SIBLINGS AND FRIENDSHIPS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

by

AMANDA DETRAZ

(Under the Direction of Zolinda Stoneman)

ABSTRACT

The purpose of this qualitative study was to explore how families of children with ASD, parents or caregivers, as well as siblings, perceive friendships and how they assist the child with ASD in navigating friendships. The study consisted of semi-structured interviews focused around the family, friendships, and strategies to assist the child with ASD with friendships. The findings exemplified characteristics of the friendships of the children with ASD, how siblings actively and passively assist in friendships, and how parents step out of their own comfort zones or their normal routine to find support and make socialization opportunities happen for their child with ASD. This information has important implications for individuals that support or work with children with ASD and their families.

INDEX WORDS: Autism spectrum disorders, children, siblings, parents, friendships
SIBLINGS AND FRIENDSHIPS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

by

AMANDA DETRAZ

BSFCS, The University of Georgia, 2013

A Thesis Submitted to the Graduate Faculty of The University of Georgia in Partial Fulfillment of the Requirements for the Degree

MASTER OF SCIENCE

ATHENS, GEORGIA

2015
ACKNOWLEDGEMENTS

First and foremost, I would like to acknowledge and thank my family, Brian, and my friends for all of the love and support they have provided me with over my graduate school career journey. They have constantly encouraged me and radiated positivity towards me. They have all stood by my side throughout it all. Without them, I definitely would not have been as successful.

I would also like to thank my Child Life cohort, Human Development and Family Science family, my major professor, and my committee members. I could not have accomplished this endeavor without the assistance from my major professor, Dr. Zolinda Stoneman. I owe much thanks and appreciation to Dr. Stoneman for taking me under her wing my first year of graduate school and mentoring me. My committee members, Dr. Charlotte Wallinga and Dr. Rebecca Lieberman-Betz, have also played huge roles in my success during graduate school. I will always appreciate the never-ending inspiration and drive provided to me from Dr. Wallinga from day one. Dr. Lieberman-Betz has contributed a wealth of knowledge and advice that have assisted me in multiple ways.

I have been very lucky to have such a great, supportive, and uplifting group behind me over the past two years. I am forever grateful to you all!
TABLE OF CONTENTS

ACKNOWLEDGEMENTS ........................................................................................................ iv

LIST OF TABLES .................................................................................................................. vii

CHAPTER

1 INTRODUCTION ................................................................................................................. 1

   Purpose of the Study ......................................................................................................... 2

2 REVIEW OF LITERATURE ............................................................................................... 4

   Autism Spectrum Disorders ............................................................................................ 4

   Children with ASD .......................................................................................................... 5

   Adolescents with ASD ..................................................................................................... 5

   Adults with ASD .............................................................................................................. 6

   The Need for Intervention .............................................................................................. 7

   Interventionists in Current Literature ........................................................................... 7

   Siblings as Facilitators .................................................................................................... 10

   The Role of Parents ........................................................................................................ 12

   Research Questions ........................................................................................................ 13

3 METHOD .......................................................................................................................... 14

   Participants ..................................................................................................................... 14

   Procedure ......................................................................................................................... 18

   Interviews ....................................................................................................................... 19

   Data Analysis ................................................................................................................... 19
LIST OF TABLES

Table 1: Demographic Characteristics of Mothers ............................................................16
Table 2: Demographic Characteristics of Siblings ............................................................17
CHAPTER 1

INTRODUCTION

According to the American Psychological Association’s DSM-V, an autism spectrum disorder (ASD) is an umbrella term that describes a disorder that is characterized by challenges with verbal and non-verbal communication, someone who is highly dependent upon routines, and is usually accompanied by constant and ritualistic behaviors (American Psychological Association, 2013). Today, 1 in 68 children are affected by ASD. This statistic is astounding and the prevalence of ASD is still rapidly growing, with ASD being the quickest growing developmental disability in the United States (Autism Speaks, 2014). Since ASD is defined on a spectrum, individuals with ASD often experience ASD differently, some with more challenges than others. There are still many individuals with ASD that face the constant challenge of socializing with others and creating lasting friendships. Some difficulties that are common to individuals with ASD are impaired eye gaze, low joint attention, few verbal initiations, and deficiency in developing age-appropriate friendships (Owen-DeSchryver, Carr, Cale, & Blakeley-Smith, 2008).

Past research has focused on exploring the socialization process between a person with ASD and others (Causton-Theroharis, Ashby, & Cosier, 2009), promoting social interaction for people with ASD (Owen-DeSchryver et al, 2008), and how teachers can help facilitate friendships for children with ASD in the school setting (Rossetti, 2012). Despite the amount of research on individuals with ASD and their family members, there
appears to be no published research on the effects of having a typically developing sibling or parent involved in facilitating new friendships for people with ASD. For siblings, some examples of how the facilitator role could be exemplified could be modeling positive socialization, providing emotional support, helping with conversations, providing transportation to social events, or observing their brother or sister interacting with others and stepping in when needed. The child with ASD will have the opportunity to work through any issues they may be having, as well as have someone to ask questions to when needed. Parents can also carry out these roles as facilitators for new friendships, but it may be most important for them to be aware of the facilitator role in order to support the siblings of the children with ASD. Siblings of the children with ASD may see the parents as role models for being a facilitator for their brother or sister. Some parents may also be considered to be facilitators while overseeing and guiding the interactions within the sibling relationship. Since the sibling relationship is the longest lasting family relationship (Tsao, Davenport, & Schmlege, 2012), by implementing this support in childhood, hopes are that the benefits would last a lifetime. Their brother or sister may have the ability to help the children with ASD connect and relate to others in an easier fashion or be someone that they can role-play through different common interactional situations. The benefits of this facilitator relationship for the typically developing sibling may also include a better understanding of ASD, of their brother or sister with ASD, and of their sibling relationship in general.

Purpose of the Study

The purpose of this study is to explore how families of children with ASD, parents or caregivers as well as siblings, perceive friendships and how they assist the
child with ASD in navigating friendships. This study has the potential to provide information and knowledge to researchers in the field to create interventions and resources to support families of children with ASD.
CHAPTER 2
REVIEW OF LITERATURE

*Autism Spectrum Disorders*

Could you imagine a life without your friends? What if you wanted friends but you did not know how to get them? Imagine that you knew how to get friends, but you were not successful. It is very common for people with ASD to feel this way daily. There are many reasons why people with ASD may struggle with socialization. The majority of these reasons are symptoms of ASD, which include impaired eye gaze, few verbal initiations, and insufficient joint attention (ability to coordinate attention with another person in a conversation). Salmon (2012) found that individuals with ASD have experienced stigma and social isolation, which can also contribute to problems with socialization.

It is important to keep in mind that the difficulties with socialization can differ from person to person (Owen-DeSchryver et al., 2008). Individuals with a diagnosis of an ASD may face different levels of challenges, some individuals will find socializing with others as a challenge whereas others may not. These challenges may also look different across the life span. Even though the issue of making friends can affect numerous individuals with ASD, the literature is still very limited and barely addresses the fact that most individuals with ASD do not fully understand the meaning of friendship. Although, it has been demonstrated in past studies that making friends is the most difficult aspect for individuals with ASD. If they do establish a friendship, they must also continue to
maintain the relationship by interacting in positive ways (Daniel & Billingsley, 2010). As you may imagine, this could be very intimidating for individuals who have impairments with socialization. These individuals with ASD face these challenges throughout their entire life, but inventions in recent research are focused on attempting to support these difficulties early on.

Children with ASD

Children without ASD yearn for companionship, intimacy, and closeness in order to advance relationships from acquaintances to friendships. Children with ASD define friendship as companionship with less intimacy and emotional connectedness than children without ASD. This shows that children with ASD have a different understanding of what a friendship actually means (Calder, Hill, & Pellicano, 2012). They exhibit less sharing, less social interactions, and more parallel play than children without ASD. They engage in solitary behaviors more often than cooperative interactions and create reciprocal friendships less than their peers without ASD (Calder et al., 2012). Research by Calder et al. (2012) supports these statements by finding that children with ASD are drawn to create friendships that were qualitatively different from their peers without ASD. This does not mean that the children with ASD did not associate with their peers; it simply means that there is a large variation in the ideas of peer interactions and friendships among the children with ASD (Calder et al., 2012).

