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Children's Constructed Meanings of Sisterhood When an Older Sibling Has Autism

by

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DISSERTATION

Submitted in partial fulfillment of the requirements for the degree
of Doctor of Psychology in the Department of Clinical Psychology
at Antioch University New England, 2013

Keene, New Hampshire



Department of Clinical Psychology

DISSERTATION COMMITTEE PAGE

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**CHILDREN'S CONSTRUCTED MEANINGS OF SISTERHOOD WHEN
AN OLDER SIBLING HAS AUTISM**

presented on April 25, 2013

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Abstract

Sibling relationships have been recognized as important in facilitating the acquisition of emotional and social understanding and even assisting in cognitive development (Sanders, 2004). Sibling relationships that include one child with a disability are especially significant and worthy of study, as typical siblings tend to take on more responsibility for their siblings' care across their lifespan (Cicirelli, 1995). In attempting to understand these sibling relationships in childhood, past researchers have largely relied on parent report and behavioral observations. In order to advance the field's understanding of sibling relationships when one child has autism, this study asked children to voice their perspectives and share their experiences. More specifically, four school-aged girls who had an older brother with autism were asked to individually complete a kinetic family drawing and participate in a semi-structured interview. Interpretive Phenomenological Analysis (IPA) was then utilized to investigate these girls' constructed meanings of sisterhood. Analysis resulted in the discovery of superordinate and emergent themes relevant to role enactments, the felt experience of these roles, and the significance of togetherness. Additional themes appearing particularly relevant to sistering a brother with autism were also discovered. These superordinate and emergent themes are described in detail and are then considered in terms of alignment and departure from the existent literature. Lastly, limitations of this study and implications for clinical work and future research are addressed.

Keywords: Autism; Childhood Sibling Relationships; Role Perception;

Sibling Role Relationships; Sisterhood

Chapter 1

I Love Him More Than Anybody in the Universe

By Olivia Kersey (National Autistic Society, 2008)

My brother Dan with the head of hair.
He is a firework, bursting off in all directions -
When happy a grinning balloon, when released making loud noises and chaos.
A bird, flapping hard, taking to the skies
Bursting with fun, laughter and sometimes food!

When he is agitated
He is a war, explosions going off all the time.
I get hurt, but he doesn't mean it
However many sore patches there are.

When sad he is a sobbing heap
A deflated bouncy castle.
But I can cheer him up
With a few big hugs, a tickle, and a kiss.

He is a lucky dip
You never know what you will get.
But although he's autistic and quite badly too
I love him more than anybody in the universe.

The poem above was written by a 10-year-old girl who has a brother with an Autism Spectrum Disorder (ASD). As the poem progresses, it becomes clear that this young girl's feelings toward her brother are quite complex. However, her expressions of acceptance and unconditional love are especially poignant and telling of a largely positive relationship. Even at this young age, the quality of this young girl's relationship with her brother is significant, as the kind of sibling relationship established in early childhood remains relatively stable throughout life (Cicirelli, 1995). In fact, recent research suggests that sibling relationship quality is more stable overtime within sibling dyads that include a person with autism than within typical sibling dyads (Orsmond, Kuo, & Seltzer, 2009).

In the field of psychology, the significance of sibling relationships in typical dyads has

long been recognized by psychoanalysts, family therapists, and developmental psychologists (Sanders, 2004). As noted by Sanders, sibling relationships can facilitate the acquisition of emotional and social understanding and even assist in cognitive development. The sibling relationship is especially significant when one child has a disability as this unique relationship often persists throughout life. In most cases, typically developing siblings take on responsibilities for their disabled brother or sister at an early age and these responsibilities only increase across the lifespan (Cicirelli, 1995). Such important relationships certainly warrant the attention of researchers.

Statement of the Purpose

A handful of studies have examined the unique relationship between siblings when one sibling has a disability. Historically, however, research has focused on the impact of a disabled sibling on the psychological development of the typical child. These early studies have been criticized for their inaccurately simplistic and negative depiction of sibling relationships (Kersh, 2007). In the 1980s, researchers began to grant attention to the childhood sibling relationship itself. These studies were instrumental in acknowledging the complexity of sibling relationships; however, the methodologies that were utilized restricted the amount of information gained. These studies relied on accounts offered by parents and objective behavioral observations, whereas very few went directly to the source—to the children themselves. As a result, the voices of children who participate in these relationships have remained largely unheard (Edwards, Hadfield, Lucey, & Mauthner, 2006). To advance our understanding of sibling relationships when one child has a disability, in this dissertation, I ask children to voice their perspectives, and share their experiences. I investigate how typical children construct meanings of sisterhood when their older sibling has autism.

In arriving at this objective, I have made three compelling decisions: (a) to focus on sisters, (b) to focus on sisters who are later-born, and (c) attend to meaning making around role relationships.

The decision to focus on girls' experiences was informed by gender differences evidenced in outcome studies examining the adjustment of typical siblings of children with autism. Research suggests that girls are at greater risk for more negative outcomes. For instance, Orsmond and Seltzer (2009) recently found that adolescent sisters report higher levels of depressive and anxiety symptoms than brothers. Girls also tend to take on more caretaking responsibilities as compared to brothers (Bank & Kahn, 1982) and this gendered trend is maintained throughout adulthood (Meyer, 2000). Given this responsibility within the relationship, negative outcomes in these girls may have an adverse impact on the quality of care that the autistic sibling later receives.

The decision to focus on later-born girls was based on research suggesting that they face more challenges when an older sibling has a disability. Parental expectations, for typical siblings, differ qualitatively depending on birth order (Mendelson, de Villa, Fitch, & Goodman, 1997), and the first-born most often has more expectations placed on them (Bank & Kahn, 1982; Mendelson et al., 1997). When the first-born child has a disability, expectations must shift. It seems reasonable to suppose that parental expectations held for the younger, typical child then become less clear. East's (1998) research even suggests that a perceived negative experience with a first-born child can contribute to lowered expectations for later-born children. Beyond these complexities in parental expectations, a later-born typical child faces added challenges as he or she comes to surpass the older child with regard to various abilities. This has the potential to create a greater degree of role conflict than when the typical child is older (Farber, 1960).

For the purposes of this dissertation, sisterhood is conceptualized as a role perception rather than a communal sense of solidarity. Here, sisterhood is considered the perceived experience of fulfilling the role of sister. The decision to focus on meaning making within role relationships was informed by the existing literature on sibling role relationships. This literature suggests utility in viewing siblings as two actors playing out particular roles in their interactions with one another. These roles are significant in that they are prescriptive; constraining behavior to that which is socially expected and accepted. The presence of autism has a unique impact on role relationships, even when compared with other disabilities (Stoneman, 2001). Both the establishment of these relationships, and their developmental course, are distinctively influenced by the particular constellation of skills and deficits that typify autism (Stoneman, 2001; Stoneman, Brody, Davis, & Crapps, 1989).

Despite autism's apparent influence on developing role relationships, meaning making around the typical sibling's role has not yet been studied. Meaning making is a fundamental process in the human experience that allows us to make sense of our social world, our relationships, and our sense of self (Bruner, 1990; Gergen, 2009). However, there are no studies to date that examine this phenomena related to the roles involved in sistering a child with autism. This qualitative exploration will address an apparent gap in the current literature through investigating what it means to be a sister of an autistic sibling. It is my hope that this study will shed new light on the lived experience for girls navigating these complicated relationships.

Chapter 2: Review of the Literature

Sibling Relationships

Though mid-20th century developmental theorists, such as Anna Freud and Donald Winnicott, proposed hypotheses describing the nature of sibling relationships, it was not until the 1980s that the field of psychology demonstrated substantial interest in the systematic study of the topic. Since that time, much has been discovered about typically developing sibling relationships; including an appreciation of the overwhelming complexity and variability that exists, both within a single relationship, and across families. Notably, a wealth of data has emerged from studies utilizing self-report, parent reports, and observational methods. A distillation of multimodal investigations describes childhood sibling relationships along four dimensions: (a) Warmth/Closeness, (b) Relative Status/Power, (c) Conflict, and (d) Rivalry (Furman & Buhrmester, 1985). Though these dimensions appear simple enough, how they relate to the quality of sibling relationships is more complex.

Conventional wisdom may lead some to conclude that warmth and closeness are associated with more positive relationships whereas relative status and power issues, conflict, and rivalry are associated with more negative relationships. However this conclusion is as simplistic as it is false. Sibling warmth/closeness and conflict are not polar opposites but are instead independent aspects of sibling relationships (Furman & Buhrmester, 1985). In a review article, Brody (1998) makes a strong argument for the importance of both prosocial interactions, such as expressions of warmth and closeness, and conflicted interactions, such as those associated with power issues and rivalry. Brody further contends that it is the balance of prosocial and conflicted interactions that contributes to the significance of sibling relationships in children's social, cognitive, and psychological development. With these findings it is perhaps

unsurprising that scientific investigation into sibling relationships is no simple task. However, the value of such inquiry is substantiated by studies examining the significance of sibling relationships.

Significance of typical sibling relationships. Research suggests that in young childhood, play between siblings facilitates the development of important social skills. Judy Dunn (1993) found that frequent cooperative play with an older sibling was associated with young children's success on tasks that required perspective taking and emotional understanding. Within play, social rules and expectations are also played out (Dale, 1982, as cited in Dunn, 1983) along with attitudes towards social rules, discipline, and justice (Freud & Dann, 1951, as cited in Dunn, 1983). Social development can also be enhanced through sibling conflict. As noted by Brody (1998), "conflict can provide an opportunity for siblings to vent their emotions, express their feeling, and practice open communication" (p. 17). The balance between sibling conflict and supportiveness enables the development of skills necessary for conflict and anger management along with emerging empathic understanding and nurturance (Brody, 1998). The development of social skills within the sibling relationship also appears to positively influence a child's functioning outside the home; sibling bonds are associated with better peer relationships and school adjustment (Brody, 1998).

During naturally occurring interactions in childhood, siblings contribute to each other's cognitive development. More specifically, the sibling relationship provides the opportunity for siblings to enhance language skills, semantic capabilities, and concept formation (Brody, 1998). In middle childhood, older siblings develop the necessary skills to explicitly teach younger siblings cognitive concepts and language skills, to the benefit of both children (Brody, 1998). Though parents are typically more skilled in adapting their teaching style to meet the

developmental needs of the younger child (Brody, 1998), research suggests that children in middle childhood can effectively contribute to their younger siblings' concept attainment (Circirelli, 1972). With regard to the older sibling, Smith (as cited in Brody, 1998) found that preadolescents who spent small amounts of time teaching younger siblings achieved higher reading and language scores, and had higher overall achievement, than those who did not adopt this teaching role.

The sibling relationship also contributes to psychological development and emotional health. The sibling relationship contributes to a child's sense of self in that the child must grapple with the fact that he or she is "simultaneously individual *and* one of a series" (Edwards et al., 2006, p. 39). This quandary leaves siblings seeking independence and separation on the one hand, and connection and intimacy on the other (Edwards et al., 2006). Attending to sameness pulls siblings together, whereas attending to differences creates necessary separation (Edwards et al., 2006). The themes of sameness and difference then contribute to how a child thinks about his or her sense of self (Edwards et al., 2006). The sibling relationship also influences the emotional context of the home environment. Even in the face of marital turmoil, an older sibling can help safeguard a younger child from emotional consequences (Brody, 2004). Similarly, results of a study conducted by Gass, Jenkins, and Dunn (2007) suggest that the experience of sibling affection protects against internalizing problems in the face of numerous stressful life events. In fact, "sibling affection was found to persist over and above the effect of mother-child relationship quality" (Gass et al., 2007, p. 172). The lifelong implications of these findings are quite compelling; strengthening the sibling relationships in childhood may help prevent the development of future emotional difficulties in the face of significant life stressors (Gass et al., 2007).

Sibling role relationships. Siblings can be viewed as two actors playing out particular social roles in interactions with one another. Researchers have operationally defined these roles as “patterns of behavior that have social meaning” (Stoneman, 2001, p. 137). Roles are prescriptive in that they constrain behavior to that which is socially expected and accepted by the players involved. The scripts are both socially constructed by external forces such as predominant discourse, and more locally by relational interaction (Edwards et al., 2006). Parents in many ways transmit the predominant discourse. Through their influence, they explicitly and implicitly communicate expectations for sibling roles (Mendelson et al., 1997; Stoneman, 2001). Siblings however are not passive recipients; instead they together negotiate and experiment with roles within the context of play in an attempt to meet the needs of both players (Stoneman & Brody, 1982). From this perspective of role relationships, the sibling relationships can then be thought of as a series of role enactments.

In 1982, Brody, Stoneman, and MacKinnon first operationalized five sibling roles as observed between siblings and peers during play with a popular board game. These five roles included (a) teacher, (b) learner, (c) manager, (d) managee, and (e) playmate. These five roles were once again observed within child chosen activities between siblings and their peers (Stoneman, Brody, & MacKinnon, 1984). In further exploration of these dynamics between siblings, Brody, Stoneman, C. MacKinnon, and R. MacKinnon (1985) investigated the role enactments between both preschool-aged and school-aged sibling pairs as they engaged in naturalistic activities in their homes. Seven roles were observed: (a) teacher, (b) learner, (c) manager, (d) managee, (e) helper, (f) helpee, and (g) observer. The researchers found that the manager and helper roles were most often assumed by older siblings in both age groups, whereas observer, managee and helpee roles were most often assumed by younger siblings in both age

groups. Further, older school-aged girls assumed the teacher role most often, while younger school-aged girls assumed the learner role most often. Taken together, these results suggest that particular role relationships may be associated with birth order and can be further influenced by gender. Stoneman et al.'s (1989) study four years later yielded similar results with older siblings taking on the role of teacher, manager, and helper roles most often; in particular, older sisters engaged in teaching the most often.

Developmental considerations. Perhaps not surprisingly, typical childhood sibling role relationships are most often asymmetrical according to birth order. In everyday interactions, older siblings typically enact more dominant roles (i.e., teacher, manager, helper) and whereas younger siblings enact more nondominant roles (i.e., learner, managee, helpee; Stoneman, 2001). This occurs as an older sibling attempts to teach or help the younger, less experienced sibling (Brody et al., 1985; Stoneman et al., 1984). Interestingly, Stoneman et al. (1984) found that these role asymmetries were not enacted with older non-related peers; more specifically the younger child took on the manger role more often as the older peer was more willing than the older sibling to take on the complementary managee role. These findings suggest that role asymmetries are a unique aspect of the sibling relationship rather than a personality characteristic of particular siblings. Over the course of development, sibling role relationships become more symmetrical (Buhrmester & Furman, 1990; Circirelli, 1982) as developmental discrepancies narrow with age and siblings interact more as playmates.

Impact of disability. The presence of a disability in one child has a unique impact on evolving sibling relationships. Over 50 years ago, researchers began to investigate the impact of a disabled child on the family system, and the development of the typical sibling. Early explorations ignored the variability and complexity of sibling relationships; wide sweeping

pessimism prevailed. Indeed, results of these studies suggested that the presence of a child with a disability was detrimental to both family integration, and the development of typical siblings. As an example, Farber (1959) investigated “arrest in the family cycle” (p. 8) and reasoned that parents would likely experience impeded development in their own life careers, and normal siblings would experience role confusion. Results of Farber’s study led him to conclude that the enduring dependency of the disabled child had a particularly negative impact on the typical sibling’s adjustment in relation to the mother. He recommended the institutionalization of disabled boys, for the benefit of both female siblings and the marital relationship. On the whole, early studies like Farber’s supported the idea that sisters’ increased responsibility for caretaking led to psychological problems like depression, anger, anxiety, and antisocial behavior (Farber, 1959; Grossman & Gath, as cited in Kersh, 2007).

