut off.

I remember it being weird my brother couldn’t talk yet and the way he played with some of his toys and then my mom, I forget exactly who told her [he had

autism], but then she explained to me that he was going to need a lot of therapy and a lot of help.

That autism is kind of a learning disability I think. I'm not really sure but I say, oh I guess, it's kind of like a learning disability.

The spectrum aspect of autism made understanding the disability difficult due to symptom variance and because even “the doctors do not know why autism is severe in one person and not another.” Despite the information learned, some participants felt their understanding was tenuous which made autism difficult to explain to others. Having knowledge was not a guarantee against misconceptions. For example, some believed autism is a “mental hardship,” “it is a secret,” and “it is his preference not to be social.”

Alternatively, several participants appreciated knowing the definition of autism because it provided an explanation they could give to others and was “a lot easier diagnosis to explain than other diagnoses.”

Experiencing Behaviors

A variety of behaviors from the sibling with ASD were reported by the participants. There was only one participant who recognized his brother with autism was “calm compared to other people with autism.” The other participants described annoying to significant, even violent behaviors. These behaviors included: making noises reminiscent of a baby, bringing toys everywhere, watching preschool movies and television shows, excessive scratching of his face, and acting like a “little brother”

despite their brother's age. Some participants were physically targeted by their brother's aggression including having fistfuls of hair pulled out. Some video games were not played at home because their brother with ASD could not discern the difference between reality and the games. "He tends to take things into real life. Not like to a serious point but like he acts it out." Other behaviors the brother had included: complaining about leaving their home to eat at a restaurant, name calling, living "in his own world," and playing video games excessively. Perseveration and loud vocalizations annoyed participants.

There were more behaviors experienced and endured by the participants. Glass was not kept in some homes as it would be broken and the sibling affected by autism would incidentally cut himself having no awareness of the pain or bleeding typically induced from a cut. "He walked by me and there was a big trail of blood behind him because he had stepped on a bottle. It broke and a big piece of it had gotten lodged in his foot." Firearms were not allowed in the home. Visits by others were greatly affected. "We didn't grow up with people coming over." Some remembered getting together with family friends when younger but that changed. Visiting a family friends' home depended on their brother's behavior and if the participant's family had any available time for visiting. Participants shared that their family's busy schedules caused by their brother with autism left little time for peers and social situations.

As their perspectives were shared, some remembered how difficult it was when they were younger. Their sibling with ASD would have numerous loud screaming

meltdowns. The “fits” interfered with sleeping and “being at their best,” especially, even more currently, during finals week. “When he has those outbursts it’s typical for me not to get very much sleep. I’ll just wake up and I won’t get back to sleep.” Doors were shut in an attempt to block the noises and screams. Food had to be protected or it would be stolen from their plates.

For some participants, social development was affected. Their brother did not want to play when the two siblings were younger. Another participant did not know how to play with children who were developing typically because only the dogs and the older brother who was non-verbal and self-harming were known to him. This adolescent explained,

The biggest role model I had was the dogs. I played with them, like if you run through the yard and wait until the dogs tackle that was pretty much tag. Then I got into the bad habit of grinding my teeth because my brother was doing it a lot. He also liked banging his head against the wall. I started doing that, too. The only real role models I had to help me socialize were stuff I read in my books, the dogs and my brother. And none of the three were really that perfect.

When peer interactions were available, odd behaviors had been well established and peers began taunting this adolescent.

Other participants found their ability and/or desire to have conversations limited. Small talk was difficult. Being antisocial or communicating on-line was easier.

I met a friend after the first four weeks of school and we started chatting online. I contact him with Skype. That's how we talk. It depends when he has internet access to get online otherwise I don't see him [through Skype] for about a week or so.

They are the gaming nerds at the school so I went over there, sat down and didn't really say anything. I was trying to just say, "Hey, guys, how's it going?" But I can't do that. I am incapable of doing that. I don't know why but I'm a bit of an introvert.

Being Responsible

I'm the one who has to get him back into bed and get him water and things like that even though my other brother sleeps right next to him. It would be easier for him but I'm the responsible one.

Obligations arose and sacrifices were made. Brothers and sisters had experiences of caring for their sibling with ASD including watching them when parents were not home, and being the substitute helper when the employed helper had time off. According to one adolescent, "if we are in a large crowd I have to make sure he doesn't get lost or anything or something like that." Needing to watch their sibling interfered with time spent with friends. "Free time" was affected. Despite missing time socializing, a number of participants felt taking care of their brother was their duty.

Some participants admitted to feeling anxious about this responsibility especially when alone with their brother and that the responsibility was more difficult than caring for other siblings, for siblings with no disability, or for their friends' siblings. They indicated having more responsibility for their brother with ASD than the responsibility their friends had to their siblings. Some reported learning responsibilities earlier than their friends and having adults notice how responsible they were.

I mean [helping] is mostly time I'm already home. Or if there's something I need to go to, hopefully, we can get the helper to stay a little longer so it's not a huge deal. But it's still an obligation that I have so I'll make sure that I'm here on time for whatever I need to do... Yeah, I think it makes me a lot more responsible.

Sharing Space

By virtue of having lived together, siblings knew each other's likes, dislikes, interests, strengths, and weaknesses. Horrific behaviors were endured and responsibilities were expected but these did not keep the sibling from becoming a companion to their brother.

So, the latest trip to Walt Disney World we had, my brother was throwing fits because he wanted to be in his own bed. I comforted him by having both of us sing a duet from the Lion King like the Timone and Pumba duet, "Can You Feel the Love Tonight?"

As companions, the two siblings had fun together. Some siblings played ping pong together or jumped on the trampoline; played games or did puzzles; or, they drew, colored, and made art projects for their brother. “He allows me to draw and color things for him. We play games together.” One pair of siblings quoted movie lines jointly despite annoying their parents. “I quote movies with him. It’s just my parents get annoyed whenever I do it.”

They joked together.

We joke around a lot. We bond over like TV shows and movies and stuff. Yeah, we both got Netflix recently and we’ve sort of been watching shows and we like the same food which is mainly bad, unhealthy food. Yeah, we just bond over that sort of stuff.

The participants noticed strengths in their brother with autism. One adolescent shared a story about a conversation she had with her sister who is neurotypical about their brother with ASD. The two siblings had fun as they witnessed their brother flirting. This was a strength their brother had that they did not.

My sister and I, we’re like, “he is a flirt, this is funny,” and I said to her, “He’s got more game than us. What are we doing wrong?” It was just kind of funny when you think about it.

One participant recognized his brother knew more about technology, “because I’m pretty sure that even with autism, my brother is still smarter than me. I mean he knows a lot more about technology than I do.” Despite the brother’s knowledge about technology, the

participant helped his brother if he got stuck on a computer game, “Whenever there is a level in a game on the computer that he can’t complete, the first person he goes to is me.”

By sharing the same space with a brother with autism, participants used their knowledge of and love for their brother to include him and help him as well as they could. Children’s movies were watched so the brother could be included in family time. “One of the movies we can watch as a family where everyone including our brother can sit down is ‘Tangled’.” Participants helped their brother. One sang to calm him. Another reminded their brother to finish what he was saying as he got lost in perseveration. One participant knew his brother needed to be guided and not yelled at to avoid severe consequences in their shared space.

My little sister isn’t as used to our brother as I am, because she doesn’t know how to handle him. Like I know, you can’t really yell at him or be mad at him for anything because it’s rude and really terrible to yell at somebody who doesn’t understand what you are saying but also because that doesn’t work for him. He doesn’t really understand anything and he’ll have a really bad fit. So, you basically have to guide him by taking his hand or something like that.

Evoking Emotions

The participants expressed affirmative feelings about having a sibling with severe ASD. “I have so much fun with him and he’s been such a good influence on me.”

Participants were protective and developed patience toward their brother. As they were

both getting older, the relationship between the two siblings went through positive changes. One participant shared that their brother with autism modeled assertive behaviors because he “had more game” than they did by approaching anyone he found attractive. Others started feeling comfortable, confident, and proud about having a sibling with autism. There was affirmation that having a sibling with ASD was positive. “I know others aren’t as fortunate as I am to have a brother with autism.” The participants felt love toward their sibling, but with it, came pain.

He’s like a piece of me. Whenever people laugh at him they laugh at me, or if you are saying something about him you are saying something about me, too. He’s my lifeline. He’s a joy to have around. He’s a piece of my heart basically, despite the fact that whenever we go out, he’ll just complain and complain and complain. I can’t really say that I don’t love him because I do to the bottom of my heart.

Even though the participants expressed positive feelings as a result of having a sibling with ASD, they still felt that they had to balance having an “okay” life while being safe for their sibling. “I would love to own a firearm but I can’t do that because my brother could set it off, hurt, or injure someone or himself.”

Conversely, the participants disclosed animosity and negative feelings toward their sibling with ASD. They were worried that the population at large was making assumptions and judgements regarding whether the participants were disabled. Their sibling with autism was kept a secret from others because they were embarrassed and afraid of what others would think.

People are still learning [about my brother]. I'll just mention off handed that my brother did something or I went somewhere with him. Really, because we have so much to talk about at school, home doesn't get talked about much.

A number of participants found their brother with severe autism to be frustrating and annoying.

He'll remember word for word and repeat it over and over again, or sound effects from video games like Mario and Sonic, like Mortal Combat or SpongeBob. He'll just remember every little detail. Every little sound effect, every word that they say, he'll just repeat it until he finds something new to repeat over and over again.

And it's just . . . I want to choke him sometimes because...he bugs me and my friends.

A lot could happen, like what happened yesterday is my brother started to get upset because his tablet wouldn't download videos. And so, he had a ginormous outburst. And when he does that it really frustrates me and I get like flustered.

Several noted it was hard to have a non-verbal sibling and used words like: depressed, sad, and stressed to describe their feelings.

I remember when I didn't have games I would start thinking of really sad things that sort of go with depression...like my family.

While we game, my friend and I talk about what's going on in our personal lives. The main reason we play games together, not only is it just to have contact with

each other, but also to keep our minds off of school or family matters, that kind of thing. It's sort of a stress reliever or a release from that.

Some participants felt lonely and at a loss because their brother could not participate in a shared life with them. One adolescent felt defeated due to the lack of reciprocity from their brother. Another participant shared they were not the preferred friend of their brother but their mother was. Then another sibling felt alone with his brother with ASD when the eldest sibling went to college. "The only other person I know with a brother with autism has a lot of other siblings so he has help around but now that my brother is in college, it's really just me."

The participants often felt sad about the fact that their sibling did not have a "typical life" and that living with autism was hard for everyone. There was no "typical life." The participants did not always know if their brother with autism had friends and they regretted missing everything that comes with playing with a sibling. They noticed they matured while their brother did not. A few participants felt a combination of anger and sadness as a result of "being the older sibling" to their chronologically older brother. "He's just like the baby brother in my eyes and that I have to watch out for him and look after him." Some felt restricted not being allowed to get upset by their sibling. As the participants shared their perspectives, some became vulnerable to guilt. They struggled to recall any story involving their brother or to name a strength he had. They had a sense of helplessness. Some were reconciled to the fact that nothing had or would change about their brother. "He's the same today and he hasn't changed at all."

The participants felt denial and ambivalence. The importance of caring for the sibling with autism was minimized by some participants, who thought it was “no big deal.” Others reported there was no effect having a sibling with severe autism; “My brother’s around but he doesn’t really bother me or anyone,” however, their emotions were not neutral.

Several participants seemed to have assimilated their feelings about their brother. There was an acceptance and resolve expressed by them.

I can’t imagine my brother without autism.

I don’t know what it’s like not living with a brother with autism.

It’s just always been this way.

Mitigating factors like having another sibling to relate with and having an active life helped neutralize feelings.

I’ve got my brother but then I’ve got my little sister, too. She’d always want me to sleep in her room and she’d always want me to play with her.

I still treat him like a normal brother. I still treat him the same as my other brother.

Sometimes I’ll just leave for a little bit, go talk to my friends and then when it’s time to go I’ll go back with my family.

I don't really bring him up a lot. Because I just have no reason to. I mean I'm busy with gaming, cars, WWII stuff, and band.

The participants were also indifferent.

I don't really know, about his special school program. I know there are a few kids that I've met or I've seen in the halls or something. Um I don't know. I don't really see them all that often, so I don't know all the details.

Um, with my relationship with my brother, it's okay. We aren't too close but we don't not like each other.

Some participants shared their various defenses, particularly avoidance which seemed to be used along with fantasy, to help them remove themselves emotionally from the feelings evoked in the relationship with their sibling with severe autism. They wished their brother was harmless or hoped the autism would disappear and not affect their brother anymore. "My sister sometimes talks about maybe if he didn't have autism he wouldn't do things like he does." They avoided the reality of their living situation by being active with gaming, taking AP courses, listening to music, and spending time away from home.

Chapter VI

Becoming Me While Living with You

Where Chapter V, Living with my Sibling, provides a concrete understanding of the life the participants have growing up in a family with a sibling affected by severe autism, this chapter shares the results of the adolescents' personal narratives. They shared the story of who they were in consequence of their brother. The properties include: Who I Am, Actions Speak Louder, "I Have (Other) Feelings, Too," and If Only the World Knew.

