A Phenomenological Case Study of the Impact of Autism Spectrum Disorders on the
Sibling Relationship

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DeAnna L. Henderson
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This dissertation titled
A Phenomenological Case Study of the Impact of Autism Spectrum Disorders on the Sibling Relationship

by
DEANNA L. HENDERSON

has been approved for
the Department of Counseling and Higher Education
and the College of Education by

Mona Robinson
Assistant Professor of Counseling and Higher Education

Renée A. Middleton
Dean, College of Education
ABSTRACT

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Director of Dissertation: Mona C. Robinson

The purpose of this study is to understand the impact that Autism Spectrum Disorder (ASD) has on the sibling relationship. This dissertation examines the perspectives of siblings of children with ASD. If 4 million children are born in the United States every year, approximately 26,670 children will eventually be diagnosed with an ASD (Center for Disease Control and Prevention, 2009). Since nearly a third of all children with a developmental disability have a sibling, it is important to understand the impact that disability has on the sibling relationship. ASD is a developmental disability that has increased in prevalence over the last couple of decades. The interaction between siblings appears to be of great importance to the sibling relationship (Knott, Lewis, & Williams, 1995). This has even more significance to siblings of children with ASD because a deficiency in social interaction is a cardinal feature of the disorder. For this reason, it seems probable that the interactions of children with ASD and their siblings may differ from other children with siblings both with and without a disability (Knott et al., 1995).

This is a qualitative study using naturalistic inquiry. A phenomenological case study was completed to understand how ASD impacts the sibling relationship. The study included five adolescent participants ranging from 11-18 years of age. These participants
lived in both urban and rural settings and were within close age proximity (5 years) of their sibling. Data were collected by digitally recorded semi-structured interviews, field notes, and observations. Through data analysis the researcher identified themes and patterns that emerged regarding the sibling relationship.

The major findings of this study indicate that having a sibling with ASD does impact the sibling relationship. Four major themes emerged from the analysis of the data. These themes are: “The hardest part of ASD is feeling absolutely helpless,” “That’s just the way our family is,” “Having a sibling with ASD has actually impacted my life for the better,” and “It’s a blessing and a curse.”

Another finding of this research confirmed the need for specialized interventions for siblings of children with ASD. The researcher found that children have a voice that must be heard and respected. Through this research, siblings were given an opportunity to state their wants and needs. The participants stated that more information regarding their sibling’s disorder would be beneficial. This finding is imperative for mental health practitioners and service providers. It provides a backdrop for providing effective and appropriate treatment interventions for siblings of children with ASD.

Finally, this research documents the need for parents, service providers, and policy makers to recognize and provide the opportunity for treatment interventions specifically for siblings of children with ASD and families of children with ASD. This research also highlights the impact that ASD has on the health and functioning of the entire family. Understanding this influence is vital to the development of key strategies and interventions for families of children with ASD.
Approved: 

Mona Robinson
Assistant Professor of Counseling and Higher Education
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CHAPTER 1: INTRODUCTION

In an effort to understand the impact that Autism Spectrum Disorders (ASD) has on the sibling relationship and provide appropriate services to these individuals, I conducted a qualitative study of five siblings of children with ASD. The goal of this study was to identify themes related to the impact of having a sibling with ASD. By identifying the themes, effective interventions may be designed to enhance the relationships of siblings and family functioning. This chapter provides the statement of the problem, significance, purpose, my research question, methodology, and definition of common terms found in this type of research.

Background of the Study

In the United States, about 52.6 million people have a disability (Mac, 2002). As the population ages, this number is expected to increase. Historically, individuals with disabilities have been discriminated against and denied access to housing, jobs, and inclusion in society through attitudinal barriers. Treatment for individuals with a disability was based solely (1) the socioeconomic status of the person’s family and (2) whether the disability manifested itself in a violent or non-violent manner (Rubin & Roessler, 2001).

In an effort to protect the rights of individuals with disabilities, in 1973 the Rehabilitation Act was passed. This act required states to provide services for people with disabilities in any program conducted by federal agencies, in programs receiving federal financial assistance, in federal employment, and in the employment practices of federal contractors (2006). According to Rubin & Roessler (2001), the act had five purposes: (1)
serve individuals with severe disabilities, (2) promote consumer involvement, (3) stress program evaluation, (4) provide support for research, , and (5) advance the civil rights of persons with disabilities (p. 45). This was the first civil rights legislation to prohibit discrimination of individuals with disabilities and to link federal funding to the implementation of this law (Mac, 2002; Rubin & Roessler, 2001).

There are five sections to the Rehabilitation Act that addressed discrimination. Section 501 will prohibits discrimination in hiring by the federal government. According to Rubin & Roessler (2001), “the most important feature [of Section 501] is to establish the federal government as a model agency for promoting the recruiting, hiring, and advancing of workers with disabilities” (p. 55).  Section 502 addresses accessibility issues for individuals with disabilities. This section established the Architectural and Transportation Barriers Compliance Board (ATBC) to enforce the accessibility standards (Rubin & Roessler, 2001, p. 57).  Section 503 requires that all federal contract recipients of monies exceeding $10,000 ensure affirmative action and prohibits discrimination. Section 504 says that individuals with disabilities not be excluded or denied access to federal programs solely based on their disability (Rubin & Roessler, 2001).

In addition to the Rehabilitation Act of 1973, the Americans with Disabilities Act (ADA) have been instrumental in providing protection to individuals with disabilities with regards to employment and other aspects of life. The goal of the ADA is to ensure that employment opportunities are accessible for individuals with disabilities. There are five areas in which the ADA offers protection: Title I: Employment, Title II: Public Services, Title III: Public Accommodations, Title IV: Telecommunications, and Title V:
Miscellaneous Provisions (Rubin & Roessler, 2001). According to the U. S. Department of Justice (DOJ), Title I requires employers with 15 or more employees to provide qualified individuals with disabilities an equal opportunity to benefit from the full range of employment-related opportunities available to others (2005). Title II requires that State and local governments provide equal access and opportunity to participate in programs, services, and activities. In addition, public transportation authorities may not discriminate against people with disabilities in the provision of their services. Title III forbids, “discrimination on the basis of disability that would prevent persons with disabilities from having the full and equal enjoyment of the good, services, facilities...” (Rubin & Roessler, 2001, p. 122). This title is applied to businesses, and nonprofit service providers that are public accommodations, privately operated entities offering certain types of courses, and examinations, privately operated transportation, and commercial facilities (DOJ, 2005). Title IV requires access to telecommunications such as telephone, television, and radio to all individuals including those with a disability (Rubin & Roessler, 2001). Title V provides protection to individuals who address discrimination concerns covered by the ADA. Agencies are not able to retaliate against individuals who make such allegations (Rubin & Roessler, 2001).

While the ADA has been in commission for several years, discrimination is still present for individuals with disabilities. Obviously, the goal is for people with disabilities to be treated as equal members in society, yet there are still industries that have barriers that exclude individuals with disabilities. According to two studies by the U.S. General Accounting Office (GOA), compliance with the ADA was at 67% in one
study and 74% in another (Rubin & Roessler, 2001). While society has made strides toward full inclusion of individuals with disabilities, there is still work left to do.

While it is expected for older individuals to acquire disabilities, it may be surprising that the younger generation has an increasing rate of disabilities too (Mac, 2002). It is estimated that one in six children ages birth to 17 have some type of developmental disability (Webb, 2006). Furthermore, from 1991-1994 the number of children with a disability increased by 1.5 million and the number of young adults with disabilities increased by 1.9 million (Mac, 2002). As cited by Mac (2002), The U.S. Census Bureau's Survey of Income and Program Participation (SIPP), reported in the February 2001 Americans with Disabilities: Household Economic Studies that 12.7% of children ages 6-14 have a disability.

With rising rates of childhood disability, it is imperative that appropriate treatment and services are implemented. When enacting these services, it is imperative to remember that the needs of children with a disability vary significantly and are directly related to the impairment, the symptoms, and its manifestation in that child. The success of children with disabilities is tied to the individualized plans for them. For many years, parents and other individuals have fought to obtain the necessary services for children with disabilities and include these children in society. For instance, The Education for All Handicapped Children Act of 1975 (EHA) Public Law 94-142, was the first law passed requiring education for children with disabilities (Rubin & Roessler, 2001). While legislation regulating the education and services provided to children with disabilities has been in place for 25 years, these children still face discrimination and exclusion (Mac,
This act was replaced by the Individuals with Disabilities Act (IDEA) which “requires public schools to make available to all eligible children with disabilities a free appropriate public education in the least restrictive environment appropriate to their individual needs” (DOJ, 2005). In addition, IDEA requires and Individualized Education Programs (IEP) for each student that outlines the plans and services for each student. Parents, teachers, services providers must all participate in the development of these IEPs.

The number of individuals with disabilities continues to rise. In fact, people with disabilities are the nation’s largest minority group, and the only one that any person can join at any time. It is estimated that all people have about a 20% chance of becoming disabled at some point during their work life (U.S. Department of Labor, 2009). Despite the fact that there has been significant legislation enacted to support the full inclusion of individuals in society, there are still considerable advances that need to be made. With increasing numbers of people with disabilities, there will be increasing situations that will arise that will need to be addressed. A particular issue that will need to be discussed is the family and how disability impacts that unit.

Statement of the Problem

In the United States, nearly 30% of children experience a moderate to severe chronic illness or disability, and nearly all of these children live in a household with at least one sibling (Cox, Marshall, Medleco, & Olsen, 2003). Atkinson and Crawford (1995) indicated that 80% of children with disabilities have a typical developing sibling. Having a sibling with a disability appears to be a common phenomenon. Since this is a
prevalent situation, it is noteworthy to discover the impact that having a sibling with a disability has on the normal developing sibling. Moreover, it is necessary to outline services that can assist the typical developing child deal with this occurrence.

The discovery that a child has a disability has a profound effect on the family (Marinelli & Dell Orto, 1999). One common denominator for families of children with a disability is stress. Stress represents both a psychological and physiological reaction to a perceived threat that requires some action or resolution. Stress is essentially reflected by the rate of all wear and tear caused by life (Hans Selye, 1956). Family stress is present in all families living with chronic disease and disability (Case-Smith, 2007). However, families with children diagnosed with ASD experience stress at higher levels than other families. Parents of children with autism report greater levels of stress and depression and lower levels of marital intimacy than parents of children with typical development, or parents of children with Down’s syndrome (Fisman, Wolf, & Noh, 1989). In a 1997 study, Kasari and Sigman sought to examine the relation of parental perceptions and observed parent-child interactive behaviors. One aspect of the study focused on parental perception of stress and parenting. Parents of 28 children with autism, 26 children with mental retardation and 28 typically developing children completed the Parenting Stress Index (PSI). The PSI is a self-reporting measure that explores stress associated with parenting. The investigators found that parents of children with autism indicated higher levels of stress than parents of children with mental retardation and normal developing children (Kasari & Sigman, 1997).
Within the family, the sibling relationship serves as the child’s first social network and sets the foundation for social interaction with the family and others outside the family system. Franco and Levitt (1997) conducted a study with 56 children and their mothers to understand the social networks of preschool children. The children were between the ages of 4-5 and the mothers mean age was 35.49 (Franco & Levitt, 1997). Their research had four specific focuses (1) to interview preschool children about their social networks, (2) to compare the children’s concept of social networks to that of their mothers, (3) to assess the extent to which differences between child and mothers viewpoints are accounted for by the child’s familiarity with mother-reported network members, and (4) to examine the linkage between characteristics of preschoolers’ social networks and their acceptance by teachers and peers. Franco and Levitt found that preschoolers and parents were consistent in identifying the social network. All children identified parents, friends, siblings and extended family as a part of their social networks. The authors reported that mothers typically listed the same people as members of the child’s social network: parents, siblings, friends and extended family members. What this means is that young children are aware of the social support received from siblings and that this relationship is foundational and vital to the development of social cues and interactions. While it is known that a child with a disability affects the family and ultimately the siblings, it is unknown how ASD affects the sibling relationship.

The prevalence of ASD is on the rise and the reason for this increase has not yet been pinpointed. According to data recently released by the Centers for Disease Control (CDC), about one percent of 8-year-olds in the United States have an autism spectrum
disorder. This is a 57 percent increase from the rate found in 2002 using the same research methods (CDC, 2009). It was previously thought that ASD is a prevalent developmental disorder that affects approximately 2-6 per 1,000 (from 1 in 500 to 1 in 150) children (Centers for Disease Control, 2006). Some speculate that the increase is due to more awareness about the disorders, while others indicate it is because there are improved testing measures. Individuals with ASD have difficulties with social interaction, verbal and non-verbal communication, and display repetitive behaviors (NIMH, 2009). It is estimated that more than 1.5 million Americans live with some form of ASD, including more than 100,000 children served under Individuals with Disabilities Education Act (IDEA) (U. S. Government Accountability Office, 2009).

It is well-known that individuals with ASD have trouble with communication, social interaction, and display stereotypic behavior (Rapin, 1991). Chawarska, Klin, and Volkmar (2008) stated that, “symptoms of autism center on areas of social interaction and communication, and are often accompanied by delays in multiple areas of functioning, including motor and nonverbal cognitive development” (p. 12). Furthermore, Chawarska et al. (2008) reported that in the social domain, individuals with ASD display, “diminished eye contact, limited interest in social games, turn-taking exchanges, low frequency of looking referentially at parents, and preference for being alone” (p. 12). Stereotyped or repetitive behaviors are also a concern for individuals with ASD. Siegel (2003) stated that “children with autism tend to eschew novel objects, and actions, and prefer familiar actions with new or old objects, which in the absence of imagination in play, leads to a limited, stereotyped, and repetitive play repertoire” (p. 98). Each child is
unique and this may be manifested differently. However, some ways that this may appear
daily is the child with ASD’s preference for routine and rituals, or an obsession or
fixation with objects. Additionally, the child with ASD has poor comprehension of
communication as typically developing children would understand it. Children with ASD
have deficits in communication such as body language and facial expressions, and spoken
language. Children with ASD miss the social cues that are exhibited in interaction, do not
display or use body language, and facial expressions to the full extent, may not speak
verbally or delayed verbal communication (Rapin, 2001; Siegel, 2003).

The sibling relationship is probably the longest relationship anyone will have.
Also, research has documented the importance of the sibling relationship. Knott, Lewis,
and Williams (1995) reported that the sibling relationship is one that lasts a lifetime.
They also noted that the sibling relationship is like a classroom for learning about social
interaction where children learn how to communicate, interact, and play appropriately
(Barnes & Austin, 1995; Brody, 1998; Knott et al., 1995). Since the relationship serves as
a learning tool that shapes communication and social interaction with others, it is
important that the sibling relationship is strong and viable. Hence, it is important to
understand the impact that ASD may have on the sibling relationship.

There have been many studies surrounding the impact of disability on the family
system (Marinelli & Dell Orto, 1999; Soresi, Nota, & Ferrair, 2007). Many of these
studies have specifically centered on the impact a child’s disability has had on parents or
primary caregivers (Neely-Barnes & Dia, 2008). Specifically, a multitude of these
studies have focused on the adjustment of parents, the financial burden of parents, and the
increased stress levels of parents. Soresi, Nota, and Ferrari (2007) conducted a study to, “examine the efficacy of personalized and specific interventions of parent training aimed at improving the quality of life for families with disabled children” (p. 248). The authors found that parents who participated in this intervention demonstrated increased satisfaction with family relationship, and support, well-being, and knowledge. In addition, Duchovic, Gerkensmeyer, and Wu (2009) studied the association of perceived social support, personal control, and child behavioral problems to the distress in parents of children with mental health problems. Specifically, Weiss (2002) in her study of 120 parents (40 parents of children with autism, 40 parents of children with mental retardation, and 40 parents of children with normal development) found that parents of children with autism have significantly higher levels of depression, anxiety somatic complaints, and burnout as parents of normal developing children or parents of children with mental retardation. These authors found that parenting a child with a mental health disability did in fact increase parental stress. While these studies are significant, these studies do not report the impact that having a sibling with a disability has on the typical sibling.

Additionally, there have been some studies regarding siblings of children with disabilities. These studies oftentimes focus on the adjustment of the sibling without the disorder and use a quantitative methodology to collect and analyze the data. Naylor and Prescott (2004) recognized the challenges that siblings face when a brother or sister has different abilities. The authors conducted a study with 55 siblings of children with disabilities between the ages of eight and eighteen. They found that siblings of children
with disabilities need to have a voice, need to be heard, and need to be participants in research. Although there is literature that discusses the impact of having a sibling with a disability on the non-disabled sibling, many of the studies are quantitative in nature, and focus on the adjustment of the non-disabled sibling. Additionally, the research is inconclusive on what the effect of having a sibling with a disability has on children. Some cite positive benefits (McHale, Sloan & Simeonsson, 1986; McHale & Gamble, 1989; Kaminsky & Dewey, 2002), while others cite negative adjustment (Bagenholm & Gillberg, 1991; Rodrigue, Geffken & Morgan, 1993; Hastings, 2003). While it seems the literature in this area is sufficient, these studies do not highlight the sibling’s point of view. This study used qualitative methodology to explore the relationship of siblings when one has been diagnosed with ASD. On the rare occasion that this subject matter is found in the literature, there is a paucity of studies that report the sibling’s perspective of the sibling relationship when one sibling has ASD. Most of the literature provides the parent’s prospective and not the sibling’s opinion.

In summary, ASD are developmental disorders that impact the social interaction, and communication of individuals, as well as the individual’s ability to engage in cooperative and imaginative play. The prevalence of ASD continues to increase in the United States while the reason for this increase is not clearly known. Moreover, the literature documents the importance of the sibling relationship, which serves as the first place children practice their social skills and learn to interact with others. Having a child with a disability in the family is known to increase stress and have a profound effect on the parents. However, there is a shortage of literature that documents the impact that
having a sibling with ASD has on the sibling relationship. This study will explore the influence of ASD on the sibling relationship.