Adolescents with ASD

The main concern for adolescents with ASD related to friendships is establishing the relationship (Daniel & Billingsley, 2010). In adolescence, friendships tend to develop greater depth and intimacy, which could pose more problems for adolescents with ASD.
The case study by Carrington, Templeton, and Papinczak (2003) found that the adolescents with ASD had a very hard time talking about their issues with friendships, because they found it hard to explain what friendship means to them. The adolescents with ASD could better explain what qualities defined someone who was a bad friend, which may align with and speak for their experiences. The researchers also found that the high school participants used the concept, ‘masquerading’, to explain how they do not fit in and try to cover up their differences. For some adolescents with a disability, they might not prefer to masquerade their disability but instead consider ‘coming out’. ‘Coming out’ refers to at the point at time when someone with a disability tells another person they have a disability, explains their disability to someone else, or advocates for their disability in public. This usually only occurs when the person with a disability trusts their peers because they do not want their disability to get in the way of the friendship. If coming out to another person happens, it is a crucial event for adolescents with ASD. Many adolescents with ASD find comfort from stigmatization and isolation by finding friendships with other adolescents with disabilities. They were also comforted and enjoyed spending time with their peers and friends in places that felt safe for them (Salmon, 2012).

**Adults with ASD**

Past research has told us very little information about the ways these difficulties affect individuals’ daily social lives past the childhood and adolescent years. The literature that does exist implies that individuals with ASD improve their social skills as they get older, but in actuality they go into adolescence and adulthood with continued problems with socialization (Stokes, Newton, & Kaur, 2007). It has also been shown that
siblings of children with ASD are less engaged and supportive of their brother or sister as adults (Oppenheim-Leaf et al., 2011). This is very sad to think about because adults with ASD are faced with much more social challenges. One difficult aspect for adults with ASD is that romantic relationships are becoming more common. This could cause more discomfort with socialization for the adults with ASD because they see their peers and friends without ASD creating these more intimate relationships that they do not know how to create or maintain, or have difficulty.

The Need for Intervention

As it is evident from the past research over the life course for individuals with ASD, this is an issue that needs to be explored. Some past researchers have described friendship as the most important human relationship (Salmon, 2012). If individuals with ASD live without addressing their difficulties with friendship, they could be missing out on a crucial aspect of their lives, making and building relationships. Researchers in the past have attempted to address this issue by training individuals to work with people with ASD, especially children with ASD. These trained individuals may range from teachers, peers, parents, to siblings. The individuals were not always trained to implement interventions, but the next few sections will explain how they were shown to be effective at helping improve the social problems faced by individuals with ASD.

Interventionists in Current Literature

School is the primary place children and adolescents establish friendships, so it reasonable to utilize teachers and peers to help the individuals improve their social skills (Daniel & Billinsley, 2010). Calder et al. (2012) studied what friendship meant to children with ASD in mainstream primary schools and had many interesting findings.
The researchers found that the majority of parents of students with ASD in the study’s sample believed that the teacher’s priorities were focused on academics and behavior. These parents were mostly unaware of interventions that were implemented to focus on their child’s peer interactions.

The teachers in the study mentioned that the classmates did not always reject the children with ASD, but the classmates did not choose them for friends. The teachers also noticed a lack of reciprocity and motivation from the children with ASD, which they believed was the root of the issue. Social motivation is a driving force for human interactions and behaviors, but it has been shown in past research that children with ASD have less than others. Some of the teachers mentioned being discouraged after many unsuccessful tries to include the children with ASD into games with their classmates during unstructured breaks, and they noticed that the children with ASD showed a preference for being alone. Teachers found that at certain times they had to step in and directly tell the student with ASD how to communicate with their peers. They also mentioned that it was helpful to encourage other classmates to include the children with ASD in their activities.

For the study by Owen-DeSchryver et al. (2008), the researchers focused on the field’s changing emphasis from adult-directed to peer-directed teaching strategies for helping individuals with ASD. The study looked at the social interactions between students with ASD and their classmates in inclusive school settings. The training included educating the peers on why it is important to develop friendships with the students with ASD, helping them realize that all students (not just the students with ASD) have special abilities and needs, and providing concrete information through a guided
discussion that would help them interact with the students with ASD. After their study, they found that peer training is in fact a reasonable and effective strategy for increasing the number of interactions between students with ASD and their classmates. They found that the students with ASD practiced reciprocity more often because of the increased interactions and that the other classmates who were not trained to interact with the students with ASD picked up on the ways to socialize with them as well.

Since there has been some successful research with teachers and peers facilitating and initiating interactions with individuals with ASD, using parents as interventionists should have a similar effect since they are the ones that know their children the best. The research of Ormond, Krauss, and Seltzer (2004) shows that this is true. Ormond et al. (2004) focused on the mother’s role in socialization and how her role affects the child with ASD. The researchers concluded that the mothers played a central role in regards to their sons’ or daughters’ social and recreational activities, since they were the ones who were generally in control of those situations. They found that it was crucial for the mothers to encourage and facilitate their son or daughter to be involved in social and recreational activities in order to evolve and preserve friendships. One important finding that set this study apart from others is that the researchers established a relationship between the family members creating and sustaining their own social life and how this affected the adolescent or adult with ASD’s ideas of friendships. They found that the family members’ relationships may have ripple effects into how the adolescent or adult with ASD perceive socialization and friendships.
After reading through the past literature on different types of interventionists, I believe it is vital to consider siblings of children with ASD as facilitators of friendships. Ferraioli, Hansford, and Harris (2011) mentioned that, “the brothers and sisters of children with ASD have the potential to be very important in the lives of their siblings, both during childhood and adulthood” (pg. 413). They also found that including siblings in treatment for individuals with ASD increases the siblings’ satisfaction with the relationship, enhances the number of responses for the individuals with ASD, and strengthens the engagement level for both siblings. There has been considerable amount of literature connecting the involvement of a sibling in treatment to affirmative outcomes for the individual with ASD, but there are a limited number of studies deriving evidence for using siblings as interventionists over other potential options.

Siblings of children with ASD dream for their brother or sister with ASD to play with them and tend to get very discouraged when their brother or sister does not respond to their requests. This is very common and can be very hard for the siblings of children with ASD to understand. Since the sibling relationship is the longest lasting relationship within the family, fixing these problems while the children with ASD are still young could be beneficial for family outcomes, as the child gets older (Tsao & McCabe, 2010).

Siblings of children with ASD would be ideal candidates to play the interventionist role because research has shown that siblings are great at behavior reinforcement. Behavior reinforcement is important because the children with ASD can generalize their experiences with their siblings to their classmates and peers in the community. Not only are there positive effects for the child with ASD, sibling and
parents benefit as well. The siblings of the child with ASD develop a higher sense of effectiveness and satisfaction from successfully interacting with their brother or sister with ASD. These reactions give the sibling the feelings of closeness in the sibling relationship, especially since they have the perfect opportunity to detect positive characteristics in their brother or sister with ASD. The potential radiating affirmative qualities make the parents’ lives much easier in reference to the improvement in their children’s relationship. The families may now be able to enjoy cooperative social and play activities to build on the skills learned by the child with ASD.

After reading about how effective teachers, peers, and parents can be as interventionists, it only makes sense that siblings should be just as effective or more effective. Past research has focused on the fact that it is beneficial for siblings to be involved with their brother or sister with ASD as ‘interventionists’ and not so much as ‘facilitators.’ I see these two roles in different lights because interventionists are trained to act and teach something in a certain way, but facilitators are not specifically trained. The Merriam-Webster dictionary defines a facilitator as, “one that helps to bring about an outcome (as learning, productivity, or communication) by providing indirect or unobtrusive assistance, guidance, or supervision” (Merriam-Webster’s online dictionary, n.d.). I believe it would also be helpful for sibling facilitators to observe their brother or sister’s interactions with their peers, educate their brother or sister on certain sticky social situations, be present for any questions that may arise, and step in to help with socialization as needed. In order for the sibling of the child with ASD to be an effective teacher for their brother or sister, many factors need to be considered. The factors that may relate to the sibling’s ability to implement the intervention or facilitate socialization...
include the sibling’s age, procedural understanding, and the appearance of difficult behavior by their brother or sister with ASD (Ferraioli et al., 2011).

