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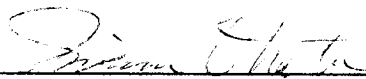
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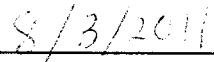
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Running Head: SIBLINGS OF CHILDREN WITH AUTISM

Siblings of Children with Autism: A Family Systems Approach

By

Mina Ohata

**Thesis**

Submitted In Partial Fulfillment of the Requirements for the Degree of

Master of Arts In Clinical Psychology


In The Graduate School, Eastern Illinois University

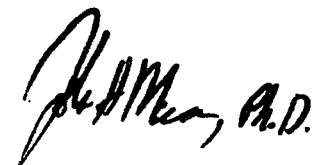
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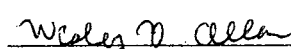
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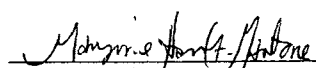
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### Abstract

In the present study, experiences and perceptions of siblings of children with an autism spectrum disorder, as well as their mothers, were examined using family systems theory as a guideline. Because previous researchers reported inconsistent findings related to possible positive and negative effects of having a sibling with an autism spectrum disorder, the present study collected descriptive data by means of interviews in order to obtain in-depth information. Five siblings (ages ranged from 6 to 14) of children with an autism spectrum disorder and their mothers participated in the study and described in their own words their experiences of having a child with an autism spectrum disorder in their families. Despite their varied ages, siblings were able to provide insightful information about their experiences and perceptions related to having a brother or sister with an autism spectrum disorder. Based on their responses, themes related to family systems theory and the family life cycle, as well as positive qualities, strengths and needs of the families and the children with an autism spectrum disorder, were identified. The results of the present study also indicated that parental reports might not always be the same as the perceptions of their children. Practical implications of the present findings related to treatment and interventions are described. Additionally, future directions and limitations of this research are discussed.

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## Siblings of Children with Autism: A Family Systems Approach

Today, more and more people are aware of a developmental disorder called autism.

Autism is the most well-known of the Autism Spectrum Disorders (ASDs), which are a group of neurodevelopmental disorders whose symptoms range in level of severity (NINDS, 2009).

Although substantial changes have been proposed for the fifth edition, in the current Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> edition, Text Revision (DSM-IV-TR; APA, 2000), autism spectrum disorders are described as Pervasive Developmental Disorders and include Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS).

According to APA (2000), children with autism exhibit impairments in reciprocal social interactions and communication skills and have restricted, repetitive, and stereotyped patterns of behaviors, interests, and activities. In other words, they are likely to struggle with both verbal and non-verbal communication, may have trouble understanding social cues and developing relationships, and show atypical behaviors, such as hand flapping and excessive preoccupation with certain objects. Symptoms of autism are present before the age of three, and autism is diagnosed more in boys than girls (APA, 2000).

Previous studies have examined how the unique characteristics of autism and ASD affect family members. Additionally, some researchers have applied different theories, such as Piaget's cognitive developmental theory and the diathesis-stress model, to explain what it might be like to have a child with autism in a family. In the present study, family systems theory is used as the framework to understand how different factors related to a child with autism can affect family members, especially siblings. There are a few reasons for examining influences on siblings of children with autism. First, siblings are likely to stay in each other's life far longer than their

parents; in fact, sibling relationships are typically the longest relationships people have in life (Gallagher, Powell, & Rhodes, 2006; Orsmond & Seltzer, 2007). Although parents have a huge impact on children's lives, siblings will ordinarily start out as play mates and gradually develop important lifelong bonds and provide continual support to each other (Findler & Vardi, 2009; Orsmond & Seltzer, 2007). Secondly, because brothers or sisters are often the first close friends a child has, interactions among siblings are a primary source for children to acquire and practice social and communication skills (Verte, Roeyers, & Buysee, 2003). According to Orsmond and Seltzer (2007), sibling interactions can provide many learning opportunities and experiences and promote emotional, cognitive, and personal development. Although their experiences are not always identical, siblings typically have similar experiences when they grow up and are raised by the same parents or guardians. In addition, they likely have similar relationships with other family members, including parents and grandparents. There is much to learn from siblings, therefore, about family life. Finally, much of the previous research on families has focused on parents, especially mothers, of children with autism. Understanding how each member is affected by having a child with autism in the family can help identify strengths and needs of a family. Siblings have much to share about their experiences, feelings, and needs associated with having a brother or sister with autism. By taking notice of their personal stories, we can learn how siblings' needs can be best met, as well as how to minimize problem situations and maximize opportunities for growth within a family.

### *Family Systems Theory*

A family is not simply a collection of individuals but is a complex system involving interdependent members (Minuchin, 1985). Family systems theory defines a family as an organized, complex system that is in continual transition and whose functioning may be altered

by changes in the behavior of one member, relationships among family members, or any other changes that occur over time (Cox and Paley, 1997; Powers, 1991; Thomas, 2001). Each family system develops its own sets of rules, patterns of behavior, boundaries, strategies, and procedures, all of which are directed toward maintaining the system. Although the family system has the ability to adapt to changes within as well as outside the system, it tends to remain fairly stable in how it functions over time (Minuchin, 1985). Numerous factors can contribute to how a family functions across different life stages. When a child has a developmental disability, such as autism, there may be unique stresses and challenges in a family's life. For example, other typically developing children in the family may be reluctant to be with the child with autism in public due to the sibling's atypical behaviors (Morgan, 1988). Seeking and receiving adequate professional help such as speech, occupational, and behavioral therapy can also create a financial burden and a stressful, busy schedule for parents. Because family systems theory is relevant for families of children with autism, an overview of the key points from family systems theory follows.

*Family Subsystems and Boundaries.* According to family systems theory, each family system is composed of smaller units called family subsystems, which are separated by boundaries (Minuchin, 1985). Examples of family subsystems are the parental, marital, parent-child, and the sibling subsystems. According to Minuchin (1985), individual family members are also considered to be subsystems. The boundaries among subsystems in a family can be crucial in determining how a family functions. Healthy boundaries are "clear but flexible," which allow the subsystems to differentiate from each other and function effectively, such as adapting to changes (Cox & Paley, 1997). In contrast, boundaries that are too vague or rigid can bring about problems for family members. If the boundary between the child subsystem and the parent

subsystem of the family is vague, for example, the parents may place too many responsibilities on the typically developing children (Parke & Gauvain, 2009). Some children, especially older ones, may take on supervisory or disciplinary roles and become more like teachers or parents to their younger siblings (Morgain, 1988; Powers, 1991). Moreover, when children are not successful at completing age-inappropriate responsibilities, they may receive negative feedback or even be punished due to the unreasonably high expectations placed on them. In another case, one parent may become overly involved with a child with autism, leading to the neglect of other family members. This over-involvement can lead to other children's recognition of differential parental treatment (Kowal & Kramer, 1997). In either case, unhealthy boundaries among subsystems can be problematic for the family.

Additionally, it is important to note that the family systems approach was implemented unfairly in the past when describing subsystems and boundaries for families of children with disabilities, including autism. Parents, especially mothers, of a child with a disability were blamed for any atypical development of the child (Brown, 1999). Professionals and researchers of family systems theory today understand that the behaviors of family members do not cause autism. Instead, the family systems approach helps us recognize that healthy boundaries among subsystems are likely to promote better family functioning for all families.

*Homeostasis.* Because they must respond to daily events as well as long-term challenges and changes, families must be able to adapt and change. According to family systems theory, families attempt to achieve a state of balance, or homeostasis, by developing a pattern of rules or strategies that govern how they interact and react to challenges and changes (Cox & Paley, 1997). When a family develops certain patterns of functioning, this pattern typically becomes stable over time. Once a family develops homeostasis in its functioning, the family is likely to

resist changes in how it operates (Minuchin, 1985). Therefore, if a family develops unproductive interaction patterns, the family may struggle with problems of adapting without realizing their resistance to change. A family that has developed productive interaction patterns, on the other hand, may have an easier time adjusting to challenges and changes. For instance, how a family responds to a diagnosis of autism will depend, in part, on how the family functions as a unit (Leal, 1999). One family may approach the diagnosis as a challenge, another as a catastrophe. A family who views the diagnosis as a catastrophe may have difficulty adapting to the unique needs of a child with autism and instead expect the family and household to continue on as before. The family who views the diagnosis as a challenge may be better able to adjust or change, as necessary, to incorporate the needs of the child with autism into how the family functions as a whole.

*Mutual Shaping.* As noted by Parke and Gauvain (2009), family systems theory allows us to examine how changes in one member or subsystem can affect other members, subsystems, and the entire family, a phenomenon called “mutual shaping.” Because of the interdependence that exists among members of a family system, changes experienced with regard to any part of the system will cause changes for the system as a whole (Cox & Paley, 1997). According to family systems theory, each member and subsystem (e.g., parental subsystem and sibling subsystem) of a family can influence one another and the entire family both positively and negatively (Morgan, 1988). Family systems theory also lets us explore what factors contribute to these changes. For example, if parents are experiencing difficulties with parenting a child with autism and have a poor support system, this stress may spill over in their interactions with their other children or to their marital relationship. On the other hand, if parents receive adequate social and professional support and are thus less stressed, they may have more time and energy for all of their children

and their partner. Positive changes for parents may also help promote positive interactions and relationships among siblings. The point of mutual shaping is that changes in one part of the system, whether in an individual or in a relationship or subsystem, will affect the entire family system (Parke & Gauvain, 2009). The changes may be profound or subtle, but they can have system wide effects. Acknowledging the effects of mutual shaping, therefore, can play an important role in understanding a family system and in promoting adaptability in the family.

*Shared and Non-shared Environments.* Another factor that needs to be considered is the difference between shared and non-shared environments among family members. A shared environment is defined as the conditions or experiences shared by children raised in the same family (Jenkins, Simpson, Dunn, Rasbash, & O'Connor, 2005). Examples of shared environments include such factors as the socioeconomic status of the family, the neighborhood where the family resides, the employment status of the parents, and the school district the children attend. Thomas (2001) argued, however, that how a specific environment is experienced is unique to each individual. In other words, even when the entire family is exposed to the same environment and circumstances, individuals within the family may experience these factors differently. Therefore, a non-shared environment is a set of conditions or activities experienced by one child in a family, but not shared with another child in the same family (Turkeimer & Waldron, 2000). Experiences not shared would include factors related to the individual characteristics of a particular child. For instance, two siblings may attend the same school throughout their educational experience (a shared environment), but the sibling with autism may have been in special education classrooms, and the typically developing sibling participated in typical classroom settings (a non-shared environment). Another example is when the siblings reside in the same home (shared environment) but have different styles of communication (non-



shared environments). In the case of a child with autism who is nonverbal, family members may respond to the child differently from the typically developing sibling. These examples illustrate that the same environment is not necessarily experienced in an identical manner even when siblings grow up in the same household and are subject to similar circumstances. Even small differences in non-shared environments may cause differences in how siblings develop, and we cannot assume a homogeneous environment for all siblings from the same family (Turkeimer & Waldron, 2000). This notion of non-shared environments and how it may influence the development of family members may be overlooked by both professionals and family members.

### *Family Life Cycle*

All families go through different stages of the life cycle as they progress. Depending on which family life cycle stage they are in, they experience different challenges and joys. According to Turnbull, Summers, and Brotherson (1986), a family life cycle for a child with disabilities, such as autism, consists of seven stages: the couple only stage; childbearing and having a preschool child stage; having a school age child stage; having an adolescent in the family stage; launching children out of the family home stage; postparental stage when there are no children residing in the home; and the aging parents stage. Moreover, transitions from one stage to the next require changes in the family system (e.g., different developmental needs), which tend to bring about stress on family members (Powers, 1991). Each transition can be more challenging to those families who are resistant to change due to established homeostasis or interaction patterns (Powers, 1991). Additionally, when a family has a child with autism, the family may face “special stress” in addition to typical challenges at each stage (Turnbull et al., 1986). For instance, when a couple finds out that their two-year-old son is autistic, accepting the diagnosis, uncertainty of his special needs, and finding appropriate treatment may produce

additional stress on the family. Furthermore, the additional stress can be above and beyond that experienced by most families in the childbearing and having preschool children stage. An understanding of the stage of the family life cycle as well as any additional stressors that a family may be experiencing will help professionals promote healthy family functioning.