**Purpose**

The purpose of this phenomenological case study is to understand the impact ASD has on the sibling relationship from the perspective of the sibling without ASD. Research indicates that siblings share a unique and important relationship with one another within the family unit that has been found to be imperative to the development of social skills in childhood (Dunn, 1988; Dunn & Munn, 1986; Knott, Lewis, & Williams, 1995). It is in the sibling relationship where most children first learn the social skills necessary to interact reciprocally with others.

The interaction between siblings appears to be of great importance to the sibling relationship (Downey & Condron, 2004; Knott et al., 1995). This has even more significance to siblings of children with ASD because individuals with ASD have a deficiency in social interaction and communication and display repetitive, restrictive behaviors. For this reason, it seems probable that the interactions of children with ASD and their siblings may differ from other children with siblings both with and without a disability (Knott et al., 1995). The central research question that this investigator answered was how does ASD impact the sibling relationship?

**Significance**

The purpose of this study was to describe the impact that ASD has on the sibling relationship. This study is significant because there is a scarce body of literature regarding the influence that ASD has on the sibling relationship. This research offered a
detailed description of the sibling relationship when impacted by ASD from the sibling without ASD. The literature documents those families of children with disabilities experience an increased level of stress (Dell Orto & Power, 2007; Duchovic, Gerkenmeyer, & Wu, 2009). Siblings are an important part of families. They play a vital role in socializing one another and preparing each other to interact with the outside world.

Family Systems Theory asserts that “family members are part of an interactive, interdependent network in which behavior in one individual or subsystem affects the others” (Brody, 1998). Another way of viewing this is, a change in one family member will constitute a change in the rest of the family (Gladding, 2002). Due to the reciprocal nature of the system, and to fully understand an individual, one must examine the system as a whole (Corey, 2001). Within the context of the family systems perspective, not only does each member have a role, but each member’s role is interconnected to all other family members. For example, in a family unit where a child has a disability, parents experience higher levels of stress than parents of typical developing children (Soresi, Nota & Ferrari, 2006). The stress that is felt by parents will impact the lives and interactions of the other members in the family. This may be manifested in reduce time spent with children or significant other, or diminished leisure time to engage in family activities. Based on this assumption grounded in family systems theory, it is expected that siblings of children with ASD will experience increased levels of stress. Wolf, Fisman, Ellison & Freeman (1998) reported that typical developing siblings may deal with less parental attention, increased care responsibilities, risk for poor peer relations,
lower level of participation in outside activities. In addition, there are numerous studies that speak to the complex issues, increased stress, and the adjustment that parents face when a child has a disability (Case-Smith, 2007; Soresi et al., 2007; Turnbull & Turnbull, 1997). Whereas, there are a small number of studies that speak to the way siblings perceive the impact of the disability (Carter, 2008; Neely-Barnes & Dia, 2008; Robertson, 2002). Duchovic et al. (2007) discussed the need for more interventions for families of children with disabilities. Specifically, Case-Smith (2007) recommends that future qualitative research explore the sibling experience when a child has a disability because the research in this area is minimal.

This researcher has gained a better understanding of the sibling perspective and identified the impact that ASD has on the sibling relationship. Specifically, four themes were revealed: “The hardest part of ASD is feeling absolutely helpless”, “That’s just the way our family is”, “Having a sibling with ASD has actually impacted my life for the better”, and “It’s a blessing and a curse.” Respondents talked about the attitudinal barriers faced by their siblings and families on a regular basis and how they want to educate others about autism to eliminate this type of barrier. In addition, participants discussed a desire to change the difficult aspect of their brothers and sisters lives. Participants also reported having a flexible and adaptive family. When complicated situations arise, respondents stated their family is able to address and resolve them. Siblings indentified the positive aspects of having a sibling with ASD such as improved personal characteristics and having a close knit family. They identified being more patient, understanding, and accepting of others. Finally, participants in this study reported
that they have mixed emotions about having a sibling with ASD. As previously reported, participants are more tolerant of difference and thoughtful. Participants also discussed how their sibling’s behaviors negatively impact their lives and the way others view their family. Through this research and confirmation of existing knowledge, I have uncovered specific recommendations for clinicians, other service providers, and parents to better assist siblings of children with ASD. Counselors need to be a resource for families of children with ASD. It is important that counselors and service providers provide information about the disability, the characteristics, manifestation, and treatments. Being knowledgeable and sharing that knowledge, counselors will empower families to make informed decisions about their child’s and their family’s care. Finally, counselors should assist parents with educating family members regarding the child’s disability and potential impact on the family. I have also made recommendations for parents of children with ASD. It is imperative that parents have a purposeful conversation with your typical child(ren) about the disability, symptoms, and behaviors. Also, parents should plan activities so that all members of the family are able to participate. This will enhance the cohesiveness of the family unit. Parents also need to be available for your children to discuss concerns, and/or frustrations. In addition, caregivers must be well-informed about appropriate resources available to you, your children and your family. Finally, parents must be able to advocate for your family, and needed services.
Research Question

Given the literature, this researcher analyzed the following question; how does ASD impact the sibling relationship? This question can best be answered through exploring qualitative methodology.

Overview of Methodology

Qualitative methodology is used in research to gain an in-depth understanding of human behavior. Qualitative research methods, according to Glesne (2006), “are used to understand some social phenomena from the perspectives of those involved, to contextualize issues in their particular socio-cultural-political milieu, and sometimes to transform or change social conditions” (p. 4). Furthermore, while quantitative research methods are designed, and utilized to make generalizations regarding some identified population, qualitative research methods are used to understand a certain phenomenon, population, or event (Glesne, 2006). The purpose is to understand individuals’ beliefs, attitudes, and behaviors from the participants’ perspective. This can be accomplished using a variety of methods. Qualitative research uncovers unexplored areas of behaviors and brings to light the uniqueness of the phenomenon being studied.

Within qualitative research methodology there are several different approaches. These approaches include: 1) narrative research, 2) phenomenological research, 3) grounded theory research, 4) ethnographic research, and 5) case study research. Narrative research is defined by Creswell (2007) as, “a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected (p. 54). This can be done with an individual or a group of people whom share an action or event. It
involves identifying themes and retelling the stories in sequential order. Phenomenology describes the essence of lived experiences for individuals regarding a shared concept or phenomenon (Creswell, 2007). The investigator discovers significant themes and describes the fundamental nature of the occurrence. Grounded theory requires the researcher to extend beyond describing or understanding a process and develop or generate a theory regarding it (Creswell, 2007; Patton, 2002). This theory will evolve from the collected data and help explain or understand the process under study.

Ethnographic research involves understanding a cultural group (Creswell, 2007). These researchers generally immerse themselves in the population under study and through observation uncover the meaning of the behaviors, language, and interaction among the group (Creswell, 2007; Patton, 2002). Developing a thorough description and analysis of a single case or multiple cases is the focus of case study research. This type of research often times involve several sources of data collection methods including interviews, observations, and documents (Creswell, 2007).

Phenomenology was chosen as an approach because the study was to understand the essence of each participant’s story while conceptualizing all the stories and arriving at common themes across all of the participant’s experiences. Creswell (2007) held that “a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (p. 57).

Additionally, this researcher chose case study research as a research design for this study. Creswell (2007) stated that “case study research involves the study of an issue explored through one or more cases within a bounded system” (p. 73). However, this is a
single case study with multiple units of analysis. Furthermore, with case study research, the emphasis is on understanding why the individual does what he or she does and how behavior changes as the individual responds to the environment (Ary et al., 2002). This is an appropriate approach because the study aims to understand each participant’s perspective on having a sibling with ASD and how it has impacted that relationship.

There are various methods used in qualitative research. Rubin and Rubin (2005) suggest that qualitative interviewing is a way of finding out what others feel and think about their worlds. “Through qualitative interviews you can understand experiences and reconstruct events in which you did not participate” (p. 3). According to Berg (2004) there are three types of interviewing: 1) structured, 2) semi-structured, and 3) unstructured. Structured interviewing adheres to a strict format with pre-set questions whereas unstructured interviewing is open and only the subject matter is prearranged. A semi-structured interview may have a set of predetermined questions; however, the interviewer is free to ask follow-up questions and diverge from the ordered list of questions (Berg, 2004). The interviewer, when conducting this type of interview, may also adjust the wording of the questions, level of language, and add or delete probes, and questions (Berg, 2004). I chose a semi-structured interviewing process due to its flexibility. This type of interview may have a set of predetermined questions; however, the interviewer is free to ask follow-up questions and diverge from the ordered list of questions (Patton, 2002). The question list provides a frame of reference and ensures a systematic and methodical interview for all participants. The investigator, when conducting this type of interview, may also adjust the wording of the questions, level of
language, and add or delete probes, and questions (Berg, 2004). This is the approach best suited to elicit the information from the participant’s viewpoint, and the primary method explored in this qualitative study.

Also, the researcher used observation. While interviewing the respondents, I noted the behaviors and interactions of the family. Three of the participants were observed in their homes, one respondent was observed in a restaurant, and one participant was not observed because the interview was conducted over the telephone. Observation entails the systematic noting and recording of events, behaviors, and artifacts in the social setting chosen for study (Marshall & Rossman, 2006). Observations allow the interviewer to observe the context in which the participants interact (Patton, 2002). Additionally, direct observations allow the researcher to see things that may be invisible to the participant. Sometimes people are unaware of behaviors, facial expressions or other things that may enhance the researchers understanding of the phenomenon. If participants are unaware they are not able to report these, oftentimes, helpful facts. This section discussed the methods that were used to gather data; next, the limitations of this study will be addressed.

Limitation of Study

No research design is perfect (Marshall & Rossman, 2006). The limitations of this study are: (a) time in the field, (b) sample size, and (c) participant availability. Glesne (2006) stated that the time in the field will not be known with certainty. Instead, it is suggested that researchers have a flexible timeline to guide the study. According to Marshall and Rossman (2006) “no qualitative research is generalizable in probabilistic
sense, the findings may be transferable” (p. 42). There are no rules for sample size in qualitative inquiry (Patton, 2002) there are some guidelines. Sample size is dependent upon the purpose of the study, access to participants, time, and resources (Patton, 2002). As the instrument, the researcher must be aware of biases they hold. Glesne (2006) recommended that researchers monitor their subjectivity and look for the ways that subjectivity influences the data analysis process.

The researcher would have liked to have spent more time in the field observing the siblings’ and families’ interactions. However, that was not possible due to the time constraints and the strict adherence to schedules to ensure continuity for the sibling with ASD. In quantitative research, generalizability is one of the goals and many quantitative researchers see this as a limitation of qualitative research. In qualitative research the goal is to understand and transfer the knowledge gained, not to generalize. Quantitative researchers seek a larger sample size to facilitate generalizability, whereas qualitative researchers seek small sample sizes for in-depth understanding (Marshall & Rossman, 2001). However, to build credibility the researcher used multiple sources of data to enhance credibility of the data. Another limitation is the researcher as the instrument by which the data were collected. The researcher has more than five years of experience working with families, and children from all walks of life, but no direct experience working with children diagnosed with ASD. Finally, a limitation of this study is participant availability. Although during the screening process the time commitment was clearly outlined, once in the field many participants were not available for observation outside of the interview time.
Definition of Terms

The following terms are offered for clarification:

**Asperger’s Disorder** - severe impairments in social interactions, and the development of restricted, repetitive patterns of behaviors, interests, and activities. There are no clinically significant delays in language acquisition as with ASD (APA, 2000).

**Autistic Disorder** - qualitative impairment in social interaction; qualitative impairment in communication, and restricted repetitive, and stereotyped patterns of behavior, interests, and activities. Additionally, delays or abnormal functioning must be present in the aforementioned areas with onset prior to age three and the maladaptive behavior is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (APA, 2000).

**Childhood Disintegrative Disorder** - marked regression in multiple areas of functioning following a period of at least 2 years of apparently normal development. In addition, after 2 years but before age 10 the child has clinically significant loss of previously acquired skills in at least two of the following areas: language, social skills, bowel or bladder control, play, or motor skills. Also, children exhibit social and communicative deficits, and behavioral features observed with ASD (APA, 2000).

**Developmental Disability** - the Administration on Developmental Disability defines developmental disabilities as severe, life-long, and attributed to mental, and/or physical impairments which manifest themselves before the age of 22 years, and likely to continue indefinitely.
Dual parent—a family with two parents, either biological or adoptive, who is solely responsible for care of self and child/children (Gladding, 2002).

Family—those persons who are biologically and/or psychologically related, who historical, emotional, or economic bonds connect, and who perceive themselves as a part of the household (Gladding, 2002).

Mental Health Professionals/Clinician—professionally licensed such as: counselors, social workers, psychologists, and psychiatrists to provide counseling services.

Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)—there is severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviors, interests, and activities but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder (APA, 2000).

PDD—pervasive developmental disorders, is another name for Autism Spectrum Disorders (ASD).

Rett’s Disorder—multiple specific deficits following a period of normal functioning after birth. Between ages 5 and 30 months, head growth decelerates and there is a loss of h, and skills. There is also severe impairment in language development. It is terminal and generally only females develop the disorder (APA, 2000).
Service Providers—individuals and organizations that offer a multitude of services such as: physical therapy, occupational therapy, and behavioral interventions for individuals, and families.

Siblings—one of two or more offsprings having one common parent.

Single parent—a family that includes one parent, either biological or adoptive, that is solely responsible for care of self, and child/children (Gladding, 2002).

Systems Theory—a theory, sometimes known as general systems theory, that focuses on the interconnected of elements within all living organisms, including the family (Gladding, 2002).
CHAPTER 2: REVIEW OF LITERATURE

Introduction

The purpose of this chapter is to examine the relevant literature related to Autism Spectrum Disorders, families of children with disabilities, and specifically, siblings of children with a diagnosed autism spectrum disorder. The purpose of this study is to understand, and the impact that ASD has on the sibling relationship. In order to understand this research, it is important to review the literature in context. The review of literature is divided into five broad areas: (1) ASD, (2) sibling relationships, (3) siblings of children with disabilities, (4) siblings of children with ASD, and (5) Family Systems Theory Approach.

Autism Spectrum Disorder

History of ASD

Historically, Kanner (1943) first spoke of autism as a congenital disorder. In his early work regarding autism, Kanner identified the social difficulties, repetitive behaviors, or inability to change of the children he studied. Kanner made a clear and distinctive difference between early infantile autism and schizophrenia. However, other researchers remained convinced that this disorder was an extension of schizophrenia and most of this research was lost.

In 1944, Asperger identified “autistic psychopathy” which later became known as Asperger Disorder. Wing and Gould (1979) enhanced our understanding of autism and clarified the manifestations of the characteristics that become widely known with autism.
After conducting an epidemiological study, Wing and Gould spoke to a spectrum or continuum that had different manifestations and thus the term ASD was born.

Ruettter expanded upon Kanner’s original report and outlined four major components of autism: 1) early onset, 2) distinctively impaired social development, 3) distinctively impaired communication, and 4) unusual behaviors (Chawarska, Klin, & Volkmar, 2008). Based upon Ruettter’s and Kanner’s research this diagnosis was included for the first time in the *Diagnostic and Statistical Manual of Mental Disorders, Third Edition (DSM-III)* (Chawarska, et. al, 2008).

*What is ASD?*

Autism Spectrum Disorders (ASD) or Pervasive Development Disorders are disorders typically diagnosed during childhood that cause severe deficits in three areas: verbal and non-verbal communication, social interaction, and repetitive behaviors. There are five disorders in the ASD category: Autistic Disorder, Asperger Syndrome, Rett Syndrome, Pervasive Development Disorder-Not Otherwise Specified (PDD-NOS), and Childhood Disintegrative Disorder. The most common of these disorders are Autistic Disorder, Asperger Syndrome, and PDD-NOS, with Rett Syndrome and Childhood Disintegrative Disorders being rarely diagnosed and having specific diagnostic criteria (Moldin & Rubenstein, 2006). Autistic Disorder is defined in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* by

A. A total of six or more items from (1), (2), , and (3), with at least two from (1), , and one each from (2), , and (3):
1) Qualitative impairment in social interaction, as manifested by at least two of the following:
   
a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
   
b) Failure to develop peer relationships appropriate to development level
   
c) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people
   
d) Lack of social or emotional reciprocity

2) Qualitative impairment in communication, as manifested by at least one of the following:
   
a. Delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)
   
b. In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
   
c. Stereotyped, and repetitive use of language or idiosyncratic language
   
d. Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:
a) Encompassing preoccupation with one or more stereotyped, and restricted patterns of interest that is abnormal either in intensity or focus

b) Apparently inflexible adherence to specific, nonfunctional routines or rituals

c) Stereotyped, and repetitive motor mannerisms

d) Persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (American Psychiatric Association, 2000, p.75).

**Characteristics of ASD**

A fundamental feature of ASD is the qualitative impairment in social interaction. Individuals with a diagnosis of ASD encounter stumbling blocks when participating in the reciprocal relationship necessary to engage in social interaction (NIMH, 2009).

Children with ASD may have trouble reading and deciphering the social cues that people exhibit when interacting. Children with ASD may express feelings in ways that are different from the norm. For example, even when the situation calls for passion, children with ASD often appear stoic and emotionless. This can cause severe damage to the sibling relationship as the child with ASD may not be able to understand the sibling when he or she tries to engage in normal play or conversation. If not adequately educated about
the disorder, the siblings without ASD may not understand why their sibling doesn’t bond with them or express normal emotional ties. Sibling interaction is vital to the development of healthy relationships and if either sibling isn’t able to learn these skills at home, it impairs both children’s ability to interact and grow into healthy, well-adjusted adults.

