

"I will tell you about playing with my brother, but not about his autism":

Perceptions of social interaction from the voice of child who has  
a sibling identified with Autism Spectrum Disorder

by

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## ABSTRACT

Autism Spectrum Disorder (ASD) is experienced in a variety of ways within families particularly among siblings with and without ASD. The effects of ASD on sibling relationships are integral to family life. While some studies have examined sibling relationships, research regarding sibling roles exhibited during play activities and social interactions is lacking. Further, siblings' voices are rarely revealed in research on play. In response to a need for greater understanding of the role of play among siblings impacted by ASD, this dissertation used a cultural historical activity theory lens to understand how play and social interactions evolved among siblings since childhood development is informed by access to and participation in play. Siblings may be considered actors with unique cultural histories as they create and re-create their own identities through play. In this study, an emphasis was placed on the complex processes siblings experience while locating their own niche with their families. The study focused on the use of a variety of tools, division of labor, the rules families utilized to interact and how these rules were disturbed. As a result, the study offers a more complete understanding of how play and social interactions affect the ways ASD impact siblings, families, and community members. This study provides holistic views of the development and impact of sibling play on identity development and relationships.

## DEDICATION

To my beloved family who has always believed in me more than I believed in myself.

To my dear husband, Patrick, thank you for your continuous love, and your steadfast  
patience and encouragement.

To my wonderful children: Drew, Kelsey, Katie and Matt - your intelligence, humor,  
thoughtfulness, and unending love have been invaluable in my life and happiness.

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## PREFACE

I have worked with numerous children diagnosed with autism spectrum disorder (ASD) and their families in home and school environments. I have witnessed the impact of ASD and the supports, responses, and interventions that it engenders from professional, familial, and lay communities. As siblings observe reactions of strangers, therapists, educators and even parents, they may be afraid of asking certain questions or revealing negative feelings in case their questions or feelings upset their parents. I think it is important not to essentialize or generalize the impact that ASD has on children and families. I have struggled with the conflicting, and limiting, ideas about ASD, families, and various responses. Working with different families has led me to believe that there are many perspectives about normalcy and ASD. I have learned to view each and every perspective as valid and valuable. Unfortunately, dominant discourses around ASD, normalcy, psychology, medical and deficit thinking can be problematic. Rigid, prescribed ideas can be limiting and detrimental to individual and family potential.

As a parent of a child labeled with a disability, I believe that labels are not necessarily the problem. A diagnosis or label may be the only avenue a parent has to pursue vital services needed to provide adequate education and social services for their child. This is one of the major problems with 'labels'; an individual cannot get help or services without the label. Nonetheless, I consistently trouble the notion of labeling and the term autism spectrum disorder. The use of the word "disorder" implies the person is "dysfunctional" leading members of lay and professional communities to identify the labeled individual as an "other" (and potentially the family as well). The pathologizing and constraining effects of diagnosis and labeling



have life-long implications for the individual who has been labeled as well as the rest of the family.

My son's degree of autism precludes him from participating effectively in some social interactions. However as a family, we have never considered this a leading factor in the way we describe him to others. I have had a lot of difficulty listening to the parents in my study who did not use “person-first language.” Yet, I also felt, even as an insider, it was not my place to correct them. On the other hand, I continually educate community members to understand the importance of putting a person before any diagnosed label. I wondered if my reluctance as a researcher to question the parents’ choice of language was due to feeling a deep personal commitment to these families who were also insiders. Their insider status trumped my own beliefs about the importance of framing disability in a particular way.

I continually struggle because while I am moving away from labeling I use terms to “label” the children in my study, such as autism, ASD, identified and diagnosed. Even though I believe that labels are not the crux of the othering problem, once someone has a label, the labeling problem is there. My writing has been fraught with my own internal tensions about what words to use, why, what meaning the words have, who is this being written for, and how the autism continuum gets socially constructed and culturally reified as a binary: a disability that one either does, or does not have.

Therefore, in this dissertation, I tried to act as a facilitator of knowledge, utilizing my ‘insider knowledge’ while privileging my participants with the vernacular used in their homes. In this dissertation, I have decided to use the term Autism Spectrum Disorder (ASD) to identify the child participants labeled with the autism

diagnosis. Since each child within this study falls in different areas of the autism spectrum and all parents describe and label their children with ASD, I thought it appropriate to show consideration and respect to these families by using this term since it is both part of each family's culture as well as well as the language of current research and scholarship in the field.

## Chapter 1

### INTRODUCTION

*Our siblings. They resemble us just enough to make all their differences confusing, and no matter what we choose to make of this, we are cast in relation to them our whole lives long.*

*~Susan Scarf Merrell*

Many memories have stayed with me from my teaching days. I remember how every morning I was greeted by a cherubic face, a little boy parroting “good morning Miss Amy.” His little face usually still had remnants of breakfast on it, his hair was tousled and his voice was robot-like, but everything about Jack melted your heart. Jack was a seven-year-old boy who had been diagnosed on the autism spectrum. He was partially-verbal, although much of his speech was echolalic. His favorite phrase was “good morning Miss Amy”. Although this phrase was repeated several times a day, it was music to my ears. Even though Jack seemed eager to increase his communication skills, most often he communicated his needs to his parents and sister through grunts, mumbled nonsense words and pointing. This type of communication was not always effective. When he did not receive immediate gratification from a request, he began grabbing, pinching and screaming; these behaviors created many difficult situations for his family, especially when they were in a public setting.

I met Jack and his family when I was teaching at a private day school for children with Autism Spectrum Disorders (ASD). Although Jack was not in my classroom, I worked with him after school during therapy hours on communication and social skills. I would spend at least 15 minutes with his mother and older sister, Rachel, when they arrived to pick Jack up from school. One particular day, Rachel

was very excited to tell me a story about the previous weekend. Since she was Jack's primary playmate, she spent many hours a week playing games with him. "Jack played a game of "Go Fish" with me AND he TOOK TURNS!" she told me with more excitement than she could contain. Rachel was bursting with pride as she relayed the interaction she and Jack experienced. However, her entire persona quickly changed as she began another story about "helping take care of Jack when mom and dad had things to get done." This story suggested that, at least at times, she assumed the role of teacher or therapist, instead of friend and playmate. I began to wonder about my own children and their experiences over the years with their brother who is identified with Asperger's Syndrome (AS), one of a number of diagnostic categories associated with ASD. Is it important to understand if siblings adopt particular roles when interacting the child identified with ASD? If so, why?

During my time as a special education teacher, I experienced many such situations with other siblings. Through my experiences with my children and the families I have worked with, I have discovered that family members have a tremendous amount of knowledge, know-how, and understanding regarding ASD due to the families' own experiences. Their knowledge has not been gathered from books, lectures, or classrooms; consequently, it could be very valuable to researchers, educators, and other professionals. Since I am also a parent of a child identified with AS, I became increasingly concerned about issues surrounding the impact of having a sibling with ASD on other children in the family. For example, brothers and sisters develop their own identities, social skills, and companionship in part through their interactions with one another as well as provide each other with mutual support. However, the core features of ASD may affect how these features of siblings'

relationships develop. Over the years, I witnessed situations in which my children supported each other in learning a variety of skills including social interaction abilities. However, many social situations have focused on my youngest child perhaps as a result of the impact of AS on his ability to navigate social contexts. As a consequence of sometimes awkward and uncomfortable interactions, our family life has been more public and vulnerable than families who do not have a child identified with ASD. This realization regarding the family struggles and issues surrounding the increased labeling and diagnosis of ASD has partially guided me to conduct this study.

Researchers are increasingly recognizing the role of sibling relationships on development (Aronson, 2009; Baker, 2000; Ferraioli & Harris, 2010; Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007b), in addition to an increased understanding of how children experience having a sibling with ASD. Sibling relationships are central within family life. The factors that affect the quality of sibling relationships include: coping skills, dominance, affection, companionship, intimacy, admiration and competitiveness and social support (Smith & Elder, 2010). With the rising number of individuals identified with ASD, it is imperative for researchers to understand siblings who may be experiencing particular kinds of challenges due to living with a sibling with ASD. Studies have found that siblings of children with ASD have greater risk of internalizing and externalizing behavior problems such as quarreling (Bagenholm & Gillberg, 1991; Kaminsky & Dewey, 2002). However, very little research has been completed regarding children's perceptions of their relationships when their sibling is identified with ASD (Kaminsky & Dewey, 2001). The majority of research on siblings has been done either on young siblings

(Kaminsky & Dewey, 2001; Kresak, Gallagher & Rhodes, 2009; Ross & Cuskelly, 2006), on others' perceptions of siblings functioning such as parents and teachers (Kaminsky & Dewey, 2001, 2002; Rodger & Tooth, 2004) or on a comparison model indicating differences between typically developing siblings and children with ASD, Down syndrome or other developmental disorders (Christensen, et al., 2010; El-Ghoroury & Romanczyk, 1999; Rivers & Stoneman, 2008). A central issue that researchers face in conducting research with young children is that they are still too dependent upon their parents as well as not developmentally equipped to have a complete understanding of their experience (Dickey, 2008). These issues have resulted in studies involving children with disabilities to be either retrospective in nature or based upon the reports and observations of parents or others instead of interviews or observations of the siblings themselves (McHale, Sloan, & Simeonsson, 1986).

Nonetheless, the sibling relationship has been found to be a key vehicle for the development of a variety of social and communication skills (Knott, Lewis, & Williams, 2007). Kaminsky and Dewey (2001) have reported children with ASD are more likely than other children with disabilities to be unresponsive or to respond inappropriately to their sibling's attempt to engage them. Siblings often lack the knowledge and understanding to successfully interact with their brothers or sisters with ASD.

For siblings, occasions to interact in play represent critical learning opportunities as well as a chance to connect with one another. Play is the vehicle through which these lifelong connections are created and strengthened. For Jack and Rachel, play was essential to their relationship and social interactions. Did

Rachel understand that the success of their interactions and relationship was due to her adoption of specific roles?

This study will provide a better understanding of the perceptions of children regarding their siblings with ASD, and serves as an important step for expanding thoughts on socialization within children with ASD and other children with social delays. Expanding the research on ASD beyond its history of behavior modification interventions to include sibling perspectives on play may further inform social interventions in the future. For purposes of this study, the following assumptions are made. First, children can speak for themselves, giving opinions and explanations to their perceptions (Soto & Swadener, 2005). Second, children, with and without disabilities, are social and intellectual resources for one another (Ferraioli, Hansford & Harris, 2011; Petalas, Hastings, Nash, Dowey & Reilly, 2009). Last, siblings co-construct the roles they perform in their family structure through negotiation and benefits to the family (Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007b). The following sections of this chapter consist of the following: (a) a review of ASD; (b) the impact ASD has on not only the individual with the label but also siblings and other family members; and (c) the effects of ASD on sibling relationships; and finally, (d) the background of play.

### **Background of Autism Spectrum Disorder**

ASD is a complex developmental disability that affects a person's ability to communicate and interact with others" (Autism Society, 2007). ASD affects individuals in the areas of communication and social interaction as well as repetitive and stereotypical behaviors. In addition to these areas, unusual learning needs, attention, and sensory processing patterns are often present. Due to the complexity

of ASD and its increased incidence, additional demands have been placed on early intervention and educational systems, attributable to (a) the unique ways children with ASD process and respond to information, (b) the variability in ASD's impact on individual children, and (c) the often extreme and unusual communication and socialization challenges of children with ASD. Statistics show that ASD is impacting an increasing number of children, affecting an estimated 1 in 88 children in the United States ([www.cdc.gov](http://www.cdc.gov)). With the growing number of individuals identified with this disorder, soon every household and family will be affected by ASD in some manner. For example, a neighbor, a classmate, a child, or a co-worker may either themselves be identified or have a family member identified with ASD. One major issue with this growing disorder is the fact that there are no physical characteristics that are solely connected to ASD. A person labeled with ASD looks like everyone else, which contributes to a number of issues with community understanding regarding ASD. Members of the community tend to misinterpret unusual behaviors and judge the individual, parents, and/or family members. The fact that there is no particular "look" associated with ASD leads to continued frustration and feelings of marginality. The judgments, criticisms, and misunderstandings are harmful to individuals labeled with ASD as well as their family members. While this complex disorder is affecting more and more families throughout the U.S., there is very little information about the extent of its impact on the emotional, intellectual, and social lives of family members and overall family health.

### **Diagnostic Criteria**

Each of the diagnoses along the spectrum of autistic disorders— Autism, Asperger's Syndrome, and Pervasive Developmental Disorder—Not Otherwise



Specified (PDD-NOS)—are marked by social functioning that is characterized by impairment in the use of multiple nonverbal behaviors, failures to develop appropriate peer relationships, lack of spontaneous sharing with others, and lack of reciprocity in social or emotional exchanges (APA, 2000). Educators and families consider deficits in social behaviors to be a major concern for children with ASD (Bass & Mulick, 2007; Toth, Dawson, Meltzoff, Greenson, & Fein, 2007; Rivers & Stoneman, 2003). Children with ASD have difficulty with awareness of the social world around them; therefore, they do not independently develop the skills required for social interactions. In the next section, I examine the impact of ASD on individuals with the ASD label and their siblings organized by schooling, friendships, and familial relationships.

### **Impact of ASD on Individuals with the ASD Label**

**Schooling.** Early childhood education has been recognized as having an important impact on the future success of children (Bee & Boyd, 2004). This is true for children with and without disabilities, making activities, curriculum and classroom practices a matter of great importance. However, children with ASD are often unable to attend and participate in school without multiple supports. In these situations, learning can become challenging. Nevertheless, children with ASD can significantly benefit from educational interventions and strategies that consistently focus on optimal outcomes aimed at the individual's strengths and weaknesses when proper support services are in place.

Current interventions attend primarily to teaching adaptive and/or behavioral altering skills. A critical curriculum component for children with ASD is the improvement of social interaction skills. Children with ASD should be taught

within inclusive classrooms with their peers whenever possible (Loop, 2009; Pierce-Jordan & Lifter, 2005). This setting ensures that children with ASD are not segregated from their peers and opportunities for incidental learning from more competent social models. Inclusive classrooms provide many opportunities for learning social skills in natural settings. However, Bass and Mulick (2007) caution the need for specific supports to aid in socialization development to prevent the child with ASD from experiencing social isolation. The authors explain the importance of peers providing the child with ASD with more opportunities to practice social skills in a variety of play activities.

*ASD is part of special education law.* The Individuals with Disabilities Education Act of 2004 (IDEA) is the authority regarding eligibility for special education services in school systems. Federal regulations guide states and local school district implementation of special education. This legislation was designed to ensure six principles regarding the education of children with disabilities: (a) children with disabilities receive free and appropriate public education, (b) that education is delivered in the least restrictive environment possible; (c) that determination of disability is made through a multidisciplinary team that uses multiple assessments to determine educational disability; (d) that families are informed in their language *and give their consent* from the beginning when their children are being referred for concerns; (e) that procedural safeguards are in place to protect the rights of children and families to disagree with the findings of the school; and (f) that individualized educational programs are designed when a child has been determined to have a disability. IDEA identifies 13 categories of educational disability under which a child may be classified, if an educational disability is found. According to IDEA

regulations, the definition of autism is as follows:

(c)(1)(i) Autism means a developmental disability significantly affecting verbal and nonverbal communication and social interaction, generally evident before age 3 that adversely affects a child's educational performance. Other characteristics often associated with autism are engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routines, and unusual responses to sensory experiences. The term does not apply if a child's educational performance is adversely affected primarily because the child has an emotional disturbance, as defined in this section.

(ii) A child who manifests the characteristics of "autism" after age 3 could be diagnosed as having "autism" if the criteria in paragraph (c)(1)(i) of this section are satisfied (IDEA, 2004, p.7).

The identification of ASD should be completed by a team of professionals who have training, experience, and credentials in diagnosing and treating children with ASD.

According to IDEA, the child with ASD must be educated in the least restrictive environment and receive a free and appropriate public education.

**Friendships.** Strain and Odom (1986) remind educators that children need to be taught social skills such as greetings, initiating and responding to others, and imitation of play behaviors and conversation skills. This is imperative for children with ASD since they exhibit atypical social interaction styles. Given that children with ASD infrequently interact with peers outside of inclusive environments, interventions need to be designed to maximize opportunities for children to engage in social interaction together (Lee, Odom, & Loftin, 2007). Peers as well as siblings

play a crucial role in the socialization of independence and peer-related social skills that affect the child's long-term adjustment to social situations (Kaminsky & Dewey, 2001; Knott, Lewis, & Williams, 1995; Lee et al., 2007).

*Social competence of children with ASD.* Previous research has found that social deficits exhibited by children with ASD limit their opportunities to interact with others, including family members (Kanner, 1943; El-Ghoroury & Romanczyk, 1999; Bass & Mulick, 2007). A defining characteristic of ASD is the lack of pretend play (APA, 2004), in addition, the development of play skills for a child with ASD often does not follow that of a typical developing child (Boutot, Guenther, & Crozier, 2005). Therefore, professionals propose that peer-related social competence be a fundamental goal for early childhood programs (Brownell, Ramani, & Zerwas, 2006; Jordan, 2003) and families receive the support needed to enhance the interactions between family members and the child with ASD (El-Ghoroury & Romanczyk, 1999; Senner & Fish, 2010). Family members are important because they are the individuals with whom the child interacts with most frequently.

Research studies have revealed findings that suggest that in children with ASD pretend play skills are important predictors to later social abilities. In addition, children with ASD have the ability to participate in pretend play when they do not have to generate their own ideas (Cook, 2008). Curricular programs that include pretend play as a functional skill may be important within the cognitive domain for children with ASD (Barten & Wolery, 2008). Teaching children to play is important because play reinforces emerging developmental skills. Play can be found in a multitude of settings, is flexible, offers a foundation of developing leisure skills, increases social and communicative interaction with peers, and increases learning in

natural and inclusive settings (Barten & Wolberg, 2008; Casby, 2003; Ginsburg, 2007).

**Familial relationships.** When parents display positive attitudes and acceptance of the disorder, siblings appear to have higher adjustment and positive attitudes as well (Howlin, 1988). Siblings growing up in the same household tend to primarily learn social skills from each other by imitating, modeling, and reinforcing the positive and negative behaviors they see at home and then perform these learned behaviors in other social environments. Children with ASD tend to exhibit more social skills when interacting with their sibling (Knott et al., 1995) and siblings tend to be more nurturing and offer more prosocial behaviors (Kaminsky & Dewey, 2001). This relationship has been found to exist unequally though, with one sibling assuming a more authoritarian role, allowing the child with ASD to interact without being responsible for the initial bouts of engagement (Dunn, 1988; Knott et al., 1995).

McHale et al. (1986) and Bagenholm and Gillberg (1991) indicated sibling relationships with children with ASD, with intellectual disabilities, or without disabilities were very similar especially in terms regarding descriptions of their relationships. When siblings discussed participating with their siblings in the same activities, they reported that their positive feelings were much higher in comparison to engaging in dissimilar activities (Rivers & Stoneman, 2008). However, it has been found that relationships are at risk of higher negativity when the child with ASD exhibits greater complexity, unpredictability, and inexplicability of characteristics relating to ASD (Rodrigue, Geffken, & Morgan, 1993). This is an important finding because it points research in the direction of looking for contexts that might increase

positive relationships between siblings with and without disabilities.

### **Impact of ASD on Siblings**

Research on sibling relationships when one child has a disability has focused on patterns of interaction between siblings as well as the attitudes and feelings of a sibling toward their brother or sister with a disability (Cicirelli, 1995). Kaminsky and Dewey (2001) showed that sibling relationships are characterized by less intimacy, prosocial behavior, and nurturance in families of children with ASD than in families with children diagnosed with other developmental disabilities. Cicirelli (1985) concluded that sibling interactions are essential and powerful components of socialization that foster the development of instrumental and affective relationship skills. Nonetheless, research remains inconclusive; both inconclusive findings and conflicting hypotheses complicate what can be gleaned from existing studies about the impacts of having siblings with ASD. Most of the studies concentrate on parents' reports regarding sibling relationships (Glasberg, 2000), with limited first hand descriptions by siblings who are not diagnosed (Cuskelly, 1999; Glasberg, 2000; Knott et al., 2007; Ross & Cuskelly, 2006; Schuntermann, 2007). This suggests that the field needs a robust body of research to help parents and siblings understand and be prepared for the possible implications of having siblings with ASD.

**Schooling.** School offers an implicit timeline for the development of social skills and relationships which offers a preview of siblings' futures as adults (Schuntermann, 2007). Previous sibling reports of school and academic experiences vary, although most children described increased pressure to do well in school to compensate for their brother or sister's lack of ability in school (McHale et al., 1986). Siblings also conveyed self-doubt. For example, "Sometimes I wonder how smart I

am myself” one child reported (McHale et al., 1986, p. 409). Howlin (1988) found that children with siblings with ASD had significantly higher rates of language-related problems, such as speech delays, reading, and spelling than children with siblings diagnosed with Down’s syndrome.

**Friendships.** Children described positive reactions when discussing how friends responded to their sibling with ASD or mental retardation. “My friends like to come over and play with my brother/sister” (McHale et al., 1986, p 409). Rivers and Stoneman (2008) also found peers showed the desire to continue their social initiations toward children with ASD in order to increase social interactions and engagement. However, some children described situations in which they tended prefer staying at home. These children reported being lonely, having no friends and feeling the need to “keep their brother or sister with autism company” (Bagenholm & Gillberg, 1991, p. 304). Benderix and Sivberg (2007) confirmed these findings stating that found many siblings describe their peer relationships as “poor, with few friends and constant feeling of being prevented from bringing friends home” (p.417).

Peer relationships change and transform dramatically from preschool to elementary school and then again during adolescence. As these transformations occur, children begin to rely less on their parents and more upon their peers (Schuntermann, 2007). Some research has been linked to negative or hostile relationships between siblings to problems with social reasoning and behavior problems in school and peer relationships (Dunn, 1988; Schuntermann, 2007). Since many of the same processes occur in developing social relationships with peers as with siblings, it would be expected that negative or positive characteristics would carryover from one to the other.

**Familial relationships.** Goehner (2007) concluded the effects for children with a sibling identified with ASD are feelings of isolation, anger, fear, confusion and most of all guilt for having these feelings at all. Macks and Reeve's (2007) study supports these conclusions. They reported ASD as a severe developmental disorder that poses difficult challenges for all family members. Some of these challenges include, "restricted family activities...inappropriate public behaviors...excessive time, energy and resources spent on child with ASD.... resentment [from sibling] for not inviting friends home" (p.1061). Most studies have shown that rates of major depression and anxiety are increased for all immediate family members living with an individual with ASD (Bagenholm & Gillberg, 1991; Petalas, Hastings, Nash, Dowey, & Reilly, 2009). Benderix and Gillberg (2007) convey similar findings when they discuss seven content categories in which five of these categories had negative implications. Hastings (2003) results also revealed negative adjustment outcomes for siblings of children with ASD, however findings highlight that neither maternal stress nor behavioral issues related to the child with ASD predicted sibling adjustment.

Even though the majority of research studies have focused on negative outcomes related to having a sibling with ASD, Verte, Roeyers and Buysse (2003) emphasized that adolescent girls had significantly higher positive self-concepts and higher social competence. Similarly, studies have also shown that having a sibling with ASD fosters psychosocial and emotional development within a stable family unit (Macks & Reeve, 2007). Longitudinal research has found interactions between siblings reinforce and increase social behaviors, as well as confirm children with many social partners demonstrate rapid cognitive growth and a better understanding



for other's mental processes (Bee & Boyd, 2004).

### **Siblings of Children with ASD**

Sibling relationships span the course of our lives. The sibling relationship begins early in life and is often the longest relationship a person will experience. Research literature regarding sibling relationships continues to vary significantly when discussing results of closeness, commitment, and warmth (Bischoff & Tingstrom, 1991; Buhrmester & Furman, 1990; Mascha & Boucher, 2006). Since it typically begins so early, relationships among siblings generally span longer timeframes than relationships with parents, children, spouses, and friends. Siblings usually share genetic characteristics and histories of shared environmental and contextual influences that can result in similar attitudes, cultural patterns, knowledge, beliefs, and personality traits (Meyer, Ingersoll, & Hambrick, 2011). Sibling relationship can also be characterized in terms of conflict, competition, resentment, intimacy, and support (Lockwood, Kitzmann, & Cohen, 2001; Seltzer, Greenberg, Orsmond, & Lounds, 2005). In families that include members with special needs, sibling relationships can easily exceed 65 years, a timeframe that endures longer than any other relationship span (Conway & Meyer, 2008; Orsmond & Seltzer, 2007b).

Given that the sibling bond is categorized as one of the most important relationships in an individual's life, the nature of the relationship is thought to have a significant impact on psychological functioning of each individual (Dunn, 1992). The emotional functioning of siblings is another area in which research remains mixed. Some argue that siblings who have a brother or sister with a development disability are at greater risk for developing social and behavioral problems (Orsmond

& Seltzer, 2007a), while other researchers have found no meaningful difference between siblings with or without disabilities (Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003).

Since the sibling relationship is likely to have distinct impacts childhood, adolescence, and adulthood, we understand how important siblings are to each other and how much their relationships affect development and growth from infancy through adulthood. Typical developing siblings can be considered ‘experts’ regarding their sibling’s behaviors. Yet, these relationships and their impact on everyone involved are poorly understood, under-researched, and under-theorized.

### **Play as the Foundation for Sibling Relationships**

Childhood play has a well-established role in the development of social, linguistic, and intellectual skills that may also have important implications for how children with ASD and their siblings learn to relate and persist in their relationships over time. Childhood play is an important avenue for socialization. Through play, children develop the fundamentals for social skills such as taking turns, problem solving, collaboration skills, communication skills as well as the ability to take multiple perspectives. Thus, play has a powerful potential for establishing and maintaining sibling relationships and identities.

Although play studies provide general support for a relationship between language and play, the exact nature of the relationship is not clear (Lewis, 2003). Play provides both context and readiness for the development of social, cognitive, and communication skills (Johnson, Christie & Wardle, 2005). In a report by the Committee on Educational Interventions for Children with Autism, the National Research Council (2001) emphasized play as one of five priorities for skill

development in children with ASD. In fact, children with ASD develop important social skills through the exploration of different forms of play, such as pretend play utilizing objects (Lifter, Ellis, Cannon, & Anderson, 2005). These social skills facilitate meaningful participation in family and community activities.

While discussions of play usually include its function in child development, rarely do these discussions involve input from siblings or peers of children with ASD. Even though there has been an increase in research regarding siblings of children with disabilities in the past decade, there is still much that is unknown. The majority of studies that examine sibling relationships within this population typically use data to focus on siblings during a particular developmental period, usually either early childhood or adulthood, however fail to address adolescence. Other studies focusing on childhood sibling relationships primarily use parent reports instead of using child reports regarding their own feelings and perceptions of their relationship. This study seeks to highlight the voices of children who have a sibling with ASD. The notion of a child's voice in research has been noted as being "a powerful rhetorical device, socially constructed" (Komulainen, 2007, p. 11). Accordingly, this approach contends children are not only shaped by community, but also shape their communities in their own unique ways (Prout, 2000). When researchers acknowledge children's agency by valuing their words as important information, they make steps toward an improved understanding of the child's interactions with peers and siblings. This approach reveals a multidimensional social construction that provides children some control over their lives (Komulainen, 2007).

Play is a valuable tool to promote learning developmental skills such as the following: (a) cooperation, (b) self-control, (c) curiosity, (d) independence, (e) self-

awareness, and (f) communication. These skills are imperative as children's need to interact with their communities and surroundings increase. Persistence is a protective factor that has been deemed directly related to the quality of sibling relationship (Rivers & Stoneman, 2008). Children with ASD often do not respond to their siblings' initiations to play, or negatively respond (e.g., screaming or aggression) leading many siblings to stop their bids for interactions. Siblings who do persist and continually attempt to engage with their brother or sister have reported stronger and more positive relationships (Hansford, 2011).

Dunn (1998) concluded siblings respond to a considerable amount of variability growing up in a family with a child diagnosed with a disability. Interactions with siblings are the major source of social interactions for children with ASD in the early developmental years (Orsmond & Seltzer, 2007b). Research has shown that siblings make the ideal playmate and source of support for a child with ASD during the childhood years (Kresak et al., 2009; Orsmond & Seltzer, 2007b). Siblings may experience a decrease in intimacy during adolescence due the sibling's need to establish their own independence from the family (Schuntermann, 2007). In adulthood, siblings of an individual with ASD reported having less contact with their brother or sister; however, the relationship had the same degree of positive affect as in the adolescent years (Orsmond, Kuo, & Seltzer, 2009). Yet, the research regarding adult sibling relationships when one sibling has ASD is still limited and continues to present mixed results.

### **Benefits of Play**

Play is a phenomenon that has intrigued educators, psychologists, researchers, and others who have attempted to define it, understand it, explain it and

connect it activities for decades. Although the debate continues, most researchers accept that play can be defined by merging the attributes of play activities rather than looking for the presence or absence of one definitive trait. Play is a means of helping children learn; an element of being freely chosen by the child, personally directed in a process of trial and error in which the child learns new activities, and intrinsically motivated (Johnson, Christie, & Wardle, 2005). Play exposes a child's problem-solving skills as he/she demonstrates how the child thinks, plans, and organizes (Bass & Mulick, 2007). A child can be exposed to a world of new and novel activities, while he/she controls the rules surrounding their play in a vehicle. Play appears to be a natural phenomenon for most children that begin early in an individual's life. Play serves an important role in the socialization process, which is supported by many theorists (e.g. Parten, Piaget, Sutton-Smith, Vygotsky).

In a report by the Committee on Educational Interventions for Children with Autism, the National Research Council (2001) emphasized play as one of five priorities for skill development in children with ASD. Lifter et al. (2005) stated children with ASD develop important social skills precisely through the exploration of different forms of play, focusing on pretend play, play with objects, sociodramatic play and peer play. These social skills appear to facilitate meaningful participation in family and community activities in preparation of adult life (Corbeil, 1999).

Although teaching children with ASD may be a challenging endeavor due to the unique array of social impairments or deficits they exhibit, it is important that children with ASD are given the opportunity to explore and develop through play. However, throughout the stages of play development, children have many opportunities to grow physically, emotionally, socially, and intellectually.

Play is a cognitive, affective activity that requires children to have and employ play knowledge. Social interaction is also a cognitive activity that requires children to have and employ social knowledge. Play helps build emotional development in children with and without disabilities. Play enables the transmission of culture through social interaction, which is critical to the social and cultural identities of children (Sutton-Smith, 1981). Previous research has shown young children, who learn to play with others, share and take turns display greater degrees of success later in life. Children should be given many opportunities to interact with peers (Parten, 1932). In order for children with ASD to develop more robust social learning strategies, they need opportunities to engage in play. An understanding of theories that attempt to define and explain play can provide researchers with basic guidelines to promote play in children with and without disabilities. Play should be valued for its ability to help children explore and understand the social and cultural world surrounding them.

### **Relationship Development within Play**

Several studies have confirmed the impact of having a child with ASD (i.e., Bagenholm & Gillberg, 1991; Conway & Meyer, 2008; Kaminsky & Dewey, 2001; Smith & Elder, 2010). Play can provide a bridge for siblings to experience meaningful interactions to support the development of communication and social skills. Siblings may be able to sustain their brother or sister's attention and interest in play activities. Siblings tend to have different roles than parents serving as support and social partner for the child with ASD within play activities. This unique relationship establishes a secure environment for the child with ASD in which the child will play alongside his or her siblings to support the advancement of play

(Ferraioli, Hansford, & Harris, 2011; Schuntermann, 2007; Stahmer, Ingersoll, & Carter, 2003). These sibling relationships are dynamic and always evolving as each individual sibling ages. This led me to believe it is important to understand and know how children create their identity and adopt particular roles.

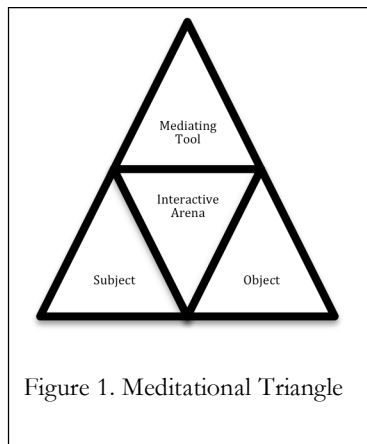
### **Identity Development within Play**

Few studies have focused on the impact of social behaviors in relation to developing personal identities for siblings of children with ASD (Dunn, 1988; Stoneman, 2001). Siblings identify with each other even when one sibling is diagnosed with a disability (Buhrmester & Furman, 1990; Knott et al., 2007; Orsmond et al., 2009). Since the sibling may at times assume a parental role while participating in caretaking of the child with ASD, the sibling may become overly responsible— a role usually associated with being the first born (Schuntermann, 2007). If these expectations become a major part of the child's life, there may be increased sibling conflict, less positive sibling interaction, behavior problems, depression, increased anxiety, and resentment (Bachraz & Grace, 2009; Ross & Cuskelly, 2006; Stoneman, 2001). However, since many factors affect the complexity of the social, environmental, and emotional influences on social development of siblings, it would appear inappropriate to make any assumptions without further research in this area. These kinds of psychological frames that position siblings with parental-like functions as something negative are very rooted in a U.S./Whiteness/middle or upper class point of view of family relations. It is important to remember there are other cultural views of family structure where children who take on parental-like functions are perfectly normal and natural (Rogoff, 2003).

## **Theoretical Grounding: Cultural Historical Activity Theory**

While sociocultural theory began with the work of L.S. Vygotsky and his colleagues, it has been significantly expanded and modified over the last couple of decades. At the most basic level, this theoretical perspective is based upon relationships. Some theorists (e.g. Wertsch, 1993) have focused their approach on mediated action, while others approach activity theory emphasizing analysis of activity and social conditions as a process of change (Sawchuk, Duarte, & Elhammoumi, 2006). The theory of socio-cultural historical context is based upon human experience where Vygotsky (1976) stated, “human learning presupposes a specific social nature and a process by which children grow into the intellectual life of those around them” (p. 88). Cole and Engeström (1993) define activity systems as “historically conditioned systems of relations among individuals and their proximal, culturally organized environments” (p. 8). Expanding this relationship, Leont’ev pointed out that there are greater cultural and historical contexts, which also influence these actions. To further explain these greater cultural and historical contexts, Engeström (1999) expanded Vygotsky’s relational triangle to include rules, community, and division of labor. These systems evolve over time, and have a complex mediational structure (Engeström, 2001) represented in diagrams representing the different elements that shape human activity, and the relationships between these elements. Engeström (1999, 2001) describes the evolution of activity theory in three generations. The first generation centered on Vygotsky’s notion of mediation, creating the mediational triangle as the triad of subject, object, and mediating artifact (Engeström, 2001). (Figure 1). However, Engeström discussed the shortcoming of this model was its focus solely on the individual.





In the second-generation activity system model, Leont'ev expanded on the original model focusing on 'action' being purposeful as the essential principles of this framework (Worthen & Berry, 2006). This leads to a focus on sociocultural activities that situate individuals to interact with the surrounding communities, and its socially developed rules. Leont'ev's work highlighted the influence of community on activity, including the role of division of labor into this model (Engeström, 2001). In this collective activity system, the use of tools and artifacts is not only viewed within the individual subject but also his or her community. This allows for the development of collaborative work and socially distributed activity (Engeström, 2001; Worthen & Berry, 2006). Activity theory attempts to describe two levels of change for individuals: internalization and externalization (Engeström, 1999). Internalization maybe considered responsible for the reproduction of culture. As an individual relates to another through the various components of the triangle, they are adapting to each other through a socio-cultural way of being. Externalization occurs as components of the activity system attempt to influence and change the outcomes of the primary activity. For example, when new tools are utilized, new rules may be implemented. These new tools or rules become interconnected to all the other elements of the triangle; therefore create a change throughout the system. Furthermore, the relationship between the process of internalization and

externalization within individuals attempts to simultaneously maintain and transform their current socio-cultural historical system.

Figure 2 represents the second-generation model, where at the top of the triangle, the *subject* acts on the *object*, and the activity is mediated by *artifacts* (including symbols and tools). These are the “visible” elements of the activity. The elements at the bottom of the triangle depict the social, cultural and historical factors that influence the system: the *community* that subjects are part of, the *rules* of such community, and the *division of labor*, the distribution of roles and responsibilities within the activity system (Cole & Engeström, 1993).