### *Cognitive Appraisal*

In addition to recognizing a family as a complex system and understanding transitional stress associated with the family life cycle, it is important to acknowledge family members' coping behaviors at an individual level in order to understand why interpretations of an event or situation may differ from person to person. Some previous studies incorporated a concept called cognitive appraisal to examine how people perceive stressful events or situations and cope with them (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Fong, 1991; Glasberg, 2000). Cognitive appraisal is a process in which a person examines if a given event or situation is positive (e.g., pleasant) or negative (e.g., stressful) and then chooses a course of action based on the initial judgment (Folkman et al., 1986). According to Folkman et al. (1986), the former part of cognitive appraisal is referred to as *primary appraisal* (evaluating whether an event is positive or negative to the person) and the latter part as *secondary appraisal* (deciding what to do to cope with it). Additionally, an individual's cognitive appraisal can vary depending on his or her cognitive ability (e.g., Piaget's cognitive developmental stages) and how much information and resources the person has at that moment (Folkman, et al., 1986). Available information and resources may include coping skills, support systems, past experiences, and how one understands or views the situations or events. For instance, some children may perceive the amount of time and attention their parents must devote to their sibling with autism as a positive characteristic of the parents because of cognitive development level, support from parents and other relatives, and

understanding of the situation. On the other hand, other children may perceive the exact same behavior as a negative characteristic.

According to Folkman et al. (1986), after individuals come to view an event or situation as positive or negative, they next explore what they can do to deal with it and evaluate if they are capable of taking possible courses of actions. For example, as a result of positive cognitive appraisal, some children, who recognize the special needs of a sibling with autism, may decide to help their parents by volunteering to carry out some household chores or relieve their parents of caretaking responsibilities by including the sibling with autism in their play or social activities. Cognitive appraisal, therefore, can play a significant role in an individual's perceptions of situations and in her or his decision-making processes. Moreover, if professionals and/or family members can recognize cognitive appraisal of each member, they can help strengthen or change ways of perceiving situations to promote better functioning of the whole family.

#### *Previous Research on Siblings of Children with Autism*

Previous studies have examined how a child with autism affects other children in the family. Some researchers have found negative influences on siblings, including poor behavioral adjustment (Hastings, 2003), poor social communication skills (Toth, Dawson, Meltzoff, Greenson, & Fein, 2007), less intimacy and nurturance (Kaminsky & Dewey, 2001), and poor language development (Toth et al., 2007; Yirmiya, Gamliel, Shaked, & Sigman, 2007). Others have reported a positive impact, such as less quarreling and competition in sibling relationships (Kaminsky & Dewey, 2001), and positive self-concept, as well as higher social competence (Verte, Roeyers, & Buysse, 2003). Additionally, there have been some researchers who reported both positive and negative impacts on siblings depending on other variables, such as gender of siblings, verbal ability of children with autism, the amount of stress experienced by parents, and

family sizes (e.g., Pilowsky et al., 2004). The main problem with interpreting the studies on siblings of children with autism has been these inconsistent findings.

*Research Designs.* The inconsistency in the results from previous research on siblings of children with autism may be due to differences in research designs. With regard to participants, some studies (e.g., Kaminsky & Dewey, 2001; Macks & Reeve, 2007; Pilowsky et al., 2004; Yirmiya et al., 2007) focused on autism only, but others (e.g., Goldberg et al., 2005; Rivers & Stoneman, 2003) included autism spectrum disorders, such as PDD-NOS and Asperger's disorder. Furthermore, even within the studies that used children with autism only, there appears to be differences in certain characteristics of the participants. For example, the ratio of boys to girls who participated in the studies was different from study to study. Also, age differences between siblings and children with autism varied. Specifically, some studies used younger siblings (e.g., Goldberg et al., 2005) and others used older siblings (e.g., Kaminsky & Dewey, 2001). In addition, the severity of autism ranged from low-functioning to high-functioning in various research studies (e.g., Pilowsky et al., 2004; Yirmiya et al., 2007).

Interestingly, there are also differences in the way researchers confirmed the participants' diagnoses in their research designs. Goldberg et al. (2005) and Pilowsky et al. (2004), for instance, administered the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994), which is known as a reliable measure, to confirm the diagnosis of autism. Other researchers, such as Macks & Reeve (2007) and Kaminsky & Dewey (2001), seemed to choose participants based on reported diagnosis and did not employ any additional diagnostic assessments of their participants. In contrast, Toth et al. (2007) and Yirmiya et al. (2007) appeared to be more cautious than many researchers and used more than one diagnostic measure,

including ADI-R and Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, DiLavore, & Risi, 1999; Lord et al., 2000) to confirm the diagnosis of an autism spectrum disorder.

*Sibling Development.* Moreover, the fact that each study seemed to examine different aspects of development may be another reason for inconsistent findings in research on siblings of children with autism. For instance, Hastings (2003) focused on behavioral adjustment of siblings of young children with autism who participated in an intensive applied behavior analysis (ABA) intervention, and collected data through two questionnaires given to their mothers. In addition, the author used the Autism Behavior Checklist (ABC; Krug, Arick, & Almond, 1980) to examine severity of autism. This study specifically examined the effects of severity of autism and levels of social support available to the families and how these factors affected sibling adjustment. After comparing the obtained data with normative data, Hastings (2003) concluded that severity of autism had no significant negative impact on sibling adjustment and that levels of social support might have a moderate effect on adjustment problems.

Instead of behavioral adjustment, Macks and Reeve (2007) examined emotional and social adjustment of siblings. In their study, data were collected from both siblings of children with autism and their mothers using inventories, such as Children's Depression Inventory- Short Form (CDI-S; Kovacs, 1992) and a demographic questionnaire developed for this study. As a result, they found positive influences on siblings. According to Macks and Reeve (2007), siblings of children with autism had more positive self-concepts and overall positive personal characteristics when compared to children who had a brother or sister without a disability.

Goldberg et al. (2005) and Yirmiya et al. (2007) looked at communication abilities of siblings. In particular, they examined social and communication behaviors in children who were younger than their sibling with ASD. They measured nonverbal communication skills in siblings

by videotaping interactions with a trained experimenter and concluded that the younger siblings were at risk for atypical social and communication skills. Likewise, Yirmiya et al. (2007) found a negative influence on younger siblings of children with autism. Their study was longitudinal and they tested cognitive and language abilities of the same participants twice, when they were at 24 months old and again at 36 months of age. After using scores of siblings of typically developing children for comparisons (matched design), Yirmiya et al. (2007) concluded that siblings of children with ASD demonstrated more difficulties in receptive and expressive language skills.

*Sibling Relationships.* Sibling relationships are another area of study that is commonly examined by researchers. For example, Kaminsky and Dewey (2001) found both positive and negative impacts on sibling relationships by comparing siblings of children with autism, Down syndrome, and typically developing children. They collected data through a behavioral scale and questionnaires given to all siblings and their parents. In addition, they matched siblings from each group based on demographic information (e.g., age, gender, and birth order). When compared to siblings of children with Down syndrome and typically developing children, Kaminsky and Dewey (2001) reported less intimacy, nurturance, and prosocial behaviors in sibling relationships when one of the siblings was diagnosed with autism. The researchers also reported some positive findings. Both siblings of children with autism and Down syndrome reported greater admiration of their siblings and less quarreling and competition in their relationships than siblings of typically developing children (Kaminsky & Dewey, 2001).

Some researchers (McHale, Sloan, & Simeonsson, 1986; Glasberg, 2000) have used an open-ended interview procedure to obtain in-depth information from siblings of children with autism and additional demographic and background information from their parents. In studies by

McHale et al. (1986) and Glasberg (2000), responses were coded so the results could be statistically analyzed. McHale et al. (1986) asked questions about sibling relationships (e.g., “How much time do you spend with your brother/sister?”). Additionally, they read statements with regard to sibling problems (e.g., “I have trouble explaining to my friends about my brother/sister”) and asked siblings to respond with “yes” or “no.” After obtaining all the responses, McHale et al. (1986) compared responses from siblings of children with autism with those from siblings of children with mental retardation and typically developing children. They concluded that there were no significant differences among the three groups in terms of sibling relationships.

*Theories.* As described in the research examples mentioned above, procedures, participants, measures used, research designs, and types of data collected have varied across studies that have examined what is like to have a sibling with autism. Not only have research methods varied, but theories used to support the research have varied as well. For instance, Glasberg (2000) used Piaget’s cognitive developmental theory to examine cognitive abilities of siblings of children with autism and their understanding of their siblings’ disorder. In contrast, Orsmond and Seltzer (2009) applied the diathesis-stress model and tested how the interaction of genetic vulnerabilities and environmental stress can affect the well-being of siblings of children with ASD. Due to the theoretical differences in previous research studies such as these, it is extremely difficult to draw definitive conclusions about the outcomes of children who have a sibling with autism, especially because theoretical orientation influences what is studied and how it is researched.

Participants in Glasberg’s study (2000) were siblings of children with ASD, and the author examined siblings’ understanding of autism and related disorders. This study used the

same methods as a previous study investigating children's understanding of various physical illnesses (Bibace & Walsh, 1979), which applied Piaget's theory of cognitive development as a framework. Some examples of the questions Glasberg (2000) asked in the interview were "Have you ever heard of [autism]?", "How do people get [autism]?", and "How does having [autism] make your brother/sister's life different than it would be without [autism]?" The terminology used in the questions (e.g., autism and Asperger's) was modified, based on which term parents usually used at home. When compared to developmental norms, Glasberg (2000) reported that the reasoning skills of siblings of children with autism were delayed, although their cognitive reasoning skills did improve with age. Although siblings of children with autism participated in the research of McHale et al. (1986) and Glasberg (2000), neither study addressed the impact on siblings of children with autism, as well as strengths and special needs for a family, based on the concepts from family systems theory and the family life cycle.

#### *Family Systems Theory and Research on Siblings with Autism*

An understanding of families is important when investigating sibling relationships. Unfortunately, there have not been many researchers who have used family systems theory as a basis for investigating families with a child with autism (e.g., Morgan, 1988; Rivers & Stoneman, 2003; Sivberg, 2002). Researchers who have incorporated family systems theory in their studies typically used samples with broader diagnoses, such as children with disabilities (e.g., Wehman, 1998) or handicaps (e.g., Powers, 1991) in general. In the limited research investigating family systems theory and families with a child with autism, very few researchers have examined siblings. Rivers and Stoneman (2003) studied the effects of marital stress and social support on sibling relationships. Based on data collected through self-report from typically developing siblings and parental report, they found that high marital stress and greater access to



formal social support (e.g., professionals) were associated with more negative aspects of sibling relationships (unkindness and avoidance), which was contrary to the researchers' predictions. Rivers and Stoneman (2003) concluded that social support did not buffer the impact of high marital stress on negative sibling behaviors. Although Rivers and Stoneman (2003) suggested that high involvement with formal support services could possibly increase family stress, which in turn affected sibling relationships negatively, this correlational study did not provide much insight on factors that may have led to the results. It is also possible that families who access formal social support may be significantly different from those who do not. For instance, families who seek professional support may be experiencing substantially more negative family interactions or more stress than those who do not seek professional help. Even after formal social support, they may continue to experience more negative relationships with family members than those family members who had less of a need for professional support.

### *Summary*

Some researchers have suggested that a child with autism in a family does not necessarily adversely affect the development of siblings and may in fact have a positive influence. Other research has shown that siblings of children with autism can be affected negatively in some situations. These inconsistent research findings may be due to differences in research foci, designs, methods, and participants, as well as theoretical orientations guiding the research. Although family systems theory is applicable to research on siblings of children with autism, very few researchers have used family systems theory as the theoretical guideline for their research. A better understanding of the lives of siblings of children with autism is critical because of following reasons. First, it is essential for researchers and practitioners to understand strengths and needs of each family member in order to maximize opportunities for growth within

a family and to promote a positive environment for a child with autism to learn and grow.

Secondly, siblings typically play significant roles in the lives of children with autism. Moreover, we have much to learn by taking notice of siblings' personal stories because they have much to share about their experiences, feelings, and needs associated with having a brother or sister with autism.

### *The Present Study*

Because previous research on the potential influences of having a sibling with autism has been limited and because there have been inconsistent findings reported in the research literature, the goal of the present research study was to obtain in-depth information from siblings of a child with autism, as well as their parents, through individual open-ended interviews. In this study, siblings and parents described in their own words their experiences with having a child with autism in their families. Emerging themes related to family systems theory and the family life cycle were identified and discussed. Therefore, qualitative, descriptive data were collected. The results of this research can potentially provide insightful information for parents, siblings, and professionals who work with families of children with autism. Because it is not always easy for professionals to obtain in-depth information from family members, the practical implications of the findings of the present research study can assist in development of better treatment approaches for children with autism and their families. The results of this study may also provide additional information to help maximize the effects of interventions and treatment. Moreover, results from this research will help identify variables that are important for future quantitative research investigations.

Because this is a qualitative, descriptive study, no specific hypotheses or predictions are made. Instead, the purpose of this study is to obtain detailed and subjective information

concerning family members' experiences and perspectives on what it is like to have a child with autism in the family.