Another cardinal characteristic of ASD is a deficit in communication and is generally one of the first symptoms reported by parents to clinicians (Seligman, 1998). It is postulated that many children diagnosed with ASD may not ever acquire verbal language skills (Rapin, 1991). If children with ASD are not able to communicate verbally with their siblings, it could cause a strain on the interaction, and impair the relationship. Additionally, children with ASD may develop repetitive phrases, sayings, and/or echolalia (parrot what they hear) (NIMH, 2009). It has been reported that children with ASD commonly become fixated on these responses and may deliver them within a conversation even when it is not an appropriate reply. Learning to communicate and transfer the skills learned are essential functions of the sibling relationship. If either sibling is unable to complete this process, the ability to engage socially with the world may be hindered. Adolescents are characterized by fitting in with peers. Any difference, however slight, may cause disruption to the peer relationship. Siblings of children with ASD may be embarrassed because their sibling displays improper language skills which may cause both children to be ostracized.

In conjunction with deficits in social interaction and communication, children with ASD exhibit repetitive behaviors and/or interests. Rapin says, “Autistic children
regularly display repetitive movements such as flapping of hands when excited, twirling, humming, running around in circles, rocking, head banging, twisting of the fingers, or twiddling locks of hair, sometimes to the point of baldness” (1991, p. 754). Children and adolescents may be embarrassed by the behavior that the siblings exhibit and therefore disengage from them. Additionally with the pressure of fitting in, the siblings may not want their sibling with ASD to play nor communicate with friends. More notably, children with ASD resist disruptions to daily schedules or routines. In considering this resistance to change, children with ASD appear to have an unusual tolerance for monotony (Rapin, 1991; Wing & Potter, 2002). Consequently, a structured environment is paramount for children with ASD to be more successful (Levin, 2005). Siblings may tire of the strict adherence to the same schedule or routine. Because of this obsessive repetition, siblings may not be able to participate in recreational or extracurricular activities. This can lead to the child without a disability resenting both the parents and the sibling.

*Diagnostic Criteria*

The diagnosis of ASD usually involves a two-step process. The first step is a developmental screening or a well baby check (NICHD; NIMH). This screening examines the child’s progress in normal stages of development. If there is an identified delay at this stage, the child is referred to professionals for further screening and evaluation.

The next step in the diagnostic process usually involves the use of screening tools developed specifically for ASD. Charwarski et al., discuss this process and identify a
number of screening instruments. The Checklist for Autism in Toddlers (CHAT), the Modified-Checklist for Autism in Toddlers (M-CHAT), and the Social Communication Questionnaire (SCQ) are examples of tools used to determine symptoms of ASD in toddlers. The CHAT is a short questionnaire which is filled out by the parents and a primary health care worker at the 18-month developmental check-up. It aims to identify children who are risk for social-communication disorders (National Autistic Society, 2009). It consists of two sections: the first nine items are questions asked the parents, and the last five items are observations made by the primary health care worker. The key items look at behaviors which, if absent at 18 months, put a child at risk for a social-communication disorder (National Autistic Society, 2009). M-CHAT is a screening tool for children between 16 and 30 months of age. While the M-CHAT does not diagnose ASD, it does assess risk for ASD (Hayhurst, 2009).

The SCQ is another instrument used to assist professionals identify social and communication deficits in children. Previously known as the Autism Screening Questionnaire (ASQ), this brief instrument helps evaluate communication skills and social functioning in children who may have ASD or ASD Spectrum Disorders. Completed by a parent or other primary caregiver in less than 10 minutes, the SCQ determines whether an individual should be referred for a complete diagnostic evaluation (Western Psychological Services, 2009). The tools identified here are just a few examples of instruments used; there are many others that assist professionals with the diagnostic process.
A concern with the diagnostic process is that professionals, school personnel, and other mental health practitioners do not have one standardized instrument to use to diagnose ASD. Although the \textit{DSM-IV-TR} is the most widely used method for diagnosis (Rapin, 2001), the criteria are strictly behavioral and allow for subjective interpretation. Additionally, the diagnosis is often not accepted across professional discipline and the process for families has to be repeated.

\textit{Prevalence of ASD}

Autism Spectrum Disorder is diagnosed on the basis of behavioral criteria and clinicians might apply criteria differently to arrive at a diagnosis of ASD and related disorders; therefore, determining the prevalence is challenging. Diagnoses of ASD have risen rapidly in the past two decades, with prevalence of the disorders jumping tenfold over rates reported prior to 1990. According to a 2007 report by the US Centers for Disease Control, an estimated 1 in 150 8-year-old children in the United States live with an ASD (Hayhurst, 2009). The most recent epidemiological estimates places the prevalence of all ASD combined at around 50–60 per 10,000 school-age children (Chakrabarti & Fombonne, 2005; Fombonne, 2005; Schieve et al., 2006). If four million children are born in the United States every year, approximately 26,670 children will eventually be diagnosed with an ASD. If the prevalence rate had been constant over the past two decades, we could estimate that about 560,000 individuals between the ages of 0 to 21 have an ASD (CDC, 2009). There is no evidence to suggest why the diagnosis of ASD has increased. Speculation regarding the increase suggests a greater media presence surrounding ASD, than previously. Fombonne (1999) stated that more complete
diagnoses and a broader definition of Autistic Spectrum Disorders are the reasons for increased attention.

According to the *DSM-IV-TR* (2004), ASD are more prevalent in boys (except Rett syndrome), siblings of children with ASD, and children with certain developmental disorders such as Fragile X syndrome, mental retardation, and tuberous sclerosis. Moldin, and Rubenstein (2006) report a 3 or 4 to 1 ratio of boys to girls having ASD found in epidemiological studies, and a ratio of up to 10 to 1 for many research samples. These researchers also assert that due to the rarity of ASD in females, small sample sizes have been a major limitation in many studies.

*Etiology of ASD*

There does not seem to be a consensus regarding the etiology of ASD. Some hypotheses have been generated but none have been proven. The most common hypotheses include: genetic factors, environmental concerns, and neurologic/biologic reasons. Evidence has recently pointed to genetic factor, i.e. genes liability, causing ASD (NICHD, 2009). Using linkage and association strategies to identify susceptibility genes, very promising findings with respect to loci on chromosomes 2 and 7 as well as leads on other chromosome locations were found (Rutter, 2005). Rutter hopes that within the next decade the actual susceptibility genes will be identified. The Autism Genetic Resource Exchange is recruiting genetic samples from families to continue research on genetic causes of ASD (CDC, 2009).

Dziedzic (2007) reported that the brain in a child with ASD develops abnormally. It is thought that the brain of a child with ASD is smaller than a normal developing
child’s. This difference in size is thought to manifest the symptoms associated with ASD. Specifically, it was stated that a shrunken amygdale may explain the social impairment in children with ASD (Dziedzic, 2007).

Controversial Causes of ASD

Vaccinations have had a major impact on the medical world. In fact, “Vaccines are one of the greatest achievements of biomedical science, and public health” (Centers for Disease Control and Prevention [CDC], 1999a, p.247). Historically, researchers took many risks to develop vaccinations (Miller & Reynolds, 2009), and because of these risks numerous diseases can be prevented. People rely on vaccinations to stay well, and prevent illness. This is especially true for children as they need to be protected from diseases that can occur during early childhood. To ensure individuals receive vaccines on time, the Centers for Disease Control, the American Academy of Pediatrics, and the American Academy of Family Physicians jointly publish a schedule of recommended immunizations each year. Today, young children receive 14 standard vaccinations to prevent disease (Miller & Reynolds, 2009).

Safety measures have been put in place to ensure that vaccines are harmless to the recipients. In addition, if there is some adverse affect to a vaccine, there are procedures in place to address that as well. Miller and Reynolds (2009) report that, the National Childhood Vaccine Injury Act was passed in 1986, and created the National Vaccine Injury Compensation Program, which provides compensation for those found to be harmed by specific vaccines (p. 168). Moreover, the act requires healthcare providers to report any serious adverse events that occur within 30 days after vaccination with any
vaccine. The reports must be submitted to the Vaccine Adverse Event Reporting System (VAERS), which was set up in 1990, and is managed by the CDC, and the Food and Drug Administration (FDA) (Miller & Reynolds, 2009).

While vaccinations have been extremely beneficial to the medical world, recently parents have had major concerns with the risk associated with childhood vaccines (Miller & Reynolds, 2009). Parents have had some concern with the Measles, Mumps, and Rubella (MMR) vaccination, and the use of thimerosal in certain vaccines. Particularly, a concern regarding the ethyl mercury contained in the preservative thimerosal, which has been used in vaccines since 1931.

*Thimerosal and Autism*

In 1999, the California Department of Developmental reported that the rate of autism had increased 273% over the past 10 years (Baker, 2008). Many parents and advocacy groups pointed to thimerosal in childhood vaccinations. In 1999, The U.S. Food and Drug Administration (FDA) ordered the removal of thimerosal from vaccinations (Charwarska et al., 2008). Even though this additive was removed, a 2003 study in Denmark found that autism rates there continued to increase (Late, 2008). This finding was not unique to Denmark. Recently, in the United States, the prevalence of ASD has increased. According to researchers with the Health Resources, and Services Administration (HRSA), Centers for Disease Control, and Prevention (CDC), and Massachusetts General Hospital, the new estimate found that roughly 1 in 90 U.S. children ages 3–17 were given an ASD diagnosis in 2007 is significantly higher than previous reports which the CDC estimated 1 in 150 (NIMH, 2009). Although thimerosal
has been removed from vaccines, the rates of ASD have continued to increase, and there hasn’t been scientific support, this hypothesis is still prevalent today.

**MMR and Autism**

Dr. Wakefield and 12 coauthors reportedly investigated 12 children referred to the Royal Free Hospital and School of Medicine with chronic enterocolitis and regressive developmental disorder (Eggerston, 2010). This study described 12 British children who appeared to develop symptoms, characteristics of autism, and gastrointestinal problems after a period of apparent normal development (Wakefield et al., 1998, as cited in Baker, 2008). The authors reported that in 8 of these children, parents associated the onset of symptoms with their child’s MMR vaccination. Furthermore, the authors asserted that there may be an environmental cause of autism linked to the MMR vaccine (Meek, 2004). From this, a controversy was born (Eggerston, 2010). This research was groundbreaking because for decades researchers have been trying to uncover the cause of autism. Additionally, these results caused many parents in Britain to refuse the MMR vaccination for their children, and as a result it has been speculated that the measles incidence increased (Meek, 2004; Scandals, 2004). This debate was prominent not only in Britain, but spread to the United States as well. Many parents and attorneys joined the fight against the MMR vaccination due to their belief in Dr. Wakefield’s study citing that MMR vaccine may cause autism.

The debate escalated when it was discovered that a portion of the children that Wakefield, and his co-researchers studied were carefully selected, and some of Wakefield’s research was funded by lawyers acting for parents who were involved in
lawsuits against vaccine manufacturers (Eggerston, 2010). Many people believed that Dr. Wakefield acted unethical in the research, and these people began to deflate the findings. In fact, Britain’s General Medical Council found that Dr. Wakefield had indeed been unethical in this research study (Eggerston, 2010).

In 2004, 10 of the 13 authors retracted the study’s interpretation stating that the evidence did not establish a causal link between MMR vaccine, and autism (Chawarska, Klin, & Volkmar, 2008; Meek, 2004; Sugerman, 2007). Several of the authors wanted to be as far removed from this controversy as possible. Specifically, Simon Burch wrote in the Lancet, “There is now unequivocal evidence that MMR is not a risk factor for autism — this statement is not spin or medical conspiracy, but reflects an unprecedented volume of medical study on a worldwide basis” (as cited by Meek, 2004). While many of the authors joined the retraction of the article, Dr. Wakefield’s signature was notably absent (Meek, 2004).

No Link Found

Since the Wakefield controversy, vaccinations have been viewed dubiously. There have been numerous reports in the media regarding a link between autism, and vaccinations, and this has become a widely accepted cause of ASD. While vaccinations have been thought to cause ASD, this is speculated, controversial, and unproven. Brent Taylor, and colleagues (former colleagues of Dr. Wakefield) designed a study that identified all 498 known patients with autism spectrum disorders (ASD) in North East Thames who had been born in 1979 or later, and linked them to an independent regional vaccination registry. The researchers found that while the prevalence of ASD had been
increasing, there was not a drastic increase after the introduction of the MMR vaccine (DeStefano & Chen, 1999). “Taylor and colleagues’ analysis showed no association between vaccination, and onset of regression provides especially persuasive evidence against the hypothesis that MMR may cause or exacerbate autism” (DeStefano & Chen, 1999).

Recently, another study concluded that there was no scientific evidence that any part of a vaccine or combination of vaccines cause ASD (CDC, 2009; NIMH, 2009). The Institute of Medicine (IOM) conducted a scientific review on the link between thimerosal (a mercury-based preservative that is no longer used in vaccinations), and ASD as well as between MMR, and autism. Based upon that review, The Immunization Safety Review: Vaccines and Autism reported that a link between ASD, thimerosal or MMR was not found (NIMH, 2009). Moreover, there is no conclusive evidence that any vaccine or vaccine additive increases the risk of developing autism (CDC, 2007b). In addition, the US Court of Federal Claims ruled that there is no association found between ASD, and vaccinations (U.S. Department of Health and Human Services, 2009). “The Court found, after reviewing 5,000 pages of transcripts, 939 medical articles, 50 expert reports, and hearing testimony from 28 experts, that the MMR, and thimerosal-containing vaccines, independently or together, were not causal factors in the development of autism or ASD” (U.S. Court of Federal Claims, n.d.).
Dissenting Opinions

While many researchers do not believe that vaccinations cause ASD, Dr. Andrew Wakefield, a former British surgeon and Dr. Bernadine Headley, former Director of the National Institutes of Health, are not ready to dismiss the link.

In an interview with CBS correspondent Sharyl Attkisson, Dr. Healy states that vaccines for the vast majority are safe; however, she believes that there may be a susceptible group of individuals who may be at risk for developing autistic like characteristics as a result of receiving certain vaccinations (2008). Even further, Dr. Healy stated that instead of dismissing the link between autism and vaccines as irrational, researchers and the government should utilize appropriate resources to explore it further. She contends that the NIH in 2004 stated that there shouldn’t be any further research on susceptibility groups. Dr. Healy believes this is because of the fear of damage to the public health community (Attkisson, 2008).

Dr. Healy is not alone in her beliefs. There are numerous parents who believe that a vaccination caused their child’s autism or autistic characteristics. Mylinda King, a mother, believes that a battery of vaccinations changed her and her son’s life forever. According to a news story by Sharyl Attkisson, Mrs. King son, Jordan, was a vocal, and vivacious baby. His mother stated that after routine vaccines, her son withdrew from the world. Jordan is one of nearly 5,000 autism claims filed in federal vaccine court. Most claim that mercury, or MMR shots, or both, resulted in their children’s autism (Attkisson, 2008).
Treatment

There is no single best treatment for all children with ASD (CDC, 2009; Rapin, 2001). Common treatment approaches for ASD include: applied behavior analysis (ABA), pharmacology, and dietary interventions.

ABA

ABA has been the most popular treatment method for individuals with ASD (Rapin, 2001). ABA is used to teach new skills, increase new positive behaviors, continue positive behaviors and reduce behaviors that interfere with learning. A key component of this treatment is parental involvement due to the intense nature of the treatment. It is highly structured and generally operates for forty hours a week. The following are different types of ABA:

a) Discrete Trial Training (DTT) is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored.

b) Early Intensive Behavioral Intervention (EIBI) is a type of ABA for very young children with an ASD, usually younger than five, and often younger than three.

c) Pivotal Response Training (PRT) aims to increase a child’s motivation to learn, monitor his own behavior, and initiate communication with others. Positive changes in these behaviors should have widespread effects on other behaviors.

d) Verbal Behavior Intervention (VBI) is a type of ABA that focuses on teaching verbal skills.
However, recently there has been some concern regarding the actual effectiveness of ABA for ASD. Researchers using the Early Intervention Program (EIP) studied 60 children with ASD. The participants were divided into three groups of 20. One group received the EIP, another group received reduced intervention, and the last group was the control group without any intervention. EIP was an intensive and rigorous intervention with behavioral principles being applied for more than 40 hours per week. Lovaas and colleagues reported that around 50% of the participants improved their spontaneous deliverance of adaptive behaviors and were able to be put into mainstream classes. It was further noted that participants demonstrated improved IQ scores (Lovaas, 1987). The initial study conducted by Lovaas (1987) has been scrutinized and researchers have identified some problems (National Research Council, 2001; Shattuck & Grosse, 2007). Webster, Feiler, and Webster (2003) have identified these problems as: selection bias, delay in treatment, lack of randomization, and different assessments used for pre/post testing. These findings make the results of this study nearly impossible to generalize. The National Research Council (2001) stated most research, like the Lovaas study (1987) has focused on efficacy in small samples under tightly controlled clinical conditions, where individual treatment outcomes vary widely. When this treatment was tried in a community setting with fewer controls the results were mixed as to its effectiveness (Moldin & Rubenstein, 2006). Reed, Osborne, and Corness (2007) studied the effectiveness of 3 early interventions in a community-based sample over a period of 10 months. These interventions were ABA, special nursery placements, and portage. A total of 53 participants were identified and took part in the study. Reed et al., (2007) did not
find any evidence of recovery from ASD. Whether Lovaas’ approach is inherently more effective than other treatment approaches has not yet been demonstrated (Moldin & Rubenstein, 2006).