As noted by Kersh (2007), these early studies are open to criticism on the grounds of methodological concerns, and contemporary relevance. Specifically, many such accounts were retrospective reports of adult patients interviewed by psychiatrists; they thus failed to acknowledge the existence of well-adjusted siblings. Further, early research also relied heavily on unreliable subjective measures. Moreover, since the time of these first studies, the stigma around disability has decreased, and the standard of care has increased. For example, people with disabilities are no longer removed from society, and hidden behind the walls of institutions. Instead families are provided with more supportive, community-based services. Laws protecting the rights of disabled children, effective strategies to educate them, and public awareness campaigns, have also led to new understandings. The research conducted 50 years ago chronicles a narrative of disability held at that time; contemporary families with a disabled child are grappling with a much different set of challenges and opportunities. For example, more recent

studies suggest that some parents believe that the presence of a disabled sibling has contributed to more maturity and independence (Glendinning, 1983, as cited in Stalker & Connors, 2004) and more altruism and responsible behavior (Tozer, 1996, as cited in Stalker & Connors, 2004) in their non-disabled child. Even when parents described negative impacts, these were not necessarily confirmed in children's accounts. Indeed, when siblings were asked directly for their perceptions, researchers found far fewer negative findings than when parents were interviewed. Specifically, the childhood sibling relationships were portrayed as more positive and more variable (Stalker & Connors, 2004).

Of course, sibling role relationships are still greatly influenced by the presence of a disability. As noted earlier, in typical development, sibling role relationships become more reciprocal and balanced over time (Circirelli, 1982). When a younger sibling has a disability, just the opposite occurs: the relationship actually becomes more asymmetrical over time (Stoneman et al., 1989). Studies suggest that both the degree of impairment associated with the disability (Brody, Stoneman, Davis, & Crapps, 1991), and the contributions of the family system (Costigan, Floyd, Harter, & McClintock, 1997), influence the extent of the role asymmetry. Specifically, more symmetrical sibling bonds are found when disabled children are only moderately impaired (Stoneman et al., 1987), and when the family socializes as whole. Role asymmetry is more pronounced when the sibling pair is left alone (Costigan et al., 1997), likely as the demand for caretaking is greater.

Birth order and gender effects found in typical sibling role relationships are also complicated by the presence of a disability. Through direct observation of play, Brody et al. (1991) confirmed that, unlike typical dyads, the younger sibling took on more dominant roles. With regard to gender effects, younger boys took on the helping role more often than comparison

younger brothers and sisters of typical siblings, though younger sisters of a disabled child occupied the helping role most often.

In the studies cited above, the term “disability” typically refers to mental retardation; mild, moderate, or severe. Some studies may have included children with autism in their disability group as these children can also have significant cognitive deficits (Costigan et al., 1997), whereas other studies actively excluded them (Brody et al., 1991; Stoneman et al., 1989). However, when children with autism were acknowledged as a separate group, or studied independently, findings suggested that autism has a unique and significant impact on sibling role relationships (Stoneman, 2001).

Autism

According to the Centers for Disease Control and Prevention (Rice, 2009), 1 out of 110 eight-year-old children had an Autism Spectrum Disorder (ASD) in the surveillance year of 2006. An even more recent study suggested that closer to 1 out of 91 children aged 3 to 17 have an ASD (Kogan et al., 2009). The term Autism Spectrum Disorder currently refers to three diagnoses: (a) Autistic Disorder, (b) Asperger’s Disorder, and (c) Pervasive Developmental Disorder, Not Otherwise Specified. These children evidence a range of behavioral challenges, stereotyped behaviors, restricted interests, communication abilities, and general cognitive abilities. Common to all three diagnoses is a clear deficit in the development of social interaction skills (American Psychiatric Association, 2000). The presence of an ASD has a unique impact on family life, and the sibling bond, affecting the quality of the sibling connections and roles.

Impact on sibling subsystem. The presence of a child with an ASD places unique stressors on the entire family system. For example, compared to the parents of children with Down syndrome or a psychiatric diagnosis, research suggests that parents of children with autism

endure higher levels of chronic stress (DeMyer; Holroyd et al.; Holyroyd & McArthur; Wolf et al.; as cited in Blackledge & Hayes, 2006) and typically experience more guilt and shame around their child's condition (Blackledge & Hayes, 2006). According to a study conducted by Keenan and colleagues (2007), over 80% of parents surveyed reported deficits in their child's social, communication, and self help skills along with sleeplessness as causing the most difficulty in family life.

Children with autism evidence deficits in social relatedness, and are often described by parents as being in their own worlds (Keenan, Dillenburger, Doherty, Bryne, & Gallagher, 2007). These children rarely initiate social activities and lack social emotional reciprocity (Charman & Baird, 2002); they have poor attention, play, and imitation skills (Gillberg et al., 1990); and lack eye contact and appropriate use of gestures (Adrien et al., 1992). Children with autism vary in the degree they are able to communicate. Some children may completely lack expressive and receptive languages skills (Manning-Courtney, Molloy, Murray, & Messerschmidt, 2003) whereas may have more qualitative, semantic or pragmatic difficulties (Rapin, 1997). With regard to sleep problems, children with ASD take longer to fall asleep and wake more often, and for longer periods, than same-aged typical peers (Honomichl et al., 2002). Children with autism also require less sleep less overall (Goodlin-Jones, Tang, Liu, & Andres, 2008) and at the extreme may sleep for as little as three to four hours a night, draining the physical and emotional resources of the family (Norton & Drew, 1994).

The typical child confronts novel relational challenges with their sibling with an ASD. According to Norton and Drew (1994), siblings may be especially confused and hurt by the unpredictable behavior of their brother or sister with autism. As children with autism are often unaware of their effect on the environment, they may behave as though they do not care for

others. For example, they may damage their brother or sister's toys or belongings for little reason, and without apparent remorse. Additionally, typical siblings' explicit displays of affection are often met without reciprocation or outright rejection; this can feel wounding, and certainly complicates the bonding process (Norton & Drew, 1994). As children with autism struggle to communicate their needs, it is not uncommon for children to become aggressive with their siblings (Carr & Durand, 1985; Koegal, Stiebel, & Koegal, 1998). Parents play an important role in mediating this aggression, through controlling the antecedents and consequences around the behavior. Parents, by providing the autistic child with functional communication skills, can significantly decrease aggression in their child (Koegal, Stiebel, & Koegal, 1998). Without similar mediation, typical children must find ways to both manage their siblings behavior and their own physical and emotional responses.

Outside the home, in more public settings, relational challenges for siblings can intensify. Typical children often fear criticism and ostracism when their brother or sister acts out publicly (Norton & Drew, 1994). As noted by Norton and Drew, "Unpredictable behavior in a person who appears to be normal causes negative reactions in people observing the behaviors, and they tend to think of the individual as a 'brat' instead of realizing that inappropriate behavior may be part of a disability" (p. 70). Same-aged peers may be especially unsympathetic as they may be very confused by the observed behavior.

Despite these challenges, siblings often develop sensitivity to the needs of their brother or sister with autism (Keenan et al., 2007). Children at a young age may also assume a "self-imposed sense of responsibility" for the safety of their sibling (Konidaris, 2005). Parents have also reported maturity and independence (Glendinnin, 1983), as well respectfulness and altruism in the typical child (Tozer, 1996). Overall, young children speak positively of their sibling

relationship whether the sibling has a disability or not (McHale, Sloan, & Simeonsson, 1986).

Impact on sibling role relationships. On the whole, researchers have found a high level of sibling interaction when one child has a disability (Stoneman, 2001). However, an exception to this conclusion was found in dyads where one child had autism. Less interaction, limited variety of social bids, and decreased responding to one another was found in studies comparing these dyads to typical siblings, and those with one Down syndrome sibling (Knott, Lewis, & Williams, 1995; Strain & Danko, 1995, as cited in Stoneman, 2001). Thus, the presence of autism differs from other disabilities in its impact on the frequency and scope of sibling engagement.

If autism limits the frequency and scope of sibling engagement, the opportunity to negotiate roles is likely also circumscribed. According to Stoneman (2001), siblings acquire role relationships through both play and parental influence. When one child has a disability, typical siblings must adjust their roles in order to appropriately account for the particular challenges posed by the sibling's disability (Stoneman, 2001). Role modification occurs as the typical sibling attempts to foster social interaction in the context of play (Stoneman, 2001). When done successfully, a more positive sibling relationship is enabled. Given that the frequency of the usual play interactions is low when one sibling has an ASD, typical siblings have much less opportunity to modify roles through play in order to best learn how to best participate in the relationship. With the usual avenues for connection less available, parental influence and direction becomes increasingly important in helping to negotiate role relationships when one sibling has an ASD. Recent research supports this hypothesis. For example, Orsmond et al. (2009) found that parental support is predictive of more positive sibling relationships, even into adulthood.

The roles that are ultimately enacted are important in that the child will come to make meaning out of these interactions. From a social constructionist perspective, the meanings that are made will ultimately shape both the child's reality of his or her social world and his or her sense of self. This meaning making will then influence how the child acts upon the world, including how the child acts as a sibling.

Meaning Making

The cognitive revolution of the 1950s was founded on the following notion: "the central concept of a human psychology is *meaning* and the processes and transactions involved in the construction of meanings" (Bruner, 1990, p. 33). Unfortunately, early cognitive researchers and theorists attended insufficiently to the strength of this conviction. Instead, they granted their attention to the mechanisms that enabled human meaning making (Bruner, 1990). Bruner, however, returned to the concept of meaning itself, explaining that meaning allows us as humans to make sense of our world. Specifically, he argued that beliefs, desires, intentions, and commitments shape the way the world is both experienced and acted upon. This is because these variables inform the way people talk about why they and others act as they do. Such folk talk is critical as it informs the way relationships are carried out. This process of meaning making is a joint, relational process that is mediated by the existing culture. It is through our inevitable participation in culture that allows us to not only understand others, but ourselves as individuals. With this realization, Bruner was able to conclude that meaning is not only fundamental in human psychology, but it is both communal and accessible.

Present-day appreciation for meaning making has been further influenced by growing acceptance of the social constructionist perspective. From the social constructionist perspective, Gergen (2009) contends, "what we take to be the world importantly depends on how we

approach it, and how we approach it depends on the social relationships of which we are a part” (p. 2). Said differently, what we take to be the world is not determined by an external reality or truth; rather, how we understand the world is shaped by negotiated meanings determined within social relationships. From this perspective, individuals are active and interactive in their meaning making processes. This is important as the way the past and present are storied within relationships then influence possibilities for the future.

With such compelling emphasis on meaning making, and its relational basis, it is unsurprising that researchers have more recently begun to look at meaning making within sibling relationships. Instead of focusing on parental interviews and observations, contemporary researchers are turning to the children themselves and asking for their personal perceptions. At this time, children’s perceptions regarding the sibling relationship, the autistic sibling, and the autistic’s sibling’s role have been studied.

Perception of relationship. In a thoughtful, qualitative study, McHale et al. (1986) investigated sibling relationships of children with autistic, mentally retarded [sic], and non-handicapped brothers and sisters. As part of the study, a 26-item, open-ended interview was administered. The interview addressed three domains: children's attitudes toward their siblings and the sibling relationship, children’s perceptions of their siblings’ roles in the families, and consideration for handicapped siblings in the context of children's relationships outside the home. The experience of having a sibling with autism or mental retardation was highly variable, with some siblings reporting very negative experiences, and others reporting very positive. The experience of non-handicapped children in typical sibling pairs was much less variable. In addition, siblings viewed their relationship with their brother or sister with autism or mental retardation as more positive in the following situations: when the concerns around sibling’s

future, feelings of rejection, and parental favoritism were perceived as minimal; when children believed that the handicapped child was reacted to positively by parents and peers; and when the typical siblings felt able to cope with the particular challenges posed by the disability.

Kaminsky and Dewey (2001) also examined sibling relationships across three conditions: when one child has autism, when one child has Down syndrome, and when both children are developing typically. In order to examine their perceptions, the typically developing children were given the Sibling Relationship Questionnaire (SRQ-brief version; Buhrmester & Furman, 1990). A checklist and questionnaire were also given to the parents to measure the severity of autism, and adaptive functioning of the child with autism or Down syndrome. Results suggested that children with an autistic sibling perceive less intimacy within their sibling relationships when compared to children with a typical sibling, or a sibling with Down syndrome. Children with an autistic sibling also experienced less nurturance from their sibling than in either of the comparison groups. In addition, children with an autistic sibling also reported less pro-social behavior than those children whose sibling had Down syndrome. However, children with an autistic sibling, or sibling with Down syndrome, also reported greater sibling admiration, less quarrelling, and less competition in the sibling relationship than children within typical dyads. Taken together, the presence of autism seems to limit perceived emotional closeness, with regard to intimacy and nurturance, while also limiting rivalry in the form of quarrelling and competition. In these unique dyads, the reported sibling admiration even at a greater emotional distance is particularly compelling.

Perception of autistic siblings. Stalker and Connors (2004) specifically investigated the typical child's perception of his or her disabled sibling. A range of disabilities were included in this study: cerebral palsy, muscular dystrophy, attention deficits, learning disorders, and autism.

The researchers found that “most children were very fond of their disabled brother or sister” (p. 227). In addition, most children were very aware of their sibling’s disability but did not consider him or her to be intrinsically different. As would be expected in typical sibling pairs, the typical children often noted “feelings of fondness and loyalty underlying routine bickering, irritation, and rivalry” (p. 228). Interestingly, when differences were noted, the differences were typically accepted as part of the child rather than something that needed to be changed.

A minority of children communicated more negative perceptions of their sibling’s impairment. For instance, 3 of 24 children communicated that their siblings’ difficulties were related to badness or naughtiness (Stalker & Connors, 2004). These dyads shared some common characteristics. In all of these cases the disabled child had a learning disability or attention deficit. These relationships were very poor and included physical aggression. Also, none of these children were fully aware of their sibling’s disability. Stalker and Connors concluded that the child’s perception of the disabled sibling was related to the quality of the sibling relationship. In more positive sibling relationships, most children were aware of the sibling’s impairment, but did not see the sibling as fundamentally different or bad. Instead, perhaps the shared family life and information about the disability overshadowed perceived difference.

Perception of autistic sibling’s role. As noted above, McHale et al. (1986) researched sibling relationships of children with autistic, mentally retarded, and nonhandicapped brothers and sisters. Their study was unique in that they considered the children’s perceptions of the disabled sibling’s role within the family. Within open-ended interviews, the children were asked about their involvement in activities with and without the disabled child, and their family members’ feelings toward the disabled child. Results indicated that siblings of children with autism or mental retardation perceived slightly less positive roles for their brother or sister than

in typical sibling dyads. However, the mean of the groups' perception of the sibling's role was still positive, just not as strongly so. This study did not describe the meaning of this finding, as the study focused on the quality of sibling relationship overall.

Autism shapes unique sibling role relationships; yet no studies to date have examined the typical child's perception of his or her own sibling role when their sibling has autism. What does it mean to be the younger sister of an autistic sibling? This qualitative study begins to consider that question, with an eye toward the implications for the future of this most lifelong relationship.