Who I Am

Overall, having a sibling with severe autism was attributed to who the participant was as a person and how they viewed themselves. However, a number of participants wanted it clearly known that they were more than just the sibling of a person with ASD. School, their parents, other siblings, and friends had an effect, too. Some participants knew they had negative personal attributes they could ascribe to their sibling with ASD. However, most participants described personal characteristics credited to their brother

with ASD such as having understanding and thoughtfulness, being genuine, and being more mature than their peers.

You know, originally, I would have said [having a brother with autism] doesn't help me but I now see that it helps me because it's kind of hard to get along with kids with disabilities. Since my brother and I get along with each other really well, I am able to get along with practically everyone at my school. Like, I'm not the most athletic but some of the more athletic kids they keep asking me to sit at their table because I can usually get along with them.

Understanding and thoughtfulness were the attributes most frequently named when describing the ways in which having a brother with ASD influenced them. "I roll with it" was a description of having a tolerance for people, being non-judgmental, having an easy-going nature, and being empathetic, patient, and helpful.

Having my brother has taught me to not judge other people first and just always give them a second chance.

I've learned that life is too short to argue with people you like or care about.

I have an internal appreciation of people.

If I hear someone say retarded or something in a derogatory tone, I'll say something like "Hey, don't say that. That's not really cool." I won't judge them if they don't really know because I know some people aren't exposed to this sort of thing.

The attribute of understanding was something the participants felt they learned, but they were specific about when understanding was warranted. In other words, they were not understanding under all circumstances.

I guess a characteristic I have is, not understanding why a fairly intelligent individual might act ignorantly. I don't feel the need to be as understanding with them as I do with other little kids or with people like my brother.

Genuineness was an important attribute of one participant who did not want to be phony.

I never really was one for putting on a fake face or something while around other people. I guess I only had three or four really good friends at school because they shared the same mindset as me. The friends that I had over, I don't remember any of them having an issue with my brother. I just described him to my friends, for real.

Some participants stated they were different from other adolescents because they matured faster having a brother with autism than their peers who did not have a sibling with a disability. They believed that negotiating the "outside world and home world" takes sophistication not demonstrated by other adolescents, who were "self-centered, narcissistic, and cliquey." Maturity was shown at home when the participants' sibling was playing with toys or watching programs meant for younger children and the adolescent would choose to join in their brother's activity while managing other expectations of home, school, and peers.

Unlike most of my friends, who are, yeah, not as mature as me, I understand people have other things to do other than be with me. So, it's just a general understanding that I'm not the most important thing to them or to anyone in the universe. I do have a place for myself and I understand that I do have an importance to the world but I know I'm not the most important thing in the world.

Negative qualities included being an introvert or an outcast, being too nice or passive, being anti-social or "fringy" (marginalized), and being socially awkward or "quirky." Although many participants reported being fair and objective with other people, intolerance prevailed for some participants or occurred varyingly for others. Participants' intolerances were felt towards everyone, towards those uneducated about autism, or towards those educated about autism but who chose to derogate those with ASD despite the knowledge they have about the disability.

I think that having a brother with autism affects me in many ways like it affects some of the things I do. It affects what I like to hear and what I don't like to hear.

I don't like hearing people complain about their life.

Having a sibling with autism produced vigilance whereby insensitivities directed towards or about people with disabilities were clearly noticed by the participants.

Walking down the halls of my school, you'll hear derogatory things like "Oh my God, you are acting so retarded." It makes me angry because they don't know what it's like to actually be around people who are like that. I want to whip

around and tell them, “My brother actually has autism,” but I know that they’d just laugh at me and tell me I’m being too serious.

Actions Speak Louder

Activities, jobs, school, sports, volunteering, responsibilities, and obligations kept the participants busy. Many but not all participants were influenced by their brother with autism when choosing one endeavor over another. As the participants shared their stories, their actions provided another lens into their life with autism.

The participants’ brother with autism had a strong influence on the kinds of activities that the participants took part in or cared about. Involvement in chorus, debate team, speech club, and musical performance occurred partly because their brother was nonverbal and did not participate in conversations.

I enjoy giving speeches and I don’t know if that’s because I don’t have a sibling at home I can talk to. I don’t really talk to my brother that much because he doesn’t listen necessarily...I wouldn’t say I do speeches because I don’t get to talk to him, but I would say I do really love talking and that’s one of the places I can go and do a lot of talking.

Some participants liked listening and talking because they may not have been able to talk much with their brother with ASD. However, others may not have felt the need to do much talking. “I don’t know why I’m incapable of small talking. You’d think I’d be able

to do that but I'm a bit of an introvert. Maybe I've developed into an introvert because of my brother."

Participants also volunteered for organizations that were specific to special needs because they had a brother with ASD. "I definitely want to be involved in some way helping that part of the community so I volunteer for special needs. I know he's definitely impacted me in a good way."

The participants acted with perseverance about personal care and physical activities because their brother with ASD did not. Decisions were made to be more hygienic as their sibling with ASD had difficulty with self-care.

I don't know if that's because he was like ultra "I don't care" or because I'm just a bit quirky that way but, I'm not necessarily a neat freak, not a germ freak but a little more concerned about them possibly than most people.

Persevering through cross country, track, and racing happened because running and persisting with training were uninteresting and arduous for their brother. "Since he isn't able to do certain things that I can do like running, I decided to keep training."

Some participants were diligent with their schoolwork.

I think that it's really important to do the best you can. My brother does the best he can and then so do I. That's another thing that brought my friends and me together. We like doing homework and talking about school and doing well.

Participants choose to write about autism and about having a brother with autism for school projects when they could have chosen other topics of interest. "I wrote a poem

about autism and got called to the school office. They asked if I could read it during second hour over the intercom to the whole school.”

Some of the participants’ actions included the promotion and display of acceptance of people with ASD and other special needs. “See I’ve got my (ASD) shirt on.” Some found that it was helpful knowing and living with autism because they could identify others with autism and act appropriately in various situations.

I actually remember in Walmart one time there was a teenage boy and he had a Blues Clues boom box with him. He was listening to it and throwing it. At first, I was kind of like “Okay, that guy’s weird. What’s he doing?” and then I began to realize, “Oh he must have autism. He must be on the spectrum.”

I kind of had a feeling that someone in cross country might have some sort of autism so I just didn’t get mad when he didn’t really talk to me.

The participants acted on their tolerance and gave consideration on how to handle difficult situations. Participants responded when derogatory comments about the special needs of others or of their sibling were overheard at school and in the general public. One participant chose to defend the person with special needs despite feeling “in the minority.” Another influenced the offender by telling him to check his behavior. While, another adolescent shared his stance on special needs and explained what special needs are, hoping education would end the intolerance.

I understand autism and understand kids with special needs and stuff, so when other kids would laugh about it I was there standing up explaining. I truly know

what it is and they don't really know what it is so they don't know what to do. I would help those kids and tell them, "It's nothing. They (people with special needs) are like us; just part of their brain just doesn't grow as fast."

"I Have (Other) Feelings, Too"

Self-reflection and personal encounters gave the participants ample opportunities to experience emotions. The participants generally expressed negative feelings but were able to be optimistic and manage their emotions productively. Being protective, managing extra responsibilities, recurring negative incidents, and stress contributed to the many feelings expressed. "My brother had a ginormous outburst. And when he does that it really frustrates me and I get like flustered. I was just really frustrated so I shut everything off and went to bed."

On the affirmative side, one participant felt happy with her life, was grateful, and saw value in loving. "I appreciate those who've come across my life. I'm loving and caring. I'm part of one big happy family." Another was able to calm quickly after moments of upset. "It's a lot easier for me to calm down." A third participant did not take disappointments personally. "Like even if the plans don't really work out, it's fine. I know I'll find time to be with my friends."

On the negative side, the participants experienced anger, frustration, sadness, discomfort, anxiety, annoyance, and embarrassment. Some participants had seen their brother laughed at but they felt some relief in believing "he did not know this was

occurring.” It was apparent throughout most of the interviews that strong convictions about people with special needs were held by the participants. When these were disregarded, the emotional push back was intense. Derogatory comments, the word “retarded,” poor treatment, and laughing at disabilities caused anger. Participants handled their outrage by confronting, avoiding, arguing, and disliking.

Whenever people make fun of him because he acts different from everyone else it's like, he likes to bring toys with him and he'll play with stuffed animals or something like that and where people will laugh at him and I'll tell them, “Back off. That's my little brother. He's autistic. It's not funny to me.” People will think it's a joke but then, no, it's not a joke. He has a disability and that's nothing to laugh at or make fun of not just towards him but towards everyone with a disability.

If derogatory terms were used by someone “ignorant” about autism or other disabilities, attempts were made not to be frustrated or judgmental towards the “uneducated.” One participant felt angry about his brother but not at his brother. “Like I know, you can't really yell at him or be mad at him.” This same participant was personally aware that he became annoyed quickly by things rather than by people.

With people I can normally be very like very very patient but with inanimate objects and things like that, I get annoyed far faster. Like if I'm trying to get the computer to do something I will get annoyed much quicker.

Autism in their families led to sadness and some jealousy because “other families don’t know how lucky they are having a mentally stable family.” Sadness was also felt when thoughts about how their brother with autism would feel if he knew he was being laughed at by others. One participant courageously shared feeling discomfort when people with obvious physical disabilities were near. “Sometimes I’m still uncomfortable with those with special needs that are more visible like those who need wheelchairs. Sometimes I’m a little bit more uncomfortable of that.” This quandary was being actively self-examined because it made no sense to the participant to have those feelings since their brother was very impaired by his autism.

Some participants experienced embarrassment and described feeling anxious. Some felt uncomfortable with people and kept away from large crowds. Another participant had an issue with loud sounds but did not inform anyone about the issue. Concerns about being personally laughed at or being thought to be “too serious” silenced another from defending a peer with special needs.

They’ll be behind me and I’ll want to whip around to tell them, “My brother has a legitimate mental handicap and you’re using it as an insult. I want you to know that’s not fair to me, to him, or to anyone who has a mental handicap,” but I know they’d just laugh at me and tell me I’m being too serious.

If Only the World Knew

The passion voiced during the interviews was documented here with some of the participants strongly expressing their philosophy about the world. They provided ideas about how to categorize everyone in the world and expectations of how things should work.

The participants asserted that there is hate and sadness in the world and gave suggestions about how to deal with them. Although one participant felt there is “lots of hate in the world,” they believed everyone should be accepted because everyone has differences. The desire for “acceptance of all” was emphasized by many of the adolescents interviewed. “I just think to myself, ‘Boy, this world would be going on better if you people would just learn’.” A couple participants gave their ideas for coping: accept difficult situations and move on; and, sad people should think of something good. “I’m a pretty happy person and when people are sad I’m just like ‘Stop being sad. Think of something that’s good’.”

Participants sought to make sense of the world by analyzing and categorizing the behavior of others. There are “jerks” in the world who “make fun of people with special needs” and “tolerant” people who do not. One participant categorized people by their behaviors which helped him have some order for understanding how people behave. The designations given were: the brother with autism acted a specific way; the sibling, who was developing typically, acted another way; and school people had their way of acting.

The passionate sentiments of a few participants about how the world should be viewed were summarized in this statement: if they, the world, only knew having a sibling with autism was fun, a joy, and made our family special, they would feel as proud.

Chapter VII

Friending

When given the opportunity to discuss friends, many themes emerged. The “where’s,” “what’s,” and “why’s” were shared. Most participants eagerly conveyed the influences their friends had on them. Participants reminisced about long-time friends and recalled friendships from early grade school days. One participant explained the process of becoming friends. “So we would make awkward conversation and find something in common and then we would just talk about that and the friendship would grow from there.” Several participants shared stoic to humorous narratives about the start of a friendship.

There was this one guy from class who was a very cheerful type. He would keep on talking about himself. It got annoying. That’s how we met. But we became friends because for some reason, I could not remember the teacher’s name and he reminded me again and again. That’s how we first became friends.

I made a friend. She’s such a weirdo. We kind of bring the worst out of each other in terms of weirdness. She was kind of quiet and a little weird. We were like “woo weirdness,” skipping in gym. We would skip because, why not?

One of my best friends was this guy. He was getting picked on because his voice was different from all the others and he was smaller. I stepped in and stopped the bully from bullying him. Afterwards I got bullied a little bit but then the bullying stopped and that guy and I became friends.

Some participants could not recall how they met their friends. Others remembered friends they had years earlier and then wondered what happened to those friends.

She was pretty cool. I have no idea what happened to her.

Oh my gosh, I remember her now! I sat with her during eighth grade. She was like my bestie but I only saw her during lunch so it was like lunchtime bestie. She was awesome. I tried to keep in touch with her but that didn't really happen. We saw each other at Walmart at Christmas of freshman year and we were like "oh my gosh" but I haven't talked to her since.

The following properties: Friends by Number, Defining Friend, Where We Met, Qualities of a Friend, "My Friends Shape Me," and Hanging Out express the participants' thoughts about friends.