Dietary

Elder, Shankar, Shuster, Theriaque, Burns, and Sherrill (2006) and Irvin (2007) have begun to explore other options in the treatment of ASD. One is dietary intervention. Dietary intervention is based on the idea that food allergies or an insufficient amount of a specific vitamin or mineral may cause symptoms of ASD. A response to this is to have gluten-free, casein-free diet. Gluten is a substance found in the seed of cereal plants such as wheat, oat, and rye. Casein is a protein found in milk. There are mixed results with the diet intervention and the diet is extremely difficult to follow. Parent and teacher report children with ASD have been cured of ASD, have acquired language, and showed marked improvement in social relatedness after completing this diet (Elder et al., 2006). To date, however, there are insufficient empirical data supporting these claims and no published reports of double blind controlled clinical trials that use the most widely accepted diagnostic instruments and direct behavioral observation to test dietary effects.

Elder et al. (2006) conducted a study to test the efficacy of a gluten-free and casein-free (GFCF) diet in treating ASD. They used randomized, double blind repeated measures crossover design. The sample included 15 children aged 2–16 years with ASD. Data on autistic symptoms and urinary peptide levels were collected in the subjects’ homes over the 12 weeks that they were on the diet. Group data indicated no statistically significant findings even though several parents reported improvement in their children.
Statistically no significant findings may be the effect of small sample size and/or large within-group variance (Elder et al., 2006).

Irvin (2006) also conducted a case study to test the effectiveness of the gluten-free and casein free diet, in reducing maladaptive behaviors with a 12-year old male child with ASD. An analog assessment consisting of attention, demand, play, and self-restraint interruption conditions was conducted within two diet phases: gluten/casein-free and regular diet. Irvin’s findings suggest that the gluten/casein-free diet had no decelerative effect on the frequency of Aleck’s behavior problems as measured within any of the analog conditions conducted. In essence, there was an absence of behavioral benefit derived from the consumption of a gluten/casein-free diet as provided for the participant (Irvin, 2006).

According to Alpert (2007) the assumption behind the diet is that people with ASD often have gastrointestinal abnormalities that allow unusual amounts of digestive by-products into the body (the so-called leaky gut syndrome). The by-products of gluten and casein, according to one hypothesis, disrupt brain function by altering opioid activity, which is involved in pain regulation, and social bonding. Shattock, Kennedy, Rowell, and Berney (1990) posit that the gut leakage triggers a harmful immune response. These hypotheses have not been proven; in fact, scientists have not even confirmed that people with ASD have a higher-than-normal incidence of gastrointestinal problems. The enthusiasm is grounded more in hope than in science; so far researchers have no evidence that dietary interventions can alleviate the symptoms of ASD (Alpert, 2007; Elder et al, 2006; Irvin, 2006).
Medication

Another treatment is medication. While there is no medication that can cure ASD, certain medications can treat the symptoms associated with these disorders (Malone Gratz, Delaney, and Hyman, 2005; NICHD, 2009; Rapin, 2001). The medications that are most often used are: 1) selective serotonin reuptake inhibitors (SSRI), 2) tricyclics, 3) psychoactive/anti-psychotics, and 4) stimulants. SSRIs are a group of antidepressants that treat problems resulting from an imbalance in serotonin (a neurotransmitter). Fluoxetine, and Fluvoxamine are SSRI’s. In one trial, Fluvoxamine was given to 15 adults and a placebo was given to 15 adults with ASD for 12 weeks. Fifty-three percent of the participants who received Fluvoxamine versus the given placebo were categorized as responders on the Clinical Global Impression scale (McDougle, Posey & Stigler, 2006). This drug can reduce frequency, and intensity of repetitive behaviors; decrease irritability, tantrums, and aggressive behaviors; and improve nonverbal communication such as eye contact (NICHD, 2009).

Psychoactive/anti-psychotic drugs are the most widely studied (Malone et al., 2005; NICHD, 2009). These drugs decrease hyperactivity, reduce stereotyped behaviors, and minimize withdrawal, and aggression (NICHD, 2009). Some examples of anti-psychotic drugs are Haloperidol, Risperidone, and Olanzapine. Tricyclic antidepressants are used to treat depression and obsessive-compulsive behaviors. A negative aspect of tricyclic antidepressants is that they have more side effects than SSRIs.

Lastly, stimulants are most often used with higher functioning individuals and are used to increase focus and decrease hyperactivity. Examples of stimulant drugs used to
treat ASD are: methylphenidate, levoamphetamine, and levodopa. Moldin and Rubenstei
(2006) reported numerous studies that have been conducted; all with mixed results. The effects of levodopa, and levoamphetamine were compared in a double-blind crossover study conducted in 12 children with schizophrenia, and autistic features. Levoamphetamine resulted in worsening of the symptoms and was poorly tolerated (McDougle, Posey, & Stigler, 2006). Another study with stimulant drugs using methylphenidate resulted in improvement of 60% of the participants. Methyphenidate was given to 15 participants with ASD for 6.5 months and 9 participants had decreased hyperactivity and impulsivity.

*Education of Children with Disabilities*

The Education for All Handicapped Children Act (EHA) Public Law 94-142, which was enacted in 1975, was the first law passed requiring education for children with disabilities (Rubin & Roessler, 2001). This legislation was passed to ensure that the needs of individuals with disabilities were being met by states. Currently named the Individuals with Disabilities Education Act (IDEA), this legislation arose from dissatisfied parents and lawmakers due to the exclusion of the many children with disabilities from the public education system. Under the original law, states had to provide programs, and services for children age 3 to 21 years. However, in 1986 an amendment was passed requiring services from birth (Government Accountability Office, 2004).

There have continued to be amendments to the EHA. In 1990, the name of the EHA was changed to IDEA. In 1997, IDEA was reauthorized and required states to
provide transitional services to assist individuals with disabilities with the move into adulthood and that these services should begin at age 14. Specifically, for states to receive funding under this act, “the states had to implement procedures for identifying, locating, and evaluating all children with disabilities and for ensuring that children with disabilities are educated with children without disabilities to the greatest extent possible (Rubin & Roessler, 2001, p. 69).” The act also maintains that an, Individualized Education Program (IEP) be developed for each child. IEP’s must contain, “annual goals and short-term instructional objectives; services and aids to be provided; a rationale for any time away from the regular classroom; required modifications in assessment and testing; timelines, frequency, and location for services; a statement of transition services from age 14 as they relate to school services and age 16 as they relate to adult agency linkages; and procedures for determining educational progress and notifying parents (Rubin & Roessler, 2001, p.69-70).”

The IEP is a fundamental component of IDEA. It’s the driving force of planned services for individuals with disabilities. The IEP outlines the necessary services and direction for children with disabilities. This is a collaborative effort to include the parents, teachers, and important service providers to ensure that the child is receiving the most appropriate services to help them advance.

_Educating Children with Autism Spectrum Disorders_

Children with autism or an ASD diagnosis are covered under IDEA and therefore required to receive a free and appropriate education. According to a report to the Chairman and Ranking Minority Member, Subcommittee on Human Rights and
Wellness, Committee on Government Reform, House of Representatives on Children with autism, it is estimated that more than 1.5 million Americans live with some form of autism, including 100,000 children served under IDEA (Government Accountability Office, 2004). There has been a 500 percent increase in the last decade of children with ASD receiving services under IDEA (p. 6).

A variety of services and educational treatments have been provided for children with ASD to include: special education teachers, aides, speech therapist, behavioral therapists, occupational therapists, physical therapists, counselors, and/or psychologists (Government Accountability Office, 2004). These services are individualized and dependent upon the needs of the child. Additionally, these services are not fixed and generally change over time. IDEA Part C requires both early intervention programs, whereas; Part B requires services from age 3 to 21. Early intervention services may include treatment to address the developmental delays and can be home based or community based. Part B services are usually educational services designed to address the child’s educational needs and assist with the transition to adulthood. Providing educational services for children who have ASD varies and many school systems do not allocate an appropriate amount of resources to maximize the child’s potential (Winerman, 2004).

Other Relevant Legislation

Rehabilitation Act

In an effort to protect the rights of individuals with disabilities, in 1973 the Rehabilitation Act was passed. This was the first civil rights legislation to prohibit
discrimination of individuals with disabilities and to tie federal funding to the implementation of this law (Mac, 2002; Rubin & Roessler, 2001). There are four sections of the Rehabilitation Act: 501, 503, 504, and 508. There are five sections to the Rehabilitation Act that addressed discrimination. Section 501 prohibits the federal government from discriminating against individuals with disabilities in hiring. According to Rubin & Roessler (2001), “the most important feature [of Section 501] is to establish the federal government as a model agency for promoting the recruiting, hiring, and advancing of workers with disabilities” (p. 55). Section required architectural, and transportation accessibility for people with disabilities. Section 503 requires that all federal contract recipients of monies exceeding $10,000 ensure affirmative action and prohibits discrimination. Section 504 says that individuals with disabilities not be excluded or denied access to federal programs solely based on their disability (Rubin & Roessler, 2001). Section 508 “establishes requirements for electronic and information technology developed, maintained, procured, or used by the Federal government” (DOJ, 2005).

In 1974, and 1976 the Rehabilitation Act was amended to extend the services. In 1978, the Act was amended again to allocate millions of dollars and to include individuals with severe disabilities (Rubin & Roessler, 2001). The amendment in 1984 required states to provide a client assistance program and in 1986 the amendment remained focused on services for individuals with severe disabilities and required an integration into society emphasis. In addition, the 1986 amendment added a supported
employment component and authorized state rehabilitation agencies to offer this service (Rubin & Roessler, 2001).

*ADA*

In 1990, the American with Disabilities Act (ADA) was passed and provided protection to individuals with disabilities and prohibiting discrimination against them. The ADA prohibits discrimination on the basis of disability in employment, State, and local government, public accommodations, commercial facilities, transportation, and telecommunications. It also applies to the United States Congress.

To be protected by the ADA, one must have a disability. An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such impairment, or a person who is perceived by others as having such impairment (Rubin & Roessler, 2001). The ADA does not specifically name all of the impairments that are covered. While a list of impairments would be helpful, it would be difficult for the list to be exhaustive.

The ADA has five titles: Title I: Employment, Title II: Public Services, Title III: Public Accommodations, Title IV: Telecommunications, and Title V: Miscellaneous Provisions (Rubin & Roessler, 2001). Title I of the ADA ensures that qualified individuals with disabilities are provided equal opportunities for employment. Title II of the ADA states that public service organizations cannot deny services to people with disabilities participation in programs or activities which are available to people without disabilities. In addition, public transportation systems, such as public transit buses, must
be accessible to individuals with disabilities (Job Accommodation Network [JAN], 1997). Title III states that all new construction and modifications of existing structures must be accessible to individuals with disabilities. For existing facilities, barriers to services must be removed if readily achievable (JAN, 1997). Title IV states that telecommunications companies offering telephone service to the general public must have telephone relay service to individuals who use telecommunication devices for the deaf (TTYs) or similar devices. According to JAN, this title also requires closed captioning of federally funded public service announcements (1997). Title V includes a provision prohibiting either (a) coercing or threatening or (b) retaliating against the disabled or those attempting to aid people with disabilities in asserting their rights under the ADA (JAN, 1997).

*Family Systems Theory*

Family systems theory is grounded in the viewpoint that “the family is viewed from an interactive and systemic perspective” (Corey, 2001). “A family includes interconnected members and each member influences the others in predictable and recurring ways (Van Vesor & Cox, 2000). It is a fundamental belief that members cannot be understood in isolation from their family unit and that each member functions as a part of the team and has an interrelated relationship (Corey, 2001; Gladding, 2002). Thus, when a family member has a disability, every member of the family is impacted, and in turn, influences the individual with the disability. These influences can be both positive and negative. For example, the way that parents adjust to the discovery that their child has a disability will significantly impact the amount of stress the family experiences
(Burke & Cigno, 1996). An empowered parent is knowledgeable and confident about strategies that are effective in working with their child, is able to handle and maintain structure, is able to identify and access necessary services. If the parent is empowered this improves the outcomes for the family (Brookman-Frazee, 2004). When parents, families or caregivers have the necessary information about the disorder or disease affecting their loved one, they are able to make valuable decisions regarding the child’s care. Being informed enough to make these decisions without constantly relying on medical providers, clinicians or other professionals empower the caregiver (Bailey, 2001; Murray and Mandell, 2004; Turnbull 2006). Conversely, the authors stated that an unempowered parent may exhibit behaviors and attitudes that reflect frustration, stress, depression, helplessness, and overall dependence on service providers (Brookman-Frazee, 2204, 196). An unempowered parent may be less likely to make proper decisions regarding their child’s care or advocate for their child and family’s rights. This may result in poorer outcomes for the child and the family. Marinelli and Dell Orto (1999) discussed the importance of recognizing this reciprocal relationship and the potential for either adaptive or maladaptive influence.

According to Corey (2001) “[the family systems] perspective is grounded on the assumptions that a client’s problematic behavior may (1) serve a function or purpose for the family; (2) be a function of the family’s inability to operate productively, especially during developmental transitions; or (3) be a symptom of dysfunctional patterns handed down across generations” (p. 387). All family members are important to the overall function of the unit. For example, parents typically earn or bring in the necessary
resources needed for the family to survive. The child’s role in the family is usually to maintain order and cleanliness of the living environment. If the adult does not provide the essential resources, it may impair the child’s ability to complete their role and vice versa. Staying with the same scenario, if adequate resources such as food, clothing, and shelter are not provided, the child may not attend school on a regular basis. This may in turn cause the family to be investigated by the local child protection agency. Finally, again remaining with the aforementioned scenario, these parents may be exhibiting behavior that they observed growing up. This may be the model their parents handed down to them. Understanding this interactional unit is an imperative factor to understanding the individual (Corey, 2001; Gladding, 2002).

A criticism of this approach is that it ignores the individual. However, the family systems perspective does not deny the impact of individual symptoms, concerns or behaviors, instead; it encompasses how individual situations impact the other members of the family (Corey, 2001). In essence, family theorists understand that the individual is rooted in larger systems and there is a reciprocal nature to the relationship.

Another aspect of family systems that is important to discuss is birth order. Researchers have studied the impact of birth order on individuals and there are a number of perspectives. These range from personal characteristics, intelligence, and personality. Adler identified five psychological positions of children: oldest, second of only two children, middle, youngest and only (Corey, 2001). Firstborn or eldest children are high achievers and typically act as caregiver for the younger siblings (Pollett & Nettle, 2007). They are generally described as especially confident, determined, organized and
controlling (Fritz, 2006). Studies have shown that adults who were first-born children are over represented in a diverse array of high achieving groups, such as Nobel Prize winners, classical music composers and U.S. presidents (Fritz, 2006). Middle children often feel out of place and typically are labeled as defiant. While middle children have the rebellious nature, they are also more flexible and adaptable in difficult situations (Fritz, 2006). Younger children are often “spoiled” and pampered by the family (Corey, 2001; Fritz, 2006). Only children are considered high achievers and may be viewed as less cooperative than other children (Corey, 2001).

Adjustment to Disability

“A disability or chronic illness, [whether congenital or not], has a profound impact on one’s life adjustment, opportunities, and quality of life” (Dell Orto & Power, 2007, p.121). Because of this great impact, it is believed that individuals go through an adjustment period which is comprised of stages. Livneh and Antonak (2005) indicated that adaptation to an acquired disability consists of six phases: shock, anxiety, denial, depression, internalized anger, externalized hostility, acknowledgment, and adjustment.

The initial stage is characterized by disorganized thinking and devastation. People may feel the sudden nature of their changed situation and are overwhelmed by the reality of it all. For some individuals, the realization that their lives have and will changes has not set in and they may be characterized by “psychic numbness, depersonalization, cognitive disorganization, and often dramatically decreased mobility and speech” (Livneh & Antonak, 2005, p. 20). Next, individuals move to a panic-like state. While in this stage, people tend to worry excessively. This anxiety is rooted in
uncertainty about the future whether that is the social, educational or vocational future (Livney & Antonak, 2005). This is followed by denial that the disability is permanent and that their world will be forever changed. This is usually a defense mechanisms used by individuals to escape the reality of their situation. Individuals in this stage often negate the reality or the gravity of their condition and develop unrealistic goals regarding recovery (Livney & Antonak, 2005). The authors stated that individuals accept facts that support their ideas, and picture of reality but minimize any dissenting facts or information (p. 21). Mourning of a loss and depressive symptoms follow this stage. Individuals report, “feelings of despair, helplessness, hopelessness, isolation, and distress” in this stage (Livney & Antonak, 2005). The fifth stage is characterized by anger and questioning. It is common for people to blame themselves and hold personal guilt for their condition. People, while feeling this anger, may also engage in self-injurious behaviors. While people go through a stage of anger typically self directed, they also pass through a stage of external hostility. Individuals in this stage may direct hostility toward people they feel have a hand in their disability or condition. Livney and Antonak (2005) reported that “aggressive acts, other-blaming verbalizations, and behaviors, feelings of antagonism, demanding, and critical attitudes, abusive accusations, and passive-aggressive modes of obstructing treatment are usually manifest during this phase” (p. 21). During the final stages individuals begin to actualize their new life. During the acknowledgement phase individuals “accepts himself or herself as a person with a disability, gains a new sense of self-concept, reappraises life values, and seeks new meaning, and goals” (Livney & Antonak, 2005, p. 22). Finally, the authors asserted that
individuals theoretically enter the adjustment phase. This phase is reflective of both an emotional and a functional limitation acceptance. Here a positive self-worth is reestablished, possibilities are realized, goals are actively sought after and individuals are empowered to overcome road blocks to accomplishing these goals (Livney & Antonak, 2005, p. 22).

