

DESCRIPTIVE ANALYSIS OF THE SIBLING RELATIONSHIPS FOR FAMILIES  
WITH A CHILD WITH AUTISM SPECTRUM DISORDERS

by

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## ABSTRACT

The present study examined mothers' and sisters' perceptions of the sibling relationship for children who have a sibling with autism. The study occurred within the context of a strengths-based computer workshop called the iStar SketchUp Workshops. The siblings were involved in the workshops along with their brothers. Seven siblings and 6 parents were interviewed to see how they perceived the sibling relationship within the context of everyday life and within the context of the workshops. Using thematic coding, themes from the interviews were identified. The themes highlighted differences in the way that the siblings and parents framed the sibling relationship within everyday life activities versus within the workshops. Within the context of everyday life activities, the siblings focused on helping their brothers and playing with one another. The siblings also described how they had a sense of duty to their brothers because they were family. On the contrary, the mothers focused on the challenges of the sibling relationship, which they attributed to differences in learning style, which ultimately led to their perceptions of siblings engaging in separate activities. In contrast, both the siblings and parents perceived their brothers and sons differently in the context of the workshops. In the context of the workshops, they saw them as boys who possessed amazing skills and fit in with their peers. The sisters had a sense of pride for their brothers' accomplishments and the mothers spoke more positively about their children's relationships. Implications for interventions for children with autism spectrum disorders are discussed.

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## INTRODUCTION

Sibling relationships tend to be the longest relationships that people have during their lifetimes (Cicirelli, 1995). These relationships are unique because, unlike peer relationships and friendships, they are not chosen (Cicirelli, 1995). Often times, siblings provide an important source of support to one another throughout their lives (Stoneman, 2001). Lempers and Clark-Lempers (1992) found that siblings often perceive one another as providing companionship, intimacy, and nurturance. Because of this particular relationship, siblings can have unique and major effects on one another's development (Furman & Buhrmester, 1985).

Nurturance and conflict within sibling relationships can provide siblings with experiences that can enhance the development of emotional understanding, self-regulation, and a sense of belonging and comfort (Brody, 2004). Research examining sibling relationships in families in which a child has a disability has yielded mixed results. Some studies demonstrated that siblings of children with disabilities have higher incidents of behavioral and psychological problems (Summers, White, & Summers, 1994). Conversely, other researchers reported that having a sibling with a disability increased the child's sense of empathy, patience, self-confidence, and social competence levels (Hastings 2003; Kamsky & Dewey 2002; Verte, Roeyers & Buysee, 2003) One disability that is increasingly common is autism spectrum disorders (ASD). Autism is a spectrum disorder characterized by three diagnostic criteria: 1) communication delays

and impairments, 2) impairments in social interactions, and 3) the presence of restricted and repetitive behaviors (APA, 2000). Autism Spectrum Disorders (ASD) include diagnoses of Asperger's Syndrome, High Functioning Autism, Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) and classic autism. According to the Center for Disease and Control and Prevention (CDC, 2012), 1 in 88 children in the United States has ASD. Utah has the highest rate in the country with 1 in 47 children having a diagnosis of autism; making autism the fastest growing developmental disability in the state. Typically, autism affects boys five times more than girls. The autism rate has increased by 157% from 2002 to 2008 (CDC, 2012). The increased number of children with autism nationwide and in Utah also contributes to a dramatic increase in the number of siblings who have a brother or sister with an ASD. Compared to siblings of children with other disabilities, children with autism typically have normal life expectancy, which means that these relationships are particularly important because they often last longer compared to siblings with other disabilities (Smith & Elder, 2010). Few studies were found on the population of siblings of children with autism. The present study examined multiple perspectives on the sibling relationship for children who have a sibling with autism. The study focused on the sibling relationship in two contexts: everyday life and the computer workshops. The context of the computer workshops were explored as the workshops were designed to build on the strengths of youth with autism to promote social engagement and job skills.

## LITERATURE REVIEW

### Research Examining Outcomes for Children with a Sibling with ASD

Past research on sibling relationships for individuals who have a sibling with autism most often focused on child outcomes such as internalizing and externalizing behaviors. These studies have examined outcomes for children who have a sibling with ASD, as opposed to describing outcomes for the child with ASD. Some research has demonstrated positive outcomes of having a sibling with a disability, whereas other studies have shown negative outcomes. For example, Smith and Elder (2010) found that children who have siblings with autism had difficulties with adjustment, coping, and intimate relationship skills because of the added stress in the family from having a child with a disability. Mothers of children with ASD rated their neurotypical children as having more behavior problems and fewer prosocial behaviors when compared to reports from mothers of neurotypical children without a sibling with ASD (Hastings, 2004). Similarly, Ross and Cuskelly (2006) found that siblings of children with autism exhibited 40% more behavior problems than peers without a sibling with autism (Ross & Cuskelly, 2006). In addition to these studies, Macks and Reeve (2006) found that parents rated the social and emotional health of their neurotypical children more negatively when there was a child with ASD in the family compared to parents who did not have a child with ASD.

On the contrary, other researchers reported that having a sibling with autism increased the child's empathy and patience (Hastings 2003; Kamsky & Dewey 2002). Other positive findings include greater self-confidence and social competence in children with a sibling with autism relative to children with neurotypical siblings (Verte, Roeyers & Buysee, 2003). In comparison with siblings of typically developing children, siblings of children with High Functioning Autism were not more likely to have adaptation problems (Verte, Roeyers, & Buysee, 2003).

