

Kara D. Sage<sup>1</sup>  
Brinda Jegatheesan<sup>2</sup>

# Parents Socializing Sibling Relationships in European American and Asian American Families of Children with Autism in the United States<sup>3</sup>

## Abstract

*This study examined how parents in a European American and an Asian American family socialize sibling relationships. We describe parents' beliefs about autism and how these beliefs influence awareness-building of disability in their typically developing children and the expectations that parents have for sibling relationships. The role of parents in socializing sibling relationships is also described. Analyses were based on in-depth interviews with parents. Findings indicate that the two sets of parents differed in their beliefs, expectations, and practices. Sibling relationship outcomes also differed in the two families. Implications for research are described.*

*Key words: Autism, Sibling relationship, Asian and European American families.*

## Introduction

Sibling relationships are one of the most important bonds in a family. Siblings typically share many common family experiences, including social and emotional intimacy, thus this relationship is significant to the development of a child (Cicirelli, 1994; Kramer & Bank, 2005).

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<sup>1</sup> M.Ed., M.S., University of Oregon, Email: [kara@uoregon.edu](mailto:kara@uoregon.edu)

<sup>2</sup> Ph.D., Corresponding author, Department of Educational Psychology, College of Education, Box 353600, University of Washington, Seattle, WA 98195, USA. Email: [brinda@u.washington.edu](mailto:brinda@u.washington.edu).

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The experiences of children who have a sibling with a disability are unique and come with their fair share of trials and tribulations (e.g., McHale, Sloan, & Simeonsson, 1986). The experience of disability also varies significantly between children of different cultures, languages, and religions (e.g., Braun, 2008). A substantial number of studies have indicated that having a sibling with a disability is a negative experience for children, leading to low self-concept, behavior problems, depression and loneliness (e.g., Gold, 1993; Verte, Roeyers & Busse, 2003). While it is commonly understood that parents play a significant role in the quality of sibling relationships, research has neglected studying parental influences on sibling dyads (Stoneman, 2005). The present study is a step in that direction.

### **Sibling Relationships in the Context of Autism**

Autism is a complex disorder with impairments in social interaction and communication (DSM-IV, 2000). Children with autism do not always have severe special needs, and there is a continuum of impact for these children. Regardless, autism presents unique challenges for siblings that may or may not exist for siblings of children with other special needs. Research on the lives of siblings of children with autism is an expanding field (Stoneman, 2005), but currently most research focuses on middle-class European American families who have children with autism, despite the fact that immigration is on the rise in the United States (Welterlin & LaRue, 2007).

Previous research suggests that positive and negative effects coexist for siblings of children with autism (see Orsmond & Seltzer, 2007, for a review of literature). On the negative side, siblings can feel neglected and overburdened by responsibility (e.g., Breslau, 1982; McHale, Sloan, & Simeonsson, 1986; Tew & Lawrence, 1973). With severe special needs, siblings might also be exposed to frightening behavior, such as tantrums (Benderix & Sivberg, 2007) and aggression (Ross & Cuskelly, 2006). Positive effects of having a sibling with autism include high family cohesion and less sibling rivalry (Kaminsky & Dewey, 2001; Meyer & Vadasy, 1994; Orsmond & Seltzer, 2000). In some cases, siblings of children with autism do not adequately understand the disability. Children's reasoning may mature with age, but this maturation is delayed for illness and disability norms when they lack specific knowledge. Knowledge of autism between 5 and 17 years of age remains within the boundaries of preoperational thought (Glasberg, 2000). Furthermore, parents often overestimate their children's understanding of the impact of autism.

Research has documented that children with autism want to engage with their siblings. El-Ghoroury and Romanczyk (1999) observed nine families with children with autism in dyadic family interactions on home visits. Results indicated that although mothers and fathers exhibited more play behaviors with children with autism, children tried to initiate more play with their siblings through verbal requests. This study makes the important point that adults can enhance the sibling bond by creating opportunities for their children to play together. Kramer (2010) also suggested that adults should focus on nurturing cooperative relations amongst siblings by promoting social competence and minimizing conflicts between siblings.

### **Parenting and Family Influences in Sibling Relationships of Children with Disabilities**

Despite the fact that parents play an important and influential role in sibling relationships of children with disabilities, there is limited research on this topic. The following is a summary of the available research.