In addition to personal adjustment to disability, individuals face attitudinal barriers, systemic barriers, as well as physical barriers. Physical barriers can include inaccessible buildings, transportation, and lack of reasonable accommodations. These can be readily seen and addressed. Systemic barriers are often difficult to eradicate but laws and policies help to alleviate concerns in this arena. However, attitudinal barriers may be the most difficult obstacles to overcome. Attitudinal barriers are the negative, misleading, and deceiving thoughts, words, and phrases that society uses to describe individuals with disabilities. These thoughts, attitudes, words, and phrases give a gross misconception about individuals with disabilities.

*Familial Adjustment to Child Disability*

Marinelli & Del Orto (1999) recognize that a chronic illness or disability does not just happen to the child, it happens to the entire family. Not only will the child with the disability go through an adjustment process, each family member will undergo change as well. This means that the diagnosis and treatment will impact the entire family and require system adaptation not just individual adaptation (Berry, 1995). In addition, Marinelli and Dell Orto (1999) maintained that family members must be educated about the disability and the systems in order to provide support. The authors also stated that the
family response to the individual with the disability will either enhance or hinder the child’s psychosocial functioning. When families are supportive, all members of the family can have a healthy adaptation. However, when the family has maladaptive functioning, all members will be negatively impacted as well.

Families often time have to face attitudinal barriers too. This can be manifested as stares to parents, comments to siblings or many other behaviors or actions. Awareness is crucial to help eradicate these types of impediments. This demonstrates the need for family members to be provided the necessary information regarding the disability and characteristics to help educate others.

Brookman-Frazee (2004) stated that an empowered family is able to identify needed services, balance routines, and make significant decisions regarding care, and this ultimately improves the functioning of the entire family. It is imperative that families understand the diagnosis and have reliable information from which to make informed decisions.

**Sibling Relationships**

The sibling relationship is probably one of the longest lasting relationships most people have (Deater-Deckard, 2002). Siblings share a unique and important relationship within the family unit and are important to one another in the process of learning social skills (Knott et al., 1995). The interactions among siblings provide an unparalleled opportunity for children to learn about themselves and others. Additionally, these relationships provide one of the first chances for children to learn about appropriate play, communication, and interaction (Barnes & Austin, 1995; Brody, 1998; Knott et al., 1995).
Through repeated interaction, siblings serve as teachers for their brothers and sisters. These encounters with one another provide the opportunity for children to practice on their communication and social skills (Brody, 1998). For instance, the conflict that siblings experience can serve as practice for the conflicts that may be experienced later in life. Abramovitch, Pepler, and Corter (1982) showed that children develop a style of social exchange with their siblings which they subsequently use with their peers. Sibling relationships can be seen as a safe haven in which to have successes and failures when learning to develop social skills. The social skills achieved through sibling interaction are used throughout life in other social relationships (Brody, 1998) and when children do not have siblings in the home, they miss the opportunity to practice these skills.

Downey and Condron (2004) conducted a study to determine if: a) children with more siblings exhibit better social and interpersonal skills than children with fewer siblings, b) associations between sibship, the number of siblings, size, and social skills persist despite statistically controlling for a wide range of covariance, and c) are particular kinds of siblings more important than others for the development of social skills? The sample consisted of 20,649 cases and received input from parents, teachers, and the children. The average age was 6 years and 2 months, and all were in kindergarten. The majority of the children were White and 15% were Black, 6% were Asian, and 5% other (self-identified). Seventeen percent of the children were only children. The modal number of siblings was one, and 26% had two siblings, 10% had three siblings, and 5% had four or more siblings. Downey and Condron (2004) found that
children with siblings exhibit better social and interpersonal skills than children without siblings.

_Only Children_

It has been said that siblings provide a safe place for children to practice the social skills that are used with family members, peers and the outside world (Kitzman, Cohen and Lockwood, 2002). There have been studies that document the benefit of having a sibling in the home (Brody, 1998). Based upon that information, it would be expected that only children would have deficits in the area of social skills since they do not have a sibling in the home.

Kitzman et al. (2002) studied 139 school-aged children to compare the social competence of three groups: only children, first born children with one sibling and second born children with one sibling. The authors found that only children were similar to classmates in terms of number of close friendships and friendship quality, but were less liked by classmates as a group. The authors also found that only children were more likely to be victimized and aggressive in the peer group, which suggested that having a sibling may be especially helpful for learning to manage conflict.

Downey and Condron (2004) studied the impact that siblings have on social and interpersonal skills. The sample was based on over 20,000 cases which were originally collected by the National Center for Education Statistics in 1998-1999. The researcher excluded 611 cases from the original data. Information was gathered from parents, teachers and children. The authors found that typically, children with siblings have improved social and interpersonal skills than children without siblings.
In summary, only children are able to gain necessary social skills. However, the aforementioned studies demonstrated that only children skills may not be as sharpened as the skills gained by children with siblings. Furthermore, only children may need further development of their conflict resolutions skills.

*Sibling of Children with Disabilities*

Growing up with a sibling with a severe disability would be expected to have an influence on the social and emotional adjustment of family members. It is a fundamental belief of Systems Theory that a change in one part of the system results in a change in the other components (i.e. other family members) (Corey, 2002; Gladding, 2002). Each family member is viewed as a part of the system, therefore the changes a child with a disability experiences affect change within all the other members of the family. Studies conducted by Brookman-Frazee (2007) and Soresi, Nota and Ferrari (2007) concentrated on the adjustment of and assistance to parents of children with disabilities. As the family systems approach suggests, siblings of children with disabilities are not then exempt from experiencing the stress and strain that often accompanies having a family member with a disability. Even though siblings experience the challenges of having a family member with a disability, they are oftentimes ignored and referred to as the invisible or forgotten child (Naylor & Prescott, 2004).

Wolf, Fisman, Ellison and Freeman (1998) indicated that the non-disabled sibling may encounter less parental attention, increased care responsibilities, risk for poor peer relations, lower level of participation in outside activities, and loss of companionship. Norton and Draw (1994) agree with the previous study and stated that having a sibling
with a disability may alter family interactions due to the focus on the child with the disability. Depending upon the condition and its severity, the child with the disability may consume large amounts of the parents’ time. Parents may need to minimize anomalous behaviors, transport the child with a disability back and forth to medical or therapeutic appointments, and advocate for services. The child without a disability frequently remains at home with a babysitter, alone, or at the medical, rehabilitative or clinical appointments with the parent and sibling. The sibling without the disability may not have the opportunity to spend quality time with parents, siblings, or peers and may leave the sibling malnourished in the area of communication, and social skills (Polit & Falbo, 1987).

The financial impact of having a child with a disability in the household is also experienced by family members. Turnbull and Turnbull (1997) indicate that because an enormous amount of time is spent caring for the child with a disability parents typically work fewer hours which results in a loss of income. Whether dual or single parent, all households are affected by the loss of an income. This can cause a strain on other family resources, whether plentiful or scarce, and result in a total loss of income for single family households. The National Center for Childhood Poverty (NCCP) reports that more than 80% of children with mental health needs do not have health insurance to cover the costs of required medical, therapeutic, or rehabilitative services (NCCP, 2009). The money that would normally pay for basic needs such as shelter, food, and clothing may be reallocated to cover required medical, rehabilitative, and other needs. In addition, recreational or extracurricular activities may be non-existent because money must pay for
the services considered necessary for the child with a disability. “Likewise, the time, and energy needed to identify interventions, provide care for the child, and for siblings, and monetary stress from loss of time at work, and/or the cost of additional therapies places stress on existing family resources” (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005, p. 195).

McHale and Gamble (1989) have documented that having a sibling with a disability can be a lifelong adjustment impacting several aspects of life (Bagenholm & Gillberg, 1991; Knott, Lewis & Williams, 1995; Roeyers & Mycke, 1995). Disappointingly, there isn’t much evidence that says conclusively whether having a sibling with a disability has positive or negative outcomes. Some research points to negative effects of having a sibling with a disability (Bagenholm & Gillberg, 1991; Hastings, 2003; Rodrigue, Geffken & Morgan, 1993), while other research highlights positive effects or no difference in having a sibling with a disability (Kaminsky & Dewey, 2002; McHale, Sloan & Simeonsson, 1986; McHale & Gamble, 1989). As stated, most research focuses on the adjustment, whether adaptive or maladaptive, of the sibling.

Naylor and Prescott (2004) studied 55 siblings of children with disabilities in an effort to explore the relationship between the non-disabled siblings, and the child with a disability. They further sought to explore the need for individual expression and support for the non-disabled siblings. The researchers used both qualitative and quantitative methods. The results suggest that there was a desire and need for a support group for siblings of children with disabilities. Additionally, Naylor and Prescott found that children were eager to have an adult listen to them express their feelings, although
reluctant to identify negative feelings relating to their sibling with a disability. Naylor and Prescott stated that future research should be disaggregated and focus on the sibling of children with disability and not the entire family. The researchers felt that while focus on the family is important, siblings tend to be marginalized and their needs may go unaddressed due to reluctance to express their true feelings regarding the family situation (Naylor & Prescott, 2004).

**Siblings of children with ASD**

Building a solid relationship with siblings can be difficult. Because individuals with ASD display aberrant behaviors, and problematic social and communications deficits (Kaminsky & Dewey, 2002), developing a socially appropriate relationship may present challenges for siblings of children with ASD. In addition to dealing with the taxing behaviors, siblings oftentimes have to cope with changes in family roles, structure, and activities. Siblings may have feelings of guilt, shame, and loss of parental attention (Rodrigue, Geffken, & Morgan, 1993). Furthermore, families of children with ASD have increases in parental and family stress and may have trouble accessing adequate resources to meet the needs of the child with ASD and the family. These challenges may affect the well-being and functioning of the family and ultimately the sibling relationship.

There is a plethora of scholarship discussing the impact of ASD on parents and their perspective; however, there is a lack of literature surrounding the non-disabled sibling’s perspective on their relationship with their sibling with ASD (Carter, 2008; Holl, 1998). Few studies have been conducted to explore the impact of ASD on the sibling relationship from the perspective of the typical sibling. Kaminsky and Dewey
(2001) stated that there is no previous literature that addresses how ASD influences particular aspects of the sibling relationships. Furthermore, Holl (1998) stated that little research has been conducted on the sibling relationship in families with children diagnosed with ASD.

Knott, Lewis, and Williams researched the interactions between siblings of children with ASD and evaluated these relationships to siblings of children with Down syndrome. The researchers studied 30 siblings. One dyad included 15 siblings in which one child had ASD and the sibling did not. The other dyad included 15 siblings in which one child had Down’s syndrome and the other sibling did not. The results of the study showed that although siblings with ASD initiated play and interaction less often than children with Down syndrome, they did engage in prosocial behaviors and demonstrate the use of some social skills. The authors also found that children with ASD showed similar levels of initiations and response when compared to normal developing siblings. It was noted that the dyads with the sibling with Down syndrome spent 58% of their available time together, whereas the dyad with the sibling with ASD spent only 28% of their time together (Knott et al., 1995). Additionally a univariate analyses showed that the dyads where one sibling had Down syndrome had more prosocial initiations and more agonistic initiations than the siblings where a child had ASD. Knott, Lewis, and Williams’s (1995) research on sibling relationships demonstrated the impact that ASD may have on the sibling relationship but fails to document the sibling perspective of their relationship with their sibling with ASD.
Other studies have been conducted offer differing findings regarding how siblings view their relationship with their sibling with ASD. McHale, Sloan and Simeonsson (1986) indicated that the sibling’s view the relationship in a similar manner to children whose siblings do not have a disability. However, Bagenholm, and Gillberg (1991) found that although siblings reported having a positive sibling relationship with their sibling with ASD, they reported significantly less positive attitudes towards their sibling and significantly less positive descriptions of their sibling’s role in the family relative to comparison siblings.

McHale et al. (1986) also reported that normally developing siblings viewed their relationship with their sibling with ASD or Down syndrome more positively when they accepted the child’s role as a member of the family, perceived minimal parental favoritism, and were not worried about the future of the child with the disability. This study demonstrates the need for this research to aid in understanding the impact of knowledge regarding ASD, its etiology, and features on the sibling relationship.

Kaminsky and Dewey (2002) conducted a qualitative study with 90 siblings using the Sibling Relationships Questionnaire (Buhrmester & Furman, 1990). This study examined the factors of dominance, affection, companionship, intimacy, admiration, and competitiveness in the sibling relationships of children with siblings that have ASD, Down syndrome and in siblings with normal development. Dominance refers to authority and control, affection indicates tender attachment, companionship signifies intimate friendship, intimacy implies personal or private nature, admiration means to hold in high esteem, and competitiveness denotes rivalry. The results of the study were similar to the
findings of Bagenholm and Gillberg (1991) who reported that participating siblings of children with ASD reported less intimacy with their reference sibling and less nurturance by their reference sibling than siblings of children with Down syndrome, and participating siblings of children with normal development. Participating siblings of children with ASD also reported less prosocial behavior in their sibling relationship than participating siblings of children with Down syndrome. Again researchers explore the sibling perspective but fail to capture the perspective of the sibling relationship.

Mocks and Reeve (2007) studied 51 children who had a sibling with ASD and 35 siblings of non-disabled children to compare the psychosocial and emotional adjustment of siblings of children with ASD and siblings of non-disabled children. The researchers found that siblings of children with ASD reported positive psychosocial adjustment. However, the results indicated a negative relationship between demographic risk factors and the positive adjustment of the non-disabled sibling. Additionally, Macks and Reeves believe that future studies on siblings of ASD are warranted.

Summary

The review of literature signified a need to conduct a study to understand the impact that ASD has on the sibling relationship. Although there was literature that discussed the impact of having a sibling with a disability on the non-disabled sibling, much of it is quantitative in nature, and/or focused on the adjustment of the non-disabled sibling. Even when the relationship aspect of siblings was explored, the studies did not offer an in-depth view of the phenomenon. Oftentimes, the perspective of the sibling is not opined. Parents, particularly the mother, provided the viewpoint on the sibling
relationship. While the parents’ perspective is important, it may be more or at least equally important to understand this imperative relationship from the sibling participating in the relationship.

Furthermore, the child with ASD is challenged with deficits in the areas of social interactions, social communication, and stereotyped behaviors (Rapin, 2001), and it is presumed that this will have an impact of the sibling relationship. Despite efforts being made to understand the impact that ASD has on the sibling relationship, little had been done to gain the perspective of the non-disabled sibling. Thus, this study explored the impact ASD has on the sibling relationship from the perspective of the sibling without ASD. The researcher identified improved interventions, practices, and services to address the needs of siblings and families that have had this experience. Finally, this research added new insight and information for practitioners, parents, and researchers.
CHAPTER 3: METHODOLOGY

Introduction

This chapter describes the methodology that was employed in this study. It discusses the rationale for the methodology, site selection, selection of participants, and the data collection procedures. This chapter also incorporates the research questions and the methods of data analysis. This chapter has been organized using six headings: 1) rationale for research design, 2) research approach, 3) site selection, 4) participant selection, 5) data collection methods, and 6) data analysis. A qualitative study was conducted to explore five siblings of children with a diagnosed ASD to understand the impact of the disorder on the sibling relationship. The following research question was posed: How does ASD impact the sibling relationship?

Rationale for Methodology

The study attempted to develop a deeper understanding of the impact of ASD on the sibling relationship. In order to achieve this goal, this research study was exploratory. Qualitative research allows the phenomenon to be explored, understood, and/or described. According to Gay, and Airasian (1992) qualitative research or interpretive research is defined as the collection of extensive narrative data on many variables over an extended period of time, in a naturalistic setting, to gain insights not possible using other types of data. The central focus of this type of research is to provide understanding of a social setting or phenomenon as viewed from the perspective of the research participants; whereas quantitative research is defined as the collection of numerical data to explain, predict, and/or control phenomena of interest (Gay & Airasian, 1992). Qualitative
research methods were employed by this researcher to allow the researcher to gain insight into the world of siblings of children diagnosed with ASD. In addition, through this methodology, the inquirer was able to give voice to the siblings’ perspective of living with and sharing a relationship with a sibling with ASD. This point of view is missing from the literature and this study will add to this body of knowledge.

Historically, qualitative research has not been viewed as favorably as quantitative research (Berg, 2004). Many researchers and individuals in the natural sciences world believed that qualitative research was not as credible and therefore less valid. Slowly, qualitative research has gained popularity and credibility. Qualitative research has become prominent in both the social sciences and related fields (Denzin & Lincoln, 1994). Prior to this, it was extremely difficult to find sources and publications regarding qualitative methods (Berg, 2004). This was due to the belief of many researchers that, “there is no such thing as qualitative data. Everything is either 1 or 0” stated by Kerlinger as cited by Berg (2004, p. 25). This statement refers to the idea that only studies that can be explored quantitatively are important and worthy of investigation.

It is important to recognize that qualitative research has had an increase in status and popularity. “People strive to comprehend the world in which they live and work to help them manage their relationships, their jobs, and their problems (Rubin & Rubin, 2005, p. 1). Qualitative inquiry grants the opportunity for individuals to appreciate the naturalistic world. “Qualitative research is pragmatic, interpretive, and grounded in the lived experiences of people” (Marshall & Rossman, 2006, p. 2). When an understanding of those experiences is sought, qualitative research is the best approach.
Research Design

A research design is a systematic plan to organize the research study. This guide outlines what data needs to be collected, how the data will be collected, and how the collected data will be analyzed. As cited by Creswell (2007, p. 5), a research design is the “entire process of research from conceptualizing a problem to writing research questions, and on to data collection, analysis, interpretation, , and report writing (Bogdan & Taylor, 1975).

Conceptual Framework

A conceptual framework describes what is to be studied and the presumed relationship between that what is studied (Miles & Hubermon, 1994). It embraces the multiple realities and perceptions of its participants and recognizes that the emergent discoveries are as they should be (Moreno, 1995). The following section describes the theoretical framework used in this study. This study was guided by a phenomenological case study approach and utilized systems theory to analyze the data. The characteristics of this research design are described below.