Differences in the results of the studies could be attributed to the severity of the child's autism and the age of the sibling. Researchers demonstrated that older siblings seemed to adjust better to having a sibling with a disability than younger siblings. Individuals with siblings who have a more severe disability in regards to verbal ability have more behavioral problems and poorer socialization skills (Pilowsky, Yirmiya, Dopplet, Gross-Tsur & Shalev, 2004).

### Sibling Perceptions of the Sibling Relationship in Families with a Child with ASD

Relative to research focusing on child outcomes, little research has examined children's perceptions of having a sibling with autism. A few studies have examined the quality of the sibling relationships through the perception of the neurotypical sibling. Benderix and Sivberg (2007) interviewed 14 siblings from 5 families that had children with autism that were getting ready to be moved into a group home. Using content analysis, seven themes were identified: 1) having a sense of precocious responsibility, 2) feeling sorry for the sibling with autism, 3) being exposed to frightening, abnormal

behavior, 4) having empathetic feelings for the child with autism, 5) hoping that the group home would be a relief for the family, 6) physical violence in the family made the siblings feel unsafe and anxious at home, and 7) having a sibling with autism affects relationships with friends negatively. From the siblings' point of view, early intervention programs that were adapted to the unique needs of each family were extremely important. The siblings felt that if their parents had received more support in how to handle challenging behaviors, and if the siblings had received counseling to help them express their concerns and feelings, then having a brother or sister with autism would have been less challenging.

In another study, Sage and Jegatheesan (2010) focused on the perception of siblings with autism in the context of two cultures using case studies. Two families were involved in this study- one European-American family and one Asian-American family. The main differences that were found in this study related to the cultural views of the etiology of autism. The parents of the Asian-American child believed that their son's disability was caused by bad karma or from evil deeds that had been performed in the past, whereas the European-American family believed that their son's autism was caused by genetics. These differing views on etiology of the disability ultimately affected how the parents viewed and acted toward their child. The children's views of their brothers were directly linked to their parents' views on the etiology of the disability.

In another study aimed at the sibling relationship, Rivers and Stoneman (2003) examined how marital stress and support predicted the quality of the sibling relationship. They examined 50 parent-siblings triads, consisting of one parent and their child with autism as well as one typically developing sibling. They found an interaction effect

between marital stress and social support as a predictor of the sibling relationship. The benefits of social support were only found in families that reported positive sibling relationships. Siblings that were in families characterized by marital stress and unfavorable sibling relationships did not show any positive changes in the sibling relationship, even when provided with social support resources. Rivers and Stoneman also found that parents' reports of the quality of the sibling relationship were lower than sibling self-reported scores, indicating that parents perceived the sibling relationship more negatively than did the siblings themselves. This study points to the importance of examining multiple perspectives on sibling relationships, rather than relying solely on parent report measures. The present study examined the sibling relationship from the perspective of both the parents and typically developing siblings of children with autism.

Also focusing on the perceptions of the sibling relationship, this study interviewed siblings who had a brother or sister with autism. Eight typically developing siblings participated in semistructured interviews that focused on the siblings' knowledge and perception of their brothers' autism and their perception of their relationship with their brother (Petalas, Hastings, Nash, Dowey, & Reilly;2009). They found that there was an overall negative impact on the child who had a sibling with autism due to other people's reactions of their brothers and they hoped that their brothers' behaviors would change. They also found that the siblings could identify some positive aspects of their relationship with their brothers including being able to discuss support sources. The current study will use the same interview method to gain a perspective of how siblings view their brothers and how having a brother with autism has impacted their lives. However, this study will

focus on how providing an opportunity for participation in a shared activity may affect the sibling relationship.

In another study, Kaminsky and Dewey (2001) studied 90 typically developing children with siblings who had autism, Down syndrome (DS), and no disability. Typically developing siblings and their parents completed questionnaires on the sibling relationship. They found that siblings of children with ASD and DS reported significantly greater admiration of their brother or sister than siblings of typically developing and significantly less quarreling and competitive behaviors.

Orsmond and Seltzer (2007) also compared sibling relationships in families with children with autism compared to families with a child with Down syndrome. Seventy-seven children had siblings with autism, and 77 had siblings with Down syndrome. The siblings completed questionnaires about their involvement with their siblings as well as the impact of the sibling on their own life and their own coping skills and feelings. The siblings of individuals with Down syndrome reported higher levels of positive affect in their relationships with their brothers and sisters than did the siblings of children with ASD. Children with siblings with ASD were significantly more likely to report that their relationship with their mother and father had been impacted both negatively and positively than the children with siblings with Down syndrome. While this research focused more on comparing the perceptions of the siblings between different disabilities, the current study will focus only on examining the perceptions of siblings with autism. The current study will add to the descriptive literature on the perception of sibling relationships. This study will explore how the siblings of the participants in the SketchUp workshops perceived their brothers' experiences. It will also examine how the siblings

perceived their relationship with their brothers in a more general context. Kamnisky and Dewey (2001) suggested that sibling relationships that involve a child with ASD might be impaired due to the characteristics of autism. One of the challenges is the lack of shared time between siblings in joint activities due to differentiating competency levels (Stoneman, 2001). One way that sibling relationships might be enhanced is through participating in joint activities that are interesting to both of the children involved (Stoneman, 2001). The present study examined sibling and parent perceptions of the sibling relationship among siblings in which one sibling has autism. Perceptions of the relationship were evaluated in the context of a computer workshop for children with high functioning autism. The purpose was to understand better the relationships between the children with autism and their siblings in the context of a strengths-based workshop.