The Role of Parents

While siblings are focused on working with their brother or sister with ASD, it is important for parents to consider how to foster a positive family environment for their children. Through their parents, siblings understand about the roles they are expected to perform and the contexts for when the role taking needs to take place (Stoneman, 2001). Parents can help reinforce communication between both of their children and step-in to assist as needed. Parents need to keep in mind the potential harmful effects of differential parenting as they balance the relationships between their children. Parents are not capable of always treating siblings in the same family identically, but should be aware of the possibility of being perceived as favoring one child over another. Differential parenting is associated with decreased prosocial behavior, less engagement, increased conflict, and larger competition. Research has documented that this often occurs within families of children with disabilities (Rivers & Stoneman, 2008).

Petalas et al. (2009) found that effective communication between parents and siblings of children with ASD appeared to help the adjustment of the sibling to their brother or sister with ASD. With the parent always being available to talk, siblings were able to get a better understanding of ASD, their brother or sister’s behaviors, and seek support from a parent to share their feelings related to their brother or sister with ASD. Parents can also be another resource for their child with ASD as they practice using skills learned from his or her typically developing brother or sister. Parents may also set up play dates with peers for their children with ASD to practice generalizing skills learned
within the family to other peer environments. Calder et al. (2012) found that children with ASD who had more play dates were more successfully engaged with peers in the school setting and more positive responses to interactions.

Research Questions

Based on the review of the literature, it is clear that the family members play an influential role in the friendships of children with ASD. It is unclear how the families of children with ASD perceive friendships and how they support the friendships of the children with ASD. As a result, this study seeks to examine the following research questions:

1. What do the family members think about friendships? Friendships of the child with ASD?

2. What do the family members do to assist the child with ASD with his or her friendships?
CHAPTER 3

METHOD

Participants

Families were recruited through support groups for parents and caregivers of individuals with ASD in the greater Atlanta area from a listing of support groups on the Autism Speaks website (Autism Speaks, 2015). A few of the families were also recruited through the process of word of mouth from the researcher’s personal connections. Five families that have a child with ASD took part in this study. A mother and sibling of the child with ASD from each of the five families participated in the study. If there was more than one potential sibling participant in the family, the mother decided which sibling would participate in the study and was given guidance to try to pick the one that would be most familiar with the friendships of the child with ASD (or who could better relate to the interview questions. The sample met the following criteria: the family has at least two children, one of whom has an ASD, the child with ASD is in between the ages of 5-16 years old, the sibling of the child with ASD is in between the ages of 7-16 years old, and the mother is at least 18 years old. The interviewer relied on parent reports to determine if their child has an ASD diagnosis along with an IEP in place.

Table 1 shows the demographic characteristics of the parents that participated in this study, who turned out to be all mothers of a child with ASD. All of the mothers were white (non-hispanic) and four of the mothers were married, with one being separated from her husband. There was a wide age range between the mothers, with the youngest
being 35 years old and the oldest being 60 years old. They all had at least two children, three of the mothers had three children, and one mother had six children. Table 2 shows the demographic characteristics of the siblings that participated in this study along with the demographic characteristics of their brother or sister with ASD who did not participate. All of the children with ASD were males. Four of the children with ASD had been diagnosed at a young age, but one child with ASD was diagnosed less than one year ago. Four of the siblings that participated were younger than their brother with ASD and only one sibling participant was the older sibling in their sibling dyad. Three of the sibling dyads were male-male with two being female-male.
Table 1

Demographic Characteristics of Mothers

<table>
<thead>
<tr>
<th>Family Number</th>
<th>Age</th>
<th>Race/Ethnicity</th>
<th>Marital Status</th>
<th>Education Level</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>35</td>
<td>White (non-Hispanic)</td>
<td>Separated</td>
<td>College degree</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>46</td>
<td>White (non-Hispanic)</td>
<td>Married</td>
<td>College degree</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>45</td>
<td>White (non-Hispanic)</td>
<td>Married</td>
<td>Graduate degree</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>60</td>
<td>White (non-Hispanic)</td>
<td>Married</td>
<td>Some college, technical school</td>
<td>6</td>
</tr>
<tr>
<td>5</td>
<td>61</td>
<td>White (non-Hispanic)</td>
<td>Married</td>
<td>College degree</td>
<td>3</td>
</tr>
</tbody>
</table>

Note. The demographic characteristics of the mother participants are presented above. This information was obtained through the Family Information Form (Appendix D). Age = mother’s age (in years), Marital status = marital status at the time of the interview.
Table 2  
Demographic Characteristics of Siblings

<table>
<thead>
<tr>
<th>Family Number</th>
<th>Sib age &amp; gender</th>
<th>Sib w/ ASD age &amp; gender</th>
<th>Age of ASD diagnosis</th>
<th>Location of ASD diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>9, male</td>
<td>10, male</td>
<td>10</td>
<td>Clinical psychologist</td>
</tr>
<tr>
<td>2</td>
<td>8, male</td>
<td>12, male</td>
<td>4</td>
<td>Clinical psychologist</td>
</tr>
<tr>
<td>3</td>
<td>10, female</td>
<td>13, male</td>
<td>5</td>
<td>Stanford Uni. Hospital</td>
</tr>
<tr>
<td>4</td>
<td>14, male</td>
<td>7, male</td>
<td>2</td>
<td>Children’s Hospital Boston</td>
</tr>
<tr>
<td>5</td>
<td>9, female</td>
<td>14, male</td>
<td>6</td>
<td>Clinical psychologist</td>
</tr>
</tbody>
</table>

Note. The demographic characteristics of the sibling pairs are presented above. This information was obtained through the Family Information Form (Appendix D). Sib age & gender = age (in years) and gender of the sibling participant, Sib w/ ASD age & gender = age (in years) and gender of the sibling with ASD, Location of ASD diagnosis = where the child with ASD received his diagnosis of ASD, Stanford Uni. Hospital = Stanford University Hospital.
Procedure

This study implemented qualitative research methodology to explore families’ perceptions on friendships and ways they assist with friendships. With semi-structured interviews containing open-ended questions and probes, this study was able to obtain more in-depth information from the mothers and siblings of the children with ASD. The semi-structured interviews were scheduled in advance when mothers verbally agreed to participate in the study. The interviews took place in either the home of the family or at the Institute on Human Development and Disability on the UGA campus. To begin the study, the interviewer read over the Parent Consent and Permission Letter and gained informed consent (Appendix B) from the mother to participate in the study as well as the sibling of the child with ASD. The mother gave consent for their child, the sibling of their child with ASD, to be involved in the interview. After, the mother filled out a Family Information Form (Appendix D) to provide demographics and information about the diagnosis of the child with ASD. Then the mother was interviewed and the interview was audio taped. The mother interview questions can be found in Appendix E. The mothers were asked about their children, their children’s relationships (with each other, friendships, and mutual friendships), their family environment, and the ways their family assists the child with ASD with friendships. The interview questions also contained probes to assist in getting the information from the mother in stories and examples as well.

Afterwards, during the same visit, the interviewer met with the sibling of the child with ASD. The study was explained to the child and assent was gained from the participant using the Youth Consent form (Appendix C). This provided the siblings with
a better understanding of what the research study is about, why it is important, and the roles they will have during the study. The sibling was then interviewed and the interview was also audio taped just like the mother’s interview. The siblings were asked details about themselves, their brother or sister with ASD, their relationship, their understanding of ASD, their friendships, the friendships of their brother with ASD, and the ways that they assist their brother with ASD with friendships. A full list of the sibling interview questions can be found in Appendix F.

**Interviews**

The interview questions used for this study were self-created instruments since there were not any instruments in the literature that focused on the research questions of this study. The interview questions were first developed by the researcher, and then reviewed multiple times by the researcher’s university professors. All of the semi-structured interviews were conducted face-to-face in an environment that was comfortable for the participants. The mother interviews lasted approximately 45 minutes to an hour and the sibling interviews lasted around 20 to 30 minutes. For all of the interviews, only the participant and the researcher were present in the room where the interview was being held. This way none of the answers of the mothers could influence the siblings and vice versa. This allows provided the participants with a sense of privacy in case they would not talk about certain situations with other family members present.