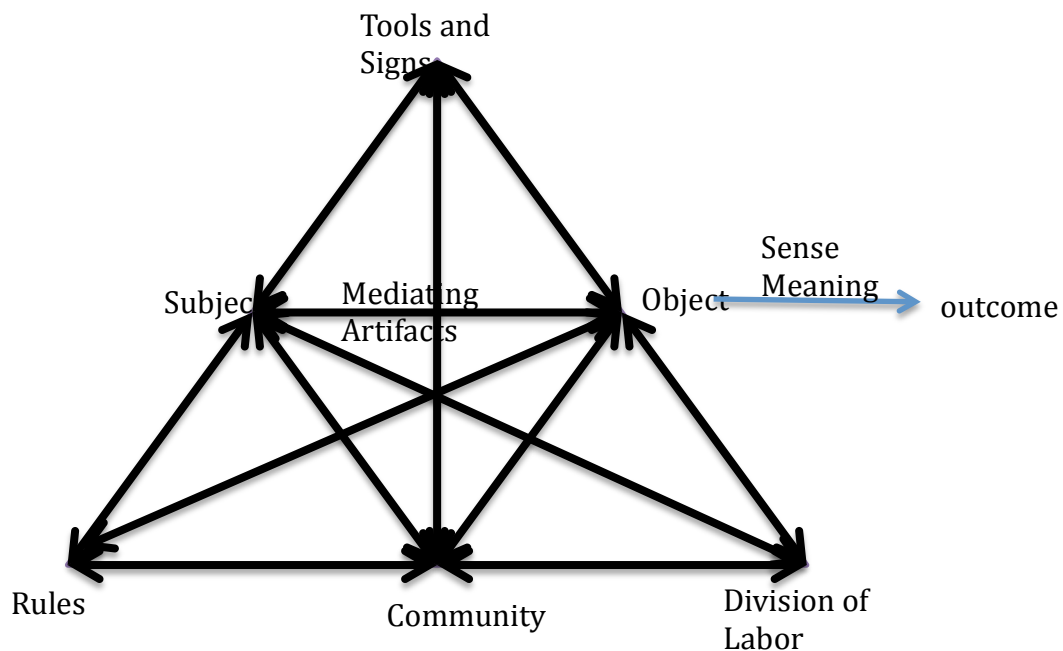
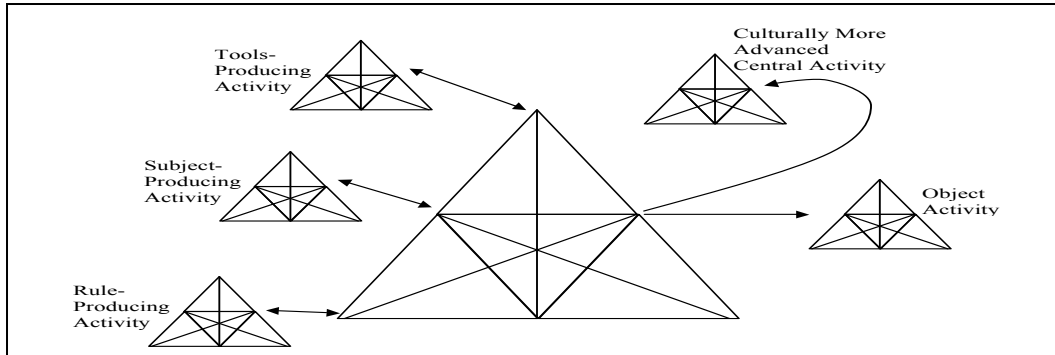


Figure 2. Engeström's (1987, p.78) model of activity theory-second generation. It incorporates the elements of rules, community, and division of labor.

The subject is “a member (or better yet, multiple different members of local activity, through whose eyes and interpretations the activity is constructed” (Engeström & Miettinen, 1999, p.10). In this study, the subject-object relationship is

that experienced between the siblings with the activity directed towards the outcome of play and social interactions. The stories, activities, items used to play, types of play, difference between peer and sibling play and so forth, comprise the tools and artifacts through which the siblings mediate their social outcomes. Furthermore, rules can be seen as defined by society, the activities and most importantly by the participants. The extension of the triangle delineating the division of labor is both horizontally between the members of the community and a vertical division of power and status (Engeström, 2001). Collaboration with other individuals creates zones of proximal development (ZPD) for each person involved, enabling them to go beyond their current capacity by grasping and constructing new mediating tools and signs (Vygotsky, 1978). Furthermore, each component of the activity triangle is a part of their own activity system where they also produce activity (Figure 3).



*Figure 3.* The interrelationships between basic schemata of activity triangles (University of Helsinki – Center for Activity Theory and Developmental Work Research, 2004).

The three central elements in the system interact (subject, object and community) mediated by artifacts and the community’s rules and division of labor. However, Michael Cole (Engeström, 2001) voiced concern with “deep seated insensitivity of the second generation activity theory toward cultural diversity”

(p.135). This follows the assumption that individuals are always learning something that is not static, and at most times, not defined or understood ahead of time.

Applying this framework to the system of relationships allows me to understand the process of learning and changing through forms of activities as these are being created. The process offers a unique understanding of how individuals transform their personal lives and practices while using their *community, rules* and *division of labor* to create meaningful activities. Consequently, an activity system is never static. It is always affected by changes in other activity systems with which it has a relationship just as it affects changes in those activity systems. The application of activity theory to a particular activity system, families with children with ASD, is a unique contribution of this dissertation study.

### **Communities of Practice: Participation and Identity**

Lave and Wenger (1991) presented one of the most influential approaches for learning-by-doing within a community. In their work, *Situated Learning: Legitimate Peripheral Participation*, they proposed an approach that defines learning as an integral part of the social practice. Their unit of analysis, *communities of practice*, refers to “a set of relations among persons, activity, and world, over time and in relation with other tangential and overlapping communities of practice” (p.98). Communities of practice constantly renew themselves across time, as new members become apprenticed through a process of *legitimate peripheral participation*. Within this process new members are identified, members and the nature of the community are transformed. Utilizing the lens of *legitimate peripheral participation* to view learning progressions, observing members of the community shift from a peripheral position (novice) to a full participant (expert). Communities may vary in their expectations of

participant roles, however all community members move from novice to expert over time. This involves the use of artifacts and engagement in activities in recognizable ways. For example, the role of playmate belongs to siblings and other extended family members in some communities, however the activities may crossover to the parent while meeting physical needs of the child (Rogoff, 2003). A view of “learning-as-doing” extends the focus of apprenticeship to the organization and structure of the community and its resources that allow learning. Even though expert members do not always engage in explicit instruction of the practices with novice members, they do play an important role in making available resources for novice member gain legitimate access to social practices (Lave & Wenger, 1991).

The relationship between learning and the social situations in which it occurs is explored by Lave and Wenger (1991) as situated learning in certain forms of social co-participation. Instead of focusing on the acquisition of certain conceptual structures and the process of cognitive processes, these authors ask, “what kinds of social engagements provide the proper context for learning to take place” (Lave & Wenger, 1991, p.14). This challenges researchers and educators to rethink what it means to learn and what it means to understand. Learning does not take place only in an individual’s mind but is a process that takes place in a framework of participation between members. It is therefore important to emphasize the motivation and identity of members in the community.

Communities of practice are defined as groups of people who share a passion for something they do and learn how to do it better as they interact regularly. There are three essential components that distinguish communities of practice from other groups: 1) a shared area of interest, 2) a shared practice, and 3) an engagement in

discussions and activities that lets members share knowledge and learn from each other. Figure 4 is a model of play that illustrates the process in which the sibling, known as the expert, teaches the novice child or child with ASD varying play skills and patterns resulting in increased positive sibling interaction.

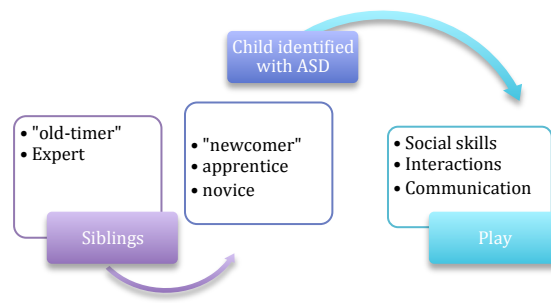


Figure 4: Expert/Novice Dilemma

Siblings usually act as the expert when guiding their brother or sister who has been identified with ASD in play and social situations. Studies of apprenticeship emphasize the blended character of learning and work practices as the apprentice was learning by doing the activity. Furthermore, Lave and Wegner (1991) remind us “learning is not merely situated in practice – as if it were some independently reifiable process that just happened to be located somewhere...” (p. 35).

Learning is an active process. It involves the whole person not just within performing new activities, task, and functions. The social and physical environment effects learning, for this reason learning should take place in real-life situations. Sibling interactions are essential and powerful components of socialization that provide authentic situations to develop relationship skills. Social interactions and collaboration through an activity allow learning to be aligned with the needs of the individual. This means learning is being fostered through meaningful tasks for both siblings. For example, as the child interacts with their brother or sister through a

play activity, social engagement is being learned and reinforced by the sibling with ASD. This motivates both children by providing a rich context for learning that positively affects the nature of interactions between brothers and sisters. It is important to remember that relationships are a key component to learning. Siblings work together to solve problems and share information.

As the child continues in the role of expert guiding their brother or sister through apprenticeship to community participator, the expert gives the siblings with ASD a reason to 'need' the information regarding how to interact or at least understand...learn and acquire knowledge in ways that are important to them. Etienne Wenger said, "Learning changes who we are by giving us the ability to participate, to belong, and to negotiate" (1998).

Theoretical frameworks are an integral component of any research study and provide a foundation for researchers' conceptual frameworks that guide them to examine an experience or phenomenon. The theoretical framework that guides this study is grounded in cultural historical activity theory (CHAT). CHAT provides a useful tool for examining the complex relationships that are actively engaged in educational systems and models the system through a triangle organizer. Activity theory as clarified by Engeström (1999) builds upon the earlier socio-cultural historical theories of Vygotsky and Leont'ev. CHAT theorists differentiate between internal and external activities. For example, traditionally cognitive processes are thought to be managed internally. However, utilizing the CHAT triangle we understand that these internal processes cannot occur in isolation from the external factors that contribute to learning. This framework allows for the examination of the interaction and intersections of multiple factors (Worthen & Berry,

2006). CHAT provides an ecological approach to analyzing the triangle of relationships between an individual learner, the social community in which the learner operates, and the tools and artifacts that mediate learning in the physical world (Lave & Wegner, 1991). Learning is a social and cultural process that is practiced and achieved in different ways by different individuals. CHAT emphasizes a socially mediated engagement and collective activities between the individual and their environment explaining how tools (artifacts) shape the way we interact with a particular structure. Language may be considered one of the ultimate 'tools of all tools'. This activity is the practice, which significantly involves the context of meaningful, goal-oriented, and socially determined interaction between an individual and their surrounding environment.

Children are continually learning constantly shifting concepts that are incompletely defined, and are likely to be at best unfamiliar, and often perceived as dynamic. This recognition of the continually emerging nature of learning itself has implications for the ongoing translation among siblings. Children, identified with ASD or their siblings learn new forms of activities as they are created. Since social interaction is a key in which an individual's life develops, Vygotsky reasons we must examine and study the world around the child in order to understand participation in activities that require cognitive and communicative functions (Cole, 1985).

Engeström's activity theory is also based upon relationships (Engeström, 1999).

This theory is based upon the socio-cultural historical context of human experience where Vygotsky (1976) stated, "human learning presupposes a specific social nature and a process by which children grow into the intellectual life of those around them" (p.88). In view of the fact that culture is continually negotiated stance, individual



development reflects the historical and cultural expectations of the community. The development of the child is interdependent with cultural tools through activities with skilled “peers”. Goal-directed actions are not fixed and can dynamically change with the individual. The descriptive framework of activity theory considers the entire activity system beyond just one user. It accounts for environment, history, culture, role of the artifact, and motivations (Engeström, 1999).

In this study, I draw on these theoretical notions as I seek to understand the sociocultural factors that effect and influence how siblings interact during play activities. I posit that the relationships between children and their sibling identified with ASD serve as mediating spaces for negotiating identity, self-awareness, resilience, and social capacities during every day play and social interactions. In order to reposition children within the discourse of sibling relationships, to be considered an active participant in this research, and to give due weight to the perspectives of children, this dissertation was grounded in the theoretical underpinnings of activity theory, communities of practice, and play to hypothesize the role that play plays in the lives of siblings with and without ASD.

### **Conceptual Framework**

Despite the fact siblings play a significant role in facilitating social interactions, and are typically the closest peers of children with ASD, research seldom (or rarely) examines their perspectives. Even though a considerable amount of research has been conducted regarding how a sibling is affected when one sibling has a developmental disorder other than ASD, very little research has focused on the individual when one is identified with ASD (Orsmond & Seltzer, 2007). Most of the

attention of scholarly studies and mass media is focused on the individuals identified with ASD and their parents, overlooking the effects of ASD on siblings.

To explore the sibling relationship through play interactions in my research, I view these relationships through sociocultural and cultural historical perspectives. Specifically, I draw from concepts of situated learning and communities of practice (Lave & Wenger, 1991), principles of communities of guided participation (Bass & Mulick, 2007; Rogoff, 2003; Wolfberg, 2009), and cultural historical activity theory (Cole & Engeström, 1993; Engeström, 2001; Weisner, 1993). Siblings act as play guides to their brother or sister with ASD to foster prosocial social skills within the natural context of a typical play setting. Ideally the child with ASD will apply these new social skills in all environments when prompted by peers. Children's engagement in play allows them to become familiar with their community and surroundings. Child's play often imitates adult and other community roles they observe. Rogoff (2003) stated a child's access to the involvement in their community greatly influences other areas of guided participation. Even though many middle-class U.S. parents believe their involvement in their preschoolers' development of pretend play, other communities believe this is a role of the other children within the family or community (Rogoff, 2003). These approaches allow me to identify the various intricacies that influence the sibling relationships and play between siblings, the mediating tools that facilitate social interactions, and the various roles and division of labor in the spaces where sibling relationships occur.

I believe that understanding how children define play activities and social interactions with their siblings will further inform social interventions in the future. Research and interventions regarding children with ASD have historically centered

around behavioral changes in the individual although they do not include and do not consider the ecocultural perspectives on sibling relationships.

My conceptual framework evolved as I delved further into previous research studies, the ASD literature, as well as ongoing personal conversations with other parents of children with ASD. The CHAT model grounds my conceptual framework. CHAT emphasizes the social nature of learning and how behavior and culture itself emerge through interactions between individuals and their surrounding/environments. This focus on the dynamic exchange between people and contexts explains why tool mediation plays a central role within the approach (Rogoff, Baker-Sennett, Lacasa & Goldsmith, 1995; Wertsch, 1991). Engeström (n.d.) defines an activity system's subject as "the individual or subgroup whose agency is chosen as the point of view in the analysis." As my knowledge base of CHAT increased, it led me to believe this may be a new lens to investigate the topic of social interactions and play among siblings when one is identified with ASD. This framework has organized my explorations of systems of play between siblings when one child is labeled with ASD. Using CHAT, I have been able to conceptualize how play influences the development of identity through cultural histories and the mediation of the tools and rules available to each family member. My conceptual framework has been grounded in my own personal and professional observations as a special education teacher, researcher and parent, and is guided by the interplay and relationships among three focal points: (a) play, (b) siblings, and (c) child development within the activity system called play.

**Play.** Children build an awareness of the world through play, using simple and complex reciprocal interactions. The development of play serves many

functions in child development and the development of sibling relationships while being informed by the child's cultural histories. Vygotsky highlighted how play is an inherently social and collective process for children (Vygotsky, 1976; Bergen, 2002). Much like Piaget, Vygotsky believed children learn many skills through play. A child's initial experience of the world begins through exploratory play to gather new information about an item [tools] or environment [community]. Play activities are considered the foundation of social engagement as children interact through an emerging set of rules guided by the family structure and history. These experiences, rules, and tools facilitate the ability to participate in shared activities.

Tools are created and transformed during activity and are imbued with particular cultural assumptions which are the historical remnants of the activity that produced them (Cole, 1998). Tools shape the way individuals interact with reality. Rules within play are constantly being disturbed due to interaction with tools as well as others. Tools such as emerging language and evolving physical and cognitive development are not static since they are also the object of outcome loops that migrate back into play as a new or modified rule or mediating tool that enhance the nature of play and contribute to its utility as a developmental playground.

Vygotsky argued that a child's development is established by the social interaction with others integrating tools, rules, and the division of labor within each play activity.

Vygotsky described the activity of play as the center of a child's development with all the developmental tendencies compressed into this behavior (Vygotsky, 1978) allowing for change or adaptations when facing the same or similar situation. Since social interaction is a key in which an individual's life develops, Vygotsky reasoned that we must examine and study the world around the child in order to

understand how participation in social interactions and play activities require cognitive and communicative functions in formal and informal environments contribute to development (Cole, 1985). Although some activities children with ASD participate in, such as nontraditional manipulation of objects, repetitive rocking and flapping of hands or objects, or non-joyful expressions, may not be considered 'play' by others, these activities should be considered part of social interactions and play activities. Play behaviors are the fundamental basis for social skills development, language development, and communication abilities (Lee, Odom, & Lifton, 2007). As the child's knowledge and understanding of a play activity expands, the child transforms approach to social situations and decision-making.

**Siblings.** The review of literature on siblings of children with autism or other developmental disabilities suggests that sibling relationships can be significantly affected when one sibling is identified with ASD. This may also lead to adjustment problems within some populations of children. Much social research has focused on peer interactions, and only a handful of social research has concentrated on family interactions, especially sibling interactions. Even though in many families siblings may become life-long friends, it is important to recognize that families also have very different patterns that shape and develop relationships among and between generations. Further, previous sibling interaction research focused on children with ASD has emphasized teaching siblings who are not identified with ASD how to use new behaviors to increase interactions with their brother or sister with ASD (Trent, Kaiser, & Woley, 2005; Tsao & Odom, 2006). Siblings may adopt a number of roles in order to assist in the caring of the child identified with ASD meaning the sibling participates in activities that are regulated by the existing conditions, which are

unique to each family. Their interactions are important mediators that can influence how siblings establish friendships, handle negative situations, resolve conflicts, and interact socially with others. Siblings have been found to be as influential as parents, teachers, and other adults (Orsmond et al., 2009). Siblings as the subject within an activity system participate in transforming the system's object-outcome as a result of their motives or desires (Engeström, 1999; Sawchuck et al., 2003). Depending upon the structure and cultural identity of the particular family, siblings may spend the majority of their time together. Even though there may be many individuals involved within this play activity, each individual may have their own specific motive and/or desired outcome. The formation of family rules and division of labor within the family structure creates the development of social relationships and individual identities. These components are informed by experiences within the family, experiences within the community, reactions to the identification of ASD within the family and current social knowledge. Another important aspect of sibling relationships is the potential outcome for enhancement of emotional bonds and social growth.

**Childhood development.** The trajectory of growth and development mediated by culture and cultural histories form another kind of activity system bounded by time. Individuals learn through observing others' behavior, attitudes, and outcomes of those behaviors. Jean Piaget declared learning occurs as a child adapts to the environment through the processes of assimilation and accommodation. Jean Piaget (1962) asserted that play had a central role in a child's early identity development as the child increases their knowledge of social rules and norms within relationships. According to Piaget's theory, children's intellectual

growth is partly affected by physical development and partly due to interactions' with the child's environment. CHAT provides a descriptive tool to explain how learning occurs within the social position of growth and development utilizing the examination of a child's actions, roles, standpoint and reactions as they fulfilled their wants and desires while immersed in the division of labor among community rules. He believed a child must be equipped with the tools and mediating instruments to think, communicate, and understand what is happening around them if they are going to be able to interact with individuals within their surrounding environments. The actions of children's experiences with play activities, social interactions with their sibling(s), peers and others [outside their family], and the nature of their family networks in regards to support needed for all children in the family shape, inform and guide social development. Piaget's understanding of a child's development preceded Vygotsky's belief that social interaction plays a fundamental role in the process of cognitive development (Piaget, 1976; Vygotsky, 1976). The cultural nature of learning is emphasized in sociocultural learning theory. Because play is a form of learning for children (Piaget, 1962), the use of sociocultural learning theory may provide a lens through which to view the access and participation of children identified with ASD in play with their siblings. CHAT's approach assists in understanding the richness of actions and operations within a family structure all-encompassing individual learning and actions.

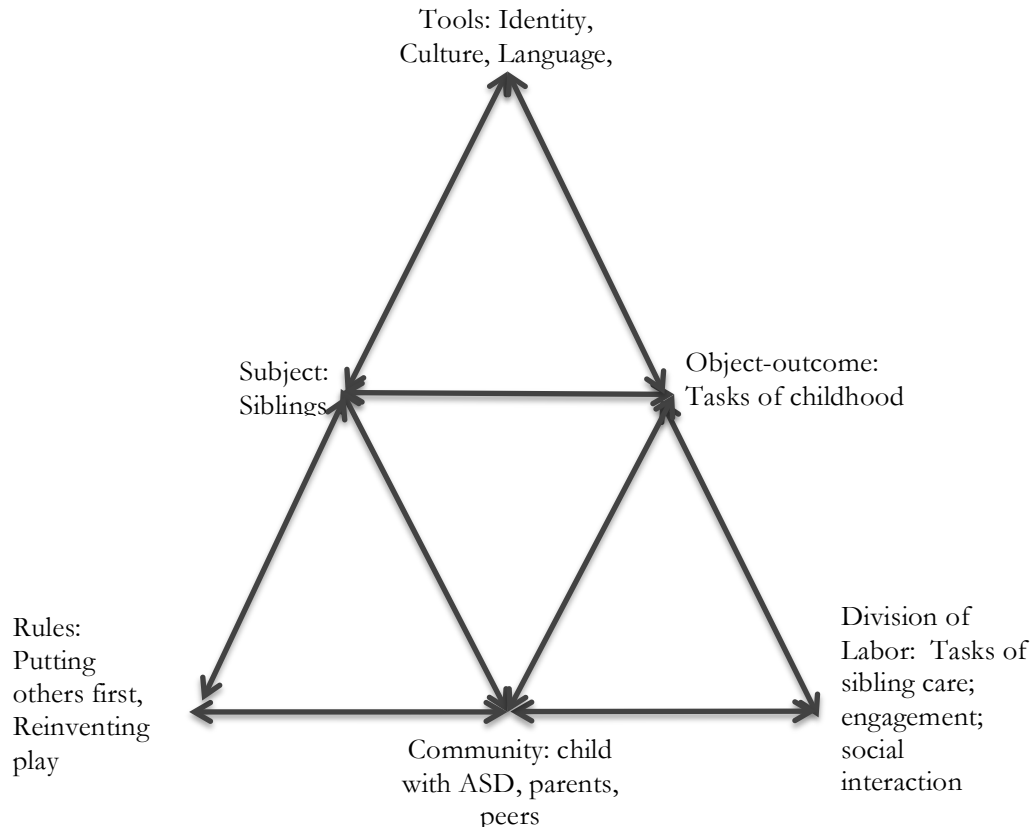


Figure 5: Conceptual Framework

I build upon the understanding that CHAT provides an ecological approach to analyzing the sibling relationships utilizing the Engeström triangle providing a mode to examine relationships between siblings, social community, tools and artifacts that mediate learning in the family structure. The components of the CHAT model suggest we cannot fully understand the effects of ASD on sibling relationships without considering the social, physical, and emotional environments surrounding the family structure. This notion is particularly important to consider due to the reality that the siblings of children identified with ASD often operate within a world in which they put others first, follow rules of others and utilize the tools the child identified with ASD is willing to use. In particular, I am interested in exploring the



way siblings socially interact and engage in activities of play when at least one child in the family is identified with ASD and the interrelationships between the sibling, the child with ASD, and the artifacts within a social environment.

One of the biggest strengths of the CHAT frame is its ability to understand a learning activity in any context. The process of learning and understanding roles and identity formation within a family structure can be analyzed by examining interactions using tools, rules and division of labor between family members in contextual situations. Because this study was designed in an effort to investigate play within sibling relationships for children who have a sibling identified with ASD, the siblings not identified with ASD were the subjects of the activity system in question. Based on my theoretical views, I imagined listening to the voices of the children as they spoke of the experiences they have had in the realm of play with the child identified with ASD would assist in my understanding of how these siblings' relationships are affected by ASD. Through the approach of video-cued interviews and observations, I anticipated drawing out multiple perspectives and interpret them to address my research questions.

Moreover, the activity system of play is ever evolving and not static, following social development and expanding knowledge in an iterative process of change. Using multiple stories from siblings through the use of video-cued interviews contribute to an understanding of play activities young children enjoy engaging in with their sibling identified with ASD. By the use of the CHAT lens, I was able to investigate elements of social interaction and play activities siblings use to develop social engagement with the child identified with ASD. Each of elements (tool, rules, division of labor) overlaps and interacts with one another in particular

ways that help to describe and inform the development of sibling relationships and social development for siblings with and without autism.

### **Purpose of the Study**

The purpose of this qualitative study is to explore the sociocultural factors that effect and influence how children interact with their siblings who have been identified with ASD, as defined by the sibling through stories of their play together. Positioning the sibling as the expert who has the ability to share insights regarding the child with ASD in order to conceptualize socialization of siblings when one is identified with autism spectrum disorder is a step toward understanding “what’s next?” in the concept of sibling relationships.

### **Rationale**

Siblings have a history of being overlooked in both scholarly studies and the mass media. Much attention has been paid to the needs and struggles of individuals with ASD themselves, as well as on those of their parents. Research and interventions regarding children with ASD mostly center on behavioral changes. Expanding research to include more than the traditional behavior modification interventions offers comprehensive views of the community surrounding the individual with ASD.

The review of literature on siblings of children with ASD or other developmental disabilities suggests that sibling relationships can be significantly affected when one sibling is identified with ASD. This may also lead to adjustment problems within some populations of children. Much social research has focused on peer interactions, and only a handful of social research has concentrated on family interactions, especially sibling interactions. Further, previous sibling interaction

research focused on children with ASD has emphasized teaching siblings how to use new behaviors to increase interactions with their brother or sister with ASD (Trent, Kaiser, & Woley, 2005; Tsao & Odom, 2006). Since siblings spend the majority of their time together, they can be considered ‘experts’ regarding each other’s behaviors especially when one sibling is identified with ASD. Understanding the perceptions of siblings regarding the behaviors of their brother or sister with ASD can be an important step for expanding social skills, including play activities for these children.

Children build an awareness of the world through play, using simple and complex reciprocal interactions. The development of play behavior serves many functions. A child’s initial experience of the world begins through exploratory play to gather new information about an item or environment. Play behaviors are considered the foundation of social engagement. These experiences facilitate the ability to participate in shared activities. Although some activities children with ASD participate in, such as nontraditional manipulation of objects, repetitive rocking and flapping of hands or objects, or non-joyful expressions, may not be considered ‘play’, these activities should be considered part of social and play activities for children with ASD. Play behaviors are the fundamental basis for social skills development, language development, and communication abilities (Lee et al., 2007).

Further research regarding children who have a sibling with ASD guiding researchers to understand how ASD affects the children’s perceptions of social interactions and play activities with children with ASD will further inform social interventions in the future.

### **Research Questions**

The overarching and guiding questions addressed in this study are:

1. How do siblings of children with ASD describe activities and interactions that they define as play with their siblings?
2. How do siblings of children identified with ASD define engaged play with their siblings?
3. How do siblings of children differentiate between play with their peers and with their siblings?
4. What kinds of learning happen (particularly around the social domain) when these siblings are socially interacting or playing?

### **Operational Definitions**

Autism, siblings, and play are all terms that are universally utilized and shared among disciplines. However, these terms may have different meanings depending on the user. This section serves as a reference for readers to clarify the terms used throughout this study. In order to proceed, it is necessary to provide definitions for four key terms used in the overall question guiding this research: Autism Spectrum Disorder, siblings, and play.

- Autism Spectrum Disorder: Autism is a pervasive developmental disorder. Its symptoms include differences and disabilities in many areas including social communication skills, fine and gross motor skills, and sometimes-intellectual skills. Classifications under the Autism Spectrum umbrella include: autism, Asperger's syndrome, PDD-NOS, Rett syndrome and childhood disintegrative disorder

- Pervasive Developmental Disorder—Not Otherwise Specified (PDD-NOS): *is one of the autism spectrum disorders and is used to describe individuals who do not fully meet the criteria for autistic disorder or Asperger syndrome.*
- Siblings: A sibling is defined as one of two or more individuals having one or both parents in common; a brother or sister. For purposes of this study, ‘sibling’ will be used to indicate the participant or the child who has not been identified with ASD.
- Play: increased focus on an activity, participation, motivation and freedom of choice by the individual engaging in the play activity, cheerfulness which is accompanied by smiles and laughter, flexible and spontaneous allowing children to use their natural environment to promote learning and socialization; involving an individual’s ability to interact with their natural surroundings and others to enhance knowledge including eye-to-eye gaze, facial expression, gestures, joint attention, and interest in activities others are participating in. However, due to the intricate, multidimensional phenomenon of play this definition may be evolving dependent upon the siblings’ responses.

### **Importance/Significance of the Study**

Sibling relationships are central to family life and the factors that affect the quality include: coping skills, dominance, affection, companionship, intimacy, admiration and competitiveness and social support (Smith & Elder, 2010). Due to the rising prevalence and complex qualities of ASD, as well as the significant impact on families, it is imperative to increase research studies evaluating sibling

relationships. Siblings support each other in the acquisition of a variety of skills. Play skills improve many areas of typical development in areas of enhancing language skills, promoting motor development, facilitating cognitive growth, but children with ASD do not possess these play skills naturally requiring more support from their sibling.

While discussions of play are fundamental in the construct of child development, rarely do these discussion involve input from siblings or peers of children with ASD. Even though there has been an increase in research regarding siblings of children with disabilities in the past decade, there is still a lot we do not know. This study seeks to foreground and privileges the voices of siblings who are part of a family with a child identified with ASD focusing on their understanding of how play mediates learning and social relationships between themselves and the child with ASD. My dissertation study will contribute to this growing body of literature by exploring comprehensive views of community surrounding the individual with ASD. Expanding this research to include more than the traditional behavior modification interventions offers understanding how children 'look' at play activities with children with ASD will further inform social interventions in the future.

This work can serve as a reference point for future discussions and studies regarding the socialization between children both identified with and without autism spectrum disorder. This study will provide a better understanding of the perceptions of young children regarding their siblings with ASD as an important step for expanding thoughts on socialization within children with ASD and other children with social delays.

## Chapter 2

### LITERATURE REVIEW

*“Play is the beginning of knowledge.” Unknown*

Chapter one provided an overview of sibling interactions regarding play activities involving one sibling who has been identified with autism spectrum disorder (ASD). Siblings are generally the most important “peer” in a child’s life. A significant amount of the current literature regarding siblings focuses on effects of birth order, family size, and gender, although relatively little research has been completed on the effects of ASD on sibling relationships through the voice of the sibling. According to researchers Conger, Stocker and McGuire (2009), Mascha and Boucher (2006) and Orsmond and Seltzer (2007b), siblings share a unique relationship with each other that usually lasts a lifetime. Many factors have been highlighted in the research. For example, sibling relationships provide experiences that may promote the development of emotional wellbeing, self-regulation, a sense of belonging, and comfort for adolescent and adult siblings (Orsmond & Seltzer, 2009). Unfortunately, many children with ASD are considered unable to participate in play activities as children would expect or these children do not interact a great deal with their sibling who is not labeled (Kennedy & Kramer, 2008; Kresak et al., 2009). Peer and sibling interactions are an important factor in a young child’s social development. Exposure to differences of opinion, negotiation, competition, cooperation, and communication with other children aids in acquisition of interpersonal relationship skills (Coplan, Rubin, & Findlay, 2006). Researchers and theorists have hypothesized children utilize play to shape their interpretation of the world around them as well as their own identity (e.g., Bergen, 2002; Mead, 1934;

Parten, 1932; Piaget, 1954; Vygotsky, 1976). Kaminsky and Dewey (2001) stated that an important source of social development and self-worth could emerge from positive sibling relationships.

This chapter synthesizes the literature relating to ASD, sibling relationships, and play. While the research questions guiding this dissertation focus specifically on the voices of siblings without ASD, I have chosen to examine ASD, sibling relationships and play to have a better understanding of the dimensions that influence relationships among siblings with and without ASD. The following questions will be answered: 1) in what ways does ASD impact siblings in their relationships and social interactions? and, 2) how does play shape and influence the development growth within siblings' relationships? The literature review is organized in three sections including the literature relating to: (1) sibling and ASD, (2) importance of play, and (3) socio-cultural views of play.

### **Approach to Selecting Sources**

Articles and books related to sibling play, relationships and interactions, siblings of individuals with ASD, and the importance of play to child and skill development were identified by conducting electronic and ancestral searches. Criteria for inclusion in this literature review included the selection of articles that: (a) were published between 1997 (when the emphasis on family involvement was added to the IDEA) and 2011, (b) were published in peer-reviewed English-language journals or books, (c) described data with qualitative, quantitative, and/or mixed methods designs; not including essays, editorials, or other manuscripts discussing individuals with ASD, play and/or siblings primarily in a conceptual manner, (d) included children who had a sibling identified with autism spectrum disorder, (e)



focused on siblings' relationship and examined play activities, and (f) disaggregated data results for children with ASD if more than one disability is included in the study. The year 1997 was significant because although in 1990 in P.L. 101-476, autism was considered a separate category, however it was not until IDEA Amendments of 1997 (P.L. 105-17), that the overall goal was to have an "equal and respectful partnership between schools and parents" (IDEA, 2011). Studies that included individuals labeled with high-functioning autism (HFA), Asperger's, or Asperger's syndrome (e.g., Howard et al., 2006; Petalas et al., 2009; Rutherford & Rogers, 2003) or adult siblings (e.g., Heller & Arnold, 2010; Orsmond & Seltzer, 2009; Orsmond et al., 2004) were not included in the review due to the targeted population of this study. Children with HFA or Asperger's syndrome normally demonstrate the ability to use meaningful language, maintain a conversation, pick up on social cues and engage in play activities requiring less consistent support for these children (Attwood, 2007).

I included Google Scholar, Education Full Text, OVID, and PsychoInfo in my search of digital databases. In order to reliably scrutinize all research databases, the same search terms and Boolean operators were utilized for all searches. I combined the following descriptive terms and key words in the searches to maximize the number of potential studies: "*play*," and "*siblings*," and "*autism [Autism Spectrum Disorder, ASD]*," and "*relationships*." I connected these terms until all possible combinations were exhausted. This search of the literature produced 19,700 articles. After deleting duplicates and selecting only the studies regarding sibling relationships when one child is identified with ASD and play, I narrowed down the selection to 805 articles. Additional articles were identified in the reference sections of articles

retrieved from the databases and of review articles and book chapters on this topic (i.e., ancestral methods).

The majority of articles (61%, n=490) were published in journals dedicated to ASD such as *Autism: International Journal of Research & Practice* (n=278), *Focus on Autism and Other Developmental Disabilities* (n=56), *Journal of Autism and Developmental Disorders* (n=147), *Education and Training in Autism and Developmental Disabilities* (n=5), and *Research in Autism Spectrum Disorders* (n=4). Special Education journals produced 16% of articles (n=125) in journals such as *Journal of Special Education* (n=6), *Journal of Developmental Disabilities* (n=7), *American Journal on Intellectual and Developmental Disabilities* (n=1), *International Journal of Disability Development and Education* (n=2), *Mental Retardation* (n=3), *Mental Retardation and Developmental Disabilities Research* (n=3), *Remedial and Special Education* (n=2), *Teaching Exceptional Children* (n=2), *Exceptional Children* (n=88), *Young Exceptional Children* (n=10), *British Journal of Developmental Disabilities* (n=2), and *Topics in Early Childhood Special Education* (n=6). Journals focusing on child development and psychology such as *Early Child Development and Care* (n=6), *Child Psychology & Psychiatry* (n=8), *Journal of abnormal child psychology* (n=1), *American Academy of Pediatrics* (n=1), *American Journal of Orthopsychiatry* (n=1), *Child and Adolescent Psychiatric Nursing* (n=3), *Child Development* (n=5), *Child: Care, Health and Development* (n=3), *Journal of Cognitive and Behavioral Practice* (n=1), *Journal of Infant, Child and Adolescent Psychotherapy* (n=2), *New Directions for Child and Adolescent Development* (1 article), *Counseling Psychology Quarterly* (2 article), *Pediatric Nursing* (n=1), *Pediatric Psychology* (n=1) published 4% (n=36), and 2 articles were published *Psychology in the Schools*. Journals with the focus of family studies and therapy such as *Child and Family Studies* (n=1), *Journal of Family Studies* (n=2), and *Family Therapy* (n=1)

were another 0.05% of articles. Other educational journals had 3% of articles, these journals were *Early Childhood Education* ( $n=5$ ) and, *Education and Treatment of Children* ( $n=21$ ). Finally, 0.07% of articles were published in journals with focused in a specific subject area as *American Journal of Sociology* ( $n=1$ ), *Mind, Culture and Activity* ( $n=1$ ), *Journal of Applied Behavior Analysis* ( $n=1$ ), and *Journal of Behavioral Therapy* ( $n=3$ ).

### **Siblings and Autism Spectrum Disorder**

An embarrassment, a bother, pest; these are all words I would have used to describe my brother Greg when I was nine and he was five. Of course, Greg was born ‘normal’ in the conventional sense that he had 46 chromosomes, no overt signs of disease, that is, until the shrieking and hand flapping started. Greg didn’t speak till he was three, developed slowly, ate with the worst table manners I could imagine, and frankly, I wanted him out of the house. Why did I have to have an autistic brother? It wasn’t fair! I was embarrassed to introduce him to my friends...Today, if I were asked what I thought of Greg, I would proudly describe him as bursting with energy, funny at times, and admittedly, sometimes a pain in the butt. But I no longer pity him as a victim but praise him as fighter, brother, even, at times, a friend (Aronson, 2009, p.49).

The above passage describes the transformation of a sibling’s feelings regarding her brother who was identified with autism. This passage was thought to reflect the feelings that are faced in any sibling relationship in Western cultures, especially one with the added concerns and problems related to adjusting to a sibling labeled with autism (i.e., Benderix & Sivberg, 2007; Kaminsky & Dewey, 2002; Mascha & Boucher, 2006; Orsmond & Seltzer, 2007b; Ross & Cuskelly, 2006). In

this section, I explore the complex relationships that are described in articles and books that chronicle the experiences of having a sibling on the autism spectrum. The literature on sibling relationships has suggested that those relationships can be characterized in terms of warmth, commitment, conflict, resentment, as well as a tremendous source of support for children, adolescence, and adults.