Chapter 3: Methodology

In order to achieve greater understanding into how typical young children construct meanings of sisterhood when their older sibling has autism, a qualitative study appeared most appropriate. The rationale behind this statement will now be explained through a discussion of the ontology and epistemology that form the foundation of this study. The appropriateness of Interpretive Phenomenological Analysis (IPA) will then be described and followed by an outline of specific methods.

Rationale for a Qualitative Study

Ontology. According to Mertens' (2005) book, *Research methods in education and psychology: Integrating diversity with quantitative and qualitative approaches (2nd ed.)*, the first step in the process of conducting research is establishing a worldview. Mertens emphasizes the importance of recognizing a philosophical orientation, also called paradigm or system of knowing, because of its influence on the decision-making processes throughout the course of research. Ontology, or view of the nature of reality, is contained within philosophical orientations and is thus central to a researcher's worldview. Further, ontology is deserving of attention in the present study.

The accepted ontology here can be described as primarily constructivist with a hint of realism. Accordingly, reality is not viewed as a singular objective entity. Rather, realities are constructed and thus pluralistic in their idiosyncratic nature. Further, an individual's reality is not static but is open to change. As Mertens (2005) sums, the task of the researcher with a constructivist orientation is to "understand the multiple social constructions of meaning and knowledge" (p. 18). Realism influences the present understanding in a subtle fashion; the usefulness of systematic study in the social realm is recognized. However, at the same time, the

traditional acceptance of an objective reality that can be grasped is firmly rejected.

In recognizing realities are socially constructed and developmentally informed, the current study must acknowledge and investigate each respondent's idiosyncratic reality. There is no singular reality to be discovered but rather there exist multiple constructions to be revealed. Systematic study into commonalities of constructed realities cannot result in the discovery objective reality. Instead, systematic study can offer insight into how children in a given context make sense or personal meaning of a shared experience.

Epistemology. Epistemology resembles, and is informed by, ontology but is slightly narrower in scope. Rather than addressing the nature of reality, epistemology addresses the nature of knowledge. Under the constructivist umbrella, a system of knowing must recognize the reciprocal influence of the researcher and researched; in doing so, the nature of knowledge can be accepted as interactive, interpersonal, and co-constructed. From this perspective, Mertens (2005) recognizes that the scientific value of objectivity is replaced by confirmability. An important aspect of confirmability is the practice of reflexivity in which the researcher's values (Mertens, 2005) and epistemological assumptions are made explicit (Guba, 1981). This explicit explanation is considered important as it influences the researcher's construction of questions and the presentation of findings (Guba, 1981). In practice, the influence of the researcher must be recognized, and implicit assumptions must be made explicit, as knowledge itself is interactive in nature.

Interpretive Phenomenological Analysis (IPA)

In order to investigate how typical young children construct meanings of sisterhood, it is important to reiterate that each child's reality is socially constructed. Therefore, the current study acknowledges and investigates each respondent's idiosyncratic reality. Further, the reciprocal

influence of the researcher and researched are also acknowledged as the present study accepts knowledge as fundamentally interactive in nature. Taken together, Interpretive Phenomenology Analysis (IPA) appears to be an appropriate methodology as it focuses on personal meaning making and acknowledges a double hermeneutic in the research process (Smith, Flowers, & Larkin, 2009). The study participant will attempt to make meaning of her experience, then the research will attempt to make meaning of the participant's meaning making.

Description of IPA. According to Smith et al. (2009), Interpretive Phenomenology Analysis (IPA) is concerned with how people make sense of experiences. As an interpretive process, the authors recognize that a double hermeneutic is realized as the researcher attempts to make sense of the participant's sense making around his or her experiences. Consequently, the researcher only has access to the experience through the medium of the account provided by the participant. In order to best grasp the experience, IPA focuses on the detailed investigation of each case. In doing so, the researcher hopes to understand "in detail what the experience for this person is like, what sense this particular person is making of what is happening to them" (Smith et al., 2009, p. 3).

Smith and Osborn (2008) contend, "the best way to collect data for an IPA study and the way most IPA studies have been conducted is through the semi-structured interview" (p. 57). This is because the semi-structured interview enables a dialogue in which initial questions can be adapted in response to the understandings contributed by the participants. In addition, the researcher is granted the freedom to explore areas of interest offered by the participants through the use of probes. For these reasons, a semi-structured interview was conducted.

Methods

The specific methods utilized in IPA will now be covered with particular attention to the

young age of the participants. Special considerations in this study included ethics, informed consent, and procedures around the semi-structured interview.

Sampling and Selection

IPA studies are typically limited to small sample sizes due the approaches emphasis on quality over quantity (Smith et al., 2009). From a pragmatic standpoint, the extensive analysis of complex human experiences could not possibly be accomplished in a limited timeframe with a large sample size (Smith et al., 2009). Smith et al. recommend a sample size of three to six participants for a student project. In line with this recommendation, participants included four school-aged girls who had an older brother with autism. Given IPA's demand on verbal abilities, school-age was restricted to the ages of 9 to 12 years-old. Autism was defined here by the diagnostic criteria for Autistic Disorder contained in *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association, 2000). Refer to Appendix A for specific diagnostic criteria. According to the DSM-IV-TR, the most prominent features of Autistic Disorder include marked abnormality or impairment in social interaction, communication, and markedly restricted repertoire of activities and interests. The typical child had never been diagnosed with a psychiatric disorder or developmental delay, or possessed a medical diagnosis that significantly impaired the child's adaptive functioning.

In IPA, homogeneous samples are chosen purposefully, typically by means of referral, opportunities, or snowballing (Smith et al., 2009). The present researcher made contact with a director of site development within LUK, Inc., a not-for-profit social service agency, who had access to families of children with autism. This contact offered a practical opportunity for contacting potential participants. The director of LUK, Inc., approved this study along with Antioch University's Institutional Review Board.

With the necessary approval, referred families were emailed a letter inviting them to participate in the present study. In this letter, the source of the referral was shared, but emphasis was placed on the volunteer nature of participation. It was stated that recipients of this letter would not be penalized in any way if they chose not to participate, nor would their choice to participate or not participate be communicated back to the referral source. A discussion of potential benefits of the study were also included along with a brief overview of testing procedures. The consent form was appended to this letter. The researcher again addressed the issue of consent with those who choose to participate over the phone and on the day of the structured interview (see Appendix B).

Ethical considerations in working with children. Smith et al. (2009) highlight a focal ethical guideline in conducting any research project; that is to avoid harm. In order to adhere to this basic guideline, special considerations in researching children's experience must be addressed. Hill (2005) offers several ethical considerations to consider when working with children. Such themes include the involvement of children in the research design, consent and choice, and addressing the possibility of harm or distress.

Research design. Child participants did not actively contribute to the formalized research design. However, the children did contribute to the format of the interview in that they were provided the opportunity to expand on information they considered important during the interview process. This opportunity was essential in adhering to the qualitative methodology of IPA.

Consent and choice. Informed consent was complicated by the young age of the participants. Parents consented for their child's participation with a signature on a formalized IRB approved document (see Appendix B). The young children also signed a separate

developmentally appropriate assent form (see Appendix C). As noted by Smith et al. (2009), participants—in this case the parents of participants—must express consent for data collection and dissemination of outcome data. With regard to data collection, parents and participants were informed of the topics that would be explored in the interview. Parents and participants were also informed of their right to withdraw at any time during the process of data collection. With regard to outcome data, consent was acquired for the use of verbatim transcripts edited for identifying information, and replication of kinetic family drawings. Parents and participants also consented to having the interview audio taped in order to ensure accuracy in data collection.

Parents were informed that children would be given the choice to have their parent in the room or not. This was done under the assumption that some children may feel more comfortable with their parents close by, whereas others may appreciate privacy in sharing their personal experience. All participants chose to meet alone with the researcher.

Possibility of harm. An important power differential exists between the adult researcher and the child participant. Children are considered a vulnerable population in that they are physically weaker, have little political or economic voice, and they are largely dependent on adults due to their lack of knowledge and experience (Lansdown, 1994). Given this power differential, adult researchers are obligated to protect children from harm in the research process (Morrow & Richards, 1996). This involves granting attention to emotions (Levin, 1994) which may include “fear of failure, threats to self-esteem, reactions to invasions of privacy, conflict, guilt, or, embarrassment when acting as respondents” (Beresford, as cited in Davis, 1998, p. 328). In addition, Morrow and Richards recommend that children’s developmental capacities be acknowledged and inform research design and technique; whether this means engaging children in natural mediums of drawing or storytelling or more question and answer formats. Lastly,

Morrow and Richards recognize the responsibility of adult researchers in interpreting data in ways that best represent the child.

Data and Collection Procedures

Data collection occurred in the children's homes. It was important that the participants felt comfortable in sharing their ideas, and therefore the context of the home appeared most appropriate. A child's home is more likely to communicate informal expectations and encourage more freedom of expression than the setting of a school or an academic assessment room (Morrow & Richards, 1996). After obtaining written consents, audio recording began with the use of a digital recorder.

Data included demographic data, family drawings, transcripts of interviews, and the notes and reflections of the researcher. The researcher's notes included observations made during the interview concerning the participant's eye contact, general temperament, enthusiasm, activity level, etc. and the researcher's sense of rapport and possible impact of the home setting on the interview.

Demographic Data. Demographic data were obtained from the parent as such questions may confuse a child and leave the child believing that there are right and wrong answers within the structured interview (Morrow & Richards, 1996). See Appendix D for the demographic form that was completed by the participant's consenting parent. Demographic data included the following: participant's age and ethnicity; sibling with autism's age and sex; composition of the family; location of the interview; and any other relevant information offered by the participant's parent.

Kinetic Family Drawing. A Kinetic Family Drawing (KFD) was used as an artifact to assist in the inquiry of the structured interview. The KFD is a projective tool most typically used

to elicit a child's perception of their family, but has also been utilized in personality assessment and the identification of pathology. The KFD was not quantitatively analyzed as interpretive tools have been greatly contested in their reliability and validity (Handler & Habenicht, 1994). As recommended by Handler and Habenicht in the conclusion of their extensive literature review, the KFD was used as a tool for clinical inquiry.

The act of drawing is considered a familiar and natural activity that would give the child participant time to familiarize herself with the researcher. This activity also allowed the researcher time to build positive rapport. The completed drawing then served as an artifact in the semi-structured interview. As noted by Westcott and Littleton (2005), "the introduction of an object or artifact into an interview context can dramatically impact on the process of joint meaning-making, serving as an effective joint referent" (p. 148). In past research, the presence of an artifact has served to support children in giving more thorough and complex responses during discussions (Westcott & Littleton, 2005). This draw-and-tell technique has also been successfully utilized in past studies with children in order to address difficult topics such as childhood cancer (Rollins, 1990) and fear (Driessnack, 2006).

As in traditional administration, each child participant was handed an 8.5 x 11 inch white sheet of paper as well as standard box of ten colored pencils. The child was then instructed: "Draw a picture of everyone in your family, including you, doing something. Try to draw whole people, not cartoons or stick people. Remember, make everyone doing something, some kind of action" (Burns & Kaufman, 1972). After the child indicates that she was done drawing, the structured interview began, with the drawing serving as an important referent.

Structured interview. The interview schedule for the semi-structured interview is included in Appendix E. Westcott and Littleton (2005) make the following suggestions when

conducting research with children: use open-ended questions (i.e., “wh” questions) that encourage longer responses even in young children; avoid closed-questions; avoid suggestive questioning that may lead a child to answer in one direction rather than another; do not repeat questions in the exact same form as children may think their previous answer was wrong; avoid interruptions and allow for silent pauses; do not assume meanings attached to language or terminology. These suggestions influenced the construction of the interview schedule and offered guidance for how the interview itself should be conducted.

Transcription. In IPA, audio-recorded interviews are typically transcribed at the semantic level. “One needs to see all the words spoken including false starts; significant pauses, laughs and other features are also worth recording” (Smith & Osborn, 2008, p. 65). Margins on both sides of the transcript should be large enough to allow for analytic comments and reflections (Smith & Osborn, 2008). IPA recognizes a double hermeneutic in the researcher’s attempts to make sense of the participant’s sense making around his or her experiences. Therefore it was important that the researcher’s thought process be recorded in written form along with the transcription of the interview. Matrices were utilized as they allowed for tracking both the interview and researcher’s thought processes (see Appendix F). To protect confidentiality, original audio recording were destroyed after analysis; all transcripts were also edited to conceal identifying information.

Quality Control

Guba (1981) proposed four criteria for assessing the trustworthiness of studies conducted within the naturalistic paradigm. The naturalistic paradigm recognizes multiple realities, interrelationship of researcher and respondent, skepticism around generalizability, researchers as instruments, and the benefits of emergent research designs being conducted in natural settings

(Guba, 1981). The constructivist ontology and epistemology of the present study fit more closely with a naturalistic paradigm than a rationalistic paradigm and therefore the aspects of trustworthiness proposed by Guba are recognized. Naturalistic aspects of trustworthiness according to Guba include the following: (a) credibility: must account for discovered patterns and address them in their entirety, (b) transferability: phenomenon must be described within the context in which it occurs, (c) dependability: stability of data is important but instabilities must be accounted for as they may result from different realities, and (d) confirmability: data must be confirmable to determine a degree of neutrality.

Guba (1981) also proposes methods to enhance trustworthiness and these were incorporated into the present study's methods. For instance, in order to enhance credibility, referential materials were collected. These included the audio recordings of the semi-structured interviews. In order to enhance transferability, descriptions of the study's context were included in the researcher's notes. In order to enhance dependability, the trail to data was recorded in the descriptions of methods, and the analysis process allowing for a potential audit. Finally, in order to enhance confirmability, reflexivity was practiced in the discussion of epistemological assumptions above.

Data Analysis

IPA's focus on personal meaning requires that researchers capture and attend to the complexity of each participant's idiosyncratic experience. Smith and Osborn (2008) recognize that the best way to do justice to such experiences is through, "sustained engagement with the text and a process of interpretation" (p. 66). The process of this interpretation will now be explored.

Smith et al. (2009) describe analysis within IPA as an "iterative and inductive cycle" (p.

79). The process is not linear and requires both flexibility and open-mindedness. Further, analysis is ultimately a “joint product of the participant and the analyst” (Smith et al., 2009, p. 80) and thus requires reflective engagement with the data. In accordance with these ideas, the following steps in IPA analysis are proposed by Smith et al.

Step 1: Immersion into first transcript. This first step involves reading and re-reading the first transcript. The purpose of this is to situate the respondent at the focus of the analysis and overcome the impulse to simplify and summarize the data. Active engagement is of central importance in this step. This type of engagement allows for discovery of the narrative’s structure and locating more detailed sections and/or contradictions.

Step 2: Initial examination of semantic content and language use. As the most time-consuming step, the second step is to examine the semantic content and language use with an open-mind. The purpose here is to begin to identify the ways the respondents talk about, understands, or thinks about the issue at hand. Close analysis is necessary to produce comprehensive notes that do not simply reflect the researcher’s expectations. The discovery of a descriptive core will likely result that concerns the things that matter to the participant and the meanings of those things. Examining language use in the context of the participant’s lived world will lead to abstracted concepts and potentially the discovery of overarching patterns. Refer to Appendix F for a visual display of how exploratory comments were tracked.