Friends by Number

The recruitment process informed prospective participants of the study's purpose: to learn about friendships when someone lives with a sibling with severe autism. Despite this knowledge, some participants had given little thought about friendship even after

agreeing to participate in the study. They admitted to not having been previously asked about the topic. Throughout the interviews memories of previous and current friends arose. Participants had groups of friends that included up to five close friends. This friend group did nothing unless the other four friends were present. One participant asked, “Can I tell you about all of my friends because there aren’t that many?” and then named more than eight friends throughout the interview.

Details were enthusiastically shared if there was a best friend. Most presented information about one to two best friends and named additional friends with the caveat “but they aren’t a best friend.” During one interview, a participant admitted to having ten best friends but with more thought, admitted to having no best friends but had a lot of friends. “I mean, I’m friendly to everyone at school but who I consider best friends are about 10 or more. I mean whether I think of them as a best friend or not, they are all my friends.”

Several participants admitted to having no friends. One participant recalled a time when they were younger and had no friends.

There would be people who I thought were my friends and said they would save me a spot and play with me but they never would. As I got older I started to think about it more. I realized that they were trying to exclude me and to this day, I still don’t understand why.

While some gave numerous reasons for a lack of friends: the participant’s personality, no time, living in an unincorporated area, and having no interest in people. One participant

ambivalently admitted to not caring about friendlessness but watched shows about friends.

I have better things to do with my time [than have friendships]. But I'm happy with my life. I'm not the most social person and I'm not the most extroverted person and maybe that's why friendships are more difficult for me...For me, it's just wonderful watching these main characters in this show I watch, go through friendship problems. It's a really good show because they deal with problems like mature people instead of like teenagers.

Defining Friend

A friend was characterized as someone usually close in age, who you spent time with in-person or over technology, and who had something in common with you. The question 'What is a best friend' was described as someone you spend the majority of your available time with. They were called "main friend," friend friend," or "my BFF." Best friends knew almost everything about each other or knew things not shared with other friends. Some best friends became brother or sister-like.

Best friends had "good friend chemistry." They were the people when you visited it felt like no time had passed since the last visit. "Over school breaks we can get together. Last time we did, we got her from her house and she just came over to my house for a couple hours. It was as if nothing had changed." Some participants noticed that some best friends shared physical similarities with each other. "My teacher told me he

had never met two kids from different families who looked and acted as alike as me and my friend.”

The participants defined different categories of friends. Close friends were defined as people who were around and who did “stuff” with them but they did not know personal things that a best friend knew. School friends were “friends and not acquaintances.” Acquaintances were described as people they knew through others, “a friend of a friend.” An associate was thought to be a minor friend so some time was spent with this person but not much.

Very few participants had a significant other. These relationships were defined as “the” relationship consuming a majority of time that previously would have been used for other friendships. Some participants described crushes and told stories of friends-turning-informant when they told the target of the “crush” that the participant was attracted to him.

Where We Met

Proximity, availability, and commonalities contributed to the development of friendships. Most friends met for the first time at school with gym and lunch being the most amenable classes for friendships to start. Longer term friendships began in their neighborhood “across the street” or in church. One participant shared meeting a good friend who lived in “an area where many bad families” lived nearby. They became friends “out of necessity.”

One participant admitted that extracurricular activities help with meeting other people.

I've done debate for a while and I've just started doing speech because I took speech class and I did a lot better in it than I did in debate. So, I started to do the speech club, too. I'd say I made some friends in speech and debate, too.

Examples of extracurriculars where friends met were book club, band, badminton, a job, technology club, camp, and volunteering. One participant made a friend during a support group for siblings with a brother or sister with autism. "My brother's old school had this group where people who had siblings with a disability go and talk about it. There is only one person from the group I'm still friends with." The support group fizzled as the group members got older but the friendship continued.

Various family members had a role in helping participants develop friendships. One participant's parents allowed him to visit only one home, a family friend's home. Another participant recalled becoming friends with their mother's friend rather than with the friend's daughter. A cousin was given the label of friend. Brothers and sisters were named as friends; while only one of the siblings with severe autism was named a friend.

Social peer groups were significant for developing friendships. One participant described the effect of snowballing. "With any other friends that I had, they are sort of like friends of my other friends, that kind of thing." One group was named "the best friend" group although its only members included the participant and the best friend. In other groups, adolescents joined and left regularly, whereby new people were met and

could potentially become friends. A couple participants admitted to being a 'fringe' member in several social groups allowing them to float between the groups.

Qualities of a Friend

If participants did not spontaneously speak about their friends' qualities, they were asked, "What are some things about your friend, as a person, that contributed to you becoming friends or remaining friends?" The answers were similar to their personal qualities. Their friends were "nice," shared their "same values," and were trustworthy. Friends had to be "non-prejudiced" and they had to have treated people with special needs well. True friends were those who were "there for you." Participants had friends whom they were "happy to be around" and had the "same sense of humor." Their friends could relate to them.

We were kind of similar in our personality. We are fun people. My friends are funny people.

Well, me and him both have the same sense of humor. When it comes to joking around we don't discriminate against any kind of joke unless it's really bad. We have the same mindset for that.

It felt comfortable to be around their friends. "We immediately clicked and then I found out later that we both had siblings who had some sort of special need." There were friends who lived in "different" or "messed-up" families and participants empathized with them. "A lot of the friends I do have tend to have some kind of family issue or some

abnormality that sets them aside from everybody else.” Some participants were comfortable being friends with “socially awkward” peers or to peers “no one else liked.” One described finding friends with differences from ‘stereotypically normal’ people.

Honestly, I don’t really want to be friends with everyone else because they are sort of narcissistic or egotistical. They are like stereotypical. Hanging out wouldn’t be much fun because they would only talk about the same thing, like football.

Communication skills were important qualities for most friends. “We like talking to each other and I think that’s important.” The participants wanted friends who had these skills although communication was expressed variously, in-person or through technology. Some participants preferred communicating through social media using texting or photos or even by communicating via gaming. “Sometimes we will text each other randomly at night and just talk about our day.” Verbal communication was not necessary for their relationships to endure.

Some friendships did not last as other qualities became apparent. One participant spoke of a former friend who “debated everything” and liked arguing. Another learned of a friend’s differing philosophical opinions. Friends became annoying, “jerk-like,” “racist,” and “anti-feminist.” One friendship ended ambiguously as “we just drifted apart.”

“My Friends Shape Me.”

The relationships had reciprocity. Participants felt they had an influence on their friends and their friends also influenced them. There was a reliance on each other. They helped and supported each other. The help was also for practical matters like providing homework, band, and theater support. “Ever since he started, I sort of helped him out because I was in concert band one year before he was.” Friends listened empathetically, helped with their “problems,” allowed each other to be “real,” and defended each other from bullies: “I remember right after she was bullied after I confronted the bully, we started chatting with each other more. That’s how we got to be closer friends.”

A few participants felt their friends were “part of the family” and shaped their view of what “family” means. “My friends are all a part of our family in some way, shape or form. Even my mom accepts them as like step kids or something like that.”

Some participants felt so strongly about their friendships, they developed a belief of “not letting things that happen now affect relationships or things that might happen in the future because they are just things and relationships are really what’s important.”

“Shaping” and being in a friendship had less positive effects for some participants. Behavior with their friends or within their friend groups was “checked” by the superior members of the group, thus followers remained followers. There were debates in the relationships and some participants felt they had to take on the role of mediator or peace-maker so the friendships could proceed.

Well, I don't want them to turn to me and ask, 'who do you agree with?' I don't really want to pick sides because I don't want to lose either of them. I just, trying to sort it out, say, 'alright, here's who I think might be right based on logic'.

One participant understood the "shaping" effect and knew opportunities were missed because the family moved frequent. It interfered with the participant's ability to learn from peers "how to make a good impression."

Participants were shaped by people they believed to be their friends when the supposed friend hurt or offended them.

My friend basically took a crap all over my job relationship with my manager because I recommended him for the job saying he's really good and then he quit the first day. My manager's not only going to think I'm a liar but also that I don't hang with the best people.

Friendships also provided practice for integrating loss. It was a common experience for all the participants to have friends move or attend different schools. "We've had our issues because junior year started with one of our friends transferring and then things just went downhill after that. Everyone became so distant." One participant felt disappointed when a friend chose time with a boyfriend rather than spend their time together. "Our friend will get into a relationship and she'll be so caught up in that. We'll have to tell her, 'Your boyfriend isn't really everything you know.'"

Very few participants believed friendships did nothing to shape them. They described themselves as home-bodies and did not have friends, only "companions."

Being with family was more important than being with peers. However, for many participants, friendships held an intense significance. One adolescent felt their friends shaped them into the person they “are today.” They were happy for having friends.

I know that they are the two friends who will always be there for me and I know that I can't really part with either because they shaped me into the person I am today. Some aspect of me, they brought that out, which I wouldn't have brought out myself.

Hanging Out

One word described the most frequent leisure activity shared by friends, hanging. Most enjoyed spending time with their friends. They did it at school by their lockers, at lunch, and at recess. They hung out outside of school, too. Hanging with friends was “cool” and they got to “do their own thing.” However, when there was “drama or arguing,” the preference was not to spend time together. For a few participants hanging out was not enjoyed and was not done. The most frequent reason given was they had “no time” or their friends had no time to hang out. Other reasons included having too much homework. While some participants felt they spent “enough time with people at school so there was no reason to be with friends after” school. A couple participants mentioned preferring to hang with family members.

Arrangements to hang out were made in a variety of ways. Some participants fell into the role of planner. Some had long-standing plans in place. Other plans were made

cooperatively or by negotiation with “everyone’s input (being) considered.” Two participants allowed their friends to make arrangements. Plans were made in school, through on-line group chatting or texting. Group chatting was the most difficult because it was “confusing.”

When the plans consisted of hanging at someone’s home, more than half the participants reported their friend’s home was chosen. Reasons for this included:

My friend’s house is bigger and there’s a basement.

My friend has no brothers or sisters so the house is all ours.

There is nothing to do at my house. Besides, it’s just easier to go to their house.

We stay up too late hanging and that’s okay with my friend’s parents but not with my parents.

In one case, friends gathered at a participant’s home and then they went to another friend’s home to hang out. Another participant reported having only one friend visit their house once. When friends did hang at the participants’ homes the most frequent pastime was gaming.

The interests that brought the friends together continued to be something they did when hanging together, but as the friendships developed other shared interests were discovered. Talking was an activity all friends did together. Gaming was named by all but one participant. It allowed friends to hang out without needing to be in the same house. Sometimes, this was the only way friends spent time together. Loneliness and boredom

occurred when the internet failed and gaming ended. Examples of other leisure activities included: movie going, watching anime, playing board games, watching sports, swimming, inventing games, photography, researching cars and guns, visiting town, writing and sharing stories, bowling, and exploring the internet. Friends enjoyed making each other laugh and being goofy.

Even though my parents say we are too old for it, we dress up and go trick-or-treating.

My one set of friends is wild and crazy and they would randomly burst into Hamilton on the front steps of the school.

Friends went to school events and parties together. They also hung out to help each other with homework or get school projects done although study time frequently turned into talking time.

One way to maintain friendships was through conversation. Emotionally laden conversations contributed to friends feeling more connected.

We kind of became friends because we were sitting next to each other and she comforted me after my language arts teacher went on a rampage about how she hated me in front of the class.

I talk to her because her parents are divorced so she understands more about the hard times of a family, not that I have hard times at all, but I could probably trust her more.

She felt she had nobody else but me to talk to because everyone else was busy and then she relied on me the most. I would try and help her get her grades up, make her focus in class, and actually have her get to class. When she said she's done, she's giving up. I'd tell her you can't give up.

However, some participants engaged in minimal conversation or avoided them. "I would just sit there with my book and sometimes look over. Sometimes I'd just watch them but if watched too long they would say, 'so, what do you think of this?' " They listened and rarely contributed to a discussion. On the other hand, one friend taught a participant how to stop talking during class and later how to modulate the volume of their conversation so the two "would not get in trouble by the teacher again."

Participants used various ways to communicate including phone calls, texting, emailing, facetimeing, and on-line chatting. Social media sustained some friendships after friends moved too far to visit or when friends were antisocial. "We are both very reclusive, so we don't really go see each other outside of school. We talk and text each other outside of school." An appreciation of non-verbal social media was explained by some participants who needed more time to gather their thoughts before sharing. Certainly, friends talked about school, homework, their leisure plans, and other interests but some topics were not discussed. A few friends did not talk about their family just as some participants did not share about their sibling with autism.

Chapter VIII

My Brother and My Friends

Friends shared through hanging out, conversing, attending school together, or because they lived across the street. Most friends knew the participant's sibling with autism but a few did not. Nearly every participant had a friend with a sibling affected by a disability. In *My Brother and My Friends*, the property *This Much is Known* gives details about how participants' friends learned about the brother with severe autism and the types of conversations this knowledge provoked. The other property, *The Benefit or Burden*, delineates their perspectives regarding the influence having a brother with severe autism had on their friendships.

This Much Is Known

For the majority of participants with friends, the existence of their brother with autism was known. "I didn't see any problem with talking about my brother. There was no problem with it." Participants found it easier to talk about their brother when they believed the friend was "easy-going" or during times when life was "less complicated, like in 5th grade." Some participants had to "warn" their friends about the behaviors they

might see while visiting. Friends exchanged funny or charming stories about their siblings. Some participants made certain their brother was introduced to their friends when the opportunity arose.