**Data Analysis**

Since all of the semi-structured interviews were audio taped, once the interviews were complete, the researcher transcribed the data verbatim for analysis. By transcribing the interviews, the researcher obtained written documentation of the interviews and was
able to elicit themes from the interview data more clearly. After the interview data had been completely transcribed, the researcher begun to look for commonalities across the interviews with hopes that there was obvious themes across all of the families’ responses to the interview questions. The qualitative analysis software used for the study was NVivo. NVivo is a qualitative data analysis computer software package produced by QSR International. The researcher coded for themes relating to friendships with broader themes in the beginning with the results containing specific themes that emerged. Powerful quotes and examples from the transcribed data were also coded to help show meaning and emphasis for the themes found within the data.
CHAPTER 4

RESULTS

The researcher discovered, in regard to the research questions, three overarching themes that emerged from the qualitative data, which were used as focused codes: (a) friendships of children with ASD, (b) how siblings assist with friendships of children with ASD, and (c) how parents assist with friendships of children with ASD. The data in each of these three main codes is divided into sub-codes for organizational purposes. Data supporting each of the following codes will be discussed in the following sections.

*Friendships of Children with ASD*

One of the most prominent themes throughout the interviews was detailed information about the friendships of children with ASD. When asked about the friends of the child with ASD, mothers went into detail with stories and examples. This question puzzled many of the siblings during their interviews, like they were unsure how to describe the friendships of their brother, so most of the examples in this theme come from the mother interviews. This theme includes some descriptions of how the children with ASD view friendships, characteristics of their friends, and how they interact with friends. This theme relates to the first research question, how the family perceives friendships. The sub-categories below discuss in further detail how the families exhibited this theme and the connections between the families’ responses.

*Acceptance*
Acceptance is a crucial aspect to obtain before a friendship occurs between two individuals. Each family described acceptance in some form when talking about the friendships of the child with ASD. It was interesting to hear how the concept of acceptance varied across the children with ASD. Two out of the five mothers spoke about how their son with ASD wanted to be accepted by their peers but was not. One mother described her son’s yearning to be accepted by saying:

He craves friendships. Like he needs them. He needs people to like him. He just wants to be accepted and for them to love him and be his friend. He just desperately wants friends. He just wants a friend to love him and to hang out with, desperately, but he can’t get it.

Another mother described how her son with ASD wanted to be accepted by using the example of how her typical developing children get invited to numerous birthday parties but he does not and he recognizes it. This mother spoke about how her son with ASD did not understand why his brothers were getting to do things with his friends that he isn’t getting to do, but she related it back to how he was unintentionally unaccepted by his peers by stating, “He has not been invited to any birthday parties but I do not think it is because any of the kids in his class do not like him, I think they just do not think about it.”

A few of the mothers spoke about how each of their sons with ASD are only accepted by those they are close with, especially those they have grown up with. One mother gave an example of this phenomenon by describing how friends younger than her son with ASD accept him:
He gets along really well with a 9 year old and an 11 year old. They can play. I think it is because he knows he is older and they look up to him. They have known him their whole life so they do not think there is anything weird or different, they just listen to him.

It is obvious from the examples above; some children with ASD recognize that their peers do not accept them and some of them want to be accepted. On the other hand, there are some children with ASD who are not accepted by their peers, but this is not of concern for them. A mother talked about how her son felt this way by saying, “He doesn’t want to play with anyone. He has no desire to play with anybody. He just wants everyone to leave him alone.” After recognizing that the concept of acceptance could vary from child to child with ASD, like with typically developing children, it is also important to keep in mind that some children with ASD do feel accepted and are accepted by their peers. For the participants in this study, this was not the case.

*Being friends with another child with a disability*

It is important to note that three of the mothers talked about their son with ASD being friends with at least one other child with a disability, with two being another child with ASD and one with ADHD. When talking about how their son befriended another child with a disability, the mothers all talked about how they thought it was because their sons could relate better to someone similar to them. One mother became very emotional when describing how the friendship of her son and another boy with ASD, not just because she was happy for her son but also because she was happy for the friend and the friends’ parents:
He has 1 friend who has ASD, who is a year older than him, and it is hysterical. The friend was very late diagnosed, but if you tried to talk with him, he just never spoke. He is so quiet. The first time we put them together, I was at the house meeting the parents as well and you could hear the boys upstairs. Talking is not a problem for my son by the way, but you could also hear his friend talking too. His mom was like, “Oh my gosh, he feels comfortable already!” His parents were crying, they had never seen that. It was way cool. They are very good friends.

Another mother also highlighted how her son with ASD felt comfortable when around his friend with ASD, “The boy was in the 5th grade and my son was in 2nd, so he kind of led my son, and he led him in directions that my son liked to be, so he felt safe.”

Not only were the words comfortable and safe used to describe the friendships between the two children with disabilities, similar was another characteristic that emerged from the interviews. These friendships seemed to be rewarding for the mothers who described them because they knew their son was a friend with someone who was in a similar situation. The siblings did not talk about their brothers being friends with other children with disabilities, which could mean they did not realize their brothers were friends with other children with disabilities.

*Interact with others when interested*

Many mothers spoke about how their children with ASD would choose to interact with peers when they were interested in what the peers were doing or when the peers could engage in something the child with ASD was interested in. The mothers spoke about various situations in which their son with ASD may interact with others when interested, such as in the classroom at school or play dates at home. One mother received
a report from her son’s teacher saying that he was doing better interacting with the groups of boys because he knows what his peers are interested in. For example, when his peers talked about pokemon, her son would engage in conversation with his peers because he would have something to talk about since he was also interested in pokemon. Another mother spoke about how her son played with his siblings and his siblings’ friends when interested in what they were doing:

If they say that they are going to the trampoline, he is all over that. He will get outside with them and if anyone suggests a game of tag, he is there. He loves to play tag. He loves to run with them. All of the boys that come over here on a regular basis know that he is a little different and there are certain things that you cannot do to him or you will set him off.

This mother continued to talk about how sometimes the interests of her son do not match up with other children his age. She found this to be problematic when it came to her son making friends his own age. She said:

I think he automatically gravitates towards adults. I think it is just because all of the stuff he talks about, kids are not going to be interested in that. They are not going to want to know the per capita income of Brazil. That is the kind of stuff he is interested in—history, science, and random facts.

Another mother spoke about how her son is very against playing sports because of the sensory experiences associated with them and how he uses his dislike as an influencer for his friendships:

Most of his close friends are not super sports enthusiasts, some of them play one sport or so, but that is not their primary thing in life. Those who are super sports
oriented, he is not friends with. He can talk about it, but that is where I see the big dividing line between him and his peers. He will say people who are really involved in sports are generally not his closest friends, sometimes because there is not enough in common, other times some of them can just be a little more harsh because he cannot throw a football as well as they can.

This result can assist family members or other individuals who attempt to provide socialization opportunities to children with ASD by serving as a reminder to focus on the interests’ of the child with ASD. Although this may not impact every child with ASD, it was prevalent in this study’s participants that children with ASD engaged in conversation and interactions when they focused on their own interests.

_Unable to relate to age groups other than his own_

Another interesting finding that was common among multiple families was that the child with ASD was able to relate to multiple age groups, not just peers his own age. Since it is not as common for children to be able to relate to individuals of many different ages, this is something important to keep in mind. By focusing on the fact that children with ASD could develop friends in many different appropriate age brackets, this could broaden the opportunities for friendships and may help support those that have trouble relating to individuals their own age. A few of the mothers shared stories of how their sons related to multiple age groups, but most of the time their sons were able to relate to different ages because it was related to what their shared interests were. For example, one mother explained how her son relates to older children at their church, “He is friends with the older college students who intern at our church. He does the AV equipment at our church, he is the only one in 7th grade helping with that.” This boy’s sister also talked
about how he can relate to a lot of different ages as long as it is relating to certain topics he is interested in.

Additionally, a mother echoed this by saying that her son likes to engage with others by talking about topics that are not of interest to individuals his age. She shared a time where her son talked about a topic that was not age appropriate during a play date, “It was an outdoor play date with the rest of the Mom’s Club and most of the kids that were going to be there were like under 8. He wants to start talking about Hitler and Nazi Germany.” She talked about how because of his higher order of thinking and advanced interests; he was able to relate better to children older than him as well as some adults as well.