Step 3: Developing emergent themes. In order to develop emergent themes, the extensive data set that now includes the original transcript, and the researcher’s exploratory comments, must be reduced. This is made possible by shifting the focus of attention toward the exploratory comments. Both the whole of the transcript and its parts, a hermeneutic circle, need to be held in mind during this process. As the researcher attempts to produce concise

representative statements, the developed emergent themes will certainly be a reflection of both the participant and the researcher. Refer to Appendix F for a visual display of how the emergent themes were tracked.

Step 4: Search for connections among emergent themes. This step involves searching for connections among emergent themes that can be charted or mapped. Not all emergent themes need to be included in the creation of a structure that highlights the most important aspects of the participant's account. In order to do this, the emergent themes can be listed and then rearranged into clusters of related themes.

Step 5: Move to the subsequent cases. The steps listed above will then be repeated with the three other cases. It is important that the researcher make an effort to bracket and set aside findings from the previous case in order to do justice to the idiosyncratic experience of each participant.

Step 6: Look for patterns across cases. This step involves switching to a more theoretical mindset and considering all four cases together. Relabeling or reconfiguring of themes may be necessary as one searches for the most potent themes. These themes may then be displayed visually and then translated into narrative form (Smith & Osborn, 2008) in which themes are then once again expanded and explained in detail. During this process, it is essential that the researcher's interpretations are clearly distinguished from participant's words.

Chapter 4: Results

Participants

Participants included four girls, aged 9 to 12 years, across two families that included an older brother with autism. The first family interviewed included six family members, a mother, father, 17-year-old brother with autism, 15-year-old sister, and the two participants aged 12 years and 9 years. The family self identified their ethnicity as Caucasian. The second family interviewed included five family members, a mother, 14-year-old sister, 13-year-old brother with autism, and the two participants aged 11 years and 10 years. The family chose to not identify their ethnicity. The interviews took place at the two families' kitchen tables.

Kinetic Family Drawings

Three out of the four participants completed their kinetic family drawings before the structured interview. The fourth participant expressed that she did not like drawing, asked multiple questions, and had difficulty moving beyond a grid she had drawn. Given this participant's difficulty completing the task, she was given the option of completing the drawing after the interview, which she agreed to. After the interview, the participant was able to add one member of her family to the drawing before expressing that she did not want to continue. The interviewer initially responded with encouragement and then abided by her request to end the activity.

During this initial phase of the research, all four participants sought clarification of the task. Each question was responded to with reiteration of the directions so as to not unduly influence the participant's process. Two out of the four participants also verbally expressed uncertainty around how to best portray their families. With regard to the finished products, three out of the four participants completed detailed and colorful drawings including all members of

their family as noted in their demographic questionnaires (see Appendix G).

Analysis

Once all four interviews were transcribed, analysis began with immersion into the first transcript. The first transcript was read and re-read in order to direct focus to the participant's thought processes and meaning-making, and away from the researcher's urge to simplify the data. Secondly, semantic content and language use were attended to and noted as exploratory comments. In this stage, the majority of notations were closely tied to explicit content.

Interpretative noting was less frequent and worded as questions or hypotheses. Thirdly, emergent themes were developed. In this process, the focus was directed primarily to the exploratory comments while the whole of the data was also held in mind. Emergent themes were developed with an attempt to reduce the data through concise statements that most accurately represented the data as understood by the researcher. The difficulty of this step lay in the need to step away from the participant's language, in order to facilitate organization and interpretation of the data (Smith et al., 2009). To ease this process, and increase accountability, a separate document was created to track any re-wording of emergent themes. Fourthly, emergent themes were then listed and arranged under super-ordinate themes. Emergent themes appearing irrelevant to role relationships and/or the impact of autism were set aside as long as they seemed more peripheral to the experience of sistering. This process was then repeated with the three other transcripts. Lastly, all four transcripts were considered together. As the most potent themes were identified, relabeling or reconfiguring of themes occurred with attempts to represent both idiosyncratic meanings and the sum of the data.

The resultant super-ordinate and emergent themes will now be explored. For a visual representation of these themes, refer to Appendix H.

Role Enactments

All participants discussed role enactments in the context of the semi-structured interview. These roles were most accurately subsumed under the labels of caregiver, caregivee, household helper, teacher, learner, playmate, and rival. Super-ordinate themes are presented in bold below and emergent themes are italicized.

Caregiver role as central in sistering. Three out of the four participants referred to the enactment of the caregiver role. The caregiver role is defined here as the providing of care, help, and/or support to another sibling. The caregiver role is noted as a central component of sistering due its connection to the definition of sister and overall salience within and across transcripts.

Definition of sister includes caregiving. Three out of the four participants referred to caregiving in their response to “What is a sister?” and “What does it mean to be a sister in your family?” When defining a sister, participants most often offered a synonym or concrete response and then proceeded to note caregiving. For example, Respondent D succinctly responded to the question of “What is a sister?” with “Siblings. Someone who is always going to be there for you. Like care for you. Be there when you need them.” When defining a sister in their particular families, two out of the three participants, who mentioned caregiving, specifically noted taking care of their brother with autism. For instance, “Someone to help with watching brother.... And same time, like, just being there for each other” (Respondent A). The third participant defined being a sister in her family more generally as “being kind” (Respondent B) and “helping each other” (Respondent B) without specifically referring to her brother.

Discussion of sistering includes examples of caregiving. Three out of the four participants noted examples of caregiving in their discussion of sistering. Participants most often used words like “watching” and “helping out” in their referencing of this role. These terms were

explored when vaguely presented. For instance, the interviewer asked, “What would be an example of helping out in your family?” and the participant responded by clarifying, “Well, like. Watching the younger ones like *Younger Sister. Brother* sometimes” (Respondent D). Of the three participants who noted examples of caregiving, two provided examples solely of taking care of their brother with autism. For instance, “Well, *Brother* sometimes if he gets very anxious about doing something I try to make him feel better...” (Respondent B). These two participants were the youngest within their household.

Caregiving is connected to good sister perception. Three out of the four participants noted caregiving in discussing their perception of a good sister. For example, when asked, “What does it mean to be a good sister?” a participant responded, “Um. Like I said, watching out for everyone. Helping out. Being there when they need you to be” (Respondent D). As in this example, one participant did not specifically refer to taking care of her brother with autism. However, the two youngest in their households specifically noted taking care of their brother with autism while discussing what it means to be good sister. For example, one of the younger participants noted, “...Help with your um siblings, help mostly, help a lot with Brother cause he has trouble understanding things...” (Respondent B).

Caregivee role. One out of the four participants referred to the enactment of the caregivee role. Caregivee is a term used here to refer to the act of receiving caregiving. As the youngest in her household, one participant discussed instances of her older sisters and her brother with autism taking care of her. For instance, she noted an example where she hurt her knee and both her typical siblings and her brother with autism tried to help. She concluded this example by saying, “it’s very nice knowing that they’ll help you when you need it” (Respondent B). She also talked about how her brother with autism has responded to her sadness. Specifically,

she explained, “Yah, when I’m, if I’m sad or um he’ll bring you a bear and start playing with you and he’ll be very nice....” (Respondent B).

Household helper role as central in sistering. Three out of the four participants referred to the enactment of the household helper role. This role refers to the act of contributing to household maintenance. The role of household helper is noted as a central component of sistering due its connection to the definition of sister and overall salience within and across transcripts.

Definition of sister includes contributing to household maintenance. Two out of the four participants noted contributing to household maintenance when defining what it means to be a sister in their family. The two participants used the language of “help(ing) out around the house” (Respondent A).

Discussion of sistering includes examples of contributing to household maintenance. Three out of the four participants noted examples of contributing to household maintenance in the their discussion of sistering. Examples included “cleaning stuff” (Respondent A), “help out with cooking” (Respondent B), and “doing dishes and stuff like that” (Respondent D).

Contributing to household maintenance is connected to good sister perception. Three out of the four participants noted contributing to household maintenance in their discussion of what it means to be a good sister. Examples included “help out.... Around the house and stuff” (Respondent A), “do my best (giggle) to pick up stuff around the house” (Respondent A), “help do things around the house” (Respondent B), and “helping out” (Respondent D).

Teacher role. One out of the four participants referred to the enactment of the teacher role. The teacher role refers to the act of teaching other siblings. The one participant was the youngest in her household, and the youngest interviewed, at age 9 years.

Definition of sister includes teaching. In her definition of what it means to be a sister in her family, one participant noted teaching her brother with autism. Specifically, she responded “helping him like, teaching him stuff” (Respondent A).

Teaching is connected to good sister perception. In discussing her perception of a good sister, one participant noted difficulty in providing discipline, but added “It’s kinda like teaching him at the same time...” (Respondent A).

Learner role. Two out of the four participants referred to the enactment of the learner role. The learner role refers to being taught by other siblings. Two participants within the same family noted they had learned from their older siblings when asked, “Where did you learn what it means to be a good sister?” The two participants referred to their older typical siblings, and one participant also referred to her brother with autism.

Interviewer:	Where do you think you learned what it means to be a good sister?
Respondent A:	Um. (Pause) Kinda, I think from <i>Brother</i> . Cause like you have to learn like how to help him and stuff.... So it kind of helped me, like.... At the same time my other sisters too though. Kind of like, trying to do what they do.

The participants discussed learning through experience and modeling rather than explicit teaching.

Playmate role. All four participants referred to the enactment of the playmate role. The playmate role refers to engagement in structured and unstructured play interactions. Two out of the four explicitly noted enjoyment in the playmate role when engaging with their brother with autism.

Discussion of sistering includes examples of engaging as playmate. All four participants noted engaging their brother with autism as a playmate. One participant additionally noted engaging her older and younger typical siblings as well. Some examples of engaging siblings as

playmates included "...I'll play catch with him with a little rubber ball or something.... Tickling him too" (Respondent A), "...mostly I just play with him with his bears a lot" (Respondent B), and "play games in the pool.... And just play board games and stuff" (Respondent D).

Enjoyment in playmate role. Though the tone of playmate discussion was most often positive, two participants explicitly noted their enjoyment in engaging their brother with autism as a playmate. For instance, one participant noted, "Like we'll pretend they're going somewhere. We'll plan trip and stuff and it's really fun to play with him" (Respondent B).

Rival role. Two out of the four participants referred to the enactment of the rival role. The rival role refers to quarrelling. Both of these participants were from the same family and used the term "fighting".

Definition of sister includes fighting with siblings. Two participants noted the rival role in their definition of a sister. When responding to "What is a sister?" one participant added, "sometime fight with each other cause they're siblings and that's kinda what they do" (Respondent B). When asked what it means to be a sister in their family, one participant noted "Um well normally, we kinda fight a lot but um we all love each other,..." (Respondent B) and another noted, "I don't know, we fight with each other a lot" (Respondent C).

Not fighting is connected to good sister perception. One participant included the absence of fighting in her definition and discussion of a good sister. For instance when asked what it means to be a good sister she noted, "I don't know, talk to you siblings....Don't fight with them" (Respondent C). She later added that her older sister sees her as a good sister because "I'm the only one that doesn't fight with her" (Respondent C).

Beyond Role Enactments

Beyond the enactment of different roles, all participants discussed togetherness.

Togetherness was discussed in terms of how it relates to the closeness of relationships and the presence of rivalry. The felt enjoyment of togetherness was also noted along with the particular importance of togetherness in sistering their brother with autism.

Significance of togetherness in sistering. The ways in which the participants discussed togetherness suggests its importance in sistering. The experience of togetherness and its impact on relationships was not specifically targeted in the pre-determined questions for the interview. Despite this lack of cuing, all participants' arrived at the topic.

Much togetherness is related to closeness of relationship. Three out of the four participants connected much togetherness to the closeness of relationships. For instance, in discussing her older sister's relationship with her brother with autism, one participant noted "...I think that just cause *Oldest Sister's* like been with him longer.... That she's just kinda more attached to him" (Respondent A). Another participant in explaining whom she most often plays with noted, "Usually it's with *Younger Sister* cause like we are kind of closer..... Cause *Oldest Sister* is busy a lot. And she is with friends and stuff. So me and *Younger Sister* have to, together most of the time" (Respondent D).

Much togetherness is related to rivalry. Two out of the four participants, within the same family, connected much togetherness to rivalry.

Um, we fight about, just like after we spend too much time with each other, we just fight over like almost everything, like who gets to pet the cat, who gets, and we'll fight about pretty much anything. Like why did this person get the biggest, um, piece of, plate of pasta for dinner or something. But, um, overall we don't like fight about too many things. It's normal, just like, we kind of, we don't, we don't fight a lot. But when we fight, we fight for pointless reasons.... Yah. It's cause we just, after being with someone you kinda just get annoyed with everything they do. (Respondent B)

Neither of the two participants noted their brother with autism in particular.

Enjoyment in togetherness. Two out of the four participants noted enjoyment in

togetherness in sibling relationships. One of these two also noted enjoyment in whole family togetherness. For example, “It’s just fun. It’s.... It’s fun to be around him” (Respondent A) and “...me and my sister like spending time with each other” (Respondent B).

Togetherness with brother is an important addition to playmate role. Three out of the four participants noted togetherness as an addition to playmate engagements with their brother with autism. For instance, “.... Sometimes just sitting with him” (Respondent A), “I kinda just go outside with him and talk with him...” (Respondent B) and “....I would go on walks with him and stuff” (Respondent C). One participant suggests that togetherness may present opportunities to respond to her brother’s unconventional and unexpected play engagements. When asked about something that she and her brother recently did together, she noted “The last thing was probably, I think it was yesterday, I was just sitting in my mom and dad’s bed with him.... And he just started giggling and hugging me (slight giggle)” (Respondent A).

Experience of Roles

All four participants discussed their experiences relevant to role enactments. Caregiving was discussed as a positive and negative experience. All participants actively balanced positive and negative experiences, and some participants expressed insecurities and frustrations.

Caregiving as a positive experience. One out of the four participants explicitly discussed caregiving as a positive experience. This participant was the youngest in her household, and the youngest interviewed, at age 9 years.

Caregiving is experienced positively. One participant noted taking care of her siblings as positive experience. She refers to taking of her typical siblings and her brother with autism.

Interviewer: Mhmm. How does it feel to be a sister in your family?

Respondent A: Umm. Kinda makes you feel good, like to know that you’re helping someone (slight giggle).... Mostly *brother*.... At the same

time still my other siblings too..... Mostly *brother* (giggle).

Caregiving as a negative experience. Three out of the four participants discussed caregiving as a negative experience. Caregiving was conveyed as more negative when experienced as difficult, unsuccessful, or involving role crossover.

Taking care of brother is experienced as difficult. Three out of the four participants discussed caregiving as more negative when experienced as difficult. For instance, one participant noted,

Interviewer: Okay. Is there anything that makes it not so much fun?

Respondent A: Well like, he'll have like hissy fits sometimes.... Kinda have to calm him down. Like.... He kinda just starts bursting into tears when he doesn't get what he wants, and.... And it takes little while to calm him down.

Another participant specifically verbalized a difference between taking care of her younger siblings and her brother with autism. She noted, "Well with *Younger Sister* it's a little easier cause she can tell you what she wants, what she needs help with. But *Brother*, can't." (Respondent D).

Taking care of brother is experienced as negative when unsuccessful. One out of the four participants noted caregiving as a more negative experience when unsuccessful. This participant was the oldest interviewed at age 12 years. This participant mentioned the negative experience of unsuccessful caregiving on three occasions throughout the interview. For instance, when asked if it is easy to be a good sister, noted "Um. Sometimes. There's sometimes it gets a little hard. Like when *Brother* gets angry and you don't know why. It's kinda frustrating cause you can't help him" (Respondent D). Frustrations is understood here as a negative experience.