Participants noticed that conversations about their brother with autism occurred less frequently than conversations about any other family member, whether it was about their family or about their friends' family. Only the participants who kept their brother a secret or who did not consider sharing the information, had friends without the knowledge. "They know I have a sibling or siblings, but not much more because I go to one high school and he goes to another. So they don't really know much besides his name and I have a brother." Some friends knew the participant's brother was in special education but the diagnosis was not divulged. Other friends encountered the participant's brother while on the phone. "I don't know if my friend knows my brother has autism but he knows he has a mental disorder because I don't mute my speaker phone sometimes."

Friends asked very few questions about autism or the participant's brother. They wanted to know where the brother with ASD went to school and how old he was. Some friends did not have questions because they knew "about autism from their parents" or "because they were aspiring med students." Participants believed their friends' were indifferent about having information regarding their brother because:

They have a lack of interest.

They are teenagers.

My friend feels uncomfortable talking about my brother.

My friend considers how uncomfortable I am talking about my brother.

The Benefit or Burden

All participants were asked if living with severe autism affected their friendships and the majority responded affirmatively. One participant felt his brother with autism indirectly influenced how his friendships were. “As far as my friendships have gone, he’s never been directly influencing any of them but more of an indirect way.” It was the participants’ friends who were open and willing to listen when they wanted to talk about their brother with ASD.

We’ve discussed that there have been situations where we don’t like how people treat people with special needs. My friend told a story when she was at Great America. Someone wasn’t being respectful of her sister’s service dog wanting to pet the dog. Then I told a story about the time someone was laughing at my brother and I defended him.

One participant, who did not share information about his brother with ASD with his friends, wanted to learn from other teenagers who have a sibling with severe autism, what their friendships are like. “I don’t really know a lot of people with siblings with autism so that would be interesting to find out.”

The participants were concerned about bringing friends over to the house and meeting their brother due to his “annoying” and “embarrassing” behaviors but were surprised to see that most friends were positive and accepting of the brother with ASD. Prior to friends visiting, participants warned their friends “not to be weirded out” by their

brother's behavior. Most friends accepted this, making "hanging out" more relaxed. Sometimes the brother with severe autism paid no attention or seemed to pay no attention to the visiting friends. Many participants were humbled by and grateful for their friends when they joined their brother's play.

They were really, really nice to him. They got his number and then he texted them. They texted him back. I just thought that was so cool.

Whenever they come over they'll play the Wii with him. It's like a fun party.

All the girls at school wanted to dance with him at a dance. He had lines of girls wanting to dance with him.

They reported their friends were protective of their brother, loved him, found him to be fun, and treated him like a younger sibling.

However, some participants were burdened by the risk of having friends visit because their brother's behaviors were too severe or caused too much anxiety for the participant who never knew what their brother might do. For some, no friends were allowed and there were "no birthday parties at home ever." If friends took a chance and came over, sometimes they had to endure attacks of negative comments and the possibility of leaving early. The participants' brother would bother game playing between the friends or become extremely upset if he lost a game. Sometimes, only one specific friend was allowed to visit, "I've sometimes invited a friend over because we want to hang out. It's usually just been one friend I could invite...because she lived fairly close and she was my best friend."

Unfortunately, some participants experienced a variety of bad feelings because they had a sibling with ASD. Some felt guilty about having friends.

I have friends and this one day Mom said to my brother, “you have a friend here.”

She told me his eyes kind of lit up. But it was only the hair dresser. He hates getting his hair cut so she lied about a friend for him being at the door. Anyway, I felt a little bit bad. I want him to have friends, too.

Others were jealous because their friends’ siblings are typically developed and verbal.

Finally, one participant understood that it was developmentally appropriate for adolescents to feel burdened by siblings in general, “All of my friends are trying to get away from all their siblings.”

Chapter IX

Findings

The findings provide “an abstract theoretical understanding of the studied experience” (Charmaz, 2006, p.4) of the thoughts, perspectives, and meanings given to friendships by siblings of brothers and sisters affected by severe autism. This answers the main research questions: how do adolescents who have a sibling with severe autism experience their friendships, and if living with autism has affected the participants’ friendships, how has this affected them? Each finding is supported by the various result chapters. Reference to the appropriate results and properties is provided for each of the five findings outlined in this chapter.

Finding 1: Living with severe autism is often difficult for adolescent siblings.

Sibling relationships provide opportunities for developing social competency by learning to compete fairly, to negotiate and compromise, and to understand ambivalent feelings within relationships. Certainly, familial circumstances create experiences for siblings to negotiate living life together. However, autism adds another dimension to the tug-of-war of sibships. The adolescents living with a sibling with severe autism

experience limited social reciprocity: “He’s usually in his own world.” They experience limited to no communication: “He doesn’t talk, like, at all,” and “Hey, Mom, why doesn’t he ever talk since he’s older than I am?”

Previous research concerning the impact of having a sibling with autism studied these various domains: psychosocial difficulties, social adjustment, behavioral or prosocial behavior, and emotions. Results ranged from finding a positive impact to no impact to a negative impact in all the domains considered. This study discovered that participants considered living with a sibling with severe autism to be difficult (Chapter V: Experiencing Behaviors, Being Responsible, Sharing Space, and Evoking Emotions). Some were reluctant to share this fact while others used clichés to describe it. “It would be a totally different world if he wasn’t autistic.”

The siblings with ASD have to be kept safe and calm and that means that sacrifices have to be made. ASD can lead to disruptions and tantrums that can interfere with sleep, studying, and other activities of daily living. The possibility and inevitability of inappropriate behavior in public generates fear and embarrassment for the adolescents. They remain vigilant while attempting to avoid physical harm inflicted by their sibling with severe autism.

The participants feel annoyed, anxious, lonely, angry, and sad. Their sibling’s behaviors are the annoyance and they result in anger. “There are times when I do get really really mad.” Frequently, the adolescent minimizes this feeling saying, “It’s not a huge deal.” Hate was admitted by one participant. Anxiety occurs for three different

reasons: when in public or when friends visit because their brother's behaviors are odd and spontaneous; when the adolescent has thoughts that others might think they have autism because their sibling has it; and when generalized anxiety disorder is present. Loneliness is experienced especially when the adolescent is the only sibling in the home. Sadness underlies the tales shared about the sibling with autism.

The adolescent, who may be younger than their sibling, finds a shift in roles that usually does not occur when siblings are typically developed. They watch their sibling when their parents are away. Adolescents have the added responsibility of keeping their sibling safe because their sibling is unable to comprehend danger. "As [children with siblings who are disabled] grow older, they have to redefine their role and begin to assume a superordinate position" (Kennedy, 1985, p. 257).

Finding 2: The adolescent's sense of self is affected by their sibling with severe autism.

The adolescent stage of development affords the opportunity to self-reflect in the abstract and also verbalize those thoughts. Adolescents are acquiring a personal sense of identity and adopting a personal value system. "They are much more likely to describe themselves in terms of personal beliefs, characteristics, and motivations." (Markus & Nurius, 1984, Research on Self-Understanding section, para 2). Giving thought to oneself although seeming narcissistic allows the second individuation to advance. Self-reflection provides an avenue to learn who the adolescents are as people.

This research found adolescents who were self-reflective about the contributions their brother with severe ASD had on their sense of self. The adolescents find positives about their sibling and about living with their sibling (Chapter VI: Who I Am, Actions Speak Louder, If Only the World Knew). They give considerable credit to their sibling with autism for contributing to their “better” character including the personal traits of patience, understanding, and thoughtfulness which are cultivated from living with their sibling with severe ASD.

Having an awareness of disabilities and respect for diversity is valued by the adolescent both within themselves and a value they would like others to have. Personal pride evolves when other people notice the level of responsibility the adolescents can handle and manage.

All of my teachers, since 2nd grade, would say, “He’s great with [a student with autism], he listens to him, knows what he’s trying to say, and helps him through it.” I normally get partnered with him just because I’m the only person who knows how to deal with him.

A number of the adolescents feel so strongly about their brother with autism their sense of self includes altruism. They are involved in volunteering and belong to inclusive recreational clubs. They are devoted and diligent about becoming successful because their sibling cannot be. “Since he isn’t able to do certain things that I can do, I decided I had to keep running for him.” Responsibilities, disability awareness, and altruism precede insightfulness and maturity other teenagers have yet to develop. This maturity is valued

by some adolescents but considered a curse by others. All acknowledge maturity is a component of their self-concept.

Being aware of one's surroundings, at home and then away from home, leads to the realization that something is different with the adolescent's brother and different with other people. Understanding that people have challenges is generalized by the adolescent when they show compassion towards everyone. They contemplate the reasons people behave the way they do, accept their presumptions about the behavior, and feel no animosity towards it. The adolescents are empathic. However, some of the teenagers believe that it is possible to be too amiable.

All the other girls, they'd say, "You can't let her push you around like that. That's not nice."

Because honestly, I don't really like telling people I don't want to be around them anymore.

I'll try and act nice to him but you can clearly tell that I'm upset with him.

Some adolescents with siblings with autism know other people have challenges but do not feel compassion towards them. They are apathetic, indifferent, and aloof towards people in general. These adolescents have the fewest friends and describe themselves as homebodies or antisocial.

The adolescents identify patience, honesty and 'being real' as important aspects of who they are. They expect adults and friends to be as authentic as they are. Although the

adolescents with a sibling with severe ASD describe themselves as being patient, they have little patience for people who are unreliable, dishonest, or uncaring.

Some adolescents hold personal beliefs that people should cope with difficulties and that grudges should not persevere. “Just deal with it.” As a way to cope, they strive to be positive. “Having a disability or any problem doesn’t make you any different. It just makes you more special, not in a bad way but in a good way.”

The most insightful of the adolescents understand how they fit into the world and how they have something important to give to the world: “I understand that I do have an importance to the world,” and “I want to help out and do stuff that makes the world a little better place.”

Finding 3: Adolescents with siblings affected by severe autism describe friendships similarly to descriptions given by other adolescents.

During the adolescent stage of development, relationships expand beyond the bounds of the family and these relationships hold more significance for the teenager. The adolescents in this study give similar details of friendship as would be expected from any adolescent. These descriptions include how and where they met, what they do, and what their friendships mean to them.

My teacher told me he had never met two kids from different families who looked and acted as alike as me and my friend.

Sometimes we will text each other randomly at night and just talk about our day.

Commonalities and time are factors necessary to secure and maintain friendships. Typically, friends live nearby, attend the same school, and participate in the same club or sport. “I’ve done debate for a while and I’ve just started doing speech. I made friends in both speech and debate.”

The adolescents’ who have a sibling with severe autism, and their friends’ interests are similar to any other adolescent. These include gaming, “hanging,” and sports (Chapter VII: Qualities of a Friend, Defining Friend, Where We Met, Hanging Out). In 2015, the US Department of Labor’s Bureau of Labor Statistics found adolescents spend about two and a half hours per week, when averaged over one year, in social leisure activities including playing games or using computers for leisure; socializing or communicating; and exercising (sports and recreation).

For any friendship, communication happens between the two people with some regularity. “We like talking to each other and I think that’s important.” For adolescents, they might catch a brief moment together between classes or spend lunch together. Social media is used principally to communicate with friends. Some adolescents use gaming as a tool to communicate as well.

Friendships provide growth opportunities for adolescents with or without a sibling with severe autism and lead to the development of “a sense of connectedness with others and individuating the self” (Savin-Williams & Berndt, 1990, p. 279). Intimate knowledge is shared with friends where they learn about life outside the family; develop empathy;

discover new interests; recognize there is no “typical” family; and experience grief if the friendship ends.

Finding 4: A sibling with severe autism affects the physical space and practical experience that their adolescent brother or sister shares with friends.

Parents strive to maintain safety in their home. Adolescents with a sibling with autism have this same goal when it comes to protecting of their friends (Chapter VII: Hanging Out; Chapter VIII: The Benefit or Burden). Safety is a concern when a sibling with severe autism is violent and unpredictable. Friends do not visit the adolescent’s home if the sibling with severe autism is prone to extreme behaviors. The sibling with severe autism may have a fit if the adolescent’s friend visits the home because the sibling with severe autism may see the visit from the friend as an intrusion. These circumstances make the adolescent’s friends vulnerable to physical aggression and verbal outbursts. For adolescents who have friends visit, an explanation is typically given before the friend arrives.

If I were to invite someone over I would tell them about my brother or about the things that could happen because it would be fair to my brother and to them if he did do something out of the ordinary.

Other behaviors make it difficult to “hang out” at the adolescent’s home. The brother with autism is too loud for friends to visit at the house. Sometimes, the brother is unable to share with either their adolescent sibling or the adolescent’s friend. “My

brother's bugging us. He's trying to get us to let him play or he's trying to get us to get off even though the Xbox is mine." Another behavior interfering with friends being together in the adolescent's home is the invasion of personal space.

So, my friend is over at our house and because we don't have a lot of people over ever, she was someone different to my brother. I kept explaining to her that he wanted to get really close to her because she was a new face in our house. My brother likes to get up in people's faces.

When visiting, some friends try to ignore their friend's sibling with autism or try to ignore his behaviors. Sometimes, the sibling with severe autism is either the topic of conversation or is never mentioned.