Adult intervention in sibling dyads leads to compliance when one child has a disability (Dallas, Stevenson, & McGurk, 1993). Assistance from mothers led children with disabilities to play a more active role in play, and directions from the mother increased cooperation amongst children. Furthermore, increased negative interactions with mothers lead to more conflicts amongst siblings, suggesting that there is a significant maternal impact on sibling relationships when it comes to conflict (McHale & Gamble, 1989). Maternal negativity was also associated with higher levels of child depression and anxiety, as well as lower self-esteem. In addition, parents can be trained to elicit positive behaviors, such as cooperation, in their children (Strain & Danko, 1995). Mothers and sitters were taught to encourage typically developing siblings to engage in positive behavior and use certain social skills to benefit the child with autism. Their encouragement of positive interactions led to an increase in positive initiations and responses among siblings, and an increase in adult praise of children. This training also led to more spontaneous prompting of children at home. This research makes it clear that parents play a key role in nourishing sibling relationships, and that they can be trained to help sustain these sibling relationships.

Family variables have also been documented to impact sibling relationships. VanRiper (2000) studied the impact of family variables on sibling relationships when one child has special needs. Results showed that families with lower levels of family demands, a higher number of resources, superior coping skills, and higher levels of affirmative problem-solving communication between parent and child experienced greater sibling well-being. Findings illustrate how sibling outcomes are dependent on family variables. Gallagher and Powell (1989) agreed that family variables affect sibling outcomes, pointing to the effects of family size, socioeconomic status, and child characteristics (e.g., temperament or illness severity) on the adjustment of siblings.

### **Studies on Ethnically Diverse Families**

European American parents of children with autism have been documented to attribute their child's autism to a range of possible causes. These included birth related trauma, vaccinations, diet, birth of another child, toxins in the natural surroundings, congenital damage, allergies, and other such medical attributions (Gray, 1995; Goin-Kochel & Myers, 2005; Lingam, Simmons, Andrews, Miller, Stowe, & Taylor, 2003).

While much is known about Western perspectives, scholars in the field have critiqued a general lack of studies with culturally and linguistically diverse families of children with autism (Welterlin & LaRue, 2007; Zionts & Zionts, 2003). Dyches, Wilder, Sudweeks, Obiakor and Algozzine (2004) note the scarcity of knowledge on how multicultural

families appraise autism within a cultural context, the challenges and stressors they face, types of support they receive, and how they adapt to raising their child with autism.

How parents raise and socialize their children is dependent on their cultural and religious beliefs, values, and practices. In many cultures, parents draw upon their cultural beliefs to make sense of their child's disability and the reasons for having a child with a disability. It has been documented that most Latino mothers of children with developmental disabilities perceived their child in a positive way (e.g., blessing, make parents more compassionate), while a small percentage of the mothers (3% of 250 participants) believed that they were being punished for their sins (Skinner, Bailey, Correa & Rodriquez, 1999; Skinner, Correa, Skinner & Bailey, 2001). Jewish Israeli parents in Shaked (2005) also had positive interpretations (e.g., child accorded a high spiritual status) of their child with autism.

In much of the Asian culture, having a child with a developmental disability is taboo and is perceived negatively by the community at large. Cultural attributions concern divine punishment because of sins committed in present or past lives. Parents feel shame, embarrassment and guilt, prompting them to remain private about their child's diagnosis and hesitating to seek assistance (Chan & Lee, 2004; Groce & Zola, 1993; Uba, 1994). The need to 'save face' often prompts parents to keep the child's disability a secret from even the closest relative (e.g., child's siblings, grandparents). In a qualitative study of 23 Asian immigrant mothers of children with developmental disabilities (Jegatheesan, 2009b) many of the mothers had negative cultural beliefs about having a child with a disability and many mothers reported that they experienced community related embarrassment due to such stigma. Similarly, Asian Indian parents in Gabel (2004) also harbored negative beliefs, such as their child's disability was a punishment from God for sins of the parents.

Positive beliefs were found among South Asian Muslim parents with children with moderate to severe autism. These parents perceived their child as a gift from Allah and that they were chosen to take care of His special child (Jegatheesan, 2009a; Jegatheesan, 2005; Jegatheesan, Miller & Fowler, 2009).

The impact of maternal influence in the sibling relationship of a child with autism has been documented by Jegatheesan and Witz (under review) in an ethnographic case study of a South Asian Muslim immigrant mother and her two sons: an 11-year-old typically developing son and a six-year-old son with autism. The mother's positive interpretations of disability (e.g., child is a blessing from God; chosen parents to protect Allah's child) contributed to the mother being proactive in creating an advanced level of awareness in her typically developing son, which she firmly believed would enable him to support his brother with autism at all levels. The mother was also instrumental in teaching her typically developing son to be compassionate through the teachings of Islam. The authors found that the typically developing brother was extremely empathetic and protective of his brother and had a positive interpretation of disability.