Taking care of brother is experienced as negative when involves role crossover. Two out of the four participants noted caregiving as a more negative experience when it involved role

crossover. These two participants were the two youngest within their households. Examples of role crossovers included a younger sibling providing discipline, directives, or help to their brother with autism.

Interviewer: Do you think it's easy to be a good sister?

Respondent A: Um. (Slight pause) Yah. I think sometimes it's kinda hard.... Especially around brother cause sometimes you just can't calm him down. You have to do something about it. You can't just try to be nice or, you kinda have to do something stern to kind of get him to stop.

One participant additionally noted her brother with autism's sensitivity to role crossover.

Interviewer: Hmm. So he kind of gets along a little bit better with the younger ones, but he doesn't like being told what to do by them.

Respondent B: Yah, but, even if it's like um something like um what do you want, um, butter or sauce on your pasta?....Or, would you like chicken nuggets for dinner, like something like my mom told us to ask him, he'll get really annoyed for like, um, but Mom supposed to tell me that, like I'm just saying that for Mom cause she's in the middle of something.

Balancing of positive and negative experiences. All four participants portrayed ambivalence in discussing their experience of sistering through minimizing negative aspects of sisterhood. One participant additionally balanced negative experiences with positive experiences.

Minimizes negative aspects of sisterhood. All participants minimized negative aspects of sisterhood. Some participants did this by offering qualified language, such as “But, overall we don't like fight about *too many* things...” (Respondent B) or “I mean *Younger Sister* and I can get along *sometimes*” (Respondent C). Some participants used more contradictory or confused language such as, “The rest of the time he's usually in a bad mood, but, most of the time he's happy” (Respondent A) or “But it's, it's not bad but it's not hard, it's really in between” (Respondent B). On each occasion, the participant ended the thought on a less negative note.

Balances negative experiences with positive experiences. One out of the four participants balanced negative experiences with different, positive experiences. For instance, Respondent B noted the negative experience of being hit by her brother with autism, and spoke to the positive of learning how to endure such behaviors. Respondent B also noted feeling bad that her brother with autism had to leave home because of the aggressive behavior directed towards her, but feeling happy that he was getting “the help that he needs.”

Insecurity and effort in role fulfillment. Two out of the four participants noted insecurities around successful role fulfillment with their brother with autism. Two out of the four participants also acknowledged the importance of effort in the fulfillment of roles.

Insecurity around good enough sistering. The two youngest participants in their households noted insecurities around being a good enough sister. Respondent A expressed worry that she did not spend enough time with her brother, and Respondent B expressed worry that her brother’s aggressive behaviors were her fault. More specifically, Respondent B noted, “...I was kinda like sad that like it was kind of mostly my fault, like, maybe, I always thought like well maybe if I didn’t act that way or maybe I didn’t do this, maybe he’d like me more...”

Acknowledges the importance of effort in role fulfillments. Two participants noted the importance of effort in role fulfillment. For instance, Respondent B noted trying her best to make her brother with autism like her. Respondent D noted the importance of trying her best to figure out what it is that her brother needs.

Frustrations surrounding parental favoritism. One out of the four participants noted frustrations around parental favoritism, specifically citing inequities in the discipline of her siblings.

Frustration around unequal discipline of younger sibling. One participant noted her

frustration around the discipline of her younger sibling. She expressed feeling that punishments are not fairly distributed. She noted an example during the previous night where the two girls hit each other, and because their mother only saw the eldest hit, only the eldest was sent to her room. She added that her younger sister then lied about the hitting incident, and was never disciplined.

Frustration around unequal discipline of brother. The same participant noted frustrations around unequal discipline of her brother with autism. She noted that the punishments applied to her brother are often not followed through, or not received as an effective punishment.

Respondent C: I just. (Pause) He just, gets away with it. He doesn't get in trouble for it.... And Mom says she's going to take away his laptop and he yells about it one time, she just forgets about it.

Interviewer: Mmm... So I'm guessing those sorts of consequences are different for you.

Respondent C: Yah.... I mean if I do something, I get in trouble.... If he hits me, he just gets sent to his room but he's usually in his room.... So it's no different.

Sistering a Brother with Autism

All participants noted aspects of sistering that appeared uniquely impacted by the presence of autism in their brother. These included discussions of the additional stressors of a public sisterhood, examples of their brother leading the way, finding humor, experiencing brother's younger developmental age as a positive, and creating alignments with their brother through understandings.

Additional Stressors of Public Sisterhood. Two out of the four participants noted the additional stressors of a public sisterhood. The two participants were the two oldest interviewed, at 11 and 12 years old. These participants discussed how their brother's behavior can be more disruptive in public, resultant stress can be minimized when people know brother; one participant

noted her desire to protect her family's privacy so as to avoid additional stressor.

Brother's behaviors can be more disruptive in public. The two oldest participants noted that their brother's behavior can be more disruptive in public. For instance, one participant was asked if there was anything less enjoyable about being a sister to her brother with autism. Respondent D then noted her brother's difficulty waiting for food in public. She explained that her brother might get angry, and begin to cry, or try to touch strangers as a way of asking for help. Another participant noted that her brother's aggressive behaviors in particular caused her to lose friends at school.

Stress minimized when people know brother. The two oldest participants also noted that the stress caused by brother's public disruptive behavior was minimized when people knew their brother. One participant noted that a sleepover was helpful, in that her friends had a chance to meet her brother and observe how he acted. Another participant noted, "... When we go to softball and stuff everybody knows him so like when he gets grumpy there, no one really, it's not like they get mad about it, they just feel bad for him too" (Respondent D).

Desire to protect family's privacy. One out of the two participants additionally noted a desire to protect her family's privacy all together. She discussed getting angry with her younger sister when she would publically talk about their family. Specifically she noted, "I'm like *Younger Sister*, you don't have to tell the whole school all about our family.... It's really not their business" (Respondent C).

Brother leading the way. Three out of the four participants discussed examples of their brother leading the way. This was done in terms of granting and reflecting on their brother's prominent impact on the family system and the nature of interactions. The two youngest participants in their household attended to their brother with autism first in their discussion of

family drawings. One participant noted how her brother sets the emotional tone of the home. Two participants within the same family also noted how their brother's rigidities can create challenges in daily activities, and how interactions with their brother often are usually limited to his preferred interests.

Brother is attended to first in discussion of family drawings. When asked to tell the interviewer about their kinetic family drawings, the two youngest participants in their households attended to their brother with autism first. One participant pointed him out first, while the other began talking about her brother's interests.

Brother sets the emotional tone of the house. One out of the four participants discussed how her brother with autism sets the emotional tone of the house. This participant was the youngest in her household and the youngest interviewed at age 9 years. Specifically she noted, "If he's upset, that kinda makes everybody a little upset.... So usually when he's happy, everyone is" (Respondent A). She later noted her enjoyment in seeing her brother happy and agreed that his happiness is contagious.

Brother's rigidities create challenges in daily activities. Two participants within the same family noted their brother's rigidities as creating challenges in daily activities. For instance, one participant discussed how difficult it is to get her brother to follow through with plans that he does not like. She later described an example of a planned family trip to Florida that was canceled because of brother's fears of newness and change.

Yah, it's really like he plans our schedule. Like, this summer we tried to go a place in Florida, but *Brother* was like no I can't go on airplanes, I can't go on airplanes, like cause he's never, so it's like no I'm not going. So we had to, we had to um, just stay home most of the time, but, It was um, it was sad that we didn't get to go... (Respondent B).

Another participant discussed her brother's rigidities as creating obstacles in spending time with her friends: because of her brother refuses to get into the car, she cannot be dropped off at her

friend's house.

Interactions often surround brother's preferred interests. Two participants within the same family noted examples of interactions surrounding their brother's preferred interests. Both participants discussed examples of playmate engagements around their brother's focal interest in "Build-A-Bears". One participant shared examples of her brother initiating play with the bears as well as her self. Both participants also discussed their brother's rigid sibling preferences, and the impact this had and continues to have in their relationships. For instance, Respondent B noted the following example:

He had this phase that he hated me so much, like, and he loved OLDER SISTER, so there was a bunch of times where he had to go to the hosp, he was, um having so much trouble like being with me that sometimes he'd go to the hospital, because he just couldn't control himself.

At the time of the interview, Respondent B was preferred and Respondent C was not.

Respondent C appeared significantly impacted by this when she noted, "... He doesn't want to talk to me so I don't talk to him.... I don't even try anymore." This same participant also discussed her brother's phases of strongly preferring one parent over the other.

Finding humor contributes to the fun of sistering brother. Two out of the four participants discussed finding humor as contributing to the fun of sistering their brother with autism. Both discussed finding humor in their brother's behavior and experiencing sistering their brother as fun.

Finds humor in brother's behavior. Two participants within in the same family discussed finding humor in their brother's socially unexpected behaviors. One participant laughed as she noted how her brother "when he's happy, he'll just go like really close to your face (slight giggle) and start smiling (giggle)" (Respondent A). Another participant noted how her brother can be sent to go tickle different family members and how everyone will laugh, including her brother. This

participant also found humor in her attempt to understand her brother's behavior. For instance, she noted with laughter, "He's always looking to eat. So, and like he eats way too fast. It's almost like he thinks (giggle) someone's going to take it from him (giggle)" (Respondent D).

Being a sister to brother is experienced as fun. Two participants within the same family discussed the fun of being a sister to their brother with autism. For instance, both siblings responded to the question of "what is it like to be a sister of *brother*" by noting that it is fun. When asked how it feels to be a sister in her family, one participant elaborated "Umm. It's actually, it's fun cause like most, we goof around a lot at home. Some families don't do that. So like, especially with *Brother*, he makes it more fun. Like when he sings and stuff (giggles)" (Respondent D).

Brother's younger developmental age experienced positively. Three out of the four participants noted positive aspects of their brother's younger developmental age. One participant noted increased family togetherness and two additional participants noted enjoyment in their brother's younger qualities and interests.

Spends more time with family because of younger developmental age. One participant, the eldest interviewed, noted that her brother spends more time with the family than most other adolescents of the same chronological age. Specifically, when asked how her experience might compare to other families, she noted that it would not be as much fun to be in another family and added, "I think if we had a brother that age, he might not like to hangout with us as much" (Respondent D).

Enjoyment in brother's younger qualities and interests. The two youngest participants in their household noted enjoying their brother's younger qualities and interests. One participant noted a younger quality in that "he seems so young kind of.... Cause he's always so happy like that" (Respondent A). Another participant noted how her brother can act older in some respects,

but also acts younger in that he is still interested in toys.

Alignment Through Understandings. All four participants discussed aligning with their brother through understandings. Different participants noted understanding their brother's preferences, behaviors, and emotional experiences. One participant noted empathizing with her brother and another participant noted a stance of curiosity towards behaviors that are not yet understood.

Understands brother's preferences. All participants noted an understanding of their brother's preferences. Preferences were discussed as likes, loves, and favorites. One participant conveyed nuanced understanding of her brother's preferences noting that "he likes going in the pool... but he hates going under water though so he just walks around" (Respondent D) and "he likes board games. He doesn't actually play them but he loves moving the pieces around" (Respondent D). One participant also noted her brother's use of a preferred toy as a way of confronting fears. She explained the following:

he likes to pretend his bears do all these things, and sometimes he does it like if we want to, me and my sisters, or something that he can't or is too afraid to do, sometimes he'll make his bears do it. (Respondent B)

As an example, she noted how brother would pretend his bears were on an airplane, which he was very scared of himself.

Understands brother's behaviors. Three out of the four participants noted ways of understanding their brother's behaviors. For instance, one participant noted the following:

Um, also, *Brother* normally when he runs.... It's like therapeutic for him. So he'll run outside, when he runs, he'll run for like a few feet, stop, and then tap something. Run a few feet, then tap something. It's something like therapeutic for him. (Respondent B)

Two participants within the same family noted understandings of more unpleasant behaviors such as their brother's sibling preferences and spending less time with certain family members.

For example, Respondent C explained, “I mean I get it that he doesn’t want to spend every second of the day with his little sister.... I get that he’s a teenager now and he doesn’t want to spend his time with his family.”

Understands brother’s emotional experience. Two out of the four participants noted understanding their brother’s emotional experience. Each of these two participants noted this type of understanding on at least seven occasions. Confusion, anxiousness, fear, happiness, anger, calm, and sadness were among some the emotions discussed. For example, one participant explained how she might understand her brother’s tears. “Like sometimes he just starts crying for no reason. Like when he doesn’t get his way or when he’s hungry he just starts crying like he’s angry. But sometimes he just cries like he’s really, really sad” (Respondent D).

Empathizes with brother. One out of the four participants noted empathy for her brother. This participant was the eldest interviewed, at age 12 years. When asked about her experience of her brother’s public disruptive behavior, the eldest participant noted, “I kinda feel bad for him cause he can’t tell you what he wants” (Respondent D).

Stance of curiosity toward behaviors that are not yet understood. One out of the four participants noted a stance of curiosity toward behaviors that she did not yet understand. This participant was the youngest in her household.

- | | |
|---------------|--|
| Respondent B: | He’s really smart and it’s hard to think about what’s going on in his head. |
| Interviewer: | How do you think kind of being confused by those things might impact how you are as a sister? |
| Respondent B: | I don’t think it really, like impacts me.... It just makes me very like interested in how he does that.... And want to know a little more. |

In this example, the participant appears to convey both confusion and curiosity.

Chapter 5: Discussion

This study explored how four school-aged girls construct meanings of sisterhood when their older brother has autism. The superordinate and emergent themes that were understood as salient to these girls' individual and shared experiences will now be considered in terms of alignment and departure from the existent literature. Following this discussion, limitations of this study and implications for clinical work and future research will be addressed.

The IPA methodology yielded numerous emergent themes. In the process of analysis, I prioritized most accurately representing the participants' lived experiences, rather than attempting to reduce the data to inform fewer, and more categorical conclusions. The process of reduction would have required a confidence in an objective shared truth; a confidence that poorly aligns with IPA's ideographic principles and is not easily established with such a small participant pool.

Role Enactments

One of the first studies investigating role enactments operationalized the following roles: teacher, learner, manager, managee, and playmate (Brody, Stoneman, & MacKinnon, 1982). Later studies maintained some of these roles and additionally defined others. For instance, seven roles were described by Brody et al. (1985): (a) teacher, (b) learner, (c) manager, (d) managee, (e) helper, (f) helpee, and (g) observer; and five roles were described by Brody et al. (1991): (a) manager, (b) teacher, (c) helper, (d) playmate, and (e) interactor. This particular study marks a departure from these early observational studies in that children were asked to voice their perspectives surrounding sistering. Through the process of holding in mind each child's portrayal of their experience and the whole of the data, seven roles were identified: (a) caregiver, (b) caregivee, (c) household helper, (d) teacher, learner, (e) playmate, and (f) rival.

Though participants often used the language of “helping”, the simplicity of the helper and helpee roles did not accurately reflect the participant’s portrayal of their experience. Participants used the language of helping to refer to both helping their siblings and helping with household maintenance. As will be noted in more detail below, helping siblings was described with more texture and affect, as opposed to the more neutral portrayal of helping with household maintenance. Therefore the distinction was made between caregiving and household helper roles.