*How Siblings Assist with Friendships of Children with ASD*

Another main theme that emerged from the data was how siblings assist their brother with ASD in relation to friendships. All of the families discussed ways in which the sibling assisted the child with ASD with friendships, either actively or passively. The mother participants provided clear examples of how the siblings assisted, while the sibling participants provided more stories examples. More than one family expressed each of the sub-categories explained below.

*Introducing brother with ASD to his or her own friends*

There were two mothers that believed that the biggest way that the sibling assisted in the friendships of their sons were that they introduced them to his or her own friends. In both of these families, the child with ASD made the majority of his friends because of his sibling bringing them over to play and interacting with them outside of the home. This was even the case if there was a gender or age difference between the siblings. One
mother described this phenomenon by saying, “The thing that my daughter has done that has helped my son the most is have her friends over here so that he gets that exposure to people.” The siblings did not only provide the children with ASD an opportunity to make friends by introducing them to their own friends but also just offered pure exposure to people to practice interacting with others.

One sibling talked about how she has introduced her brother to her friends’ siblings. This is another way siblings’ friends were considered to be a helpful factor in relation to the friendships of the children with ASD. The sibling said:

My brother really connects with my best friend’s little brother because they both love video games, so that works out. It is funny because where we use to live; my best friend’s brother was my brother’s best friend too. I guess you could say we are kind of friends with the same friends.

This finding was found among families where the siblings were no more than five years apart in age, but in both cases, sisters assisted their brothers with ASD by introducing them to their own friends. A mother explained how when another sibling pair came over to play with her children that the boys and girls matched up no matter what the ages were:

If there is a sibling, it is almost always the boy for my son and the girl for my daughter. I don’t think, even if the ages are mixed when we have friends were the girl is older and the boy is younger, you still have the boys together and the girls together. They will sometimes, depending on the weather and how much time we have, all go out and jump together on the trampoline. There are also some active Wii games that they like to do together as well.
This mother emphasized the importance of this type of group interaction for her son with ASD and how it made a difference in his number and quality of friendships. The two mothers that credited the siblings mentioned that this invaluable assistance has taught their sons with ASD more than the siblings could imagine or realize.

**Involving brother with ASD based on what he is interested in**

A few families explained how the siblings have a great understanding of what their brothers with ASD are interested in doing, how they will interact with them and others when they are engaging in something that they enjoy. These siblings in particular have figured out when they should invite their brother with ASD to join in their play activities because they know they will participate if it is something they enjoy doing. One mother described how her younger son includes her son with ASD when he has friends over to visit:

He will ask my son with ASD if he wants to come with him. He is really good about that, especially if he knows they are doing something that he really enjoys doing. He will say, “Hey, we are going to go over to the trampoline, or we are going to ride our bikes, or we are going to go outside and play tag,” so he is really good about that.

The families that talked about how they used this method normally utilized it when children were visiting their home for play dates. This finding tells us that these siblings are very in tune to their brothers’ interests and understand that they will engage with others when they do things that they enjoy. This is something that may siblings do without realizing it, but it could be helpful for siblings that have trouble engaging their sibling with ASD in play or conversation.
Speaking up to help others understand their sibling with ASD

Children often do not understand why some children act differently than them, which could lead them to be mean and make fun of those children that they perceive as “different”. Like many other children, this happens to children with ASD as well. Some of the siblings in this study are aware of how other children may treat their brother with ASD differently and feel the need to speak up to help them understand why their brother is acting a certain way or talking about a specific topic. A mother explained how her younger child is aware of how other children may pick on his older brother with ASD, “They kind of understand that if they are in a group of friends and their friends start to make fun of my son with ASD, they will call a stop to it. They are both very careful about that.”

A sibling shared how she educates other children on her brother’s interests when they get aggravated on him being fixated on a topic for a longer period of time:

We will be on the trampoline or something and my brother likes to play video games more than just going outside for fun. He will ask some random kid, “Do you want to go play this game?” The kids will be like, “No, we are jumping,” because they probably just like jumping on the trampoline or playing, but my brother doesn’t. The kids will get made at him because he will just keep asking. I will say to the kids that he just wants to play because he does not like to jump or anything and I will remind them not to say that.

This sibling says that she often helps other children and friends understand why her brother is acting a certain way, especially when they are in a group setting, without bringing up the term autism. This assists her brother with ASD by helping him avoid
conflict with others and also helps the other children not label him or view him as
different because they have a better understanding. For instance, in the above example,
the sibling says that her brother doesn’t like to jump because he wants to play video
games. In being a voice for their brothers with ASD, the siblings can provide their
brothers with more opportunities for friendships.

Passive acceptance of assisting sibling with ASD

A few of the siblings exemplified passive characteristics of acceptance that
showed that they were unsure they could do anything to assist their brother with ASD.
One mother explained how her younger son has never known his brother with ASD to be
any different, so he does not recognize that he could assist in any way. In both cases that
the sibling was a younger sister, they talked about how they did not try any direct and
obvious methods for assisting their older brother with ASD. One of the younger sisters
said, “Mostly, I won’t help him make friends because he won’t ask me to help.” A
different younger sister went into further detail by saying:

   He may just feel like it is a lot of pressure to have someone else especially if I am
two years younger than him and I am sticking up for him. I am a girl. People are
going to be making fun of him.

   Another mother and sibling from the same family talked about how the siblings
just leave their brother with ASD alone, but still look out for him when needed. The
sibling explained that, “We try just to leave him alone because that is when he seems the
most calm. When he is forced in a situation that he does not like being in, that is when he
does everything he can to get out of it.” This sibling believed that there was not much he
could do to assist his brother with ASD besides talk with the other children he is around.
The mother said that the siblings do not try to engage him in play or interactions with others because they believe it will make him more upset in the end.

Siblings that exhibited this passive acceptance explained this trait by saying that they did not know their brother to be any different, their brother did not ask for help, or they did not think there was any way that they could help the child with ASD except leave him alone. These siblings all mentioned that they recognized that their brother might be able to use some assistance socially in certain instances, but did not always use active strategies to assist. If they did use active strategies, such as invite their brother to play with them, they did not always recognize that they were assisting their brother or characterize it as being helpful when asked.

*How Parents Assist with Friendships of Children with ASD*

The last overarching theme to come out of the data was how parents assist with friendships of their child with ASD. All of the mother participants mentioned some way that they were actively assisting their child with ASD with social skills and/or friendships. Not only did the mother participants explain how they assist their child with ASD with friendships, but also some of the sibling participants recognized how their parents assisted their brother or sister with ASD as well.

*Seeking out socialization opportunities*

The most prevalent way that parents assist their children with ASD is by seeking out socialization opportunities. The mother participants spoke about how they involve their son in extracurricular activities, set up play dates, and sign them up for local social skills camps or groups. A few mothers spoke about how they helped their son find a hobby outside the home that provided them with an increased level of peer interaction,
such as church youth groups or boy scouts. One mother addressed the fact that she is shy in social interactions, so she really had to step out of her own comfort zone to assist her son with ASD in finding socialization opportunities. She said, “He gives out his phone number and stuff. I made them little cards with my number on it, because I was like, “Okay we can do this!” Since I am not very social either, I am very shy. We can do it together! I just feel different from the other moms, so it is hard to adjust to that too.”

Another mother talked about her own personality and how it helped her easily seek out the socialization opportunities for her son by saying:

The benefit of being a scheduled and organized person is that if you really want to make sure your kids get together with other kids, you have to be organized and I am always the one that is contacting my friends. “Hey what about this time block? What about this? Can we do this? I will come pick up your kid or we can meet here.” Whatever it is, I mean I am not saying it is all about me, but I will make it happen. You have to! It is not like the others do not want their kids playing with my son, but they just do not make it happen as well, so I make sure that it happens.

The mothers shared stories of play dates that were successful as well as unsuccessful ones. They talked about how they only set up ones with other children that they predicted to go well, but sometimes a few unforeseen circumstances made the get together to go the wrong way. For example, one mother shared a story of how her son was put in a hard place when he had a new friend come over that she arranged:

The kid that came over just wanted to play video games and they were video games that we do not allow our son to play. Also, my son was taking a personal
sabbatical from video game playing, and so the kid just kept pushing my son to play video games. My son was like, “Really?” and the kid said, “Well you can just watch me play.” My son stood up for himself and said, “No that is not what I am doing!” I had set that one up and it only lasted two hours, but I am really careful with them being as successful as possible. If I do not know if it is going to go really well, then I would always rather it leave good and have it again than rather it go bad.