Along similar lines, the purpose of the current study is to develop an understanding of how parents socialize sibling relationships in two families with one child with autism and one typically developing child. This study is comprised of in-depth case studies of two families: one European American and one Asian American family in the Pacific Northwest region of the United States. Data are drawn from interviews with the parents. The following research questions guided the study: (1) What are parents' beliefs about having a child with autism? (2) What are parents' expectations for sibling role relationship? (3) What role do parents play in socializing sibling relationships?

### **Method**

This study is part of a larger qualitative study designed to examine the beliefs and experiences of disability in young children who have siblings with autism (Braun, 2008). The larger study used multiple methods such as interviews with the parents and children, observations of family interactions and video recorded observations of sibling interactions during play in the homes of two families. The use of multiple methods helped ensure the trustworthiness of the data and findings. The primary source of data for this paper are interviews conducted with the parents, however child friendly interviews with the children and video recorded observations of the siblings at play also contributed in important ways to understanding the influence of parents on the relationship between the children (we have provided a brief description of child interviews and video recorded observations in the section on procedure). A qualitative methodology was chosen because it was particularly suited for the task of examining parents' views and beliefs about disability, their expectations for their children and their relationships and the role they play in socializing sibling relationships. Consistent with the philosophy of qualitative methodological approach, we sought to use interviews with parents as a forum for their voices to be heard.

### **Participants**

Two (one European American and one Asian American) families from a large city in the United States participated in this study. Each family had a son with autism and an older son who was typically developing. Parents and their children (with autism and typically developing) participated in the study. Table 1 provides a summary of the parents' background and Table 2 provides a summary of the children.

### **Instruments**

A demographic questionnaire was developed in order to collect descriptive information about the parents, such as their age, education level, occupation, number of years in the U.S, and ethnicity as well as information about their children (e.g., age, gender, age at diagnosis, gender).

An interview protocol was developed after a review of the existing literature on parent influence on sibling relationships of children with autism. The interview topics centered around parents' beliefs about having a child with autism, their role, expectations and socialization practices.

Table 1.  
*Family Information*

Family	Ethnicity	Native language	No. of years in the US	Religion	Education (Mother & Father)	Occupation (Mother & Father)	Age (Mother & Father)	Primary caregiver	Number of children	Language spoken at home	SES
Smith	European American	English	Born in US	Catholic	M: Associate's Degree F: Bachelor's Degree	M: Sales F: Operations Management	M: 38 years F: 42 years	Both parents	2	English	Middle
Nguyen	Asian American	Vietnamese	Mother: 9 years Father: 18 years	Catholic	M: Bachelor's Degree F: Bachelor's Degree (both from Vietnam)	M: Unemployed F: Building Maintenance	M: 43 years F: 48 years	Mother	2	Vietnamese (primary language), English	Low

Table 2.  
*Child Information*

Family name	Name, age, & gender of child with autism	Name, age, & gender of typically developing child	Language spoken with children	Related services for child with autism
Smith	Joey 4 years old Male	John 7 years old Male	English	Speech, physical, occupational, and ABA therapy, IEP
Nguyen	Tyler 5 years old Male	Trevor 7 years old Male	Vietnamese (primary language), English	IEP, some therapies at school

Our purpose in this study was not to generalize our findings but to understand, in-depth, parents' beliefs about disability and the ways in which they influence and socialize sibling relationships in two culturally different families. The main criteria for selecting the two families as final cases were based on relevance to the phenomenon, diversity across contexts, and opportunity to learn about complexity and contexts (Stake, 2006). The recruitment process involved posting flyers around the city and personal contacts with families. The final two families were selected as the best matched pair of families, given that they both had two sons of approximately the same age, with the younger son being diagnosed with autism. Inevitably, the families varied on some potentially influential aspects, such as socioeconomic status. We will touch on how these factors could have also affected the sibling relationship and home environment throughout the results and discussion (see Braun, 2008 for a more thorough review).

### **Procedure**

**Interviews with the parents.** Four audio-recorded semi-structured interviews totaling approximately five hours per family were conducted with parents in their homes. Interviews with the Vietnamese family were conducted in Vietnamese with the help of an interpreter of the same ethnicity. Interviews in Vietnamese were transcribed and then translated into English by the interpreter. Interviews with the European American family were conducted in English by a researcher of European American origin. Parents were interviewed about their beliefs in having a child with autism, socialization practices, and their roles and expectations for their children. Questions for subsequent interviews were developed based on our analyses of the previous interviews. In this manner, a deeper understanding of the issues and themes that emerged in the previous interviews was sought in the additional interviews.