### **Developing an Understanding of Autism Label**

One important factor in determining the impact of living with an individual who has been identified with autism is the sibling's knowledge and understanding of the disorder (Ferraioli & Harris, 2010; Ross & Cuskelly, 2006). Kresak, Gallagher and Rhodes (2009) and Stalker and Connors (2004) remind parents the type and amount of information needed by siblings would change over time depending upon what they have been told, overheard or observed. The children seem to go through a process of developing an understanding of the disability and learning ways to cope or working around the differences their brother or sister may have (Aronson, 2009; Conway & Meyer, 2008; David, 2008). Glasberg (2000) completed a study to explore the understanding siblings of children with autism spectrum disorders had regarding the diagnosis, treatment, and behaviors associated with this disorder. Surprisingly, siblings often did not know about the disorder, were confused, or simply misinformed. However, most of the siblings reported "seeing the effects of their sibling's disability on their own lives", (Glasberg, 2000, p.152). The impact of autism on siblings is as important as how siblings understand the effects of the disorder. Research has revealed sibling's positive perceptions and understandings of the child with autism are associated with sibling adjustment and relationship outcomes (Bachraz & Grace, 2009; Petalas et al. 2009; Stalker & Connors, 2004). Parental

communication is key in the sibling's understanding and knowledge this disorder (Bachraz & Grace, 2009).

### **Sibling Relationships and ASD**

Researchers have been interested in the relationships and sibling interactions of children with developmental disabilities, including ASD, over the past few decades, although findings have been mixed (i.e., Kaminsky & Dewey, 2001; Rivers & Stoneman, 2003; Foden, 2007). During childhood, siblings of children with ASD spend a substantial amount of time with their brother or sister. Research regarding sibling relationships has found that some sibling pairs experience warm, supportive relationships (Orsmond & Seltzer, 2007b), while other sibling pairs experience conflict and isolation (Rivers & Stoneman 2003). These mixed findings may stem from the effects of numerous variables, such as marital stress, poverty, age of siblings, type of community, and size of family; as well as no ideal sibling relationship has been identified (Beyer, 2009; Stoneman 2005). Most research focuses on the psychological strengths of the family with less research on the relationship between the community cultures in which a family resides and the assets of the family. Thus, a large part of our understanding resides in thinking about the assets of the family rather than the intersections and connections between families and their communities. The locus of research can constrain how families are characterized and understood.

It has been hypothesized that a sibling's relationship is generally established in the early childhood years and extends into adulthood (Orsmond & Seltzer, 2007a; Ross & Cuskelly, 2006). This may explain why most research regarding siblings and the impact of ASD on sibling relationships is completed during childhood years.

Previous research has shown that sibling relationships show considerable continuity throughout childhood, adolescence, and adulthood, although recent studies have focused on personal, interpersonal and ecological variables that affect these relationships (Barak-Levy, Goldstein & Weinstock, 2010; Orsmond & Seltzer, 2007b). Siblings begin as play partners and become sources of support through daily contact (Orsmond & Seltzer, 2007b). However, since research studies include multi-age groupings without taking into account the stages of development throughout childhood and adolescence, it is unclear as to the extent stages of life affect sibling relationships (Orsmond & Seltzer, 2009).

Coplan, Rubin and Findlay (2006) found that the parent-child relationship as well as parenting behaviors, not only maternal attention, was a precursor to the child's ability to participate in social and nonsocial types of play with others. For example, a secure attachment between the child and parent during infancy, related to more types of play, interactions that are more social and more secure relationships with peers and siblings. Siblings stated the child with a disability required more attention and parental resources leaving the sibling with less time with their parent resulting in varied feelings.

Parents' relationships and interactions with their children identified with ASD has been a major focus of research, while less research has focused on the experience of siblings of children with ASD. Studies that have been conducted are inconsistent with their findings, however most agree that the voice of the sibling is missing and should be considered as important as the perceptions from the parent (Senner & Fish, 2010; Stalker & Connors, 2004). Bischoff and Tingstrom (2007) stated children's experiences with siblings varied greatly depending upon maternal

attention. The importance of parental social support differed depending upon family size with the larger family size having a positive satisfaction factor relating to sibling relationships (Orsmond & Seltzer, 2007b). Schuntermann (2007) states a significant implication occurs when siblings begin to assume multiple parenting roles resulting in inappropriate responsibilities, less positive sibling interaction, and decreased parental support. Some report that siblings show no major negative effects (Benderix & Sivberg, 2007; Foden, 2007); whereas others indicate siblings have less favorable attitudes and interactions with their sibling with ASD (Barr & McLeod, 2010; Kaminsky & Dewey, 2001; River & Stoneman, 2008; Stoneman, 2001). While still other studies report no significant effect between siblings (Bachraz & Grace, 2009), however Orsmond, Kuo and Seltzer (2009) reported that typical adolescent siblings received more parental support than typical adult siblings. It is important to the sibling relationship that parents remain dedicated to restoring imbalances and committing personal time to the child not identified with any type of disorder or disability (Barr & McLeod, 2010).

Relying on the parents as the primary informant regarding sibling relationships creates binaries of favorable and unfavorable attitudes and positive and negative interactions. When researchers add the voice and perceptions of the young sibling, the intersectionality of these binaries may help determine the hopes and expectations of the longest lasting relationship of one's life. Although there can be significant differences in the quality and characteristics of a sibling relationship, by utilizing the voice of the sibling, researchers can begin to better understand the complexities and essential factors that help these relationships develop, flourish, and become constrained.

**Sibling interaction when one child is identified with ASD.** One of the first socialization activities an individual experience occurs within interactions between brothers and sisters, sibling relationships are crucial to our social development. Children appear to utilize these interactions to develop, practice, and improve social relationships, including peer relationships. These interactions provide children unique opportunities to experience companionship, rivalry, and a full range of other emotions (Conger et al., 2007; Lockwood et al., 2001; Petalas et al., 2009). Although, only a handful of research studies have concentrated on family interactions – specifically, effects of autism on sibling interactions, even though research has revealed sibling intimacy has been linked to peer social competence for children (Aronson, 2009; Blacher & Begum, 2009; Floyd et al., 2009). Conger, Stocker and McGuire (2009) and Tsao and Odom (2006) stated that siblings may also develop increased social competencies and foster personal strengths through their experiences with the child identified with developmental delays such as autism.

Caro and Derevensky (1997) reported findings from a study utilizing the Sibling Interaction Scale in which distinct roles were assumed by siblings in their interactions with each other. Siblings assumed the roles of teacher, leader, and manager more than the role of equal playmate or learner when interacting with the child identified with a disability (Trent et al., 2005). Although these roles have potential of causing conflict among siblings, Stoneman (2005) suggests these roles are based upon the perceived expectations set forth by parents. Nonetheless, these roles may also serve a positive benefit by initiating more interactions between siblings.



**What affects social interactions between siblings.** In order to understand how ASD affects sibling relationships, researchers have historically utilized a larger body of literature that includes siblings of individuals with developmental disorders other than ASD (i.e.; Bagenholm & Gillberg, 1991; Knott et al., 2007; Orsmond & Seltzer, 2000; Orsmond & Seltzer, 2007; Rossiter & Sharpe, 2001). Although children's sibling and peer relationships will likely show reciprocal influences, nature of these influences appears to be dependent upon both on the developmental level of the children and the specific dimensions of sibling and peer relationships being studied (Lockwood et al., 2001). Despite the fact that many of the research studies conducted on the effects of having a sibling identified with a developmental disability have included children with mental retardation compared to children with autism, the results are as mixed as studies regarding interactions.

Relationships between brothers and sisters are often referred to as the most influential, longest lasting relationship of a person's life. Researchers, psychologist, psychiatrists, and other professionals have been intrigued by the factors that influence sibling relationships over the last few decades. Relationships between siblings, with and without disabilities, have a complex interplay of factors including birth order, age, gender, parental factors as well as individual coping skills, temperament, conflict, understanding of the disorder, and role of sibling. Although research remains unclear regarding the impact many of these variables have on sibling relationships, some effects appear consistently in results.

Research findings discuss mixed reports on the perspectives of sibling relationships. Kaminsky and Dewey (2001) showed that sibling relationships are characterized by less intimacy, prosocial behavior, and nurturance in families of

children with ASD than in those families with children identified with other developmental disabilities. Barr and McLeod (2010) reported significantly less positive experiences regarding siblings, although Rivers and Stoneman (2003) stated siblings had relationships that are more positive with their siblings with autism than their parents. As well as in a meta-analysis conducted by Sharpe and Rossiter (2002), they suggest the negative effects of having a sibling with mental disabilities such as autism may be overstated and additional research is needed to determine the long-term effects related to internalizing and externalizing behaviors. Meyer, Ingersoll and Hambrick's research (2011) found siblings' adjustment effects toward their sibling with autism were related to maternal depressive symptoms and not simply autism severity and behavior problems of the child with autism. Similarly, Foden (2007) described stories from siblings recounting the pride they felt while teaching their siblings with ASD new skills. Petalas, Hastings, Nash, Dowey & Reilly (2009) adds to this research recounting stories of distinctive, idiosyncratic skills, achievements, imaginative play and positive memories told by proud siblings.

When compared to siblings of children with mental retardation or other developmental disorder, siblings of children with ASD may experience more isolation and frustration within the relationship (Orsmond & Seltzer, 2007a; Schuntermann, 2007), although several studies have refuted these basic conclusions. For example, the quality of relationships between some siblings with and without disabilities has been positive in terms of warmth and closeness, and these siblings spend significant amounts of time interacting with each other (Rivers & Stoneman, 2003; Mascha & Boucher, 2006; Foden 2007). Studies have suggested that the quantity and quality of interaction between the pair is significantly poorer relative to

sibling dyads affected by other developmental disabilities (Rivers & Stoneman, 2003; Kaminsky & Dewey, 2001). Through practice and modeling of social behaviors these interaction structures have been found to impact individual functioning in other social relationships (Floyd, Purcell, Richardson & Kupersmidt, 2009).

**Effects of having a sibling identified with ASD.** Some research studies suggest that having a sibling with a disability in the family have negative effects on a child's adjustment, while other studies suggest positive effects, and still others state no differences than have siblings with no identified disabilities (Beyer, 2009; Hastings, 2003; Kaminsky & Dewey, 2003; Smith & Elder, 2010). Goehner (2007) concludes the effect of being a sibling in a family with a child with ASD as feelings of isolation from family along with anger, fear confusion, and most of all guilt for having these feelings. Macks and Reeve (2007) support this belief claiming autism is a severe developmental disorder that presents particularly difficult challenges for the family unit quoting reasons of "restricted family activities...inappropriate public behavior.... excessive time, energy and resources spent on child with ASD...resentment [from sibling] for not inviting friends home" (p. 1061). Unfortunately, Hastings (2003) found negative adjustment outcomes for siblings of children with ASD, showing siblings of a child with ASD as having more peer problems, overall adjustment problems, and lower pro-social behaviors as compared to a sample.

Kaminsky and Dewey (2002) found that although siblings of children with autism and Down syndrome (DS) have feelings that are more positive and less negative behaviors, siblings of children with autism reported less intimacy, less prosocial behaviors and nurturance than the sibling of children with DS. Siblings of

children with autism also reported negative reactions are related to their siblings' aggressive and uncontrolled behaviors related to characteristics of ASD leading to embarrassment for the sibling, difficulties explaining the disability, and increased household responsibility (Mascha & Boucher, 2006; Seltzer, Orsmond & Esbensen, 2009). Some studies reported that siblings of individuals with autism "admired" their siblings more and described their relationships as having less conflict, quarrels, and competition than the typically developing comparison group (Kaminsky & Dewey, 2001). Rodger & Tooth (2004) suggest there is a movement away from portraying overly negative effects of having a sibling with a disability and towards an acknowledgement of positive influences. The authors state, "It is recognized that families with a child with a disability offer siblings unusual opportunities for growth and maturation and development of qualities, such as sensitivity, nonjudgmental attitudes, and awareness of individual differences" (p. 54). Since research regarding sibling relationship remains mixed, it appears the focus of future research should be directed towards underlying conditions in which positive sibling relationships can be developed.

**Developing coping skills for siblings.** Siblings of individuals with autism have to cope with the unique set of challenges placed upon the entire family. Coping strategies can be developed by first encouraging the sibling to share how they are feeling and any concerns they have for their sibling with ASD (Beyer, 2009).

Consistent with current research literature, Seltzer, Orsmond and Esbensen (2009) found adolescents used more emotion-focused and fewer problem-focused coping strategies than adults. Rivers and Stoneman (2003) stated that allowing the sibling access to social supports groups might alleviate problems and stressors. Similarly,

Orsmond and Seltzer (2007a) found effective coping strategies for the undiagnosed sibling resulted in relationships that are more positive. Research with parents with children with ASD has revealed social support occurs from immediate to extended family, friends, neighbors, medical professionals and parental support groups, although relatively few studies have been conducted regarding social support for siblings of children with ASD (Conway & Meyer, 2008; Kaminsky & Dewey, 2002; Seltzer et al., 2009). In addition to demands to cope with the effects autism may have on sibling relationships, Petalas, Hastings, Nash, Dowey and Reilly (2009) describe siblings' need to cope with attitudes and reactions of others, peer comments and the need to "explain their siblings condition" (p.393).

**Sibling as the teacher and/or peer.** Brothers and sisters play important roles in each other's lives influencing social interactions both in and out of their family. Over the years, the roles of siblings may take on many different responsibilities to each other such as, teacher, friend, companion, protector, enemy, competitor, and role model. When one of the siblings is identified with a disability, these roles can be significantly altered affecting the attitudes and interactions among siblings. As well as, sibling relationships are likely compromised when children perceive unequal attention from one or both parents; this is especially true when one child has a disability (Schuntermann, 2007; Stoneman, 2001).

Siblings are the individuals who most frequently interact with the child with ASD. One of the major challenges for these siblings is learning how to interact and play with the child with ASD. Past research has concentrated its efforts regarding sibling interactions for children with ASD in the area of teaching the undiagnosed sibling new behaviors to increase the overall interaction with their sibling with ASD

(Beyer, 2007; Knott et al., 2007; Kresak et al., 2009; Trent et al., 2005; Tsao & Odom, 2006). Studies have begun to show that siblings have demonstrated the ability to effectively model and improve the social interactions of their siblings with ASD (Bass & Mulick, 2007; Harper, Symon, & Frea, 2008; Knott et al., 2007; Stahmer et al., 2003). Teaching the sibling to promote play by incorporating the ritualistic behaviors of the child identified with autism has shown to increase social interactions (Baker, 2000). In a 2009 report, Blacher and Begum discuss finding children with autism respond favorably to initiations by their sibling, as well as imitate sibling during free play. However, when El-Ghoroury and Romenczyk (1999) observed play dyads between parents, siblings and children with ASD, they discovered parents initiate play twice as much with the child with ASD than the sibling while the children with ASD initiated play with the sibling significantly more times than with their parents. Play interactions are important for children especially children with ASD because they serve as a stance to facilitate early peer interaction and communication (El-Ghoroury & Romenczyk, 1999). These positive interactions serve as a stepping-stone to social competence for the child with autism.

It has been further suggested, however, that play activities and social skills may be a more appropriate forum for sibling training than academic or self-help skills, especially when the children are younger (Lee et al., 2007; Toth et al., 2007). Several studies have examined whether sibling training generalized to settings that are more natural by recording sibling behaviors during free-play sessions before and after sibling training (Bass & Mulick, 2007; Lee et al., 2007; Tsao & Odom, 2006; Tsao & McCabe, 2010). For example, Rutherford, Young, Hepburn and Rogers (2007) conducted a study with children teaching how to initiate interactions, prompt

responses, and reinforce social behaviors of their preschool-aged siblings with severe intellectual disabilities. Sibling training led to increased levels of social interactions (i.e., social initiation of one child immediately followed by response of other child) between the sibling dyads.

### **The Importance of Play**

Play is special for children. Through play, young children learn and develop in areas of thinking and memory, sensing and moving, and listening and communicating. Children are able to try new skills, explore, and develop relationships. Play is not only “fun”; it is a child’s “work” (Gussin Paley, 2004; Piaget, 1962) and their way of learning about the world around them. The following sections review the literature regarding the history of play, the socio-cultural views of play benefits of play, and types of play activities.

### **History of Play**

Play has long been positively associated with childhood. Developmental theorists attribute children’s play to their growth and learning and should be included in early childhood curriculum (Bowman, 1993). The relationship between social and play behaviors as asserted by theorists (i.e., Parten, 1932; Piaget, 1962) is strengthened through a cognitive-developmental perspective, which claims play is a pro-social activity that foster the individual’s learning and interpretation of the surrounding world (Lifter & Bloom, 1998). The social aspect of play begins when the child begins to notice the play of others (Jordan, 2003). Children continue to pursue activities that are fun and enjoyable, this is how we learn about the world around us.

Theories of play were first developed during the eighteenth and nineteenth centuries. Throughout the years, educators, psychologists, and theorists have been fascinated by the way children play. By the late 1800's, elementary schools were universal creating a definite place for children to play games (Sutton-Smith, 1981). Although school playgrounds were primitive, they did not restrict the children to playing in small areas, nonetheless school playgrounds have always followed a hierarchy of rules. Play is free, voluntary, and spontaneous in so far as the authority of each of the players. From early schoolyards to now-a-day playgrounds, each contains the same rules that exclude certain groups of children from many games.

Present day play has become much more sophisticated than play displayed by previous generations of children. Children's play has become saturated with commercialized modes of play, complicated toys, and video games. Many toys do not promote creative play in children undermining one important purpose of play – developmental of creativity and imagination. Play is an important part of a child's development. Through play, children explore and learn about their world as well as developing imagination, creativity, social skills, and problem solving skills. In 1932, Mildred Parten categorized the stages of children's play that continue to provide a standard definition for describing a child's developmental progress in social play.

Jean Piaget and Lev Vygotsky were two of the most influential theorists in child development, most notably in the area of children's play. According to Piaget, play is a paradigm of assimilation directing accommodation in a child's world (Pellegrini, 2009); different forms of play correspond with different developmental stages in a child's life. For example, a child puts on a hat and become a chef, policeman, or cowboy. The hat is a symbol of the role the child must attain,



however the child must have learned about these roles through prior experiences before incorporating them into their play world. Vygotsky combined the affective and cognitive aspects of development in order to explain his theory of play (Smith, 2010). He was primarily focused on pretend play and how children utilize play for wish fulfillment due to the notion that the child was releasing themselves from limitations of the current situation (Pellegrini, 2009; Smith, 2010). For both Piaget and Vygotsky, play was described as the opportunity for children to learn more about their world (Smith, 2010). Mildred Parten's (1932) influential work created a description of children's social behavior as it occurs concurrently with cognitive development in early childhood through her *Scale of Social Participation*. Parten (1932) developed her scale from systematic observations of the social activity and play behaviors of children in preschool. This scale continues to be a significant tool utilized in understanding children's social behaviors.

The close relationship of social and play behavior as suggested by theorists (i.e., Parten, 1932; Piaget, 1962) is supported by the cognitive-developmental perspective, which states that play is a prosocial activity that fosters one's learning about and interpretation of the world (Johnson et al., 2005). Body posture, gestures, eye contact, hand movements, and other nonverbal components of language often interfere with a child's ability to understand all communication used by others (Koegel & Koegel, 1995). Play is an activity that can be utilized to improve communication skills with peers through initiation and practice (Parten, 1932).

Even though researchers continue to agree that it is difficult to define play as well as determine when play is occurring, current theories of play are generally organized around four themes: play as progress, play as power, play as fantasy, and

play as self. These themes have been inspired in large part by the work of Brian Sutton-Smith (Pellegrini, 2009; Scarlett, Naudeau, Saloni-Pasternak & Ponte, 2005). Often the differentiating aspect of a child's perspective of play from that of an adult revolves around the 'function' of play.

Current play theories surround a variety of trends that use 'play' as the basis of discussion. For example, Maria Montessori utilizes free play and exploration to inform her practice of allowing children to engage in free play in educational settings. These discussions entail play as being good for children's physical, emotional, cognitive, and social development that prepares children for the future (Saracho & Spodek, 1998; Scarlett et al., 2005). An understanding of play as voluntary, enjoyable, and pleasurable to children assists researchers with guidelines to promote educational play in children (Saracho & Spodek, 1998). Despite the fact that play make take on many forms, defining the value of play continues to include assisting children in exploring and understanding various roles and interaction patterns in their social world (Pellegrini, 2009; Rubin & Coplan, 1998; Saracho & Spodek, 1998; Scarlett et al., 2005).

### **Play and Learning**

There are five basic elements that define play: 1) Play is inherently motivating; 2) Play activities are the child's choice; 3) Play involves some level of imagination; 4) Play is enjoyable; and 5) Play keeps the child engaged (Boutot et al., 2005; Wolfberg, 2009). Play behaviors are typically first observable around one year of age and the complexity and flexibility of play is influenced by increasing cognitive awareness and maturation as children progress through the differing stages of play (Christensen et al., 2010). According to Lindon (2002), children may increase

physical development including fine and gross motor skills, when given appropriate space and resources to play. In preschool, many children improve fine and gross motor skills like balance, laterality (awareness of left and right sides of their body), spatial orientation, and muscle coordination of large muscle groups (Elkind, 2008). When the child masters these skills, it allows for enhanced play-based activities and social competencies.

As children increase their awareness and understanding of self and the world around them, many essential skills are developed in the areas of physical, language, social and cognitive development. Because of play, children are exposed to concrete and meaningful activities in natural settings that enhance these skills (Gleave, 2009). However, deficits in social and communication skills highly affect the child's ability to participate in sustained play or social interactions. These difficulties reinforce the importance of promoting play skills to children with autism for their development.

The generalization of play skills may also be linked to a creative way of thinking resulting in a generation of novel association and cognitive ideas (Elkind, 2008; Johnson et al., 2005; Rodman, Gilbert, Grove, Cunningham, Levenson, & Wajsblat, 2010). As a child with ASD progresses throughout the school day, they encounter settings with diverse materials, which could lead to opportunities for communication and social interactions with peers. At the same time as children increase their awareness and understanding of self and the world around them many essential skills are developed in the areas of physical, language, social and cognitive development. Research has shown children sometimes use pretend play to spontaneously navigate through experiences, events, and feelings that overwhelm them (Lindon, 2002). They may choose to create stories, try out adult roles, form

superheroes, and heroines, anything they could not do in reality. As a consequence of play, children are exposed to concrete and meaningful activities in natural settings that enhance these skills (Johnson et al., 2005).

**Cognitive development.** Play is a vehicle for interventions to encourage the development and growth of creativity, increasing imagination, dexterity, and strength in the areas of physical, cognitive and emotional growth (Ginsburg, 2007). Since the implementation of No Child Left Behind Act of 2001, a national trend focusing on academic fundamentals has resulted in the decrease of other creative academic subjects, such as art, music and social sciences, as well as recess and physical education. This trend may have serious implications for the social and emotional development of children because of the diminishing focus on organized play, free play, and physical activity (Bergen, 2002; Ginsburg, 2007).

The Alliance for Childhood put out a report Spring 2009 titled “Crisis in the Kindergarten: Why Children Need to Play in School,” which concludes that kindergartens have changed dramatically in the last two decades. The report showed that play materials such as blocks, sand and water tables, and props for dramatic play “have largely disappeared” from more than 250 full-day kindergarten classrooms studied. Most children had half an hour or less a day for playtime, and some got no playtime at all (Miller and Almon, 2009). In a 2009 report for Playday Make Time! Campaign, Gleave reported that children’s free playtime has decreased more than twelve hours in the past 25 years. Joan Almon, the group’s executive director explains through play children are able to develop language, express their creativity, expand social skills, problem solve – “take on every aspect of life” (Miller and Almon, 2009). Critics of NCLB blame the increased pressures to focus on

academics even with the youngest students without regards to social and communication skills. Research studies have revealed in children with autism pretend play skills are important predictors to later social abilities. Curricular programs that include pretend play, as a functional skill, may be important within the cognitive domain for children with autism (Barten & Wolery, 2008). However, many early intervention programs for children with autism continue to focus primarily on teaching pre-academic skills to prepare these students academically to be included in inclusive education classrooms (Scattone, 2007). Teaching children to play is important for all the developmental skills play reinforces within a child. It is important to differentiate that while a peer may benefit from generally supervised play, children with ASD would have increased benefits from guided play where they are taught and guided how to interact within the play environment.

Interactions between siblings reinforce and modify social behavior (Bee & Boyd, 2004; Ferraioli et al., 2011) as well as advance the development of cognitive growth for both children. As the sibling becomes more aware of others, they become less egocentric. In Jean Piaget's (1954) theory of cognitive development, Piaget utilized the term egocentric to describe the pre-operational stage of cognitive development typically from 18 months to six years old. This is a cognitive state in which the child sees the world only from own perspective (Ferraioli & Harris, 2010), a state that may be used to describe how a child with ASD sees the world around them. The sibling relationship occurs in the most natural of environments, therefore utilizing this relationship to increase social interaction skills should be recognized as a valuable resource and effective approach for various interventions (Knott et al., 2007; Tsao & McCabe, 2010).

**Social-intellectual development.** Social play is critical to the development of cognitive, social, and cultural competence of children (Bass & Mulick, 2007). Children associate free time with freedom, independence, and choice; however, play of this nature is often limited. Ginsberg (2007) highlighted the combination of busy family lives and increased academic commitments have negatively impacted children's free time, affecting their cognitive, physical, social, and emotional stability. A key issue that appears to be emerging here is the theme of social awareness and social motivation (Foden & Anderson, 2010). The answer for social interventions is to keep the interactions with peers fun and entertaining. For individuals with ASD, it is imperative to incorporate generalization into learning play skills.

Previous research has shown young children, who learn to play with others, share and take turns display greater degrees of success later in life. Pierce-Jordan and Lifter's (2005) study supports previous evidence that in order for a child to have the ability to combine social and play activities, they must possess cognitive effort. These researchers found an inverse relationship between the complexities of social and play skills. For instant, when a child, with or without an identified disability, engages in a complex social or play interactions, their play activities are less complex. Social and play behaviors require the use of cognitive skills, concurrent engagement in these behaviors involves one activity utilizing more cognitive resources than the other activity (Bissinger, 2009; Pierce-Jordan & Lifter, 2005).

Play that is directed by adults rather than by children themselves does not require the same level of skills, initiative and decision-making, and so does not offer the same learning experience. However, children associate play directed by teachers as "playful" in a social context then play with peers (Howard, Jenvey, & Hill, 2006).

## **Socio-cultural Views of Play**

Research on children's play usually highlights its critical role in child development for children. Constructivists, like Piaget, help practitioners understand how internal mental processes such as meaning making through assimilating new information or accommodating understanding to new concepts develop over time as young children engage the world around them (Piaget, 1962; Erikson, 1950; Loop, 2009). No one instructional strategy will be successful for all children with ASD, although play assists children learn through exploration and imitation leading to increased developmental skills. Despite the fact that many children with ASD have unique patterns of development, educators can utilize their strengths to support learning in areas of difficulty (NRC, 2001). Since every experience a child may contribute to the development of their brain, children with ASD need to be given ample opportunity to participate in social and academic activities.

Theories of learning are constructed around the assumptions about “the person, the world, and their relations” formulating “a dimension of social practice” (Lave & Wenger, 1991, p.47). To study the nature of social practice and participation, I draw from approaches that center on the social and cultural underpinnings of these processes. First, I define main concepts in sociocultural theory, focusing on cultural-historical activity theory (Cole & Engeström, 1993; Engeström, 1987; Engeström, 2001) that helps me conceptualize sibling relationships when one sibling is identified with ASD. Then I focus on two approaches that inform my analysis of interactions and relationships: situated learning (Lave & Wenger, 1991) and communities of practice (Wenger, 1998). These two approaches consider the nature of cognition as socially distributed, instead of being contained in

individual minds (Cole & Engeström, 1993). They also provide useful models to examine activities and practices within relationships and communities.

Sociocultural theorists suggest that learning is a dynamic activity that is mediated and modulated by internal processes as well as external tools that are as complex and ephemeral as language itself and as simple as a stick or a spoon used to knead dough. Learning in this view embeds cultural as well as social and intellectual activity (Vygotsky, 1976; Rogoff, 2003; John-Steiner & Mahn, 1996; Cole, 1985). Play takes place in a variety of settings including school, park, home, backyard, etc. Although these settings may be very different, each can be considered socially constructed settings especially since play varies in different cultures. When considering the value of play in different cultures, understanding the relative value of play and work may assist in defining play activities (Pellegrini, 2009). For example, in a study conducted by Ungerer and Sigman (1981), they stated children with ASD displayed play behaviors in structured and unstructured environments playing with manipulatives (toys). A series of research studies revealed that children with ASD engaged in play activities with peers when observed in inclusive classrooms (McHale, 1983; McHale, Olley, Marcus, & Simeonsson, 1981). The development of play curriculum allows children with and without ASD to create meaningful relationships, increased communication, and social behaviors.

Vygotsky believed children learn many skills through play. He argued that a child's development is established by the social interaction with others. Vygotsky (1976) described play as the center of a child's development with all the developmental tendencies compressed into this behavior. Vygotsky's theory of the 'zone of proximal development' offers two important perspectives regarding the role



of play in learning. First, he emphasizes the social aspect of learning through the gap between what a child is capable of completing independently, and what a child can do within the social context of more experienced peers or adults (Vygotsky, 1976). A child's aptitude for learning is "revealed and indeed is often *realized* in interactions with more knowledgeable others" (Wood, 1998, p.26). Second, Vygotsky argued that the activity of play "enables children to achieve higher levels of cognitive functioning" (Wood, 1998, p.80), was in fact a zone of proximal development. Vygotsky asserts that by interaction with the environment and other people, neural networks and cognitive schemas emerge that are we understand as development (Vygotsky, 1976). Play settings provide circumstances where this is possible.

In these theoretical works two critical themes for research emerge: (1) children's worlds and their experiences within these worlds are different from those of adults; and (2) play occurs in a social context.

### **Summary**

Reviews of social play for individuals with autism reveal many complexities of the issues in these activities. It is clear that individuals with autism have difficulty producing pretend play, but it is less clear whether these issues are due to a basic inability to pretend, or something else (Jarrod, 2003) especially since some play theorist believe that play is naturally part of every child's world. However, if this were true then neither social interactions of a child's everyday life nor the cultural values and norms of the child's life would matter to the development of play (Pufall & Pufall, 2008). Usually, children symbolize activities they see adults doing and the values that are important to their society through their play. The more the child can live close to adults in daily life, without many restrictions, the more contact he or she

will have with the routines of the society, and the more realistically he or she will be able to represent it in play activities. Nonetheless, some societies stress play as a means to meet the social and intellectual skills necessary to function in society, others stress more skill-oriented outcomes from play (Pellegrini, 2009). For example, children in Botswana were observed using objects related to their respective work role (hunters and cooks/mothers) to play, until work using this object replaced play (Pellegrini, 2009). Children learn through interactions with their social environment (society and cultural) and personal hands-on experiences. Children learning through problem solving experiences with people such as their parents, siblings, peers, teachers, acquiring new skills, and concepts achieve this. This suggests cross-cultural comparisons and multicultural activities may add a unique contribution to children's self-esteem and cultural pride.

The possibility of social play for individuals with autism suggests the need to change social interactions and play activities that will increase the ability for the individual to engage in meaningful relationships (Wolfberg, 2009). As children are exposed to various social settings and environments, such as preschool, day care, outings to the park, etc., they become more aware of the construction of play. Koegel, Werner, Vismara, and Koegel's (2005) study supports data that play date interventions may increase peer interactions, peer interest and mutual enjoyment during play activities. This provides hope that these children would want to participate in future play activities together as well as with other children. However, consideration should be given to the different cultural factors that come into play when considering play curriculum or interventions. While Western culture may believe that play is a means of learning, other cultures believe work is a means of

learning. It may be best to follow a model designed to say ‘play is a child’s work (Gussin Paley, 2004; Vygotsky, 1976).

Stalker and Connors (2004) reported most siblings did not see themselves intrinsically much different than they saw their sibling. Often any difference mentioned did not affect the sibling relationship, instead it was accepted was an integral part of the individual with autism that made him or her who they were (Stalker & Connors, 2004). Since siblings are most likely to have the most contact with the child with autism, with the exception of the mother, they are likely to have an abundance of information regarding their brother’s or sister’s likes, dislikes, concerns, fears and needs (Conway & Meyer, 2008). Research should continue to explore the role of siblings and children with autism in order to develop social connections at home, school, and in the community.

The more that is known about the nature of sibling relationships involving children with autism, the more empowered professionals could be in guiding parents to assist their children in improving the relationship with one another as well as helping the children directly. Evidence reveals both similarities and differences in the quality of sibling relationships with and without one sibling with autism (Seltzer et al., 2010). Although having a brother or sister with autism is often considered a stressor for siblings, family characteristics may also impact how this relationship develops and matures over time.

Even though there is not just one correct, precise perspective of how a sibling relationship should appear, an understanding of the processes that promote positive, supportive relationships between siblings and the sibling with autism can provide meaningful information regarding how to further strengthen their

relationships. We are just beginning to understand the factors influencing the sibling relationship and the outcomes of these relationships, as well as how parents' perceptions often differ from those of their children. Thus, when considering siblings' needs, it is important to obtain sibling self-reports as well as parent reports (Senner & Fish, 2010).

It is clear that children with autism require direct support to facilitate their social interaction, communication, and play. If we begin to make play an essential part of every child's daily curriculum as well as home and community life, we may be one step closer to moving that child further up the developmental ladder. Gaps in the research include a lack of intervention studies, a lack of the perspective of people with disabilities for a mutual view at the relationships, and research across the lifespan with siblings to see how their relationships and needs change over times (Heller & Arnold, 2010). The literature review supported the need to closely investigate the internal and external effects on a child with a sibling identified with ASD through self-report methods. Due to these gaps, the next obvious step for research is finding how to improve sibling relationships involving children with autism through play and social interactions. These findings helped shape the motivation behind the current study, which utilized video-cued interviews to gather information more easily from the children themselves.

## Chapter 3

### METHODOLOGY

Chapter three provides a description of the instruments and procedures that were used in this qualitative interview study. In this chapter, I provide a description of the methodological and analytical tools that allowed me to explore the relationships between children diagnosed with ASD and their siblings through *the voices* of the children. First, I describe the process and rationale behind selecting the participants and settings for this study and the procedures I used in identifying each. Next, I detail the methods of data collection, including interview protocols and data analysis. Finally, I discuss briefly the limitations of the present study's methodological approach; specifically explaining how interviewing methods are appropriate to examine the complexity of the perspectives of children (Clandinin & Connelly, 2000; Clark & Statham, 2005; Fargas-Malet, McSherry, Larkin, & Robinson, 2010). An interviewer must maintain a flexible approach to interviewing children in order to obtain their subjective experiences. Children will be more likely to talk about their experiences in greater context when the interviewer encourages them to describe events of their daily lives through story telling (Mauthner, 1997).

This study focused on understanding the perceptions of children regarding the relationship they have with their brother with ASD as an important step forward in expanding social skills, including play activities for these children. Children build awareness of the world around them through play and social interactions with others. Play behaviors are fundamental underpinning for social skills development, language development, and communication skills (Lee et al., 2007). Since siblings spend so much of their time together, they become integral parts of each other's exploration

of new environment, skills and experiences, as well as ‘experts’ regarding each other’s behaviors. However, this relationship can be significantly affected when one sibling is diagnosed with ASD. My intent was to understand how siblings’ lives and relationships might be complicated when one sibling has been identified with an ASD label, while listen to the perceptions of the child through their own voice.

Theoretical concerns that motivate this study guided the selection of my methodological approach. First, I needed an approach that allowed the voice of the child to construct their own interpretations of who their siblings are. Although interview is a method frequently used for research in teaching, personal lives and identities, bringing the voice of the young child is regarding their perceptions of their sibling is understudied. Vivian Gussin Paley’s stories taught us to listen as she became aware of the voices of children in her classroom.

My voice drowned out the children’s. However, when... [children] said things that surprised me, exposing ideas I did not imagine they held, my excitement mounted...I kept the children talking, savoring the uniqueness of response so singularly different than mine...Indeed the inventions tumbled out as if they simply had been waiting for me to stop talking and begin listening (Gussin Paley, 1986, p.125).

By listening to the stories children tell regarding their experiences and lives, I provide an opportunity for them to express their opinions and feelings. Rather than influence the children with my ideas and assumptions, I wanted to find out what was important to them. In addition, I needed a method in which I could present authentic stories spoken in the voice of children without injecting myself into this socially mediated milieu. For any communication, it is important to ask how words

and various grammatical devices are being used to build and sustain or change relationships of various sorts among the speaker, other people, social groups, cultures, and/or institutions.

### **Research Design**

This study used an ethnographic video-cued interview approach (Tobin, Wu, and Davidson, 1989). In this approach, all participants viewed video-clips of themselves and their sibling and then had the opportunity to talk about the activity they were viewing. This technique utilized stories and the child's life examples to prompt responses regarding play activities with a child diagnosed with ASD from the perspectives of their sibling by collecting a focused sampling of how children think and talk about their relationships. Creswell (2005) suggested researchers describe the lives of individuals and write narratives about their experiences through the eyes of the individual utilizing a set of data obtained from the individual. In this study, interviews revealed how children felt about their relationship with their sibling diagnosed with ASD. However, the video itself was not data per se; rather, it was used as a meaningful stimulus and reflective interviewing tool (Tobin, 2000). In this study, the videotape contains scenes of typical play activities and/or social interactions between siblings. The purpose of this research was to examine the ways children think and talk about their relationship with their sibling diagnosed with ASD in an attempt to better understand the child's perceptions. Moreover, these findings provided a descriptive interpretation of how a child looks at play activities with their sibling versus peers.