## METHODS

### Computer Workshops

We created workshops, using Google SketchUp, a three-dimensional (3D) modeling program, for children with autism to draw upon their visual-spatial and nonverbal reasoning strengths (Caron, Mottron, Rainville & Chouinard, 2003). The workshops focused on areas that tend to be more difficult for children with autism such as social skills and personal relationships (Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). The workshops were two hours long and were held at the University of Utah in a computer lab. Each child had his own computer and was able to create his own project using SketchUp. We have a facilitator who uses SketchUp professionally who leads the workshops. Other members of our research team also help at the workshops. The siblings of the participants are invited to attend and participate in the workshops. The parents of the participants have also participated by playing an active role in developing and giving input to the program.

### Participants

Interviewees were siblings and parents of the participants who participated in the Google SketchUp Workshops. All the siblings of the workshop participants were invited to participate through an email sent to the parents. The parents also were invited to

participate in a separate interview to discuss their perceptions of the siblings' experiences with the workshops.

Seven siblings participated in the interviews, along with 6 mothers. The siblings were between the ages of 7 and 15 ( $M = 10.41$ ,  $SD = 3.04$  years). All of the siblings were female. Five of the sisters were younger than their brothers were and two of them were older. The majority of the brothers had a diagnosis of high functioning autism but not all had an official diagnosis. There were two groups of children who participated in the Google SketchUp Workshops. One group was from a local charter elementary school, and the other was a group of children from various schools in Salt Lake County. The children from the charter school participated in workshops during school, and the other group of children participated in after-school workshops.

### Procedures

Since most of the siblings in the after-school workshops had attended and participated in some of the workshops, some of the siblings had developed rapport with members of the research team. Since many positive relationships had been developed, they agreed to participate and seemed to be comfortable during the interviews. For the sibling participants at the charter schools, with whom a relationship had not yet been established, the research team invited them to participate in the workshops before the interviews to establish rapport. They also were invited to join their brothers after school to see what their brother designed using SketchUp during the workshop.

Before the interview was conducted, the parents gave consent for their child to participate. At the start of the interview, the participants also gave assent to participate.

The participants were informed that they could refuse to answer any of the questions that were presented during the interview. The interviews were conducted in a place that was comfortable for the child that was arranged previously by the parents and the interviewer.

The interviews focused on the siblings' perception of their brothers' participation in the Google SketchUp Workshops and their experiences with having a sibling with ASD. Each interview lasted approximately 20 minutes long and was audio recorded. The interviews were transcribed verbatim from the audio tape to a word document. Next, the data was analyzed using qualitative methods.

The parents also were interviewed to gain their perspectives on the workshops in relation to their children's relationships. They were asked questions about their children's relationships in the context of the workshops and within the context of everyday life (See Appendix A).

### Data Analysis

A qualitative approach was used for data analysis. The transcriptions were read, coded and themes were identified. This was done by two researchers who initially coded the transcripts and identified themes separately. After an initial pass through the transcripts, the two coders discussed the themes they had identified and made revisions as necessary. Then they reread the transcripts to check for validity. After another revision of themes, the themes were presented to an existing research team for feedback and revisions. Following this, the two coders again reread the transcripts and revised the themes. After this process, the themes were presented to the parents to ensure that they correspond with the child and parents' perceptions.

## RESULTS

The interviews focused on the siblings' and the parents' perceptions of the sibling relationship and the relationships in the context of the Google SketchUp Workshops. The two themes that emerged through the thematic analysis and the coding were framing sibling roles and relationships within of everyday life and reframing of the sibling roles and relationships within the iStar Workshops. These themes emerged from several subthemes. Some subthemes were identified by both the sibling and the parent, and some were specific to either the siblings' perceptions or the parents' perceptions but not both. These themes and subthemes are discussed in greater detail below (Figure 1).