In addition, parents were also contacted to provide their interpretations and explanations about some of the comments made by the typically developing children during their interviews (the child's interview is described briefly below). This helped clarify and provide additional insights about the influence of parents on the siblings' relationships and the children's perceptions. The first author maintained a log of conversations with the parents at all times.

**Interviews with the typically developing children.** A semi-structured interview using the 'draw-and-tell technique' (Driessnack, 2005) was conducted with the typically developing children. Children were asked to comment on their views of a disability like autism, perceptions of their siblings with autism, and their relationship with them. For example, the typically developing children were asked to draw what autism meant to them, an activity they enjoyed together as brothers, and drawing how they felt when around their sibling. For more information about interviews with the children, please refer to Braun (2008) and/or Sage and Jegatheesan (2010).

**Video recorded observations of siblings at play.** The two brothers from each family engaged in a 30-minute free play session at their home one week after the draw-and-tell

session. We sought to examine their relationship, communication, and interaction style in a natural activity. Disruptions in the environment were minimized, as children with autism are often challenged by changes to their environment or schedule. Parents and children gave permission to videotape the play session, and parents were invited to be present. Siblings played with standard toys chosen by their mothers, and shown to be liked and familiar in their daily lives. For more information about the play sessions with the children, please refer to Braun (2008) or Sage and Jegatheesan (under review).

### **Ethical Issues**

Formal ethics approval was obtained from the Institutional Review Board at the University of Washington. Both families provided parental consent. Parents were informed of their rights (e.g., withdraw from the study at any time). The Vietnamese family was offered the choice of having the consent letter in their native language. Each participant was assigned a pseudonym to protect his or her identity. A Vietnamese interpreter provided language assistance to the Vietnamese family, lending interpretation and translation services during the interviews and transcribing and translating the interviews after the interviews were complete.

### **Analysis**

Analysis was an ongoing process during the research. The constant comparative method of analysis was used (Glaser & Strauss, 1967). This method is grounded in the data and inductive. A line by line multiple coding of parents' narratives was completed independently by the two authors (Barbour, 2001; Miles & Huberman, 1994). Analysis of the videos included coding of each play episode focusing on the theme of play (free, structured, solitary or mutual play; maternal involvement, intervention, directives, and play expectations; sibling mood, emotion, and positive or negative verbal and physical behavior). The two authors engaged in discussions of the interpretations to reach their final interpretation. In this manner, categories and codes were derived through repeated reviews of the transcripts. Consistent with the concept of grounded theory (Lincoln & Guba, 1985), original themes were altered, eliminated, or merged, which revealed new or different perspectives. The constant comparative analysis required the researchers to continually go back and forth to the data coding (Bogden & Biklen, 1982). During the process of triangulation, the authors collaborated with the parents and two members of the Vietnamese community by providing copies of the transcripts to gain their reflections, interpretations, and clarification of specific issues. The authors met with these individuals to discuss interpretations to ensure accuracy in their conclusions. Interpretations were emailed to the Smith family and discussed with the Nguyen family by the interpreter. They believed our interpretations to be accurate, thus no changes were made to their transcripts.

### **Results**

We begin the next section by providing a general description of the family. We then describe parents' beliefs about having a child with a disability, their expectations for sibling relationships, and the role they play in socializing the relationship between the siblings.



### **The European American Case Study: The Smith Family**

The Smith family had two children, a typically developing son named John (age 7) and a son with autism named Joey (age 4). Joey “scored very low in all his developmental tests” and demonstrated behavior that was related to his disability (e.g., self-stimulatory behavior, preference for sameness). However, he had improved significantly with regular therapies, occurring both at school and in the home on a consistent basis. The Smith parents both reported that this made him a relatively easy child to get along with and reduced child demands and care. According to both parents, John and Joey were very close to each other.

The Smith parents were knowledgeable about autism and learned how to provide support to both their sons by reading books and on-line articles about autism. Therapists and teachers also provided them with adequate information and advice. Although both the parents worked during the day, the Smith parents had a flexible schedule. This allowed them to spend a considerable amount of time with their children. The parents reported that they often participated in their children’s activities and gave suggestions on how to make games inclusive of one another. The family spent a lot of time talking about the children’s achievements and hobbies. The Smith family lived in a spacious two-story home with a large fenced backyard. Age appropriate toys for both their children were in abundance. Children were observed to be involved in free and rough and tumble play.