*Research Questions.* Family systems theory suggests that having a sibling with autism can influence a child's family experiences and development. The research questions guiding the present study are:

- In their own words, what are the actual perceptions and experiences of siblings of children with autism?
- What are the strengths and needs of families with a child with autism?
- How can family systems theory be applied to families of children with autism?
- What can practitioners and researchers learn from family members of children with autism in order to maximize the effects of treatment and interventions?

## Method

### *Participants*

Five siblings of children with an autism spectrum disorder, between the ages of 6 and 14 (mean age = 11.2), as well as their mothers, participated in this study. All names were changed in reports of this research in order to ensure confidentiality and the pseudonyms of child participants are presented in alphabetical order – Andrew, Brittney, Clare, Danielle, and Erin. Mothers of the target siblings were informed about the study at the monthly meetings of parent-led autism support groups, via a flyer, or by a psychiatrist of two of the children. Those who were interested in the study provided the researcher with their contact information in order to schedule an appointment for individual interviews. The participants were recruited in the Midwest. Although a few of the target siblings reported to have diagnoses of other mental disorders, such as depression, anxiety, attention deficit hyperactivity disorder, and oppositional

defiant disorder, their mothers confirmed that all five siblings who were interviewed in the present study did not have a diagnosis of a developmental disability, including autism spectrum disorder. All participants were Caucasians and resided with their brother or sister with ASD, as well as both of their parents. Only one of the target children had other siblings besides a brother with autism. Four children have a brother or sister with a confirmed diagnosis ASD and one has a sister with a provisional diagnosis of Asperger's disorder.

Andrew was a 6-year-old boy who has an older brother with Asperger's disorder. Andrew was the only male participant in this study. His brother was diagnosed with Asperger's disorder at the age of two and currently receives several specialized treatments, including speech, occupational, and feeding therapies, as well as psychotherapy. Another participant was Brittney who was 14 years old at the time of the interview. She has a younger brother who was diagnosed with high-functioning autism at the age of eight, as well as three other younger siblings. The only therapy Brittney's brother receives is behavioral therapy. Clare was a 14-year-old girl. She has an older sister who has been diagnosed with high-functioning autism since the age of seven. Her sister has been receiving speech therapy at school, and it is her only treatment at this time. Danielle, a 9-year-old girl, was another participant who has an older brother with Asperger's disorder. Her brother received this diagnosis a few weeks before the interview and has just started social skills training. Lastly, Erin was a 13-year-old girl who has an older sister with a provisional diagnosis of Asperger's disorder. According to Erin's mother, when Erin's sister was 9 or younger, her pediatrician and teachers had started mentioning that she exhibited characteristics of Asperger's disorder. However, she has not been able to receive a full diagnostic assessment due to insurance and financial issues. Her mother also reported that her daughter with a provisional Asperger's disorder had just started seeing a psychiatrist, and the psychiatrist stated

to the researcher that her diagnosis was “provisional” at this time. Table 1 summarizes demographic information for the participants.

### *Materials*

Interview questions were developed for use in this study. Some interview questions were based on the questions used in previous studies (i.e., Glasberg, 2000; Kaminsky & Dewey, 2001; McHale et al., 1986), and other questions were developed specifically for the present research study based on concepts from family systems theory, family life cycle, and cognitive appraisal. Parents were asked to complete a questionnaire to report their demographic information. The questionnaire included specific questions regarding the diagnosis for their child, when the diagnosis was given, verbal ability of their child, and the treatment and/or interventions their child is currently receiving, as well as the family structure and occupations of parents (See Appendix A for a copy of the questionnaire). Parents also responded to interview questions about their family experiences associated with having a child with autism; appendix B contains a copy of these interview questions for mothers. Appendix C presents a copy of the interview questions developed for siblings of children with autism. For both mothers and children, the interview questions were intended to allow participants to describe their experiences and perceptions of having a child with autism in a family.

Mothers were also asked to complete a Family Support Scale (Dunst, Jenkins, & Trivette, 1984), which was used in a previous study (See Appendix D). There were nineteen questions regarding support resources available to their families during the past 3 to 6 months, and the mothers answered each question by circling the best description of their situations on a scale of 0 to 4 (0 = Not at all helpful; 1 = Sometimes helpful; 2 = Generally helpful; 3 = Very helpful; 4 =

Extremely helpful). Because some of the resources might not be available to every family, the mothers were instructed to cross out the questions that did not apply to them.

### *Procedure*

The author informed families of children with ASD about the study by attending monthly meetings of two different parent-led autism support groups, by distributing a study flyer, or with help of a psychiatrist. The psychiatrist shared the information of this study with parents of his patients who have a brother or a sister with ASD. Those who were interested in the study provided their contact information, and mothers who volunteered to participate were contacted later to make individual appointments. Next, each participant was visited at a mutually convenient time and in a mutually convenient location for the interview, which included family homes and a park. Before each interview began, the purpose of the research study and what would take place was explained to each participant, confidentiality was assured, and informed consent from parents and assent from children was obtained. In order to obtain all of the information stated and to confirm its accuracy, each interview session was audiotaped; participants consented to their responses being recorded during the informed consent procedure.

Mothers were asked to complete the questionnaire presented in Appendix A first and answered the interview questions described in Appendix B. All mothers answered their interview questions outside of the presence of their children. Then, children were asked questions stated in Appendix C. While children were interviewed, the mothers completed a Family Support Scale. Two of the children, Andrew and Erin, requested their mothers be present in the same room at the time of their interviews. Whenever necessary, follow-up questions were used to help clarify or expand on a response. Participants were given as long as necessary to respond to the interview questions. When each interview came to an end, participants were thanked for their participation

and the goals of the research were reinstated. Additionally, the participants were debriefed and reminded that a summary of this research project would be available to them upon their request once the study was completed.

## Results

Interview responses of siblings of children with an autism spectrum disorder, as well as their mothers' responses are summarized in this section. First, mothers' answers to the Family Support Scale are summarized.

### *Results from Family Support Scale*

Table 2 provides a summary of the number of mothers who endorsed each item on the Family Support Scale. Based on their responses, it appears that the majority of mothers perceived their spouses to be the most helpful support to their families; four out of five mothers answered that their husbands were extremely helpful, and the other mother described her husband as generally helpful. Next to support from husbands, it seems that most mothers identified their own children, family or child's physician, professional helpers (e.g., social workers, therapists, and teachers), and school/day care center to be quite helpful. Responses to other possible sources of support varied significantly from mother to mother. Take "Spouse's relatives" as an example, one mother found them to be extremely helpful, two mothers identified them as generally helpful, and one mother described them as not at all helpful. Interestingly, it seems that their own parents, spouse's parents, and other parents were not perceived to be very helpful by these mothers. In addition, it appears that the mothers did not find church and social groups/clubs to be helpful resources.

*Results from Individual Interviews*

The participants' responses to the interview questions are summarized in this section. The responses from mothers are presented right after each child's responses in order to provide additional information about the target siblings as well as their families. To ensure confidentiality, child participants' names and other identifying information were changed. The pseudonyms of the five siblings who were interviewed are Andrew, Brittney, Clare, Danielle, and Erin in the reports. For other individuals mentioned in the siblings' responses, their names were replaced with their relationships to the target sibling. For example, when Andrew mentioned the name of his brother with Asperger's disorder, the name was replaced with "my brother." Profiles of all five siblings' interview responses, as well as their mothers, were created using the steps in creating profiles in qualitative research suggested by Seidman (2006) as a guideline. A summary of mothers' responses to the interview questions # 1, 2, 8, and 9 are presented in table 3.

Seidman (2006) stated that the first step to share and analyze interview data is reducing the data. All of the interview questions and additional probes during the interviews have been removed. In addition, after reviewing the interview material carefully, any redundant passages and/or repetitive words (e.g., "you know") as well as irrelevant information, such as detailed information about toys they played and movies they watched, were omitted. Furthermore, because the siblings' responses were in a spoken language, there were a number of informal contractions, including "wanna," "kinda," "gotta," and "gonna." These words were all replaced with formal ones (e.g., "wanna" → "want to") in order to make the transcripts more appropriate for a written format as suggested by Seidman (2006).



The next step, according to Seidman (2006), is to read the rest of the responses in order to determine what is important and put them together appropriately. In this process, simple transition words (e.g., “But”) were inserted between sentences so that readers could better understand the contexts of the siblings’ stories. Additionally, when the sibling answered the interview question with “Yes/Yeah” or “No/Not at all/Not really,” the words from the interview questions were inserted to clarify the meaning of the passages. As Seidman (2006) advises, all the inserted words were placed in brackets to let readers what had been added. The profiles of the participants are presented next in alphabetical order.

**Andrew (6 years old)**

My brother has autism. I don’t know a lot [about it], but I know some things. My brother doesn’t like autism. Autism is when people yell and get upset all the time. Sometimes my brother gets upset about himself. I want to make him stop, but I don’t know how to make him stop. I don’t know anything else. I don’t remember when he told me [that he had autism].

[I spend] a lot of time [with him]. [We] play with action figures. That’s it. Action figures and animals. And we play with our dog (pet). [I like that] he is nice, [and there is] nothing [I do not like about him]. I never get mad at him. I think he feels that I am nice.

I don’t remember [if my parents ask me to help him]. [But] I like helping him. At our sitter’s place, there is a kid who doesn’t like me very much, so he tries to beat me up. My brother tries to take care of me. [He] sticks up for me. He reads to me too.

Our parents spend time with all of us. [My family is different from other families] because they are not the same bodies. They have different bodies. We do different things too like have lunch, snack, and play video games. Maybe [my family is the] same as my uncle’s family

because they are nice and we are nice. Everybody else in his family is nice. I don't know [what will happen to my brother when he is older]. But I know he is going to get a car.

### Andrew's Mother

I feel really guilty as a mom because I feel like my husband and I don't spend the time with Andrew that we should. We don't read to him. We don't play catch with him. There are a lot of things that we don't do with him. So he is playing ball right now. He wants to fit in with his friends, but he is struggling. It's like, "If we played with him more [and] practiced with him more, he would probably have an easier time [fitting in]." [But things] we have to do everyday with his brother rob us a lot of time. I always rationalized it with Andrew by reminding him he doesn't have autism, so he is already a step ahead of his brother. Which is true, but he is still a step behind his peers and he hasn't reached the age [level] the other kids are starting to reach. Andrew developed normally, but he doesn't have a big brother who plays catch with him, [so] it affected Andrew in a way.

His brother is really smart. He is unintentionally the most hilarious person I have ever met. [But] it's hard right now [because] he is at the age [when boys starting to experience puberty]. Part of me says, "Maybe he is just crabby all the time because he is almost 12." His brother is like having three kids, so Andrew is like the fourth child. [I do] not [have] energy [left for] Andrew [because] I am just exhausted. Luckily he is laid-back. I'm not as strict of a disciplinarian with Andrew as I would like to be. But again, luckily he is good. There is a big age difference [between Andrew and his brother], so he is not saying stuff as inappropriately as his brother is. But usually with Andrew, I can say "Andrew, that's inappropriate" and he will just stop. But with his brother, I have to go on and explain because their personalities are different. I can tell he is annoyed by me because I am constantly nagging him. But Andrew is easy going.

He doesn't cause much trouble, and he is more timid and stays in a background. He is just kind of laid back and watches and observes. I think with his brother I put more pressure on him because he is intelligent. I would tell him things to try and put a positive spin on autism like "You know you've been given gifts and you've been given a mission. You have to use these gifts to make the world a better place." I wouldn't say stuff like that to Andrew. Andrew's role in the family is to be a goof ball. I sit back and enjoy that. I need that. Maybe that's very selfish, but it's complicated. I spend more *time* with Andrew, but I spend more time *working* with his brother. Andrew is a mama's boy – he would come snuggle with me, but his brother doesn't. So in that regard, I spend more time with Andrew because it's more that "mommy-son" thing because he is 6. His brother is older, so he is growing away from me. With his brother, I spend more time dealing with coordinating therapies and planning this, planning that. I spend more time and energy on him, and in terms of time-time, he is closer to his dad right now. He walks the dog with dad. They have a connection.

We had problems with [our] neighbors. I have seen older kids in the neighborhood picking on Andrew because of his brother but Andrew hasn't figured that out and neither has his brother yet. We tried to talk to the neighbors but they just screamed at us and made bunch of threats, so we had to call the police. It's gotten really ugly. Now we are not allowed to be in their property and they are not allowed to be in ours. It's hard. Holidays are not what other families have. Andrew's brother usually has meltdowns because of all that excitement. A lot of people like to judge [us] and say, "Discipline more!" Because we are in a small town, people know us. We are always known as "that" family. When you are different, you stick out. Everything is different [from other families, and] everything is the same [as other families]. [Andrew's brother and I] scream at each other – "mom stuff." That's pretty normal. [Also], luckily Andrew's

brother travels well. We can go to amusement parks, and we went to Hawaii this year. Andrew and his brother get to laugh and goof [just like other families].