Another mother explained how she seemed to set up the play dates most often when her son was feeling down about his friendships. She said that, “He has had a couple of times when he says, “I don’t have any friends.” So when those kind of things come up, I try to make plans to do something with other families.” When asked, the siblings also recognized that their parents went out of their way to set up play dates for their brothers with ASD. One sister said that both of her parents “try to introduce him to new friends, if they know so and so has a boy who is around my brother’s age and they think that they will connect, then they try and get them together.” It was noticeable that many of the siblings recognized the importance of their parents reaching out to others to assist their brothers with ASD.

Some of the siblings also discussed how their brothers were involved in social skills groups and how their parents found this opportunity for their brothers as well. Three mothers spoke about how they found local social skills groups in their area to go to at some point in time, but all of them mentioned that there are not enough of these resources available in the community. One mother talked about how she is sending her
son to a social skills camp this summer but she has at least an one hour commute to the camp, which will be tough on the entire family system.

*Setting children with ASD up for success before interacting with others*

It was common across four families that the parents talked to their children about play dates and interacting with friends beforehand or if they were having a hard time with certain peers. Guidelines and parameters were normally discussed if the mother was leaving their son at another child’s house or if a friend was coming over to their house. When mothers were around while their sons played with other children, they talked about how they watched for body cues from their son to know if the play date was going successful and if they needed to intervene. A few mothers talked about how they get nervous not being able to monitor their son with ASD when he travels to other houses for play dates saying that he can be overwhelming for parents who are not use to him. Some examples of guidelines that mothers shared that are discussed beforehand are remembering his manners, not being super loud, giving other children a chance to talk as well, some conversation topics are not as appropriate as others, and remembering to give others’ their personal space.

One of the mothers shared how she often asks her son questions to prepare him for a visit with his friends such as, “What are the three things that you are going to have planned? What is something else you can do besides video games? What are you going to talk to them about?” She said that she often had these conversations with both of her children so that her son with ASD did not feel like he was the only one that needed this guidance. The sibling mentioned that these conversations happen but she talked about how she knew that they happened to benefit her brother. She said, “We use to talk to my
brother before he interacted with friends a lot. We would just ask him question like, “What do you always do when you eat? You say please and thank you!” Now that he is older, we do not as often because he understands and is more well behaved.”

One family use to often implement role-playing with the child with ASD was younger and struggling with interacting appropriately with peers. The mother shared an example of how they utilized role-playing:

One example of role-playing we have utilized in the past is when the kids received birthday cards in the mail from grandparents out of town. I always make them call their grandparents and thank them. My girls will get on the phone and the grandparents will ask about school, whatever is going on in their life and they will have a conversation that goes both ways. So then my son will call and say, “Hi!” Then it is silent, so then I was like, “Okay now we are going to practice before you call now.” We will role play as a family, “Okay what if grandpa asks you what you did in school today or how is school going? What are some things you can say back to him instead of just “Hi!””

In all cases, the parents led these types of assistance for their son with ASD, but it is important to keep in mind that the siblings were normally just as involved in the conversations beforehand and role-playing situations. This is crucial to remember the impact that siblings can have on influencing the social skills of children with ASD with and without their parents’ help.

Using positive reinforcement

Two mothers discussed how it has always been imperative for them to remember to use positive reinforcement when talking with their sons about their social
development. This was addressed when asked what they have done in the past that was not successful at supporting their son with ASD. One of the mothers honestly admitted her mistake with not using positive reinforcement before:

The biggest thing that I have caught myself doing that I really try not to do anymore is using negative reinforcement. I have to give him positive reinforcement because if I catch what he is doing wrong, and I am negative, it will just send him spiraling down. Even in school with his teachers, if he does three things during the day and one of them was good and I pick that one great thing to make a big deal out of it, the next day he will do that one great thing at least three times. So for me, it was just easy to say, “You are doing that wrong,” “Don’t sit like that,” or “Don’t move like that.” That does not help him. For me when I am like, “Hey, when you were sitting there like this with your legs crossed, that was so good!” and make a big deal out of it, he will just repeat the good behaviors.

This is something that could be a great reminder for all individuals that interact with children, much less children with ASD. When focusing on and cheering for the positives, children will have higher chances of altering their behavior to gain that praise in further situations.
This study explored how family members of children with ASD perceived friendships, the friendships of the child with ASD, and how they assisted the child with ASD with friendships. The results of this study show that there were some similar experiences of the five families that participated, but no two families had the same experiences and supports when it came to the friendships of their child with ASD. The following discussion has been organized to address the research questions, the past literature, and how it relates to the coordinating results of the study.

All of the participants together, the mothers and siblings, provided copious amounts of information about friendships and the friendships of the child with ASD in their family. As mentioned earlier, Calder et al. (2012) noted that children with ASD generally have less intimacy and emotional connectedness within relationships, but that children without ASD yearn for companionship, intimacy, and closeness. One of the main themes of friendship in this study, acceptance, emerged as a prevalent feeling or characteristic that many of the participants’ family member with ASD exemplified when it came to friendships. Many of the mothers spoke about how their child with ASD yearned to felt accepted and wanted by his peers. It is easy to assume and stereotype those individuals that have greater hard ships with communication and relationships may avoid those situations, but in actuality, that is not always the case.
It is common for individuals with any disability to feel and experience stigma and social isolation, including individuals with ASD (Salmon, 2012), and the mothers that addressed how their sons with ASD wanted to be accepted, mentioned that their sons felt stigmatized or isolated at some point during their life, or was currently still experiencing it. To overcome these negative feelings, some of their sons with ASD worked around the stigmatization by becoming friends with other children with a disability. This is understandable because they found companionship with another child their age that understands how they feel and they can better relate to. Some of the children with ASD may have experienced this, but utilized strategies to broaden their amount of interactions with others, such as being more successful with socializing with people outside of their age and interacting about a topic of interest. For the children with ASD that were able to relate to individuals older and younger with them, it was not always be appropriate for them to start a consistent friendship together, but the child with ASD was still able to practice crucial social skills that could be implemented within other relationships in their lives.

The autism spectrum itself greatly affected all of the results from this study, as expected, but more so in the friendships portion. During the mother interviews, the mothers shared the difficulties experienced by their son with ASD when it came to friendships. The most common difficulties shared were spontaneous appropriate conversations, eye contact, and personal space. One mother explained how her son has never had a true friend, has never been interested in interacting with others, and she was not able to relate to most of the interview questions. Her older son that participated in this study also was unsure how to appropriately answer some of the interview questions at
times as well. This is the only family that experienced this in the study. Since their family member with ASD seemed to face adversity more often with friendships, the autism spectrum affected how they responded to questions they were asked.

Many factors are at play to influence the dynamics within the family system, including the autism spectrum, but age and gender made some siblings more ideal than others to serve as facilitators of friendships for their brother with ASD. Some of the age ranges of the sibling pairs did not allow for the facilitator role to be feasible or realistic. For instance, one pair had a seven-year age difference. With these siblings, they may not interact with the same groups of peers or interact with others in the same settings. In the two families were the typically developing siblings were younger sisters, gender influence factors were present in the interview question responses. The younger sisters explained how they did not offer to assist their brother or step in certain circumstances because they did not want to embarrass their older brother.

This relates back to gender influences because the sisters recognize that their older brothers may seem “weak” in their peers’ eyes if their little sisters have to step up for them. In some instances, this may lead to the sibling not being a great option as a facilitator because the siblings’ assistance should never alter the needs or happiness of the child with ASD. It was obvious that the sibling pairs that were the same gender and less than five years apart, some facilitator roles of the sibling were already taking place without it being called that.

Following the interviews, most participants, especially the mothers, showed signs of recognizing the potential impact that the sibling could have on their son with ASD. If they were unaware of this before the study, this study helped them highlight and focus in
on the ways that their other children assist their son with ASD and how they can continue in the future. Since most of the mothers did mention that they included the typically developing siblings in the conversations before play dates and role-playing practice with their son with ASD, this helps lessen their chances of falling into differential parenting practices. By doing this, the parents also create a teamwork feeling as a family to assist the child with ASD, which could also spillover into other areas of their lives. Also by including the typically developing siblings, the sibling relationship satisfaction may increase as the engagement level for both siblings is strengthened (Ferraioli et al., 2011).