Other practical experiences adolescents with a sibling with severe autism face include having to care for their sibling with autism which limits social time spent with friends.

An additional consequence of having a sibling with severe autism for some adolescents includes a delay in social skill development. Some adolescents with a sibling with severe autism prefer using texting and email rather than talking to friends. This gives them time to gather their thoughts. Some prefer the role of follower or lack an interest in speaking to others. While for some adolescents with a sibling with severe autism, their social skills have either matured or coping strategies evolved. They have a sense of pride when they realize they have the role of planner and organizer for their friends. "I'm the more knowledgeable one. I normally am the one who asks what we

should do and makes sure it happens.” The adolescents with a sibling with ASD are very familiar with schedules “since people with autism like to have a schedule” and find comfort having a plan in place.

Friendships are vulnerable when one friend has a sibling with severe autism, because pragmatic limits are present and social skills may be affected.

Finding 5: Living with a sibling with severe autism emotionally affects adolescent friendships and the thoughts given to friendships.

Emotions give meaning to relationships and having a sibling with severe autism does impact the thoughts and feelings of adolescent friendships (Chapter V: Evoking Feelings; Chapter VI: Who I Am, “I Have (Other) Feelings, Too,” If Only the World Knew; Chapter VIII: The Benefit or Burden). The sibling relationship is typically the first peer relationship a child knows. Each sibling acts as a social facilitator to the other. Some of their narrative is developed together. Unfortunately, play and relating are diminished with autism so the adolescents in this study had limited, if any, opportunity to develop this first friendship.

Despite having a limited first friendship with their sibling with autism, most participants have successful peer relationships. They, as most adolescents, are making the shift from the family to having more significant relationships outside the home. This age group is developmentally more capable of emotively describing their friendships.

However, the ability to share and report emotionally charged content is difficult for some

adolescents in the study and the level of comfort varies for each person. Some feelings are quite apparent while others are hidden.

Inspiring and poignant stories about brothers and friends arouse various emotions. Adolescents feel an important part of them is accepted when their brother with severe autism is accepted by their friends. "It's like we are all one big happy family."

Appreciation and joy are felt as friends attempt to or do include a sibling in play.

My three guy friends play my brother's video game with him because they're like older brothers to him. They'll protect him. Whenever I need them to play with him or help him, they'll play or help him. I know they understand him.

The adolescent is relieved when friends visit and their sibling's behaviors are tolerable.

Other times, fear and embarrassment are present for either the adolescent or their friend.

I've been on the phone with my friend when my brother's had an outburst and my friend would say, "Wow, is that's your brother back there?" I'd say, "Yeah, it's him." "You should come over here and really relieve yourself." And I'd tell him, "That sounds nice."

Sometimes I would have a sleepover. It was only my best friend who came and my brother would have a bath. He sometimes would go around the house after his bath doing his own thing, being naked, and we'd just look at the wall. We gave him privacy by looking away and so my friend wouldn't feel uncomfortable.

The adolescent feels sad that they are missing out when the brother's behaviors interfere too greatly to have friends visit. "There've been times when I may not have had people

over as much because my brother is here and I just didn't want to go through the whole hassle... Yeah, I've had less people come over." They also feel guilty for having friends because the sibling cannot enjoy a similar relationship. The adolescent with a brother with severe autism may even feel jealous of their friends because the adolescent understands they do not have the experience of living with siblings that are all developing typically like their friends do.

At times, embarrassment, shame, and denial interfere with friends learning about the sibling with severe autism. He is a secret or his diagnosis is a secret. Some adolescents are ambivalent or indifferent concerning their friends' knowledge about their brother with severe autism. But the adolescent is relieved when the adolescent feels supported by friends and can share information and stories about their sibling.

On the other hand, because adolescents with siblings affected by autism are deeply hurt when they hear offensive comments or witness intolerance by other, they expect their friends to hold the same convictions they do towards people with disabilities. If the adolescent learns their friend does not, they will end the friendship.

Lastly, having a sibling with severe autism affects an adolescent's stress level adding an emotional vulnerability to social interactions even with friends. Emotional and physical exhaustion from limited and disrupted sleep plus dealing with chronic tantrums weigh on adolescents. Their energy is drained, coping is diminished, and judgement is tried. "I'd wake up to my brother screaming and I'd go to school in a mood, like 'I don't

want to talk to anyone.’ Someone would say “Hi” and I’d tell them, ‘No, not today, leave me alone’. Most of my friends know what that means.”

Adolescents with siblings with severe autism are vulnerable to a host of emotions that both positively and negatively affect their friendships including guilt, fear, and sadness that contrasts with happiness, empathy, and joy.

Chapter X

Theoretical Discussion and Clinical Implications

Theoretical Discussion

Developmentally, adolescents are in the midst of “renegotiating the integration and the balance between being in contact with [the original attachment figures] and being autonomous” (Ammaniti & Sergi, 2003, p. 59). Intrapsychically and interpersonally, adolescents are getting ready to move beyond their family. This is no different for most adolescents living with a sibling with severe autism. “All of my friends are trying to get away from all their siblings” is a sentiment voiced by one participant but probably held by the others. This shift happens not only for social-emotional reasons but because there are biological changes occurring hormonally, neuropsychologically and cognitively (Ainsworth, 1989).

The evidence reported in this study substantiates the idea that adolescents living with a sibling with severe autism are affected personally and relationally. This can also be supported theoretically. Attachment, object relations, and development of self provide theoretical understanding for recognizing the impact living with autism has on both the interpersonal and intrapsychic development of adolescents and friendship.

Theoretically, friendship has been given limited consideration in psychodynamic literature. In 1963, Leo Rangell wrote “On Friendship” for the *Journal of the American Psychoanalytic Association* and in 2000, he mentions this seminal work stating, “[On Friendship] remains a solitary article in the literature on this most important object relationship” (p. 455). Rangell describes how Winnicott’s idea about the transitional object might be considered someone’s friend.

It...comes to serve as an early, if not a first, "friend," an external adjunct to a tender and inexperienced ego in its struggle to master the helpless state. We might conceive of a progression from the initial human relationship, then a displacement to an inanimate object, or to an animate but nonhuman one (pet), and then, after mastery of certain inner conflicts or inadequacies, back to the human again. (1963, p. 15)

Despite the lack of theoretical examination about friendship, some connections will be made throughout this discussion about the effect living with severe autism has on the friendships of adolescents with neurotypical development.

Severe autism interferes with either the affected person’s development or demonstration of the development of a sense of self and object, as well as, affect regulation. Considered an object relations theorist, Winnicott’s thoughts about the development of the self illustrate both philosophical and psychological understanding of the difficulties borne upon a person with autism and their siblings (Kirshner, 1991).

It is through “Hegel’s conception of the intersubjective origins of the self, in

which the self emerges only in an encounter with another subject” (Kirshner, 1991, p. 157) that Kirshner describes as being “implicit in the work of Winnicott” (p. 157). “When I look I am seen, so I exist. I can now afford to look and see. I now look creatively and what I apperceive I also perceive” (Winnicott, 1971/2006, p. 154). How much ‘looking’ does autism allow? The sibling has not been “seen” by their brother with autism despite the sibling looking and seeing. It is the “essence of the self [that is] being constructed in response to the unfolding dialogue with another, [and is] being shaped by the specific encounter” (Kirshner, 1991, p. 161). So, the sibling-self must emerge differently while the encounter with the brother with autism-subject is almost void. This does not seem to bode well for siblings and their future encounters including friendships.

According to Meissner (2007), “Friendship seems to fall under the object relational perspectives of the self as relational” (p. 234). Object relations theory regards relatedness as the primary motive for psychic development (Ainsworth, 1969), interpersonal relations, and mental health. The question becomes what aspects of the self are integrated and used in relation with friends when earlier experiences with a sibling affected with ASD are different from most sibling relationships?

Adolescent development, attachment, and development of the self add to this discussion. Ammaniti and Sergi (2003) use a developmental and attachment perspective to report four different areas of change for adolescents who have had a conventional early experience prior to entering this stage of development. Living with a sibling with severe

autism adds a dynamic needing further discussion because it is not “a conventional early experience.”

Ammaniti and Sergi (2003) describe the first area of adolescent change as “joining the peer group” (p. 59) which affords members the opportunity to meet other peers with similar interests and experience a life uniquely theirs (Savin-Williams & Berndt, 1990). Peer groups provide an opportunity for friendships to develop. Group membership is described in detail by most participants under the guise of extracurricular activities, lunch table meetings, and “hanging out” in small clusters. The quality of the adolescents’ participation varies from full involvement and satisfaction to fringe involvement and limited satisfaction. Some have no group affiliation suggesting development is following a slower trajectory or a resistance to progress in the “detachment from the attachment figures” (p. 59).

Another aspect of finding success in a peer group can be directly correlated with sibling relationships and the aggression it causes. Sibling rivalry, famously addressed by Freud (1909), has a value in the development of peer group association.

“Competitiveness, hostility, and envy as well as feelings of love, tenderness, and concern” (Kieffer, 2008, p. 162) are feelings that exist in the sibling relationship and provide practice for the times the feelings emerge in peer groups. These emotions must be managed for success in peer groups. Once the capacity for love and friendship with siblings happens it is possible to make friends (Sherwin-White, 2014). Joseph (1973) holds a similar view to the role aggression has in peer relationships.

Friendships ... allow for the expression of forceful, directive, assertive behavior in relation to the other person without a destructive or hostile element necessarily being involved. In fact, many friendships do depend upon this degree of active approach on the part of one or the other of the comrades. (p. 207)

For the majority of the participants reporting rewarding group experiences, the effect of having a sibling who cannot promote social norms leads one to presume a second sibling fills that potential gap by modeling socially appropriate behaviors or other experiences are provided. Those struggling with the development of peer relationships certainly have no “first peer” to rival, to aggress against, and compete with to aid in the promotion of social appropriateness. Unfortunately aggression, which does not bode well in most adolescent friend groups, has been found to be the most reported interaction problem by siblings in their relationship with a brother with a non-specified severity level of ASD (Ross & Cuskelly, 2006) and may have been a factor for those participants with limited peer group success.

Other participants are influenced by a strong or enmeshed affectional bond with their sibling with autism. Their narrative describes satisfaction being home with their sibling and a lack of desire for peer experiences. The personal descriptions of “antisocial” or “home-bodies” named by a few participants seem to validate their lack of peer relationships or joining peer groups. Again, the adolescent does not experience a sibling relationship that would lead the adolescent to pursue friendships.

While the experience of sibling relationships may impact peer group membership and friendships, the ability to regulate emotions is also necessary. Freud (1921) states, “Almost every intimate emotional relation between two people which lasts for some time—marriage, friendship, the relations between parents and children—leaves a sediment of feelings of aversion and hostility” (p.101). However, in adolescence in particular, there is “an increased need to regulate affect and behavior” (Steinberg, 2005, p. 69) with less influence and regulatory support provided by the attachment figures.

Accordingly, the second area reported by Ammaniti and Sergi (2003) requiring change during the adolescent stage of development is the “affective changes due to the progressive detachment from the attachment figures” (p. 59). Mastering detachment is difficult and increases the risk for internalizing problems like depression, distress, and/or anxiety for any teenager (Fisman, Wolf, Ellison, & Freeman, 2000; Gold, 1993; Ross & Cuskelly, 2006). It is an emotionally-charged slow loss. Adolescents with a sibling with ASD are additionally vulnerable because they are living with an extra loss, the “loss” of a sibling who relates typically.

Furthermore, their role, and perhaps, their bond with the sibling with ASD differs from sibling relationships that do not include a severe disability. The adolescent has a bond more similar to a parental bond having to respond to their sibling’s needs and to keep them safe. Participant thoughts of “sad things” and “being left alone” with the sibling with autism may slow the process of managing and regulating emotions necessary

for detachment from attachment figures with the potential consequence of interfering with the development of friendships.

But does detachment truly occur? While Ammaniti and Sergi define detachment as moving from the attachment figure to gain autonomy, Ainsworth (1989) doubted a detachment transpired. “There is good reason to believe that even an optimum degree of autonomy does not imply cessation of attachments to parent figures” (p. 710). She used terms like “attachment bond” (p. 711) to describe the changes in adolescence. Indeed, in 2009, Meissner wrote “recent findings from longitudinal studies of childhood and early adolescence indicate that attachment statuses established in infancy and childhood tend to remain relatively stable during adolescence” (p. 283). This is good news for the study participants. There is less loss than earlier mentioned as the attachment with parents continues.

However, this raises two issues. First, whether it is attachment, a degree of attachment, or detachment, regulating affect remains an expectation as adolescence moves forward developmentally. An example of emotional regulation from the study includes the participant’s narrative of handling the responsibility of caring for their sibling with autism despite being anxious and then having pride in accomplishing such a reluctant and difficult task. Another example was the adolescent discussing the consideration given to having an “okay” life so the brother could stay safe versus having a riveting life. Both examples demonstrate the one “psychic achievement of...adolescence,” which Blos (1962) described as “the mastery of emotions” (p. 174).

Second, the inevitability of their attachment figures' death leaves the now adolescent envisioning life without them, without them to parent and care for the sibling with severe autism. Adolescents think about their potential future responsibility to their sibling with ASD and what that means for their personal life. Will they have the "freedom to pursue and commit to a love object outside the family?" (Sharpe & Rosenblatt, 1994, p. 508) is a question replete with emotional significance needing regulation.