Andrew has been asking questions lately. He noticed that his brother didn't have a lot of friends. One day, his brother was cranky. Then, Andrew said, "That's why he doesn't have any friends because he is like that." I didn't know exactly what he meant by that, but I asked him "What's autism? Do you know?" Then, he would say, "Well, it's when people scream and yell all the time." [He is] kind of right. When his brother went to the hospital [because] his anxiety got out of control, we explained more about anxiety to Andrew. Andrew knows more than he thinks he does. He sees more and he notices more, but he just hasn't made that connection as autism. We never hid [his brother's autism] from Andrew. I don't remember if we actually had Andrew sit down [and talk about autism], but I do remember one time maybe when he was a little younger, he said, "Why don't I go to Speech?" and I said, "Because you don't have autism." This year, he started to go for Phonics. Then, he asked me, "Do I have autism now?" I said, "No, you don't have autism. You can't say L's and R's right." "Oh, okay." So [autism] has kind of always been there. We always have talked about it.

Andrew and his brother are very good buddies. They really are. I think Andrew's personality compliments his brother perfectly. Andrew, as I said, has this goofy and sort of laid-back personality. He is kind of timid sometimes, and his brother is not timid. So it's good when they have to go somewhere new or take them to a sitter, his brother is out-going and "Come here Andrew!" He is protective of Andrew. Now Andrew is older, he is the goof ball. When we went to Hawaii and when we came home, there was a boy screaming on the plane the whole eight and half hours. It was horrible, and Andrew's brother can't tolerate that. I thought, "Oh this is going to be bad." Then, Andrew started making fun of the boy and he got his brother laughing. They

made fun of the boy the whole time. I mean the boy couldn't hear Andrew, but I wasn't about to tell him to stop either. They just made fun of the boy the whole way home and it worked out well. That's what I've been seeing more and more. Now that Andrew is getting older, their sense of humor connects. They play at the same level right now. Right now is real good because mentally in some ways his brother is six. In some ways, Andrew understands things better than his brother. Andrew is starting to develop this attitude of "I know more than you!" or "I get this better than you!" He knows there is something going on, and now he is taking almost a big brother role in some areas. I know in a few years he will be like a big brother. He will be, so I keep trying to tell him, "Your brother is your best friend and you need to always be there for him." We are lucky that they are very close.

**Brittney (14 years old)**

Overall, my brother is really nice. He wants to be. He is fun to hang out with, but he has his moments where he gets so angry at people or becomes very controlling. He is really into boy stuff, so I play along with him. Sometimes he gets mad, but honestly it's difficult for him to be around people. When he is home, he is so much different from when he is out. He is more hyper and he runs when he is outside the home. When he is at home, he is normal. He gets moody sometimes and throws tantrums, but he doesn't do that much anymore since he started counseling. When someone comes to our house, it all depends on if he knows the person and how long he has known the person, all that kind of stuff. If he doesn't really know the person, he will act just like he does outside home. He is not comfortable. When he generally gets to know someone, he starts to be more of himself. I noticed that when he is comfortable, he wants to touch that person more. He likes to touch anything that looks appealing to him. His favorite person in the world is my boyfriend. He likes to do everything with my boyfriend. He just wants

to be with my boyfriend. When we go out somewhere, he says that he wants my boyfriend to come with us. He used to hide behind mom, but now he hides behind my boyfriend like when he is scared in public.

My mom told me a lot about autism because me and my mom are pretty close. She has told me that the half of his brain is autistic and the half is normal. She explained to me why he does the things he does. I really can't explain it. I try to understand it as best I can. He is very stubborn, and we fight a lot, but I know that it's harder for him to understand things. I know sometimes he just can't help himself, so I try to either prevent those moments or deal with them the best I can. If he gets mad at our siblings, I'm usually the one that steps in so that he won't beat them up when he is upset.

One day my mom said that we are taking my brother to a counselor because they think he has autism. They tested him and my mom told me about autism. She just kind of sat me down and told me everything. I was like "That explains a lot about him." She does read a lot of books about autism. She likes to get really involved with it. When she is done reading the books, she passes them down to me, so I'd like to read a lot of books about it too. We also go to an autism meeting every month. There we hang out with a lot of people who are autistic. Now that we got to be around autism so long, we can see it in other people. We can pick out autism traits. My mom told me that if there is an autistic child in a family, siblings usually gather traits from the autistic child. I try to understand that because I see it a bit in myself and my brothers and sisters. Not having autism, but autism traits. It could be because we are so close.

My brother (with autism) and I usually spend a fair amount of time [together]. We are not on top of each other, but we are not completely distant. We watch movies and play *LEGOs*. Sometimes we draw. He likes to be on a trampoline all the time. He sometimes comes over to my

room and watches me play games on my phone. Or he shows me his *Pokémon* stuff and tells me about them, like simple stuff. He is very passionate about them. [With my other siblings, I] play *LEGOs*, do hair, [and] we play X-BOX (video games) with my boyfriend. I watch the Disney channel with my sisters. Sometimes if there is a movie the boys are very psyched about, I'll watch the movie with them. On Saturdays, I baby-sit, so I spend most of my time with my siblings then. [I spend] the same amount of time with each of my siblings.

I like that my brother (with autism) is really entertaining and he is very passionate. If he cares about something, he will really make it happen. He really likes *Pokémon*, but *Pokémon* is not real. He wants to become a scientist when he gets older and wants to make real *Pokémon*. I think it's really adorable how he thinks. I love his imagination. He is so creative. It is really beautiful to me. Another thing, the kids like to watch him draw. My brother is always so creative. He comes up with such different things, like ghost people and stuff. He makes me laugh. He made ordinary things come to life. He always does. He likes visual arts, like making stuff rather than drawing. He can make anything into anything. Another thing I like about him is that he doesn't care what other people think. The other day he had arrows on his head. My mom asked him, "So what did your friends say? Did they make fun of you?" He said, "I don't care because I like it." I thought that was nice. He really doesn't care. One thing I don't like about my brother is his really short temper. When things don't go his way, the whole world is passing down on him like he [would] start yelling, screaming, and getting my sister's things.

I really don't know how he feels about me. He is not really a talker. He is more action. I mean sometimes he comes up and hugs me. He never really tells [me] what he feels. Most of the time [he listens to me better than others] unless I tell him something too complex. Like I said, I watch him [at home] on Saturdays when my parents and other siblings go wrestling because he

can't handle wrestling. It's too loud and too much for him. He freaks out, so he stays home with me and [our youngest] sister. Every so often, we go out to places. My mom will take care of him, but I will take care of the others. So I don't take care of him then, but my mom will take care of him because it can get crazy sometimes. When he gets scared, my mom will tell me, "take your sisters to the car and make sure they are okay." So I'll just sit in the car with them. When he is acting out, I know they won't act out too because they know things can get a lot worse. He can't help it as much as they can.

My parents don't ask my siblings to do the things I do, but they do ask them to do little things like ask them to get stuff. Nothing major. They are younger. I don't mind [helping my brother] at all. He is my brother. My brother tries to do what he can [to help me]. It's in his mind, but he doesn't really know how. Like when I was sick, he gave me a hug. I said [to my brother], "You're going to get sick." Then, he said, "I don't really care. I still love you." He always makes me pictures. I have a really nice *Pokémon* picture on my wall he made for me. He likes to make me pictures and he tells me that I have to hang them on my wall or he won't make me any more pictures. So I have pictures on the half of my wall. It's very specific, what he can "help" with. That's his way. One day, he got my mom a bar of soap, so I said, "It's his thoughts that count, mom."

Actually, I can have special needs too; mine are [depression and anxiety]. Every Thursday, me and my brother have to see a counselor. So I guess my parents spend a fair amount [with me and my brother]... I think it's more of the other kids who feel left out because they don't have any special things they have to do. With the littlest girl, it's different because she spends half of a day with mom. But I don't know about the other two. Well, they have wrestling. So Saturdays, they get to spend time with mom. I guess it kind of evens out.



[My family is different from other families]. Normal families, they are nothing like my family. I don't know why our family is so much different. It's hard to explain. It's just different. We are not anything like other families. When I look at other families, they just seem different. Our family is odd... We are an odd family I guess. I don't know [how we are odd], [but] maybe the way some of us act. We act kind of crazy all the time. Like my brother running around... Probably, the way we look. My mom let us look however we want. If we want to look crazy, then we can look crazy. She lets us have free sprits. We [also] have similarities to other families... the same lifestyle, just different types of people I guess. We probably do the same things as other families do. We are the same, but not the same. Like our dinner may be completely different from other people's dinner like having breakfast for dinner. So we *do* different things. I guess they (other families) could be a boring family that sits around and they don't have much interaction within the family. I think our family is a lot cooler than those. My parents let us be free. They let me be *me*.

I've always thought, "What's going to happened to my brother (with autism)?" I've come up with lots of possibilities. I think either he's going to get really stable, be really happy, be really successful, and may be able to support himself, or he can't live separately and live with my mom because he isn't "that" high-functioning. When he is older and my mom and dad are gone, he's going to be with me. I completely accept that. I can't really tell now, but he does have a lot of hopes. He hopes to become a scientist. I know he is brilliant in math. He is like brilliant in that. He loves art classes. I'm hoping for his best.

### Brittney's Mother

Brittney knows quite a bit [about autism] because she is very involved. At the time we got the diagnosis, we told her and we told the other kids [about autism]. Brittney is the oldest and

she has been very helpful to me. I can't do [the things I need to do] without her help half the time. When she knows I am sick or something, she is like, "Go lay down, I will make dinner." She steps right in. That's what she always does because she is the oldest. She is almost like a second mother. Brittney and her brother (with autism) still have a brother-sister thing. He sometimes doesn't want to listen to her [and he says] "Brittney is not my mother." But she can probably handle him better than everybody else.

I take Brittney to her brother's appointments, so she spends a lot [of time] with him. We had to put so much time and effort into her brother (with autism). Other kids think they are getting treated unfairly. For a while we couldn't do anything normal [because of] her brother's meltdowns. We couldn't even get someone to visit [our house] because he would always go crazy, bite something, or hurt somebody. Also, stares from other parents... My kids are good with him, but other people aren't. I think it's more difficult for Brittney and other kids because they have to suffer from it because of her brother (with autism). If we did go somewhere, he would act out and they would all be embarrassed. Or they would have to help me, especially Brittney. I would have to deal with him, and she would have to take the little ones. When her brother (with autism) is next to me and he is comfortable, he can be so funny. He can be very loving to people he is used to. [Also], he doesn't care what everybody else thinks. Not many people can say that. He can do what he wants to do. I guess he is a lot of trouble but I wouldn't change him. I don't know if my kids think he is a problem, but it's always interesting. That's one positive thing- it's never dull.

[My parenting style is] a little bit [different for her brother (with autism) than for Brittney and her other siblings]. I try to keep it as the same as possible, but you do have to be a little different. Her brother's room is kind of off-limits. If he is not going to say yes for someone to

come in there, then no company [is allowed in his room]. He can leave a mess, but he knows exactly where things are. If one thing is missing or out of place, then we are in trouble. He has rules and stuff, but he gets away with things. Everybody has to do homework and everybody has consequences, but I may have to tell her brother (with autism) three times, but I don't tell other kids three times. [Things] have to be exactly the way her brother (with autism) expects to be, so I think it's hard for other kids and it's hard for me and my husband too. I treat Brittney's brother (with autism) more like a younger kid, but he doesn't like it. He is getting older and realizes what I do, and it's bugging him.

For sure, [my family is different from other families] in a lot of ways. I think we are very accepting. We can laugh at ourselves, our mistakes, and our problems. We can laugh about everything. We are just the way we are. I think [having a family member with autism] actually make us more of an accepting person and I think my kids hopefully be more accepting because of their brother. We want the same things as everybody else wants in their lives, like do well and be successful. I want our kids to get whatever they want to get in their lives, but it is not as easy [for us]. Some of it is having a big family too. I mean financially one or two kids would have been a lot cheaper. So financially to me, it's different from other families.

**Clare (14 years old)**

My sister is like really nice. She loves animals and she loves holding our dog. She is a real sweetheart. I really love her because she is my sister. I know that autism... autistic people... they have it in their brains, and they can't really socialize as easily. They're just not social. They are smart and they are shy. I know so much so I can't name it all. I don't know [when I first learned about autism]. I was so young. By the time my mom told me and I actually understood, I was probably 6 or something. I don't remember learning it, but I just remember knowing my

sister. I remember sometimes I wondered, “Why does she do that?” or “Why is she like that?” Then, my mom would be like, “Well, that’s part of who she is. Part of her autism.” Then, I would be like, “Ah... okay.”