Case Study

“Case study is a qualitative approach in which the investigator explores a bounded system (a case) or multiple bounded systems (cases) over time, through detailed, in-depth data collection involving multiple sources of information and reports a case description and case-based themes” (Creswell, 2007, p.73). This researcher used case study to understand the relationship between the typical siblings and their siblings diagnosed with ASD. In addition, the case study approach was used to understand how
the disorder impacts the participant’s behavior and relationship with their sibling (Ary et al., 2002). This researcher views case study as a research design, and uses it as such (Creswell, 2007).

There are many types of case study. The type of case study is determined by the size of the bounded case. These types include: single instrumental case study, collective or multiple case study, and intrinsic case study (Creswell, 2007). In a single instrumental case study, the researcher identifies an issue or concern and finds a case to illustrate the issue. A collective case study is similar to the single instrumental case study in that the researcher selects an issue or concern. But instead of finding a single case, the researcher finds multiple cases to illustrate the issue (Creswell, 2007). In this study, the researcher used a single case study with multiple units of analysis.

**Phenomenology**

This research was also guided by a phenomenological approach. This was the best approach to use with this research because the researcher wanted to describe in detail the experiences and perspective of individuals who on a daily basis live and interact with a sibling diagnosed with ASD. A phenomenological study “describes the meaning for several individuals of their lived experiences of a concept or a phenomenon” (Creswell, 2007, p. 57).

Phenomenological interviewing is used to describe the meaning of a concept or phenomenon that several individuals share (Marshall & Rossman, 2006). This researcher sought to understand from the siblings’ perspective and in their own words their experience as a sibling of a person with a diagnosed ASD. Since the goal of this study
was to understand the perspective of siblings with brothers and sisters with ASD, phenomenology was an appropriate framework. The information gathered by this researcher intends to improve or develop practices to assist individuals who experience this phenomenon. Furthermore, phenomenology assisted this researcher to develop a deeper understanding of the phenomenon across multiple siblings’ experiences. The strength of phenomenology is that it allowed the researcher to enter into the lived experiences of the participants to understand their world from their perspective.

Systems Theory

The family systems theory holds that individuals are best understood within the context of relationships and through assessing the interactions within an entire family. According to Corey (2001) this perspective is grounded on the assumptions that a client’s problematic behavior may

1. serve a function or purpose for the family;
2. be a function of the family’s inability to operate productively, especially during developmental transitions;
3. be a symptom of dysfunctional patterns handed down across generations.

There is one central tenet that is agreed upon among family system practitioners. That tenet is that the family is interconnected and a change in one results in a change to each individual and the system as a whole (Corey, 2002; Gladding, 2002). Additionally, the family provides that primary context for understanding how individuals function in relationship to others and how they behave (Corey, 2002).
Because this research sought to understand the context in which the participant experiences having a sibling with ASD as a part of a system (i.e. family), both systems theory, and qualitative methodology were the best approaches to use as a lens through which to view the data.

The Context of the Study

The research was conducted in central Ohio and surrounding cities. This allowed the researcher to travel to the participants and observe them in their natural setting. It was my hope that interviewing the participants in their natural environment would enable them to relax and be more open to talk with me. Furthermore, the investigator expected participants to feel at ease answering the interview questions since it was an environment in which they were most familiar. The participants were from rural, suburban, and urban communities which included affluent, middle class, and lower middle class families. In addition, some of the families were two-parent households, blended family households, as well, as single family households.

Site Selection

In 1966, The Nisonger Center was founded as an interdisciplinary program of the Ohio State University. The United States Administration on Developmental Disabilities has designated Nisonger Center as a University Center for Excellence in Developmental Disabilities (UCEDD). According to the marketing material, the mission of The Ohio State University Nisonger Center is to work with communities to value and support the meaningful participation of people with disabilities of all ages through education, service and research. The Center provides assistance to organizations, families, and service
providers to promote inclusion of people with disabilities in education, health, employment, and community settings.

This site was chosen because of its programs specifically for individuals and families with children diagnosed with an ASD. The Nisonger Center had the Aspirations Program that is a two-fold focus. First, the Aspirations program assists young adults with an ASD to develop and improve social and vocational skills. Second, a research component collects both pre and post data on participants. Additionally, Nisonger Center has an Autism Spectrum Disorder Clinic that provides assistance to families through an interdisciplinary evaluation of their child’s abilities and challenges. Finally, the Nisonger Center Director, Tom Fish, was instrumental in establishing Ohio SIBS (Special Initiatives by Brothers and Sisters). This organization assists adult siblings of individuals with disabilities come together and share information regarding their shared experiences. Upon speaking to the director of the center, the researcher was able to gain access to the group members to speak to them about possible participation in this research study.

Additionally, while at a training offered by the Nisonger Center, the researcher met several parents who have children with ASD. The researcher discussed the inquiry and received positive responses from four individuals at this conference. At this particular time it was not discussed if the families met the specific criteria. Information was exchanged in order for the families to be contacted at a later date.
I chose to obtain participants from this site because of the extensive history the Nisonger Center had with individuals who experience the phenomenon that this researcher wanted to study.

Gaining Entry

Gaining entry to my sample was somewhat difficult. This was due in part because of limited interaction with the subjects under study. However, as an employee at the university where the sample engaged in services, the entry was a little less complex. Gaining entry took several steps: 1) approval from the Institutional Review Board (IRB), 2) contact with site, and 3) finally contact with potential participants.

The examiner submitted my proposal to the Institutional Review Board (IRB) and received the approval to conduct the research. This researcher first contacted a Program Coordinator at the Nisonger Center, and was directed to another Program Coordinator at the Nisonger Center. My contact was well-known among the subjects under study and had many contacts, and listservs that were directly linked to the population. Once contact was made, the research was discussed. This individual was instrumental in removing barriers that might have otherwise been present with regards to accessing the desired participants. Through his assistance, the researcher recruited three participants for individual interviews. The other two interviewees were recruited through word of mouth about the research. Consequently, snowball sampling was an unintended aspect of this sampling strategy.
Sample and Population

Purposive sampling strategy was used in this research. Creswell (2007) stated that purposive sampling “means that the inquirer selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study” (p. 125). In addition, criterion sampling methods were used to find research participants for this research study. A criterion sample strategy involves identifying participants who have experienced the phenomenon under study (Creswell, 2007). One participant was identified through natural conversation with the researcher about the topic of study. There were three homogeneous aspect of this sample: 1) all were siblings of children diagnosed with ASD, 2) were between the ages of 11-18, and, 3) all were within 5 years of age of their sibling. All other aspects of the sample were heterogeneous as the criteria for participation in this study were met.

While the researcher had a planned sample size, the actual sample size was emergent. The research planned to have eight participants. However, saturation was reached after five participants. Redundancy in qualitative literature is described as, “asking at least some of the same questions to different people in separate roles in ways that allow you to check your interviews for consistency” (Rubin & Rubin, 2005).

Selection of Participants

Recruitment

The researcher took the following steps in the recruitment of participants. The Program Coordinator at the Nisonger Center identified potential participants based upon the criteria set for this research. Next, the Coordinator sent out an email to all of the
potential participants and asked that they contact me directly if they were interested in participating. The interested participants contacted the researcher and discussed the study further and talked about what participation in the study would require. If these individuals were still interested, the investigator emailed the consent forms which provided more information. Finally, a follow-up email was sent to the potential participants to schedule a time for the interview and observation.

The participants in this study were purposefully selected. This type of sampling utilizes “information-rich cases from which the researcher can learn a great deal about issues of central importance to the purpose of the inquiry” (Patton, 2002, p. 242). A criterion sample strategy was used to ensure all of the participants had experienced the phenomenon being studied. Again, the participants in this study were all siblings of children with a diagnosed ASD and were able to lend a unique understanding of their experiences with the studied phenomenon. Creswell (2007) stated, “criterion sampling works well when all individuals studied represent people who have experienced the phenomenon” (p. 128). The following criteria were used to select the participants in the study:

a) individuals between the age of 11 and 18

b) individuals with a sibling with ASD, and

c) individuals whose sibling is within five years (plus or minus) of their current age.

Table 3.1 highlights simple demographic information about the participants.
Table 3.1

Illustration of the Participants of the Study Providing Pseudo Names, Gender, Race, and Sibling Disability

<table>
<thead>
<tr>
<th>Participants</th>
<th>Age</th>
<th>Gender</th>
<th>Race</th>
<th>Sibling Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ava</td>
<td>17</td>
<td>Female</td>
<td>Caucasian American</td>
<td>Autistic, and PDD-NOS</td>
</tr>
<tr>
<td>Ella</td>
<td>16</td>
<td>Female</td>
<td>African American</td>
<td>Asperger’s Syndrome</td>
</tr>
<tr>
<td>Jordan</td>
<td>12</td>
<td>Male</td>
<td>African American</td>
<td>Asperger’s Syndrome</td>
</tr>
<tr>
<td>John</td>
<td>11</td>
<td>Male</td>
<td>African American</td>
<td>PDD-NOS</td>
</tr>
<tr>
<td>Chris</td>
<td>16</td>
<td>Male</td>
<td>African American</td>
<td>Autistic Disorder</td>
</tr>
</tbody>
</table>

The participants in this sample are diverse in age, gender, and with respect to the disorders representative of the spectrum. There were two female participants and three male participants. The oldest participant in the study was 17 years old, two were 16 years old, one was 12 and the youngest participant was 11. Three participants were in high school (grades 9-12), one in middle school (grades 6-8) and one was in elementary school. Interestingly, four of the participants were African American and one was Caucasian American. There were three disorders represented in this study: Autistic Disorder, Asperger’s Syndrome and PDD-NOS. According to APA (2000), individuals diagnosed with Autistic Disorder have impairment in social interaction, communication and exhibit restrictive and repetitive behaviors, interests and activities. Individuals diagnosed with Asperger’s Syndrome have impairments with social interaction and restrictive and repetitive patterns of behaviors but do not have the deficit in communication. Autistic Disorder is the most severe disorder on the spectrum; while, Asperger’s Syndrome is the least severe as it relates to the characteristics of the disorders.
PDD-NOS encompass all of the characteristics of Autistic Disorder but the criteria are not met for a specific disorder on the spectrum (APA, 2000). All disorders have a significant impact on the lives of the individuals with the disorders as well as the families.

The researcher intended to interview eight participants and observe the sibling and family interaction; however, after interviewing five participants, the researcher reached redundancy, which means no new information was presented. Due to these families having structured lives and a strict schedule, the researcher’s time observing the interaction was limited. Parents wanted to maintain the continuity for the sibling with ASD as routine is especially vital to the sibling’s wellbeing.

Rationale for Selection Criteria

This particular age range was chosen because the researcher believed they would be able to articulate and answer the interview questions posed. Children younger than 11 years old may not be able to communicate their feelings and perceptions clearly. This research explored the impact of ASD on the sibling relationship. Therefore, all participants have been able to provide knowledge regarding the observable phenomenon. Last, the five-year age range was selected. One lesson learned from a pilot study conducted was that siblings who were not close in age (within 4-5 years) did not have relevant information to provide regarding their sibling. Thus, to prevent this from happening again, the researcher narrowed the age gap.

Although there are no rules for sample size in qualitative inquiry (Patton, 2002), there are some guidelines. Creswell (2007) maintained that one guideline is to
accumulate comprehensive detail from few sites or individuals. Additionally, the sample size is dependent upon the purpose of the study, access to participants, and time and resources (Patton, 2002). Gay and Airasian (1992) discussed choosing a sample that is large enough to produce the necessary information for thick detail, but not too large as to offer redundant information, called data saturation. So, unlike quantitative research where the goal is generalizability and hence a large sample size is required, qualitative research seeks to understand in depth and breadth and information-rich cases are sought.

In this research study, 5 individuals who met the prescribed criteria were interviewed and observed. The participants were observed in their home while interacting with their siblings, and family’s. Most often, the siblings remained in their own silos and were not engaging one another. The researcher observed the siblings in their natural environment while the siblings were engaged in normal daily activities and routine. For example, during one interview, the child with Asperger was in the basement painting a portrait and the other sibling was upstairs reading a book. Neither sibling appeared concerned with the other. During another interview, the sibling with Asperger was on her way to some sort of theatrical practice while the sibling with autism was up in her room. While interviewing yet another participant, his brothers were in their room watching a movie and only ventured out briefly to find out what was happening. This allowed the researcher to gain a thorough understanding about the phenomenon being studied.

Data Collection Methods

There are several data collections methods that are common in qualitative research. Marshall and Rossman (2006) identified three primary methods that qualitative
researchers use for gathering information. Primary methods involve gathering information from the source directly. These three methods are: 1) participating in the setting, 2) observing directly, and 3) interviewing in depth. “Observation involves the systematic noting and recording of events, behaviors, and artifacts in the social setting,” (Marshall & Rossman, 2006, p. 98). Kvale and Brinkman (2009) say that an interview is a conversation with structure and a purpose. This researcher used external, nonparticipant observation and interviewing. Both are described in more detail below. Secondary, or supplemental, methods may also be used. Secondary methods involve gathering information from someone or something else outside of the original source by analyzing documents, and material culture. Some ways to do this include: 1) life histories and narrative inquiries, 2) historical analysis, 3) film, videos, and photography, 4) interaction analysis, and 5) questionnaires and surveys (Marshall & Rossman, 2006). Two primary methods used in this research: interviewing and observations. These methods are described in detail below.

*Interviewing*

Interviewing is one of the most universal methods in qualitative research (Byrne, 2001; Patton, 2002). Interviewing is an essential way of gathering data because it is perceived as "talking," and talking is natural Griffee (2005). Berg (2001) stated that an interview is a conversation with a purpose.

Four of the five interviews were conducted face-to-face, and three were conducted in the participant’s home. One was conducted at a restaurant located at an equal distance between the participant and the researcher homes. The last interview was conducted over
the telephone due to the distance and the schedules of the participant. Although this setup did not allow for observation, the information gathered from the participant was still valuable to the study. According to Garbett and McCormick there are advantages and challenges to conducting interviews over the phone. The authors stated low cost; no traveling of long distances and the ease of using this method are some of the benefits to conducting a phone interview. The interviewee may not provide detailed information and the interviewer would not be able to detect the nuances of the face-to-face interaction (Garbett & McCormick, 2000). Qualitative interviewing was used to go beyond the surface level and gain a comprehensive awareness of the situation. Researchers agree that qualitative interviews provide access to the context of people’s behavior and thereby provide a way for researchers to understand the significance of that behavior from the participant’s perspective (Seidman, 1998). Additionally, Rubin and Rubin (2005) suggest that qualitative interviewing is a way of finding out what others feel and think about their worlds. “Through qualitative interviews you can understand experiences and reconstruct events in which you did not participate” (p. 3). Conducting qualitative interviews allowed this researcher to examine a world in which otherwise she would not have been privy to without being granted access by the interviewee. In addition, using a phenomenological method allowed the researcher to gain a deeper understanding of the participants experience with this phenomenon from their perspective.

Four of the five interviews were taped using a digital recorder with the permission of the respondents and their parents. The other interview was done over the phone and field notes were written to capture the data. All participants were asked the same
preliminary questions and the interviewer was free to ask follow-up questions and diverge from the ordered list of questions. Marshall and Rossman (2006) stated that, “the purpose of this type of interviewing is to describe the meaning of a concept or phenomenon that several individuals share” (p. 104). Also, the researcher was able to adjust the wording of the questions, and add or delete probes, as necessary (Berg, 2004). With this structure, the interviewer guided the interview, to obtain rich, thick description from the participant’s perspective, but did not extinguish the interviewees’ point of view. Moreover, this structure allowed the researcher the flexibility to dive deeper when appropriate. Patton (2002) asserted that the semi-standardized process permits the researcher to probe and ask follow-up questions if necessary to elucidate and illuminate the particular subject. Employing a semi-structured interview permitted the researcher to explore these themes as they materialized. This was an extremely beneficial process in the field and a strength of qualitative interviewing.

The use of semi-structured interviewing was an imperative aspect to this study because it includes children as participants and the level of comprehension may vary. Phenomenology seeks to understand through explicit and emergent themes, patterns, and similarities (Creswell, 2007). The semi-structured interview encouraged the investigator to be organized and utilize the interviewees time efficiently. Also, this process allowed the data collection method to be more methodical and comprehensive by delimiting in advance the issues to be explored (Patton, 2002) while maintaining the flexibility to be exploratory and emergent.
The interview was interactive and the participants were able to ask questions. In addition, field notes were taken during the interview to be sure to capture the essence of the participant’s comments and to note any non-verbal gestures and facial expressions. Rubin and Rubin (2005) stated that “even when you are recording electronically, you should still take some notes” (p. 111). Not only does this ensure that you are present, but it forces you to listen intentionally to your interviewee (Rubin & Rubin, 2005). It is important to note that while recording the interview is helpful, there are some concerns that may arise. Rubin and Rubin (2005) cited distractibility as a disadvantage. The recorder was small and discrete to minimize the distraction. The authors also stated that researchers may lose their recall ability. To reduce the likelihood of that, field notes were taken in conjunction with the use of an audio recorder. The researcher received permission from the participants to take field notes and record the interview prior to conducting the interview.

Participant Observation

In addition to semi-structured interviews, this investigator employed nonparticipant observations. Observation took place in the participant’s home for four of the interviewees. Two interviewees were interviewed outside of their home environment due to the distance, time, and scheduling. Although the researcher was not able to observe these participants in their natural environment, some information regarding interaction was still noted such as sibling interaction, child-parent interaction and parental support. The examiner hoped to spend more time in the field observing the participants, however, once in the field this changed. While the participants and their families were
aware of the observation component, many wanted to follow the family schedule as much as possible. As a result, the observations were conducted on the same day as the interview. About 1-2 hours were spent with each participant and their families, with the exception of one who was not interviewed in person.