The two roles of caregiver and household helper appeared most central in the portrayal of sistering due to their connection to the definition of sister and overall salience within and across transcripts. When asked, “What is a sister?” three out of the four participants noted the caregiver role and two out of the four referred to the household helper role. Additionally, three out of the four provided examples of the two roles in their discussion of sistering; they also noted both when describing their perception of a good sister. Perhaps what can be gleaned from the apparent centrality of these two roles is that these three girls experience both caring devotion within the sibling subsystem and a commitment to the pragmatic functioning of the larger family system. They also acknowledge that this dual experience is what is desirable in terms of expectations of a good sister.

The caregiver role was discussed in terms of taking care of both typical siblings and their brother with autism. When providing examples of caregiving, the two youngest in their households solely provided examples of taking care of their brother with autism. This may suggest that caregiving is endorsed in their understanding of sistering, however these two participants are most likely to engage specifically in the caregiving of their brother. Further support for this hypothesis can be found in the literature. Studies examining role asymmetries suggest older siblings assume dominant roles most often (Brody et al., 1982; Brody et al., 1991).

Therefore, as the youngest child in her household, it would make sense that she is less likely to enact the dominant role of caregiver with her older typical siblings than with her developmentally younger brother with autism.

One out of the four participants referred to the enactment of the caregivee role, meaning that she discussed receiving the caregiving provided by her siblings. As the youngest in her household, this participant noted the caregiving provided by both her older typical siblings and her older sibling with autism. What appears particularly interesting is her discussion of how her brother responds to her sadness by bringing her toys, attempting to play, and being “very nice”(Respondent B). Children with autism have theory of mind deficits, which means deficits in their ability to take another person’s perspective. This type of deficit usually complicates the experience of empathy; however, this appears to be a striking example of empathy. Though the participant’s brother responds through his own lens by offering an object of his preferred interest, this apparent empathy is notable and may reflect a unique closeness within their sibling relationship.

One out of the four participants referred to the enactment of the teacher role in describing what it means to be a sister in her family. More specifically, this participant noted teaching her brother with autism as central to the experience of sistering within her family. This participant also referred to teaching her brother when describing what it means to be a good sister. Given the discussion above, perhaps it is unsurprising that as the youngest in her household; she discusses enacting the dominant role of teaching solely with her brother with autism. The absence of teaching in other participants’ meaning making is also potentially interesting given its prevalence in observational studies (Brody et al., 1982). Perhaps school-age girls are more likely to understand their teaching behaviors as aspects of caregiving.

Enactment of the learner role was described by two participants within the same family. When asked where they learned what it means to be a good sister, the two participants noted learning from their older typical siblings. One participant also referred to learning from her older brother with autism. The more explicit learning described in observational studies was not described in the participants' meaning making processes (Brody et al., 1982). Instead, the participants discussed learning through experience and modeling rather than explicit teaching. Perhaps this reflects children's natural aptitude to learn through example, rather than through the sharing of conceptual knowledge that is less easily generalized. This type of learning also exposes children to the utility or usefulness of the skill.

All four participants referred to the enactment of the playmate role in their discussion of sistering. All four discussed examples of playing with their brother with autism, and one additionally noted examples of playing with her typical siblings. These playmate engagements included minimally structured activities like catch, tickling games, jumping on the trampoline, singing songs, and pretend play. More structured activities like board, video, and pool games were not described as played in the traditional rule-bound way. For instance, one participant noted the following two examples: "He loves watching us play Wii. Like racing car games cause he thinks it's funny when we fall off" (Respondent D) and "He likes board games. He doesn't actually play them but he loves moving the pieces around (giggle)" (Respondent D). Discussion of these conventional and less conventional play engagements was conveyed in a largely positive tone. Two participants explicitly noted enjoyment in enacting the playmate role with their brother with autism. The playmate role has been described as an egalitarian role relationship (Brody et al., 1982) and perhaps the experience of enjoyment of this role is related to experiencing equality or sameness with their brother.

Two participants within the same family referred to the enactment of the rival role when defining what it means to be a sister within their family. One of these two also noted the rival role when defining a sister more generally. The connection of this role to the definition of sister suggests centrality in the two participants' understanding of sistering as involving rivalry. One participant additionally noted the absence of fighting in her perception of a good sister, and then proceeded to note that her brother and younger sister do not see her as a good sister. Endorsing the idea that *I fight with my siblings, therefore I am a bad sister* appears to contradict the shared idea that sisters fight. This is important in that this type of meaning making influences how relationships are experienced and carried out (Bruner, 1990). Therefore, the participant's endorsement in this sense of *bad sister* may be playing a role in the strained sibling relationships that she portrays.

Taken together, the caregiver and household helper roles appeared most central to how three participants define sistering. Two participants within the same family additionally granted the rival role centrality in defining sistering. Examples of the playmate role were also prominent across all participants' discussions of sistering. The caregiver, teacher, and learner roles were less salient but important within individual meaning making.

Togetherness

All participants arrived, unprompted, at the topic of togetherness, suggesting its importance to the participants' understanding of sistering. Three participants described the impact of togetherness on the closeness of sibling relationships, suggesting the more togetherness, the closer the relationship. Two participants described the same impact on rivalry, suggesting the more togetherness, the more rivalry in the relationship. The participant who made both these connections reinforces the idea that rivalry and closeness exist as two separate

dimensions of the sibling relationship (Furman & Buhrmester, 1985). The amount of rivalry in sibling relationships does not determine the amount of closeness; for instance it is possible that a relationship be high in closeness and high in rivalry (Furman & Buhrmester, 1985).

Three participants also noted togetherness with their brother as an important addition to playmate engagements. They offered examples of sitting, walking, going outside, or talking with their brother. According to one participant, spending time with or being in the presence of her brother appears important in that it presents opportunities to respond to her brother's unconventional and unexpected play initiations. Children with autism typically show deficits in their ability to initiate social interactions; therefore, these experiences may be particularly rare and especially valued within the sibling relationship, at least for this one participant.

Experience of Roles

When reflecting on how it feels to be a sister in her family, one participant explicitly described the caregiver role as a positive experience. She noted how it "feels good" (Respondent A) to know that she is helping someone, particularly her brother. The caregiver role was portrayed in a more negative light when the role enactment was experienced as difficult, unsuccessful, or involving role crossover.

Examples of role crossover included a younger sibling providing discipline, directives, or help to their brother with autism. Farber (1960) discusses a development process in families including a child with a disability, where a younger typical child simultaneously experiences intellectual and role crossover. This developmental phase is thought to bring about sibling conflict and anxiety, as roles are renegotiated (Farber, 1960). One of the two participants who described role crossover did indeed discuss her brother's keen sensitivity to this crossover, and the conflict that can result from these incidents. The other participant discussed more anxiety

reactions to this experience noting its difficulty, and “feeling bad” (Respondent A). Together, perhaps these two participants are supporting Farber’s hypothesis. It is also interesting that these two participants were the youngest in their households; the earlier-born participants did not note this negative experience, perhaps suggesting that they have resolved role renegotiation, or that the dissonance is greater, the larger the age difference.

All participants actively balanced positive and negative experiences through minimizing the more negative aspects of sistering. Some participants did this by offering qualified language, whereas others used more contradictory or confused language. One participant balanced negative experiences with different, positive experiences. The process of this subtle balancing may convey an experience of ambivalence. Ambivalence is more often talked about in terms of adult sibling relationships (e.g., Bedford, 1989; McGraw & Walker, 2007) however appears quite salient in all participants’ experience of sistering. Perhaps the participants were less able to portray a solely negative experience because of their acknowledgement of the impact of their brother’s autism; and in turn they suggest a more mature sense of ambivalence or ability to hold both the positive and negative.

The two youngest participants in their households expressed insecurities with regard to good-enough sistering and conveyed this experience in terms of worries. One participant worried about not spending enough time with her brother, and the other worried that her brother’s aggressive behaviors were her fault. It is potentially interesting that these are also the two participants who discussed negative experiences surrounding role crossovers. Their insecurities around good-enough sistering may or may not be related to the felt discomfort of role crossover, or their hypothesized involvement in the process of role renegotiations. They may also have been expecting too much of themselves. Either way, these worries appear in excess of what may be

expected in typical sibling relationships. Two participants also discussed the importance of well-intentioned effort in confronting the difficulties sistering their brother with autism. They potentially felt good that they were trying, even if not always successful in the interactions.

One participant discussed frustrations surrounding perceived parental favoritism. More specifically, she expressed frustrations around the unequal discipline of her younger sibling and her brother with autism. Given that this participant also reported strained relationships with her younger sister and brother, this finding appears to align with research suggesting that perceived parental favoritism is inversely related to positive sibling relationships in families including a child with a disability (McHale et al., 1986). Additional studies have also suggested that the presence of autism in particular limits rivalry in the form of quarrelling and competition; however, this participant, in particular, reminds us that these relationships are not utterly devoid of rivalrous interactions and feelings (Kaminsky & Dewey, 2001).

Sistering a Brother with Autism

In addition to role enactments, togetherness, and the experience of roles, all participants discussed aspects of sistering that appeared potentially unique to the experience of sistering a brother with autism. These included discussions of the additional stressors of a public sisterhood, examples of their brother leading the way, finding humor, experiencing brother's younger developmental age as a positive, and creating alignments with their brother through understandings. The literature to help us understand these themes is sparse. Thus, these themes may best be understood as interesting qualitative findings, and the beginning points for future research.

The two eldest participants discussed the additional stressors of a public sisterhood, noting that their brother's behaviors can be more disruptive in public. These participants also

discussed how this stress was minimized when people developed an understanding of their brother from getting to know him through sleepovers, or exposure at sporting events. The importance of perceived acceptance in children's social context has been noted in the literature. For instance, McHale et al. (1986) found that sibling relationships are perceived as more positive when typical children believe that their peers react positively to their sibling with a disability. In the present study, the participant who conveyed more strained sibling relationships also described losing friends when peers failed to understand her brother's aggressive behaviors. Given this experience, this participant's wish to protect her family's privacy can be understood.

Two participants discuss their brother's prominent impact on the family system. When describing their kinetic family drawings, the two youngest participants in their households attended to their brother first. This may suggest their brother's prominence in the family system and/or more simply reflect perceived expectations knowing about the goals of the research process. However, one of these participants offers further support for the former hypothesis by proceeding to describe how her brother sets the emotional tone of the house. She relates how her brother's positive or negative emotional state impacts the emotions experienced by other family members. If her brother is feeling happy, others are likely to feel happy; if her brother is feeling upset, others are likely to feel upset. This described contagion may be impacted particularly by the presence of autism; the autistic brother may express emotions in overt and extreme ways that then pull the family system into action. This participant's brother conveys upset emotions by crying, and attempting to hold other people's hands; two behaviors that are unusual for a typically developing 17-year-old, and likely pull the family system into reparative action. Similarly, he overtly expresses happiness by laughing, hugging, and tickling others. Dysregulated behaviors such as these may galvanize family members to action, to take necessary

steps to help him act more calmly.

Two participants within the same family further discussed their brother's prominent impact on daily activities and interactions. They describe how their brother's rigidities create challenges in daily activities, as he fears newness and change. Children with autism typically have difficulty tolerating change, as their ability to shift cognitive sets can be limited (American Psychiatric Association, 2000). Change in routines can be experienced as hugely disruptive and anxiety provoking, even if the change simply includes taking a ride in the car to bring a sibling to her friend's home, as described by one of the participants. Children with autism also have restricted interests (American Psychiatric Association, 2000). Two participants described how their interactions with their brother often surrounded his preferred, focal interest (in "Build-A-bears). Both participants also described their brother's rigid sibling and parent preferences. These strong play and relational preferences have the implicit value of controlling family life in ways that can be restricting and difficult. It is particularly hard at an emotional level to be the non-preferred sister.

Two participants within the same family discussed how finding humor in their brother's behavior contributes to the fun of sistering. The two find humor in their brother's socially unexpected behaviors, and when asked "what is it like to be a sister of brother", they describe the experience as fun. Humor has been touched upon in the family resilience literature as useful in providing "respite and lift spirits" during difficult times (Walsh, 2003, p.13). Following this line of thought, humor may be especially helpful to siblings enduring the stressors associated with sistering a brother sometimes behaving in such atypical and extreme ways.

Three participants discussed positive aspects of their brother's younger developmental age. One participant described increased family togetherness, noting that her brother spends

more time with the family than would be expected of a typically developing adolescent of his same chronological age. The two youngest in their household additionally noted enjoyment in their brother's younger qualities and interests. Perhaps these characteristics are described as positive because they narrow the chronological gap for these young participants and provide the opportunity for more shared interests.

All four participants discussed various understandings of their brother with autism. Understandings of preferences, behaviors, and emotional experiences were reported. These understandings are likely important in facilitating closeness in relationships with autistic children, whose social communication skills are limited (American Psychiatric Association, 2000). The eldest participant interviewed additionally noted more explicit empathy for her brother. The youngest participant also portrays curiosity toward behaviors that she does not yet understand. Taken together, it appears that although autistic individuals may have difficulty developing a theory of mind, it is possible that their siblings become even more perceptive and attuned. The girls in this study were working hard to learn how to understand their brothers' lived experience and unique communication styles.

Limitations

The small sample size of four participants warrants caution in generalizing findings. Interpretive Phenomenological Analysis (IPA) is a method "concerned with the detailed examination of human lived experience" (Smith et al., 2009, p.32) and is not meant to produce sweeping conclusions. Instead, the findings here reveal idiosyncratic meaning making processes of four individuals as understood and interpreted by the researcher. The value here is placed on depth. From the philosophical standpoint of Mary Warnock, with depth we may arrive at what is essentially human (as cited in Smith et al., 2009), but that which is shared and communal is not

to be decided here.

The age of the participants may have also limited the researcher's access to the fullness of their lived experience. IPA relies heavily on verbal expression and language. Given the young age of the participants, their ability to communicate through language is not fully developed. The youngest participant, at 9 years-old, expressed difficulty verbalizing her experience on multiple occasions, noting variations of "I don't know (giggle). I don't know how to word it (giggle)" (Respondent A). Though an alternative means of communication was offered through the kinetic family drawing, the drawing itself was not analyzed due limitations in supportive research for doing so.

One participant evidenced hesitancy and reservation surrounding the kinetic family drawing. This participant asked many questions and eventually communicated her disinterest and dislike of the task. Beginning the interview process with an aversive activity may have offset her more natural response tendencies to the interview questions. Further, it remains unclear if she would have responded differently to interview questions if she were presented with an activity she found enjoyable. However, the interview and drawing were not discarded, as her difficulties appeared to extend beyond the act of drawing and instead additionally reflect strained sibling relationships.

Clinical Implications

Clinical implications may be derived from the results of this study. First and foremost, it appears that the experience of role fulfillments is central to understanding the lived reality of sistering a brother with autism. Within a clinical interview, girls would be done a disservice if only asked questions surrounding roles (ie., "Do you take care of your brother and how often?"). Instead, girls can be asked to talk about their experience of caregiving, playing, fighting, etc., so

that both positive and negative experiences can be addressed, held in therapist's mind, and weighed in relation to each other. For instance, increasing positive caregiving experiences may be a more realistic goal of therapy than eliminating caregiving responsibilities all together. As gleaned by three participants, the experience of caregiving as difficult, unsuccessful, or involving role crossover may be experienced negatively, and therefore a therapist may seek to target and limit these specific experiences, or help children understand better why it may feel hard for them.