I spend mornings with her. We hang out downstairs. I can’t say that’s the time [when we are] just two of us. I hang out with her if she is playing a game and I want to watch or if we are watching movies together. But we don’t hang out that much because we want to do our own things. I just want to be on Facebook, and she just wants to play games or whatever. We don’t hang out that much on average days, but you know we are just really close. When we were younger, we used to play pretend all the time. We chased each other. We were laughing all the time and playing catch. All that fun stuff. We hung out non-stop because we didn’t have all this computer stuff. [It was] definitely fun. We don’t have a lot in common, but we usually watch TV together or movies. I watch her play a game or she watches me play a game. Or we just talk because [there is] nothing else to do.

I like that she is a really sweet soul. She is really forgiving and she doesn’t look at bad sides of things – she is positive. She comforts me and tells me that I can do whatever... takes my mind off... I appreciate that a lot. She is a really sweet soul, and I’m glad to have her as my sister. [But] I don’t like that we are not alike because I think it would have much better to hang out with her if we had something in common. I mean it. We have not much in common. I know it’s part of her autism, but sometimes when I hear her repeat things over and over again, it kind of gets on my nerve. But then, I get over it, because you know it’s not her fault. I try to look at good things more than bad things because I don’t want to hate my sister. I love my sister. I really don’t know [how she feels about me]. I think she thinks I’m annoying sometimes. (laugh) I think she looks up to me because I’m so different from her and I kind of do some things she doesn’t

[do] but she may want to do. She sometimes says that she is jealous that I have all these friends and I have all these fashion senses. I think she thinks I'm cool. I hope she does. [But] I don't want her to think she should be more like me.

My parents ask me sometimes to help my sister with what she needs to do [or] she can't do. If we have guests over, I may help my sister interact with some of the guests. Mostly, it's social things. Because she needs help with that and I can help her. One time there was this person over here, I don't remember who that was. I could tell my sister was kind of nervous. We were young. My mom was like, "Say hi" and she was like, "Hi..." I mean I could tell she was nervous, so sometimes I had to jump in and say to my sister, "Tell her (the guest) about the funny thing you did!" So I would just give her something to talk about. That's what I usually do. That's my job. I don't really mind [helping her]. I'm used to it by now. At first, I was kind of upset that I had to do all these work and I thought like, "Why do I feel like I'm taking a bigger load than my older sister?" Then I was like, "No... I'm just aware of what she doesn't do." I don't mind as much because she needs help and I don't mind offering it. When I was younger, I don't think I helped her as much other than giving her something to do or someone to talk to. Other than that, I didn't intentionally help her because I didn't know I was supposed to help her back then. Sometimes my mom would be like, "Hey, Clare. You want to help your sister with this?" and I would be like, "Okay..." I don't really remember how I was adjusting because I was so young. [My sister helps me too]. I used to suffer from depression. Sometimes when I kept things inside, I needed someone to talk to. But no one was... I felt was there. Even though I knew there were a lot of people there, [there was] no one I felt like talking to. Sometimes I talked to my sister about these things. She would understand [me] and everything ended up being okay.

She gave me someone to talk to. She is a sweet soul and I'm really happy for that because if I didn't have anyone to talk to, I would still be depressed and it's not fun.

My parents don't really spend time with us because they have jobs and they do work a lot. But, if they do spend time [with us], I think that's an equal thing – sometimes a little more for her and sometimes a little more for me. Usually my sister would show them her artwork, go to movies, grab something to eat, or play games. My parents would just be with her doing whatever she wants [to do]. I love my family. There are some conflicts, but my family is kind of different because I have an autistic sister, I have ADD, my mom had cancer, and my dad... normal! (laugh) We are a little different, but I like that because being different gives me more meanings. We are [also] like a lot of families [because] there are two parents and children and other families go grocery shopping [like we do] but in many ways, we are different.

I have no idea [what will happen to my sister when she is older] because sometimes I have a feeling that she doesn't have too much experience about all that stuff, but I think it's getting better because my parents have been asking her to do different things like dishes and laundry. I imagine she is going to stay here (at home) until college. I honestly have no idea. She is going to stay here as long as it takes for her to get these skills because it's going to be hard to live by yourself if you don't have the skills.

### Clare's Mother

Clare is a very gentle spirit and her sister hurts her pretty bad at different times. I think Clare is more sensitive in some aspects. Clare may not say she is hurt, but she gets hurt pretty easily. [The relationship between Clare and her sister is] a rollercoaster, [but] they've been on a very good improvement as far as what they are feeling toward each other and accommodating [one another]. Clare knows quite a bit [about autism] because our family does presentations at

different places and we include her. I started a parent group in 2002 because I couldn't imagine being a young parent and going through this without having a lot of family support or having some kind of support. I'm grateful that I didn't have her sister when I was 18. We had our careers established and we had money to spend on therapies.

[Clare asks questions about autism] a lot. Sometimes she asks me, "Do you think that is her Autism or she is just being stubborn?" We talked to Clare and her sister both about autism a long time ago. I think when Clare got diagnosed with ADHD, it helped her empathize a little more. We definitely spent a lot more time with her sister explaining [what ADHD is]. [But] we didn't spend as much time explaining to Clare [about autism]. Partly because we didn't really want to because we want one of the girls to be normal and expect each other to figure it out. I don't think that's her burden. She doesn't need to be concerned with everything but certainly some [of it].

[The diagnosis of autism had influenced us] a lot. [The first] three years, we felt uncomfortable being away from home, so we did everything at home. And then, we went two years where we had to learn how to be like Sherlock Holmes and figure out how to make things work. We had to put a lot of energy and we had to be very creative and figure out what her interests are to reach her potential. So the focus changes as they grow up. Our first focus was "survival". Then, our focus [became] "how do we help her grow?" and "how do we help her to be successful?" [My parenting style is different for Clare than for her sister because] I can't parent them exactly the same. I didn't have to work [as] hard for Clare. With her sister, sometimes I have to put some instructions in place, whereas Clare needs a lot more abilities to be creative so I let her [be creative]. [Also], I talk to her sister's teachers, [but] I don't talk to Clare's teachers. [So] I'm definitely more involved with her sister, which is tough on Clare

sometimes. I think in the past [my time was spent] a lot more on her sister. When we were on “survival” mode, we would spend a lot of time on her. When we get into coping like we learned that we could take her dog with us so that we could do more things, then it allowed us to settle Clare’s sister and spend more time with Clare. So it just depends on where we are. Clare knows that. [So] I think [my time spent parenting] is pretty close to 50/50.

I actually think that our family runs smoother than other families. The reason is because we worked so hard at the beginning. Now we are benefiting from that. We all have good conflict resolution skills and we have good strategies because we had to [gain those skills] due to necessity. Probably the biggest challenge we had as a family is a lot of times on the weekends the girls just want to chill here. Sometimes [when] we need to do some things, we had to tell the girls the night before, “Here is what we are going to do.” We had to actually over-communicate when they expect to have their own plans. They are teenagers. I think it’s kind of normal. Probably [we] still have the same checklist [as other families] every day, like homework, lunch, have breakfast, and get dinner. We have the same big checklist we have to go through, so those things are all the same [as other families]. The big differences are that neither one of my girls are social and have a lot of family members they don’t like. Clare’s sister has a best friend, which is awesome. So they do stuff together. But I would say probably not the degree of a lot of families. I look at my sister in-law and her two kids. They got soccer, football, and so on. They got like three or four activities a day. We may have a couple activities a week, so that might make us different [from other families].

**Danielle (9 years old)**



My brother is kind of mean when comes down to arguing, [but] he is very smart. [I don't know why he is mean to me sometimes.] [I do] not really [know about Asperger's], [but I have heard my mom saying, "He has Asperger's].

When I'm playing outside and he is inside, because I like to go play outside sometimes. [We do] not really [play together] because he doesn't want me to play with him. [We don't spend much time together] maybe except for playing the game systems. We play the game systems together, Wii, X-BOX, and Playstation, [but we do] not [play] very much [anything else].

I like that he is very smart. I wish I could be more like him. He knows math very well, like multiplications and stuff. [Also], he can read, [but he doesn't read to me]. He reads like boy books. [I don't like] when he gets mad [because] he says something mean like he calls me stupid or something. He gets mad when I have to do school work and he doesn't want to give up the computer and whenever we get into arguments. [We argue about] almost everything. I don't know [how he feels about me]... maybe just as a sister. [If I were to guess if he likes me or not], I would say a little bit of both.

[My parents don't ask me to help him] unless he is sick. [When he is sick, they usually ask me to] make him soup or bring him something to drink. [I] sometimes [do mind helping him] because he doesn't help me. I think [my parents spend time with us for] about the same [amount of time]. [My parents and brother do] not [do] a lot [of things together] because most of the time, they go to the movies or sometimes they go to a park.

[My family is different from other families] in a lot of ways. We got bad guys and good guys [in our family]. Bad guys are mean and they go to jails and stuff. I think that both of my grandmas, my mom's side and dad's side, and my two uncles [are the bad guys]. Good guys are like my mom, my dad, my brother, and me. [But] maybe [my family is also similar to other

families] a tad bit because all my friends have a family of four like we do, and they get sick and we kind of do [too].

[When my brother gets older], probably he is going to have a nice job like own[ing] a game store. He is going to have a nice house and a car. Probably he will [also] have money [because] he is smart.

### Danielle's Mother

[The diagnosis of autism] helped me understand a lot more about him. Now I understand why he has to have things like he does and why he gets so upset when I do disrupt him. It kind of helped me actually plan in advance, so he could be prepared. [I do] not [think Danielle knows about autism] that much. I've been trying to slowly explain it to her as I understand it and trying to put it in words that she can understand. She doesn't mess with her brother as much because she kind of understands when he gets mad, he is mad. She doesn't mess with his stuff as much anymore, because she understands that he has to have them in a specific place and in a specific order. So she understands a little bit. I hate to say this, but there really isn't [a relationship between Danielle and her brother because] her brother doesn't like to be around her. If I won't let him play his videogames and watch TV, he will sometimes play with her [as] his last resort.

[But] most of the time, he will still play by himself. When Danielle was playing soccer, I couldn't pay attention to her because her brother was trying to sneak off and go be by himself.

[My parenting style] was different [for Danielle than for her brother]. [Before receiving the diagnosis of Asperger's], I was a lot harder on her brother because if I were to tell him something, he would be zoned out. [Then], I would get more upset with him because he is the oldest and he is supposed to set an example for his sister. [But] I'm not [hard on him] so much anymore because like I said, I understand more about him. [My time is spent] mainly toward

Danielle because she needs my help more than her brother. I hate to say that, but it's because her brother doesn't want to spend time with me. If I give him a hug, he pushes me away. If I give him a kiss, he wipes his face. [But] he is so intelligent. He can carry on adult conversations if he really wants to. I'm 31 years old and he blows my mind. Some of the words he uses, I have to look them up in a dictionary. That would be the most amazing thing about him. [Also], when he wants something or wants to accomplish something, he does it. There is no "if" or "but". He is going to do it. It's kind of encouraging.

[Overall, my family is different from other families] in a lot of ways. Normal families can pick a place and go somewhere. They don't have to plan it in advance, and they don't have to constantly remind their kids, "Hey, we're going to do this," to let them be prepared that they are going to do something. They can do more things together as a family than we can. They can show emotions. We are definitely different. We don't even spend time together because he doesn't want to. We don't have a place to go as a family. He doesn't even want to eat dinner with us at the same table. [But] we all love each other.

**Erin (13 years old)**

My sister is crazy [because of] the way she acts. She hides in her room. What's so interesting about staying in your bedroom? I don't want to stay in one spot like forever. [But] she would probably say, I'm crazy [and] mentally insane. [She likes things that I don't like]. [I haven't heard of Asperger's but I have heard of autism]. People with autism have attitude problems like mood swings and can't control it.

[During] vacations, I spend time with her, but during home days, [we] never [spend time together]. We used to watch TV together, when we had only one TV, but that didn't turn out so well. I play video games with her for like 15 minutes until she doesn't want me there. She

doesn't want me to be around her [so I usually don't spend time with her]. [During vacations, we] go swimming, go places, and go shopping, [but it happens only] once a year.

[I like that] my sister draws. [She is good at it]. [But I don't like] her personality. She is always in her room, and all that. She put scary stuff like dark anime, [which] is death oriented, on Facebook. [I think] she wishes I were dead. [We don't get along well]. I don't know [why]. [Probably it's just personality difference]. [My parents don't ask me to help my sister and she does] not really [help me either].

She is in her room all the time [so my parents don't spend much time with her]. [Other families] do stuff different from us like doing stuff together. [We are not the same as other family at all]. I don't know [what will happen to my sister when she gets older, but] she will be a writer [because she is good at it].