In order to understand interviewing approaches for children with and without disabilities, I reviewed various studies that have been conducted to examine

children's perspectives on their own lives (Clark & Statham, 2005; Danby & Farrell, 2004; Fargas-Malet et al., 2010; Tobin et al., 1989). Interviewing can be utilized for measurement of a particular issue or to gain an understanding of an individual or group perspective. Even though there are many interview standards, an interview can be a one-time brief exchange, or it may take place over multiple sessions, there is no one common procedure for interview research (Fontana & Frey, 2000; Kvale, 1996). There are interviewing approaches for children that allow adults to communicate with young children absent their parents (Gussin Paley, 1986; Tsai, 2007). Research completed by Hill (2006) and Stafford, Laybourn, Hill and Walker (2003) reinforced thoughts that children appreciate opportunities to 'have a say' about their preferences. Clark and Statham (2005) describe a model termed the Mosaic approach that can be applied to work with young children either in small groups or individually. The Mosaic approach draws on the belief that each child is "strong, competent and active, and able to express herself through the languages of children (Clark & Statham, 2005, p. 46). This approach allows the researcher to use interview techniques, which give children the power to be experts regarding their own lives. Vivian Gussin Paley (1986) urged those who explore children's stories to listen "with curiosity and care" (p. 131), giving authentic child involvement to children. Furthermore, understanding the interview process as well as the dynamics of these special relationships, not only guides my analysis of data, additionally provide ethical considerations associated with conducting research with children (Brugha, Sturt, MacCarthy, Potter, Wykes & Bebbington, 1987; Clark & Statham, 2005; Komulaninen, 2007).



This method is retrospective meaning making, a way of understanding actions, organizing events and connecting and seeing the consequences of actions over time (Chase, 2000). The individual has the ability to give their story details to construct and reconnect with their own reality. Accordingly, these stories communicate what happened including emotions, thoughts, and interpretations from the child's point of view establishing "why narrative is important in the first place" (Chase, 2000, p656). Thus, for this study, multi-voiced ethnographic stories will be used to understand autism spectrum disorder and play experiences from the siblings' perspective.

**Children's voice.** Recent literature regarding children has begun to discuss the importance of the child's voice (e.g., Clark & Statham, 2005; Davis, 1998; Dockett, Einarsdottir, & Perry, 2011; Gussin Paley, 1986; Komulainen, 2007; Lewis, 2003; Lundy, 2007; Soto & Swadener, 2005). Most children are used to being asked questions from adults for a wide range of purposes ranging from testing knowledge in an academic setting to responding to quizzes to answering probes in the media. Previous research suggests it is beneficial to allow children to use their own language as well as their own way of communicating, asking them clarifying questions when necessary, rather than Past discussions of children's voice have revolved around whether adults truly listen to what children are saying, as well as how to effectively hear the child's words (Gussin Paley, 1986; Komulainen, 2007). Clark and Statham (2005) state a possible reason for lack of attention to a child's voice as childhood being commonly known as a time when children are not mature enough to understand their views, make their views known or act upon these views. Researchers tend to focus upon those who are most capable of articulating their

views through traditional venues, excluding children who are hard to reach or must be approached differently. This lack of attention to the voice of younger children reflects how early childhood is viewed by society, as a time in which children are not yet able or mature enough to make their own views known. Danish researcher, Qvortrup, stated: “Children [are] often denied the right to speak for themselves either because they are held incompetent in making judgments or because they are thought of as unreliable witnesses about their own lives” (Qvortrup, 1994, p.2). Vivian Gussin Paley (1986) states the best way to engage children in ongoing conversations to hear their voices above the voices of adults, is including the opportunity to explore the “three Fs – fantasy, friendships, and fairness” (p.126). Engaging young children as participants in research practice is considered an “active process of communication involving hearing, interpreting and constructing meanings” based on spoken discussion and expanded to “include the many different verbal and non-verbal ways young children chose to communicate” (Clark, 2005, p. 491). This approach creates a venue in which research involves the child’s view of their own world – what is important to them, their feelings, what makes them happy and secure, sad and unsure, and what meanings they attach to the people and activities in their lives. The emphasis on children’s perceptions is intended to acknowledge the primary source of knowledge regarding the life of a child comes from the child, especially since children may give greater meaning to a topic or event than what is deemed important to an adult (Clark & Statham, 2005).

Very frequently, research involving siblings draw on the behaviors of children without an identified disability as control groups within comparison model studies. This includes research entails concerning particular features, characteristics, or

behavior that is of particular interest to the researcher(s). However, as researchers we should question how comparing the behavior characteristics of one sibling to another would give us the nature of the causes of this behavior. Furthermore, research on the sibling relationship when one child has a disability has addressed both the pattern of interactions between the individuals and the subjective attitudes of a sibling towards their brother or sister with a disability (Cicirelli, 1995). The majority of this research on the nature of sibling interaction has been examined by conducting interviews or completing surveys with adolescences, young adults, and parents (e.g., David, 2008; Dunn, 1992; Floyd et al., 2009; Heller & Arnold, 2010; McHale et al., 1986; Stalker & Connors, 2004). El-Ghoroury and Romanczyk (1999) conducted observations of family members' interactions toward children with autism. However, the voice of the younger child continues to be a gap in the literature.

**Triangulation.** Qualitative analysis, in essence, involves interpretive work, characterized by the inclusion of the “perspectives and voices of the people whom we study”, as well as explicitly considering one’s own role within this process of interpretation (Strauss & Corbin, 1994, p. 274). The integrity of qualitative research rests, to a great degree, on identifying clearly one’s own place within the research, and striving to thoroughly include the perspectives and viewpoints of the research participants. Triangulation is typically a strategy (test) for improving the trustworthiness of the data of or evaluation of findings (Mathison, 1988). A close analysis of the children’s recorded interviews was supplemented with information gathered during the semi-structured parent interview and observations collected in field notes and videos of children engaged in play and social interactions. These

different ways of collecting data were guided by qualitative research methods (Clandinin & Connelly, 2000; Craig & Huber, 2007), and their triangulation proved beneficial in gaining a better understanding of the perceptions of the children in this study. The data I collected in the form of field notes during interview interactions with participants, assisted me in addressing my research questions numbers when the children and parents discussed the play activities demonstrated within the video clips.

Field notes were detailed accounts of my observations during drawing sessions and interviews. Field notes followed this schema:

- Participants: how they behave, interact, dress, react to questions
- Structural features: what the actual room and environment look like, who chose the location, why, how they chose this location
- Process of session
- Reflective notes: reflections on my own experiences that might influence the way I categorize what I observe.

Lastly, an audit trail was kept throughout collection of data concluding with data analysis. An audit trail is a transparent description of the research steps taken from the start of a research project to the development and reporting of findings. These are records that are kept regarding what was done in an investigation (Clandinin & Connelly, 2000). It is important to have a clear description of research design; decisions taken regarding data analysis, steps taken to manage, analyze and report data (Malterud, 2001).

## Methods

### Participants

Six total families were included in this research study. Even though families were recruited from a large, diverse metropolitan area, the description of these particular families resulted in representing only a fraction of this population and must be taken into consideration when discussing implications of this study. All families are deemed included in the same specific demographical, socio-economical description. The families in this study reside in suburbs with none of them living within the inner city of this metropolitan area or outside in rural areas. All fathers have careers in professional-type occupations such as computer analysis, engineers, financial advisor, cardiologist, and executive for a professional sports team. According to the U.S. Census Bureau (2010), the number of stay-at-home mothers has declined from 5.1 million in 2009 and 5.3 million in 2008, while the number of working moms has increased by 4% since 2006. Even though each of the mothers had previous careers, they all decided to become stay-at-home moms when their children were born.

**Children.** In chapter one I told the story of Rachel and her brother, Jack. I knew that their story could not be unique to only them, but how do other children react to their siblings with ASD? To answer my question, “how do siblings describe the experience of growing up in a family that includes a child with autism?”, I needed to question and acquire the voice of other children with siblings diagnosed with ASD. As reviewed in chapter two, the current literature revolves around the voice of the parent, professional, paraprofessional, teacher, and older adolescent or adult sibling. For this study, I chose to investigate the answers to my questions by

interviewing children aged 7 to 9 years old (hereafter referred to as *sibling*) that have at least one sibling diagnosed on the autism spectrum. The voice of siblings aged 7 to 9 years old is missing from the current literature. The gender of the sibling was not a criteria of the study, however, five out of six sibling participants were girls. All of the children identified with ASD were boys, which follows the current statistics of 5:1 ratio of boys identified over girls (CDC, 2012).

Barbara Rogoff states in *The Cultural Nature of Human Development* (2003), that as children begin to grow beyond the toddler years, they begin to assume roles that contribute to their family and community. The years between 5 to 7 are typically an important time of transition regarding the child's responsibilities and status in their community. By the time children are between the years of 8 to 10, they become competent and valuable assistants in many families. Developmental literature reflects that about age 5 to 7 years children begin to be responsible and teachable, while at about 8 to 10 years, parents expect children to understand and help, with competence and responsibility (Rogoff, 2003). However, it is important not to give too much credence to standard, specific age expectations because family and community influence is strongly related to these opportunities and the degree of participation in certain activities. Family life varies greatly and has a multitude to factors that influence the outcome of child development and sibling relationships. The relationship between birth order and the child's personality has been debated for many decades beginning with Alfred Adler (1928). Some research has shown that sibling relationships may be impacted by many different factors such as temperament and sociability (Dunn, 1992; Kaminsky & Dewey, 2001). However, birth order did not appear to be a factor with the children in this study. Even though, two siblings

were older than their brother with ASD and the other four siblings were younger, all siblings adopted leadership roles within their relationships.

Participants in this study were 6 children (not diagnosed anywhere on the autism spectrum, i.e., Pervasive Developmental Disorder, Pervasive Developmental Disorder-Not Otherwise Specified, Autism, or Asperger’s Syndrome) aged seven to nine years old and their parents who were living in the same household with the sibling classified with ASD. The participants are identified as sibling throughout this dissertation. The parents in this study have described the other children as on the autism spectrum. The children’s diagnoses were determined by physicians or licensed psychologists specializing in the assessment and diagnosis of children with Autism Spectrum Disorders. These children all attend their neighborhood public school located in their community. Research states that age differences, gender, and the ages of the children within the family may account for the strengths and weaknesses in sibling relationships (Dunn, 1992). The number of children in each family varied from five children (with the sibling as the youngest in the family) to two children in the family. The number of children within the family and the gender of the sibling did not appear to be a distinguishing factor in the sibling relationships.

Table 1 gives a visual representation of the families in this study.

Sibling	Age	Birth order	Child identified with ASD	Age	Birth order	# Children in family
Christy	9	1 <sup>st</sup>	Max	8	2 <sup>nd</sup>	2
Carson	8	4 <sup>th</sup>	Elliott	5	5 <sup>th</sup>	5
Amana	7	4 <sup>th</sup>	Ita	9	3 <sup>rd</sup>	4
Ainsley	7	5 <sup>th</sup>	Erik	9	4 <sup>th</sup>	5
Emma	7	2 <sup>nd</sup>	Emerson	10	1 <sup>st</sup>	2
Kadee	7	2 <sup>nd</sup>	Weston	8	1 <sup>st</sup>	2

Table 1. Sibling Pairs

The following paragraphs present short profiles describing each participant and their families. I provide a brief overview of their behavior and interactions with their sibling, as presented to me from their parents before the first interview session. The analysis of their social interaction and play activities with their sibling is presented in detail in Chapter 4.

The children were able to demonstrate the ability to verbally communicate stories and answers during the interview; even though, recent research has stated children with little or no speech should be given the opportunity to exert some control over their communication with others (Komulainen, 2007). For purposes of this study, children needed to have the ability to tell their stories regarding their sibling and play activities to me.

Christy is the 9 year-old sister of Max<sup>1</sup>. Max attends a private day school for children with autism, however started his schooling at within a public school district. Max is described by his parents as being diagnosed on the severe end of the autism spectrum with echolalic speech patterns. He has been diagnosed since the age of two. Max's mother recalled the diagnostic process as a "natural progression". He has received early intervention for speech and occupational therapy (OT) starting at the age of two, physical therapy (PT) at three years old and then music therapy soon after. He began attending an inclusive preschool program when he was three years old. Since Christy and Max are only 10 months apart in age, she attended the same preschool. Their mother believes this exposure to children with diagnosed disabilities shaped Christy's disposition. Christy and Max are the only children in

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<sup>1</sup> All names are pseudonyms



this family. Their father works in computer industry and their mother is a stay-at-home mom. Christy attends the local public school. She is described by her mother as being a thoughtful, loving sister who has many talents including singing, musical instruments, and drawing. “She taught herself to play [the piano] that song and some other songs. What amazes me about this is when he [Michael] hears that melody, he knows – could sing along with it... it is pretty amazing”(mother of Christy and Max interview November 7, 2011). Christy stated she could not wait to be old enough to teach at her brother’s school.

Carson is the 8 year-old brother of Elliott. Carson is the second to youngest child among five with Elliott at the age of five being the youngest. Elliot attends the same school as Max, however since he is only 5 years old, he has only recently begun attending school. Elliott is non-verbal with emerging communication skills, and according to his mother, he frequently uses physical aggression as a major source of communicating his needs. “It’s because he still hasn’t figured out how he’s gonna communicate, so he is frustrated” (Carson and Elliott’s mom, interview November 28, 2011). However, the episodes of aggression are decreasing every day, especially since he is learning other modes of communication. These include gestures, vocalizations, and basic sign language.

Elliott was diagnosed “at-risk for autism” at the age of 19 months, even though his parents started talking to doctors when he was only 14 months old. One year later, Elliott received a diagnosis of autism on the mild to moderate end of the spectrum. “Now he’s severe, so he’s gone – but I’ve seen a lot of the kids that are delayed at the get-go seem to not crash like the ones that seem typical and then go backwards” (Carson and Elliott’s mom during interview November 28, 2011). She

stated that their extended family (grandparents, uncles, aunts, etc.) have been the most difficult part of having Elliott diagnosed with autism. They do not understand and continually tell his parents, they are wrong and should have him institutionalized. That is something that this family would never consider. Instead, they have been a very close, supportive family giving each other the encouragement needed to “make it through difficult times”. Elliott now receives speech, OT and PT weekly.

Carson is in the 3<sup>rd</sup> grade at a local public school. He loves to play football and Wii (video gaming system) with his brother. Besides Carson and Elliott, there are three older children in their family. Carson told me how he is trying to teach Elliott to play football, “but it is hard for him to catch the ball”.

Amana is the 7 year-old sister of Ita. Amana and her family moved to the United States from Kenya nine years ago, shortly before Ita and his twin were born. Even though Ita’s father is a cardiologist, he knew his children would require more medical attention than they could receive in his homeland. Amana’s three oldest siblings were born in Kenya. Since their extended family is in Kenya, the lack of support and assistance is one of the hardest parts of Ita’s diagnosis.

Ita has been diagnosed with cerebral palsy and autism. He is non-verbal, unable to sign, however uses gestures and vocalizations to communicate. His twin has learning disabilities but is not diagnosed with either cerebral palsy or autism. Ita is the only child within the family with a diagnosis of autism and cerebral palsy. He receives extensive OT and PT services; although his mom said the best therapy “is being a member of our family, and not treating him differently than the other children” (Amana and Ita’s mom interview December 17, 2011).

Amana attends 1<sup>st</sup> grade at the same public school as Ita's twin, however Ita attends a private day school for children with autism. She loves to play soccer and basketball after school at the local YMCA. She also loves to read to Ita and help him learn to identify his letters.

Ainsley is the 7 year-old sister of Erik. She is the youngest of five children and only girl in the family. Ainsley is in the 1<sup>st</sup> grade at a local public school, and her brother Erik attends the same school. He is 10 years old in a 4<sup>th</sup> grade general education classroom, however receives "pull-out" services for core content curriculum and speech approximately 50% of his day. This is the first year he did not have a paraprofessional in the classroom with him resulting in such a large amount of his day being excluded from his peers. His mother told me the school has tried to force them each year to place him in a self-contained classroom. They refused to allow Erik to be placed in an environment that "would not let me grow and challenge him" (Ainsley and Erik's mother during interview, December 29, 2011).

Erik is diagnosed with autism and epilepsy. He was only diagnosed with autism six months ago. Erik has verbal abilities however he refuses to speak most of the time. According to Ainsley, this is one reason that Erik does not have any friends.

Emma is the 7 year-old sister of Emerson. She is in the 1<sup>st</sup> grade and attends the same public school as Emerson. He is in the 4<sup>th</sup> grade, however according to his mom "he will only go through fifth grade, and that's as high of an education as he thinks he needs" (Emma and Emerson's mom interview January 11, 2012). Shortly after Emerson was diagnosed, he began attending a developmental inclusive

preschool. His mom wonders if this is one of the reasons he is “done” with school. “Emma enjoyed preschool. Emerson was ‘put’ in preschool”. Currently, Emerson is in a general education classroom for 75% of his school day, receiving pull-out services for speech and additional instruction in math and reading. He had a full-time paraprofessional assist him throughout his day until “gosh, I can’t remember the year. It seems like when the economy really decreased – and all the school budgets took – yeah, he got some stuff taken away” (Emerson’s mom interview January 11, 2012). Even though Emerson’s parents believe he would benefit from the services of a classroom aide, the school has discontinued this service for children in general education classrooms.

Emma loves being at the same school as her brother. “I see him a lot in the lunch room and we hug each other” (interview January 8, 2012). She also enjoys when Emerson accompanies her to dance class, even though he just sits and “does homework”.

Kadee is the 7 year-old sister of Weston. Their mom disclosed she and her husband decided not to have any more children once Weston was diagnosed “at risk” for autism disorder. “Actually I feel lucky to have Kadee. She is a beautiful girl with a beautiful soul. If I weren’t already pregnant with Kadee, Weston would be an only child” (Kadee and Weston’s mom interview January 20, 2012).

Kadee is in the 1<sup>st</sup> grade while Weston is in 3<sup>rd</sup> grade. They attend the same public school as Emma and Emerson, however none of the children are in the same classrooms. Weston is described as verbal and according to Kadee “asks people, even strangers, lots of personal questions like when is your birthday and how old are you” (interview January 17, 2012). This does not embarrass her yet she wishes he

would not ask strangers when they are at the store. Weston receives support from the special education teacher within his general education classroom, however does not receive pull-out. This is the first year he is not receiving pull-out services for speech.

For purposes of confidentiality, the participants are referred to with fictitious names. No identifiers are being utilized in transcriptions, field notes or summaries. Once the data had been collected, identifiers were secured and only accessible to me. To preserve confidentiality, pseudonyms were assigned to each participant. The data is being kept under lock and key for a minimum of 3 years before being destroyed. At the end this timeframe, all data materials including paper, electronic and taped data will be shredded.

**Recruitment.** Families from non-profit organizations, private schools, local pediatrician and therapy programs, and local community list serves were contacted for participation in this study. These included<sup>2</sup>: (1) Turtle Academy private day school for children with ASD, (2) Frog Academy for Comprehensive Education and Life-Skills, a private, nonprofit special education program for individuals, ages 5-21, (3) State Autism Coalition, support group and information dissemination site for individuals with ASD, families, professionals and the general public, (4) Regional Research and Resource Center, a organization created to support integrative research, educational outreach, early intervention services, training and assistance for

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<sup>2</sup> 1. Local private schools offering academic, behavior therapy, speech therapy, social skills and support for children designated on the moderate to severe end of the autism spectrum; 2. Local organization managed by parents in conjunction with state service organizations that offer service support to families; 3. Regional organizations for self-directed research, serves as a satellite site for national and international projects and provides up-to-date information, training and assistance to families and professionals about autism; 4. Local pediatrician located at a private practice

families, (5) Butterfly Group, an organization dedicated to helping individuals and families utilizing evidence-based practices to teach language, social and behavior skills, and (6) Dr. Rogers, a Developmental-Behavioral Pediatrician, dedicated to evaluating young children deemed at-risk for diagnosis of autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families<sup>4</sup>.

Participant recruitment was carried out via a variety of ways. At the school and therapy practices, informational letters describing the study sent via email as well as sent home in children's backpacks to parents and caregivers whose children meet the inclusionary criteria. Families responded by calling the my cell phone, emailing, or sending back a cut-off form from the informational letter sent in their child's backpack indicating their intentions. Recruitment flyers were distributed by the developmental pediatrician at the local research and intervention center to parents of patients who met the inclusionary criteria. These flyers included my cell phone and email address. Lastly, I attended monthly meetings at autism support groups for parents speaking about my research and answering questions posed by parents. Interested parents and caregivers, who contacted me, were provided with additional information about the study. When the parents agreed to participate, I contacted the family by phone to explain the research project, gather pertinent information, and determine whether inclusion criteria for the study were met. If the family was selected to participate and verbal consent was obtained, I confirmed parental interest in allowing their child to participate, and secured permission for participation in the study. Although the children in this sample were a fairly homogenous group, meaning there are similarities in their backgrounds, they are diverse in the sense that

they hold different cultural beliefs and traditions. Parents and family possessed different cultural beliefs that influence their children's thoughts on school, family roles and recreation (Rogoff, 2003).

**Informed consent.** All parent participants signed an Informed Consent Form (see Appendix C) prior to beginning the study. The Informed Consent Form described the nature and purpose of the study to the participants as well as the risks and/or benefits. In addition, it informed the participants that their involvement was voluntary and that they could withdraw from the study at any point without consequence from their school, agency or myself. All participants younger than 18 years of age signed a Children's Assent Form (see Appendix D). The Children's Assent Form explained the purpose of the study using appropriate verbiage for their age and asked the children if they were willing to participate.

### **Setting**

Child interviews took place within the children's homes, more specifically area in which the child felt most comfortable and had chosen him/herself. Examples of areas are: kitchen table, family room, living room, child's bedroom as well as backyard. The child was encouraged to find a place in their home where they felt most comfortable talking about their relationship with their sibling.

All participants in the study lived in a large Metropolitan city. The area consists of nine suburban cities that include culturally and linguistically diverse populations offering a variety of accredited school options including public, charter and private schools (<http://2010.census.gov/2010census/data/>). The medium household income in the Metro area is \$48,711. According to the U.S. Census

Bureau (2010) the following chart represents the population ethnicity in the Metropolitan area (figure 6):

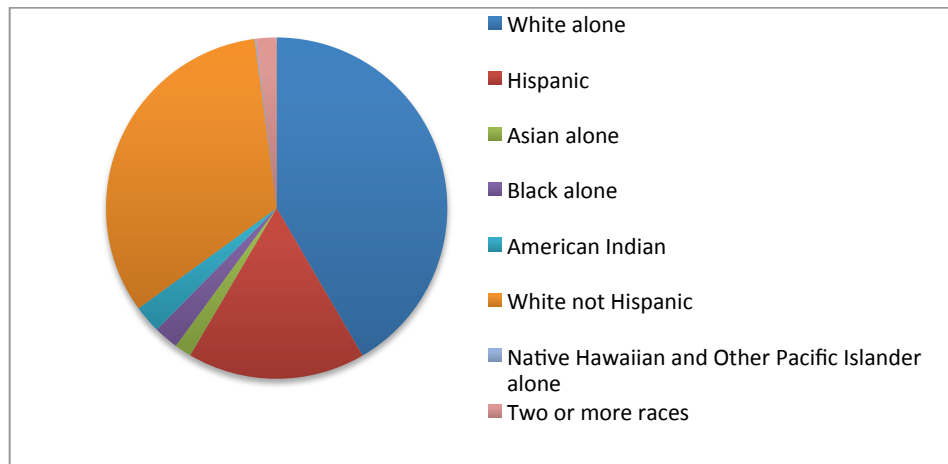


Figure 6. Metropolitan Population graph

Additionally, that there are a variety of private and public providers of services for families and children in the metropolitan area that I accessed to find my sample.

### **Procedures**

Once a parent had signed the parental letter of permission, I asked the children verbally if they would like to take part in the study by spending time with me watching videos and talking. When the child agreed to participate in the study, I asked him/her where they would like to “talk” with me, except for the two children who were interviewed at their sibling’s school. I explained to the child that I would like to find out more about their relationship with their sibling. Children signed an assent form after I explained their part in the study.

I told the child that I would show them some videos of their sibling and them playing. The parent(s) of the children participating in the study provided videos. One week prior to the interviews, I provided the parent(s) with a flip-camera to capture video of their children participating in natural play activities together;



having the parent(s) film the video ensured a natural situation for both children and did not create contrived situations that often happen in research videos. I gave the parent(s) detailed instructions regarding the type of activities to record. Even though I explained to the parents, the length of each individual was not as important as recording a minimum of thirty minutes of social interaction between their children over the week's time. One request, not requirement, was that the maximum length of each recording was ten minutes. This is due to the desire to receive a variety of videos containing several types of social interactions. The parent(s) made individual decisions regarding their perception of social interaction and play between their children. While reviewing video-clips, I discovered a wide range of activities including but not limited to: basketball, trampoline jumping, video games, singing, dancing, scooter and bicycle riding, reading books, and play on outdoor playground equipment. All videos included at least one segment of the child identified with ASD being prompted to imitate fine and gross motor skills demonstrated by the sibling. All parents stated they considered these activities typical social interactions between their children. I previewed this video before meeting with the child and parent(s), and created an unedited version of the video clips into one continuous movie.

We viewed the videos on my laptop computer. While showing these video clips, I had the child talk about the clip with their descriptions and stories. Although I had a few pre-determined questions, I allowed the child to lead the discussion regarding the video clips. The videos provoked many stories and discussions of social interactions between the children. While interviewing Emma, she asked me to rewind to a particular segment several times. She giggled and said, "this is one of my

favorites because Emerson was playing with me and it was so much fun.” This led to additional stories about similar activities. The interviews were each about 30-minutes in length, a period of time that seemed ample enough to encourage the participants to talk freely until they had nothing left to say. The thought behind this interviewing was that it would yield a body of discourse rich enough for retrieval of cultural schemas. During the interview, I kept field notes (a running account) in order to capture a whole picture of what was happening. It is important, particularly in the earliest phases of research, to keep thorough field notes to review and re-analysis while viewing the videotapes of each session. Finally, I interviewed one or both parents regarding their observations of their children playing together and the siblings’ relationship.

### **Data Collection**

Once with the child, I explained the interview procedures, obtained signed assent, and provided the child with an opportunity to explore the recording/video equipment. Additionally, I encouraged the child to ask any questions about the interview at that time, as well as any time during our time together. I dedicated some time before I asked the child to watch the videos with me to get to know the child better by playing games, telling jokes and engaging in conversation. A period of free talk facilitates a comfort zone for the child and the interviewers ability to understand the child’s communication style and concerns’ (Fargas-Malet et al., 2010).

Griffiee (2005) suggests interviewing is an effective way of gathering qualitative research data because it is perceived to the participants as talking, and talking is a natural activity. Data was collected from semi-structured face-to-face interviews using video-clips of the child and their sibling playing and open-ended

questions. Open-ended and wh- questions allow for elaboration of information that may be pertinent to the research that may not have been thought of as important when designing the interview questions (Clandinin & Connelly, 2000; Fargas-Malet et al., 2010; Tsai, 2007). Interviewing involves the gathering of data through direct verbal interaction between the participant and researcher. Creswell (2005) suggests the following protocol be administered when conducting an effective interview:

1. Determine the type of interview you will use.
2. During the interview, audiotape the questions and responses.
3. Take brief notes during the interview.
4. Obtain consent from the interviewee to participate.
5. Have a plan but be flexible.
6. Use probes to obtain additional information.
7. Be courteous and professional when the interview is over.

A digital voice recorder and a flip video camera were used during the interview for an accurate, clear recording. While accuracy is important, it is also important to remember the limitations of this method of data collection. The presence of audio and video recording equipment on the table in front of the participants during the interview may certainly have influenced the content and form of their stories. However, it is difficult to describe exactly the type and extent of beyond observing the inhibitions. For example, the children appeared uncomfortable and unable to speak beyond single word answers until they got used to the recording equipment and me.

The questions in the interview guide, which I developed after careful analysis of the video filmed by the parent(s), were used as prompts to gather information, so

the same questions may not have been asked of each participant. Each participant offered a unique perspective and insight to their life with a sibling diagnosed with ASD. The interviews were kept brief, however enough time was allotted for the interview so that the child could talk to me without feeling rushed or constrained due to time restrictions. The protocols used in the child interviews can be found in appendix A.

After I interviewed the child, I requested the parent(s) to participate in semi-structured interview following the same procedure as the child's interview. Parents were given the option of setting up another appointment if time was a concern. Parents were asked a series of 11 open-end interview questions about their children's relationship (appendix B). Specifically, this interview inquired about family size, context of their child's diagnosis, support systems, opinions of their children's relationship and activities their children participate in together. Prior to the completing this interview, the parent(s) were reminded of confidentiality and the research was voluntary.

Interviews are particularly useful for getting the story behind a participant's experiences. The interviewer can pursue in-depth information around the topic. A qualitative research interview seeks to describe the meanings of central themes in the life world of the participants. The main task in interviewing is to understand the meaning of what the participant is saying, covering both a factual and a meaning level, however it is usually more difficult to interview on a meaning level (Kvale, 1996). Semi-structured interviewing, according to Bernard (1988), is best used when the researcher won't get more than one chance to interview someone. When a researcher is able to reconstruct the same structures from the talk of a variety of

different people, then this is evidence that they share similar or the same understandings of the cultural structure (Quinn, 2005).

### **Interview Guide Design**

Open-ended interviews with the child are the primary source of data for this study. Open-ended interviews provide for flexibility, and the researcher is better able to accommodate individual needs, and individual styles of communication (Clandinin & Connelly, 2000). Therefore, the goal of my conversations with participants was to allow them the opportunity to share their stories. Participatory research techniques were used as an approach when interviewing the children. A participatory approach is described as an active technique that allows the participant to create “inclusive accounts using their own words and frameworks of understanding” (Fargas-Malet et al., 2010, p 184). Research has shown it can be difficult to interview children when relying only on conversational approaches (Fargas-Malet et al., 2010; Komulainen, 2007). As the researcher, my role was to be an attentive listener with the ability to ask questions and reflect on what I was hearing in order to respond appropriately.

Although the entire interview protocol is included in the appendices, questions asked during the interview were to focus specially on their sibling relationship, play experiences, understanding and knowledge of autism and interpersonal feelings associated with having a sibling diagnosed with ASD. Children were asked questions such as:

- Describe your favorite thing to do with your brother.
- Tell me about an activity (time) when you and your brother had a hard (difficult) time.

- Describe the best place (environment) to have a good time with your brother.
- Is it easy or hard to play with your brother?
- Do you have a lot of fun when playing with your brother?
- Do your friends ever play with you and your brother?
- What makes your brother different from you?

Questions regarding the actual video clips included:

- Can you tell me about what you are doing?
- After watching this, how does it make you feel?
- Is this something you do together often?
- How does this video make you feel?
- Do you remember how you felt when you were playing with your brother/sister?

Parents were shown the same video clips as their child was, and asked to describe the activity. Parents were also briefly told the stories their children revealed while watching the video clips, and then asked a series of questions such as:

- Do you have the same memory or feelings of this event? Tell me about it.
- What different types of activities do your children do together?
- Do your children 'play' together? Describe a typical 'play' time that you would observe between them.
- Do you feel the videos you took were representative of typical interactions between your children?

- What do you feel is the best thing about your children’s relationship?

Parents were also asked questions regarding their family demographics, their child’s diagnosis and support services.

### **Analysis and Interpretation**

As stated previously, interviews were recorded and transcribed. Because I needed a research method that would produce rich conversations, I chose to use a video-cued multivocal interview approach so that I would be able to draw a picture from the child’s stories about what is happening in their life. I followed the work of Bogdan and Bilken (2003) and Tobin (2000) to analyze data collected during interviews. This work offers more of a procedural guide rather than a strict form of analysis. Telling “stories” about reality, instead of claiming you are revealing an underlying meaning to reality describes a narrative way of knowing (Tobin, lecture notes, 2009). Studies using stories examine the ways that consistency, voice and positioning are achieved in dialogue. This phase of research involved organizing, analyzing, and synthesizing the data from the interviews into clusters and themes that emerged during data collection (first within each case and then, across the cases). According to Burnard (1994), the coding process entails making sense out of text data, dividing it into text segments, labeling the segments with codes, examining the codes for redundancy and/or overlap and finally reduce these codes into broad themes. I used my conceptual framework to help make sense of the data when creating categories for these themes.

In order to answer the question, “what kinds of activities constitute play?”, I analyzed transcriptions of the interviews comparing the child’s answers with the

video clips, as well as the video-tapes of the interview. While rereading and watching the video, I wrote down any impressions looking for emerging sub-categories within the major themes. This iterative and progressive process assisted in identifying new categories to accommodate data that do not fit the existing labels or to adjust the definition of current categories (Powell & Renner, 2003). This process continued until no themes or subcategories were identified.

The word 'voice' draws our attention to what and how the speaker communicates together with their social and cultural position from which he or she speaks (Chase, 2000). The combination of what, how, and where makes the speaker's voice particular. Utilizing a viewpoint that stories are constrained by both social resources and circumstances, the researcher emphasizes patterns in the stories and realities created (Chase, 2000; Einarsdottir, 2007). Although I am aware of the intersections produced in children's stories, I treat these stories as socially situated interactive performances. This allows me to making meaning out of the data while constructing an understanding of the child's life and views of play with their sibling diagnosed with ASD. It is important to seek these children perspectives.

Language and the world are mutually reflective and bidirectional; if you don't know the world, then the language is almost meaningless. You need to know something about the world in order to contextualize the language that is used within this world. Parents who have children with special needs understand and use a language full of acronyms, abbreviations, medical jargon and vocabulary that can be overwhelming for individuals unfamiliar with the terminology. I utilized tools from "looking awry" (Tobin, 2000; Zizek, 1991) as I reviewed the audio and videotape recording of the interviews. This included searching for such elements as aporias,



performative texts, intertextualities, slips, binaries, and enthymemes. These patterns and themes were then analyzed alongside the guiding theoretical perspectives discussed earlier.

I used my experience as a special education teacher and a parent of a child with special needs to justify my knowledge of the language the parents in this study used. However, according to Gee (2011) it is important to act like an outsider when analyzing a conversation. It helps figure out what people are trying to accomplish with their words. This is valuable when interviewing an individual who assumes you understand and speak the same *language* they speak. The use of audio and videotape recordings allowed me concentrate on the interview while it was occurring due to the fact that I could listen again to the tone, the pauses, the intonation, and other visual aspects involved in interviewing.

At this point, hypotheses were formed regarding each portion of the text and its relationship to the research questions. These hypotheses were then compared to the context and other elements of the text until the hypotheses and data had ran their course.

When analyzing data in this manner, questions of validity of the interpretations as well as analysis of lived experiences are often raised. First, I must acknowledge that I bring my own biases to this research project. In this project, I directly address those biases as part of the data that includes my own experiences as a parent of a child diagnosed with Asperger's syndrome and as a researcher. I have experienced many of the same schooling and parenting issues as the parents in this study. My three other children have gone through a variety of the same emotions and experiences over the years as the children in this study. My son was originally

diagnosed with ADHD and learning disabilities in 2<sup>nd</sup> grade and did not receive the Asperger's syndrome label until two years later. However due to this first diagnosis he was eligible for an Individual Educational Plan (IEP). Even though this did not cover his social needs, he began to receive pull-out services for curriculum content and speech. This was the beginning of my journey into the world of special education, developmental specialist, and psychologist. While this by no means succeeds in making my work un-biased or that all my biases are directly addressed, it does address the issue of researcher bias.

This method of analyzing children's stories, recollections and actions, provide insight into how children negotiate and mediate relationships within their activity system of home and community, how they negotiate and mediate any conflicts that occur within this activity system, and identify any actions of resistance and/or compliance within these conflicts.

### **Summary**

In this chapter, I introduced and described the methods I utilized to collect and organize data. I discussed the approaches I used to analyze the child's understanding of ASD, the sibling relationships through the eyes of the child, and their perceptions of play and learning with siblings and peers. The interviews offered more perspective on these topics, and provided an understanding of these areas of child development. This research contributes to the body of research regarding children with ASD by providing the voice of their sibling in regards to social and family issues. This chapter explained the methods used in this qualitative study of children's perceptions of play and social interactions with their siblings diagnosed with ASD. The next chapter presents the findings from this study.

## Chapter 4

### FINDINGS: MAKING SENSE OF LIFE WITH AUTISM

*“He is the same as everyone else, it is just that his brain works different than ours”*(Carson)

This study was my attempt to capture and interpret the responses of siblings of children with ASD to better understand their perceptions of the notion of ASD and its impact on play and social interactions within their sibling relationships. I wanted to gain a deeper sense of how siblings and their parents describe play and social interactions in the sibling relationships when one of the children was identified with ASD. Through both parent and sibling perspectives I gained a deeper appreciation of how children engage in play and socially interact within their families and make meaning of the impact of ASD on their lives in as they construct and shape their identity.

Each interview was conducted using a video-cued interview technique (Tobin, 2000). The video clips included the children engaged in play or social interactions as captured by their parents. During the interviews, the sibling and I watched video clips together while they told the story of the activity. The siblings seemed to enjoy watching themselves in the videos as well as talking about the activities. Throughout their stories, the siblings gave examples of division of labor, rules and ultimately, who held and exercised the power in the social interaction. I defined power as Wenger (1998) defines it: the degree to which individuals are able to control their surroundings including the behavior of others within that environment.

In this chapter, I address the features and themes of the interviews and observational data, contextualizing my interpretations with the work of other

researchers and scholars. This discussion is organized by the viewpoints and stories told by siblings and parents and what triggered these particular recollections. Four questions anchored this analysis. Ultimately, four main ideas presented themselves: (a) how siblings play and interact, (b) how roles are acquired and developed within the family structure, (c) how siblings make sense of ASD, and (d) family life.

### **How Siblings Play and Interact**

Play is the vehicle through which lifelong relationships are created and reinforced. It is a vehicle in which a child can be exposed to a world of new and novel activities, while he/she controls the rules surrounding their play, experiment with new identities, take risks selecting new activities, and begin to understand actions have consequences (e.g. Baker, 2000; Bass & Mulick, 2007; Boutot et al., 2005; Smith, 2010; Toth et al., 2007; Tsao & McCabe, 2010; Wolfberg, 2009). One example of turn-taking in regards to cooperation was a conflict at the point of “rules” between children involved in the social interaction or game. “We were playing with Tinker Toys™. First, Weston put one together, and then I did. We made a swing for our stuff animals” (Kadee interview). Children as young as two to three years of age appear to use guidelines for the structure and organization of their play (Cole, 1986) that can be described as rules. In this section, I explore how the siblings in this study describe their understanding of the importance of play and social interaction as an imperative part of their sibling relationship. This is an important part of children’s development of their identity around different roles such as rule maker, judge, or enabler, as well as the beginning development of the rule-bound view of how activities occur in relationships and surrounding community.