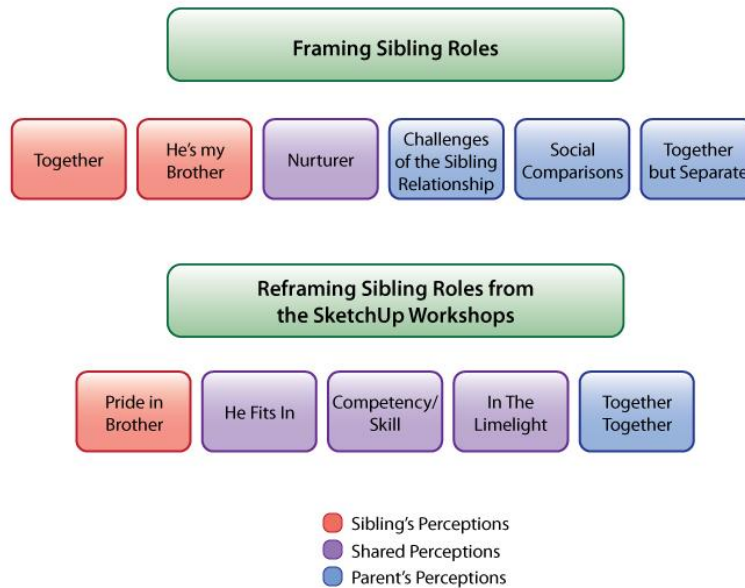


Figure 1 – Themes and Subthemes of Parents' and Siblings' Perceptions

## Framing Sibling Roles in the Context of Everyday Life

### Siblings' Perceptions: Together

The siblings easily identified activities that they enjoyed doing with their brothers. These activities included playing video and computer games, playing outside, and engaging in various types of pretend play. One sibling said “Sometimes we like to play out in the snow... go to the school and play basketball, play the Wii, watch a movie, play on our DS’s” (Jennifer). The most frequently identified shared activity was playing the Wii together. Although electronics seemed to be a central shared activity in the sibling pairs, other activities were mentioned. Fourteen-year-old Anna summed it up this way when asked what her favorite thing to do with her brother was, “Well, we do lots of stuff.” It was apparent that the siblings spent time with their brothers engaging a variety of different activities. Jessica stated “We like to hang out a lot.” Thus, siblings identified engagement in mutual activities and time spent together as a major dimension of their relationship. Their siblings provided companionship and they enjoyed spending time together engaged in activities of shared interest.

### Siblings' Perceptions: “He’s My Brother”

While the siblings easily identified the assets and challenges of having a brother with autism, many of them seemed to have a sense of duty to the sibling relationship. Many of the sisters described frustration or hardship at having a brother with autism but at the same time, the siblings acknowledged that their relationship with their brother was something that was ascribed (Cicirelli, 1995). Due to the fact that it was ascribed, they

had a sense of obligation to “deal” with the difficulties that came from having a brother who has autism. When asked what it was like to have James as a brother, Anna commented “Sometimes stressful almost because he is just so loud and annoying but I guess all brothers are, right?” Even though she liked her brother, sometimes he could be annoying. However, because he was her brother, she had to like him; she didn’t have a choice in the matter. There was an assumption on the part of the sisters that sibling relationships involved both positive and negative dimensions, and this dichotomy was the nature of the sibling relationship, rather than specific to having a brother with autism. Siblings appeared to believe that they should expect that there will be annoyances from their brothers, but they do not supersede the fact that the sibling relationship is important.

The sisters liked their brothers despite the fact that they found their brothers’ behaviors annoying at times. An older sister mentioned, “I like him. Well, he’s my brother but he’s crazy” demonstrating that she did not have a choice to like her brother or not. He was her brother so she had to like him. Anna described her relationship with her brother this way,

We totally “hate” each other sometimes, you know? Like annoy each other, but then other times he’ll be really nice. He is kind of like that friend that you have had forever that you just pick on all the time.

The siblings perceived that there were positive and negative dimensions to their relationships, as is typical of sibling relationships.

### Parents’ Perceptions: Challenges of the Sibling Relationship

Just as the sisters had expectations for the sibling relationship, the mothers also had expectations for the sibling relationship. However, the mothers tended to focus more

on the challenges of having a brother with autism whereas the sisters just accepted having a brother with autism as a fact of life. One mother talked about the challenges of having a sibling with autism in this way, “Being the younger sibling of someone with a volatile personality, I think it’s really hard. You are a survivor.” The mother acknowledged that the sister did not have choice in having a brother who can be volatile at times, thus requiring her to be a survivor.

The mothers framed the sibling relationship more negatively than the siblings did. There seemed to be an overall sense of pity for the sister in having to live with the challenges of having a brother with autism. For example, Barbara talked about the difficulty that her daughter had in having a brother who has autism by saying, “This has happened so many times. (She) bursts into tears ‘why does it have to be this way? Why do I have to have a brother like this?’” The mother perceived that it was difficult for her daughter to live with a brother who has autism.

The challenges of the sibling relationship were addressed as one mother said, “They have a really troubled relationship... because he will hurt her. He doesn’t always understand her energy and so he just kind of reacts to her. Sometimes it’s just really hard.” Mothers were more likely than their daughters to focus on the challenges to having a brother with autism, whereas their daughters identified many positive dimensions of their relationships.

#### Parent and Sibling Perceptions: Sibling as Nurturer

Both the mothers and siblings perceived that the sisters felt a need to nurture or take care of their brothers. The sisters reported that they often helped their brothers with

various tasks that came easily to the sister. Maria, an 11-year-old sister who was younger than her brother said, “I like to play transformers and build Lego sets with him. Help him out with his Lego sets that he buys.” When the sisters were asked about spending time with their brothers, the majority of them discussed helping their brothers. Even when the sisters talked about things that they like to do with their brothers, they often mentioned nurturing and caring for their brothers. For example, a younger sister talked about helping out her brother with his interactions with his friends by saying: “Most of his friends, they are pretty nice... sometimes they hang out with me if Sam is like pouty. They play with me and some of my other friends.” Her description illustrated that the sister helped her brother’s social relationships by playing with his friends if he was having a bad day. An older sister also described the caretaking that she does for her brother on a daily basis, thus fulfilling the role as a nurturer: “I don’t really see him in the morning because my school starts earlier but I know I start the shower for him and I wake him up and sometimes I make him breakfast.”

The parents also referred to the nurturing role of the sisters towards their brothers. Maria talked about the role that her younger daughter took on with her older brother by commenting, “One thing that I have noticed is Jessica kind of nurtures him, kind of care takes him a little bit.” This seemed to be a bit of role reversal because Maria’s daughter was younger than her son. In a similar case where the sister was much younger than the brother, another mother reported, “She is very strong in reading so she will walk him through his spelling words and all that kind of stuff.” These quotes demonstrated that the parent recognized that the younger sibling was fulfilling roles of the older sibling, thus taking on a nurturing role.