### Erin's Mother

I don't know [how much Erin knows about Asperger's]. When we first got the information, of course, Erin was very young. My husband and I never felt that this is the talk we need to have. We never had that talk with Erin about her sister. It's not something we made a label of. I don't think it has affected us at all. I kept everything the same [even after a pediatrician had informed us that Erin's sister displaying some symptoms of Asperger's disorder]. I wanted Erin's sister to be in the same classes and I wanted her to be around the same kids. It wasn't like we pulled back and be like "Oh, you can't do this." [We were] more like "Oh try. Go ahead." [We are] still that way. We haven't changed that. I think if we had focused more on [Erin's sister with Asperger's] and the problems, [we] would have been different [from other families who do not have a child with special needs]. But my husband and I made sure our children are no different from everybody else. I talked to my co-workers and other individuals I

have really good relationships with, and they have the same arguments [with their children]. The same “clean your room” and the same homework issues that I have. So I feel better knowing that other moms have had the same conversations that I had with both of my children.

I think [my parenting style] is different [for Erin than for her sister] only because their needs are different. I can tell Erin’s sister to do something. I don’t get much feedback [from her sister about how she feels about doing things I ask her to do], but it’s okay [because] if it’s something she doesn’t want to do like [doing] dishes, she lets me know [but] still does it. The approach is pretty easy with her. With Erin... [it’s different]. As far as rules, they both have about the same rules now, but her sister is older so she has a little bit more freedom. When Erin’s sister was smaller, [my parenting time] was [divided up] pretty equally. It shifted now because Erin’s needs are greater. Their personalities are different. Her sister is very self-sufficient and very creative. She loves her painting and drawing. She is working on her own novel right now. The whole creative, artistic side of her really has blossomed. [Also], she likes to be by herself and enjoys more of a quiet environment. [In contrast], Erin is very interactive and a social butterfly. She has a lot going on right now [because] she is going through a [puberty] phase where [her] body is changing. Having OCD, ODD, and ADHD intensifies it. [So] I think at this time I’m paying more attention to Erin than her sister.

[The relationship between Erin and her sister] is interesting. I do think there is some type of love there. I’ve seen Erin’s sister sticking up for Erin many times, but they never admit to it. They fight, scratch, and break things. They can’t go a day without fighting each other. But like I said, I have seen both of them sticking up for each other. When Erin is ill, her sister will come and ask if she is okay. It’s the same thing with Erin. I think there is some connection there, but it’s just not on a surface.

## Discussion

The purpose of the present research was to provide siblings and parents the opportunity to describe their experiences of having a child with an autism spectrum disorder in their families. The obtained interview responses addressed the research questions guiding the present study: (1) Responses from the target siblings revealed their actual perceptions and experiences of having a brother or sister with an autism spectrum disorder; (2) the information shared by the siblings and their mothers was helpful in identifying the strengths and needs of these families; (3) their described experiences and perceptions included some examples of how family systems theory can be applied to families of children with ASD; and finally, (4) their responses provided some potentially useful information for practitioners and researchers to maximize treatment and interventions. How family members' responses addressed each research question is discussed further in the following sections.

### *Siblings' Experiences and Perceptions*

The interview responses of the target siblings provided important information about their perceptions and experiences as siblings of children with ASD; their mothers' responses included information from a parental point of view. Some common themes were identified from their responses and included information relevant to how the family life cycle relates to family members of children with ASD, mentions of how characteristics of autism influences family life and family relationships, descriptions of how parenting may be influenced in families having a child with ASD, and a recognition of positive qualities of children with ASD and their families.

*Family Life Cycle.* According to Turnbull et al. (1986), families of children with disabilities with go through different stages of the life cycle as they progress and they experience different challenges and joys in each cycle. This notion was evident in the responses from the

family members interviewed in the present study. Because ages of the target siblings, as well as those of their brother or sister with ASD, varied, it is not surprising that not all families were at the same stage of the family life cycle. In these five families, four out of seven family life cycle stages were identified: Having a preschool child stage; having a school age child stage; having an adolescent in the family stage; and launching children out of the family home stage. For instance, in Brittney's family's case, the age range of the children in the family varies from 4 to 14. Thus, the family might be experiencing challenges, needs, or joys associated with multiple stages at once; the 4-year-old youngest sister stays at home most of the time with her mother (having a preschool child stage), so she gets to spend a lot more time with her mother compared to other siblings. Three other children, including Brittney's brother with autism, are all school age, but Brittney's mother reported that she tended to treat her brother with autism "like a younger kid" (having a school age child stage). In addition, Brittney is a 14-year-old who has a boyfriend (having an adolescent in the family stage), and her brother with autism "likes to do everything with [her] boyfriend" because her boyfriend is her brother's "favorite person in the world." Brittany's family, therefore, provides a great example of a family experiencing issues or joys related to multiple life cycles at once.

Although Danielle's family was at the stage of having school children, it seemed that her family was dealing with some changes at the time of the interviews because Danielle's brother had just received the diagnosis of Asperger's disorder less than a month ago. Thus, as Turnbull et al. (1986) stated, her family is likely to be facing special challenges and adjustments related to the new diagnosis of Asperger's in addition to typical stresses and joys associated with having school-age children. As suggested by Turnbull et al. (1986) uncertainty and acceptance of Danielle's brother's special needs related to his new diagnosis, as well as finding appropriate

treatment and interventions for his Asperger's disorder, are possible issues the family may be facing at this point in their life cycle.

Andrew's mother and Erin's mother reported some difficulties related to having children who are going through puberty. Andrew's brother was almost 12 years old and was described as "crabby" and wanted to sleep all the time, and Erin was a 13-year-old girl who was experiencing changes in her body. Thus, these families are transitioning to a new stage – having an adolescent in the family (Turnbull et al., 1986). Previous researchers have suggested that transitioning from one stage to the next can be challenging and bring about stress on family members (e.g., Powers, 1991). Both mothers seemed to be struggling with new needs of their children. If these families are resistant to making changes to their interaction patterns (homeostasis), this transition can be even more challenging and stressful (Powers, 1991).

In the case of Clare's family, because her sister is 18 years old, Clare shared her concerns related to her sister being independent, which indicates that this family is about to transition to a new stage, launching children out of the family home stage (Turnbull et al., 1986). Although Clare reported that her parents had started asking her sister to help out around the house, such as "doing dishes and laundry," and her sister had been learning new skills, Clare felt that her sister would need to stay with her parents "as long as it takes her to get these skills" to be independent. Overall, even though experiences of each family differed, aspects of the Family Life Cycle can be applied to all families interviewed in this research, and the results of such an application would provide useful information for practitioners and researchers concerning the issues each family may be facing at the current time.

*Characteristics of Autism.* Based on their interview responses, all five siblings have some understanding of the behavioral, social, and communication deficits associated with ASD



(APA, 2000) even though they may not have always recognized these characteristics as specific traits associated with autism. Brittney reported that her younger brother with autism was “not comfortable around people” whom he did not know well and he was “not a talker.” Clare explained that her sister was “not social” and “shy,” so Clare’s “job” was to help her sister interact with others. Both Danielle and Erin’s descriptions of their siblings with Asperger’s were similar when describing how their siblings preferred to spend their time alone instead of engaging in social interactions. Danielle reported that her brother did not want her to play with him and he did not spend much time with her. Likewise, Erin described that her sister “did not want [Erin] to be around her” so they did not spend time together. Erin also mentioned that her sister liked to isolate herself by staying in her room.

The most common activities siblings reported sharing with their brother or sister with ASD were playing video games and watching movies or television. Interestingly, these activities do not require “social interactions” and impairment in reciprocal social interactions is one of the main characteristics of children with autism (APA, 2000). Because these activities are most likely popular with the majority of the children in today’s society, however, these reports may describe a common trend for children today and may not necessarily relate to characteristics of autism.

Mothers also reported social concerns and the necessity to plan ahead for their children with ASD. Andrew’s mother mentioned problems with their neighbors and “meltdowns” they typically face on holidays. She also reported that people “judge” them and they stood out as “that family.” Brittney’s mother stated they could not have visitors in their house and it limited their social life. Moreover, she described the embarrassment they would have to face when Brittney’s brother with autism acted out in public. Clare’s mother reported that her family’s “biggest

challenge” was to get Clare and Clare’s sister ready to go out because they preferred to stay home. However, she believed that this tendency was common for “teenagers” and not related to Clare’s sister’s autism. Danielle’s mother stated that in order to prevent Danielle’s brother from getting upset and to get him prepared to go out, they needed to plan ahead. Although Erin’s mother did not report their difficulties related to social life or going out, Erin shared that her family did not do activities together as a family because her sister preferred to stay in her room.

*Understanding Autism.* These five siblings may have acquired some of their understanding of autism by experiencing their brother or sister’s behaviors, but their parents’ willingness to share information about autism may have been helpful in improving their understanding. Four out of five mothers (Andrew’s, Brittney’s, Clare’s, and Danielle’s) reported that they have talked to the target siblings about autism. For example, Andrew’s mother stated that Andrew had been “asking questions” about his brother’s autism, such as “Why don’t I go to Speech?” In Brittney’s case, she and her mother have “read a lot of books about autism” and they “go to an autism meeting every month.” Clare’s mother reported that she has been running “a parent group” and her family has done presentations together on autism, so Clare knew “quite a bit” about autism. Although it had not been long since Danielle’s brother was diagnosed with Asperger’s, Danielle’s mother reported that she had been “trying to slowly explain” about Danielle’s brother’s Asperger’s. Thus, these mothers had been sharing information about autism one way or another. Erin’s family was an exception; her mother mentioned that they “never had the talk” with Erin about her sister because they did not want to make a “label” of her diagnosis.

*Differential Parental Treatment.* Another common theme evident in the interview responses was how children’s reports of the amount of time spent with their parents was different from their mothers’ reports. According to some mothers, their time was taken up by their

children with ASD and the target siblings did not get the attention they needed. Most siblings, however, did not seem to think that their parents spent more time with their brother or sister with ASD. For example, although Andrew reported that his parents spent time with him and his brother equally, his mother stated that she felt “guilty” that she and her husband did not spend enough time with Andrew. Similarly, Brittney mentioned that the time their parents spent with her and her other siblings, including her brother with autism, “evened out,” but her mother did not feel the same way. In fact, her mother reported that they “had to put so much time and effort into her brother” that Brittney’s younger siblings might feel they were “treated unfairly.” Clare described that when their parents spent time with them, it was an “equal thing” as well. However, her mother stated that she was “more involved with her sister” and she spent “a lot more” time on her sister, especially in the past. These mothers’ reports of over-involvement with children with autism are possible examples of differential parental treatment identified by previous researchers (e.g., Kowal & Kramer, 1997).

Interestingly, both Danielle’s mother and Erin’s mother reported that they spent *less* time with their children with ASD and their focus was more towards the target siblings. Again, however, these mothers’ perceptions of the time spent together were different from the reports of Danielle and Erin that their parents spent the same amount of time with them as they did with their sibling with ASD. Overall, comments from the present research suggest that estimates of whether or not parents spend equal time with their children depend very much on who is asked.

Another example of differential parental treatment identified in the present results related to special parenting needs for children with autism. All five mothers seemed to agree that because the needs of their children with ASD were different from the needs of their children without ASD, they had to parent these children differently. For instance, Andrew’s mother

mentioned that Andrew's brother would say things "inappropriately" and she would have to explain to him why it was inappropriate, but with Andrew, she did not have to do the same because he would understand it. Similarly, Brittney's mother stated that she would have to tell Brittney's brother with autism the same things three times when she would have to tell her other children just once. Clare's mother mentioned that she communicated with Clare's sister's teachers, but she did not do the same with Clare's teachers. Additionally, some mothers reported that because their children with ASD were "smart" or "gifted," they would parent them with more pressure than their children without ASD. Andrew's mother, for example, stated that she had told Andrew's brother that he had been "given gifts" and he had to "use these gifts to make the world a better place," but she also reported that she would not say things like this to Andrew.

*Positive Qualities of Child with ASD and their Families.* Previous researchers have noted positive influences of having a child with autism in a family (e.g., Kaminsky & Dewey, 2001), as did children and mothers in the present study: Some of the influences mentioned related to positive characteristics of the child with ASD, and others related to how family life was better. For instance, Andrew mentioned that his brother was "nice" and "sticks up" for Andrew, and his mother described Andrew's brother as "protective of Andrew," as well as "intelligent." Brittney stated that her brother was "brilliant," and she liked the fact "he doesn't care what other people think." Likewise, her mother reported that Brittney's brother with autism was "smart", and his positive quality was that "he doesn't care what everybody else thinks" and "he can do what he wants to do." Additionally, they both shared their positive views of their own family. Brittney mentioned that being different from other families made them "cooler," and her mother stated their family was "never dull" and having a child with autism helped them become "accepting" of people. Clare described that being different gave her family "more meaning," and her mother

reported that because of the skills and strategies they gained due to difficulties they had faced in the past, their family ran “smoother” than other families. Danielle and her mother both stated that Danielle’s brother was “smart.” Similarly, both Erin and her mother described creative and artistic sides of Erin’s sister as her positive quality. Other positive characteristics of children with ASD mentioned by these families were “entertaining,” “sweet,” “forgiving,” and “passionate.” These statements seem to be similar to findings reported by Kaminsky and Dewey (2001) that siblings of children with autism and Down syndrome had greater admiration of their siblings than siblings of typically developing children. Moreover, acknowledging these positive characteristics of the children with ASD could help the whole family to not focus only on difficulties they experience with the children with ASD but also recognize positive aspects as well.