Emotional regulation is followed by mature cognitive functioning as the third area of adolescent change that occurs from the developmental and attachment perspectives described by Ammaniti and Sergi. These "cognitive changes with the advent of more mature functioning, such as the formal operations, the ability to reflect on one's own cognitive processes (i.e., metacognition, self-reflective function, and the ability to understand and explain ambivalence)" (Ammaniti & Sergi, 2003, p.59) move the adolescent closer to adult cognitive abilities. High school adolescents were specifically chosen for this study because they are still (most likely) living with their sibling with autism; friendships have (for the most part) become more significant for them than their family; but most importantly, because their cognitive processes have matured from childhood thinking.

Metacognition, one of the examples of a cognitive process, is the capacity to be reflective, to think about one's thinking, and to reach conclusions about the essence of that thinking (Fonagy, 1999; Tuch, 2011). One of the questions in the study, "How have

you been affected by your brother's autism with regards to your friendships," leads the participants to the cognitive process of metacognition.

While metacognition is one example of a cognitive process named by Ammaniti and Sergi, self-reflective function is another example. It is defined by Fonagy (1993) as:

Our understanding of the world around us is tied to our everyday intuitive understanding of the human mind, that of the self as well as of the other. The world we live in can only make sense if we invoke constructs like wishes, beliefs, regrets, values, and purposes, to understand the behavior of the object as well as our own reactions. (p. 978)

The participants demonstrated the ability for self-reflection about siblings and friendships as indicated by these statements:

Other families don't know how lucky they are having a mentally stable family.

Well, me and him both have the same sense of humor. When it comes to joking around we don't discriminate against any kind of joke unless it's really bad. We have the same mindset for that.

As the last cognitive process described by Ammaniti and Sergi, ambivalence is classically defined by Anna Freud (1958) as "a double trend of impulses, such as love and hate, linked together and directed toward one and the same object" (p. 104). It exists in both sibships and friendships. The sibling relationship is the first experience where ambivalence can "safely" occur (Sharpe & Rosenblatt, 1994). When someone has severe autism, it is difficult to know what type of bond, if any, is held toward a sibling

(Ainsworth, 1989), but the adolescent participant does have a bond toward the brother with autism and ambivalence exists. The participants' ability to understand and explain ambivalence as a cognitive change was not pursued in this study; however, the ability to share their ambivalence about their sibling and their friendships is present.

I have better things to do with my time [than have friendships]. But I'm happy with my life.

My brother's around but he doesn't really bother me or anyone.

It is through emotional relationships with the attachment figures that one develops the ability "to understand interactions in terms of mental states" (Target & Fonagy, 1996, p. 461). The typical sibling relationship may constitute an affectional bond or kinship bond rather than an attachment (Ainsworth, 1989), but the bond with siblings as well as with friends affects the cognitive changes in adolescence (Ammaniti & Sergi, 2003). Having the capacity to think about one's own experience is essential for healthy psychological development (Winnicott, 1971) and for realizing both affectionate and object relationships (Winnicott, 1963). The cognitive change of adolescence affords deliberation of friendship as it, too, is an object need of the human psyche (Rangell, 1973).

Finally, according to Ammaniti and Sergi (2003) "body and sexual puberty transformation...influence the perception of the self and of the others" (p. 59) and is the fourth area of change occurring during the adolescent stage of development. An adolescent's perspective of self changes as the body changes. There is concern about the

normality of the developing body. Appearance is important as noted by a participant commenting about a sibling developing neurotypically:

She has this habit where she won't pull down her shirt if it's riding up which is a pet peeve of me and my mom's. I say, "Hey, pull down your shirt, that's, you know, decency," and she's like "I don't care."

The reasons given during the study to "look good" include getting a job, looking professional, and getting friends but attracting love interests is a neglected topic in the study. Few participants have a love interest and those without claim they are too busy. However, the desire to both, "fit in" or be with the other, while "being their own person," or individuating, is emerging.

In fifth grade I didn't see any problem. There was no problem telling people my brother has autism. I didn't see why I shouldn't talk about it but now it seems I just talk about it less. I don't know why...I mean some of the stuff he does is kind of...I don't want to talk about it to a friend at school particularly.

All of the adolescent changes described by Ammaniti and Sergi can be summarized by Blos's (1962) understanding that "the process of pubescence affects the development of [the adolescent's] interests, their social behavior, and the quality of their affective life" (p. 5) reorganizing the ego, parental relationship (1967), and friendship. Friends become more important in an adolescent's interpretation of who they are and how the self is defined. Friends support the development of "a sense of connectedness with others and individuating the self" (Savin-Williams & Berndt, 1990, p. 279). Despite

the additional dynamic of having a sibling with severe autism, the adolescent can come through this developmental stage having a “self that emerge[s] from encounters with another subject” (Kirshner, 1991, p. 157) be that a parent, another sibling, or, for the purpose of this study, a friend.

Clinical Implications

[My sister] is as endearing and fanciful and truly giving as I would want any loved one to be. I can think of nothing more wonderful than to be here right now with my sister. But there is a substory. (Simon, 2009, p. 136)

Simon is an award winning author and speaker. She is the adult sibling of a sister with severe disabilities and provides a reason for clinicians to be involved with siblings like her. There is a story to be shared. The adolescents in this study told their story because they wanted others to hear it, too. More than one said they had never been asked about their brother with autism or their friendships.

Most of the stories heard...from siblings reflect a positive experience, because those are the easy stories to tell. It seems they are the only stories that society wants to hear (Strohm, 2005, p. xiii).

High functioning siblings...typically live in an environment that requires them to suppress taboo emotions, judgments, and the evidence of their senses (Safer, 2002, pp. xvii-xviii).

Strohm is a former counselor and founder of Siblings Australia. Safer is a psychotherapist. Both women have siblings with disabilities and their sentiments were heard in the narratives shared during the interviews. Although most participants did not suppress descriptions of the behaviors they endured, some tried. This suppression was learned when the adolescents explained that friends and others outside the home had no idea another brother existed. Loyalty to the family can be strong and they talk about their situation in positive terms even when it is not positive. Given that adolescents may feel the need to hide the reality of their living situation, clinicians can provide opportunities to hear their unfiltered stories and understand the various dilemmas living with a sibling with severe autism create.

Adolescence is a developmentally challenging time but for teenagers living with autism emotional vulnerabilities increase. “I would say going through life with a special brother like Eddie was more difficult as a teenager...I was very conscious of others’ reactions especially my peers,” says Connell (2014) reflecting on her life with her brother, Eddie, who has autism (p. 52).

Adolescents also contend with loss because the sibling with autism cannot be a sibling as other siblings are. There is guilt because they are not autistic and glad about this. The adolescent also has friends while the sibling really cannot be a friend similar to them. The adolescents can hate the disruptions that the sibling causes in the adolescent’s life. The sibling with ASD can cause the adolescent to lose sleep, study time, and shared time with their parents, who are busy caring for the sibling with autism. If the sibling

with autism is physically aggressive, the adolescent can feel fear or experience trauma. This leads to hyperarousal and other neurobiological effects. Front line clinicians are a qualified resource that can help adolescents with a sibling with autism work through their emotional vulnerabilities.

With the exception of the work of one theorist, Leo Rangell, the topic of friendship has been virtually ignored by the psychoanalytic field. However, front line clinicians know friends are a support to adolescents and play a vital role at this stage of development. This knowledge is used in clinical work whether the teenaged client has a sibling with severe autism or not.

It is important to recognize that some adolescents with a sibling with autism may have delayed social skills because they may lack modeling from their first peer relationship, they may have a mild undiagnosed level of autism, or they may experience ongoing stress from the commitment of caring for and living with a sibling with severe autism. Front line clinician can help develop or refine those social skills with the adolescent who has a sibling with severe ASD.

A final implication needing attention came during the recruitment phase of this study. During recruitment, various clinical and social service organizations that serve clients with autism and schools that educate students with severe autism were asked to distribute flyers. Many did not know if their clients or students had siblings. By not knowing that the children with ASD had siblings, these providers are unable to understand the family dynamics that can affect all of the members of the household.

These providers need this information, and apply it to improve their services. They must then disseminate information and offer resources for everyone in a family affected by autism.

Study Limitations

Purposive sampling is used in qualitative research studies where the participants are intentionally rather than randomly selected. This study is not generalizable to a larger population because very specific criteria had to be met to participate such as being high school-aged, having a sibling with severe autism, and agreeing to be interviewed in-person. The sample size was small with seventeen participants and not representative of the general population. A small sample size is necessary when intensive interviewing is the principal method of data collecting. This allows the participant the opportunity to convey his or her experience about living with autism and having friendships in-depth (Charmaz, 2014). The study participants all live in two Midwestern states and likely share similar cultural perceptions of disabilities.

Another study limitation is the location of the interview and the participants. Adolescents want to “do right” by their family and friends as well as please the researcher. “Alright so, how exactly should I do this?” was asked when the participant thought the researcher had specific expectations for an answer. During most of the interviews, a parent was nearby either in another room or on another level of the home,

and occasionally the sibling with autism made his presence known. These factors may have caused some hesitation by the participants to share fully.

There is certainly a developmental difference in the importance of friendships for a 14 year old and a 17 year old with a more significant shift away from the family for the older adolescent than for the younger one. This study included 14 to 17 year olds.

This study did not consider the influence the parents have regarding the meaning autism has for the family. This could factor into the relevance siblings who lives with autism view various aspects of their life including their friendships and their sibling with autism. Parents had to have time and give consent for their adolescent to participate which meant they were available and interested in offering this opportunity to their child. For these families, autism may hold a different meaning than from families who did not participate.

Lastly, member checking was offered via email. Member checking allows participants to confirm the analysis of the data or add to the refinement of the categories. Two participants responded. One participant enjoyed what had been written. The other felt the results were unfavorable.

There was a negative shadow over the experience of have a sibling with autism [in the results]. When a sibling does have autism, we make the most of it. Having a sibling with autism teaches empathy and redefines the words love and family.

Further Research

The focus of this study is limited to friendships. Other relationships including those with parents, the sibling with autism, and other siblings may hold as much importance to adolescents who have a sibling with severe autism. It may be interesting to learn from the adolescent what relationship is most significant to them and why. Perhaps, the adolescents have other, more specific ideas about factors affecting their friendships or their sense of who they are. They should be given the opportunity to voice their thoughts and perspectives.

Some of the participants experienced violence from their sibling. Trauma exposure and the effect of trauma could be another area for further study. Also, brothers and sisters living with siblings with high functioning autism may have a different story to tell.

Parents of children with autism are busy because much attention has to be given them. Another study could learn the perspectives of children or adolescents living with a sibling with autism regarding their parents' availability and the affect this may have on them.

Hopefully, more ideas have been generated from this study to further research regarding autism and the experiences of autism in families, especially the experience of having a sibling with severe autism.

Appendix A
Recruitment Flyer

VOLUNTEERS NEEDED FOR RESEARCH STUDY ON SIBLINGS AND AUTISM

Do you have a child who is a sibling to a brother or sister who has been diagnosed with moderate to severe autism?

And

Is that child between 14 -17 years old?

And

Has this child lived with their sibling with autism for at least 7 years?

Or

Are you age 18 and have a sibling with moderate to severe autism that you have lived with for at least 7 years?

If you answered Yes to these questions, you or your child may be eligible to participate in my study that will help me gain a deeper understanding of the development of friendships when someone grew up with autism in the home. Participants receive a \$15 gift card for an hour in-person interview.

The purpose of this study is to learn how the experience of having a sibling with moderate to severe autism has or has not impacted friendships for high school-aged people.

Confidentiality is assured.

This study will be conducted by Jackie Duffy-Hook, LCSW (Principal Researcher), supervised by Joan DiLeonardi, PhD (Dissertation Chair), and under the auspices of the Institute for Clinical Social Work, 401 S. State St., Ste. 822, Chicago, IL.

Please contact Jackie Duffy-Hook at jduffy@icsw.edu or (630) 962-7784 for more information.

Appendix B
Consent Forms

Leave box empty - For office use only

Institute for Clinical Social Work
Research Information and Consent for Participation in Social Behavioral Research
The experience of relationships from adolescents who have a sibling with severe autism.

I, _____, acting for myself, agree to take part in the research entitled My brother or sister has severe autism but what about all of my important relationships. What do teenagers say about all their important relationships when they live with a sibling with severe autism?

This work will be carried out by Jackie Duffy-Hook (Principal Researcher) under the supervision of Joan DiLeonardi, PhD (Dissertation Chairperson).

This work is conducted under the auspices of the Institute for Clinical Social Work; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; (312) 935-4232.

Purpose

The purpose of this research study is to learn about relationships from the perspective of high schoolers who have a sibling with severe autism. There has been no autism research conducted hearing from the adolescent sibling's voice his/her views of relationships. The results of this research study may provide other teenagers living with autism, validation or new perspectives about relationships. It may provide parents, extended family members, teachers, social workers, and other service providers a new understanding about the views of teenagers and their relationships when the teenager has a sibling with severe autism.