When speaking to the siblings about playing with their brothers, the juxtaposition of responses remained constant among all participants. “It is sometimes easy, sometimes hard” to play with the child identified with ASD. This highlighted contradictions and conflicts the siblings brought to light in our discussions. The explanations of these contradictions often depended upon the situation, place and activity, as well as whether their brother would listen to their directions and rules. Another theme involved the siblings’ desires to ensure that their interactions with their siblings identified with ASD were happy and fun: “when he is happy and smiling – I feel really happy and want nothing else” (Kadee interview). On the other hand, Ainsley voiced her concern for Erik’s unhappiness, “he usually wants to play alone, and he eats alone at McDonald’s. I just want him to be able to play with me.” Ainsley and Kadee offered examples of sensitivity and the siblings’ responsiveness to their brothers’ mood when interacting with the child identified with ASD; however, these actions have implications regarding the ways they perceived, acted upon, and thought about their relationships. Each of the girls demonstrated a different class of interest within the actions and motivations taken to ensure their social interactions with their brothers met the girls’ particular needs. The connection of these actions may not have been readily apparent however appeared to meet the same motivations for these siblings.

Carson and Elliott have two other brothers and one sister. Their mother told me that all the boys, except Elliott the youngest child, play tackle football. The videos of Carson and Elliott included jumping on their trampoline and ‘football’ in the backyard. During the interview, I asked Carson about how he felt watching the videos. “Happy that Elliott gets to jump cuz he loves it.” Since Elliott is non-verbal,

I asked him how he knew Elliott like jumping on the trampoline. Carson told me, “He always giggles and laughs sometimes. When he giggles and laughs, we know that he likes it [play or activity]. He also pulls us out to go on the tramp.” Carson is basing his knowledge of Elliott’s happiness on the recall of concrete instances, not on abstract generalizations. His memory of past events foreshadows the description of later social interactions resulting in tolerance of Elliott’s desires. Carson told me that Elliott even pulls his friends out to the trampoline to jump with him.

Whenever he pulls me, they know that he wants to jump on the tramp.

Sometimes they want to jump on the tramp with him. They just go like, ‘do you want to jump on the tramp with Elliott?’ My friends like to be around Elliott. They like to play with him. They like to play with him- this makes me happy that Elliott gets to jump cuz he loves it (Carson interview).

When I asked Carson if he and his friends play without Elliott, he said, “yeah. We like to play Wii Madden™ [video game]”. When I asked if they let Elliott play video games with them, he shook his head.

Well, he just watches us. He sits there, but sometimes stands in front of the TV or tries to take my controller away from me.....well, if it’s my controller I’ll let him. Cuz if – well, he likes to bang the controller on the couch (Carson interview).

Carson thinks when Elliott is older and “he can understand”, he will teach him how to play, but right now, “my favorite place to be with Elliott in on the tramp.” Most of Carson’s stories about playing with Elliott involved jumping on the trampoline, making him laugh and giggle.

Carson: He also likes basketball. I give him the basketball. He likes to throw it. He does not know how to shoot hoops, so we just throw it back and forth.

Interviewer: Could you teach him to shoot hoops or dribble?

Carson: No. It's too difficult for him to do, because sometimes he doesn't understand and all that stuff. I try and teach him but sometimes it doesn't work. He gives me high-fives. I can only teach him how to do high-fives (Carson interview).

Carson was very uncomfortable talking about things that Elliott cannot do. He immediately, without prompts, changed the subject to talk about things that made Elliott happy. "He likes getting his belly rubbed. Not tickled, just rubbed." Carson's clarifying comments, nonverbal gestures and inability to relay negative issues about his brother are the same typical actions any other sibling would take when they tell stories about others, especially those they care about, that cast an undesirable or adverse picture on the individual. Carson's stories indicate a level of engagement that indicates his affective state influenced by previous experiences involving Elliott. For example, Elliott's ability to play football, express a preference to jump on the trampoline but not able to partake in video games illustrate Carson's perceptions of Elliott's capacity for engagement with certain activities. His emotional responses to the situations are helpful to understand the extent of which these reactions affect his sibling relationship and social interactions with Elliott.

Emma also told me she knows Emerson is happy because "he jumps around, runs around the house. He is excited. I know 'cause he lets me play...when he is mad, he scrunches his face up and squeezes me." Emma told me:

Emerson likes playing the Wii. We play sometimes together and sometimes I just watch. Mostly I just really ask him that I can play and he says yes. When I don't want to play Wii, I just come in and watch him (Emma interview).

Emma went on to say she will just keep asking him and whine to him if he won't let her play.

Emersooooonnn – that is what I say to him until he decides to let me.

Sometimes I have to tell Mom though. But he plays with me a lot, so I don't have to do that very much. This makes me very happy. I get really excited if he lets me play with him (Emma interview).

Additionally, Kadee verbalized the same sentiment with different results:

When Weston won't play with me... I was like, "Weston." He's like, "Ugh."

Sometimes I just have to do what he wants to do, because then [if I don't] he's going to quit playing. So, I'll just do it. I don't really care about it [the play activity], unless I'm doing it [playing] with Weston (Kadee interview).

Emma and Kadee demonstrate their tenacity or measure of strength in which they dedicate time and energy to creating a strong sibling relationship. In addition to this tenacity, they both make evident the need to relinquish their own rules and boundaries around what constitutes play and give into the wishes of their brothers, even though the activities may not be what they consider engaging. Perhaps these responses are developed through the previous reactions of their parents in regards to the actions and behaviors of the child identified with ASD.

**Negotiating a place in the life of the child with ASD.** When asked, “what are your favorite things to play with Emerson?” Emma replied, “Wii, bowling and basketball at our school are my favorite things to do with Emerson. He likes to



play Power Rangers and I like to play Monster High™. But when we play together, we play Power Rangers fighting.” However, Emma as well as the other siblings stated they let the child identified with ASD determine the ‘tools’ to be used in play in order to ensure the social interaction will be enjoyable and maintained. Some of these objects include items such as: video games on Wii™, Angry Birds™, bicycle, scooter, football and playground equipment. For example while watching the video of Emerson and herself playing, Emma explained how one particular play event that occurred between her and Emerson demonstrated her open-mindedness and acceptance of play activities devised by Emerson. Even though this type of event may be typical for siblings engaged in play, usually there is an element of give and take among children. Emma’s tolerance of Emerson’s continued need to control the social interactions between them demonstrated a different level of temperance and patience of her brother’s behaviors.

We were pretending that the skateboards were our beds and those little foam things were our blankets. This was Emerson’s idea. I saw him doing this, and I wanted to do it too... It makes me happy to do things with him that he has made up (Emma interview).

Each of the siblings discussed their favorite play activity as it revolved around the wishes of the child with ASD, beginning to reveal levels of altruism and empathy as potential motivational factors within the sibling relationships. Carson repeated Elliott’s favorite play activity, as his own favorite activity - the trampoline. “He [Elliott] likes me to jump on the tramp with him, but he also likes basketball.” When Amana and Ita watch TV as part of their social interactions with each other, Amana said, “Ita -- He likes to watch *Blue’s Clues*™. I like to watch *French Father*™.

Well he gets to pick more because he goes to bed earlier than me.” When questioned about the types of activities Weston likes to do, she said, “He just likes going on the iPad and watching TV. But we do play in a bowling league and sometimes Tinker Toys. Weston doesn’t really like to play for that long.” This is another small example of how the child with ASD determines the play activity or they will not play. The desire to play with the child with ASD outweighed the siblings’ own desires regarding particular play activities. Each sibling spoke of how they were willing to abandon their desired play activity if choosing that particular activity would potentially lose an opportunity to play with their brother. Key to the play interaction between children was the willingness of the sibling to compromise for the child with ASD.

According to Piaget (1962), the generalized actions used to internalize knowledge are imitation and play. Within the concepts of *assimilation* and *accommodation*, Piaget describes approaches of interacting with the environment. Christy is the oldest of the sibling participants and appeared to be very mature in her actions and construction of rules and division of labor between herself and Max. This may be explained by applying Piaget’s concepts. The interactions between Christy and Max have consisted of the interplay between assimilating external factors or tools into existing patterns of activity, and accommodating Max’s needs for support learning the required tasks of the new activity or desired outcome of the activity. She spoke about time with Max in terms of playing together, helping him with different types of skills (imitation, modeling, turn taking, etc.) and teaching him to become more involved in the brother/sister relationship. Christy’s use of practical tools and objects allow her to logically think about the rules needed to

construct social interactions with Max. Piaget (1962) noted the process of play and imitation allows a child to adapt to the environment. As Max performs an action designated by Christy that has an effect on outcome of play and social interactions, Christy is able to identify new rules and knowledge that will impact their future activities. For example, Christy described the use of her guitar and microphone as a way of teaching Max music through modeling and her scaffolding each task into small segments. She explained how it was important to “show Max first, then let him try, and then show him again after praising him for doing a small part of the activity.” The activity of playing the guitar and attempting to ‘sing’ the songs allow Christy to act as the teacher, the mediator of the activity, the playmate and creator of the rules. Vygotsky’s zone of proximal development balances this work in which through play, individuals find new uses for everyday tools, and new tools that allow for the activity to be performed more easily (Vygotsky, 1976). This work reaffirms the approach of the role of play in learning, particularly the function of imitation to achieve external development of play activities. When asked about playing with Max she said:

Playing with Max that’s a hard question. [She put her finger to her mouth and looked up to the ceiling while thinking] Well, it still feels like I’m playing with my brother and I have fun, but I just wish he could talk. I’d want to him to be able communicate to me that would be more fun for me (Christy interview).

Whenever Christy spoke of ‘playing’ with Max, the activity involved some type of therapy or teaching. Even though the discussion of *assimilation* and *accommodation* have help enhance the explanation of Christy’s roles and attitudes

regarding interactions with Max, however it does not begin to account for the degree in which she is missing opportunities afforded to other 9-year-old children who do not have a sibling identified with ASD. Christy's parents did not reveal their thoughts regarding the extent in which she is missing typical opportunities as well as if Christy herself understands the level of difference between her sibling relationship and other sibling relationships. However, Christy's attitude associated with play and social interactions with Max were formed through participation and manipulation of activities.

It feels a little bit different, maybe like he's maybe younger than his age. I still love him very much. Well, it's hard because he never asks me to do like play like that. Sometimes he'll want me to do like little things, but not like 'Christy let's go on the monkey bars' or something like that. I just want him to be able to play with me (Christy interview).

One thing I found thought provoking within this interview (and with all the interviews) was that the siblings would justify or clarify something they perceived to find negative with statements of their love for their brother. One possible interpretation is that the demands of family life seem to produce deep levels of connectedness – but we do know that in many families with children with ASD, there is great dysfunction as well that revolves around attention, intimacy, and identity needs (Bachraz & Grace, 2009; Barr & McLeod, 2010). It was also conceivable that these siblings, especially Christy, believed that these types of actions give her 'purpose' in her brother's life as well as a place in the family. Her attention and effort with her brother help her to make a place in her family and gave her role great importance within the family structure. While social and communication skills

had a meaningful impact on how families construct social interactions and identities, it was also clear that family dynamics play a noteworthy role in shaping sibling relationships. Action-oriented communication mediated social relationships. However, it may be that siblings of children with ASD are hypersensitive to their parents' motivations to demonstrate a sense of "normalcy" within their family structure. Many times we, meaning the collective we of society, hear statements of negativity tempered with comments such as, "I don't want to gossip but...". "She is a nice person, but...", "I love how he sings but...", or "I really respect his teaching ability but...". At some level, the siblings understand that even though they notice differences, problems, or issues surrounding their brothers' behavior, to assert a critique, they must balance it by also asserting love. The siblings seemed to have a finely gauged understanding of appropriate actions and words to express what they thought and felt regarding ASD and their brothers. The ability to switch between positive and negative comments suggested that these siblings had a well-developed capacity for adapting to their audience, however it appeared they are unaware of this adaptation. The participation in conversations regarding their family structure particularly in the realm of play and social interactions with the child identified with ASD entailed negotiating the roles of speaker and listener in order to influence the conversation. During the interviews, the siblings demonstrated the strategies to ensure their sibling relationship were interpreted in an optimistic light.

**Finding a unique identity for siblings.** Another possibility for these reactions may be associated with research which has documented that siblings of children with a disability believe the reactions of strangers could be improved upon (Opperman & Alant, 2003; Pit-ten Cate & Loots, 2000; Teverovsky, Bickel, &

Feldman, 2009). These siblings thought, “people should be better informed, should behave more ‘naturally’, show more respect, and certainly refrain from staring” (Pitten et al., 2000, p. 403). All of Christy’s examples of ‘playing’ with Max included: reading and him memorizing the story of his favorite book, reinforcing positive behaviors, Max “earning a reward”, teaching him to play guitar –

Well, I’m not really learning to play I’m just strumming the guitar and I have him – I like to have him try to strum the guitar like me. When I read to him, I usually let him pick the book, but he always picks “The Old Lady of Swallowed a Fly”. That is his favorite (Christy interview).

Listening to Christy I surmised that she grew up attending therapy sessions with Max (which her mother confirmed in the parent interview). However, Christy does not have the same ambition for participating in activities with her friends as typically seen within this age category of children. She appeared to be satisfied with Max being her primary playmate and source of social interaction. Even though many families may demonstrate the same type of closeness, typically siblings rely on individuals outside of their family to fill these roles. This continued to confirm the motivation behind Christy’s actions and feelings of her role within the family structure which are to ensure a level of happiness and peace without apparent concern for her own personal needs. Even when she told me about a recent trip to Disneyland™, she spoke about doing things because “Max wanted to do it” or “I did not want to upset Max.”

Well, he does have a special pass [at Disneyland™] where he can go ahead and we get on all the rides in like two seconds. It’s very fun to go on the rides with him...Well, if he gets upset at Disneyland™ he’ll just want to go

home to the... or to the hotel and it makes me feel sad and a little bit angry 'cuz I don't want to go home. When I'm at Disneyland™, it's like its not even closing hour yet. 'Cuz whenever you go to Disneyland™ you want to stay there a long, long time (Christy interview).

I asked her if she thought she missed things because of Max. Christy's response was centered solely on their trip to Disneyland™, even though we were not speaking about Disneyland™. I believe this may have been an easier way for Christy to bring negative aspects regarding her brother into the conversation.

I don't feel like I miss out on everything 'cuz I've at least been on every ride once, but well, if he wants to go to the hotel and he insists on going to the hotel I don't want to make him mad at me and start hurting me or anything so. He loves the hotel though 'cuz he—it's fun for him (Christy interview).

She continued to talk about how important it is to her to make him happy and be with Max all the time, so she can't complain about anything. "Well, we're never like really apart. We're always together and that makes a family" (Christy interview). This appears to be Christy parroting what her parents have said to her in the past regarding their family. Many families, who share the same cultural histories as Christy, encourage their children to go outside of their nuclear family in order to find increased social situations and interactions unlike what Christy's family does for her. This situation gives the impression that Christy and Max's family believe they must revolve around each other, especially Max in order to meet his needs and ensure the family stays focused. These actions may meet the parents' need to have another person in the home that is capable of meeting the needs of taking care of Max and to alleviate some of the stress felt by the parents. However, it is unclear if

Christy's dependability was a product of their parents' need for this additional to person living in the same household.

Amana articulated her thoughts regarding play with Ita. "I like to play games with him, though it [getting him to play] is sometimes hard, sometimes easy."

Ainsley and Christy reiterate these ideas, "I love playing video games" and "I just want him to be able to play with me." The common theme among all the siblings in respect to playing with their brother was these activities made them feel "happy" and "excited". Ainsley is the youngest of the participants, summed up the feelings of the siblings, "I just wish he would say yes to me when I ask him to play." This is a major outcome desired by all of the siblings in this study, "so that I can feel like he wants to be with me" (Kadee interview). In the midst of families struggling with everyday tasks, the siblings face their own unique struggles. Through their efforts to accommodate, siblings of children with ASD may feel as if the label of ASD requires them to subordinate their own interests, which elevates the status of the child identified with ASD. For young children, this may create some detachment and disassociation from their own wants and needs. Children within families without any identified disabilities or disorders rarely perform in this manner (Sanders, 2004). The typical sibling relationship has a variety of give and take as each child's identity is created within the family structure. A major difficulty for the siblings in this study becomes the complexity of being seen as a unique person within and outside the established family structure.

**Community and play.** Strategies and tools were negotiated and substantiated with the community that had become a source of the children's social development. The community has provided feedback, models of relationships,



sources and rules for comparisons, and support for the children's social relationships. It is important to note that community groupings (such as peers, classmates, strangers) contribute to fundamentally different types of activities. When the siblings spoke about peers, other family members, and "strangers' within the community, it became clear the configuration of community defined how the siblings interacted with the child identified with ASD and the members of the surrounding community. "If they [peers] are mean to my brother, they are not my friends" (Christy interview).

Lave and Wenger's (1991) definition of learning as increased participation within a community of practice indicates that learning requires augmented attention to the ways in which the activity is established by the relationships between person, their actions, and the world. "Learning unfolds in opportunities for engagement in practice" (Lave & Wenger, 1991, p. 93) as the knowledge and skills are examined. When left on their own, the siblings demonstrate ability to find and develop play and social interactions with peers without prompting. They are able to initiate activities with particular peers, negotiate and expand, develop and transform a theme as play develops. Throughout the interviews, the siblings made evident their desire for the child with ASD to have this same ability within the community. Christy illustrated the point of fair-mindedness and patience, however the siblings did not demonstrate this point toward their peers or themselves:

Christy:           Because well, I just see a smile on his face all the time and he likes to dance with me... We were doing speech at the park with his speech pathologist and he was going down the slide

with me and swinging with me and that's also really fun for me too. I want him to do that with other kids – like if he had a friend, other than me.

Interviewer: What happens when he's not smiling?

Christy: It makes me feel a little bit sad and like he's doesn't know how to have fun and make friends—it just makes me feel sad.

I found it interesting how she said, “we were doing speech”, and so I wanted to know if she felt like this was playing. However, she continued to expound upon the separation of her peers and her sibling with ASD. Christy voiced without explanation, “he doesn't meet my friends that much... He always says how he wants to go to my school and play with my friends. But I just [say], ‘Max I wish you could go too.’” When further questioned about why Max does not get to spend time with Christy and her friends, she only answered, “I don't know.”

Friendships are one important type of child-motivated community in this activity system. This definition of learning from Lave and Wenger enables participation by the newcomer as well as the expert. “For newcomers then the purpose is not to learn *from* talk as a substitute for legitimate peripheral participation; it is to learn *to* talk as a key to legitimate peripheral participation” (1991, p. 109).

While I heard dozens of stories regarding social interactions with peers at school and the importance of these interactions, Ainsley's explanation regarding Erik's lack of friends provides a beneficial demonstration of the power of peer relationships.

During our conversation, Ainsley provided her explanation of why Erik does not

have any friends and why he would not approach another child without intense prompting.

Ainsley: He doesn't wanna talk to people.

Interviewer: Do you think you would like to change this [how he behaves with others]?

Ainsley: Yes, Erik having friends over. Him doing really, really fun things that we both like to do a lot of times. That would be good.

During this interview, I noticed that Ainsley consistently compared her relationship with Erik to her relationships with peers, in addition to her interpretation of "a good friendship." The siblings continue to report times of supporting, nurturing and becoming allies with the child identified with ASD in their shared world that is different than what the siblings shared with peers and parents. Ainsley was not the only sibling to provide ample examples of peer relationships and how their sibling with ASD behaved differently than their peers. What I found particularly noteworthy was the manner in which each of the siblings described these differences that were influenced primarily by physical attributes, not deficit behaviors. These siblings also used this philosophy when speaking about their peers.

Emma: Because I play with my friends, and also they're both girls.  
He's a boy and there's only one.

Ainsley: Because my brother has medium ears, and my friend Gavin has large ears.

Carson: My friends mostly can play Madden™ without breaking the

controllers cuz their fingers know what to do.

Kadee: Sometimes Weston's voice gets real high when he gets mad while we are playing – my friends' voices don't ever do that.

Even though the siblings major points of difference involve physical attributes, when members of the community [strangers] perform negative actions or voice derogatory comments toward the child identified with ASD, all siblings expressed feelings of anger and “are very bothered” by these remarks. This leads to speculation regarding the siblings' feelings when faced by negative situations in the community. The siblings may regard these comments as personal attacks on their own being or their family structure. This sense of responsibility toward the child identified with ASD and the protection of the family structure may be a result of the siblings' understanding of the parents' struggle with caring for a child with ASD. The siblings' empathetic feelings for the child with ASD and for their parents were noticed throughout the interviews. These feelings also explain the siblings' reactions to negative actions and derogatory comments. The experience of empathetic feelings led to an understanding of behaviors such as helpfulness and nurturing.

**Play outcome for siblings and child identified with ASD.** Sibling social interaction and play are implicated in the CHAT model. By assisting the siblings to organize concrete experiences (situated knowledge) and through their role in identity construction (situated self), social interaction and play support the relationships that form the activity triangle. All individuals establish relationships through the existence of objects, occurrences and elements of culture. If individuals [siblings] use their interactions or “relationships to acquire what they do not have, they produce a society in which relationships are in continual tension and subject to

change” (Henricks, 2012, p. 228). Both Kadee and Amana illustrate these tensions when they were discussing the binary surrounding play with Weston and Ita (respectively).

Kadee: Sometimes I like playing with Weston. Sometimes I just feel like I kind of want to quit. Sometimes I want to play with Weston and sometimes I want to play with my friends. I think some sisters are kind of annoying of their brother, that they keep bothering him. I love my brother.

Amana: Well sometimes, whenever we’re like downstairs and we’re playing something and then he like does something bad – and he like ruins the game or something I don’t want him around...but then I want to help him play the game.

In the end, all of the siblings in this study had similar desired outcomes for the child identified with ASD. These outcomes included “teaching their brother” to play using some form of communication or particular materials in order to have fun and “make him laugh.” Summing up the siblings’ stated desire for the child with ASD, Ainsley mentioned multiple times in varying ways that her foremost aspiration for Erik is “total peace.” A major topic ignored by all of these siblings was a concern for their own wants and needs. Jean Piaget (1954) claims children of this age possess feelings of egocentricity. He believed that children were only concerned with the outcome of a situation rather than another’s intentions (Lourenco, 2012). Even though this phenomenon can be supported by his research, this notion as presented by Piaget is not supported by the actions of the siblings in this study. Despite the fact that these siblings are becoming less egocentric according to Piaget’s

definition, this level of decreased egocentricity has been not found until the age of 15 to 16 years old (Kesselring & Müller, 2010; Louw, 1998).

### **How siblings experience play and social interaction as an Activity**

**System.** How sibling experience play and social interaction (as the activity system) can be examined as an activity based on CHAT by linking “experiences of social interaction and play” and “sibling relationship.” The siblings (as the subject) have developed strategies such as begging, telling parents and allowing the child with ASD to regulate the type of activity (as the rule) in order to ensure social interaction and play. They have adapted some activities that are “too hard” for the child identified with ASD and reinforce positive behavior (as the rule) to interact with the child identified with ASD in order to understand and improve the social relationship between siblings. Thus, they are each other’s first playmates, and understand what happens within the realm of play, mediated only by their shared rules (as the object) through who decides what type of play within activities such as using the controller for video games (as the tools). In addition, the social relationship and understanding of which child initiates the interaction has been changed (as the division of labor) by the siblings’ indulgence to allow the child identified with ASD to determine play activities and tools within the social interaction. The progressive child-centered culture has penetrated into the actions of the siblings, peers and community members surrounding the child identified with ASD (as the community). The siblings have continually attempted to increase their understanding of social and communication skills required to amplify play with a child identified with ASD

through interaction between all the above elements (See Figure 7).

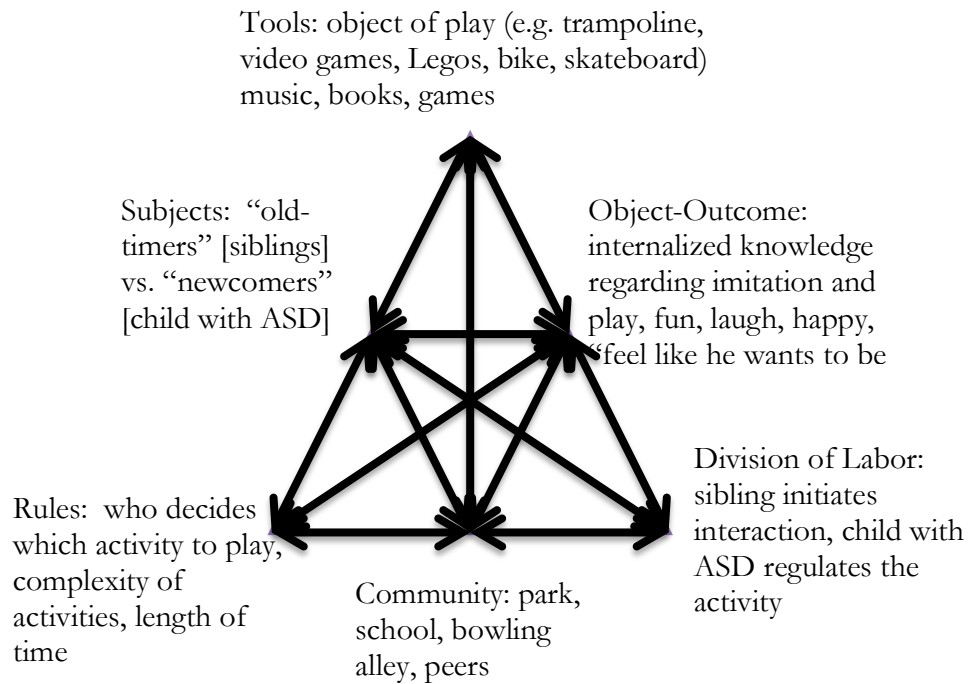


Figure 7. How Siblings Play and Interact

### Acquiring and Developing Roles within the Family

Through my interviews with the siblings of children identified with ASD, I began to suspect that they do not see deficits within their brothers. The siblings spoke of difference as a reality of life – not a deficit. However, physical attributes and differences in gender roles figure into the complexity of these relationships. Each sibling in this study has produced a sense of personal identity, an identity that has some distinguishing characteristics that are socially consequential. Even though it appears that the siblings in this study adopt particular ‘roles’ when engaging in activities with their brothers, their personal identities seem to develop through the social cohesion created as they co-construct, shift, and sustain their relationships over time and shifts in their understanding of the world around them as they grow

and develop. As a way of making meaning to their position in the community surrounding their brother, siblings begin to emulate the adult figures that play an essential role in their brother's life. In this section, I focus on the roles siblings adopt when interacting with the child in the family identified with ASD and how these roles are produced and maintained.

Even though it appears that the siblings in this study adopt particular 'roles' when engaging in activities with sibling identified with ASD, their sense of personal identity is connected through social cohesion, which produces role identification as well as sustains and reproduces it over time. Most people are aware of individuals in their lives in which they identify with and/or consciously or unconsciously emulate their behavior. Individuals choose to emulate other people for particular reasons. Sometimes they imitate actions of the role model down to the tiniest level of detail. Adult roles, such as teacher, are possibly copied due to the adult seen as the 'expert' by the 'novice' child, making their actions worthwhile to imitate at a detailed level, even though the reason for some their actions may be irrelevant and reasons unknown (McGuigan, Makinson & Whiten, 2011). In a 2008 study, Nielsen suggested that young children's focus on copying actions over outcomes may possibly be a function of their motivation to be social and interact with a role model.

Siblings adopt a variety of roles such as: (a) teacher, (b) role model, (c) peer, (d) friend, (e) playmate, (f) mediator, (g) helper, (h) protector, (i) advocate, (j) instigator, (k) manager, (l) enabler, (m) scapegoat, (n) hero, (o) mascot, (p) nurturer as well as (q) sister and brother. Through numerous activities and various forms of opportunities and experiences, children develop a myriad of roles that they emulate. These roles are internalized within the arena of interaction, role-modeling,



acceptance, rejection and modification of behaviors. This shows that sibling learning is not a simply visible change within one's self, but also a transformation surrounded by internal and external elements. Even though the siblings do not appear to display the same actions and roles with the other children in their family or with their peers, the parents in this study stated they believed that the sibling may have constructed these roles through observation and mimicking adults who play significant roles in their brothers' lives.

I think it's because of the experience, just because the way that my husband and I have to behave and everything, I think she's picked up on that. She's picked up on how everybody that works with him treats him and everything. So I think it has changed her in that way. She became a very compassionate, loving person, I think because of it (interview with Mother of Christy and Max).

Nearly every parent voiced a binary of embedded personality and learned behavior into their answers regarding their child's behavior toward her brother. To illustrate Christy's mother said, "I think that this [the roles she performs] is innate of her but it may be because of the way she's grown up with Max having autism. It is hard to know if her personality would have been different." Ainsley's mother adds, "she is a loving kid and already has learned to protect her brother [Erik] but she does not behave the same way with her other brothers." Unfortunately, the data in this study does not reveal if the same type of roles would be generated within sibling relationships if the family did not have a child identified with autism. For these families, the utility of the siblings becoming mini-therapists and teachers allows the parents to have another 'person' in the household to 'help' with the child identified

with ASD. The practicality of young children assuming more than the sibling role when another child in the family is identified with ASD may be essential to the family structure and sibling relationship. Another thing to consider is that other motivations that might be at play such as Christy's feelings that she is invested in helping Max to "get better." Christy seemed to somehow believe that doing this *work* would improve Max's behavior and social interactions and would in turn improve their family's daily social life.

From studies across disciplines, we learn families' identities are multiple, contextual and reshaped over time (Bates & Gentry, 1994; Epp & Price, 2008; Sirgy, 1982). Individual identities are constructed as "that part of an individual's self-concept which derives from his knowledge of membership in a social group (or groups) together with the value and emotional significance attached to that membership" (Tajfel, 1981, p.225). Researchers believe that self-identity is multi-dimensional, diverse and sometimes aspects compete as individuals strive for a coherent sense of self (Sirgy, 1982). In the following sections, I describe various roles that emerged in this study: (a) teacher, (b) manager, (c) enabler, (d) mediator, (e) advocate, and (f) friend.

**The teacher.** While siblings function in a variety of roles, sometimes they change roles without realizing it while at other times they make deliberate shifts while involved in a particular activity. For example, while observing Christy and Max engaged in drawing pictures together I noticed that Christy would give Max Gummy Bears when he completed portions of his picture. When I questioned her about this practice, she said, "Well, I want him to feel like he's earning something so he'll be

maybe a little bit more interactive.” When I asked her if they could just ‘draw’ together without her rewarding him, she said:

Well it is different. I like to teach him stuff because he’s younger than me and because he has lots of ‘em [teachers] and I know he’s my sibling. I love being his role model and his teacher. But usually like he has to be earning something that’s what kind of the way we do it – like if I say “Max let’s go do some music” usually, he’ll want to earn the remote [controller for the volume]. And if he didn’t choose something, I chose it for him... Just like I like when he follows me and like when I do something he’ll try to do it. I think he really loves doing things that I do (Christy interview).

Christy has taken on more than one role in the previous quote. First, she wants to ensure she is Max’s role model and teacher providing him with valuable information needed to perform daily tasks. She has created a situation in which she is the creator of the “rules,” she distributes the “tools” for the activities as well as decides on the outcome of the activity. Christy is guiding Max through these activities as the expert. Her emphasis on each activity being used as a learning tool instead of just for fun, leads me to speculate that her enjoyment in the activity comes partly from how meaningful it is to Max’s growth. The word “teach(er)” and the use of “earning/reward” point to the importance of the practice of formal learning within all activities she engaged in with Max. However, just as important, as Christy pointed out was that Max “may be a little bit more interactive” because of these routines. Stoneman et al. (1989) observed this same phenomenon in a study regarding the interactions between children with mental retardation and their older siblings.

When I asked Christy how it made her feel that Max will only play with her to earn a treat or a reward.

Well, it's okay with me as long as he still plays. And as long as it is just a small reward 'cuz I don't want him going too overboard with rewards. 'Cuz I don't want to --- everything can't be rewardful in life...I also want him to be learning when we do things (Christy interview).

I asked for an example of what this might be. Christy explained:

Sometimes he'll just repeat what I ask like if I ask him, 'What's your favorite color?' and he'll just say, 'What's your favorite color?' so instead of saying the color's name, he repeats. I know his favorite color though. It is blue.

This passage contains breaks and tensions. First, she stated that it is okay as long as Max played, and then she breaks and adds, "as long as it is just a small reward." Christy gave the impression that the rewards are used as enticement for getting Max to be interactive and participate in activities or are as a way to help him focus on the task she is attempting to teach him. It could be either but the use of the term "as long as" seemed to make this phrase a different idea especially when it's followed by the passage, "that it makes him happy."

**The manager.** In contrast, Carson talked of Elliott's behaviors throughout our conversation, mainly Elliott's screaming and occasional "head-butt[ing]", however "he does not mean to hurt me." When asked him how he felt when Elliott screamed he said, "sad, a little bit." He said the screaming was usually a product of Elliott being mad. "Well, we just put him in time out. We have a big rug in the front hallway and that is where he is supposed to go for time-out. Then after a while he gets better and he doesn't scream anymore." Since Elliott is non-verbal and on the

severe end of the autism spectrum, I wondered if he understood what ‘time-out’ was and why he had to sit on the rug by himself. Carson told me, “Yeah. We sit him down on the rug and well, after a while he gets calm. We let him up out of time-out.” Carson told me that he usually did not put Elliott in time-out, but would tell his mom or older sister, and then they “put him on the rug.” “I don’t tell him [Carson] to go to time-out, because I am his brother and almost the same age, so it doesn't work. That is why I get my mom or older sister.” In this passage the only role Carson describes for himself is sibling, however he discussed “time-out” as if he manages the protocol. He did not identify as teacher or role model as Christy did, rather he conveys a managerial or facilitator role.

Even though Carson ‘manages’ through overseeing the designated family/house rules, Amana told a story of how she needed to control Ita’s behavior in public because of his desire to obtain food items.

Well, I don’t like when he runs off in the store because then I have to chase after him and it makes me feel like really embarrassed and--- he’ll run off towards the popsicles and then I have to chase after him. Yeah and he’ll open a freezer and I have to close it and usually he’ll try to slide me around the floor and it just makes me feel a little bit upset and angry (Amana interview).

Even though Amana is two years younger than Ita, her desire to control his behavior in the community demonstrated her motivation to influence the situation. Amana and the other siblings displayed common goals in their desire to interact with the community and their sibling according to community structures put in place by practices outside the authority of the children. Due to the overlapping characteristic

of purpose and intent regarding these structures, the siblings could often be recognized by their common motivation – *control of their sibling's behavior*.

**The enabler.** Emma's mother described her children's relationship in the following manner:

She is definitely the leader, the more mature of the two. She's also the one—she lets him lead. She lets him determine what they're playing a lot. She's not bossy about it or it doesn't have to always be her idea. It can be—a lot of times they end up playing what he wants to play probably more so than even her (Emma & Emerson's mother).

Kadee demonstrated the enabler role when she spoke of the strategies she employed in order to entice Weston to play. “Sometimes I just have to do what he wants to do, because then he's going to quit playing. I'll just do it. I don't really care about it [the activity], unless I'm doing it with Weston.” Kadee and Weston and Emma and Emerson's relationships demonstrate the complexities and binaries of sibling relationships when one child is identified with ASD. Carson stated how Elliott occasionally determined the division of labor and/or rules through his actions. “He gets mad a lot. Well, whenever he gets mad at the tramp I just start jumping again and then he gets calm. That's what [I do to make things better].” These passages present the impression of a positive construction of their social worlds while the emphasis remains on the child with autism.

**The mediator.** Like Elliott, Amana also wants Ita's behaviors to stop.

Sometimes I say, ‘stop,’ and then he doesn't listen to me and then I keep on saying, ‘stop’ and he still doesn't listen to me. But, well, sometimes I tell my

Mom and my [older] brother that he [Ita] did something to me. He listens to Dad the often (Amana interview).

Amana also slips into the role of manager when she speaks of her brother's negative behavior (in her opinion). The enthymeme regarding her Dad's role in the family is interesting. Amana states that she usually tells "Mom and my [older] brother" however continues to say that Ita "listens to Dad the often." There appears to be an understood unsaid division of labor within Ita and Amana's family regarding which parent enforces the rules of the home more frequently.

The siblings also mediate situations between their brothers and peers. Such as an event that occurred while at the bowling alley involving Kadee, her brother and their peers.

One time we were at the bowling alley and he was kind of yelling at Emma, because she brought a wallet. Then she had cards in it. He was like, "Give me a card," because he thought the cards worked for [video] games. When we were leaving, he looked at Emma said, "Never bring that thing [her wallet] again." I was like, "Weston, stop it." Then Emma came out crying, he scared her. I think it scared a little boy in the room, too. That was rude.

And I told him that was not the right way to behave (Kadee interview).

The dimensions that make the role of mediator unique for children who have a sibling identified with ASD appeared to be related to previous experiences and actions of the child with ASD and/or peers. The siblings in this study demonstrate the ability to regulate the learning process by facilitating social activities through the understanding of social opportunities and development. However, it is unclear as to how the siblings developed this understanding and skill. It is possible these siblings

have been provided a context for guided participation in learning that takes place in meaningful daily activities built into the family structure.