**Parents’ beliefs about having a child with autism.** The Smith parents believed that a combination of medical factors (e.g., genetics, vaccines) affected Joey when he was 8 to 10 months old. Both parents maintained a very hopeful outlook on Joey’s life, and provided him with a vast amount of therapy. They also treated Joey’s disability with openness and pride. Mrs. Smith said,

*“I look at Joey’s disability as possibility. Anything and everything is within reach for him. Disability is not a barrier to his future, but something that can open doors for him. Joey will be capable of anything as long as he puts his mind to it...It’s important to me to let the whole world know about Joey and how proud we are of him.”*

**Parents’ expectations for sibling role relationship.** The Smith parents hoped that John would be a mentor, teacher, and companion for Joey. They added that they did not force this role relationship because it would put undue strain on their older son. Mrs. Smith said, “My expectations for him in regards to Joey are to be respectful, helpful and tolerant of him. I don’t believe I’ve ever voiced those expectations to John, nor have I had too.” Both parents felt “fortunate” that John had become what they had hoped for. Mrs. Smith stated,

*“We are lucky that John understands how to treat Joey. We have not had to coach John. He has developed his own way of dealing with Joey in a very respectful manner and became a mentor and teacher as he learned more about*

*autism. John has made accommodations in the sense that he understands that Joey may have different needs.”*

Both parents wanted John to be “himself” when he was with his brother. They stressed that it was not John’s responsibility to take care of his brother. Mr. Smith explained,

*“We as parents don't want to make Joey a burden on John. It is not John's job to care for his brother or baby-sit him at any time. We have been very respectful of John's life as well. We don't want him to feel he has to do anything out of the ordinary to care for his brother. On the other hand, we were very hopeful that John would choose to be a support piece in Joey's life.”*

The parents had equal expectations for both brothers when it came to appropriate behavior. Joey was expected to listen to his older brother and obey him. The Smith parents believed that it was important to create a balance of attention and affection between both their sons and not “dominate the landscape with Joey talk.” Both Smith parents made a genuine effort to focus on John’s accomplishments as well.

### **Parents’ role in socializing sibling relationships**

***Building awareness of autism in the typically developing child.*** The Smith parents believed that their role was to educate their typically son about his brother’s disability and to be very open and honest with him concerning his brother’s progress and the kinds of support he might require in the future. The parents informed their son John about his brother’s disability as soon as they received the diagnosis. John was five years old at that time. “Most definitely!” was Mr. Smith’s response when asked whether it was important for John to know about his younger brother’s disability. The parents reported that they gave John honest answers to his questions about his brother. They said,

*“John would ask us questions like ‘What is autism?’ ‘When will it be gone?’ We gave him pretty simple answers. We told him Joey's brain processes information differently, but that he probably understands what we are telling him. Some things such as light and sound may upset him, but that in time he will learn how to deal with these situations. Simply put, I told John he may make a basket in the first try, but Joey will take four shots and then repeat it before he makes it. In the end he made the shot and that's what's important. We told John that Joey will always be autistic.”*

Both parents’ ultimate goal for their two children was to have a seamless relationship (meaning their sons would genuinely have affection for one another, get along well, and engage in little conflict) and as a result felt that it was critical to share as much information as possible with John. They also felt that since John was the most influential person in his brother’s life, providing him with information about his brother’s disability would enable him to help his brother. His parents taught John all that he needed to know about autism (e.g., what it meant for Joey’s future and how it affected Joey’s daily

communication, interactions, etc.) so that he could fully understand his brother and build a relationship with him. They strongly believed that John had “greatly benefited” from knowing that Joey had autism as early as he did. Both parents wanted John to be proud of his brother’s accomplishments. They helped John see his brother as not being too different from other children by making life as normal as possible and by downplaying Joey’s disability in their everyday family conversations. Family conversations about Joey were mostly lighthearted.

The Smith family stated that building an awareness of autism in their typically developing son had a positive impact on the sibling relationship. For example, John found ways to communicate and interact with his brother from the time he learned about the specifics of autism. Mr. Smith said, “...He is so good with Joey you would think we had trained him, but he has learned on his own how to get eye contact and how to speak to Joey, how to work in Joey's world.” During play interactions, we found that John continually accommodated his brother. For example, when Joey lost interest in playing a board game, John immediately reached for a bubble maker, a toy he knew would capture Joey’s attention. He engaged and entertained his brother throughout the activity. Mrs. Smith said that John recognized that some days could be a real struggle for Joey and had become protective of him.

#### **The Asian American Case Study: Nguyen Family**

The Nguyen family had two children, Trevor (age 7) and Tyler (age 5), both of whom were born in the United States. Tyler was diagnosed with moderate to severe autism around his third birthday. Tyler had not received regular speech and behavior therapy, which slowed his progress. Despite Mrs. Nguyen’s request for therapy for her son, the school did not provide the family with speech and behavior therapy services. He had frequent tantrums and a preference for sameness. According to Mrs. Nguyen, Tyler was a “very demanding child to care for on a regular basis.” The brothers were not close to one another and had frequent disagreements.