The autism spectrum also affected how much the family members felt like they needed to assist the child with ASD. The mothers also mentioned how the ways that they assisted their son with ASD altered over time as their son got older, more mature, and more aware. Their ways of assisting also changed with trial and error to figure out what was effective and not as influential, which highly depends on the child, their personality, and their social frustrations associated with their disability. Many of the mothers discussed the fact that they also had to step out of their own comfort zone to assist their son with ASD, which is huge because Orsmond et al. (2004) emphasized the importance of the mothers’ involvement with the socialization activities of children with ASD.

Many of the mothers talked about how the socialization opportunities they sought out for their children were the children of their own friends, which Orsmond et al. (2004) commended to be a great practice. This way, their sons with ASD will be able to see their parents interacting with their own friends, influence the way they perceive friendships, be able to model some of their mothers’ sustaining and maintaining friendships behaviors, and feel more welcomed when interacting with children of their parents’ friends. This
also is a comfort for the mothers of the children with ASD because they do not have to “worry” about their sons when they are interacting with others outside of their home. Four out of the five mothers emphasized the importance of setting up play dates for their sons with ASD, which has been found in past research to positively impact other areas in their lives as well, such as the school setting where they are more successfully engaged with peers and have more positive responses to interactions (Calder et al., 2012).

Limitations

There were some limitations to this study that should be addressed. The first limitation being that there was a small sample size for this study. Although there were only five families that participated, the sample was overall fairly diverse. Obviously none of the families shared the same experiences with having a family member with ASD, but the variance associated with the autism spectrum was very well portrayed in the families that participated. The only commonality shared by all of the families is that the child with ASD in each family was a boy. Many of the brothers with ASD were also older than their siblings that participated as well, which lead to an overrepresentation of older brothers. Another limitation related to the sample was that all of the participants were recruited from support settings. This is a limitation because these families were already seeking support before they were recruited to participate. It is also important to remember that due to a limited number of participants and the qualitative methodology, generalization of the findings to other families of children with ASD is limited.

Conclusions

The purpose of this study was to look at how friendships are perceived by parents and siblings of children with ASD and attempt to capture how the parents and siblings
assist the child with ASD in their friendships. In summary, professionals who attempt to support the social skills of children with ASD should consider using siblings and parents as interventionists and facilitators when appropriate for the family system. There are many factors at play that make family members appropriate candidates, but family members can receive the strategies implemented by participants in this study as a starting point. This study may also provide family members with a confidence booster to help them understand and highlight how they already assist the child with ASD with friendships. If this is the case, this study may provide family members with the ignition to brainstorm how to build on the strategies already in process and what they can do to assist in the future.
REFERENCES


RESEARCH PARTICIPANTS NEEDED

We are searching for families affected by autism spectrum disorders (ASDs) to participate in a UGA research study!

About the study:
The study consists of primary caregiver and sibling interviews with questions about the family, friendships, friendships of the child with an ASD, and what the family does to support the friendships of the child with an ASD. Interviews will last 40 – 50 minutes.

Why participate?
The goal of the study is to inform future supports for families of children with ASDs and communicate the importance of the naturalistic family environment as well as family member interventions for children with ASDs.

Who can participate:
Families are eligible to participate if...
- There are at least 2 children in the family, with one being formally diagnosed with an ASD
- The child with an ASD is in between 5-16 years old.
- There is one other child in the family between 7-16 years old that may be interviewed for the study.
- A primary caregiver will available for an interview.

If your family is interested in participating or if you have any questions, Please contact Amanda Detraz.

amandadetraz@gmail.com
(404)202-7927

This study is being conducted by Dr. Zolinda Stoneman. You can contact her at zo@uga.edu or by calling 706-542-4827
APPENDIX B

PARENT CONSENT AND PERMISSION LETTER
We are asking you and your child to take part in a research study, *Siblings and Friends of Children with ASD*. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called “informed consent.” A copy of this form will be given to you.

**Principal Investigator:**
Zolinda Stoneman  
Institute on Human Development & Disability  
Phone: 706-542-4827  
Email: zo@uga.edu

**Purpose of the Study**  
The purpose of this research study is to look at how friendships and social skills are perceived by parents and siblings of children with ASD. We hope that the main study will help advance inventions and resources for families of children with ASD.

**Study Procedures**  
If you volunteer to take part in this study, you and your typically developing child will be asked to do the following things:

A researcher will interview you and your child individually at your home or at a location that is convenient for your family. You will be interviewed about your children, their sibling relationship, their individual friendships and social skills, and how you assist with friendships of your children. Your interview will be audio taped and will last approximately 40 to 60 minutes.

Afterwards, the study will be explained to your child and they will be given the opportunity to assent to participate in the study. This will provide the siblings with a better understanding of what the research study is about, why it is important, and the roles they will have during the research study. Then, your child will be interviewed about their interests and friendships, their sibling with ASD and their sibling’s friendships, and how your child helps the sibling with interacting with others. The child’s interview will be audio taped lasting approximately 20 to 30 minutes.
Risks or Discomforts

We do not anticipate any risks from participating in this study. The study is not expected to cause any harm or discomfort, either to the parent or the child. The interview with the child will be terminated if the child becomes upset, tired, or does not want to continue. If you or your child should be disturbed by any of the questions, you can choose not to answer those questions.

Benefits
The benefits that may be expected from your participation are:
The participants will have a chance to engage in an enjoyable conversation about their family and the child with an ASD by talking about their experiences and telling memorable stories. The information gained from the study will be used to develop materials for families of children with ASD focused on social interactions and friendships.

Audio recording
Audiotapes will be transcribed and coded. They will be erased after final data analyses for the study have been completed.

Privacy/Confidentiality
All individually identifying information collected about your family will be confidential and will not be released in any individually identifiable form without your prior consent, unless required by law. Abuse or neglect revealed during the research is required to be reported. All files and audiotapes related to your family will be coded by a number assigned to your family – your names will not appear on any study materials. All identifying information will be removed when the tapes are transcribed. All information will be kept in a locked, secured location. Only the researchers will have access to this information.

Taking part is voluntary
Participation is entirely voluntary. You and your child can refuse to participate or stop taking part at any time without giving any reason, and without penalty or loss of benefits to which you are otherwise entitled. If you choose to withdraw from the study, you can request to have the results of your participation, to the extent that it can be identified, removed from the research records or destroyed.

If you have questions
The investigator will answer any further questions about the research, either now or during the course of the project. Information concerning the research project can be obtained by calling Dr. Stoneman at 706-542-4827 or sending an email to zo@uga.edu.
Research Subject’s Consent to Participate in Research:
I understand the research procedures described above. By signing this form, I am
agreeing to take part in this research study. I am also agreeing for my child
__________________________ to participate in this study.

Your signature below indicates that you have read or had read to you this entire Parental
Permission Form and have had all of your questions answered.

Your Child’s Name: _____________________________________________________

Your Signature: ________________________________ Date: ______________

Your Printed Name: _____________________________________________________

Signature of Researcher: ________________________________ Date: ______________

Printed Name of Researcher: ________________________________________________

______________________________ ______________________________
Signature of Investigator Signature of Parent

Telephone: 706-542-4827

Email: zo@uga.edu

Date: _________________________

PLEASE SIGN BOTH COPIES. KEEP ONE AND RETURN THE OTHER TO THE INVESTIGATOR.

If you have any questions or concerns regarding you or your child’s rights as research
participants in this study, you may contact the Institutional Review Board (IRB)
Chairperson at 706-542-3199 or irb@uga.edu.

________________________________________
APPENDIX C

YOUTHASSENT FORM
Youth Assent

Siblings and Friendships of Children with ASD

We are doing a research study to learn more about friendships and social skills of children with autism spectrum disorders. We are asking you to be in the study because you have a brother or sister with an autism spectrum disorder. We want to learn more about the friendships and social skills of your brother/sister and talk with you about your own friendships, your brother/sister’s friendships, your sibling relationship, and how you assist your brother/sister. If you agree to be in the study, you will allow us to talk with you and ask you questions about yourself, your brother/sister, and your family. Being in the study may help researchers provide families like your own with resources. We also hope you will find enjoyment in telling us stories about your family and your brother/sister.