### Parents' Perceptions: Together but Separate

Although the parents talked about their children spending time together, they perceived that it was difficult for the children to interact with one another. The way the parents referred to their children's interaction described more parallel play than integrated play. This pattern of play was exemplified by Mary stating, "Sometimes they are just down in the playroom, and they are each doing their own thing and so they are not necessarily engaged with each other."

Another parent referred to the difficulty that her children had playing with one another in this way,

Sometimes they will play outside for... oh Ryan is not a big outside person but sometimes Jennifer can get him outside.... Sometimes they like to play on the Wii or something like that but um, they are just so different in the way that they... that their brains work that they... it doesn't come together very often.

Several parents frequently mentioned a lack of mutual engagement between their children because of differences in interests and learning styles. Mothers perceived that their children had more differences than similarities, and thus it was hard for them to engage for a long time in the same activity.

It is important to note that the siblings perceived their ability to connect with their brothers differently than their mothers. As stated previously, the sisters didn't think it was hard to interact with their brothers as was demonstrated by the ease at which they talked about activities that they enjoyed doing together with their brothers.

### Parents' Perceptions: Social Comparisons

The parents readily identified differences among their children in regards to competencies and compared their children to one another frequently. They often talked

about the strengths and weaknesses that their children possessed. The following quotes are examples from the interviews of how the mothers compared the skills of their daughter to the skills of their son. One mother talked about the differences in her children's academic skills by saying, "James is very strong in math and Elizabeth is very weak in math so he will walk her through her math. She is very strong in reading so she will walk him through his spelling words and all that kind of stuff."

Linda described her children's differences and emphasized why these differences complicated the sibling relationship. She said,

Jennifer is naturally athletic. And she is really good. I mean she is very natural and Ryan doesn't like that. Ryan, you know just approaches things from a strategic view, and she approaches it from an athletic sense so if they go out and play basketball, it's just mayhem. And the computer, the computer is hard for them to do. It's hard for them to do chores together.

Another mother attributed a lack of shared activities to differences in learning styles and social abilities in her children: "She'll sit and play the piano for a lot longer than he'll... I mean like for time wise... she likes to go on the computer and play games but she's just not that way, you know?" This mother also identified that because of these differences, it was hard for her children to engage in the same activity. Similarly, emphasizing the learning difference between her children, Linda stated, "She is not visual and he is... but you could sit down and give Elizabeth this long wordy explanation and she'd get it and he'd be lost two words into it." This mother emphasized that her children are different from one another in the way that they learn.

While these parents readily identified differences in their children, they also identified strategies to approach these differences as evidenced by the following comment, "We try to have them involved in different things because it makes it easier"

(Linda). Similarly, Maria found that her children needed to be separated in order to accomplish certain tasks more efficiently. She stated “They can’t do homework together. Homework has to be done in two separate rooms. That sort of stuff.” Thus, mothers understood that their children learned differently and found alternative ways to make necessary tasks more successful.

### Reframing Sibling Roles Through the SketchUp Workshops

The parents and siblings both discussed how their view of their brother or son had changed after the brother or son had participated in the iStar SketchUp Workshops. In the previous theme, the siblings and parents framed the role of the sibling relationship in the context of everyday life. Mothers perceived that their children were quite different from one another and had little common ground on which to connect in everyday life, although sisters did not perceive the relationship that way. When the parents and siblings talked about the sibling role in the context of the SketchUp workshops, there seemed to be a shift in the perceptions. Mary summed it up by saying,

Some things just come so easy to her and a lot of times she just looks at him and goes ‘this is so easy. ’You know? And so it kind of let there be a role reversal a little bit with the two of them. Where he was really good at it and she maybe wasn’t.

For many of the sibling pairs, SketchUp provided the first opportunity for the brother to be more competent than his sister. This success seemed to contribute to a shift in how the parents and the sisters perceived their brothers.

### Siblings' Perceptions: Pride in Brother

The sisters expressed a great deal of pride in their brothers based upon their participation in the SketchUp Workshops. For example, each of the sisters portrayed their brother as being the best or most competent in the SketchUp Workshops. As Anna said,

He is really good at making things. Because a lot of people download stuff from the warehouse and put them in little things or something but he makes stuff. I remember I saw him once. He made like a model of, I think it was some kind of gun but it was cool.

Anna compared her brother to the other boys in the workshops and noted that he was the best because he did not just use the warehouse that allows the children to use models that have already been created. Her brother used his imagination and created his own models.

Not only did the sisters think that their brothers were the best student within the workshop, they were also extremely proud of the work that their brothers were doing. When asked about her brother's projects, 9-year-old Karen responded by saying, "He has done amazing things! He's been doing zoos and dragons." Amy expressed her pride in her brother by talking about his projects in this way, "I think they were pretty cool because I don't know how to do any of that stuff and he does. And he's good with games and stuff." When asked what she thought about her brother's presentation to his classmates at school, Karen said "everyone loved it." She was so proud that her brother had created something that all of this classmates and teachers liked.

It was also common that the sisters could not recall what project their brothers were working on, but they could recall how great their brother was. Jennifer recalled, "I don't remember what he was doing but it looked awesome!" In talking about her

brother's presentation, Karen stated, "I think he did the dragon one or the zoo one or the Halo one but he did a very good job." This shows that the siblings were not necessarily concerned with the projects that their brothers had made, they just had an overall sense of pride for their brothers.