#### *Strengths and Needs of Families of Children with Autism*

Some of the responses obtained from the siblings and the mothers provided significant information about strengths and needs of these five families and these aspects are described next.

*Strengths.* There were several statements that indicated strengths of these families. Overall, these strengths included the use of cognitive appraisal to cope with and understand their family situation, the establishment of strong sibling relationships, how experiences with autism resulted in positive family outcomes, and the use of humor as a coping mechanism

*Cognitive appraisal.* Cognitive appraisal is a construct used to examine how people perceive stressful events or situations and cope with them (Folkman et al., 1986; Fong, 1991; Glasberg, 2000). An individual’s cognitive appraisal can vary depending on how much information and resources the person has at the moment (Folkman et al., 1986). Knowledge of autism can be method used to establish positive cognitive appraisal and thus can be a great

strength for families of children with autism. Brittney and Clare, for instance, seemed to know quite a bit about autism because their mothers are very much involved in autism support groups and they are willing to share their knowledge about it with the siblings. Because these siblings know much about autism, it appeared that they understood the needs of their brother or sister with autism and did not mind helping him or her. For instance, Brittney reported that because wrestling was “too loud and too much” for her brother, she stayed home with him when her parents took her other siblings to wrestling. Clare mentioned that her sister was “not social” and “shy” around people she did not know, so Clare usually helped her sister “interact” with them. Their course of actions might be the results of their positive cognitive appraisal: Because these siblings were able to understand the special needs of their brother or sister with autism due to their knowledge of autism, they decided to help their siblings and did not mind it. Brittney also reported that because she knew her brother sometimes was unable to understand things and could not help being stubborn, she tried to “either prevent those moments or deal with them the best” she could. Her statement indicates that she avoids fights because she understands his difficulties, which is similar to the results of a previous study that siblings of children with autism and Down syndrome reported less quarreling than siblings of typically developing children (Kaminsky & Dewey, 2001). Additionally, Brittney and Clare seemed to be a source of support for their mothers. On the Family Support Scale, both Brittney’s and Clare’s mothers indicated their own children to be extremely helpful.

*Positive Sibling Relationships.* Another strength identified from their personal stories was a strong sibling relationship. The relationship between Andrew and his brother was a clear example of how having a strong sibling relationship helps ease family stress. Andrew’s mother stated that personalities of Andrew and his brother “compliment” each other “perfectly”

and they were like “buddies.” She reported that Andrew was easy going, laid-back, and timid. In contrast, his brother was out going, protective of Andrew, and not timid. Andrew’s story about his brother “sticking up” to protect Andrew from bullies and his mother’s story about Andrew making his brother laugh when another child was screaming on the airplane certainly supports statements of their positive sibling relationship. They play with each other all the time, and it seems they have been helpful to one another as well. At present, they are still play mates, but they appear to have developed bonds and provide support to each other, which is consistent with the reports of some previous studies in sibling relationships (Findler & Vardi, 2009; Orsmond & Seltzer, 2007) These types of responses suggest that having a strong sibling relationship can be beneficial to families of children with ASD.

*Positive Family Outcomes.* A few families reported positive outcomes they gained as a result of their experiences of having children with ASD in their families. For instance, Brittney’s mother mentioned that they became “more accepting” people compared to those who do not have children with special needs in their families. Clare’s mother stated that because they had to “figure out” how to accommodate special needs of Clare’s sister and had worked hard as a family at the beginning, she felt her family ran “smoother” than other families. Additionally, she reported that her family had gained skills and strategies over time, which had helped them deal with various problems. Furthermore, knowing these positive changes are possible as shared by these families may be encouraging to those who are currently going through difficult times.

*Sense of Humor.* A sense of humor is an example of a strength mentioned by a couple of families. Andrew’s mother described Andrew’s brother as “the most hilarious person” she had ever met. She also mentioned how Andrew was a “goof ball” and how he helped his

brother go through tough times using his sense of humor. The use of sense of humor may be helpful to ease tensions or stress.

*Needs.* Although several strengths were evident in the statements of family members interviewed, several needs for these families were also identified. Overall, poor sibling relationships, restricted social activities, and perceived differential treatment are the main needs identified from the interview responses of the target siblings and their mothers in the present study.

*Reports of Poor Sibling Relationships.* Although some siblings seem to have relatively positive relationships with their brother or sister with ASD, others, such as Danielle and Erin, shared their difficulties of building relationships with their brother or sister with ASD. In both cases, mothers also reported difficulties in their relationships with their child with ASD. For instance, Danielle's mother mentioned her preference for spending time with Danielle because Danielle's brother would push her away and did not show any affection toward her. In addition, both Danielle and Erin reported that their brother or sister with ASD did not want them to be around. These reports are similar to the results of a previous study that siblings of children with autism reported less intimacy in sibling relationships than siblings of children with Down syndrome and typically developing children (Kaminsky & Dewey, 2001). These reported feelings of lack of intimacy could possibly contribute to creating negative or poor family relationships and could be an area of need for some families.

*Restricted Social Activities.* Responses about meltdowns and a restricted social life were frequently mentioned. For example, Andrew reported that his brother tended to "get upset about himself" and Andrew did not know "how to make him stop." Due to meltdowns that children with ASD had exhibited in the past, families sometimes avoided going to public places



or inviting people over to their houses. For example, Brittney's mother reported that her children without ASD had to "suffer" because they could not go anywhere for a while. Additionally, she stated that if they did go out, their brother with autism would act out and they would be "embarrassed." Other issues related to their social lives were reported by Andrew's mother – problems with neighbors and negative judgments from the public. As a result, these families had to limit their social activities, which seemed to increase their stress level and frustrations. Some mothers, such as Clare's mother and Danielle's mother, have incorporated a strategy of "planning ahead." However, even with these strategies, these mothers still appeared to face issues with having their children with ASD ready to go out.

*Perceived Differential Treatment.* As described earlier, although none of the target siblings reported spending less time with their parents compared to their brother or sister with ASD, mothers described differential treatment. Andrew's mother and Brittney's mother also shared their concerns that their children without ASD might feel that they were being treated unfairly. As these concerns could increase stress and possibly guilt feelings in parents, perceived differential treatment may need to be discussed and addressed with family members.

#### *Family Systems Theory and Families of Children with Autism*

Based on interview responses, family systems theory was relevant for the family members' interviewed. Four aspects of family systems theory, including subsystems and boundaries, homeostasis, mutual shaping, and shared and non-shared environments, were evident in the family stories described in the present study.

*Family Subsystems and Boundaries.* According to family systems theory, each family is composed of several family subsystems (e.g., parental, marital, parent-child, and sibling subsystems), and the subsystems are separated by boundaries (Minuchin, 1985). The responses

from three families indicated issues related to their family subsystems and boundaries. For instance, Andrew was five years younger than his brother. However, his mother mentioned that he was taking “almost a big brother“ role at the time of the interview. Similarly, Clare reported that she used to wonder why she felt like she was taking a “bigger load” than her older sister because her parents asked Clare to help her sister. In Brittney’s case, she stated that her parents did not ask her younger siblings to do the things she did, and her mother described Brittney as a “second mother” of the house. These examples indicate that their sibling subsystems may have vague boundaries and their parents might have placed too many responsibilities on these siblings without ASD (e.g., Morgan, 1998).

*Homeostasis.* Family systems theory states that families develop a pattern of functioning in order to achieve homeostasis or a state of balance (Parke & Gauvain, 2009), and the interaction patterns that a family has already developed over time may determine how the family responds to a diagnosis of autism and its new challenges (Leal, 1999). For instance, some families may cope with challenges in an active manner and others in a more passive manner. For instance, Brittney’s family reported they avoided going to public places as a family because of the embarrassment they faced in the past when Brittney’s brother acted out. Erin’s mother stated that she tried to maintain “everything the same” for Erin’s sister even after her pediatrician mentioned the possible diagnosis of Asperger’s disorder for Erin’s sister because Erin’s parents wanted to make sure their children were “no different from everybody else.” Erin’s mother’s statement indicates that her family worked to maintain their current level of homeostasis or their developed interaction patterns, even when they faced a new challenge (Minuchin, 1985).

On the other hand, three of the five families in the present study reported that they had made some active changes in order to adjust to special needs of their children with ASD. For

example, Andrew's mother stated the problems they had with their neighbors and how they had changed the way they interacted in public as a result of the previous problems. Clare's mother reported how they coped with all the issues they had faced in the past; she described that they had to work together as a family and "learn to be like Sherlock Holmes" in order to "figure out how to make things work." Even Danielle's family who recently received Danielle's brother's diagnosis described changes they had made; the mother reported that she had been implementing a new strategy of "planning ahead" because she now understood why Danielle's brother got upset when his routine was disrupted. Thus, it is clear that some families were not resistant to change and adjusted to new needs to help the family function better (Minuchin, 1985).

*Mutual Shaping.* As mentioned in the previous section on homeostasis, most families reported that because of the needs of their children with autism, the family members sometimes had to change the way they interacted with each other as well as how they approached the public. According to family system theory, changes that occur to any part of a family system can cause changes for the entire family due to interdependence among family members or mutual shaping (Parke & Gauvain, 2009). Although Erin's mother reported that they "kept everything the same," it seemed that Erin's family was not able to do things together as a family because Erin's sister preferred to spend her time alone. Families, such as Brittany's, who avoided going to public events because of the child with autism, also limited the public family experiences of children without autism in the family. Thus, the concept of mutual shaping appears to apply to some families of children with autism.

*Shared and Non-shared Environments.* The conditions or experiences that are shared by children raised in the same family are called shared environments, and those that are not shared are called non-shared environments (Jenkins et al., 2005; Turkeimer & Waldron, 2000). The

interview responses of all the target siblings indicated that they have experienced shared and non-shared environments. The five target siblings resided in the same houses and were raised by the same parents as their brother or sister with ASD (shared environments). However, as Thomas (2001) stated, although the siblings were exposed to the same family environment as their brother or sister with ASD, experiences may be unique to each sibling. For instance, there were some reports of different parenting styles for children with ASD and the sibling without ASD (a non-shared environment). In addition, Andrew's mother mentioned that she spent time with Andrew and had a "mommy-son" time, but she spent "more time working with his brother" (a non-shared environment). Because Brittney was like a "second mother" and had more responsibilities than her younger siblings, she seemed to experience a non-shared environment as well. Clare mentioned that she had a "bigger load" than her older sister and had to help her sister when guests were there, so Clare's non-shared environment was similar to Brittney's (e.g. more responsibilities than their sibling with autism). It appeared that both Danielle and Erin spent more time with their mothers because their mothers expressed that the target siblings needed more attention at the time of the interview, which indicated another non-shared environment. Thus, the concept of shared and non-shared environments from family systems theory seemed to apply to the participants.

#### *Relevant Information for Practitioners and Researchers*

Several practical implications were noted in the family stories shared by the participants in the present research. In this section, the information that is relevant to practitioners and researchers is discussed, including: Siblings' experiences and perceptions, strengths and needs of families of a child with autism, and the use of family systems theory.

*Siblings' Experiences and Perceptions.* The interview responses of the target siblings provided some important information about families of children with autism. First of all, the results of the present study indicated that parental reports might not always be the same as the perceptions of their children. As mentioned earlier, all mothers reported they spent different amounts of time with their children with ASD than they did with their children without ASD; none of the children reported this differential treatment. Therefore, practitioners and researchers need to keep in mind that information from one family member may not provide a holistic view of the family. Additionally, the responses of siblings revealed how much they knew about autism and what characteristic of autism they observed in their brother or sister with ASD. Because siblings' level of understanding of autism can influence their course of actions (e.g., be helpful to their parents or seek negative attention by misbehaving) due to cognitive appraisal, practitioners and researchers may consider assessing siblings' understanding of autism and educating those who do not know much in order to promote better understanding and support from them, which in turn would help ease stress on their parents. In addition, some children reported positive qualities of their brother or sister with ASD and their families that were not mentioned by their mothers. It is necessary for practitioners and researchers to realize that siblings can be important reporters of behaviors of their brother or sister with autism because they grow up together as playmates and closely observe their brother or sister with autism from siblings' points of view. These findings indicate, therefore, that sometimes children's experiences, perceptions, and overall points of view may be different from their parents. By acknowledging siblings' experiences and perceptions when working with children with autism and their families, practitioners and researchers may obtain new and valuable information about the families of children with autism that may influence the course of treatment or research questions addressed.