A child's good sister perception may also be important to explore in therapy. First, points of cognitive dissonance may be worthy of further inquiry. For instance, describing a good sister as someone who does not fight with her siblings may contribute to bad sister self-perception in the presence of typical rivalry. Given that meaning making influences how relationships are carried out (Bruner, 1990), a child with bad sister self-perception may then be less likely to respond to her brother with patience and helping behaviors, and instead respond in more undesirable ways. In this example, undermining the bad sister perception through normalizing the presence of rivalry, and providing psychoeducation around its developmental function, may be useful to the child and to her parents as well. Parents may have additional concerns about the vulnerability of the autistic child; sensing the playing field is not level, they may unwittingly increase the rivalry by intervening assertively. Second, thickening a child's sense of being a good sister will in turn likely lead to more prosocial behaviors. This may be accomplished through attending to sistering examples that align with the child's good sister perception, through addressing worries around good enough sistering, and encouraging parents to notice sisterly efforts as much as outcomes.

Perceptions of fairness may also be important. Past studies suggest that perceived parental favoritism is correlated with more negative sibling relationships; and one of the

participants in this study offered further support for this idea. Therefore frustrations around fairness may be explored and potentially reframed through explaining that fair is not the same equal (Attwood, 2002). Children may be supported in understanding that fairness is about providing children what they need, not providing equal treatment. For instance, consider an example of a family having chicken for dinner. A parent will cut the chicken for the 3-year-old, because he is not yet able to do so for himself. A parent may not cut the chicken for the 8-year-old, because he is able to cut it himself. This is not equal treatment, but is fair in that it takes the children's developmental abilities into account.

In terms of sistering a brother with autism, the following topics may warrant further exploration in therapy, as they were pertinent to the experience of the children interviewed. These topics include the following: potential stressors of a public sisterhood; coping with brother's prominent impact on daily activities, interactions, and emotional tone of the home environment; use of humor; experience of brother's younger developmental age; and sibling's development of understanding, and a theory of mind.

Future Research

This study has provided a brief snapshot of sisterhood in the lives of four school-aged girls. It would be potentially interesting to take a longitudinal perspective and follow the evolution of how girls, adolescents, and adults understand sisterhood when their brother has autism. Also pairing qualitative methodology with more quantitative sibling measures may shed more light on how certain meaning making processes are linked to more positive or negative sibling relationships. Additionally, the role of joy and humor may be an interesting line of inquiry given past research to suggest its impact on resiliency in typical families (Walsh, 2003). It is my hope that expanding our understanding of these sibling relationships and developing

relevant clinical applications will ultimately help sisters discover and build upon their own internal reservoirs of strength.

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Appendix A: Diagnostic Criteria

Diagnostic Criteria for 299.00 Autistic Disorder (American Psychiatric Association, 2000)

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

(1) qualitative impairment in social interaction, as manifested by at least two of the following:

- (a) marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
- (b) failure to develop peer relationships appropriate to developmental level
- (c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)
- (d) lack of social or emotional reciprocity

(2) qualitative impairments in communication as manifested by at least one of the following:

- (a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
- (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
- (c) stereotyped and repetitive use of language or idiosyncratic language
- (d) lack of varied, spontaneous make-believe play or social imitative play

appropriate to developmental level

(3) restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

- (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
- (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
- (c) stereotyped and repetitive motor mannerism (e.g. hand or finger flapping or twisting, or complex whole-body movements)
- (d) persistent preoccupation with parts of objects

- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder.

Appendix B: Informed Consent Form

**INFORMED CONSENT FORM**

Project Title:	Children's Constructed Meanings of Sisterhood When an Older Sibling has Autism
Researcher:	Jamie Carroll, M.S. Doctoral Student Department of Clinical Psychology Antioch University New England 40 Avon Street, Keene, NH 03134 Phone: (978) 430-2051 E-mail: jcarroll@antioch.edu

Thank you for volunteering to have your child participate in this project. This study will look at how girls talk about what it means to be a sister when their sibling has autism. After you read this description of the project, I will ask you to decide whether your child may participate.

1. Your presence during research procedures. I will ask your child whether or not she would like her parent present during the research activities. This choice gives your child a sense of control in the research situation. Most school-age children choose to excuse their parents. If you are excused, I will ask your child at the end of the interview if she would like to show her drawing to you, and talk about the day's activities. If so, we will invite you back into the room for a few minutes.

2. Procedure you can expect. Your child will first be asked to draw a picture of her family. Once done, your child will be asked what the characters are doing and how they feel. Your child will then be asked what it is like to be a sister. She will be asked what she does with her sibling. Lastly, she will be asked what it means to her to be a good sister. Additional questions will be guided by your child's responses. The drawing discussion, and interview will be tape-recorded for later transcription. This process will not last longer than 2 hours.

3. Taking part is voluntary. If you choose not to have your child take part, neither you nor your child will be pressured in any way. Your child will also be asked if she would like to participate. Only children who agree will be included in the study. Your child may choose to stop at any time. You can also withdraw your child from the study at any time, for any reason, without penalty. Your decision to participate or not participate will not be revealed to anyone other than

myself.

4. The benefit to your child is in the opportunity to share her experiences. Children often enjoy adult, one-on-one attention. My hope is that society will also benefit from this study. The number of children with autism continues to grow, and many of these children have typical siblings. Typical children with siblings who have autism face unique challenges, and understanding their perspective is important.

5. We do not expect your child to be troubled by the drawing activity and interview questions. If she appears distressed in any way, I will ask her about what she is feeling, and remind her that she may stop at any time. If necessary, referral to mental health services will be made available.

6. Your child's responses will remain confidential. A code number will be assigned to your child. Once audiotaped material has been transcribed (written down), the recording will be deleted. The typed transcript will show your child's code number, not her name. All identifying information included in the transcript will be changed in any report of the results. Your child's drawing will also include your child's code number. The researcher will keep your child's drawing, but any identifying information will be removed. Your child does not have to answer any interview question(s) that she does not want to.

The researcher is a mandated reporter. If you or your child presents information about harm or neglect of a child, elder or handicapped person, confidentiality cannot be guaranteed.

7. Your child's privacy will be maintained in outcome data. Quotes from the transcribed interview and drawings may be included in the final written report. All research materials will be edited for identifying information.

8. If you have any questions about the study, you may contact Jamie Carroll, at (978-430-2051) or at jcarroll@antioch.edu

9. If you have any questions about the research process, your rights, or your child's rights as a participant, you may contact Dr. Kevin P. Lyness, Chair of the Antioch University New England Human Research Committee, (603) 283-2149, or Stephen Neun, ANE Vice President for Academic Affairs, (603) 283-2150.

I have read the information provided and I give my permission to have my child

_____ (print child's name) included in the study.

Parent's Signature

Date

Please Print Name: _____

Appendix C: Child Assent Form

Child's Name: _____

Research Study on Sisterhood

I am interested in learning about what it's like to be a sister, when one of your brothers or sisters has autism. I am asking you, and other girls, to work with me to find out more about it.

If you agree to do this, I will ask you to draw a picture of your family and answer some questions. Most kids think this is fun to do. This is not a test like you have in school. You won't be graded on anything you do. All you have to do is try your best.

I will ask to keep your drawing. I will also tape record our work together so that I can remember your ideas later. When I leave, I will write down your ideas and delete the recording of your voice. I will not write your name on any papers, so that only I know who said what.

You don't have to do this if you don't want to, even if your parents gave their permission. If you don't want to do this, just tell me and I can leave. It is OK with me if you don't want to be in the study.

Do you have any questions?

If you agree to do this, I would like you to sign this paper.

The study on sisterhood has been explained to me and any questions I had have been answered. I would like to take part in the study.

Child's Signature_____
Date

Appendix D: Demographic Data

Date: _____

Participant's Age: _____

Participant's Ethnicity: _____

Location of Interview within Home: _____

Family Composition: Please list all members of the participant's family.

Relation to Participant (ie., mother, father, sister, brother)	Age of Siblings	Diagnosed with Autism (Yes/No)	Lives within Household (Yes/No)
1.			
2.			
3.			
4.			
5.			
6.			

Appendix E: Interview Schedule and Possible Prompts

Questions and Prompts about the KFD Drawing:

1. Tell me about your drawing.
 - a. Possible Prompts: Who is this person? What is he or she doing? Is this everyone in your family?
2. How does this person in the picture feel?
 - a. Possible Prompts: Tell me more about that. Why do you think that is?

Transition Statement if Needed

“Thank you for drawing this wonderful picture and telling me all about it. Is there any thing else that you would like to tell me about it before we move on?” And then, “Okay, now I am going to ask you some questions about being a sister, and I just want you to try your best to tell me as much as you can. There are no right or wrong answers.”

General Interview Questions

1. What is a sister?
 - a. Possible Prompts: It’s okay to give your best guess. I am not looking for a right answer.
2. What does it mean to be a sister in your family?
 - a. Possible Prompts: What kind of things do you do? Tell me more about that. How does it feel to be a sister in your family?
3. What is it like to be a sister of _____?
 - a. Possible Prompts: Tell me more about that. In what ways? Is there anything that makes it fun? Is there anything that makes it not so fun?
4. What do you do with _____?

- a. Possible Prompts: Tell me more about that. During (mentioned activity) what does your brother/sister do? Describe something you and _____ recently did together. How fun or not fun is that for you?
5. What does it mean to be a good sister?
 - a. Possible Prompts: Tell me more about that. Can you think of something a good sister would do? Where do you think you learned this? Is it easy to be a good sister? Are you a good sister?

Appendix F: Example of Data Display Matrices

Question 1: Tell me about your drawing.

Emergent Themes	Transcript	Exploratory Comments
Family Interaction Positive Negative Exclusion Emotional Displays Caretaking Playmate Other		

Question 2: How does this person in the picture feel?

Emergent Themes	Transcript	Exploratory Comments
Positive Tone Happy Proud Negative Tone Sad Angry Frustrated Acting Out Feelings Mutual		

Pos./Neg. Received		
Other		

Question 3: What does it mean to be a sister in your family?

Emergent Themes	Transcript	Exploratory Comments
Positive Experience		
Negative Experience		
Caretaking		
Playmate		
Other		

Question 4: What is it like to be a sister of _____?

Emergent Themes	Transcript	Exploratory Comments
Positive Experience		
Negative Experience		
Caretaking		
Playmate		
Other		

Question 5: What do you do with _____?

Emergent Themes	Transcript	Exploratory Comments
Dominant Roles (Teacher, Manager, or Helper)		
Joint Play		

Subordinate Roles (Learner, Managee, Helpee)		
Other		

Question 6: What does it mean to be a good sister?

Emergent Themes	Transcript	Exploratory Comments
Dominant Roles (Teacher, Manager, or Helper) Caretaking Joint Play Subordinate Roles (Learner, Managee, Helpee) Emotional Displays Inclusion/Exclusion Other		

Appendix G: Kinetic Family Drawings

Figure F1

Respondent A's Kinetic Family Drawing

Figure F2

Respondent B's Kinetic Family Drawing

Figure F3

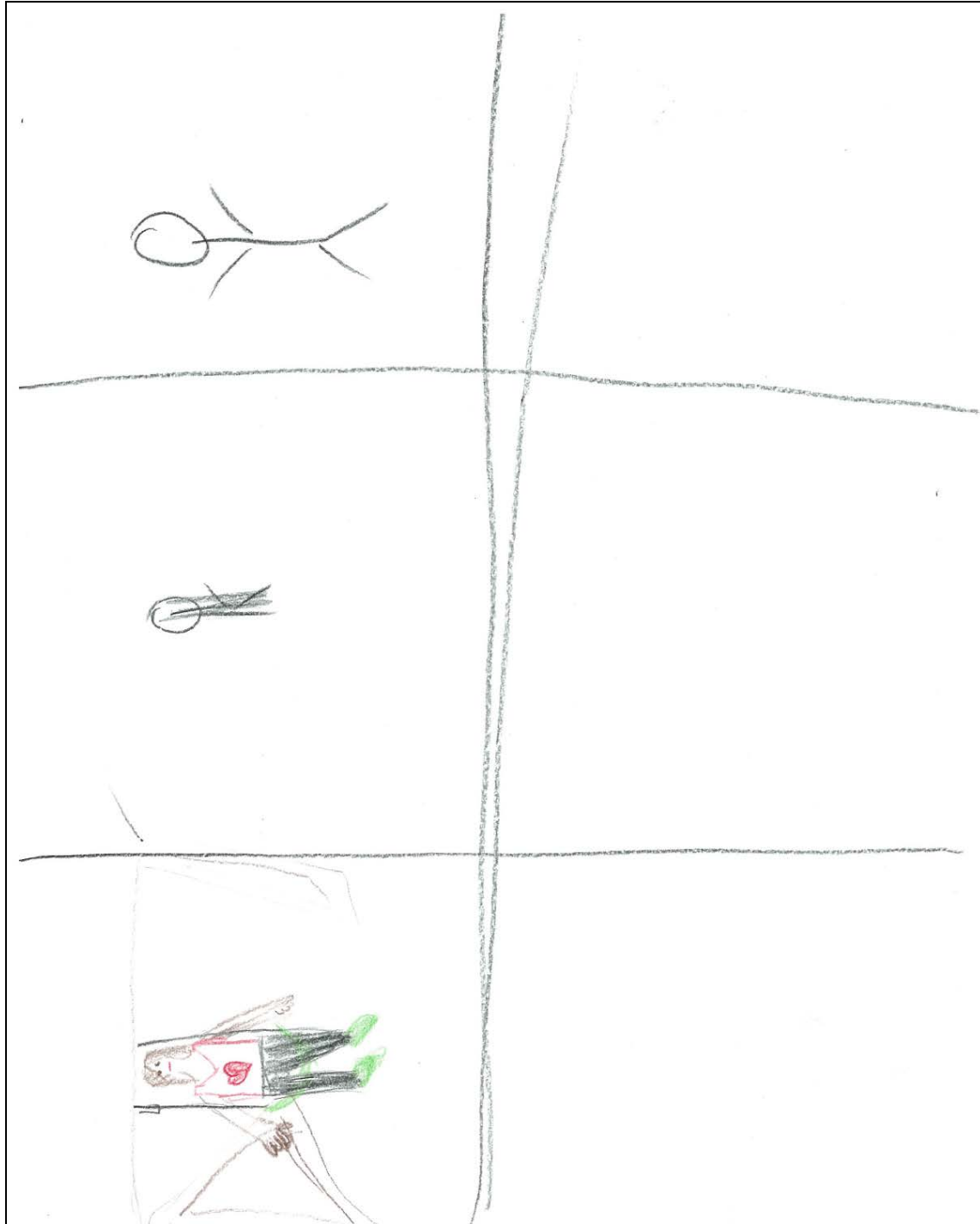
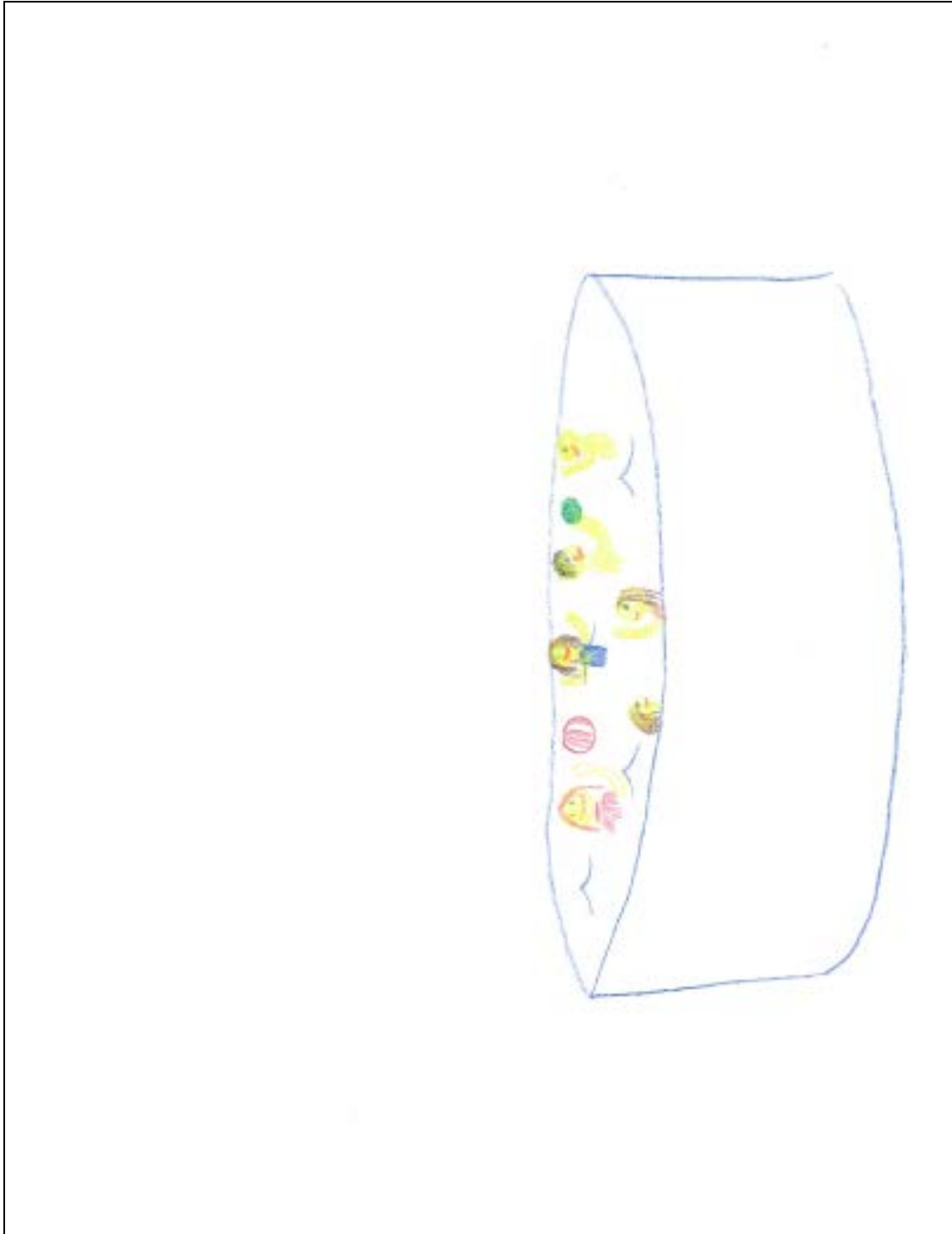
Respondent C's Kinetic Family Drawing