Anna, who is 4 years older than her brother, commented, "I am kind of proud of him sometimes because there are a lot of people like my age that don't know how to work SketchUp." She was very proud that her brother who had struggled in other areas now knew something that even people older than him did not know or understand. Thus, the sisters recognized the skills that their brothers had developed and were proud of their accomplishments.

#### Parents' and Siblings' Perceptions: He Fits In

Both the parents and the siblings discussed how their son and brother often had difficulty in social situations and with peers, but when they talked about friends within the context of the workshop, they felt like their son or brother "fit in" with those in the workshop. Anna talked about her brother's friends outside of the workshop by saying, "He's got school friends and his friends from basketball but most of them are really, kind of weird." However, when Anna was asked about her brother's friends from the workshop she mentioned that she enjoyed having the boys from the workshop come to her house because it has provided friends for her brother who were like him and who liked to do the same things that he liked to do.

Linda talked about her son's previous experience with friends in comparison to his friends at the workshops. She said:

I think it's been really good for him to be around these kids because we have done so many workshops, and so many social skills groups and so many programs and Ryan is always the highest functioning and he kind of gets nervous around the other kids and this has been kind of his peers. He doesn't have to, you know, act normal or doesn't have to worry about the other kids being affected.

The mothers were excited to have a place where their sons could go and be peers with those who were there instead of feeling like others were better than them.

Susan also talked about her son's ability to fit in with the other kids at the workshop by saying "It was somewhere that [the boys] were accepted the way they are and it's something that they could do [easily]." This was important to Susan because children at other places had not always accepted her son but in the computer workshop he had a place where he "belonged" because of his strengths in manipulating SketchUp.

In talking about the SketchUp instructor, one mother commented,

"It is really helpful to have someone like him (Steve) communicate with him on a really equal level. What I mean is that he talks to these kids with such respect and he talks to them like they are his colleagues and he respects their ideas in a way that has made my son feel really important."

The majority of the mothers commented on the fact that it was so refreshing to have an adult accept their son for who he was and this allowed their sons to feel like they truly fit in. One mother noted that this was the first time that her son had been accepted for who he was because none of the people at the workshop were trying to "fix" him.

#### Parents' and Siblings' Perceptions: Competency/Skill

Both the parents and the siblings commented on how competent their son or brother was with the SketchUp software. They were impressed with their brothers' or sons' skills and how competent they were in manipulating the software and in presenting their work to other people. Referring to a time when her brother presented his projects at

the workshops, Anna said “He looks so smart and professional” demonstrating that her brother was competent enough to present his project in a professional manner.

Amy expressed her brother’s level of competency and skill by saying, “ I know when I had my career and technical engineering class that like I was thinking ‘if only Andrew could do this for me.’ Because I had to make something on SketchUp and I wouldn’t know how to do it.” Amy acknowledged that Andrew was competent in his SketchUp skills even though he was several years younger than her.

Another sister talked about her brother’s projects by saying, “I think they were pretty cool because I don’t know how to do any of that stuff but he does. And he’s good with games and stuff.” Although this sister had a hard time pointing out other skills that her brother possessed, it was very apparent that she perceived that her brother was very skilled in his ability to work with SketchUp.

The mothers’ were also proud of their sons in the way that they learned how to operate SketchUp. One mother had watched her son use SketchUp several times. She noted, “The way that he manipulates the computer, it’s just awe inspiring.” Just as the sisters were impressed with their brothers’ abilities to present the work that they had created, the mothers were just as impressed with their sons’ presentations. Maria talked about her son’s presentations by saying “I was just so amazed the first time I saw him present. He really felt like he was an expert on this project. That was really impressive to me.”

### Parents' and Siblings' Perceptions: Creativity

The parents and the siblings loved that SketchUp gave their son or brother an opportunity to be creative. One mother noted the lack of creativity her son had prior to attending the SketchUp workshops and compared it to his ability to be creative in the workshops: "He's not the most creative person. I think it's (the workshops) been helpful for him in that it has made him feel more confident about being creative." (Linda) These mothers were excited that these workshops had given their sons the opportunity to be creative in using technology along with providing them an opportunity to master a skill.

One mother referred to the SketchUp Workshops as "a creative outlet" for her son. This mother felt like her son was a creative person but had struggled with a way to express his creativity. She was excited to be able to see her son using his creativity in a positive way with such positive feedback.

Many parents and siblings noted that SketchUp gave them the opportunity to see how their brother or their son thinks in a different way. Jennifer, a sibling, said, "I think it (SketchUp) is really awesome because I get to see like what he imagines about, what he likes to do when he has his free time." For many of these parents and siblings, this was the first time that they had been able to see their brother or son being creative and also allowed for the sisters and mothers to gain insight to their brothers' and sons' minds.

### Parents' and Siblings' Perceptions: Competition/ Limelight

The SketchUp Workshops provided one of the first opportunities for the sons to be better at an activity than the sisters. Barbara commented, "The whole SketchUp thing.... In a way that is one of things that Jack can be better at than Karen." This was a

major change in perceptions of roles for most of the families. The parents perceived that the brother had a skill where he could excel and be better than his sister. The parents loved that they had found something where their son could succeed.