The Nguyen parents reported that they did not have adequate knowledge about autism. Mrs. Nguyen said that she had little information on how to support her children during play and provided them with ideas on including each other. As a result, the brothers often attended to their own toys and indulged in solitary play. In an observation of the brothers at play, Mrs. Nguyen played primarily with Tyler and made no attempt to engage Trevor in the same activity. The Nguyen parents had a busy schedule which gave them very little time to spend with their children. The only activity Mr. Nguyen at times shared with his children was watching television and eating dinner together. Since Mrs. Nguyen shouldered the care-giving and household responsibilities, she was often unable to supervise her children. Mrs. Nguyen, therefore, had strict play rules and a structured daily schedule to minimize conflicts between the brothers when she was not around. For example, the brothers could watch television for an hour after school and they were allowed to play with each other for an hour before dinnertime. Mrs. Nguyen explained that she was busy with her household chores and childcare and as a result was frequently tired. She added that since her family lived in Vietnam, she could not turn to anyone for

help or advice on parenting. The Nguyen family lived in a small apartment with limited space for play activities (e.g., living room). They were also required to play passively and softly because of prior warnings that the parents received from the apartment management about the noise level in their home.

**Parents' beliefs about having a child with autism.** The Nguyen parents were torn between a medical explanation (e.g., child's brain damaged due to lack of oxygen during delivery), and the Vietnamese cultural beliefs of retribution as a result of evil deeds. However, they state that their cultural beliefs have an important place in their family. Mrs. Nguyen believed that her son was "paying the debt" for the wrongs deeds of her ancestors. Mrs. Nguyen also believed that her "terrified childhood" years during the Vietnam War had connections to her child having autism.

The Nguyen family lived in secrecy and fear from the time they received diagnosis of their son's condition because of the stigma associated with having a child with a disability. With the exception of her husband, Mrs. Nguyen kept her son's disability a secret from the rest of her family and community. She said,

*"When I knew that I had a child with a disability, I kept myself at home and didn't want to talk with others except school staff, because I didn't want other people to know the truth about Tyler. I myself couldn't accept the truth and would not accept his diagnosis. I felt depressed and hopeless when I received my son's diagnosis."*

Mrs. Nguyen reported that, in time, she overcame her depression so that she could provide quality care for her children. She did not believe that her son would recover 100% in the future. She did, however, recently come to believe that he could be educated and become independent.

**Parents' expectations for sibling role relationship.** Mrs. Nguyen reported that she expected her older son Trevor to be a "good role model capable of displaying altruism in a sibling relationship." She also expected him to be "willing to spend time, teach and share whatever he has with his younger brother and protect him." Trevor was also expected to work hard to "receive utmost respect from his younger brother through his thoughtful deeds." Mrs. Nguyen explained further,

*"Trevor should become a role model who sets good examples for Tyler. He should be like the mirror that Tyler sees every day. Whatever he sees in Trevor, the good and the bad will influence Tyler. I expect Trevor to teach Tyler whenever he can (i.e. read to Tyler as much as possible because it'll help both learn together) and expect him to watch out for Tyler's safety. We also want Trevor to be passive when playing with Tyler. For example, when there is a new toy in the house, Tyler can play with it first and when he gets bored then Trevor can play with it. It's usually okay because Tyler loses interest fairly quickly. I also teach him to be a nice, good, and compassionate brother and not react*

*aggressively towards Tyler when he does something wrong or annoying. Tyler has a poor attention span, and this can be frustrating for Trevor. But my husband and I want Trevor to show care for Tyler and wear a smile on his face when he is in his brother's presence despite his inner anger and frustration."*

Mrs. Nguyen did not outwardly voice these expectations to Trevor. Instead she said that she indirectly expressed them through teachable moments that occurred during informal family interactions. She hoped that he would eventually figure out his role as an older brother and his parents' expectation on how he should treat his younger brother. Mrs. Nguyen understood that it was not always fair for Trevor to constantly give up his toys and receive less attention than his brother. Her expectations and goals for sibling relationships were guided by her culture, in that the older sibling had a specific role and responsibility irrespective of his/her age.