Figure F4

Respondent D's Kinetic Family Drawing

Appendix H: Superordinate and Emergent Themes

Table G1

Superordinate and Emergent Themes Relevant to Role Enactments

Superordinate Themes	Emergent Themes	N	Examples
1. Caregiver role as central in sistering (N=3)	Definition of sister includes caregiving	3	“Siblings. Someone who is always going to be there for you. Like care for you. Be there when you need them.” (Respondent D).
	Discussion of sistering includes examples of caregiving	3	“Um. (Giggle) (Pause). Like, well this happens with <i>Younger Sister</i> a lot. Cause we share a room. When there’s thunderstorms she gets scared and I talk to her until she falls asleep” (Respondent D).
	Taking care of siblings is connected to good sister perception	3	“So what does it mean to be a good sister?”(Interviewer) “Well, normally, it’s just like help out your siblings and to help do things around the house....Help with your um siblings, help mostly, help a lot with <i>Brother</i> cause he has trouble understanding things...” (Respondent B).
2. Caregivee role (N=1)	Discussion of sistering includes examples of caregivee	1	“Yah, when I’m, if I’m sad or um he’ll bring you a bear and start playing with you and he’ll be very nice....” (Respondent B).
3. Household helper role as central in sistering (N=3)	Definition of sister includes contributing to household maintenance	2	“So what does it mean to be a sister in your family?” (Interviewer)
			“Um. Like help out. You can help around the house”

		(Respondent D).	
	Discussion of sistering includes examples of contributing to household maintenance	3	<p>“What kind of things do you do as a sister in your family?” (Interviewer)</p> <p>“Um. (Pause). Well, cleaning stuff. Well we have stuff to do but at the same time, like, I said watching <i>brother</i>....Making sure he doesn’t eat everything (giggle)” (Respondent A).</p>
	Contributing to household maintenance is connected to good sister perception	3	<p>“Why do you think that is (that you’re a good sister)?” (Interviewer)</p> <p>“Well watching brother a lot. And do my best (giggle) to pick up stuff around the house and stuff...” (Respondent A).</p>
4. Teacher role (N=1)	Definition of sister includes teaching	1	<p>“What does it mean to be a sister in your family?” (Interviewer)</p> <p>“Someone to help with watching <i>brother</i>, and.... Helping him like, teaching him stuff...” (Respondent A).</p>
	Teaching is connected to good sister perception	1	<p>“Yah. It’s kinda like teaching him at the same time. So it’s, yah I think it’s kinda hard being a good sister too” (Respondent A).</p>
5. Learner role (N=2)	Older siblings taught good sister perception	2	<p>“Where do you think you learned what it means to be a good sister?” (Interviewer)</p> <p>“Um. (Pause) Kinda, I think from brother. Cause like you</p>

			have to learn like how to help him and stuff.... So it kind of helped me, like.... At the same time my other sisters too though. Kind of like, trying to do what they do” (Respondent A).
6. Playmate role (N=4)	Discussion of sistering includes examples of engaging as playmate	4	“Um, sometimes I’ll play catch with him with a little rubber ball or something....Tickling him too” (Respondent A).
	Enjoyment in playmate role	2	“Like we’ll pretend they’re going somewhere. We’ll plan trip and stuff and it’s really fun to play with him” (Respondent B).
7. Rival role (N=2)	Definition of sister includes fighting with siblings	2*	“So what does it mean to be a sister in your family?” (Interviewer) “Um well normally, we kinda fight a lot but um we all love each other,...” (Respondent B)
	Not fighting is connected to good sister perception	1	“What do you think it means to be a good sister?....” (Interviewer) “I don’t know, talk to your siblings.... Don’t fight with them” (Respondent C).

* = Two participants from the same family

Table G2

Superordinate and Emergent Themes Extending Beyond Role Enactments

Superordinate Themes	Emergent Themes	N	Examples
1. Significance of togetherness in sistering (N=4)	Much togetherness is related to closeness of relationship	3	“Usually it’s with <i>Younger Sister</i> cause like we are kind of closer..... Cause <i>Older Sister</i> is busy a lot. And she is with friends and stuff. So me and <i>Younger Sister</i> have to, together most of the time” (Respondent D).
	Much togetherness is related to rivalry	2*	“Um, we fight about, just like after we spend too much time with each other, we just fight over like almost everything, like who gets to pet the cat, who gets, and we’ll fight about pretty much anything. Like why did this person get the biggest, um, piece of, plate of pasta for dinner or something. But, um, overall we don’t like fight about too many things. It’s normal, just like, we kind of, we don’t, we don’t fight a lot. But when we fight, we fight for pointless reasons.... Yah. It’s cause we just, after being with someone you kinda just get annoyed with everything they do” (Respondent B).
	Enjoyment in togetherness	2	“And me and my sister like spending time with each other” (Respondent B).
	Togetherness with brother is an important addition to playmate role	3	“The last thing was probably, I think it was yesterday, I was just sitting in my mom and dad’s bed with him.... And he just started giggling and hugging me (slight giggle)” (Respondent A).

* = Two participants from the same family

Table G3

Superordinate and Emergent Themes Relevant to the Experience of Roles

Superordinate Themes	Emergent Themes	N	Examples
1. Caregiving as a positive experience (N=1)	Caregiving is experienced positively	1	<p>“Mhmm. How does it feel to be a sister in your family?” (Interviewer)</p> <p>“Umm. Kinda makes you feel good, like to know that you’re helping someone (slight giggle).... Mostly brother.... At the same time still my other siblings too..... Mostly <i>brother</i> (giggle)” (Respondent A).</p>
2. Caregiving as a negative experience (N=3)	Taking care of brother is experienced as difficult	3	<p>“I help out <i>Brother</i> if he’s having trouble with something but it’s sometimes really really hard....” (Respondent B).</p>
	Taking care of brother is experienced as negative when unsuccessful	1	<p>“.... Is it easy to be a good sister?” (Interviewer).</p> <p>“Um. Sometimes. There’s sometimes it gets a little hard. Like when <i>Brother</i> gets angry and you don’t know why. It’s kinda frustrating cause you can’t help him” (Respondent D).</p>
	Taking care of brother is experienced as negative when involves role crossover	2	<p>“Do you think it’s easy to be a good sister?” (Interviewer)</p> <p>“Um. (Slight pause) Yah. I think sometimes it’s kinda hard.... Especially around brother cause sometimes you just can’t calm him down. You have to do something about it. You can’t just try to be nice or, you kinda have to do something stern to kind of get him to stop”</p>

(Respondent A).		
3. Balancing of positive and negative experiences (N=4)	Minimizes negative aspects of sisterhood	4 “But, um, overall we don’t like fight about too many things....” (Respondent B).
	Balances negative experiences with positive experiences	1 “.... I felt kind of bad, cause he had to leave.... Mostly cause of me. And I felt really bad but I also kinda felt happy that he was getting like the help that he needs but I kinda felt bad that most of the reason he left was cause of me but I knew it wasn’t really my fault” (Respondent B).
4. Insecurity and effort in role fulfillment (N=3)	Insecurity around good enough sistering	2 “Uh, I can’t think of anything. That’s kinda upsetting. Um” (Respondent A).
		“Why is that upsetting?” (Interviewer)
		“Cause like that, thinking about that now it’s just like I don’t spend enough time with him that I can’t think of anything.... Like. If I spent a lot of time with him something would come to my mind instantly (slight giggle)” (Respondent A).
	Acknowledges the importance of effort in role fulfillments	2 “So you kinda just have to try your best...” (Respondent D).
5. Frustrations surrounding parental favoritism (N=1)	Frustration around unequal discipline of younger sibling	1 “If I hit her, I get in trouble. But, she had hit me right before and I just got mad at her and she kept bugging me. Like last night, um, she hit me and I forget why, and then my mom turned around and I hit her, and she only saw me so she sent me to my room and <i>Younger Sister</i> said she never hit me.... And that’s what <i>Younger Sister</i> always does” (Respondent C).

Frustration a round unequal
discipline of brother

1 “I just. (Pause) He just, gets away with it. He doesn’t get in trouble for it..... And Mom says she’s going to take away his laptop and he yells about it one time, she just forgets about it” (Respondent C).

“Mmm... So I’m guessing those sorts of consequences are different for you” (Interviewer)

“Yah.... I mean if I do something, I get in trouble..... If he hits me, he just gets sent to his room but he’s usually in his room..... So it’s no different” (Respondent C).

Table G4

Superordinate and Emergent Themes Relevant to Sistering a Brother with Autism

Superordinate Themes	Emergent Themes	N	Examples
1. Additional stressors of public sisterhood (N=2)	Brother's behaviors can be more disruptive in public	2	"... I've lost some of my friends at school cause he would keep lashing out at school" (Respondent C).
	Stress minimized when people know brother	2	"I mean my real close friends get it, cause like when he was living there, um, with my Dad, and we were with my Mom on the weekends, he would, all my friends would sleep over on the weekends, so they'd see, hear how he acted anyway" (Respondent C).
	Desire to protect family's privacy	1	"I'm like <i>Younger Sister</i> , you don't have to tell the whole school all about our family.... It's really not their business.... Like sometimes, I'll just say it's none of their business..." (Respondent C).
2. Brother leading the way (N=3)	Brother is attended to first in discussion of family drawings	2	"So tell me who each person is in your drawing?" (Interviewer) "Well that's brother" (Respondent A).
	Brother sets emotional tone of the house	1	"If he's upset, that kinda makes everybody a little upset.... So usually when he's happy, everyone is" (Respondent A).
	Brother's rigidities create challenged in daily activities	2*	"Yah, it's really like he plans our schedule. Like, this summer we tried to go a place in Florida, but <i>Brother</i> was like no I can't go on airplanes, I can't go on airplanes, like cause he's never, so it's like no I'm not

			going. So we had to, we had to um, just stay home most of the time, but, It was um, it was sad that we didn't get to go but" (Respondent B).
	Interactions often surround brother's preferred interests	2*	<p>"So what do you do with Brother?" (Interviewer)</p> <p>"Well we don't do many like, there's not like many things, mostly I just play with him with his bears a lot.... Like we'll pretend they're going somewhere. We'll plan trip and stuff and it's really fun to play with him. Um, but mostly I kinda just go outside with him and talk with him and I like, and I normally just play with his bears and he likes um pirates and toy cats too" (Respondent B).</p>
3. Finding humor contributes to the fun of sistering brother (N=2)	Finds humor in brother's behavior	2*	<p>"How does he make it more fun?" (Interviewer)</p> <p>"Like. Cause he just like randomly just like. Lately he's been singing the Lion King a lot.... And it's all the time a different song. Like for a while it was Rubber Ducky from Sesame Street..... And you just like, you can send him to go tickle people sometimes.... And he thinks it's funny too. He laughs every time" (Respondent D).</p>
	Being a sister to brother is experienced as fun	2*	<p>"So what is it like to be a sister of <i>Brother</i>?" (Interviewer)</p> <p>"Um, like I said, it's fun.... It's just fun in general (giggle)" (Respondent D).</p>
4. Brother's younger developmental age	Spends more time with family because of younger	1	"... But, I think if we had a brother that age, he might not like hangout with us as much" (Respondent D).

experienced positively (N=3)	developmental age		
	Enjoyment in brother's younger qualities and interests	2	"Um. I think it's very nice that I have, um, my <i>Brother</i> cause he can be very nice to you and I like how's he's still like, he can act a lot older when he wants to, but a lot of the time he'll act like a little kid, and I like that he still likes toys but he's not like, he's not like, he's still a teenager, but he doesn't sometimes act like it. I like having a little, like him acting a little older.... But then I like how he still acts younger" (Respondent B).
5. Alignment through understandings (N=4)	Understands brother's preferences	4	" <i>Brother</i> , a lot of the time, he likes to run outside" (Respondent B).
	Understands brother's behaviors	3	"Um, also, <i>Brother</i> normally when he runs.... It's like therapeutic for him. So he'll run outside, when he runs, he'll run for like a few feet, stop, and then tap something. Run a few feet, then tap something. It's something like therapeutic for him" (Respondent B).
	Understands brother's emotional experience	2	"And then if it gets changed, then he gets very like, well we were supposed to do this. He gets very confused about it" (Respondent B),
	Empathizes with brother	1	"Like I kinda feel bad for him cause he can't tell you what he wants" (Respondent D).
	Stance of curiosity toward behaviors that are not yet understood	1	"He's really smart and it's hard to think about what's going on in his head" (Respondent B). "How do you think kind of being confused by those things might impact how you are as a sister?"

(Interviewer)

“I don’t think it really, like impacts me.... It just makes me very like interested in how he does that.... And want to know a little more” (Respondent B).

* = Two participants from the same family