Other parents noted that they wanted to make sure that their son continued to be better at SketchUp than their daughter. It provided an activity where the son could be in the limelight. Barbara summarized her son's thoughts by saying,

You could see in the back of his mind, 'I can't let her get better than me because she is better than me at other things: So he lets her in and there is a really big interest until she gets too much of interest and then he pushed away because he wants to be top dog.

In another quote Barbara stated, "I think that she may have felt that he was like 'I don't really want you here. This is mine. This is my place where I can go.'" Another mother noted how she liked that her son had something where he could excel and she wanted to make sure that it remained "his" thing. She commented, "And Karen has so many things that she does and she's been interested for him to teach her some stuff but you know Curt wants it to be his way and I have a feeling, that at least for a little while longer, it's going to be Curt's thing." This mother wanted to ensure that Curt was able to keep SketchUp as his unique skill by not letting Karen get too involved.

On the other hand, Maria appreciated having her daughter involved in the workshops because "his sister could be there to witness that and she could see him kind of shine and be a star and be super good at something and that she would be asking him for advice and needing his help." She loved that her daughter was able to see her brother in the spotlight. She felt that it provided a positive opportunity for her daughter to see her brother excel.

The sisters also described how the skill development in their brother had created a role reversal in the sibling relationship. The relationship evolved from an emphasis on her being an expert with everyday tasks to him being an expert with SketchUp. One sister summed up the role reversal in her statement that, “He sort of shows me what I can do when I need help.” This particular sister enjoyed doing SketchUp with her brother, and she liked when he was able to help her with things that were complicated.

#### Parents’ Perceptions: Together/Together

As discussed in the first theme, the parents talked about their children spending time together even though they were engaged in different activities while together. The majority of the parents reported a shift in the way that their children interacted with one another following the SketchUp workshops. Through the SketchUp Workshops, they were now together and had found a common activity they could do with each other.

The majority of the mothers reported how striking it was to see their children interacting positively with one another during the workshops. Barbara recalled, “One time they were like giving this presentation together. He just called her up from the audience. That was amazing! That was absolutely amazing! They normally never would have worked together like that.” The mothers felt that the workshops had provided a positive opportunity for the siblings to work together.

Maria shared how the workshops had provided an opportunity for her children to work together in a positive environment. She stated,

I just think it’s been a really great experience for both of them and it’s just really unique and special that it’s something that they can share and really enjoy together and I mean, anything that they are doing and bonding at the same time is everything that you want.

## DISCUSSION

Autism is a neurological disorder that is increasing at an alarming rate (CDC, 2012). The dramatic increase in children with ASD also creates a dramatic increase in the number of siblings who have a brother or sister with an ASD. A few studies have examined the sibling relationship in the context of one of the siblings having ASD, however, the research has been limited. The sibling relationship is very important due to the longevity of the relationship and the amount of time that siblings spend with one another through out their lifetimes. It is also of great importance because it is the first and most significant peer relationship (Powell & Gallagher, 1993). Due to the unique characteristics of ASD, the sibling relationships can be impacted, both negatively and positively. Given the importance of the sibling relationship, it is necessary to examine the sibling relationship in the context of having a sibling with ASD.

The current study adds to the qualitative literature on sibling relationships when one of the siblings has an Autism Spectrum Disorder. Through use of thematic coding, two major themes emerged: 1) *framing sibling roles in the context of everyday life* and 2) *reframing the sibling roles from the iStar Workshops*. Several subthemes were also identified. Some of the subthemes were unique to the siblings' perceptions; others were unique to the parents' perceptions. Few themes were identified by both the parents and the siblings. These themes were important in understanding the sibling relationship when one of the siblings has ASD.

Sisters often perceived the sibling relationship differently than did mothers. The biggest difference was demonstrated by the feeling that the parents viewed the sibling relationship more negatively than the sisters did. The sisters easily identified the positive aspects of their relationships with their brothers whereas the mothers more easily identified the parts of the relationship that were more difficult. The siblings discussed activities that they enjoyed doing together with their brothers. They also expressed a sense of duty to help their brother because they were family, and described how they cared for their brothers by helping them with tasks that were difficult for them. When the mothers discussed the sibling relationship within the context of everyday life, they focused more on the challenges that their son with autism contributed to the sibling relationship. The mothers often focused on the differences between their children. They frequently made social comparisons between their children and attributed their children's difficulties in playing with each other to these differences.

It is important to note that although the interviews were focused on the computer workshops, both the parents and the siblings focused on the social interactions that took place with the context of the workshops and within the context of everyday life, demonstrating that the parents and the siblings placed great importance on the social interactions of their sons and brothers. The sibling relationship was important and meaningful in both contexts. The findings of the current study are consistent with the limited research on children with siblings with ASD demonstrating that they accept their sibling and feel pride in their sibling (Angell et al., 2012; Petalas et al., 2009). As with neurotypical siblings, there were also challenges (Orsmond, Kou & Seltzer, 2009).

Similar to the youth interviewed in the Angell et al. (2012) study, the sisters in the present study appeared to have adapted to having a sibling with ASD.