Procedures used in the study and duration

You will be interviewed for approximately one hour which will be digitally recorded and later transcribed. The interview will take place in-person at a location agreed upon by you and me. Later, a shorter interview, either in-person or by phone may be needed to clarify an earlier statement or to ask something that was not considered earlier. Lastly, you will receive an email or phone call to check if the main ideas coming from other participants fit with your ideas. A \$15 gift card to a fast food chain will be given when you consent to participate.

Benefits

You will not personally benefit from being in this study. However, we hope what we learn will help other brothers and sisters from families with autism learn how other similar siblings view relationships.

Costs

There will be no monetary costs to participate unless travel to the interview is necessary. You will not personally benefit from being in this study

Possible Risks and/or Side Effects

Participating in this study may cause minimal emotional distress and/or discomfort because you will be sharing information about relationships, family, and having experienced autism. You can refuse to answer questions at any point and can stop the interview at any time. Although risk for severe distress is low, referrals for clinical assistance will be provided to you and all participants as part of the research study process.

Privacy and Confidentiality

Confidentiality and privacy will be kept. The researcher will be the only person holding any identifying information. This information will be kept separately from other research materials and kept in a personal, locked drawer for five years. This information will then be destroyed. Pseudonyms will be given if quotes are included and no other information will be included that could identify you or any person mentioned during the interview process. All digital recordings and transcripts will be locked in a private filing system and erased then destroyed five years after the completion of the dissertation.

Subject Assurances

By signing this consent form, I agree to take part in this study. I have not given up any of my rights or released this institution from responsibility for carelessness.

I may cancel my consent and refuse to continue in this study at any time without penalty or loss of benefits. My relationship with the staff of the ICSW will not be affected in any way, now or in the future, if I refuse to take part, or if I begin the study and then withdraw.

If I have any questions about the research methods, I can contact Jackie Duffy-Hook (Principal Researcher) 630-962-7784 or Joan DiLeonardi, PhD (Dissertation Chairperson), at 312-935-4232.

If I have any questions about my rights as a research subject, I may contact Dr. John Ridings, Chair of Institutional Review Board; ICSW; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; irbchair@icsw.edu.

Signatures

I have read this consent form and I agree to take part in this study as it is explained in this consent form.

Signature of Participant

Date

I certify that I have explained the research to _____ (Name of subject) and believe that they understand and that they have agreed to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

Signature of Researcher

Date

Leave box empty - For office use only

Institute for Clinical Social Work
Research Information and Parent Permission Form for Participation in Social
Behavioral Research
The experience of relationships from adolescents who have a sibling with severe
autism.

What is the purpose of this research study?

The purpose of this research study is to learn about relationships from the perspective of adolescents who have a severely autistic sibling. There has been no autism research conducted thus far hearing from the adolescent sibling's voice his/her views of relationships. Your child is invited to participate in this study because she or he is a high school-aged person with a sibling with severe autism.

What will my child be asked to do if I allow him/her to participate in this study?

If you allow your child to be in this study, he or she will be interviewed for approximately one hour which will be digitally recorded and later transcribed. The interview will take place in-person at a location agreed upon by all parties. A shorter interview, either in-person or by phone may be needed to clarify an earlier statement or to ask something that was not considered earlier. Lastly, your child will receive an email or phone call to check if the main ideas coming from other participants fit with his/her ideas. A \$15 gift card to a fast food chain will be given after your child consents to participate.

Parents please be aware that under the Protection of Pupil Rights Act.20.U.S.C. Section 1232(c)(1)(A), you have the right to review a copy of the questions asked or of materials that will be used with your children. If you would like to do so, you should contact Jackie Duffy-Hook, LCSW, at 630-962-7784 to obtain a copy of the questions or materials.

What are the risks for my child's participation in this study?

Participating in this study may cause minimal emotional distress and/or discomfort because your child will be sharing information about relationships, family, and having experienced autism. He or she can refuse to answer questions at any point and can stop the interview at any time. Although risk for severe distress is low, referrals for clinical assistance will be provided to all participants as part of the research study process.

What are the costs for my child's participation in this study?

There will be no monetary costs to participate unless travel to the interview is necessary. Your child will not personally benefit from being in this study. However, we hope what we learn will help other siblings from families with autism know how peers view relationships. The results may also provide an understanding not previously considered by clinicians, teachers, and other professionals in the autism and/or disability community.

How will the privacy and confidentiality of my child be protected?

Confidentiality and privacy of the child will be kept. The researcher will be the only person holding any identifying information. This information will be kept separately from other research materials and kept in a personal, locked drawer for five years. This information will then be destroyed. Pseudonyms will be given if quotes are included and no other information will be included that could identify the participant or any person mentioned during the interview process. All digital recordings and transcripts will be locked in a private filing system and erased then destroyed five years after the completion of the dissertation.

Subject Assurances

By signing this consent form, I agree to allow my child _____ (child's name) to take part in this study. I have not given up any of my child's rights or released this institution from responsibility or carelessness.

I understand that I may take my child out of this study at any time without penalty or loss of benefits. My relationship with the staff of ICSW will not be affected in any way, nor or in the future, if my child refuses to take part, or if he/she begins the study and then withdraws.

If I have any questions about the research methods, I can contact Jackie Duffy-Hook, LCSW at 630-962-7784 (Principal Researcher) or Joan DiLeonardi, PhD (Dissertation Chairperson), at this phone number (312)935-4232.

If I have any questions about my child's rights as a research subject, I may contact Dr. John Ridings, Chair of Institutional Review Board; ICSW; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; irbchair@icsw.edu.

Signatures

[All consent forms must be signed and dated. They must be explained to the participants and witnessed by the person who is explaining the procedure.]

Please check the appropriate box(es) and provide your signature and date below.

My child's name is _____
Print Name Date of Birth

YES, I give my permission for my child to participate in this research study.

OR

NO, I do not give permission for my child to participate in this research study.

Parent/Guardian Signature

Print Name

Date

I certify that I have explained the research to _____ (Name of parent) and believe that they understand the study and have agreed to allow their child to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

Signature of Researcher

Date

Leave box empty - For office use only

Institute for Clinical Social Work
ASSENT TO PARTICIPATE IN RESEARCH

The experience of relationships from adolescents who have a sibling with severe autism.

1. My name is Jackie Duffy-Hook.
2. We are asking you to take part in a research study because we are trying to learn more about relationships from the perspective of high schoolers who have a severely autistic sibling. No one has studied the ideas and thoughts about relationships from teenagers like you living in a family with autism.
3. If you agree to be in this study you will be interviewed for approximately one hour by me which will be digitally recorded and later typed out. The interview will take place in-person with only me and you present. Later, a shorter interview, either in-person or by phone may be needed to make certain I understood what you said or to ask you something I had not thought of earlier. Lastly, I will be sending you an email or phone call to check if the main ideas coming from other teens who were interviewed fit or don't fit with your ideas. You will get a \$15 gift card to a fast food chain if you agree to be part of this study.
4. Some teenagers may feel minimal emotional stress and/or discomfort during the interview because they are sharing information about relationships, family, and having experienced autism in their family. If you start to feel this way, you can refuse to answer any of the questions at any point and can stop the interview at any time. Everyone being interviewed will be given a referral sheet with the names and numbers of places they can call or go to if they want to talk to someone.
5. You will not personally benefit from being in this study. However, we hope what we learn will help other brothers and sisters from families with autism know how peers view relationships. The results may also provide an understanding not previously known by clinicians, teachers, and other professionals in the autism and/or disability community.
6. Please talk this over with your parents before you decide whether or not to participate. We will also ask your parents to give their permission for you to take part in this study. But even if your parents say "yes" you can still decide not to do this.

7. If you don't want to be in this study, you don't have to participate. Remember, being in this study is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop.
8. You can ask any questions that you have about the study. If you have a question later that you didn't think of now, you can call me 630-962-7784 or ask me next time.
9. Signing your name at the bottom means that you agree to be in this study. You and your parents will be given a copy of this form after you have signed it.

Subject Assurances

If I have any questions about the research methods, I can contact Jackie Duffy-Hook (Principal Researcher) at 630-962-7784 or Joan DiLeonardi, PhD (Dissertation Chairperson), at this phone number 312-935-4232.

If I have any questions about my child's rights as a research subject, I may contact Dr. John Ridings, Chair of Institutional Review Board; ICSW; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; irbchair@icsw.edu.

Name of Subject

Date

Signature

Age

Grade in School

I certify that I have explained the research to _____ (Name of child) and believe that they understand the study and have agreed to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

Signature of Researcher

Date

References

- Adolescence. (2014). In *Merriam-Webster's Collegiate Dictionary* online. Retrieved from <https://www.merriam-webster.com/dictionary/adolescence>.
- Ainsworth, M. (1969). Object relations, dependency, and attachment: A theoretical review of the infant-mother relationship. *Child Development, 40*, 969-1025.
- Ainsworth, M. (1989). Attachments beyond infancy. *American Psychologist, 44*(4), 709-716.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text revision). Washington, DC.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC.
- Ammaniti, M. & Sergi, G. (2003). Clinical dynamics during adolescence. *Psychoanalytic Inquiry, 23*(1), 54-80.
- Bågenholm, A. & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. *Journal of Intellectual Disability Research, 35*(4), 291-307.
- Bank, S. & Kahn, M. (1980-81). Freudian siblings. *Psychoanalytic Review, 67*, 493-504.

- Baron-Cohen, S., Leslie, A., & Frith, U. (1985). Does the autistic child have a “theory of mind”? [Abstract]. *Cognition*, 21(1), 37-46.
- Benson, P. & Karlof, K. (2008). Child, parent, and family predictors of later adjustment in siblings of children with autism. *Research in Autism Spectrum Disorders*, 2(4), 583-600.
- Beyer, J. (2009). Autism spectrum disorders and sibling relationships: Research and strategies. *Education and Training in Developmental Disabilities*, 44(4), 444-452.
- Blos, P. (1962). *On adolescence: A psychoanalytic interpretation*. New York, NY: The Free Press.
- Blos, P. (1967). The second individuation process of adolescence. *The Psychoanalytic Study of the Child*, 22, 162-186.
- Blos, P. (1979). *The adolescent passage: Developmental issues*. New York, NY: International Universities Press.
- Bowlby, J. (1969). Attachment and loss. *International Psycho-Analytical Library*, 79, 1-401. London, UK: The Hogarth Press and the Institute of Psycho-Analysis.
- Buhrmester, D. (1992). The developmental courses of sibling and peer relationships. In F. Boer & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 19-40). Hillsdale, NJ: Lawrence Erlbaum Associates.

- Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorders-Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report*, 63(SS02), 1-21.
Retrieved from
http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w
- Charles, M. (1999). Sibling mysteries: Enactments of unconscious fears and fantasies. *Psychoanalytic Review*, 86(6), 877-901.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage Publications.
- Charmaz, K. (2014). *Constructing grounded theory*. Thousand Oaks, CA: Sage Publications.
- Cleary, D., Ray, G., LoBello, S., & Zachar, P. (2002). Children's perceptions of close peer relationships: Quality, congruence, and meta-perceptions. *Child Study Journal*, 32(3), 179-192.
- Cohn, D., Patterson, C., & Christopoulos, C. (1991). The family and children's peer relations. *Journal of Social and Personal Relationships*, 8, 315-346.
- Coles, P. (2009). Sibling incest. In V. Lewin & B. Sharp (Eds.), *Siblings in development: A psychoanalytical view* (pp. 101-114). London, UK: Karnac Books.
- Colonna, A. & Newman, L. (1983). The psychoanalytic literature on siblings. *The Psychoanalytic Study of the Child*, 38, 285-309.

- Connell, Z., Halloran, M., & Doody, O. (2014). Living with a brother who has autism spectrum disorder: A sister's perspective. *British Journal of Learning Disabilities*, 44, 49-55.
- Cox, A., Marshall, E., Mandleco, B., & Olsen, S. (2003). Coping responses to daily life stressors of children who have a sibling with a disability. *Journal of Family Nursing*, 9(4), 397-413.
- Dishion, T. (1990) The family ecology of boys' peer relations in middle childhood. *Child Development*, 61(3), 847-892.
- Dunn, J. (1993). *Young children's close relationships: Beyond attachment*. Newbury Park, CA: Sage Publications.
- Erikson, E. (1963), *Childhood and society*. New York, NY: Norton.
- Fahlberg, V. (1994). *A child's journey through placement*. London, UK: British Association for Adoption and Fostering (BAAF), Skyline House.
- Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*. 45(4), 369-375.
- Fonagy, P., Steele, M., Moran, G., Steele, H. & Higgitt, A. (1993). Measuring the ghost in the nursery: An empirical study of the relation between parents' mental representations of childhood experiences and their infants' security of attachment. *Journal of the American Psychoanalytic Association*, 41,957-989.