**The advocate.** Telling parents or older siblings about behaviors their brothers participated in was a reoccurring theme throughout all the interviews. However, Ainsley was mostly concerned with the fact that Erik does not have any friends. This led to the unique relationship in which the younger sister was the mediator or advocate for her older brother. She made it rather clear repeating that “everything would good if Erik had some friends.” She told me that it would be more fun if he did and she would like to help him make new friends. I asked her if she thought Erik would go up to another child he did not know and start talking to him. She replied, “No not really. He doesn’t do that. Like he doesn’t wanna phone.” When questioned if she would want to change this, Ainsley said, “Yes, Erik having friends over. Him doing really, really fun things that we both like to do a lot of times. That would be good.” Throughout our time together, Ainsley continued to refer back to how she would like to help Erik make some friends so that he could have fun and not be alone all the time. This was a concern of Ainsley’s. She continued to tell me how sad she was that Erik did not have any friends and how she would like to change that for him. “[I want to] introduce him to some friends I know. Introduce him to Delaney, my friend. She’s in fourth grade too. Then he would not be alone all the time.” These developments of maturity and empathy for her brother are examples of the positive outcomes from their unique situation (Barr & McLeod, 2010). This was a feeling Emma’s mother stated, “She’s like—I hate to say like wise beyond her years, but she just has this maturity like where I just—I am really amazed at how emotional she is and emotionally attached she is at only seven.”



**The friend.** Peers often share experiences, motivations and desires. The siblings voiced their wish to also share certain experiences with the child identified with ASD. Christy talked about a family trip to Maui in which the family frequented a local shaved iced business. “Max doesn’t usually like shave ice so that kind of hurts my feelings and I feel like he’s missing out on something.” Christy’s desire and motivation to be his friend is shadowed by her feelings creating a boundary constraining the level of friendship obtainable.

Even though the siblings in this study may have been thrust into roles other than sibling before they were ready to take on the added responsibility, Kadee sums up the feelings that all of the children mentioned at least once during my interview with them. “It feels good to be helping my brother.” Kadee’s mother adds, “They really are friends. They really are. Oh my gosh, like Kadee had a sleepover, and Weston cried because he said, “You know, I'm gonna be without my best friend.” Weston revealed the role he finds most important in his sibling is friend. These shifts reinforce the argument of “being a sibling of a child with a disability is complex” (Barr & McLeod, 2010, p 162). This suggests that being a sibling of a child with special needs requires constant adjusting and shifting to accommodate and extend learning and participation.

**Rules guiding understanding of roles.** Family rules and events help to create whom each family member is, how they see themselves and how they relate to each other as well as their community. The siblings discussed events in which roles were produced through the description of things performed by the child identified with ASD in their family. Kadee believed that Weston did a variety of activities because of her modeling and guidance of his play. “I think he likes the things that I

ask him to do. I think Weston likes his life, too.” This example provides a clear example of the rule bound nature within the activity system. The instance demonstrates how spoken and unspoken rules are a part of what defines sibling relationships.

**Division of labor guiding understanding of roles.** Although Amana is younger than Ita, in the videos and observations I noticed that she was the person making decisions and helping Ita with his homework and therapy. “It makes me feel happy when I help Ita. I was helping Ita with his work [while watching videos of her and her brother]. I was watching him to do his work...putting letters on the blackboard” (Amana interview). Amana and Ita’s mother devoted much of our interview discussing her interpretation of how all of her children respond and interact with Ita due to his identification of ASD.

They don’t feel like teachers, they just feel that he’s learning; they just say, “He’s learning.” Anything they are doing with him, they try to teach him something or “Good job, Ita” so they don’t—I don’t know how to say—they play in some ways and they don’t play in others. They could play running or they could play “let’s go get this” but then when it comes down to the feeding, “Okay, Ita that’s how to scoop it. Now good job, Ita; you did it.” (Amana and Ita’s mother interview).

The examples above both illustrate and extend Engeström’s (1999) activity component, *division of labor*. Engeström described this component as “both the horizontal division of tasks between the members of the community and to the vertical division of power and status (n.d.). Examples of the horizontal division of labor (those in which the sibling partakes the authoritative lead of tasks and

responsibilities amongst themselves and the child identified with ASD) interviews in this study include:

- I need to tell him, cuz he doesn't understand not to throw rocks in the grass (Carson interview).
- She is a loving kid and already has learned to protect her brother [Erik] but she does not behave the same way with her other brothers (Ainsley's mother interview).
- He [Ita] follows us for paper. Sometimes I have to tell him "don't do that" cuz he is doing it wrong, then I tell him what paper is for (Ainsley interview).

It can be understood that the division between activity and action might be derived from the attempt to interpret the complicated and diverse relationships that exists in human life. In other words, the concept of object-related activity is to illuminate interactions between an individual or a group and their life within a culturally and historically constructed society. The siblings in this study also explained how they mediated situations between their peers and their sibling identified with ASD, such as the situation with Weston at the bowling alley as stated above. Although the siblings in this study did not implicitly state an understanding of their role within the division between activity and action, each sibling indirectly discussed the complicated relationship existing between themselves and their siblings.

**Tools guiding understanding of roles.** Human activity is itself defined by the object-orientation or motive triggering it that relates to the sixth component at

the heart of Engeström's activity system – *artifacts/tools*. The discussion of the object-orientation of the siblings' relationships has been interwoven throughout each of the previous examples and will be revisited yet again in each of the sections that follow.

While the siblings did not associate many of their actions with learned skills, the parents hypothesized that the roles adopted by siblings may be learned from witnessing therapies, doctor appointments, and intervention activities. For example, Emma's mother explained, "she's trying to be the therapist. I think we sat and talked about it. She's been to so many therapies. I think that's just now engrained in her." The influence of Christy's education, while attending Max's therapy sessions and witnessing adults interact with him has, created a variety of roles Christy has adopted over the years. Christy appears to make use of the information she has gained over the years of attending these sessions as well as witnessing the interactions Max has had with his therapists, in her interactions with Max. Even though older siblings frequently adopt adult roles such as teacher and manager when interacting with a younger sibling (Brody, Stoneman & MacKinnon, 1982), Christy was persistently using a variety of adult oriented roles when interacting with Max. The siblings clarified this point through stories and illustrations in which they described their roles, even though the siblings did not always label the role.

**Community guiding understanding of roles.** It is important to note that the community surrounding the siblings lent itself to fundamentally different types of activity. Specifically, the community including roles of teacher, protector and helper appear to be directed by the object-oriented motives of the *siblings themselves*.

Christy's discussion of the preschool she attended with her brother reminded me of

the importance of community within the structures of social interaction and personal growth.

But in pre-school I think someone like a boy was like trying to be mean and he punched a lot of kids on the playground so if he even came near my brother I would say, 'Leave him alone' but he would punch me now. And so that wasn't fun either, but I still try to fend for him even though (Christy interview).

However, Christy's continued to describe how she would develop authentic relationships with her current classroom peers and her brother fulfilling the motive of acceptance and community surrounding him.

My friends would probably be accepting of him like if I like talked about him and introduced him to them, but some people who I don't know very much would probably just like they wouldn't think very highly of him at first and then I'd have to explain it to the class (Christy interview).

When she spoke of her friends and the possibility that they would not accept Max, her voice was quieter; she looked off into the distance and appeared to leave the conversation with a conclusion that was unexpressed. In spite of this, the data in this study does not reveal if the same type of roles would be generated within sibling relationships if the family did not have a child identified with ASD.

**Object-outcome guiding understanding of roles.** When I interviewed and met the siblings in this study, I did not set out to ask what they understood about the particular roles they adopted within the family. However, the siblings each told me a story about their concerns for their siblings with ASD. It is clear that the siblings in this study find the need to communicate and relate with their brothers

utilizing particular roles in an effort to increase the amount of social interaction and play. They also touched on friendship. Each sibling regarded creating or developing a friendship for the child with ASD as a key component of his or her role in the family. Despite the fact that Amana did not invite many of her friends over to their home to play, she was still invested in Ita's happiness through socialization. Ainsley was mostly concerned with the fact that Erik did not have any friends. Throughout our time together, Ainsley continued to refer back to how she would have liked to help Erik make some friends so that he could have fun and not want to be alone all the time. She made it rather clear repeating that everything would good if Erik had some friends.

When new kid playing alone he could go up to them and say, 'Do you wanna join me?' First, he would need to say, 'Please'. Well, first he would ask him his name. 'Try to get to know him. Then he could just ask him, 'What do you like,' and they could try to see what they have in common (Ainsley interview)

Since inadequate social skills are considered a key characteristic in the ASD, Ainsley's concern demonstrated her desire to give Erik necessary skills to adopt to developmentally appropriate social skills. Siblings did reference 'deficit' without actually mentioning the deficiency they thought the child identified with ASD possessed in this one area. Each of the siblings alluded to the fact that they would like the child identified with ASD to be "more like my friends." Kadee also describes an outcome of helping create friendships:

Me and my friends are best friends forever, best friends for life, no matter if we say something really, really mean or really, really—that doesn't really

matter. I like hanging out with my friends. Ezra and Abby are his [Weston] friends. Ella and Kate are too, but they're [all] my friends. I want Weston to have friends for himself like I have friends. He needs to have a best friend forever (Kadee interview).

Emma continued this theme regarding assisting Emerson not only socialize with her friends, but also make friends of his own. She told me it is important to ensure that Emerson is able to play with his own friends when she is not around. This finding revealed the importance of warmth and closeness within the family structures involved in this study. This may be a powerful predictor of future social interactions with peers for Emerson.

Carson shifted the theme regarding friends a bit by wishing Elliott would behave more like his friends “Cuz my friends don’t have autism and they don’t scream.” Although Carson divulged many stories of socialization, his role in the outcome of his brother’s happiness appeared to central to Carson’s understanding of his role within the family. This stress may have a negative impact on how Carson views his relationship with Elliott in the future, however due to the degree of social support received, reported social interaction strategies and adaptability to Elliott’s behaviors, the impact may be limited.

### **Sibling understanding of acquiring and developing roles as an Activity**

**System.** ‘Sibling understanding of acquiring and developing of roles’ (as the activity system) can be examined as an activity based on CHAT by linking “the sibling’s sense of personal identity” and “the social cohesion by which the role is produced, sustained and/or reproduced over time.” The siblings (as the subject) mimic and model variety of actions they have learned through experiences (as the rule). They

have adapted to the tensions within the community (as the rule) to interact with the child identified with ASD in order to understand and improve the relationship between siblings. Thus, they gradually have become experts in regulating (or attempting to influence) the behavior of the child identified with ASD (as the object) using appropriate words, suitable actions and a collection of roles (as the tools). In addition, the sibling relationship and understanding of ASD has been changed (as the division of labor) by their efforts to improve social interactions within the family structure. The family-centered culture has filtered into the daily events creating variety of roles maintained by the siblings, peers and community members surrounding the child identified with ASD (as the community). The roles constructed and maintained by the siblings have continually evolved and developed over time in an attempt to increase connectivity and interactions between the siblings utilizing the above elements (See Figure 8).

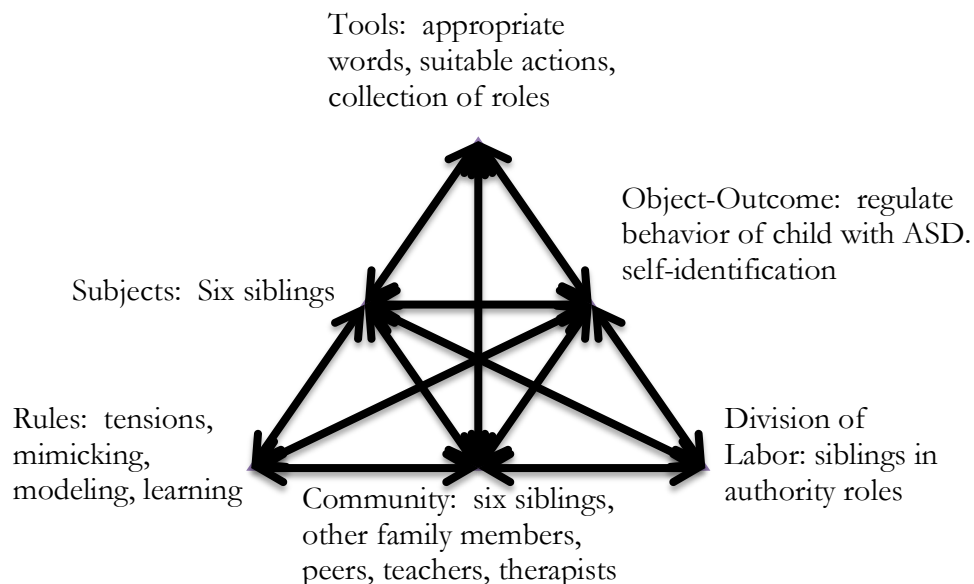


Figure 8. Acquiring and Developing Roles among Siblings and their Parents



## **Families Attempt at Making Sense of Autism Spectrum Disorder**

As we attempt to move away from pathologizing differences among members of our communities, it is difficult to find any definition of Autism Spectrum Disorder or any other disability that does not focus or assume a deficit model of thinking. Skrtic (1991) suggests, “special education must understand and, more important, free themselves from that which has conditioned, limited, and institutionalized their professional thought and action” (p 23-24).

Autism Society of America (ASA) defines autism as:

Autism is a complex developmental disability that typically appears during the first three years of life and is the result of a neurological disorder that affects the normal functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults with autism typically show difficulties in verbal and non-verbal communication, social interactions, and leisure or play activities (2012).

I chose this definition despite the fact that it focuses on the deficits involved with ASD and disabilities. This emphasis toward stigmatizing individuals due the identification of a disability or potential disability limits the individual’s social power and creates situations in which contributions to society are invisible. Research indicates when individuals are provided with a meaningful, authentic purpose that builds upon their strengths using community; learning and interactional opportunities are increased (Heydon & Iannacci, 2008). McCain & Mustard (1999) suggest the current early identification system for children may be adding to the notion of pathologizing children who do not perform well on particular screenings, thus propelling these children on a path of deficiency. This may be the reason the

parents used similar types of definitions to explain autism in regards to their children, for example:

I just tell them he is like us, but his brain doesn't work the same. Something is not allowing him to speak, but he knows. The older he gets, even though he's getting more aggressive sometimes when he gets angry, you can always look at him—if he's in trouble, you can see that he's sad in eyes, where before, it kinda was a blank stare (Carson's mother).

There is a break here, when the focus turns from “his brain” to his behaviors. The priority for Carson's mother becomes the understanding of Elliott's blank stare and inability to communicate his needs. First, she states that Elliott is “just like us”, and then the passage breaks as she adds “BUT his brain doesn't work the same.” Is this an attempt to construct the definition of autism for her children or to help them construct their own definition? It could be either but the use of “but” seems to make this phrase a different idea especially since it is followed with “something is not allowing him to speak, but he knows.” Again, “but” is pointing to the idea of outside factor effecting Elliott's communication skills. There is an additional *aporia* (Tobin, 2000) in this passage when Carson and Elliott's mother appears to change thoughts mid-sentence: “even though he's getting more aggressive sometimes when he gets angry...kinda sad.” Here again she is prioritizing his behaviors as the major factor of his being. In the interview, she left this tension unresolved and turned to sharing stories of what happens between her children at home and in the community.

In contrast to siblings, parents use terms that distinguish their son from others such as, “his brain does work”, “he has blank stares,” “lack of communication

causes him to be aggressive.” The siblings voiced other explanations, such as, “it makes him different from other people and he asks a lot of questions.” However, even though each presented definitions of autism when asked, they appeared to be uncomfortable talking about the things that their brother could not do. They also all stipulated these feelings with clarifiers such as, “he is different, but so are my friends”, “he is a boy, that is what makes him different”, “he has medium size ears, and my friend has large ears”, and “he can do other things.” Kadee summed up the feelings of all the children and parents who were interviewed for this study, “Yeah. It's just, he's different, but I still love him.”

Research in the U.S. confirms that autism now affects 1 in 88 children (Baio, 2012), yet the true numbers must include the siblings who are also touched by the labeled diagnosis. Brothers and sisters are partners for life. Brothers and sisters help you understand yourself. Sibling relationships are extremely complex and variable social relationships. Sibling relationships undergo considerable changes throughout the course of your lifespan. These relationships are shaped by special personality traits that contribute to form each individual identity as well as the identity of a family.

Even if the siblings accept and acknowledge their brother's identification of ASD, they spend a lot of time intentionally or unconsciously compensating against the deficit model of thinking. Are these situations socioculturally constructed or a product of what they hear from others? Do these siblings “parrot” their parents' thoughts and words or are they constructing their own beliefs? Each of the siblings defined autism through events, feelings and incidents in which they *experienced* autism within their own home, at school, on the playground, and in the community.

**Experience outcomes.** “We don’t really treat him – I mean I shouldn’t say we don’t treat him differently cuz we probably do, but I don’t think anybody in our house really thinks he’s different.” In this passage, Ainsley’s mother described the tension between the differential treatment of children within a family when one child is identified with a disability when asked about rules and expectations regarding her five children. On one hand she feels the need to maintain sameness in her relationship with each child; on the other hand she must also ensure the siblings also do not treat their brother differently due to his label of autism. For many children it is important how *they* are treated by their parents without justification that another sibling was given the same response at the same age (Sanders, 2004). Consistent evidence from research has shown that differential parental behavior toward one or another sibling is related to the quality of sibling relationships (Dunn, 1998; Stoneman, 2001).

Two out of the six parents addressed the diagnosis of autism openly with their children.

I explained it [autism] to her at an early age. She gets it [the label]. Yeah, I think it's because she's been around it. She understands he was born that way, so she's just kind of like, "Oh." Last night we were laying in bed and she said, "Is he always going to have autism?" She asked me that last night. I said, "Yeah" (Emma and Weston’s mother).

While the other parents spoke about the children as individuals, each having their own unique needs, all stated their families made strides to ensure the child identified with ASD was not treated differently. Research has considered this

essential for the development of positive sibling relationships (Sanders, 2004; Stoneman 2001).

Kadee voiced her thoughts regarding her brother by telling me about a time with Emma, “he [Weston] has autism and my friends don't. I'll whisper to Emma, “Weston and Emerson have autism, so you should be nice to them.” She told me this story because she wanted me to know how important it is that people are not mean to her brother “because he has autism. Anybody could have it. Not a lot of people have it. No matter what, you have to be nice to everybody you meet.”

Christy also talked about how others react to her brother's behaviors, “Well, I just say well, my brother has autism and his mind doesn't work like you and me.” Even though Kadee and Christy both spoke about reminding others to be kind and considerate, all of the siblings had this belief. There was no doubt that each of these children have the ultimate goal of creating a community of caring individuals, however it is not as clear as to how this belief or goal has been created. It may be a construction of Kadee and Christy's parents teaching or an attempt by the siblings to create relationships that reciprocate a complete community of caring.

Another common theme among the siblings was voiced by Carson, “there shouldn't be autism. Well, I would tell them [other people] that it's [autism] this thing that they're born with and they can't understand after that. They can't control their self.” However, Carson was the only sibling who believed that autism “can go away” and that someday Elliott would not be identified with autism and it would be “pretty cool.” Carson's unsaid statement and thoughts regarding his brother's behaviors left me wondering if his definition of autism is still consciously or unconsciously being constructed.

Children talk and communicate with each other using words, gestures and symbols in order to understand their needs and issues. Even though the parents were willing to speak at length regarding their son's diagnosis of autism, the more open and frank the parent, the less likely the sibling wanted to speak about ASD. The siblings eventually all mimicked Emma, "I don't want to talk about it. My mom and dad do, but Emerson says he does not want to talk about it, so I don't either" and Kadee concluded our interview with, "I don't really want to talk about autism." This led to the notion that communication alone regarding ASD characteristics would not suffice in meeting the needs of the siblings. Consideration of the way children are impacted by ASD and the emotional aspect of discussing this disorder create the need for additional *tools* to explain variances in behaviors between siblings. In addition to the need to more than just communication as a *tool* to explain differences, giving siblings *tools* to address concerns, rather than leaving them on their own with no direction, might improve situations when siblings struggle to communicate with their parents. Each of these tools would represent the siblings' way of choosing what and when to let ASD into their lives.

**Understanding community viewpoints.** It is important to remember that although parents are a major factor in the development of their children's relationship, parents are not the only factor shaping their emotional experiences. An individual's perception of their life experiences is often shaped by familial, cultural and historical contexts. Children and adults are socialized in a variety of different environments with family and peers. They are also continually collecting various viewpoints through media, education, occupations and recreation (Dunn, 2007). Ideas and images produced within these arenas affect the way individuals see

themselves. This is a process of comparison in which individuals decide whom to identify with or not depending upon their lived experiences. For example, Christy explained to me why she often does not reveal her true feelings to her brother.

He doesn't like screaming and if like for some reason if I cry or if I get hurt I start crying and then he'll look at me and he'll be—and he'll stand and just look at me and it makes me feel like—I like stop crying because I don't want him to get upset (Christy interview).

In these situations, Christy puts her brother's feelings and needs before hers' in order to ensure their interaction remains happy and calm.

Kadee demonstrated a line of thought and tolerance when she explained what would happen if everyone understood what ASD was and how it affected those identified with the disorder. "I'd just get to say he has autism and then I wouldn't have to explain it to them." She continued to clarify her feelings by justifying her response to others; mainly peers who she encounters that are mean or say negative "mean" things. "Well I wanna' tell somebody what they did wrong and I would wanna' say, "Don't do that to me" [or my brother]... Because I love my brother, but I just don't want people saying mean things about him." Kadee may have vocalized this particular sentiment, however at one point or another all the siblings agreed when peers or strangers "make fun" of the child with ASD, they feel "sad, angry, upset". It became apparent that all the siblings in this study believed reminding others to be kind and considerate to all individuals no matter the individual's cognitive, social or communicative ability.

Ainsley articulated a situation in which she was unsure if she would be able to remain friends with one of her peers. "Well, my friend, she kind of like – she like

talks slow near him like it makes me feel like she thinks like, ‘what’s wrong with your brother?’ or something and that hurts my feelings.” Ainsley continued to express how she told the friend to “quit acting like he is dumb.” This circumstance was not unique to Ainsley and according to the siblings would usually occur when the children were playing or involved in a social situation within the community. Conversely, Elliott and Carson’s mom told about a very different circumstance involving her children and peers.

We’ve been so lucky in the way that all the kids are nice. We’ve had at the park a little boy with my Elliott, who loved him, and is not related, and another kid said, “What’s wrong with him? He won’t talk. He’s in a diaper,” and that little boy hugged him and he’s all, “Leave him alone, he’s my friend (Elliott and Carson’s mom).

Similarly, Carson spoke about an incidence that occurred while in the company of his peers. “My friends all love Elliott too. They help to make him happy.”

**How siblings understand difference.** Siblings have their own constructs of what their sibling relationship is going to be like, how their sibling will behave, and what their sibling’s personality will be like. Their interactions and experiences help shape their relationship. During these interactions, each child reacts differently in part due to their personality and temperament (Dunn, 2007). When the siblings spoke about the differences between their brother, peers and/or themselves, each example involved physical attributes. For example, Ainsley described her brother in the following way, “he likes cold apple juice. He licks his hands. He washes his hands very, a lot in the days.” Ainsley told me she did not have any friends that



licked their hands and her dad was always trying to get Erik to stop doing this behavior. She believed that this was the “biggest thing” that was different between her, Erik and her peers.

Amana had no definition or understanding of autism. However when asked about this, Amana told about when Ita eats her homework, how she feels and her opinion as to why he eats her homework.

[I feel] sad...because he really likes chewing on paper. Sometimes I whine and sometimes I go tell my Mom and my Dad and I go up into my room and think about it. I think about that Ita was just tryin' to—that he didn't know that the homework—he didn't know that it was my homework and all that (Amana interview).

When probing Amana further regarding this behavior her brother participates in, she could not expand on her answer. She was unsure but thought it “probably is because of his autism.”

When Ainsley was asked what she understood about autism, she became uncomfortable and said she did not know anything. Ainsley's discomfort speaking about any diagnosis such as autism led to her constructed her definition based upon physical characteristics that make her brother different than her and her peers. I asked her if her brother was different from her, she said, “I don't know. We're two different people, a boy and a girl.” Ainsley's explanation appears to be simple relating only to physical attributes, but she did not want to discuss any other differences. Emma also did not want to have an in-depth conversation regarding autism and potential differences related to this. “[Autism is] kinda like he just doesn't do the same things as us.”

Emma's mother debates within herself when she attempted to explain how Emma did not acknowledge Emerson is different. "I don't think she would understand why anyone would ever treat him differently. I think, for the most part, I don't—she doesn't see any difference." Ita's mom explained that her children only know each other as they are, "so they can't wish for what they don't know."

Communication differences between Ita and her peers were the main issues Amana wanted to talk about, "it is hard not being able to have him talk. Because like if I make a mistake on my words [using sign language] and then he doesn't know what I'm saying. It makes me frustrated." Carson and Christy also spoke about their frustrations regarding lack of communication abilities with their brother. Carson explained his frustration by telling about his nightly prayers, "I would say 'Please let Easton talk. Please let him not have to go through this.' And now that he giggles".

Events and situations in which the siblings could not effectively communicate needs and wants between each other caused the most frustration. This frustration was not one-side as the siblings disclosed experiences and occasions in which their brother displayed behaviors related to inability to communicate their needs. Emma informed me that Emerson "sometimes when he gets mad cause I don't understand what he wants, he shoves his nails in my arms." These events make her sad but she said she understood the reason he does this. "It's because his autism."

### **Siblings understanding of ASD in their families as an Activity System.**

'Sibling understanding of ASD within their families' (as the activity system) can be examined as an activity based on CHAT by linking "understanding of experiences and difference" and "sibling relationship within the family." The siblings (as the

subject) have constructed specific behaviors and viewpoints regarding particular interactions within different situations with the child identified with ASD (as the rule). They have adapted social and communication skills that have been learned in the family and/or community (as the rule) to interact with the child identified with ASD in order to understand and improve the relationship between siblings. Thus, they gradually have become an expert on the understanding of the subject of ASD within their distinct and unique family structure (as the object) through experiences with the child identified with ASD at school, home and within the community (as the tools). In addition, the sibling relationship and understanding of ASD has been changed (as the division of labor) by their efforts to improve social interactions within the family structure. The family-centered culture has been permeated into the siblings, peers and community members surrounding the child identified with ASD (as the community). The siblings have continually attempted to increase their understanding of ASD and how it affects the child identified with this disorder

through interacting between all the above elements (See Figure 9).

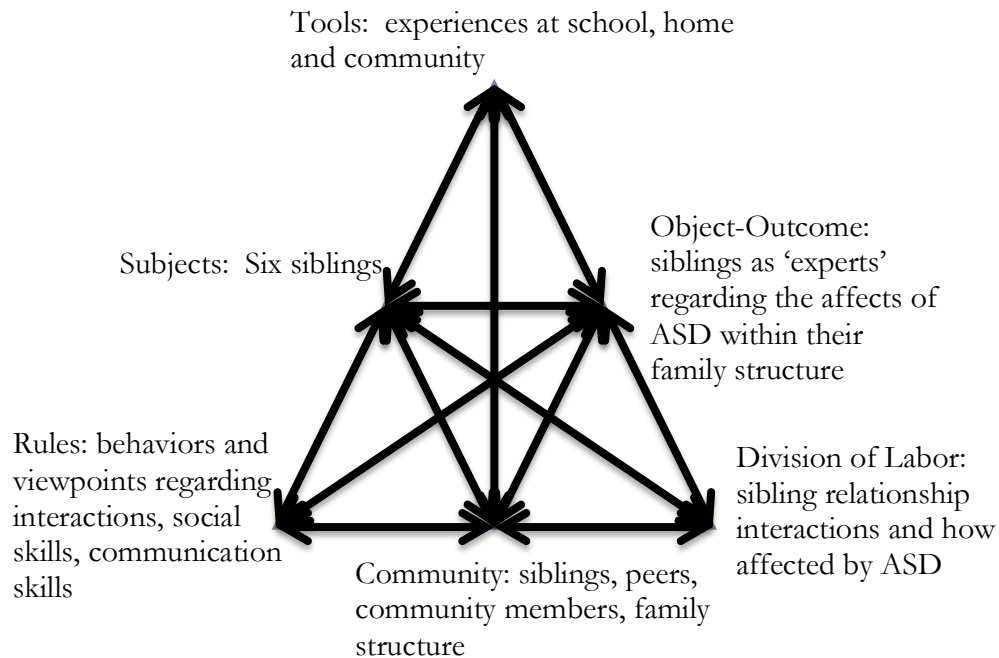


Figure 9. Making Sense of Autism Spectrum Disorder

### Life in Families with ASD

How do the parents want their children to be involved in the family, school, and community? How do they help the children become involved? In what ways do the parents construct their children's social interactions? These questions as well as many more were brought to my attention through interviews with the parents involved with this study. These parents recalled challenges of socialization and communication associated with ASD, such as difficulty in reading facial expressions, or knowing when to stop talking, or how to regulate emotions or adapt to changes in routine. The parents spoke in the realm of deficit more than difference, however a large amount of these recollections contained comparisons of the children in the family. Opportunities for social interactions are influenced daily by the multi-

dimensional environments that construct family structures. Due to family commitments with after-school activities, music and dance lessons, sports, and therapies many social interactions spill out of the household as siblings find ways to interact in the car, in waiting rooms, or other family events.

For siblings, learning is an integral part of reproductive social practice in their lived-in world. “Learning is not merely situated in practice” (Lave & Wegner, 1991, p. 35), learning within families involves a variety of interactions that transform the ways that shape sibling relationships while simultaneously limiting collective practices. Siblings’ significance in each other’s lives has been well documented in recent literature (e.g., Bachraz, Buhrmester, Dunn, Furman, Grace, Stoneman). Differences as well as similarities within personality, temperament, interest, and activities have been repeatedly explored (e.g., Dunn, 1992; Kaminsky, 2001; Petalas et al., 2009; Sanders, 2004). The way a child shapes and develops their identity is influenced by personal emotional and social experiences. Family rules and events help to create whom each family member is, how they see themselves and how they relate to each other as well as their community. Family structures are shaped and molded through each individual child, depending upon their unique set of circumstances (Sanders, 2004).

ASD often presents a great deal of struggle and stress for parents in terms of the notion of blame and feelings of guilt. The first response related to the labeled diagnosis is a picture of having a child with a ‘disability’. The opinion of others is that the child identified with a disability would bring a great amount of stress to the family resulting in the entire family becoming dysfunctional and disabled (Stoneman, 1989). Kaminsky and Dewey (2001) stated parental stress produced friction and

negative emotions among siblings. Stressors consistently conveyed within research reports concerning families with at least one child identified with ASD included: depression [parental and sibling], anxiety, lack of parental ‘time’ for children who are not identified, financial concerns, educational worries, and inadequate professional resources (Rivers & Stoneman, 2008; Senner & Fish, 2010). Families may experience an accumulation of these stressors and other demands making community outings difficult consequentially resulting in decreased social family excursions. Ainsley and Erik’s mother explained that many times it “is much easier to leave Erik at home with an older sibling instead of forcing him to go to public events.” Immediately, she began to backtrack and justify her comments and “actions” regarding Erik.

He would just rather always choose to be home. He likes to be home.

Sometimes if you force him out of the house, he’s happy once you’ve got him toward, like I got to the history museum. He ends up liking it, but it’s easier, for us especially with having older kids at home to say, “Well he doesn’t really wanna go (Erik’s mom).

Effects of ASD on siblings have become a focus of research in recent years. The National Research Council (2001) suggested that siblings of children identified with ASD might experience feelings that are more negative and emotions, such as sadness and worry than children of siblings without a diagnosed disability. Yet, current research has asserted both positive and negative effects of being a child of a sibling identified with ASD (Aronson, 2009; Benderix & Sivberg, 2007; Epkins & Dedmon, 1999; Mack & Reeve, 2007). A study conducted in Australia observed siblings of children identified with ASD have demonstrated a variety of coping strategies in order to adapt to aggression or other negative behaviors by the child

with ASD (Ross & Cuskelly, 2006). All the siblings discussed times in which the child identified with ASD physically hurt them or another child/peer:

- He hit a girl. I don't know. Maybe she was bothering him, and all he did was hit her once he kicked me in the face (Ainsley interview)
- He will head-butt me (Carson interview)
- He bit me on the head (Christy interview)
- He squeezes me (Emma interview)
- When I want the TV he just kicks me in the face (Amana interview)
- Like when he tries to grab my friends. He grabs them and he kinda does this [squeeze their arms] (Emma interview)

Even though the siblings all told of events in which the child identified with ASD exhibited some type of aggressive behavior toward the sibling or another child, these stories were brief. When the siblings spoke of these aggressive interactions, they immediately supported the child with ASD with statements such as, "I don't really care what he does, as long as he's my brother" (Kadee interview).

An important aspect of children's emotion knowledge is the understanding of cultural guidelines for expressing emotion in social interaction. Christy's mother articulated the binary happening within her daughter's emotional understanding of her brother's behaviors: "She kind of shuts down. She doesn't—she'll walk away, or she'll complain about him almost as if she was talking about a typical child or a typical brother and sister."

ASD is confusing and includes a wide spectrum of characteristics and symptoms which seemed very difficult for these young children to completely

understand, especially since every child identified with ASD is different in their own unique way. The siblings' ideas about ASD were largely informed by their experience with the child identified with ASD. Each of the siblings defined autism through events, feelings and incidents in which they *experienced* autism within their own home, at school, on the playground, and in the community. Amana had no definition or understanding of autism. She believed her brother [Ita] acted different from her because, "Well it's sorta' different because they're [Ita and Adona] twins." Other siblings in this study appeared to have the same type of experience and understanding as Amana. Kadee and Weston's mom put into words her thoughts regarding Kadee's understanding of her brother's diagnosis:

She doesn't see it [autism]. I mean, she—we can have a conversation about it [autism], and she's still gonna be like, well, I don't know what makes him [Weston] different, but okay. You're telling me he's different, but okay (Kadee and Weston's mom interview).

As previously noted, the siblings postulated the child identified with ASD through physical attributes ignoring any shortfalls. However even though the parents highlighted the uniqueness and compassion demonstrated by their children, there was also an implied negative impact regarding having a child with ASD in the family.

She wishes that he was typical. She knows she—she understands—I think at one point she's happy that her brother looks up to her and loves her so much and everything, and they never fight. I think she's happy about that. She's missing that typical sibling, that relationship and everything... I think for Christy, it's made her a better sister and just more understanding, more



compassionate, and really, I think that's really changed her relationship with her friends and everything, too, to be more understanding with some of the other kids at school that may be different and everything (Christy's mom interview).

Due to the varying impacts of ASD on the family structure and sibling relationships, it appeared that siblings in this study had difficulty developing an understanding of what exactly autism was. A crucial part of their understanding revolves around the acknowledgement that all children are different.

**Situations or events effecting conventional interactions.** Siblings noted behaviors in play, communication and interests that they considered unusual in comparison to themselves or their peers. Eating paper, difficulty eating with others, not wanting to talk to other people or have a cell phone, wrecking games and homework, and great interest in only one item such as Legos stood out as indicators to the siblings that the child identified with ASD was not following the conventional *rules* of social interaction. Such as Carson's explanation of Elliott's frequent screaming. When asked him how he felt when Elliott screamed he said, "sad, a little bit, because I think he just wants to talk. My other brothers and sister do not scream like that – we just talk."

Amana informed me several times throughout our interview about Ita's obsession regarding paper and how this behavior was so very different than her other siblings or peers. "Sometimes he gets upset and throws a fit [if he cannot have paper to eat]. It makes me feel like sort of upset that I'm getting embarrassed or he's getting embarrassed" (Amana interview).

Amana's interpretation of Ita becoming "embarrassed" brought forth questions how she knew he was embarrassed. Amana was adamant that Ita "must be embarrassed because if my friends don't eat paper and they don't throw a fit when they can't." This comparison highlighted Amana's determination that Ita was different, yet also displays some of the same traits and feelings as her peers.

*Eating.* Christy and Ainsley both discussed their dejection when it came to eating and/or meal situations with the child with ASD. "He usually wants to play alone, and he eats alone at McDonalds. When we're eating then I come over to him when I'm done" (Ainsley interview). She expanded this comment by explaining how she feels unwanted by her brother and that this behavior usually hurts her feelings. When I interviewed her mother, I asked her clarification regarding Erik's eating habits and the family thoughts about these actions.

He gets easily grossed out by other people's food, so if it's not his food it kind of grosses him out. Like he'll only like his McNuggets™ in ketchup. He doesn't really wanna see like if you have spaghetti, or something that he doesn't eat, then he's just like kind of disturbed by. It is easier for him and the rest of the family if he eats alone – I mean, not in another room but usually at the breakfast bar when the rest of the family is sitting at the table. It is more peaceful (Ainsley's mother interview).

Christy illustrated the difficult surrounding family meals in detail:

And one more thing when I'm at the table eating soup, spaghetti or something he doesn't like he'll usually back off and tries to go to the bar to eat and it hurts my feelings. That's like the worse thing that's hard for me. Well, I come and I just set my plate down there, but then he wants to go

back to the table and we'll go back and forth until I just sit down at the table by myself. Well, I want to be able to eat the foods I want. But sometimes I feel like Max's keeping me from eating the foods I want (Christy interview).

Even though Christy and Ainsley both felt disappointed about the limited amount of social interaction with the child identified with ASD during meals, neither expressed a strategy to change the fact that he dislikes eating at the same table as the rest of the family, isolating him from a typical social environment. Since the *rule* for other family members is to partake in the family meals together at the kitchen table, both expressed a desire for the child with ASD to be included in this tradition. This behavior limits the interaction between the child identified with ASD and others in the family. However identifying this frustration was the extent regarding attempts to understand these differences. Typically in siblings relationships this type of division of rules and expectations could cause feelings on rivalry and discontent between the siblings. The significance regarding the lack of rivalry and jealousy within the relationships of the siblings in this study created the possibility that the siblings only said the things they thought I wanted to hear. In spite of these responses, it is unlikely there are no feelings of rivalry among these children. The potential effect on social identity formation and experiences within play activities have been documented in previous research studies (e.g., Fueloep, Levy, Neubauer).