The iStar Workshops provided an opportunity for the siblings and parents to view the sibling relationship more positively. Because the workshops were strengths-based, they allowed the siblings and parents opportunities to see the unrecognized skills that their brothers and sons possessed. The workshops also provided an opportunity for role reversal in that the sisters asked for help from their brothers instead of the other way around. Consistent with a family systems approach, strength-based interventions that include siblings may benefit not only the child with ASD, but also affect the larger family, including the sibling relationship (Turnbull, Turbull, Erwin, Soodak, & Shogren, 2011). Involving siblings in interventions may also provide an opportunity for children to meet other youth living with siblings with ASD. Developing relationships with other children with siblings with ASD may provide opportunities for social support and the identification of coping strategies (Angell et al., 2012). Previous research on children with siblings with ASD indicated that they benefitted from talking with others who understood their situation (Angell et al., 2012). The iStar Workshops provided an opportunity for children who have siblings with ASD to meet and interact with other children who have siblings with ASD.

### Strengths and Limitations

One of the strengths of the study came from the existing relationships with the parents and children. Because rapport had been built with the siblings and the parents, the participants seemed willing to talk openly and freely about their relationship with their

brothers and their children. Due to these prior relationships, these interviews provided a rich set of data that provides ideas for future research on aspects of the sibling relationship for children with ASD.

Another strength of this study was the inclusion of the perspectives of both the parents and the siblings. Many other studies that have looked at siblings perceptions have focused only on the perceptions of the siblings. This study included mothers, which provided a different perspective on the sibling relationship. It also provided a way to compare the siblings' perceptions with the mothers' perceptions.

While this study had some strengths, it also had some limitations specific to the sample. It is important to note that all of the siblings that were interviewed were sisters. The results may have been different if brothers had been interviewed. However, all of the siblings who participated came from families of only two children so sisters were the only option. The results may have been different if the typically developing siblings had another sibling other than the brother with ASD to draw comparisons within the context of sibling relationships. Furthermore, the children who participated were all elementary-school aged. Previous research has shown that older participants are able to provide more complex descriptions of the sibling relationship; thus, future research should examine adolescent and adult perceptions of having a sibling with ASD.

It is also important to note that we did not interview the boys so we don't have their perceptions on the sibling relationship. Future research should continue to examine multiple perspectives on the sibling relationship, including examining the perspective of children with ASD. Boys were not included in the present study because they had

difficulty verbalizing their feelings about the sibling relationship. Creative methods for eliciting their perspectives on the sibling relationship are needed.

### Future Research

Although this study had some limitations, it has provided a foundation for future research within the iStar Workshops. This study could be replicated easily with another group of siblings who have a brother or sister who participates in future workshops. The data point to the importance of incorporating the siblings more into the workshops, especially the siblings who were not as involved in the workshops. Now that we know that the workshops provided the framework for the siblings to enhance their relationship with their brothers, it would be useful to use this data to enrich future workshops by including the siblings even more in the workshops. Siblings can participate in family events, presentations, and Saturday workshop classes. There could also be a workshop geared towards siblings that could focus on having the brothers teach the siblings about SketchUp or that could focus on teaching the siblings how to use SketchUp. As stated previously, it can be beneficial for children with siblings with ASD to interact with other children who have sibling with ASD and the future workshops could focus on this important relationship.

### Conclusion

Since the sibling relationship is the longest relationship that a child has, it is important to understand this relationship. This study has provided insight into how the iStar Workshops have changed the way that parents and siblings perceive the sibling

relationship. The workshops were able to draw upon the boys' interests in computers, their visual-spatial strengths and abilities and gave them an opportunity to show their parents and siblings their skills. Positive changes in parents' and siblings' perceptions of their sons and brothers also positively influenced the sibling relationships in the families.

Families are a central unit of society. The sibling relationship within families is very important relationship. Having a child with ASD can bring different challenges to the sibling relationship and to the family dynamic in general. Many parents of children with ASD are searching for support for their families and for their children. The iStar Workshops provided a support system for these parents and siblings to be able to strengthen the sibling relationship. See as these workshops provided a springboard for an opportunity to enhance the sibling relationship, other parents may want to have their children participate in these workshops to help enhance the sibling relationship.

The siblings who participated in this study demonstrated that the sibling relationship was important to them. They talked about their relationships with their brothers very candidly. They easily identified the positive and the negative dimensions of the relationship. Even though they addressed some of the negative dimensions of having a brother with ASD, the sisters focused more on the positive attributes that their brothers possessed. The sisters valued their relationships with their brothers and had a desire to understand their brothers more. They were excited to see their brothers be successful.

## APPENDIX A

### INTERVIEW QUESTIONS FOR SIBLINGS

- Tell me about a typical day in your house with your brother.
  - \*What do you do in the morning? After school? On weekends?
- What have you seen your brother do with SketchUp?
  - \*Did you ever get to see your brother present his project?
  - \*What did you think about his projects?
- What do you know about SketchUp?
  - \*Have you tried it?
- Are there things that you like to do together?
  - \*Are there things you wish you could do (more often) together?
- Tell me about your brother's friends.
- What is your favorite thing to do with your brother?
- Tell me about your relationship with your brother.
  - \*How would you describe your relationship with your brother?

\* Indicates a prompt

## APPENDIX B

### INTEVIEW QUESTIONS FOR PARENTS

- Tell me about the relationship between your children.
- What are some things that your children enjoy doing together?
- What are some things that are difficult for your children to do together?
- What was your experience with the SketchUp workshops?
- Did your other child (sibling) have a role in the workshops? If so, what was it? If not, why not?
- What did your child enjoy about participating in the Google SketchUp Workshops?
- What did your child (sibling) enjoy about the workshops?
- What were the challenges for your child (sibling) with the workshops?

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