*Strengths and Needs of Families of A Child with Autism.* Although some common themes were identified in the interview responses of family members in the present study, it was also obvious that each family was unique. When working with families of children with autism, identifying each family's strengths and needs and incorporating them in research or in practice can be beneficial not only to practitioners and researchers but also to the families. Because each family's strengths and needs will be different, practitioners and researchers can tailor treatment and interventions based on the strengths and needs of each individual family. For instance, Andrew and his brother have a very strong sibling relationship, but his brother tends to have meltdowns in public places. Based on his mother's report, Andrew's sense of humor has helped ease his brother's anxiety and stress in the past. Practitioners and researchers may consider using their strengths –Andrew's sense of humor and his great relationship with his brother– to create treatment or interventions that will alleviate some of the difficulties Andrew's brother and his family have been facing.

*Use of Family Systems Theory.* Aspects of family systems theory could be applied to the responses to the interview questions in the present investigation. By applying the aspects of family systems theory to the information obtained from siblings and their parents, practitioners and researchers can examine how the family functions as a unit and if there are any unproductive interaction patterns within the family. Some families may be resistant to change, and others may have problems with boundaries that could be addressed. For example, because Erin's parents wanted to "keep everything the same" for Erin's sister, her family may or may not continue to exhibit unproductive interaction patterns. In Brittney's family, Brittney playing a role of a "second mother" at the age of fourteen can put too much stress on her. If practitioners and researchers identify any problems within the family system, they may consider addressing the

problems in treatment and interventions in order to improve the overall family environment and family functioning.

### *Limitations of the Present Study*

Although useful information about families of children with autism was gathered in this research, it is also important to keep in mind some limitations of the present study. First, the sample size of the present study was small (five children and their mothers). In addition, the participants were all Caucasians, so a lack of diversity also needs to be considered. Additionally, ages of target child and child with ASD, severity of autism, specific ASD diagnosis, and functioning level of children with autism were not controlled for or matched in the present study. Also, because the participants volunteered for the present study, it is possible that their experiences and perceptions of having a child with autism in their families might be different from families who did not volunteer. Families who volunteered, for instance, may be more accepting of the diagnosis of autism than those who did not. All of the above mentioned considerations limit the generalizability of the findings of the present research.

Another possible limitation is that there were no comparison groups in the present study. Thus, when discussing the results, it is difficult to determine whether the responses of the target siblings were due to their experiences of having a brother or sister with ASD in their families or whether they were related to having siblings in general.

Because the locations of the interviews differed from participant to participant, it was difficult to control for distractions (e.g., a dog barking during the interview; two children requested their mothers be present when interviewed). How variability in settings may have affected responses is unknown and is another limitation.

Social desirability is another possible limitation. Although the participants were assured confidentiality and told there were no right or wrong answers, some participants might have still wondered if they would be judged based on their responses. Thus, how social desirability may have influenced interview responses is unknown. Finally, this was a qualitative research endeavor and no information related to cause and effect can be assumed.

#### *Future Directions*

For future study, it may be interesting to create age groups (e.g., elementary school, middle school, vs. high school) to examine similarities and differences of siblings' experiences and perceptions within and across age groups. This approach would allow researchers to study how siblings' perspectives change with age. For instance, Andrew's mother reported that there were some things that Andrew who was 6 years old had not yet figured out, such as he was getting picked on because of his brother. When he figures it out, his experiences and perceptions of having a brother with Asperger's may or may not change. In addition, future researchers may consider comparing siblings who have knowledge of autism with those who do not. By examining the difference, the importance of educating siblings may be revealed.

#### *Conclusions*

Overall, the results of the present study have provided much helpful information that was relevant to the research questions. All the information obtained from the siblings and their mothers provided insights to better understand what is like to have a child with autism in the family. Moreover, the present study helped demonstrate the importance of obtaining information from family members of children with autism and indicated that siblings may offer insightful information about their brother or sister with autism from different perspectives from their parents. Thus, practitioners and researchers need to keep in mind that every member of a family



plays an essential role in maximizing the effects of treatment and interventions for a child with autism. Moreover, without collecting information from all individuals in the family, practitioners and researchers may not be able to fully capture the complete picture of how the family functions and how the child of autism can be treated the most effectively.

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Appendix A

Demographic Questionnaire - Parent

1. Who has a diagnosis of autism or Autism Spectrum Disorder (ASD)? When was he/she diagnosed?

Name	Diagnosis	When

2. Please complete the following information about the rest of members in your family.

Name	Sex	Date of Birth	Relationship to the child with autism/ASD

3. Is your child with autism/ASD verbal? If no, how does he/she communicate?

YES / NO - \_\_\_\_\_

4. Does your child receive treatment or interventions at this time? If so, please specify.

YES / NO - \_\_\_\_\_

5. What is your occupation?

\_\_\_\_\_

6. What is your partner's occupation?

\_\_\_\_\_

Appendix B

Interview Questions – Parent

1. Who diagnosed your child with autism/Autism Spectrum Disorder (ASD)? What were you and your partner's initial reactions when you found out about the diagnosis?
2. How old was (the child with autism—child's name would be used here) when you first noticed that something was not quite right with his/her development? What was it that made you concerned?
3. What influence has the diagnosis of autism/ASD had on your family?
4. What are some areas of difficulties you have experienced raising (the child with autism)?
5. What are some positive things that you have experienced raising (the child with autism)?
6. Is your parenting style different for (the child with autism) than for your other children? Tell me some examples.
7. Describe how your time spent parenting is divided up among your children?
8. How would you describe your family's recent stress level? What is your family's main source of stress at this time?
9. What do you typically do to handle family stressors? Do you have access to formal and/or informal support? If so, what kind of support?
10. Do you think your family is different from families who do not have a child with special needs? In what way, do you think your family is different?
11. Do you think your family is the same as families who do not have a child with special needs? In what way, do you think your family is the same?
12. How much do you think (target sibling) knows about (diagnosis)? How did she or he learn about the diagnosis? Do you talk to him/her about it?



13. How would you describe the relationship between (child with autism) and (target sibling)?

## Appendix C

### Interview Questions – Siblings

1. Tell me about your brother/sister (name of child with autism)?
2. If child mentions autism, then will ask children: “What do you know about autism (or specific diagnosis reported by parent)?”

If child does not mention sibling has autism, then will ask child: “Have you heard of (diagnosis reported by a parent)? If so, what do you know about it?”

If child has not heard of (diagnosis), skip to Question 4.

3. How did you first learn about (diagnosis)? How old were you?
4. How much time do you spend with (child with autism)?

If there is another sibling in the family, then ask: “How much time do you spend with (sibling’s name)?”

5. What kinds of things do you and (child with autism) do together?

If there is another sibling in the family, then ask: “What kinds of things do you and (sibling) do together?”

6. What do you like about (child with autism)?
7. What do you not like about (child with autism)?
8. How do you think the (child with autism) feels about you?
9. Do your parents ask you to help or take care of (child with autism)? If so, what do you usually do for him/her?

If there is another sibling in the family, then ask: “Do your parents ask (sibling) to help or take care of (child with autism)? If so, what does he/she do for (child with autism)?”

10. Do you mind helping or taking care of him or her? Why or why not?

11. Does (sibling with autism) also help or take care of you? If yes, what does she or he do?
12. Do your parents spend more time with (child with autism) than with you? If so, what do they do with (child with autism)?
13. Do you think your family is different from other families? If so, in what way?
14. Do you think your family is same as other families? If so, in what way?
15. What do you think will happen to (child with autism) when she/he gets older?

## Appendix D

**FAMILY SUPPORT SCALE**

Listed below are sources that often times are helpful to members of families raising a young child. This questionnaire asks you to indicate how helpful each source is to your family.

Please circle the response that best describes how helpful the sources have been to your family during the past 3 to 6 months. Cross out any sources of help that have not been available to your family during this period of time.

		Not At All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
1.	My parents .....	0	1	2	3	4
2.	My spouse's parents ..	0	1	2	3	4
3.	My relatives/fun .....	0	1	2	3	4
4.	My spouse's relatives/fun	0	1	2	3	4
5.	Husband or wife .....	0	1	2	3	4
6.	My friends .....	0	1	2	3	4
7.	My spouse's friends ..	0	1	2	3	4
8.	My own children .....	0	1	2	3	4
9.	Other parents .....	0	1	2	3	4
10.	Church .....	0	1	2	3	4
11.	Social groups/clubs ...	0	1	2	3	4
12.	Co-workers .....	0	1	2	3	4
13.	Parent groups .....	0	1	2	3	4
14.	My family or child's phys- ician .....	0	1	2	3	4
15.	Professional helpers (social workers, therapists, teachers, etc.) .....	0	1	2	3	4
16.	School/day care center	0	1	2	3	4
17.	Professional agencies (public health, social services, mental health, etc.) .....	0	1	2	3	4
18.	Specialized Early In- tervention Services* ...	0	1	2	3	4
19.	Other (specify) .....	0	1	2	3	4

\*Married parent version. The single parent version has the word "spouse" replaced with "child's father" (or mother).

#The name of the program the child/family participated in was included here

Table 1

*Overview Demographics of Participants*

	Andrew	Brittney	Clare	Danielle	Erin
Age	6	14	14	9	13
Birth Order (compared to sibling with ASD) and Age Difference	Younger By 5 years	Older By 4 years	Younger By 4 years	Younger By 2 years	Younger By 2 years
Diagnosis of Sibling	Asperger's	High-Functioning Autism	High-Functioning Autism	Asperger's	Asperger's (provisional) <sup>a</sup>
Sibling's Age When Diagnosed	2	8	7	11	9 (unofficial) <sup>b</sup>
Current Treatments or Interventions	Speech therapy; Feeding therapy; Occupational therapy; Psychotherapy	Behavioral therapy	Speech Language Pathology (SLP) at School	Social Skills Training	None
Live with Both Parents?	Yes	Yes	Yes	Yes	Yes
Both Parents Work?	Yes	Yes	Yes	Yes	Yes
Any Other Siblings?	No	Yes	No	No	No
		3 younger siblings			

*Note.* <sup>a</sup> Erin's sibling just started seeing a psychiatrist, and her psychiatrist reported that her diagnosis was provisional at this time.

<sup>b</sup> According to Erin's mother, when Erin's sister was approximately 9 years old, her teachers and pediatrician had begun mentioning that she might have Asperger's disorder.

Table 2

*Number of Participants Selected Each Response on Family Support Scale Items*

	Not At All Helpful	Sometimes Helpful	Generally Helpful	Very Helpful	Extremely Helpful
Parents	2		2		
Spouse's Parents	2		2		
Relative/Kin	1		2	1	
Spouse's Relative/Kin	1		2		1
Husband			1		4
Friends		1	2		1
Spouse's Friends	1	1	1		1
Own Children		1	1	1	2
Other Parents	2	2	1		
Church	2		1		
Social Groups/Clubs	2	1	1		
Co-workers	1	1	1	1	
Parent Groups	1		2	1	
Family or Child's Physician			1	1	3
Professional Helpers (e.g. Social Workers, Therapists, and Teachers)		1		3	1
School/Day Care Center			1	1	2
Professional Agencies (e.g. Public Health, Social Services, and Mental Health)	1	1			
Specialized Early Intervention Services	1	1			

*Note.* The last question, "Other (Specify)" was removed from this table as no one had specified other resources that were available to them.

Table 3

*Overview of Additional Information from Mothers*

	Who diagnosed your child?	Initial reactions	What made you concerned first?	Recent stress level	Main source of stress	Stress reliever	Main source of support
Andrew's Brother	Speech Language Pathologist	Not surprised	- First word at the age of 2 and half	Very high	- Andrew's brother's asperger's & anxiety (Recent hospitalization)	- Respite care	- Own children - Professional helpers (e.g. social workers, therapists, teachers)
Brittney's Brother	Psychologist	Surprised	- Since head start, always getting in trouble	Moderate	- Money	- Friends - Go out	- Husband's relatives - Husband - Own children - Child's physician
Clare's Sister	Psychologist	Not surprised	- No talking at the age of 2	Moderate	- Clare's school grades	- Have a strategy - Friends	- Husband - Own children
Danielle's Brother	Psychiatrist	Not surprised	- Not affectionate - Full of anger - Fixates on certain objects	Moderate	- Arguments with Danielle's brother - Not enough help	- Be alone to cool down	- Husband - Child's physician - School
Erin's Sister	Pediatrician (Not official diagnosis)	Not surprised	- Not much talking at the age of 3	Very high	- Arguments with Erin	- Yell - Scream	- Husband - Friends - Husband's friends - Child's physician - School

*Note.* The main sources of support were the items these mothers rated the highest on Family Support Scale.