**Family structure: Division of labor.** Amana's mother admitted despite the fact that her children understand that Ita is identified with cerebral palsy and autism; they do not think it is their [the other siblings] responsibility to "take care" of Ita.

They don't think about it [his diagnosis]. They just see him as Ita. For example, if I have to say, "Could you get Ita's shoes?" They say, "He should go get it himself." They don't take it as their job to take care of brother (Amana and Ita mother interview).

Amana and Ita's mother communicated thoughts of her children all being individuals and the importance of encouraging her children to develop positive identities within their family structure, as well as the community. One of the ways this may be accomplished is by helping siblings understand the ways that ASD impacts them and provide them with the tools they need to be successful. The families in this study believed that both the child identified with ASD and the other children within the family should be given tools and strategies in order for the family interactions and social events at home or in the community to be successful.

Amana's stories regarding activities she liked to do with Ita involved travel -- Sea World, Hawaii, San Diego beach, and even the local mall. This is when she has the most fun with Ita, and she knows that he is happy. Their mother confirmed that they travel a lot and Ita is expected to accept the unstructured life of having three other siblings. They [she and her husband] do not believe in organizing or arranging events around Ita's "ability to tolerate" change in his daily schedule. This was also typical among the rest of the families in this study, which is contradictory to behavior models and therapy for children with ASD. Even though research in the area of autism interventions states it is important for children to have structured settings and schedules, Elliott's mother explained why she did not agree with this concept.

He has to [Elliott needs to be able to function in unstructured settings]. I know a lot of my friends that have autistic children; they're very structured.

We have too much going on, so it's [our daily lives] not as structured as I think would help him maybe, but with five kids—we've always said from the beginning, when he got diagnosed, he has the diagnosis, he is autistic, but we're not gonna let it take away from our other children. We're gonna help him, and our other children are gonna have their own life also. There's no resentment towards him because of that, where a lot of kids resent the special needs child because they take so much time away from the family, but he's part of our family (Carson and Elliott's mom).

Families faced a variety of effects from ASD that could have stifled their sense of capability and freedom, but for these families there was a moment where they decided to push aside the deficit, negative thinking surrounding the effects of ASD and take action. This was also the first step to acceptance of ASD and a move to better understand what they were up against.

**Experiences within the Community.** As each interview progressed, it became evident that the parents (not necessarily the siblings) have identified key “others” in their lives’ that offer a sense of belonging and support. This gives the families promise and hope that the effects of ASD can be shared with others in a way that would consequently lead to more support and less negative (deficit) ways of thinking. When others listen to the words of an insider [parent and siblings], this knowledge allows others to truly hear what could be helpful. Many stories about the child identified with ASD elaborated upon the uniqueness and capability of each child. This was further highlighted in discussion regarding conversations with those outside their family. Siblings and mothers were passionate about dispelling any common misperceptions that implies “there is something wrong with the child”

identified with ASD. It is clear through their stories each child identified with ASD is special in their own way.

I have a gang of kids [five children in the family] around this little child [Easton], so I guess if one kid's gonna pick, we've got like five to go against them. I always explain if a kid looks at my child different. We went to the park the other day and he had his shirt up. He's bigger and there were some little girls that were giggling, and I just went over and, "Oh, hey, this is my little boy. If he screams or what not, he's autistic. He can't speak," and then they were super nice to him. They aren't mean (Carson and Elliott's mom).

Siblings discussed this lack of understanding of ASD by others as a topic that generated confusion and problems with peers and strangers. Siblings highlighted their frustration with how others' lack of knowledge and understanding was a disservice to the child and family as a whole.

Christy: Well, I really don't—I try not to pay attention to 'em and just move on [when she hears comments or sees looks and gestures]. My mom has a shirt that says 'I love someone with autism' and usually that works well.

Interviewer: Do people ever like say things that make you uncomfortable?

Christy: No not really, I try not to listen – but sometimes I have a friend that will say things.

Interviewer: Do you ever talk to her about it?

Christy: Yeah all the time. I talk to all my friends about it [ASD] if they ask, “What’s wrong with your brother?” I will answer all of their questions so they know that his brain is different, but he is wonderful.

Ainsley also related to the struggle of educating peers regarding the acceptance of Erik and her own uncertainty regarding how to communicate her feelings. The limited experience with this type of communication skills affected Ainsley response. The emotional aspect of this struggle may leave her feeling helpless adding to her vast feelings of the unknown.

[when other kids laugh at Erik] He goes like, ‘stop it’ but they keep laughing. He does it in a funny voice when they keep laughing at him, but he doesn’t think its funny. He sometimes have a screechy voice when he’s very, very mad. When he’s really mad he goes like, ‘don’t make me punch you.’ It makes me really sad but I don’t know what to do or say to those kids, because I never met those kids (Ainsley interview).

Kadee identified the same type of story happening to Weston:

Well, sometimes when Weston makes a mistake, they [my friends] laugh at him. I’m like “don’t laugh at my brother. Some of the kids listen, but sometimes they just keep laughing and then I have to get really mad. After that I say “remember he has autism and I don’t want you to laugh at him anymore!” Then they stop (Kadee interview).

Others' comments are often informed by ideas of what is “normal” and what is “not normal”. This informs ideas about what siblings and parents should and should not do. An action embodied by the participants was the idea that they had

real-life knowledge that could assist others in the advancement of understanding and tolerance regarding children identified with ASD. The siblings and parents believed the value of their knowledge could help inform others and avoid perpetuating the cycle of deficit. However, the parents indicated a more vocal approach to educating community members than siblings did. This could be due to the age of the siblings in this study, not knowing enough about ASD themselves, or feeling they do not want to be singled out as 'different' themselves. This creates a question in relation to the siblings' belief that their opinions and thoughts regarding the child with ASD are legitimate and valuable. Giving the siblings the tools needed to address these instances and concerns regarding lack of knowledge may help in situations when communication becomes difficult.

**Object-Outcomes.** Conversations with the siblings about the impact of ASD on their lives consistently yielded both positive and negative effects. Concerns about siblings weighed heavily on the minds of all parents. Emma and Emerson's mom passionately expressed her position regarding her children's relationship, "We are really, really lucky that they have—I'm glad that it's a relationship instead of she just tolerates him. She's really good about tolerating him in her space, but they're actually friends." Siblings were mindful of differences and the expectations others, including parents, have regarding actions and behaviors. "Well, I wish he could understand everything" Carson told me. He continued to explain the "more that Elliott understood, the easier life would be for our family." Emma brought up the point that even though Weston is diagnosed with ASD and that often this meant that she was treated differently, received less attention from her parents, and did not get to do things with her friends all the time – she did not care. "He is funny. Yeah, he



talks about things that he—he plays with me a lot and I don't know. We hug each other cuz I love him.” This is the judgment that weighs heavily on family members of a person with ASD. The judgment may not always be explicit, but there are often times where the judgment is implied.

**Family's experience regarding ASD as an Activity System.** ‘Sibling understanding of ASD’ (as the activity system) can be examined as an activity based on CHAT by linking “challenges of socialization and communication” and “positive and negative effects of ASD within the family.” The siblings and parents (as the subject) have constructed responses to aggression and physical actions (as the rule). They have adapted strategies and communication skills that has been learned through experiences managing unusual and odd behaviors in the family and/or community (as the rule) to interact with the child identified with ASD in order to understand and improve the relationship between siblings. Siblings and parents have identified positive and negative effects over time (as the object) through emotional understanding of cultural guidelines (as the tools). In addition, the family structure, sibling relationship and understanding of ASD have been evolved (as the division of labor) by the efforts of the parents to create independent identities for their children. The family-centered culture has filtered into the community surrounding the child identified with ASD (as the community) at home, school, playground and parks. The families have continually attempted to increase their understanding of the effects of ASD on the family structure and how it affects the child identified with this disorder through interacting between all the above elements (See Figure 10).

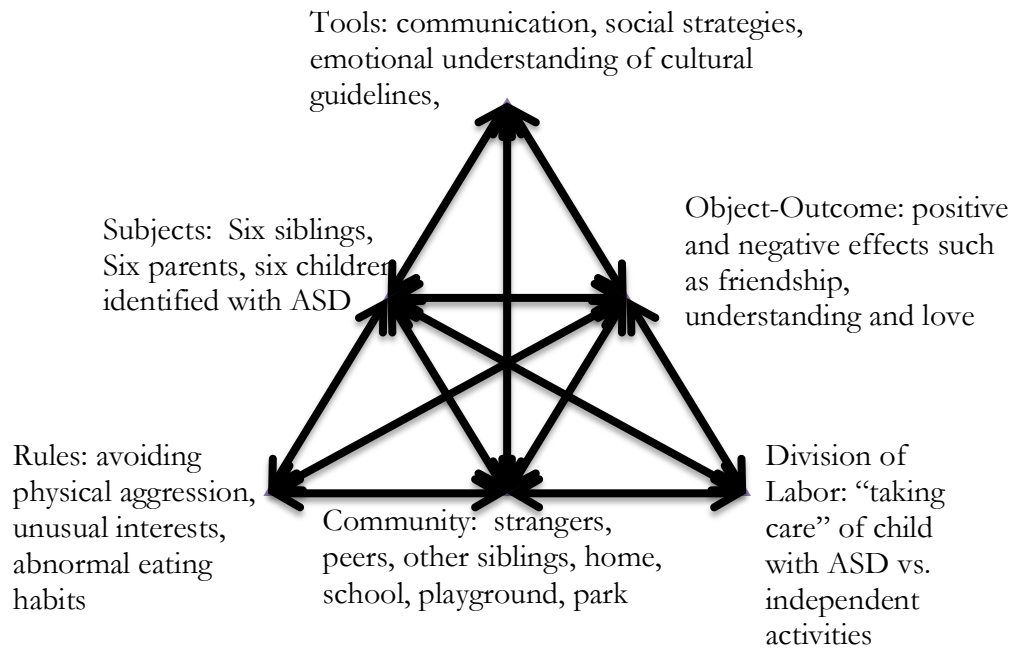


Figure 10. Family Life

### Summary

The current study provided insight and a better understanding of the social interactions and play activities between siblings when one is identified with ASD. The impact of ASD on young children may be quite influential. Findings from the data analysis deepen our understanding about how having a child with ASD impacts social interactions and development among siblings of children with ASD. Unlike previous research, this study used video-cued interviews of siblings as well as observations of the children involved in play and social interactions to elicit thoughtful responses from children. By using this type of data collection, the greatest amount of information was gathered directly from the siblings themselves. However due to the video-cued interview method for collecting data, the siblings spent the majority of the interview speaking about the child identified with ASD

even when questioned about social interaction and play activities with their peers. For example, Kadee said began telling me a story about her and her friends' favorite activity to engage in which is Monster High<sup>TM</sup>. Yet, in spite of her apparent desire to tell me about this activity, suddenly she switched modes to tell about the previous day with Weston. This departure from talking about peers was common among all of the siblings, although it was not evident as to why the siblings consistently did this.

This chapter illustrated the usefulness of cultural historical activity theory (CHAT) as a framework utilized to identify and describe informal learning situations (Sawchuk, 2006). For example, each of the siblings had multiple stories of informal play situations involving activities with their brother and occasionally peers. These activities included a variety of tools and environments such as trampoline jumping in the backyard, basketball at the school playground, bowling at the community bowling alley, games at home and the park. CHAT helps us understand how particular activities are goal-directed or purposeful interactions of subjects with objects mediated through the use of tools (Roth & Lee, 2007; Wertsch, 1991). Christy demonstrates this point when explaining her love of musical instruments, "Well, we do 'Mary Had A Little Lamb' because I just love to do music with Michael." She continued giving more details regarding her desired outcomes [her feelings], the division of labor regarding the activity [Christy teaching] and the rules of the activity [dancing]. "Well, it makes me feel glad that I'm teaching them something 'cuz I love doing that kind of thing with him. [*Music*] we're having dance as well." The decisions of assigning tasks within the play activities create levels of

power that may not be completely understood between the children in these sibling relationships.

CHAT recognizes the internalization and externalization of cognitive processes involved in the use of tools, division of labor and rules as well as the transformation or development that results from their interaction (Engeström, 1999; Engeström & Miettinen, 1999). Internal activities (that is the transition from “we” toward “me” in the development of consciousness) cannot be understood if they are analyzed separately from external activities, because internal representations and external actions transform each other (Lompscher, 2006). The ability for the siblings to mediate tools, division of labor, and rules addresses the ways in which ASD has been a focal point in their lives. These experiences have reinforced within the siblings the strength needed to manipulate mediating instruments required to meet an established goal. For example, Christy told many stories about her love of music and her desire to share this love with Max. She has taught Max to strum the guitar, use a microphone to sing and dance while engaging in play. Through these activities, Max and Christy have developed new actions and outcomes to future social interactions and play activities.

Internalization is responsible for the reproduction of culture (Engeström, 1999). Such as parents’ expectations regarding the siblings’ actions and responsibilities for assisting with the care of the child identified with ASD, as well as the siblings reactions to these expectations. When individuals are related to each other, they are enculturating each other through various components of the activity triangle. The siblings all appeared to have the same desire to please their parents with actions, even though it was not explicitly stated that the siblings were obligated

to adopt this role, the implied requirements was common. For example when the parents spoke about the siblings, they made statements such as; “she’s been an awesome help with him”, “she has so much patience with him”, “she has really learned how to communicate with him in a special way”, “she does her best to have a good relationship with him”, “He understands how to act around his brother”, and “I love to watch how she interacts with him and how she never fights with him.” According to Wertsch, moments of intersubjective understanding play an important role in internalization: “By identifying the points on which there is adult-child accord one can recognize points of intersubjectivity in the zone of proximal development. Many such points can be found in the transition from interpsychological to intrapsychological functioning,” (Wertsch, 1985, p.162).

Externalization is important when collaboration between individuals requires interactions for their activities to be conducted (Engeström, 1999). For example, when new rules are created a new division of labor is implemented (Cole, 1995). The rules and division of labor is interconnected to all other components of the activity triangle, therefore affect change throughout the entire system between subjects, such novice and experts (Lave & Wegner, 1999; Worthen & Berry, 2006). Through investigating the overlaps of externalization and internalization, this study shed light on the aspects related to developing and using the knowledge gained from these siblings. For example, Emma and Kadee were able to manipulate situations in which their brothers did not want to participate in chosen play activities to resolve conflict in their desires to be social engaged in interactions. They drew upon their knowledge of previous play interactions; they scrutinized the current situation, and took chances that engaging in formerly negotiated patterns of actions further expanded learning.

Situated learning speaks to the culture and cultural patterns that emerge between siblings about activities, identities, artifacts and communities of knowledge and practice. The evolving sibling relationship can be thought of as the inclusion of an action within the activity system. Learning norms for play and social interaction for children with ASD is the focus of many research studies (Boutot, Guenther, & Crozier, 2005; Cook, 2008; Rodman et al., 2010; Scattone, 2007). Several factors influence the process by which children with ASD acquire normative skills of play and rules that guide social interactions. Acquiring of these skills is achieved when a child with ASD interacts with their siblings as well as through community practices. There is a fundamental contradiction in the meaning to newcomers [novice] and old-timers [experts] of increasing participation by the former; for the centripetal development of full participants, and with it the successful production of a community of practice implies the replacement of old-timers (Lave & Wenger, 1991). One implication that appears to be problematic with this procedure is the social reproduction of communities of practice that inherently creates “old-timers” from previous “newcomers”. Infants and children learn responsibility, collective roles, how to handle conflicts and compromise and how to relate to others (Rogoff, 2003) but these skills are learned in different ways and in different orders, depending on the culture and community (Cole, 1995). Learning, transformation and change have the possibility of creating conflict between siblings (Sanders, 2004). This generative process imposes strategies and actions solidifying the bond within the relationship between individuals. The families in this study have learned a variety of strategies through the engagement in practice. Gradually, these families have increased participation navigating among person, tools and activities as the

novice participant contribute to the activity without necessarily understanding how their behavior affects the task. In other words, learning for all participants is a consequence of participating in activities. As the siblings and children identified with ASD consistently engage in social interactions and play activities, each began to transmit knowledge and understanding of their social world.

The analysis in this chapter addressed each of the original research questions. I learned that the kinds of activities that constitute play often exist outside what typical children might consider play. Accordingly, the siblings in this study participate in a variety of activities with their brothers that they do not engage in with peers. For example, Emma described using their skateboards as beds to roll down street while watching the clouds. When asked if she would do this type of activity with her friends, she said “no, we play *Monster High*<sup>TM</sup> or *Grease*<sup>TM</sup> like that kinda stuff.” Emma continued to explain that her friends did not understand many of the games and activities that she played with Emerson. This was echoed by Kadee, Ainsley, and Amana. Through these findings I learned that siblings of children identified with ASD define the engagement of play activities in particular ways that may be considered atypical, however consistently described as positive social interaction between the siblings and the gratification felt by the siblings. That is different than the way they define play with their peers, which seemed to include typical types of play activities, such as Barbie dolls, play acting, football and video games.

Important social learning for siblings seems to be occurring in the ways they approach feelings of empathy for others, taking care of others feelings while balancing their own emotional needs, and how to understand other individuals’

perspective of social situations. These siblings have also demonstrated the ability to circumnavigate comments regarding their families' difference and critiques about their brothers' peculiar behaviors. Communication, leadership, and reasoning skills as well as virtues of empathy, altruism and acceptance are happening (particularly within the social domain) when these siblings are socially interacting or playing. These important findings were reinforced through multiple stories regarding the siblings' desire to ensure that others were tolerant, accepting and understood the effects of ASD on an individual. In the social domains of learning relating to others by demonstrating cultural competence, accepting differences and appreciating meaningful interactions are essential levels in the process of learning.

By reporting the results of analyzing and interpreting the transcripts of the interviews with the siblings and parents using a CHAT lens, this chapter showed how listening to the stories of children who have a sibling identified with ASD offers a deeper understanding of sibling relationships using the realms of social interaction and play. Listening to the participants provides greater awareness of the effects of ASD on sibling relationships for young children. In the next chapter, I will build upon these understandings of these findings to provide further insight of the siblings' motivations, experiences and perceptions by summarizing these findings and discussing the implications of this data.



## Chapter 5

### DISCUSSION

*“He’s different, but I still love my brother” (Kadee interview)*

I believe the inclusion and exclusion of the siblings within play activities and social interactions with the child identified with ASD may become an issue in which the sibling not identified with ASD classifies themselves as outsiders. According to Johnson et al. (2005) “a sense of belonging or connectedness is a vital aspect of our identities and a basic dimension of human existence” (p. 14). Paley (1992) discussed the issue of exclusion in play in her own classroom with the rule, “You can’t say you can’t play.” I consider this imperative in the sibling relationships represented in this study, since Paley’s book discussed the social hierarchy and construction of children’s social development and identity. In this book, she described the use of rules (sign posted saying “You Can’t Say You Can’t Play”), tools (toys, play items), community (kindergarten classroom), subjects (kindergarten classmates, herself), division of labor (new with each play activity and day), and outcomes (new rules of play and social interaction in the classroom). Even though this examination of the issues involved in play activities and social engagement takes place within the classroom, similar observations were made within this study.

I began this study wondering how I might deepen my understanding regarding the thoughts of children who have a sibling identified with ASD by examining sibling relationships through the lens of socio-cultural activity. The unique contribution this exploratory study offers is to listen to the voice of children aged 7-9 years old regarding social interactions, play and the affects of ASD in the development of their sibling relationship. I wondered if CHAT would provide an

appropriate lens to deepen my understanding of sibling experiences, motivations, and insights regarding having a child identified with ASD in their family. I explored this topic through the CHAT model as a possibility of countering traditional behavioral and medical models of studying social interactions in families with at least one child identified with ASD. I aimed to answer four questions: (a) According to sibling participants, what kinds of activities constitute play?, (b) How do siblings of children identified with ASD define the engagement of play activities?, (c) How do children's descriptions of play differ between play with their peers and play with their siblings?, and (d) What kinds of learning are happening (particularly around the social domain) when these siblings are socially interacting or playing?.

In this chapter I weave insights, queries, and tensions within play and sibling relationships. More specifically, I sought to examine whether social interactions and play in sibling relationships might be described utilizing an activity system as defined by Engeström (1999) as well as the motivations behind roles and actions within sibling relationships that emerged as I began to explore my data. The impact of ASD on the family, in particular young children may be quite influential. Findings from the data analysis will allow researchers, educators and families to have a more concrete awareness as to whether or not ASD impacts social interactions and sibling development through a better understanding of the social interactions and play activities between siblings when one is identified with ASD. I discuss my analysis of data which sought to answer these questions by exploring how activity systems of play are influenced by the development of the family, cultural histories, the development of the siblings' identities within these families, and how the families mediate sibling interactions with these activity systems. This is followed by a

discussion of the limitations of the study and advanced recommendations for future research surrounding play and social interactions within sibling relationships when one child in the family is identified with ASD.

I wonder, for whom I am writing for and the story I am attempting to convey. I explore how CHAT might help to shape new understandings of play, sibling relationships and the effects of ASD for families. Bronfenbrenner (1979) struggled with the circumstance that it is always “I” who writes about children and interprets what “I” see. While I also confront this situation, I hear the siblings’ voices expressed in the discussions of play, sibling relationships and the effects of ASD in their lives. Positioning myself as an outsider in the siblings’ lives with and insiders perspective of ASD in a family, created my own internal struggle regarding ownership of the stories told by the siblings. However, I conclude that, even though the stories of play and social interactions belong to the siblings in this study, the interpretation of their words, emotions, feelings and motivations belong to me. Paley (2005), Pugach (2001) and Ferguson, Ferguson and Taylor (1992) reinforced this viewpoint as she described the value of listening to children, giving them the experience of being heard, as well as valuing their point of view as the fundamental topics that changed her teaching.

Unique from previous research, this study attempted to access information using video-cued interviews of siblings as well as observations of the children involved in play and social interactions. The use of parents videotaping their children while engaged in play activities provided a naturalistic tone to all the videos. Interpretive approaches to qualitative research rely on naturalistic methods such as observations and interviews (Denzin & Lincoln, 2000). This allows for meaningful

collaboration between the researcher and the participants ensuring fluid, adequate dialog (Ferguson, Ferguson & Taylor, 1992; Pugach, 2001). By using this type of data collection, a large amount of data gathered for this study came from siblings themselves.

### **Discussion of Findings**

I hoped to learn what effects ASD would have on play and social interactions among children when one sibling was identified with this label. Through video-cued conversations with the siblings, I imagined that giving voice to their experiences, while being listened to and heard by others, would create a space in which more information would be learned about their experiences, their relationships, and their lives with ASD. As I reflect on the process of this project, I considered my role as an interpreter of the findings as I gave meaning to the siblings' experiences of play and social interactions with their brother identified with ASD. Ferguson, Ferguson and Taylor (1992) described the role of qualitative research in special education as "telling different stories" (p. 296) as they stressed it is necessary to be open to the full context of the lives of individuals with disabilities and their families. These researchers continued to explain the importance of providing a place for voices of individuals with disabilities and their families to be heard. "Interpretivism pursues social justice one story at a time" (Ferguson et al., 1992, p. 301). Qualitative research is a vehicle for individuals who have been previously marginalized to be heard (Pugach, 2001). This paradigm enables researchers to engage in a collaborative form of "story telling" (p. 299) in order to connect multiple perspectives (Ferguson et al., 1992). "Qualitative research has been embraced as one way of understanding the complexity of disability" (Pugach, 2001, p. 450). The outcomes of this study suggest

that siblings of children identified with ASD share a common message regarding the elimination of the use of deficit model of thinking. This was confirmed many times throughout the study as the siblings continually created their own versions of ‘normal’.

### **Defining Deficit Versus “Normal”**

Even though there have been multiple research studies regarding how siblings adjust to living and growing up with a brother or sister with ASD, the findings are mixed. Some researchers report that children with a brother or sister with ASD are at a higher risk for internalizing and externalizing behavior problems (Hastings, 2003; Rodrigue et al., 1993; Ross & Cuskelly, 2006; Verte et al., 2003; Wolf) and for disadvantaged sibling and peer relationships (Bägenholm & Gillberg, 1991; Hastings 2003; Kaminsky & Dewey, 2001) compared to siblings of children with another disability. Other researchers suggest that siblings of children with ASD may not be at increased risk for such difficulties (Kaminsky & Dewey, 2002). However, none of these studies or researchers defines what “appropriate” or “normal” progress within relationships consists of. As a scholar who uses sociocultural lens to understand the world, I view the term “normal”, not as a statistical term, but as a culturally laden descriptive term with multiple meanings and uses dependent on the person or communities using it.

Dominant cultural perspectives within any society impact parents’ expectations about their children’s social development (citation). Norms play a vital role in the development of individual’s social life, from “fashioning taste for uncomfortable clothing and creating cravings for enticing but unhealthy foods to

setting strong markers for social class, race, and gender identities and role expectations” (Brantlinger, 2004, p. 490).

The siblings in this study appeared to move away from the concept of labeling and discussing individuals using deficit terms, diagnoses, and medical/behavioral terms. This was interesting due to the parent’s expressed thoughts and words regarding the label and identification of ASD within their family. The parents appeared to discuss ASD as a disorder, with medical terminology and with phrases like “his delays”, “he has deficits in this area”, “we continually seek out interventions to change his behavior in this area,” and “I wish he was more normal, but we deal with what we have.” Each of the parents appeared to believe talking about the child identified with ASD in terms of deficit and disability was the best way to ensure others, including the siblings, understand that there was a need to treat the child with ASD ‘differently’. Since this theme was so prevalent, I’ve worked to understand why there were differences between the parents and their children and what this might mean. For example Christy and Max’s mother explained that it was important to remind Christy of Max’s “diagnosis” in order to “keep peace” within the family structure, “if I’m reminding her that he has autism, [and] ‘we need to step back and you [Christy] need to think about this’, then she really doesn’t get that frustrated. She understands.” This was a sentiment expressed about all of the parents in this study, even though the siblings challenged this deficit model of thinking. The siblings seemed to see difference in physical characteristics such as gender, size, hair color, not in ability. Differences between parents and their children in making meaning of autism may factor in the development of family and individual sibling development.

Several factors influenced the siblings' attitudes and feelings about the child identified with ASD. The siblings described activities as fun, social and as a responsibility. Each revealed ways in which their participation with their brothers intertwined with their family, school and/or social lives – Carson's desire for Elliott to play with his friends on the trampoline, Ainsley's commitment to helping Erik make friends, Christy's focus on family and Kadee's desire for her friends to play with Weston. Even though it is possible to interpret these examples with an underlying assumption that the siblings have discovered the child with ASD needs help and assistance in various situations, implying the thought of deficit, this was not the impression given by the siblings. Instead, each of the siblings appeared to have figured out how to support the child identified with ASD without stigmatizing and pathologizing them.

In contrast to previous research in which children spoke about the negative impacts of having a brother with ASD, their families, as well as on the child with ASD, children in the present study spoke about the impact of ASD in their lives in the realm of the disruptions in their daily lives caused by their brother's behaviors, the allowances they made, and the atypical roles they had to assume (Petalas et al., 2009). Each of the siblings involved in this study only spoke of the negative impact of ASD and the child's unwanted behaviors if I pressed for more information, it is not clear if age or distance played a role in how the siblings constructed these feelings and behaviors. All responses were also prefaced with positive comments, compensation for the behavior and/or comment as well as statements such as, "he screams sometimes, but that is ok", "when he head-butts me, he does not mean to hurt me" or "he eats my homework, but it is ok because it's just because he likes

paper.” This appeared to be the siblings’ way of saying their brother did exhibit unusual or peculiar behaviors that are unlike other children the same age, but they had implemented various coping strategies.

Christy explained her feelings regarding her relationship with Max by saying, “It still feels a little bit different [our relationship versus sibling relationships’ of my friends]; maybe like... he’s maybe younger than his age. I still love him very much.” Kadee expressed similar feelings, “sometimes I just want a little alone time with my friends and not him, but I still love Weston. I would not trade the world for him.”

The outcome of these words may be important when investigating the differences in sibling relationships when one child is identified with ASD, especially in regards to understanding the differences of speaking in terms of labels and the use of deficit model thinking in various families. Since it was not clear as to if these siblings were attempting to fit in with peers and belonging to a community in an effort to appear ordinary and “just like my friends”, I am unable to explicitly state the contrast between parents and siblings is due to particular perceptions. Since the young sibling viewpoint is noticeably absent in the literature and the siblings themselves are rarely given the opportunity to provide information based on their personal experiences, allowing the siblings to describe their experiences, express their thoughts about the impact of ASD as well as how they define ASD has been an important aspect to the findings of this study.

### **Play and Social Interactions**

Play is a pervasive, meaningful activity that involves energy, focus and pleasure for young children with and without labeled disabilities. Despite the hundreds of play-related studies the focus has been primarily an adult focus in which



the voices of children regarding the importance of play with siblings and peers and the kinds of play spaces they prefer has rarely been documented (e.g. Christensen et al., 2010; Cook, 2008; Coplan et al., 2006; El-Ghoroury & Romanczyk, 1999; Ginsburg, 2007; Hansford, 2011; Jordan, 2003; Koegel et al., 2005; Miller & Almon, 2009). This study opens a space to think about how the patterns of play or social interactions between siblings when one is identified with ASD may be important frames of reference for later learning and social development in families as well as school and community settings.

My intention was to let the voices of siblings be heard through my words as I portrayed the siblings' social worlds. I see the siblings' stories regarding play and social interactions with the child identified with ASD as openings for understandings of the impact of ASD within the sibling relationship even though there are no definitive answers. As stated by Kalliala (2006) comments, "You have to be ready to follow small paths pointed out by the children" (p.5). The siblings' voices expressed utilizing vignettes, usually conveyed through excerpts, transcripts and sometimes actual voices and video, elicit reactions and reinforce interpretations (Soto & Swadener, 2005). I began to understand that play takes different forms and shapes depending upon the family structure, context of play and cultural background in which the siblings navigate.

Play among the siblings was shaped and modified over time as the child acquired different forms of activities, expressions, and motivations. For instances, Christy spoke of playing on the slide with Max as a form of enjoyment and fun, however this activity was eventually also used for a form of speech therapy. Max's speech therapist utilized the park equipment as a tool to incorporate play into

enhancing his therapy session in order to increase his communication skills. Christy utilized the same equipment when she played with Max as well as emulating the actions witnessed during his speech therapy sessions she attended.

I continue to wonder about the various roles and the binary of “work” and “play” that appears entrenched in the literature as well as within families and school systems. Each of the siblings’ times of “work” involving care-taking and helping with their brother, and times of “play” seemed to overlap and appeared to be the same or similar activities. It is interesting though that even though many of the activities were the same; the activities had different purposes that each sibling considered to be opposed. I have speculated about how many adults seem to justify the value of play in terms of learning and not simply due to the fact that children like to “play for play’s sake.” The way adults define play reflects the needs of adults to organize and control children’s behavior instead of allowing children to act as they will (Sutton-Smith, 1981). I find myself speculating about the sibling’s understandings of how their play could be incorporated into a variety of spaces with children other than the child with ASD. Since interaction with their friends may be difficult at times, siblings may feel distanced from other children at times, due to their unique home lives (Barr & McLeod, 2010). In addition, children who do not understand ASD or ASD-related topics and characteristics in the same way that the siblings do, others may taunt and tease the siblings about the child identified with ASD. Due to these factor as well as other unknown factors, interviews with peers and children who are in families not impacted with ASD would be beneficial to furthering the results of this research.

As the siblings continued to tell their stories about play and interactions with

their brothers, I realized how easily play could be disturbed. Siblings invested a considerable amount of energy, negotiation, and time to engage their siblings with ASD in any type of play activity. The siblings seemed to be aware of the tenuous nature of play with their brothers, relating comments that they understood at any moment the child identified with ASD might lose interest and leave the play activity. Despite the potential for failure, the siblings were persistent in their pursuit of play with the child identified with ASD. They revealed that play was a platform that helped develop and support all of their relationships. Emma said play was important with Emerson but also with her friends because “this is how we have fun and pretend we are sisters.”

Ainsley approached the value of play and social interactions through a different need. Her definition included stories of bringing children together to support Erik and her perceived understanding of his need to interact and engage with more children and not be alone. More than once she admitted her main desire for Erik was his connection with other children in order to increase his social development and “not be alone all the time.” She made it very clear that she believed Erik was missing out on fun and his lack of friends made him “not happy”. Ainsley stated how this made her very sad because of what Erik did not have. I interpreted her statements as a sense of loss for her, however as I communicate these thoughts I wonder if I am imposing my own thoughts of loss on these siblings. I am unsure I can say Erik and/or Ainsley for that matter, understand and feel loss for something that they have never had. Even though Ainsley is figuring out the multiple subtle nuances of social relationships, between both her peers and her brother, she is still attempting to decipher the complex meaning of these

experiences. I wonder if my hesitancy is due to the fact that parents, educators, and researchers constantly view the interactional processes of play and the development with relationships among children as challenging, nurturing and an internal process involving the contexts of empathy, authority, and fun (Frost, Wortham, & Reifel, 2001).

Children often do not have the opportunity to use their imagination and creativity in daily life as opportunities for play are diminishing in the modern Western world (Johnson et al., 2005; Heydon & Iannacci, 2008). As I consider this factor in the development of play activities among the children in this study, I am aware of the nature of ASD and the possibility these characteristics may constrain the motivations and desires to participate in creative, or any type of play activity. A key finding in this study was that truly understanding the sibling's motivation may be crucial to supporting them as they increase their knowledge, understanding, and skills within the area of social development beyond their status within the family structure. However, it was the moments when sibling motivation and family goals intersected that provided the richest social engagements for the children in these family structures. For example, Christy spoke of authentic activities that included music, teaching Max and fun. "Well, I don't know I just pretty much started it [playing the guitar] and then I tried to include Max, cause my mom likes me to do this kind of thing." This leads me to suggest that by deliberately seeking points of intersection between siblings' play activities and the social goals of their families, both children benefit through a source of unexpected joy that furthers the sibling relationship. Parents need to understand the importance of helping their children learn to express themselves, find sources of joy that allow them to enhance imagination and fully

participate as well as support their children connect the activities to each other in a way that builds stronger bonds to each other's world.

What I have learned about play within sibling relationships when one child is identified with ASD was that the play trajectory was not smooth and included a variety of unique, personalized forms and shapes. There were moments of stress in which the siblings attempted to engage in play with the child identified with ASD, only to be rejected. At times, that the siblings negotiated particular tools (toys, objects, music, etc.) in order to create positive interactions that could be sustained between themselves and their brothers. They also shared activities that appealed to the child identified with ASD through modeling ways to participate using tools, various rules and division of labor.

### **Siblings**

Most individuals with siblings can see aspects within their personality that are similar to that of their sibling, as well as aspects that are very different. When one child in the family is identified with ASD the similarities may be less and the differences greater. The label of ASD entails a variety of issues and difficulties for not only the individual but also for those closest to them. These difficulties often include social interaction impacting the way sibling relationships develop and unfold. Impact on the sibling relationships was not necessarily negative in these families. Siblings spoke a great deal about how they attempt to influence the social, cognitive and personal development of the child with ASD.

Since previous studies (e.g. Cuskelly, 1999; Dunn, 2007; Ferraioli et al., 2011; Goldfarb, 2000; Petalas et al., 2009) found that children spend more time with their siblings than anyone else, it is often the siblings who are co-constructors of each

other's identities. Through the lens of social interaction and practice, I hoped to gain a better picture of sibling identities in their relationships when impacted by ASD within the activity system of play. In these families, however, the parents were also a strong influence on the children's identities. The dynamic nature of the process of identity creation has created situations in which the siblings feel their role in the family is important. The process for which the siblings choose one role over another has been shaped by experiences and responses from their parents and the child with ASD. One situation in which the parents influenced the formation of identities roles in the siblings was defined by Carson and Elliott's mom when she discussed how each of her 'other' children know how to act and respond to Elliott's behaviors. "We have a lot of screaming; he [Elliott] really screams a lot, so when he giggles, they [siblings] just love it. They hug on him. They understand they must be patient and help him through his frustration." The overlapping of the interactions of screaming and hugging generate a move away from traditional dichotomies and re-define the reactions to behaviors in terms of the activity system of social interaction.

It can be argued that the construction of one's identity is an essential component to the individual's view of surrounding environment as well as the world. The previous conflicting research findings on sibling well-being (Orsmond & Seltzer, 2009), lack of information directly from siblings and lack of clarity regarding how siblings experience life as children in a family with a child with ASD, reinforces the need for additional research that captures detailed accounts and experiences surrounding the impact of ASD within families.

## **Relationships**

I thought about how the small pleasures related to seemingly insignificant things in the siblings' relationship seemed to illuminate their internal understanding of their life worlds, in the family and beyond. As I considered the described play activities and social moments I heard about, I understood these as authentic glimpses into the thinking of the siblings regarding the variety of positive and resistive ways engagement of appears in their relationships with their siblings identified with ASD.

Even though recent studies have indicated gender as a factor for predicting satisfaction and positive sibling relationships (Hastings 2003; Kaminsky & Dewey 2002; Orsmond & Seltzer, 2007b), the results from those studies do not hold true within this study, even though only one male sibling participated, there appeared to be no differences in his attitudes and actions than the attitudes and actions from the female siblings. Carson demonstrated similar relationship skills, desires and outcomes as the female siblings within this study. He continually discussed the importance of ensuring Elliott was happy, monitoring Elliott's behaviors and increasing his [Carson's] social skills when interacting with Elliott. Past research has shown that siblings of young children with ASD spend less time with and do not have a less close relationship with their brother or sister (Bagenholm & Gillberg 1991; Knott et al. 1995; Kaminsky & Dewey 2001). Participation in play and social activities are among the major factor in Christy, Ainsley, Amana, Carson, Emma and Kadee's relationships with their brothers. This is important to future research regarding the impact of ASD in family relationships surrounding play and social interactions.