External or nonparticipant observations allow the researcher to watch the activities of the individuals without participating in the activities; whereas with participant observation the investigator engages fully in the activities being studied (Gay & Airasian, 1992). Observation entails the systematic noting and recording of events, behaviors, and artifacts in the social setting chosen for study (Marshall & Rossman, 2006). Observations allow the interviewer to observe the context in which the participants interact (Patton, 2002). Additionally, direct observations allow the researcher to see things that may be invisible to the participant. Sometimes people are unaware of behaviors, facial expressions, or other things that may enhance the researchers’ understanding of the phenomenon. If participants are unaware they are not able to report these oftentimes helpful facts.

The researcher observed the interactions and activities that took place in the home. The emphasis of observation was to understand the natural environment in which the participant experienced the phenomenon. In order to capture the true essence of the observation, the researcher recorded what was examined. Field notes were written. If it was not possible to document the observations at the time of the observation, the researcher immediately documented the observations afterwards.
Finally, follow-up questions were asked of the interviewees via email. This was done to capture any missing data that the researcher thought was imperative to answering the research question.

Data Analysis

The data was analyzed using both systems theory and phenomenology. The researcher used multiple data sources: interviews, observations, and theory to explicate the data to ensure the credibility of the findings. Field notes were used to gleam more depth of the information gathered. Triangulation addresses the skepticism that arises from singular methods, lone analyst, and single-perspective interpretations. The purpose is to test for consistency and inconsistencies, and to highlight those results to find deeper insight, and meaning. The researcher used the multiple data sources to triangulate the information received and bring forth the essence of the participant’s stories.

The data analysis process consisted of six steps: 1) data managing; 2) reading and memoing; 3) describing; 4) classifying; 5) interpreting; 6) representing and visualizing (Creswell, 2007).

1. Data management: This involves organizing and gathering all the data.
2. Reading and memoing: This involves the researcher reading through all the transcriptions and making notes in the margins regarding the interviewee’s comments.
3. Describing: The researcher describes how each participant experiences the phenomenon
4. Classifying: The researcher then made a list of significant statements, quotes that emerged from the data that explain how the participants experienced the phenomenon (Creswell, 2007). These statements are then grouped together and clusters of meanings are developed.

5. Interpreting: Here, the researcher developed textural and structural descriptions of the data. Textural descriptions are the written descriptions of what the participants experienced (Creswell, 2007). After the textural descriptions are written, the researcher outlined the contextual influence on how the phenomenon was experienced. This is the structural description.

6. Representing and visualizing: After both the textual and structural descriptions are written, the researcher wrote the essence of the phenomenon (Creswell, 2007).

Data Management

The first step is data management. This phase involves organizing the data in a systematic and manageable way. This began with transcription of all of the digitally recorded data. The interviews were transcribed by a transcriptionist. The data was transcribed verbatim: including grammatical errors, digressions, and abrupt changes of focus, profanity, exclamations, and other indications of mood.

In an effort to organize the data collected, a file folder for each interviewee was prepared and all data collected from that participant were placed in the file folder. This included the transcribed interview, field notes that were written, and both the consent form, and the assent form for each participant.
**Reading and Memoing**

In this step, the researcher reviews the transcripts and makes reflective notes. Next, the researcher read over the transcripts and made notes of initial thoughts in the margins. The researcher noted similarities and differences to the literature that was read, and noted initial thoughts that materialized from the data.

**Describing**

In describing, the investigator explains the participants’ story. The researcher then wrote a summary of all of the participant’s experiences. The researcher noted significant statements, thoughts, and quotes that would help understand the experience of the phenomenon. Open coding is defined as, “the process of breaking down, examining, comparing, conceptualizing, and categorizing data” (Strauss & Corbin, 1990, p. 62). In open coding the researcher, “fractures the data and allows one to identify some categories, their properties and dimensional locations” (Straus & Corbin, 1990, p. 97).

**Classifying**

Classifying involves identifying the meaningful comments and linking those together. After identifying the significant statements, quotes, and thoughts, the researcher clustered these ideas. Axial coding is defined as, “a set of procedures whereby data are put back together in new ways after open coding, by making connections between categories” (Straus & Corbin, 1990, p. 96). The researcher made connections between categories and subcategories.
Interpreting

In interpreting, the researcher develops the essence of the phenomenon. Once the researcher identified the cluster of themes, textural, and structural descriptions were written. In selective coding, the researcher identifies the core category and systematically relates other categories. Additionally, the researcher corroborated these relationships with both confirming and disconfirming examples from the data (Straus & Corbin, 1990). The researcher read and reread the data in order to identify emerging patterns and themes as it related to the research questions and family system theory. “Identifying salient themes, recurring ideas or language, and patterns of belief that link people and settings together is the most intellectually challenging phase of data analysis” (Marshall & Rossman, 2006, p. 158).

Representing and Visualizing

In representing and visualizing, the researcher presents the narration of the essence of the experiences (Creswell, 2007). Lastly, a composite summary of the data was written outlining the findings of the relationship being studied. In addition, tables were created to help illustrate the data.

Trustworthiness and Credibility

Qualitative researchers seek to understand the experiences of their participants (Creswell, 2007). Historically, qualitative research has been challenged due to the lack of generalizability, reliability, and validity issues (Marshall & Rossman, 2006). Marshall and Rossman (1995) stated that unfortunately “qualitative research does not yet have the general acceptance that the qualitative paradigm enjoys” (p. 142). Currently, the
acceptance of qualitative research has improved. Marshall and Rossman (2006) stated “qualitative research genres have become increasingly important modes of inquiry for the social sciences and applied fields” (p. 1). However, the goal of qualitative research is not to generalize. The goal is for the research results to be transferred to similar populations and this decision “rests with the investigator that would make that transfer” (p. 143). Additionally, the transferability of a working hypothesis to other situations depends on the degree of similarity between the original situation and the situation to which it is transferred. The transferability of the research findings is decided by the researcher. The reader must decide for themselves if the findings are transferable. The researcher merely provides adequate information that can then be used by the reader to determine whether the findings are applicable to the new situation” (Lincoln & Guba, 1985).

Qualitative research strives to be credible and trustworthy. In order to enhance the credibility and trustworthiness, Lincoln and Guba (1985) suggested that the naturalistic researcher assumes the presence of multiple realities and attempts to represent these multiple realities adequately. Moreover, they suggested a researcher extend their time in the field and triangulate the data with multiple sources. Two data collection methods and three theoretical approaches were used to increase credibility and trustworthiness of the findings. Semi-structured interviews and participant observation were both used to collect data. Systems theory and phenomenology were also used to analyze the information collected from each participant, while case study was used to help frame the study.
Other techniques for addressing credibility mentioned by Lincoln and Guba (1985) include: “making segments of the raw data available for others to analyze, and the use of "member checks," in which respondents are asked to corroborate findings” (p. 313-316). This researcher utilized member checks and thick description to ensure that the participants’ words and points of view were captured correctly.

Member checks involved the researcher dialoguing with the participant about findings and checking for accuracy. Triangulation involved the researcher not only interviewing the participant, but also observing the interactions within the family. This researcher was able to verify and confirm the information that was gathered in the interview. The researcher had the opportunity to review information that seemed dissenting. Thick description involved providing a context in which the data were collected. Demographic information as well as personal information was obtained to assist the researcher in understanding the participant’s likes, dislikes, and personality. This provided background information to assist in the analysis of the data collected and give the data meaning.

Ethical Considerations

It is important that researchers do no harm to participants. The investigator followed established guidelines to do no harm to the participants in the current study. Muoustakas (1994) stated, “maintaining necessary ethical standards, establish clear agreements with each research participant, recognize the necessity of confidentiality, and informed consent, , and provide a lay summary to ensure full disclosure of the nature, purpose, and requirements of the research” (p.109).
While out in the field with the participants, the inquirer demonstrated respect for each interviewee and his or her viewpoint. Because the participants were children, prior to meeting and interviewing each participant a consent form from both the parents and the child was obtained (see appendix). The consent form outlined the details and purpose of the study, and the benefits as well as the possible risk for participating in the study. Confidentiality was addressed with each participant prior to the interview. Confidentiality refers to keeping the information received from the participant private except in matters of suicide and abuse (Marshall & Rossman, 2006). Each participant was able to choose a pseudo name for themselves to assist in maintaining confidentiality. Participants and their parents were made aware of who would have access to their birth names and how long the recorded interviews would be kept.

Reciprocity involves “giving back to the participants for their time and efforts in our study” (Creswell, 2007, p. 44). All participants were informed that they would receive a ticket to the Columbus Zoo for their participation. This was my way of showing gratitude to the participants in my study.

All participants in research deserve respect. “Respecting interviewees normally means not deceiving them, not pretending to be someone you are not, and not leading interviewees into thinking that some benefit will come to them from the research that you cannot deliver” (Rubin & Rubin, 2005, p. 97). The researcher was ethical and honest with each participant and his or her family. The intended purpose of the research, the intended benefits of participation, and how the research would be used were articulated. While none of the participants thought it necessary, the option to terminate the interview,
obtain information for immediate therapeutic support, and/or referral to psychotherapeutic assistance was available.

Researcher as Instrument

The researcher entered into this research to understand the impact that ASD has on the sibling relationship. The purpose was to explore, describe, and understand the typical sibling’s perspective on this relationship. As a professional and rehabilitation counselor, this inquirer has studied the impact that disability has on the individual and the family system, and has often heard and read in the literature how siblings of children with disabilities are called the forgotten children. The researcher has a genuine concern for siblings and wanted to highlight their needs and offer recommendations on how to best address their needs. Through the interviews with siblings of children with ASD, a better understanding of their feelings and thoughts was gained.

This investigator has more than five years of experience working with children and families that have been affected by poverty, trauma, illness, and disability. Additionally, the researcher grew up in a single family household and utilized various social services agencies, and programs. Reflecting back as an adult, the investigator recalls how instrumental appropriate social services have been in her success. Although the researcher had a supportive family, a variety of mentors at school, and participation in different programs, these experiences are why she has a passion for working with these families and children. The researcher wants to be influential in helping them achieve their full potential.
The investigator is the instrument in this study (Marshall & Rossman, 1995). Life experiences are present at all times and specifically in this study. Instead of trying to abandon those experiences, the researcher embraced and acknowledged past experiences, and the impact they may have on this research. Therefore, the researcher identified subjectivity and noted her feelings and the possible ways they may color her lens during data collection, and data analysis. Glesne (2006) recommended that researchers monitor their subjectivity and look for the ways that subjectivity influences the data analysis process. The researcher hoped to give voice to the siblings of individuals diagnosed with ASD. In addition, this researcher wanted to identify improved strategies for parents and counselors to assist siblings and families. Finally, the researcher hoped to help siblings of children diagnosed with ASD shed light on their experiences.

Conclusion

In conclusion, this chapter described the procedures that were used to collect data for the research study. A description of the research question, research design, conceptual framework, site, and participant selection, data collection methods, data analysis, limitations, self as researcher, credibility, and trustworthiness was provided.

In summary, siblings share a unique yet important relationship with one another. This relationship serves as a safe practice field to learn social and communication skills. Learning these skills can be challenging within itself. However, combine those challenges with having a sibling with ASD and the complexities compound. This researcher explored the impact of ASD on the sibling relationship from the sibling’s perspective. The next chapters present the findings of the study.
CHAPTER 4: “I AM NOT INVISIBLE”

Introduction

The purpose of this study was to understand the impact that Autism Spectrum Disorders (ASD) have on the sibling relationship. ASD or Pervasive Development Disorders are disorders that are typically diagnosed during childhood that are characterized by severe deficits in three areas: verbal and non verbal communication, social interaction, and repetitive and/or restrictive behaviors. ASD are prevalent developmental disorders that affects approximately 2-6 per 1,000 (from 1 in 500 to 1 in 150) children (Centers for Disease Control, 2009). The prevalence of ASD is increasing and will impact an increasing number of families. Due to the escalating rates of ASD, it’s important to understand the influence these disorders have on the family unit. Therefore, the research question for this study was how does ASD impact the sibling relationship? Five siblings of children diagnosed with an Autism Spectrum Disorder tell their story and help the inquirer answer the research question.

This chapter presents the story of each participant. Each sibling voiced their perception of their lived reality of having a sibling of a person with ASD. Each story is unique and describes the participant and their families. They described their sibling who has ASD and talked about the relationship they have with any other siblings. While each sibling has had an exceptional experience and story, common themes have emerged among all interviewees.

The chapter opens with a description of each sibling in order to provide context for the information given. This depiction, while concise, allows for a glimpse into the
participant’s personality, likes, and dislikes, as well as his or her life. In order to protect the confidentiality of the individuals and families, the names used here are pseudonyms and were chosen by the interviewees. Outside of the researcher and the transcriptionist, only their family and the siblings will be able to recognize themselves.

Their Stories

Five individuals with siblings diagnosed with ASD were interviewed for this study. Participants learned of the study through the Nisonger Center and other individuals who knew of the study. Contextual information about each participant is presented below.

Ella

The first participant interviewed in this study, Ella, is the big sister in the family. She is a sixteen year-old, self-identified African American female who resides with her mother, maternal uncle, and her two younger sisters. Ella’s personality is exuberant and bubbly and was displayed throughout the interview. As she spoke, Ella was smiling, engaging, and open. Ella’s family has a unique dynamic as Ella is a bi-racial young lady (African American and Caucasian), and her family is Caucasian. She and her sisters share the same mother; however, Ella has a different father. Her family consists of . . . Ella expressed that she has felt like an “outsider” due to her racial makeup and this helps her relate to her sibling with Asperger Syndrome (AS), another difference amongst the siblings. Asperger Syndrome is characterized by a significant deficit in social interaction and the development of restricted, repetitive patterns of behaviors, interests, and activities. Individuals with AS do not have impairment in communication.
Ella lives in a rural area and her home is surrounded by 5 acres of land. In order to gain access to Ella’s home, one must travel uphill on a dirt road. The property is surrounded by dark green grass and seemingly a forest of trees. When approaching the house, one might think it was spring because the grass was so green and alive, even though it is winter and pouring down raining. The land included a colonial style home, a barn, and even has a friendly dog that greeted guests when exiting the car. Along with the welcome from the family pet, Ella was expectantly standing waiting in the rain for the researcher’s arrival. Once inside the home it felt like you were on a farm with the country-style kitchen with the six-seat wooden table and horse placemats in addition to all the pictures of animals and animal figurines that are displayed throughout the house. Ella provided a tour of her home and introduced the researcher to her family. Ella’s sister who is closest in age to her was sitting in the living room reading a book, while her younger sister was in the basement working on a piece of art. Ella’s mother was also in the basement working on school work as she is currently attending college.

Ella is quite an active teenager who participates in 4H, Future Farmers of America (FFA), and theater academy. She also loves to read and write. Her family has a farm and Ella is completely involved in the maintenance of the farm and the animals. She feeds the animals in the morning before going to school and even shows horses and goats in competition. Upon first glance, her baby face and smooth skin would give the impression that Ella is very immature. However, when talking to Ella, one might expect her to be much older due to the maturity and insight that she has regarding her life and her sibling. Ella identifies herself as an introvert, but this researcher did not get that same picture.
Ella was open, forthright, and engaging when talking with the researcher. Ella’s youngest sister, who is eleven, is diagnosed with Asperger Syndrome. Ella’s other sister is a normal, thirteen year old.

*Jordan*

Jordan, the second participant in the study, was the first male interviewee. Jordan is a twelve-year old, African American who lives with his parents, his two younger twin brothers, and his paternal uncle. Jordan lives in a newly developed suburb that is growing and expanding with new businesses and home developments. When driving to Jordan’s home, you are surrounded by restaurants and shops. The researcher did not expect to see a residential area in the midst of a commercialized area. In fact, the inquirer thought houses would be quite a distance away. However, you make a left turn off the main street and find a neighborhood with a small number of luxury condominiums with attached garages. The area even has green space and trees to capture the neighborhood feel. The researcher entered the house through the garage. Once through the garage the researcher stepped into the home where the kitchen and dining room meets. The home opens up to a living room area and that is where the interview was conducted.

Jordan greeted the researcher with a reserved glance and a look of uncertainty. Jordan is small in stature for a male of his age. During the interview, he sat next to his mother on the couch across from the loveseat where the researcher sat. He glanced continuously at his mother while answering question. While engaged in conversation, the researcher learned that Jordan is a typical pre-teen in the 7th grade with characteristic pre-teen interests. He plays football, basketball, and participates in wrestling. He is also a
social butterfly stating that he “texts a lot” and enjoys the social networking sites of Facebook and MySpace while also getting out and going to the Boys and Girls Club to partake in all the activities the “club” offers. The family home has a loft with a computer, keyboard, and music equipment. Jordan’s father serves as a disc jockey and the music equipment appears expensive. The researcher made sure that she did not touch the equipment for fear that it might be damaged. This is in the loft area so that all family members are able to use the computer, but can be assisted or monitored if necessary.

Jordan shares a room with his twin brothers. One might think that three boys sharing a room would mean the room would be cramped. Surprisingly, the room is well organized with clothes, shoes, and toys all in place. The walk-in closet is extremely well organized that one could find a pin if dropped. The clothes are all hung up on hangers, the shoes are put away in shoe bags, and there is even room for a small color television. Since there are small children in the home, the researcher was surprised at such organization. The bedroom even includes a secluded area for the twins to go to be alone when necessary. Jordan is the oldest child and both of his twin brothers are diagnosed with Asperger Syndrome and have severe difficulties in social interaction and development of restricted, repetitive behaviors, interests, and activities. The twins do not have delayed communication.