You do not have to say “yes” if you don’t want to. No one, including your parents, will be mad at you if you say “no” now or if you change your mind later. We have also asked your parent’s permission to do this. Even if your parent says “yes,” you can still say “no.” Remember, you can ask us to stop at any time. Your grades in school will not be affected whether you say “yes” or “no.”

We will not use your name on any papers that we write about this project. We will only use a number so other people cannot tell who you are.

You can ask any questions that you have about this study. If you have a question later that you didn’t think of now, you can contact Zolinda Stoneman at (706) 542-4827 or zo@uga.edu.

Name of Child: __________________________ Parental Permission on File: Yes □ No □

(For Written Assent) Signing here means that you have read this paper or had it read to you and that you are willing to be in this study. If you don’t want to be in the study, don’t sign.

Signature of Child: __________________________ Date: __________________________

(For Verbal Assent) Indicate Child’s Voluntary Response to Participation: Yes □ No □

Signature of Researcher: __________________________ Date: __________________________
Family Information

Please provide the following information for the two children participating in this study:

Sibling 1 (typically developing sibling):

Child's Birth date: ___/___/____  Child's Sex: ___Male  ___Female
Child’s current age ______________

Sibling 2 (sibling with ASD)

Child's Birth date: ___/___/____  Child's Sex: ___Male  ___Female
Child’s current age ______________

Where did you receive the diagnosis of ASD for your child?
   _____Pediatrician
   _____Clinical psychologist
   _____Emory Autism Center
   _____Marcus Autism Center
   _____Other (please describe_______________________________________)

How old was your child when he/she received the ASD diagnosis? ________years

How many children do you have? ______

Are you the child's _____Mother  or  _____Father?

How old are you? ___________ Years

What is your race/ethnicity? _____White (non-Hispanic)
   _____African-American
   _____Hispanic
   _____Asian
   _____Other- please specify_________________________________________
What is your current marital status?  
_____ Married  
_____ Divorced  
_____ Widowed  
_____ Separated  
_____ Single

What is your educational level?  
_____ Less than 12th grade  
_____ High school graduate  
_____ Some college, technical school  
_____ College degree  
_____ Graduate degree
Mother Interview

1. **Tell me about your children.**
   a. Age? Grade level?
   b. School they attend?
      i. Child w/ ASD- in special education classroom or included in general education classroom?
   c. Activities they enjoy?
   d. Personality qualities?
      i. How would you describe your child w/out ASD to someone who had never met him/her?
      ii. How would you describe your child w/ ASD to someone who had never met him/her?

2. **Tell me a story that tells me about your children and explains their personalities.**
   a. What is their sibling relationship like?
   b. What activities do they enjoy doing together?
   c. How do they relate to one another? Do you have a story or example of how they relate to one another?

3. **What does your child w/out ASD think about your children w/ ASD?**
   a. What is his/her current understanding of ASD or what it means to have ASD?
   b. How has his/her understanding of ASD developed over time?
   c. How have you explained ASD to him/her?
   d. What does he/she call ASD?
   e. How do you think having a sibling w/ ASD has affected your child (more sensitive, understanding, embarrassed, guilty, etc.)?
      i. Do you have an example or story?

4. **Tell me about your children’s friendships.**
   a. How does your child w/out ASD perceive friendships? Define or describe friendships?
   b. How does your child w/ ASD perceive friendships? Define or describe friendships?

5. **Tell me about the friendships of the child w/ ASD:**
   a. Age? Gender?
   b. Disability? No disability?
   c. How many friends?
   d. How close are their relationships?
   e. How did they meet?
   f. Live in your neighborhood?
g. Where do they mainly see each other?

h. Are you friends with the children’s parents?

i. Are they related to your child? (ex: cousins)

j. How does your child w/ ASD feel or act in social situations?
   i. Story or example?

k. In what environments/settings do your children interact with peers?

l. Have your children ever attended the same school?
   i. If so, how did this affect your children?
      1. Enjoy it? Dislike it? Why? Did they ever share friends?

6. Thinking about your child w/out ASD, does this child’s friends ever come over to your home to visit?
   a. Yes- how often?
      i. What do they do together during the visits?
   b. Is your child w/ ASD present during these visits?
      i. Describes what happens when all of the children are together. Do they play together? Specific story or example?
   c. Does your child w/out ASD ever go to other children’s homes to visit?
      i. Yes- how often?

7. Thinking about your child w/ ASD, does this child’s friends ever come over to your home to visit?
   a. Yes- how often?
      i. What do they do together during the visits?
      ii. Story about a time when a friend came over to visit?
   b. No- why do you think that is?

8. Have you ever had a difficult experience when another child came to visit?

9. Does your child w/ ASD ever go to other children’s homes to visit?
   a. Yes- how often?
      i. Do you go to the home as well? The sibling?
   b. No- why do you think that is?

10. How do you assist your child w/ ASD to develop friends and socialize with others?
   a. What kinds of things have you done to help your child w/ ASD make friends?
   b. What strategies have you used to expose your child w/ ASD to friendships and socialization opportunities? (play dates, clubs, sports, etc.)
   c. What do you think has been successful? Unsuccessful?
      i. Tell me about a time when you were successful.
      ii. Tell me about a time when you were unsuccessful.

11. How does your child w/out ASD help your child w/ ASD develop friends and socialize with others?
   a. Do you think that your child w/out ASD recognizes that they could help your child w/ ASD?
   b. Do they share mutual friends?
   c. Do you think your child w/out ASD would be effective with helping your child w/ ASD develop friendships and social skills? Why or why not?
12. What would you like to see change or improve related to your children’s friendships, social skills, and relationship together?
   a. How do you think this could happen?
   b. What support do you think you need to make this happen?
13. What are your hopes and dreams for your children in the future?
   a. For child w/out ASD, child w/ ASD, & their future relationship as siblings?
14. Is there anything else you would like to tell us about your children?
APPENDIX F

SIBLING INTERVIEW QUESTIONS
Sibling Interview

1. **Tell me about yourself.**
   a. How old are you? What grade are you in?
   b. What are some things you enjoy doing?

2. **Tell me about your brother/sister (w/ASD).**
   a. What is he/she like?
   b. How would you describe your sibling to someone who has never met him/her?
   c. How would you describe autism (or term that you call it) to someone who has never heard of it?

3. **What are some things you and your brother/sister enjoy doing together?**
   a. Do you have a story or example of a time you enjoyed doing something with your brother/sister?

4. **How would you describe your relationship with your brother/sister?**
   a. Can you tell me about a time when your brother/sister did something that really irritated or aggravated you?
   b. Happy time?

5. **Is your brother/sister different from you in any ways? Similar in some ways?**
   a. Do you have a story or example?

6. **Tell me about your friendships**
   a. Who is your best friend? Tell me a little about him/her.
   b. How do you go about making friends?
      i. What is easy about it? What do you have trouble with?
   c. Where do you interact or play with your friends?
   d. Do you have any of the same friends as your brother/sister?

7. **Do your friends ever come over to your home to visit?**
   a. Yes- how often?
   b. Do they visit with your brother/sister as well or just with you?
      i. Yes- what activities do all of you do together?
      ii. Tell me about a time when you, a friend, and your brother/sister all interacted/played together at your home.

8. **Have you ever talked with your friends about your brother/sister’s disability?**
   a. Yes- what do you tell your friends?

9. **Tell me about your brother/sister’s friendships.**
   a. How does he/she make friends?
   b. Does your brother/sister make friends easily? Have trouble?
      i. Tell me more- do you have any stories or examples?
   c. Where does your brother/sister interact or play with friends?
   d. Would you consider yourself one of your brother/sister’s friends? Why?
10. How do you help your brother/sister make friends or socialize/interact better with others?
   a. Does he/she need your help? Why or why not?
   b. How do your parents help your brother/sister to make friends?
   c. Can you tell me about a time when you helped your sibling make a new friend?
      i. If no- can you tell me about a time when you helped your brother/sister get along better with other children?

11. Is there anything else you would like to tell me about your friends or about your brother/sister?