Mrs. Nguyen had some expectations for her son with autism but admitted that these expectations were not strictly adhered to. She said,

*"Because Tyler is still so young and has special needs, the entire family has been living in a way that ensures Tyler doesn't feel isolated and often he gets whatever he wants as a result. I am making some changes and would like to teach him to share, cooperate, have fewer tantrums, and be less demanding.... I am also teaching him to respect his older brother and listen to him more."*

### **Parents' role in socializing sibling relationships**

***Building awareness of autism in the typically developing child.*** The Nguyen parents did not inform their older son Trevor about his brother's diagnosis for two years. At the time of diagnosis, Trevor was five years old. The Nguyen parents believed Trevor was too young to understand a difficult concept such as autism. They were also afraid that Trevor would react negatively towards his younger brother and tease him. Eventually, Mrs. Nguyen was forced to talk to her older son about his brother's disability. She explained the reasons, "Trevor overheard a phone conversation between me and Tyler's teacher. The teacher complained profusely about Tyler, his tantrums, preference to be alone..." The telephone conversation was reported as "uncomfortable and unpleasant." Trevor had not heard such a conversation before so Mrs. Nguyen finally told him about his brother's disability.

Since then, Mrs. Nguyen has helped Trevor understand more about autism by encouraging him to read children's books with characters that have autism. She also explained the reasons behind Tyler's tantrums and for his preference to play by himself and began to enlist Trevor's help to watch out for Tyler. Mrs. Nguyen believed that Trevor should understand his responsibility as an older brother and learn on his own how to accommodate his brother now that he was aware of his condition.

Since the time Trevor has learned about his brother's disability (three months prior to data collection), there have been minimal changes in his relationship with his brother. The brothers continue to play separately and pursue different hobbies, and hence their joint interactions remain limited. During an observation of a 26-minute free play session, it was noted that both brothers indulged predominantly in passive and solitary play. They did not communicate with one another and engaged in physical fights over simple things. Trevor demonstrated a lack of interest in playing with his brother. Since Trevor learned about Tyler's autism recently, the full impact of his awareness of his brother's disability remains unknown.

### **Discussion**

Despite the need to increase our understanding of how parents socialize sibling relationships, very few studies have studied parenting and family influences on sibling relationships (e.g., Dallas et al., 1993; Strain & Danko, 1995; McHale & Gamble, 1989; VanRiper, 2000). The study reported contributes to the limited knowledge base.

Results indicate that parents played an important role in determining the overall quality of the sibling relationship. As stated by Strain and Danko (1995), caregivers' encouragement can be extremely influential in encouraging play activities between siblings and building a stronger sibling relationship. Dallas et al. (1993) also suggested that maternal intervention in play activities leads to a higher number of cooperative behaviors among siblings, confirming that parents can elicit positive behaviors between their children.

Findings from the two case studies also indicate that parents' beliefs about having children with autism affected their decision to build awareness of autism in their typically developing children. This in turn had a significant impact on the quality of the relationship between the siblings. The Smith parents believed that their son's disability was caused by a combination of medical factors. This is similar to findings reported by other scholars in their work with European American families (Gray, 1995; Goin-Kochel et al., 2005; Lingam et al., 2003). The Smith parents were open about their son's condition, and viewed disability as possibility. They educated their older son so that he could help his younger brother with autism. This awareness helped the brother define his role in the sibling relationship, nurture his prosocial behavior, and enhance his ability to adapt to his younger brother's needs. This was not the case with the Nguyen parents, who had a negative interpretation of why they had a child with autism. The Nguyen parents reported that they were paying for past sins and felt shameful about having a child with a disability. Negative interpretations of disability through cultural and religious frames have been reported in other studies of Asian families (Chan & Lee, 2004; Gabel, 2004; Jegatheesan, 2009b). As a result of negative feelings, the Nguyen parents did not inform their older son about his brother's disability for two years. The older brother's lack of awareness impacted his ability to develop the skills and compassion he needed to interact and bond with his brother. The brothers had frequent

disagreements, often did not play together, and pursued different activities in their free time. Glasberg (2000) suggested that parents often overestimate their child's understanding of the impact of disability. Children often do not have enough information about a disability or have incorrect information. The older brother in the Nguyen family did not have the same level of awareness as the older brother in the Smith family. Findings from our study as well as Glasberg (2000) highlight the importance of parents conversing about the diagnosis of autism and information about the disability with their typically developing children. The increased awareness and knowledge of their siblings' disability can assist in developing positive sibling relationships.