Children develop language, cognitive, emotional, and social skills through relationships that involve meaningful exchanges and interactions (Johnson et al., 2005). Paley (2004) believes when we acknowledge children's emotional needs; adults directly influence their social and cognitive development. Consequently, children's social interactions are characterized by interpretations in viewing situations from another person's perspective, which is reflected in their language and actions. This assumes the child has prior knowledge or experience of a particular event or activity and the peer is utilizing the same rules for the activity (Johnson et al., 2005; Sutton-Smith, 1981). As children develop cognitively, their increasingly sophisticated social schemata allow them to understand social information so that they can appropriately interpret it and act accordingly (Piaget, 1962). In addition, a certain schemata developed over time to assimilate new and different tools or experiences and to accommodate schemata to allow for new and increased activities. That is, during each stage of cognitive development, the child works to achieve equilibration between his or her internal mental schemata and the environment in order to interpret and understand the external social world (Bloom & Tinker, 2001; Piaget, 1962).

Language is another key development within play, both verbal and non-verbal language. During the interviews with the siblings, I continually heard them say phrases like "playing Monsters High", "playing Power Rangers", "playing Grease", or "playing stuffed animals." I also heard lines such as, "My favorite thing to play is..." or "I love to play \_\_\_\_ with my brother", or "We play 'this' a lot," or "This is our favorite play activity" which has led me to think about the unique play language that children use within their own play culture. Using the word 'play'



seemed to indicate the siblings' entry into the world creativity and imagination with their brother and friends. It seems as if talking about play is a way of valuing vital activities that are fundamental to the development of their sibling relationship. I also discovered that the communication that was taking place between these siblings represented a breadth of non-verbal communication. While I had understood the notion of non-verbal communication among children, I was astounded by the range of ability to communicate between the sibling and the child identified with ASD. I found the siblings perceived the world around them differently than their parents and other adults. The breadth of their knowledge regarding alternative communication skills, their ability to listen beyond the spoken word and make meaning of facial expressions, gestures and physical movements, surprised me. For example as I discussed in the findings, Amana explained her use of sign language, or "the sign language I use with Ita cuz he can't do other kinds of signs," and Carson discussed the non-verbal communication through gestures and actions he used to exchange wants and needs with Elliott. The siblings displayed the lengths they go to in order to have a positive, interactive relationship with the child identified with ASD.

Once the sibling has begun to understand their brother's social needs, particular cues are observed, interpreted, and understood, the child must develop a response to these cues by cognitively generating potential behavioral responses, deciding upon a response, evaluating the likely consequences, and then enacting a chosen response. Not only Carson, but also his friends demonstrated this skill when Elliott presented the children with his desired play activity. Through repeated practice of engaging Carson in the play activity involving the trampoline, Elliott

began to increase his social knowledge by interpreting how others would react and respond to his varied requests. During early childhood, the child's social cognition is characterized by "egocentric perspective taking" (Piaget, 1962) in which the child's person perception is limited to interpreting the physical actions of others and does usually not allow for assumptions regarding the thoughts and feelings of others.

Children's perception refers to an individual's ability to recognize and interpret other individuals' actions by watching and examining their overt behaviors, and then deducing the emotional needs of these individuals (Tsao & McCabe, 2010). During early childhood perception is egocentric and limited to the physical appearances of others, such as Ainsley's example of her friend's big ears versus her brother's medium sized ears. However, the siblings in this study have begun to demonstrate abilities to incorporate the feelings of others, especially the child with ASD and their parents, over their own needs and feelings. For example as discussed in the findings, Christy frequently explained her desire for her brother to "get his way, so that he is happy and that my mom and dad are happy too." Emma, Kadee and Carson also mentioned ability please their parents because they are able to help with the child with ASD. "I can help my mom so she is not sad cuz she can't play with my brother, and she is happy with me" (Carson interview). Carson's mother affirmed her feelings of happiness toward Carson and the other children in the family as a result of their actions, emotions and behaviors exhibited toward Elliott. This has led me to believe that the siblings understand and want to avoid the label of "bad" child. They believe the "good" child label creates a place of importance for them within their family. The "good" child attitude is often internalized with feelings of responsibility, compromise, dependability, benevolence and tolerance.

This type of attitude could be detrimental to the development of the siblings' relationship over time and may contribute to feelings of resentment toward the child identified with ASD.

Buhrmester (1992) found that siblings remain an important source of emotional support for adolescent and emerging adult siblings. Adult siblings reported no adverse effects with their relationship between themselves and their parents, however they did report significantly less contact and less positive affect in the relationship with the brother or sister with ASD. These findings may reflect difficulties in the behavior of the sibling with the ASD, such as social and communication impairments (Orsmond et al., 2007a). Since the siblings in this study are so young, it would be interesting to follow-up in their young adulthood to validate changes, if any, in their sibling relationships in regards to social interactions, roles, responsibilities and attitudes related to the impact of ASD in their lives.

### **Identity/Roles**

Throughout the interviews, the siblings defined themselves as a sister/brother, friend and helper while continually uncomfortable with talking about the ASD label. They used various tools available to them, such as responses from their brother, social rules of games and play, the discourse and various toys; as they grew into their adopted roles within the family structure. During the time that I spent with the siblings, I saw them as “pleasers” within the family structures, even though not one of the siblings or parents referred to these children with this particular term. However each of the siblings demonstrated times of doing activities or completing tasks as a way of engraining and defining their place within the family

structure by pleasing their parents to ensure their importance in helping the family run smoothly.

The siblings' evolving, emerging identities were naturally and deeply influenced by their interactions with others including the child with ASD, parents, peers, professionals and strangers within the community. The process of adaptation and growth within the family structure applies to relationships among the family members including the child with ASD. However, the findings in this study indicate the construction of the sibling's identity has substantially been impacted by their comprehension of their role in the family. The creation of each sibling's identification and role within the family was influenced greatly by the reciprocal nature of interactions within each relationship, such as reactions to particular actions or emotions.

An individual will enact many roles through their lives. The siblings utilized these different types of roles and virtues in the construction of their identities through daily actions, events, emotions and reactions to these by other people. Many of the roles that the siblings engage in are done so simultaneously and may change frequently over time as their relationships develop. For instance, Amana, Ainsley, Kadee and Emma are all younger than the child identified with ASD in their family, however over time each of these siblings have taken on a role of power and responsibility when interacting with their brothers. The dynamics of these relationships, as well as the needs of the family, evolves as understanding of ASD changes. This is particularly important because of the uniquely influential position the label of ASD has on the parents and in turn on the development of the family identity.

Play and social interactions is one approach for these conversations with children, parents, teachers, and administrators. This allows for a greater investigation of the sibling relationships when the families are impacted by the identification and label of ASD within the family. We need to focus on how we should, and could develop a greater emphasis on sibling relationships that will counter-balance the effects of ASD within the family while producing greater play and social interaction outcomes. Due to increased research within this area, we know a lot more about sibling relationships and the effects of identified disabilities within the family, however there is still little evidence that this knowledge has been incorporated into practice within schools and homes (Sanders, 2004). It is essential to build upon the current knowledge in order to learn how to construct stronger, more positive relationships using the power of these relationships synergistically so that each child has the potential to develop socially while maintaining the complexity of the sibling relationship.

Play is freedom in the world of the child and children are empowered in play (Elkind, 2008; Sutton-Smith, 1981). Play may be one of the few forums in which children can freely explore their individual emotional capacity. The siblings' understanding of what play means to their relationship became a meaningful part of our discussions as they told me about the "fun" they have with the child with ASD. While the benefits of play include social, cognitive and physical components of development, there is less mention of the motivations of various virtues such as altruism, empathy, acceptance, patience and tolerance are less mentioned. During my observations and interviews with the siblings, I witnessed all of these virtues and more. Christy, Emma and Kadee each discussed situations in which the activities

they choose to participate in were due to their desire to ensure their brothers' happiness, enjoyment or improve their social interactions even though the activity would not be chosen by Christy, Emma or Kadee when playing alone or with a peer or in other social situations. The moments they described in which they initiated a practice of compassion and caring toward the child identified with ASD. These moments were spontaneous, demonstrated how the siblings understood the play provides pleasure and more importantly were noticed by all of the parents. During parent interviews these virtues were substantiated through the following quotes: "She's a wonderful child", "Just always looking out for him", "They really are friends. They really are", "if someone was mean to his little brother, one of his friends, they wouldn't be allowed at our house anymore", and "she always chooses play with him over her friends." Therefore, ASD appeared to affect and shape the sibling's identity and the construction of the sibling relationship in ways that may be different than families not impacted by ASD.

Through the reciprocal process of relating to one another and responding to each other's emotions and behaviors, the siblings create a system of power and influence through the particular roles they choose. The power and dynamic organization in which the roles are influenced must be considered. A familial role may be just one of the many roles a person will adopt in the course of their life, however the siblings in this study have already adopted a large variety of roles that effect the interactions they have with their brothers. Even though it is typical for siblings to hold more than one role within a family, there is a clear emphasis on type of role each sibling elected to enact within each situation. The polarization of each of the roles and positions the sibling hold within the family creates discourses of

complex situations in the siblings' lives. It is evident that they all have in common the practice of rejecting pathologizing terms while ensuring favorable outcomes for play and social interactions. The siblings are not without the power needed to support and make changes within their brothers' lives. For example in the previous chapter, I discussed Christy teaching Max to play the guitar and sing, "Mary had a little lamb." While we were watching this on the video and she was described the activity included the multiple times she stopped Max because he "was not doing it right." She said she wanted to ensure that he correctly learned the song and the corresponding dance and did not allow Max to alter the words or her choreography. Christy demonstrated her control and power over the situation as well as over Max's ability to create his own play.

The difference between the siblings may be considered a factor that propels the siblings to seek roles that clearly define their purpose in the family. Each of the siblings recounted stories and events that indicated their understanding of the way they filled particular needs in the family considerably impacting the sibling relationships. For example, Christy believed her position as Max's role model was imperative to his social, cognitive, and physical development and growth. She told many stories of how he did particular activities because "he just likes to follow me and try to do the same things I like to do." Even though Christy does not indicate an understanding of the power she possesses when interacting with Max, there were many moments where socially orientated opportunities created situations in which she controlled the learning outcomes. However, there is not enough evidence within this study to suggest these siblings would not behave differently if they did not have

a sibling identified with ASD. The siblings indicated their desire to ensure happiness and peace within their peer and sibling relationships.

On the other hand, parents often understand that, even though they act in their children's best interest with the best of intentions, occasionally unforeseen consequences occur, such as the parent as one of the major factors behind the siblings adopting particular roles that may not be typical within sibling and/or family relationships. It has become apparent throughout the interviews with the parents in this study that there is a need for further examination into the reasons children of this age who have a sibling identified with ASD feel the need to adopt all of these roles. The need would help inform family and school practices to be more aware of how power operates within the adoption of particular roles and how they inform interactions between peers, parents, teachers and others. According to Heydon and Iannacci (2008) the impact on family dynamics needs to be fully considered in order to benefit those outside of the family complete understanding of the interactions. This is especially important when we consider school-diagnosed pathologies and how they can affect the relationships and interactions between parents of children with ASD, siblings, peers and teacher (Heydon & Iannacci, 2008).

## **Parents**

Parental beliefs influence actions and expectations about all aspects of their children's lives. This includes how the child is taught and develops new and unique skills, the child's role within the family and the function and importance of these roles. Many factors such as economic status, ethnicity, religion, marital status, and parents' previous life experiences impact the beliefs and attitudes of parents.

Schwarze and Winkelmann (2011) indicated parents' ability to model the emotion of



happiness is directly related to the feelings of happiness of their children. This may be another contributing factor to the construction of sibling relationships and identities. Christy and Max's family demonstrated how these and other important factors inform the development of family motivations, behaviors and attitudes. Christy discussed her family's motivation behind spending all free time together rather than apart. She said, "I don't want to have days that I don't play with Max. It is important that I help my parents with his learning." Christy's choice of vernacular and behaviors demonstrated her identity development was most likely enhanced by her parents' expectations, such as their apparent pleasure with her engagement in Max's therapy sessions, her helping, teaching and feelings toward Max. "It makes my mom and dad happy when they see me teaching Max" (Christy interview). These quotes reveal a motivation within this family that may not be seen in families not impacted by ASD, however did not appear to be a common theme among the other families in this study, making me believe this may be an uncommon phenomenon. In spite of this, I believe additional interviews focusing on this topic need to be completed in order to verify if the main motivation and belief within Christy and Max's family had become the routine of centering all support and activities around Max.

### **What are the Implications?**

Over the last few decades, the topic of sibling relationships and the differences between children in a family has been studied through a variety of lenses. The findings of this study have implications on not only siblings of children identified with ASD, but all children on issues like sibling relations, play, empathy, tolerance, understanding of difference, emotional development, social development and

communication skills. Sibling relationships are crucial to our social and interpersonal development (Aronson, 2009). Even though it is has established that siblings play a significant role in each other's lives, findings regarding this research is been inconsistent. Similarities in personality, temperament, interests and abilities have also been documented. While conducting this research, I discovered important factors affecting the adaptation or roles and impact of ASD surrounding play and social interactions. The more children played cooperatively by taking turns and interacting, the more likely they were to provide assistance and help to their sibling (Elkind, 2008; El-Ghoroury & Romanczyk, 1999). It may be useful to understand the roles of in cooperative play in the development of social skills and relationships. Children play organized group activities, through the rules set by the group of children, in order to attain additional social competence that can be traced to increased skills in cooperation, imagination, and language, cognitive and physical skills.

It is important that parents, educators and professionals understand the importance of sibling relationships and the effects that ASD can have on them so that they can incorporate this knowledge into their approach when working with such families. The more that is known about the nature of play within sibling relationships involving children with ASD, the more empowered educators and professionals could be to either guide parents in helping their children increase play and social interactions in their relationship with one another or help the children directly. As research in this area advances and further discoveries are made about the processes that these children go through and the challenges they encounter in their sibling relationships, appropriate training for professionals working with such families can be developed.

Each family has a set of rules in which the family structure performs around. Many of these rules are unspoken but are embedded in the daily interactions and experiences. One way in which families develop and establish relationships and identities is through a set of developed rules that shape each interaction. A child's identity is shaped largely through emotional, personal experiences early in life. The manner, in which families respond to distinct sets of events within the family as well as outside in the community, helps each member of that family become the person they are by directly effecting their identity.

Most individuals, particularly adults, are aware of people in their lives in which they have identified or connected with resulting in the individual emulating their style or behavior. Parents or mentors are most often indicated as a person to emulate. The siblings often adopted the actions and behaviors of adults who held positions of power and responsibility in their brothers' lives. For example, Christy spoke of situations in which she performed the same type of activities as Max's therapists. For their family this means another member of the family who is identified as a therapist or caretaker for Max, alleviating pressure and stress for the parents. However, the adoption of these roles creates added stress and responsibility for the young children in the family that may possibly result in resentment and feelings of anger toward the child identified with ASD. Even though these results have not emerged at this point, parents need to be aware of that giving the siblings additional responsibility, limiting their freedom and time away from the impacts of ASD may result negative feelings surfacing in the future.

Most parents dream about their children and the relationship their children will have before the birth of their second child. According to previous research, the

strength and weakness of the parents own sibling bond will affect their aspirations and expectations regarding how their children interact with one another (Kaminsky & Dewey, 2001; Orsmond et al., 2009). Many times parents spend time establishing their desired rules and division of labor for the children attempting to ensure the siblings have positive interactions and avoid negative emotions. However, this becomes difficult when one child is identified with ASD or other developmental disability. Even though parents typically discuss their expectations of appropriate roles and behaviors preformed between the children, this was not the case with the parents in this study. The major topic discussed between the parents and the siblings was the needs of the child identified with ASD. The parents were, consciously or unconsciously, preparing both themselves and the child not identified with ASD for the difficult adjustment period that comes with learning a family member is identified with ASD (Orsmond et al., 2009). Common reactions include both positive and negative emotions regarding the presence of ASD in the family structure (Kaminsky & Dewey, 2002).

Parents may approach the issue of familial roles with both apprehension and enthusiasm. They may have experienced the adoption of different roles as they were growing up within their own family system. For this reason, in a two-parent family, parents interact with their children differently on many dimensions. Personal histories, cultural communities, education, and religious backgrounds impact the ways in which parents support their children to adopt and explore a variety of roles within the family. Parents may discuss new roles, family rules and division of labor surrounding particular activities. Parents will also differentially deal with and address negative issues that might impact sibling and/or family relationships adversely. This

has great implications for the kinds of roles that siblings adopt. For Christy becoming a mini-therapist lessened the work and stress for her parents in terms of reinforcing particular interventions and reducing negative behaviors displayed by Max. Carson's actions as a mediator helped the family structure to ensure Elliott is provided with the appropriate structure when his parents are not around. Emma and Kadee demonstrated multiple roles however playmate, enabler, and protector were the major themes displayed by these siblings. They both talked about the importance of ensuring their brother's happiness, even though they did not talk about their own happiness. This leads to implications in other relationships in which they may become subservient to peers or other children. Ainsley and Amana also exhibited particular places within the family that allow for reduced stress, additional help and decreased responsibility for their parents.

What does this mean to the classroom? To inclusive education? To other children and the impact of disabilities within the school? Teachers should approach children, especially those who have siblings with ASD, who adopt particular roles in the classroom, such as the mother hen, class clown, 'know-it-all', bully, Miss Perfect, follower, leader, etc. with understanding as to why these roles are essential to the child's identification within the classroom. The differences that exist between children, who are and are not identified with ASD, are not inherently dependent upon classroom rules, but may involve rules, values, family culture and diversity within social activity systems. For children identified with ASD the hidden curriculum involved in classroom rules, culture and division of labor has added issues when thinking about ASD characteristics. Children typically learn these roles and rules at home, from other children, through the media, from parents, or other

adults. Within the family and classroom systems these roles may be used during play to teach the importance of tolerance, acceptance and diversity. For instance, the growing diverse population of students on the autism spectrum in each classroom creates an important reason to balance interests, skills and teach individuality in order to find common ground for children to socially interact. The findings from this study are exploratory and need to continue to be examined in order to further explore the roles children adopt as they develop their identities.

Finally, this research has implications for professionals who interact and educate families. Educators, therapists and parents should acknowledge the role siblings play in the lives of each other and how these roles impact the development of social skills while strengthening their relationship. The difficulty of obtaining participants may indicate that many parents are hesitant to expose their children to research that investigates the affects and impact of ASD on the family, particularly on young children within the family. Through informal discussions with families who chose not to participate for a variety of reasons, it became apparent these parents were concerned with the potential of “getting more bad news” regarding one of their children. However, instead of being fearful of hearing any information regarding social development of their children, the parents would benefit from understanding what they are saying about the label of ASD, social interaction and play activities within the children’s relationship. For example, the parents may want to encourage more discussion with the siblings’ regarding their thoughts and feelings concerning the impact of ASD within their social interactions with the child identified with ASD.

## **Limitations and Parameters**

One limitation to this study was in regards to generalizability. Although the sample size was small and the time spent with each family was limited, many other qualitative research studies investigating the same population have had limited sample sizes and time (Toth et al., 2007; Verte et al., 2003; Kaminsky & Dewey, 2002). In general, siblings of children identified with ASD within the age parameters of this study were a difficult population to target and access. In regards to accessing the participants, instead of identifying the siblings directly, the children identified with ASD needed to be first identified. Even though a number of parents responded to the request to participate, many did not meet all of the necessary requirements and therefore, could not participate. For example, a local developmental pediatrician assisted in the recruitment of families. Due to early intervention and diagnosis, many of these families had siblings under the age of five instead of between seven to nine years old. Some parents stated they wanted to ensure their children's relationship, especially in the realm of play and social interaction was not negatively influenced to the newly identified label of ASD. Future research might expand the sample size and the amount of time engaged in observations and interviews in order to generalize the findings. With more children involved in the study, additional analyzes and comparisons could be made as well as strengthening findings, assuming similar results were established.

Another limitation was the gender distribution of the children with ASD, 100% of the children identified with ASD were male. Due to the prevalence of males versus females identified with ASD in the population, this was expected. The time spent between these two siblings may not have included activities that would

not be considered age-appropriate or gender-specific. When siblings are closer in age and the same-sex, this may be an impacting factor to socialization in sibling relationships. However, future research may explore the relationships of same-sex sibling pairs in order to gain insight into whether or not gender influences the social interactions within sibling relationships.

Additionally, all parent participants were mothers. It is important to pursue the fathers' perspectives in an effort to generalize findings to parents. The father's viewpoint may be quite different from the mother providing further information to research. Of the families of qualified to participate, the self-selection process completed by the mothers may have had an influence on the overall findings. More specifically, there is a possibility that the mothers chose to participate due to their concerns about their children's relationship prior to the study and felt the results may in some manner benefit their children by answering the parent's questions.

Furthermore, only one interview was conducted with each sibling and parent participant. It is important to spend more time with each family in order to gain vital information and establish a rapport with the siblings and parents. In the future, more interviews over a longer period should be completed to develop a stronger understanding of sibling relationships. I caution that the words and voice that come across in this writing, are my words through the lens of an educated Caucasian professional, and mother of someone identified with Asperger's Syndrome. This lens may have influenced the ways I interpreted the data in ways that others would not.



## **Future Research**

The current study attempted to investigate the impact of having siblings with ASD on the play and identity development of typically developing siblings. We need to focus on how these findings will assist in developing a greater understanding and emphasis on the growth and development of sibling relationships among younger children aged 7 – 9 years old. Research findings have increased over the last several years, but there is still little evidence as to how to incorporate these findings into practice. Research based on these findings will generate increased awareness and better understanding of the many interrelated factors that contribute to social interactions within sibling relationships. Additionally, longitudinal research involving the same group of siblings over a period of time as they grow to young adulthood would offer valuable information regarding the long-term effects of ASD in the sibling relationship.

The data obtained in this study is rich in meaning even though it only included a small sample of families affected by the label of ASD. The sample does not demographically and culturally account for the diversity of families in terms of ethnicity, socioeconomic status, religion, age, family size or other factor. However despite these shortcomings, the study expanded on the knowledge about the effects of play and social interactions within sibling relationships when one child is identified with ASD. A greater range of family histories and demographics could not only lead to additional comparisons and analysis but also might allow for further exploration into to additional factors such as cultural expectations, ethnicity, race, gender, varying household structures and a variety of schooling.

Each of the families in this study were two parent households, which may not reflect the prevailing statistics regarding marriage and raising a child with special needs in the United States. Although divorce rates for families who have at least one child identified with ASD have not been connected to any empirical research or substantiated through census surveys, results of informal surveys have reported divorce rates as high as 80% (ASA, 2012). These rates are in contrast to the 2010 statistics provided by childstats.gov that state 68% of children ages 6-14 and 73% of children ages 0-5 lived with two married parents. Each of these factors can vary significantly. For example, some cultures encourage children to be quiet and reserved, while other cultures give children freedom to express themselves freely and openly. There is also a large variety of cultural reaction to a child with a developmental disability. That is to say, some Asian families consider this a sign of good fortune in the future, while other families may consider having a child identified with a developmentally delay a punishment (Kalyanpur & Harry, 1999). Even though the authors did not specify geographical location of the individuals discussed in this book, it is important to remember and acknowledge that many cultures may fall under the designation of “Asian.” More importantly, it is important to consider these demographic factors as critical indicators in the social and emotional development of children with siblings identified with ASD (Macks & Reeve, 2007).

Through the realm of play, children convey their capacity for empathy, cooperation, sharing and interconnectedness. The siblings articulated their acceptance of difference and cultural diversity in their discussions of play activities and social interactions. They also expressed issues surrounding how they chose the

activities they did over other options; how children are empowered in play; how the sibling play shifted and progressed over time; the importance of identity creation; diversities of play within the play scenarios created from popular culture; and the vital aspects of play within relationships. The children made it clear that play a meaningful part of their relationship with the child identified with ASD.

Parents often attempt to normalize their families according to their particular cultural histories, prior experiences with ASD or other disabilities and the impact of ASD on their marital relationship (Kuncel & Tellegen, 2009). Their own emotions and feelings create situations in which they embrace play and social interactions within their family structure. The social impact of having a child identified with ASD needs to receive more attention in research and literature (Higgins, Bailey, & Pearce, 2005). It is important to understand how ASD impacts the family, the family routine, the amount to time dedicated to therapy and services for the child identified with ASD and decreased time spent with the other children in the family. Having a child with ASD places considerable stress on the family (Orsmond et al., 2007a). Due to the negative attitudes and judgments that often surround individuals and families impacted by ASD, some family members may have felt pressure to present a socially desirable image when confronted in the community (Higgins et al., 2005). Although interviews and observations did not indicate this was a result of social desirability, I speculate the desirability to be judged favorable by others as well to be deemed having a family life as desirable by the majority of the population may explain some of the parents' actions and responses.

Childcare professionals, preschool teachers and paraprofessional's work impacts the policies and practices of a school system through a range of motivations

and implications. Therefore, their understanding the dynamics of play in informal settings like family and neighborhoods, as well as formal preschool classrooms, through an activity lens so that they can provide better early intervention services for families. These formal and informal settings could be characterized by each of the six components of the activity triangle as described by Engeström (1987). This leads me to believe it is important to identify the tremendous potential of these settings, including all the elements of CHAT (subjects, rules, tools, division of labor, communities and outcomes) as a means to increase our understanding of children's relationships especially when one child is identified with ASD. Interviews and observation data from teachers, paraprofessionals and childcare professionals would advance a deeper understanding of the needs for children in the area of play and social interactions. Stories and experiences from each of these individuals have implications for the advancement in inclusive education. It is important to ensure that teachers, paraprofessionals and childcare professionals understand the role of play and social interactions in learning and increasing tolerance in the development of tolerance among diverse populations in the formal and informal places.

Further research based upon these findings will allow for additional awareness and better understanding of play and social interaction of the many interrelated factors that contribute to effective learning in classrooms, families and daily life. This is necessary information to understand the overall impact ASD has within sibling relationships, social development of the child identified with ASD through the scope of play. Additional approaches to enhance this research would include collaborative methods

that bring together the types of media utilized in play and social interactions by siblings and children identified with ASD.

### **Summary**

This dissertation examined the ways in which siblings utilize play and social interactions to construct sibling relationships in various environments as a result of various tools, division of labor and communities. I have developed a theoretical orientation and methodology that responds to current research needs moving the field toward a deeper understanding of CHAT and its power to inform the field of research that involves children. By approaching this research through the perspective of cultural historical activity theory, this study debates the interrelated activity of individuals, their needs and goals, tools within the context, and social context of the activity. Activity evolves dynamically in the sibling relationships between children and their environment. The development of these relationships is a process of learning as changes in one's participation in an activity increases. By facilitating social interactions between themselves and the child identified with ASD, the siblings create a pattern of participation that contributes to the development of their relationships, identity and personal social growth.

Many voices from the ASD community are becoming increasingly vocal (Ryan & Cole, 2009). Parents, siblings, teachers, doctors and researchers are all voicing opinions on the development of tangible outcomes that can represent the next steps in ASD research. Many of these individuals are basing their statements and opinions on what best represents their own personal experiences. It was important to the parents to voice their concerns that community members, peers and their own children understand the impact ASD has on a family. The siblings in this

study appeared to have the same type of concerns but were more troubled with clarifying to me and to others the importance of understanding their brother was “the same as the rest of us, it is just that his brain is a little different.” Meanwhile, as actions in social interventions are developed, the end results need to impact the ways others think about, understand, interaction and ultimately experience ASD. The implications of this statement are yet to be seen, although I can imagine how it could contribute to ways professionals and others approach work with families living with ASD.

My study also speaks to the importance of understanding the relationships within a family structure when at least one child is identified with a labeled diagnosis such as ASD. These relationships shape other relationships, experiences and interactions in surrounding environments such as schools. Viewed through the lens of activity, play and social interactions may be considered actions designed to assist individuals in the pursuit of specific personal goals within a variety of relationships. For example, Emma and Kadee both spoke of particular play activities such as Monster High™ that they used to accomplish a shared social interaction with their friends, even though this same activity was not used to interact with their brothers. This study has led me to speculate whether parents might have inadvertently communicated an unspoken message that the child identified with ASD has a higher role in the family and that, the siblings must contribute to the family structure through the adopted roles and responsibilities. By presenting the importance of helping in the care taking as well as how to interact with the child with ASD, the siblings not only miss out on opportunities needed to cement and develop their

social abilities, but the parents may also inadvertently miscommunication the role the sibling holds in the family.

As with any qualitative study, the information gathered may not adequately describe the great variety of social transactions in family groups. The results in this study are specific to a small group of families within the southwestern United States; consequently, the experiences and stories put forth in this study may not align with experiences of others. Future studies should continue to investigate this topic with a larger sample of participants allowing for the ability to utilize the current findings while comparing same sex and mixed dyads of siblings, younger and older siblings, as well as mixed groupings of children (e.g., older sister with younger brother, older brother with younger sister, and the other possible combinations). Furthermore, studies should continue to examine the diversity within family structures with different populations, family forms, and demographic areas. It is my hope that the evidence and important factor of this topic will contribute as key research agendas for sibling researchers, as I know the data has inspired me to recognize there is much more research to be completed within the topic of sibling relationships when one child is identified with ASD.

My hope is that this study is a small start in the direction of investigating the effects of ASD on the sibling relationship through the realm of play and social interaction and that the siblings' voices communicated through my words, ideas and insight that may inform parents, educators and researchers. As I think about the children I observed and interviewed, I recognize they have their own understandings and explanations of the world around them as they participate in the activity system of play.

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APPENDIX A  
CHILD INTERVIEW PROTOCOL

## Interview for Child

1. I would like to show you a few short video clips that your parents took of you and your brother/sister playing together. During the video, I would like to ask you a few questions and have you tell me the story of the video. Is this OK? Do you have any questions?
  - a. Do you remember this day (event)?
  - b. Can you tell me about what you are doing?
  - c. After watching this, how does it make you feel?
  - d. Is this something you do together often?
  - e. How does this video make you feel?
  - f. Do you remember how you felt when you were playing with your brother/sister?
2. Describe your favorite thing to do with your brother/sister.
3. Tell me about an activity (time) when you and your brother/sister had a hard (difficult) time.
4. Describe the best place (environment) to have a good time with your brother/sister.
5. Is it easy or hard to play with your brother/sister?
  - a. Describe what playing with your brother/sister is like.
  - b. How often does your brother/sister try to play with you?
  - c. How often do you try to play with your brother/sister?
  - d. What made it fun (rewarding)?
  - e. What would you change to make play time more fun for both of you?
6. Are you ever embarrassed (uncomfortable, ashamed) by any of his/her behaviors at home or in public?
  - a. Tell me about this
  - b. Do you remember a time in particular?
7. Do you ever feel like you do not want to have your brother/sister around your friends?
  - a. When does this happen?
  - b. What do you and your friends do differently when playing with your brother/sister?
  - c. What do your friends say about your brother/sister?
8. Is there anything I have not asked you about, that you would like to tell me about?

APPENDIX B  
PARENT INTERVIEW GUIDE

## Interview for Parent

1. Tell me about the members in your household (name and age)
2. I would like to show you a few short video clips, from the videos you took, of your children playing together. During the video, I would like to ask you a few questions.
  - a. Please tell me your interpretation of this video clip
  - b. [Tell the parent the story told by the child] – after hearing the story told by your child, do you have the same memory or feelings of this event? Tell me about it
  - c. Is this a typical activity for your children?
  - d. How does the story told by your child make you feel?
  - e. Does it change your perception of their relationship?
3. What different types of activities do your children do together?
4. Do your children 'play' together? Describe a typical 'play' time that you would observe between them.
5. Do you feel the videos you took were representative of typical interactions between your children?
6. What do you feel is the best thing about your children's relationship.

### Background questions regarding child with ASD:

7. Tell me about your child's diagnosis and the context in which it happened:
8. Tell me about your child's (diagnosed with autism) schooling:
9. Describe your family's extended support system, including but not limited to professional services:
10. Is there anything I have not asked you about, that you would like to tell me about?

APPENDIX C  
INFORMED CONSENT

Sibling Play: From the Voices of Children with Siblings with  
Autism Spectrum Disorder

**INFORMED CONSENT AND PARENTAL LETTER OF PERMISSION**

Dear Parent:

I am a graduate student under the direction of Professor Elizabeth Kozleski in the School of Social Transformation at Arizona State University. I am conducting a research study to gain knowledge in the relationships between children diagnosed with ASD and their typically developing siblings through *the voices* of the children.

The purpose of the research is to explore the sociocultural factors that effect and influence how typically developing children interact with their sibling who has been diagnosed with autism spectrum disorder (ASD) as defined by the child through stories of their time together. Positioning the typically developing sibling as the expert who has the ability to share insights regarding the child with ASD in order to conceptualize socialization of siblings when one is diagnosed with autism spectrum disorder is a step toward understanding “what’s next?” in the concept of sibling relationships.

I am inviting you and your child's voluntary participation in this study. If you choose not to have your child participate or to withdraw your child from the study at any time, there will be no penalty. There will be no penalty if you choose not to participate yourself or withdraw form the study at any time. It will not affect your child’s educational support, treatment/care or therapy sessions. Likewise, if your child chooses not to participate or to withdraw from the study at any time, there will be no penalty.

If you say YES, then your participation will consist of taking short videos of your children at play or involved in social interactions, as well as one interview session lasting approximately 45-60 minutes at your home or another location that offers privacy. I will provide the video equipment and only need approximately 5 separate video clips lasting no more than 10 minutes. This can be done at your convenience over a week's time. Your child's participation will involve one interview session lasting approximately 30 – 45 minutes. Your interview session will occur after your child's interview session and will involve viewing short video clips of your children playing or involved in social interactions. Approximately 10-20 subjects will be participating in this study.

Although there may be no direct benefit to your child, the possible benefit of your child's participation is increased understanding of how the diagnosis of autism affects other children in the family in regards to social interactions. There are no known risks from taking part in this study, but in any research, there is some possibility that you may be subject to risks that have not yet been identified.

All information obtained in this study is strictly confidential. The results of this research study may be used in reports, presentations, and publications, but the researchers will not identify you. In order to maintain confidentiality of your records, Amy Papacek will keep all audio recordings, videotapes, transcriptions, and forms in a locked office within a locked desk. You and your children will not be identified using their name or any other identifiers. The results of this study may be used in reports, presentations, or publications but your children's name will not be used.



Any questions you have concerning the research study or your participation in the study, before or after your consent, will be answered by Dr. Elizabeth Kozleski, (480) 965-0391 or Amy Papacek (480) 760-5177.

If you have questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk; you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at 480-965 6788.

Sincerely,

Amy Papacek

Your signature below indicates that you consent to participate in the above study. Also by signing below, you are granting to the researchers the right to use your likeness, image, appearance and performance - whether recorded on or transferred to videotape, film, slides, and photographs - for presenting or publishing this research.

\_\_\_\_\_  
Parent participant's Signature                      Printed Name                      Date

By signing below, you are giving consent for your child \_\_\_\_\_  
(Child's name) to participate in the above study. You are also giving consent for your child \_\_\_\_\_(Child's name) to be audio and videotaped during play activities and interview session in the above study. Audio and videotape will be used for purposes of interview prompting and recording data and will be destroyed after a 3-year period. Audio and videotape will be kept in a locked desk within a locked office.

\_\_\_\_\_  
Signature                      Printed Name                      Date

Your signature below indicates that you are granting to the researchers the right to use your child's \_\_\_\_\_(child's name) likeness, image, appearance and performance - whether recorded on or transferred to videotape, film, slides, and photographs - for presenting or publishing this research. All identifiers will be removed from the videotape, including sound, before using at any conference.

\_\_\_\_\_  
Signature                      Printed Name                      Date

If you have any questions about you or your child's rights as a subject/participant in this research, or if you feel you or your child have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the Office of Research Integrity and Assurance, at (480) 965-6788.

APPENDIX D  
CHILDRENS' ASSENT FORM

Sibling Play: From the Voices of Children with Siblings with  
Autism Spectrum Disorder

I have been told that my mom and dad have said it's okay for me to be in a project about me, my family and play. I will be asked by the person in charge of this project to watch some videos of me and my sibling playing or doing our favorite activity together and then talk about it. The person is going to ask me to tell stories about this video and about playing with my [brother/sister]. We will talk for about 30 minutes.

I am in this project because I want to. I know that I can stop at any time if I want to and it will be okay if I want to stop.

\_\_\_\_\_  
Sign Your Name Here

\_\_\_\_\_  
Print Your Name Here

\_\_\_\_\_  
Date

APPENDIX E  
IRB APPROVAL

**To:** Elizabeth Kozleski  
SST

*for* **From:** Mark Roosa, Chair *SM*  
Soc Beh IRB

**Date:** 09/30/2011

**Committee Action:** Expedited Approval

**Approval Date:** 09/30/2011

**Review Type:** Expedited F7

**IRB Protocol #:** 1109006882

**Study Title:** Sibling Play: From the Voices of Children with Siblings with Autism Spectrum Disorder

**Expiration Date:** 09/29/2012

The above-referenced protocol was approved following expedited review by the Institutional Review Board.

It is the Principal Investigator's responsibility to obtain review and continued approval before the expiration date. You may not continue any research activity beyond the expiration date without approval by the Institutional Review Board.

**Adverse Reactions:** If any untoward incidents or severe reactions should develop as a result of this study, you are required to notify the Soc Beh IRB immediately. If necessary a member of the IRB will be assigned to look into the matter. If the problem is serious, approval may be withdrawn pending IRB review.

**Amendments:** If you wish to change any aspect of this study, such as the procedures, the consent forms, or the investigators, please communicate your requested changes to the Soc Beh IRB. The new procedure is not to be initiated until the IRB approval has been given.

Please retain a copy of this letter with your approved protocol.