- Fonagy, P. & Target, M. (1998). Mentalization and the changing aims of child psychoanalysis. *Psychoanalytic Dialogue*, 8, 87-114.
- Fonagy, P. (1999). Points of contact and divergence between psychoanalytic and attachment theories: Is psychoanalytic theory truly different. *Psychoanalytic Inquiry*, 19, 448-480.
- Fonagy, P. & Target, M. (2002). Early intervention and the development of self-regulation. *Psychoanalytic Inquiry*, 22, 307-335.
- Freud, A. with S. Dann (1951). An experiment in group upbringing. *The Psychoanalytic Study of the Child*, 6, 127-168.
- Freud, A. (1958). Child observation and prediction of development—A memorial lecture in honor of Ernst Kris. *The Psychoanalytic Study of the Child*, 13, 92-116.
- Freud, S. (1955). Analysis of a phobia in a five-year-old boy. In J. Strachey, A. Freud, A. Strachey, & A. Tyson (Eds. & Trans.). *The standard edition of the complete psychological works of Sigmund Freud* (Vol. 10, pp. 1-150). London: Hogarth Press. (Original work published 1909)
- Freud, S. (1955). From the history of an infantile neurosis. In J. Strachey, A. Freud, A. Strachey, & A. Tyson (Eds. & Trans.). *The standard edition of the complete psychological works of Sigmund Freud* (Vol. 17, pp. 1-124). London: Hogarth Press. (Original work published 1918)

- Freud, S. (1955). Group psychology and the analysis of the ego. In J. Strachey (Ed. & Trans.). *The standard edition of the complete psychological works of Sigmund Freud* Vol. 18, pp. 65-144). London: Hogarth Press. (Original work published 1921)
- Furman, W. (1996). The measurement of friendship perceptions: Conceptual and methodological issues. In W. Bukowski & A. Newcomb (Eds.), *The company they keep: Friendship in childhood and adolescence* (pp. 41-65). New York, NY: Cambridge University Press.
- Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders*, 23(1), 147-163.
- Grønberg, T., Schendel, D., & Parner, E. (2013). Recurrence of autism spectrum disorders in full- and half-siblings and trends over time: A population-based cohort study. *JAMA Pediatrics*, 167(10), 947-953.
doi:10.1001/jamapediatrics.2013.2259.
- Hastings, R. (2003a). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 33(1), 99-104.
- Hastings, R. (2003b). Behavioral adjustment of siblings of children with autism engaged in applied behavior analysis early intervention programs: The moderating role of social support. *Journal of Autism and Developmental Disorders*, 33(2), 141-150.

- Henggeler, S., Edwards, J., Cohen, R., & Summerville, M. (1991). Predicting changes in children's popularity: The role of family relations. *Journal of Applied Development Psychology, 12*(2), 205-218.
- Hirstein, W., Iversen, P., & Ramachandran, V. (2001). Autonomic responses of autistic children to people and objects. *Proceedings of the Royal Society London B, 268*(1479), 1883-1888.
- Hodapp, R. & Urbano, R. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*(12), 1018-1029. doi:10.1111/j.1365-2788.2007.00994.x.
- Houzel, D. (1996). The family envelope and what happens when it is torn. *International Journal of Psychoanalysis, 77*(5), 901-912.
- Illinois State Board of Education. (n.d.). Mission statement. Retrieved from isbe.state.il.us/aboutISBE1.htm.
- Joseph, E. (1973). Aggression redefined—Its adaptational aspects. *The Psychoanalytic Quarterly, 42*, 197-213.
- Kaminsky, L. & Dewey, D. (2001). Siblings relationships of children with autism. *Journal of Autism & Developmental Disorders, 31*(4), 399. Retrieved from Academic Search Premier database.
- Kaminsky, L. & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology & Psychiatry & Allied Disciplines, 43*(2), 225. Retrieved from Academic Search Premier database.

- Kennedy, H. (1985). Growing up with a handicapped sibling. *The Psychoanalytic Study of the Child*, 40, 255-274.
- Kernberg, P. & Richards, A. (1988). Siblings of preadolescents: Their role in development. *Psychoanalytic Inquiry*, 8, 51-65.
- Kieffer, C. (2008). On siblings: Mutual regulation and mutual recognition. *The Annual of Psychoanalysis*, 36, 161-173.
- Kirshner, L. (1991). The concept of the self in psychoanalytic theory and its philosophical foundations. *Journal of the American Psychoanalytic Association*, 39, 157-182.
- Klein, M. (1932). The psycho-analysis of children. *International Psycho-Analytic Library*, 22, 1-379. London, UK: The Hogarth Press.
- Kris, M. & Ritvo, S. (1983). Parents and siblings—Their mutual influences. *The Psychoanalytic Study of the Child*, 38, 311-324.
- Krug, D., Arick, J., & Almond, P. (1980). Behavior checklist for identifying severely handicapped individuals with high levels of autistic behavior. *Journal of Child Psychology and Psychiatry*, 21(3), 221-229.
- Macks, R. & Reeve, R. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism & Developmental Disorders*, 37(6), 1060-1067.
doi:10.1007/s10803-006-0249-0.

- Main, M. & Solomon, J. (1986). Discovery of a new, insecure-disorganized/disoriented attachment pattern. In T. Brazelton & M. Yogman (Eds.), *Affective development in infancy* (pp. 95-124). Norwood, NJ: Albex.
- Markus, H. & Nurius, P. (1984). Self-understanding and self-regulation in middle childhood. In W. Collins (Ed.), *Development during middle childhood* (ch. 4). Washington, DC: National Academies Press. Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK216778/>.
- Martz, E. (1930). Training of the mentally handicapped child. *Psychiatric Quarterly*, 4(2), 204-208.
- McHale, S., Sloan, J., & Simeonsson, R. (1986). Sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders*, 16(4), 399-413.
- Meadan, H., Stoner, J., & Angell, M. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental & Physical Disabilities*, 22(1), 83-100.
- Meissner, W. (2007). Reflections on the love commandment. *The Annual of Psychoanalysis*, 35, 223-239.
- Meissner, W. (2009). The genesis of the self. *The Psychoanalytic Review*, 96(2), 261-295.
- Mitchell, J. (2003). *Siblings*. Cambridge, UK: Polity Press.

- Mitchell, S. (1981). The origin and nature of the "object" in the theories of Klein and Fairbairn. *Contemporary Psychoanalysis, 17*, 374-398.
- Morley, E. (2013). [Review of the book] The sibling relationship-A force for growth and conflict, by J. Edward & J. Aronson, 2011. *Couple and Family Psychoanalysis, 3*, (1), 108-111.
- National Association of Social Work. (2008). *Code of ethics*.
- National Institute of Neurological Disorders and Stroke (NINDS). (2009). Autism fact sheet. Retrieved from http://www.ninds.nih.gov/disorders/autism/detail_autism.htm.
NIH Publication No. 09-1877.
- Nasaw, D. (1981). *Schooled to order: A social history of public schooling in the United States*. New York, NY: Oxford University Press.
- Neubauer, P. (1983). The importance of the sibling experience. *The Psychoanalytic Study of the Child, 38*, 325-336.
- Orsmond, G. & Seltzer, M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 313-20.
- Orsmond, G. & Seltzer, M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: testing a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders, 39*(7), 1053-1065.

- Palombo, J. (2010). Learning disorders and self-deficits: Diagnostic and treatment considerations. *Institute for Clinical Social Work, Lectures given throughout June and July 2010.*
- Palombo, J., Bendicson, H., & Koch, B. (2009). *Guide to psychoanalytic theories.* New York, NY: Springer.
- Parens, H. (1988). Siblings in early childhood: Some direct observational findings. *Psychoanalytic Inquiry, 8*, 31-50.
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry, 45*(4), 855-865.
- Pisula, E., & Ziegart-Sadowska, K. (2015). Broader autism phenotype in siblings of children with ASD-A review. *International Journal of Molecular Sciences, 16*, 13217-13258; doi:10.3390/ijms160613217.
- Puberty. (2014). In *Merriam-Webster's Collegiate Dictionary* online. Retrieved from <https://www.merriam-webster.com/dictionary/puberty>.
- Rangell, L. (1963). On friendship. *Journal of the American Psychoanalytic Association, 11*, 3-54.
- Rangell, L. (1973). On the cacophony of human relations. *The Psychoanalytic Quarterly, 42*, 325-348.
- Rangell, L. (2000). Psychoanalysis at the millennium. *Psychoanalytic Psychology, 17*(3), 451-466.

- Rodrigue, J., Geffken, G., & Morgan, S. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders*, 23(4), 665-674.
- Roeyers, H. & Mycke, K. (1995). Siblings of a child with autism, with mental retardation and with a normal development. *Child: Care, Health and Development*, 21(5), 305-319.
- Rosner, S. (1985). On the place of siblings in psychoanalysis. *Psychoanalytic Review*, 72, 457-477.
- Ross, P. & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability*, 31(2), 77-86.
- Rustin, M. (2009). Taking account of siblings-a view from child psychotherapy. In V. Lewin & B. Sharp (Eds.), *Siblings in development* (pp. 147-168). London, UK: Karnac Books.
- Rutter, M. (1972). *Maternal deprivation reassessed*. Middlesex, UK: Penguin Education.
- Safer, J. (2002). *The normal one: Life with a difficult or damaged sibling*. New York, NY: The Free Press.
- Sanders, R. (2004). *Sibling relationships*. New York, NY: Palgrave Macmillan.
- Savin-Williams, R. & Berndt, T. (1990). Friendship and peer relations. In S. Feldman & G. Elliot (Eds.). *At the threshold: The developing adolescent*. (pp. 277-307). Cambridge, MA: Harvard University Press.

- Schore, A. (1994). *Affect regulation and the origin of the self: The neurobiology of emotional development*. Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Schore, A. (2000). Attachment and the regulation of the right brain. *Attachment and Human Development*, 2(1), 23-47.
- Shapiro, T., Sherman, M., Calamari, G., & Koch, D. (1987). Attachment in autism and other developmental disorders. *Journal of the American Academy of Child & Adolescent Psychiatry*, 26(4), 480-484.
- Sharpe, S. & Rosenblatt, A. (1994). Oedipal sibling triangles. *Journal of the American Psychoanalytic Association*, 42, 491-523.
- Sherwin-White, S. (2014). Melanie Klein's thoughts on brothers and sisters. In D. Hindle & S. Sherwin-White (Eds.), *Sibling matters: A psychoanalytic, developmental, and systemic approach*. London, UK: Karnac Books.
- Silverstone, J. (2006). Siblings. In P. Coles (Ed.), *Sibling relationships*. London, UK: Karnac Books.
- Simon, R. (2009). Riding to the fountain with my sister. In D. Meyer (Ed.), *Thicker than water: Essays by adult siblings of people with disabilities*. Bethesda, MD: Woodbine House.
- Sisler, A. & Ittel, A. (2015). *Siblings in adolescence*. New York, NY: Psychology Press.

- Slade, A. (1994). Making meaning and making believe: Their role in the clinical process. In A. Slade & D. P. Wolf (Eds.), *Child at play: A clinical and developmental approaches to meaning and representation* (pp. 81-107). New York, NY: Oxford University Press.
- Smith, L. & Elder, J. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing*, 23(3), 189-195.
- Sperduti, M., Guionnet, S., Fossati, P., & Nadel, J. (2014). Mirror neuron system and mentalizing system connect during online social interaction. [Abstract]. *Cognitive Process*, 15(3), 307-316.
- Steinberg, L. (2005). Cognitive and affective development in adolescence. *Trends in Cognitive Sciences*, 9(2), 69-74.
- Strohm, K. (2005). *Being the other one: Growing up with a brother or sister with special needs*. Boston, MA: Shambhala Publications.
- Sullivan, H. (1953). *The interpersonal theory of psychiatry*. New York, NY: Norton.
- Tager-Flusberg, H. (2007). Evaluating the theory-of-mind hypothesis of autism. *Current Directions in Psychological Science*, 16, (6), 311-315.
- Target, M. & Fonagy, P. (1996). Playing with reality: II. The development of psychic reality from a theoretical perspective. *The International Journal of Psycho-Analysis*, 77, 459-479.

- Tashakkori, A. & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage Publications.
- Tuch, R. (2011). Thinking outside the box: A metacognitive/theory of mind perspective on concrete thinking. *Journal of the American Psychoanalytic Association*, 59(4), 765-789.
- United States Department of Health and Human Services. National Institutes of Health, National Institute of Mental Health. Autism spectrum disorder: Pervasive developmental disorder. NIH Publication No. 08-5511, printed 2004, reprinted 2008.
- United States Department of Labor. Bureau of Labor Statistics. (2016) American Time Use Survey (Chart by Topic: Leisure and sports activities) Retrieved from <https://www.bls.gov/TUS/CHARTS/LEISURE.HTM>.
- Updegraff, K., McHale, S., & Crouter, A. (2002). Adolescents' sibling relationship and friendship experiences: Developmental patterns and relationship linkages. *Social Development*, 11(2), 182-204.
- Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioral problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health & Development*, 29(3), 193-205. doi:10.1046/j.1365-2214.2003.00331.x.
- Winnicott, D. (1953). Transitional objects and transitional phenomena—A study of the first not-me possession. *International Journal of Psycho-Analysis*, 34, 89-97.

Winnicott, D. (1963). Morals and education. In D. Winnicott (1965). The maturational processes and the facilitating environment. *International Psycho-Analytical Library*, 64, 1-276. London, UK: The Hogarth Press and the Institute of Psycho-Analysis.

Winnicott, D. (2006) *Playing and reality*. New York, NY: Routledge. (Original work published 1971).