The two families had different role expectations for their typically developing sons. The European American parents wanted their son to be helpful, and respectful of his brother. They hoped that he would be a mentor. However, they did not force him to take on any specific role. They also believed that it was not the older brother's responsibility to take care of his younger brother with autism. The Vietnamese parents expected their son to be a teacher, a role model and guardian for his brother and wanted him to be passive with his brother during play. The older son had specific responsibilities and duties towards his younger brother that was in accordance with their Asian culture. The Nguyen parents ensured that their older son obeyed them and followed the cultural rules. The Smith parents believed in self-development of their older son, which is consistent with the more individualistic perspective of the American culture (Markus & Kitayama, 1991). The more authoritative style of parenting in instilling familial responsibilities and filial piety as seen in the Nguyen family has been documented in other studies of Asian families (Chao, 1995; 2000). Implications for sibling relationships in each family were unique given such differences in role expectations. The European American older sibling took a more active role as a teacher and mentor in his younger brother's life and genuinely enjoyed the time spent with his brother. The Vietnamese sibling took a more passive role in his brother's life, and was forced to spend time with his brother. He was found to be unhappy during these interactions with his brother with autism.

Parents' knowledge of autism, the time spent with the sibling dyad, the home environment, and the severity of the child's disability also impacted parenting and sibling relationships. The Smith parents were knowledgeable about autism and this increased their ability to enhance the quality of the sibling relationship. Mrs. Nguyen's lack of knowledge about her son's disability negatively impacted her confidence and ability to provide appropriate suggestions to her sons. She also had very limited time to spend with her sons because of her busy schedule, which was not the case with the Smith family. Both families' home environment also played a role in sibling interactions. The Smith children indulged in active and fun games in their spacious home whereas the Nguyen children could only engage in quiet and passive games in their small apartment due to noise level restrictions. Providing care for Tyler was more demanding and time consuming for Mrs. Nguyen. Such family and child characteristics played a role in the ability of parents being able to foster nourishing sibling relationships. These conclusions are in line with VanRiper (2000), who examined family variables that impacted sibling relationships when a child has Down syndrome. The author found that families with lower levels of family demands, a higher number of

resources, superior coping skills, and higher levels of affirmative problem-solving communication experience greater sibling well-being. These findings appear to hold true to these two families of children with autism.

It is important to note that the two families had different cultural, social, and economic situations. The Asian family was an immigrant family of low socioeconomic status while the European parents were born in the United States and were accustomed to spending much time with their children in a spacious home environment. As a result of their low socioeconomic status and presumably other cultural and language barriers, the Nguyen parents were not able to easily access timely services, and information pertaining to their rights, entitlements, and services for their child was less available to them. In the case of the Vietnamese family, the parents encountered problems that are common to immigrants such as a lack of understanding of autism and special education system, inability to advocate for their child, and language barriers (Jegatheesan, 2005, Jegatheesan, Fowler & Miller, 2010; Park & Turnbull, 2001). Stress from lack of financial resources and social support and separation from family also affected the Nguyen parents. These findings mirrored the experiences of Asian parents who had children with autism in Jegatheesan (2005) and Jegatheesan, Miller, and Fowler (2010). (For further information on these differential family components, see the larger study – Braun, 2008).

Disability researchers recognize that current recommended practices on parenting and siblings of children with disabilities are based on a small body of sibling research. The parents in this study demonstrated the role they play in helping siblings cooperate with each other and the factors that create challenges and barriers in building sound sibling relationships. Dallas et al. (1993) suggested that parental intervention helps children play a more active role in their interactions with siblings. Parents shape sibling relationships, and the current study demonstrates that some parents are in need of support and education to help their children form warm relationships.

### **Limitations**

Limitations of this study are related to the small sample size of two families. Generalizing the results of this study to all European American and Asian immigrant families in the United States was not the primary purpose of this study. The case study methodology made it possible to examine sibling relationships in two culturally diverse families. This study provided a window into understanding how parents socialize sibling relationships.

### **Implications for Research**

This study has documented families' experiences in fostering sibling relationships between typically developing children and children with autism. We have found that both European American and Asian immigrant parents' beliefs about autism and their expectations for their children substantially affect the quality of the sibling relationship. Particularly for the Asian family, cultural beliefs played an important role in parents



socializing sibling relationship. Future research should continue this line of research on how families support and nurture sibling relationships and the barriers they face in doing so.

### **Implications for Practice**

**Connecting parents with other parents of children with disabilities.** Professionals should strive to connect parents of children with disabilities with one another because they can be a source of support and resource for each other. Particularly, parents who share a similar culture or language can help fellow parents in a myriad of ways. Parent-to-parent support can be vital for emotional, respite, informational, and interpretation support on an ongoing basis.

**Providing sibling and other related support services.** Professionals can support parents by connecting them with sibling support organizations that teach parents how to nurture and support sibling relationships (e.g., SibShops). Such organizations are valuable avenues of learning for parents. Professionals must also maintain an open line of communication with parents and provide reassurances and help them understand important issues such as rights and entitlements as parents of children with disabilities. All these contribute towards reducing uncertainty and stress in parents.

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