**John**

John, the third participant, was the youngest in the study at eleven years of age, but the eldest sibling in his family. John was the first participant not interviewed in his home. Due to the distance between the researcher and his homes, John’s mother met the
researcher at a restaurant that was an equal distance between the two homes. John is an eleven year-old, African American male who lives with his mother and younger brother who is diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) and Attention Deficit and Hyperactivity Disorder. John’s mother is employed outside of the home and is a single parent. In PDD-NOS, there is severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviors, interests, and activities, but the criteria is not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder (APA, 2000).

John would be described as “scrawny” in build, quiet and somewhat shy in demeanor. Like Jordan, it took him some time to warm up to the interviewer. He often looked to his mother when asked a question by the researcher. His mother would offer a gentle nod of her head in approval after which he would answer the question. As the interview continued, John appeared to become more comfortable because he no longer looked for approval from his mother but answered the questions from the researcher.

During our dinner interview, John appeared to be a typical adolescent wearing jeans, a t-shirt, and tennis shoes. Both his mother and his brother were present at the interview. To my surprise, his mother paid for my dinner. John is a fifth-grader who enjoys playing on the computer, participating in sports such as baseball and basketball similar to Jordan. John loves to hang out with his friends and play games. As the
youngest in the study, John was not as talkative as the older siblings in the study, which could be indicative of his age group.

*Ava*

Ava was the eldest sibling in the study and her maturity level surpassed her age. She is a seventeen year-old, Caucasian female who resides predominately with her mother and her two younger sisters. Ava’s mother and father are married; however, Ava’s father works out of state and comes home every three to four weeks according to Ava. Ava greeted me at the door with a smile and welcomed me into her home. She is a friendly high school senior and already knows where she will attend college and sports the college choice on her hooded sweatshirt. Ava resides in an affluent neighborhood and the mere mention of the city in which she lives commands respect. All the homes in this area are well maintained and have both front and back lawns. As a matter of fact, her backyard backs up to a golf course. Although the grass was covered in eight-inch high snow, the streets were clear of snow and the pavement was easily navigated. The city had about 8 inches of snow just days before and many other less affluent neighborhood streets were still covered with snow and barely passable.

Ava was the oldest of the participants and the eldest in her family. She was very giving of her time and volunteers with Big Brothers and Big Sisters. Ava is also a tutor and babysits neighborhood children. She speaks passionately about volunteering. Her face lights up while talking about her volunteer experiences and you can tell that she enjoys volunteering and helping others. Also, Ava babysits for neighborhood children
and talks about being able to walk to the homes of the children she cares for. Ava seems well-rounded. She talks about going shopping, reading, and going to the movies.

Like Jordan, Ava has two siblings diagnosed with ASD. However, unlike Jordan, Ava’s siblings are not twins. Ava’s youngest sister, who is eleven, is diagnosed with Pervasive Developmental Disorder Not Otherwise Specified and her middle sister, who is fourteen, is diagnosed with Autistic Disorder. PDD-NOS is a disorder with severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behaviors, interests, and activities but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder (APA, 2000). With Autistic Disorder there is qualitative impairment in social interaction; qualitative impairment in communication; and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. Additionally, delays or abnormal functioning must be present in the aforementioned areas with onset prior to age three and the maladaptive behavior is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (APA, 2000).

Ava gave me a tour of her home. There was plenty of room in Ava’s house. Each sibling had their own room with painted walls. Each room was colored with the sibling’s choice of paint. On the second level, the same level of the bedrooms was an area similar to a loft in which there was a television and other recreational fixtures. This room served as a lounge area for the children outside of their personal bedrooms. The downstairs was
spacious and had a sitting room with a piano, roomy kitchen with plenty of counter space which opened into a living room.

*Chris*

The last participant in this study, Chris was interviewed over the phone. Consequently, the researcher cannot describe him. However, from the conversation, the researcher gleamed that Chris is a sixteen year-old, African American male who resides with his parents and his two brothers. He is the next to the youngest child and has four brothers who are older than he is and one younger brother. His younger brother is diagnosed with Autistic Disorder. This disorder is characterized by a qualitative impairment in social interaction; qualitative impairment in communication; and restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. Additionally, delays or abnormal functioning must be present in the aforementioned areas with onset prior to age three and the maladaptive behavior is not better accounted for by Rett’s Disorder or Childhood Disintegrative Disorder (APA, 2000). His mother works outside of the home as Obstetrics and Gynecology (OBGYN) Nurse Practitioner and his father is actively seeking employment.

Chris is a high school sophomore and is excited about the opportunities that come along with attending high school. Chris would be characterized as a typical teenager who enjoys the activities that other teens take pleasure in. Chris likes to play sports, act, and sing. His favorite sport is baseball, but he also plays basketball and football. He is also heavily involved in the performing arts. Chris sings in a choir and has been and continues to be in school plays. In addition to participating in sports, school plays, and choirs,
Chris enjoys spending time with his friends going to the movies, at the mall, and going over their houses to watch television.
### Table 4.1 Summary of Participant Profiles

<table>
<thead>
<tr>
<th>Name</th>
<th>Race</th>
<th>Age</th>
<th>Sex</th>
<th>Family Type</th>
<th>Sibling’s Disability</th>
<th>Sibling’s Age</th>
<th>Sibling’s Sex</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ella</td>
<td>African American</td>
<td>16</td>
<td>Female</td>
<td>Single</td>
<td>Asperger’s</td>
<td>11</td>
<td>Female</td>
</tr>
<tr>
<td>Ava</td>
<td>Caucasian</td>
<td>17</td>
<td>Female</td>
<td>Two-parent</td>
<td>Autism &amp; Asperger’s</td>
<td>14, 11</td>
<td>Female</td>
</tr>
<tr>
<td>John</td>
<td>African American</td>
<td>11</td>
<td>Male</td>
<td>Single</td>
<td>Asperger’s</td>
<td>10</td>
<td>Male</td>
</tr>
<tr>
<td>Jordan</td>
<td>African American</td>
<td>12</td>
<td>Male</td>
<td>Two-parent</td>
<td>PDD-NOS</td>
<td>7</td>
<td>Male</td>
</tr>
<tr>
<td>Chris</td>
<td>African American</td>
<td>16</td>
<td>Male</td>
<td>Two-parent</td>
<td>Autism</td>
<td>11</td>
<td>Male</td>
</tr>
</tbody>
</table>
Table 4.2

**Summary of Family Demographics**

<table>
<thead>
<tr>
<th>Name</th>
<th>Family Type</th>
<th>Birth Order</th>
<th>Sibling’s W/ASD Birth Order</th>
<th>Other Siblings</th>
<th>Other Siblings Birth Order</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ella</td>
<td>Blended</td>
<td>Oldest</td>
<td>Youngest</td>
<td>Yes</td>
<td>Middle</td>
</tr>
<tr>
<td>Ava</td>
<td>Two-parent</td>
<td>Oldest</td>
<td>Middle &amp; Youngest</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>John</td>
<td>Single-parent</td>
<td>Oldest</td>
<td>Youngest</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Jordan</td>
<td>Two-parent</td>
<td>Oldest</td>
<td>Youngest</td>
<td>No</td>
<td>N/A</td>
</tr>
<tr>
<td>Chris</td>
<td>Two-parent</td>
<td>Middle</td>
<td>Youngest</td>
<td>Yes</td>
<td>Older</td>
</tr>
</tbody>
</table>
Table 4.1 summarizes the demographic data collected on each individual. This table offers a glimpse at the participants in the study including: race, age, sex, family type, sibling disability, age and sex. All of the participants self-identified as African American except for one who identified as Caucasian. The siblings with ASD mirrored the participant’s race except for Ella’s sister with Asperger’s Syndrome. This appears to be unique as Black or Hispanic children are less likely to have ASD than their white peers (CDC, 2009). However, with this being such a small sample, additional studies with larger sample sizes should be conducted to examine this further. In addition, the CDC (2009) recommended more research regarding racial makeup and ASD to determine how much of the disparity may result from lower rates of diagnosis in these communities rather than lower rates of autism itself.

Two of the participants interviewed were female, while two of the siblings with ASD were also female. This is also an unusual finding because ASD is most often diagnosed in males. In fact, boys were four times as likely to be affected as girls, with 1 in 70 boys receiving a diagnosis (CDC, 2009). A majority of the participants in this study were the eldest in their family and one was the next to the youngest sibling. Three of the five interviewees were teenagers and high school students and two were pre-teens and in middle school. All of the participants had at least one parent that worked outside of the home and many of the families appeared to be middle to upper middle class. This is noteworthy because access to services influences the adjustment of the family to the child with a disability. Turnbull and Turnbull (1997) acknowledged the financial impact that child disability has on the family. The authors stated that parents usually are not able to maintain full-time employment due to the child care demands and well as the medical
demands of having a child with a disability. This results in having less money to spend on recreation, activities and sometimes basic needs.

In addition, the participants and their families were diverse in the family makeup. Three of the participants lived in a two-parent household and the parents were married. In these households, the one parent was the primary caregiver for the child with ASD. In comparison, one participant lived in a blended family household and another lived in a single parent household. Whereas, the participants who live in the two-parent household have a primary caregiver devoted to the child’s needs with ASD, the other participants parent must work, take care of the family’s needs and attend to the needs of the child with ASD. Also, Table 4.1 demonstrates the range of disorders on the autism spectrums. The disorders range in severity and presence or absence of social and communication skills, and restrictive and repetitive behaviors. Autistic Disorder is the most severe, individuals with Asperger’s Syndrome are considered higher functioning and individuals with PDD-NOS are unique in that the disorder is categorized has having aspects of all of the disorders on the spectrum. Finally, there were four African American participants in this study. This is significant as African Americans have been under-represented in research and literature (Hilton et al., 2010). Their voice adds to the paucity of literature and enhances the perspective of African American siblings and families with children diagnosed with ASD.

Table 4.2 includes information regarding family type, birth order, and number of siblings. Three of the participants lived in two-parent households in which the parents are married. One participant lives in a blended family with her mother, her siblings and
her maternal uncle. The other participant resides in a single family household with his mother. In addition, the participants in this study were primarily the oldest child in their family. Older children tend to be high achievers and serve as teachers or caregivers for the younger children in the family (Corey, 2001). The child diagnosed with ASD was often the youngest child. One participant was the next to the youngest child in their family. Three of the participants did not have any other siblings outside of the child with ASD. The other two participants had other typical siblings. This may have an impact on the sibling relationship as well as the development of social and communication skills.

Summary

In summary, this chapter helps each participant transcend their invisible nature and come alive to tell their story. Oftentimes, siblings of children with disabilities are unintentionally ignored and not heard. A variety of reasons account for this: services, treatment, and parental time and attention are given to the child with a disability. These siblings have been christened the forgotten child. Even in the literature, their voice has been left out (Naylor & Prescott, 2004). This study provides depth and breadth for siblings and offers their perspective.

Moreover, my participants have provided a glimpse into the family unit when a child has a disability. The participants and their families represent are a constellation of family types, races, class, and disorders on the autism spectrum. While the participants and their families are diverse, each family unit demonstrated that regardless of socioeconomic status and/or race, children and families can access services as long as they have a strong parental advocate. All of the participants seem to have knowledge of
and access to appropriate resources for the child with ASD. The next chapter presents the
siblings understanding of their brother or sister with ASD. The chapter provides further
enlightenment of the sibling’s perspective, ideas, and story.
CHAPTER 5: THIS IS HOW I SEE IT: PARTICIPANTS UNDERSTANDING OF THEIR SIBLINGS WITH ASD

This chapter captures the phenomenological lens embedded in the five participant’s interviews. The researcher presents the essence of their lived experiences as gleaned through their voices. The participants discussed their perception on their sibling diagnosed with ASD and the researcher brings their story to life.

_Ella_

As with the previous chapters, this chapter opens up with Ella’s voice. As noted previously, Ella is the oldest child in her family and her youngest sister has Asperger’s Syndrome. Ella was interviewed in her home and follow-up questions were asked of her via email. The interview opened with basic demographic questions about the interviewee. One of the first questions asked about the sibling was a descriptive question. The researcher asked Ella to describe her sibling. In doing so, Ella used mostly positive attributes and characteristics. Ella portrayed her sister as fun, energetic and adventurous.

[She] constantly full of energy and is bouncing off the walls. She’ll just go up to anybody and climb all over them, like a human jungle gym. [She is] energetic, creative...she’s constantly coming up with new ideas. She’s definitely outgoing, willing to try new things, adventurous, she likes to climb up into the hayloft. Did I say loud? Yeah, constantly have to tell her to quiet down and slow your body down.

Ella’s sister demonstrates classic characteristics of AS. However, it is also apparent that Ella’s sister demonstrates characteristics of many eleven year-olds, and her activity then
is also related to her age. Adolescents at this age are full of energy and constantly on the go and busy (source).

My observation is that Ella’s sister is very artistic. She showed me her all of her artwork-abstract work and paintings. From my interaction with her, she seemed confident in her artistic abilities. Whereas my interaction and observation noted the more bubbly side of Ella’s sister, Ella talked about another side. When asked about her negative characteristics, the only adverse comment that Ella used to describe her sister was when she discussed her sister’s “meltdowns”. She recalled, “Like when she meets something that’s difficult, she has a meltdown, kind of throw herself on the floor and start screaming and crying. Some of them can go on for hours...some just a couple of seconds.” Ella continued and described a typical incident with her sibling that other individuals with normally developing brothers or sisters might not have to experience with such duration or frequency.

Last year was the worst, because she had homework every single day...it took her hours. We’d sit there, and right with her to do her homework, , and if she didn’t understand, even if she knew how to do it, she’d say that she didn’t understand it, and that it was just too much work for her. She’d sit there and cry and scream. Rarely do children with normal development go on for hours with their tantrums. So again, the intensity, frequency and duration of the tantrums appeared to be unique to this researcher. When asked how she found out about her sibling’s diagnosis, Ella recollected,
Well to tell you the truth I’m not exactly sure how that came about. I mean mom’s always worked with autistic children for as long as I can remember and then I think one day we were just having a conversation about what it is that she does, and then maybe [she]just kind of go mentioned. Yeah, [it was] no big ground breaking event.

Due to her mother’s experience working with children diagnosed with ASD, her mom may have assumed that her daughter understood the disorders as well. As an individual who works with children with autism, one may expect Ella’s mother to have a conversation with her children about ASD and its characteristics. However, as evidenced by Ella’s words, this did not occur. Glasberg (2000) believed it necessary for parents to share information about autism spectrum disorders with siblings in the home. While this did not occur in Ella’s situation, Ella still had enough insight to comprehend her sister’s disability. While the mother did not have a sit down conversation, she did know that girls are less likely to be diagnosed prior to entering school. Ella’s mother talked with the researcher and conveyed her knowledge regarding the difference between girls and boys diagnosed with ASD. She stated that girls typically have fantasy type things such as fairies, unicorns, and butterflies while boys focus more on tactile things like string, and cars for lining up. She further indicated that one reason that diagnoses in girls are hard may be because these interests are similar to children with normal development. Ella’s mother shared that diagnosis in girls is “not quite so apparent some times, a lot of they’ll just kind of passed off as quirky or just...you know...a little unique. It’s kind of left at that, it’s not until usually they get to be school age and start having difficulty in the
school setting environment...that people start going...oh maybe there’s a little bit more
too that.” She continued and conveyed,

Boys will usually pick up a lot quicker than the girls because they are typically
more developmentally behind and they don’t mature quite as quickly. Um and so
it’s kind of expected for boys that have these difficulties...with the girls it’s not
really expected, so when they do show up with these difficulties it’s like it’s more
of a flag for them.

Clearly, Ella’s mom was very enlightened about the state of identification of the disorder
related to gender differences. On the other hand, Ella provided further insight into the
impact of the disorder on the sibling relationship and her own experiences as a member
of the family unit.

Ella was extremely passionate when talking about how ASD has impacted her.
Ella described how having a sister with Asperger’s Syndrome has made her a better
person and impacted her life for the better.

I believe that having a sibling with ASD has actually impacted my life for the
better. I see people walking around either completely oblivious to what Autism
is, or with a gross misconception about it, and I feel anger and pity for their
ignorance. It's only after I take several deep breaths that I realize if not for [her], I
could have ended up just another judgmental, uncaring bystander and the thought
sickens me.

Even though having a sibling with ASD can be difficult, Ella talked about a benefit of
having a sibling with ASD and how she was developing into a more compassionate
individual. When asked how ASD has impacted her sibling relationship, Ella indicated her relationship with her sister is close and that the two of them bonded beyond the usual sibling relationship because they are both outsiders. She asserted, “I guess we have that bond for kind of being outsiders. We’ve always [had] trouble with life and I’ve just kept to myself, so that’s another reason that we’ve bonded together.” As noted earlier, Ella has a complex family dynamic, and she has a different father than her siblings. Ella is African American and the rest of her nuclear family is Caucasian. This outsider reference refers to her being of a different racial group and her sister with ASD is part of a disability group. The shared experience is that they are not in the majority group or viewed as the norm. According to Rubin and Roessler (2001) individuals with disabilities recognize that they experience discrimination, stigma and bias as other minority groups. Her sister has Asperger’s Syndrome and the remaining nuclear family members are typical. This shared sense of rejection from the majority world enhances the bond that these siblings share. Ella indicated that she was not as close to her other sibling who is closer to her in age, but does not share an outsider status. When asked what type of activities she and her sister with Asperger’s Syndrome engaged in together, Ella described being close to her sister, talking to her sister, and sharing a love of reading with her sister. However, Ella clarified that her relationship with her other sister is impacted by the relationship that she has with the sister with AS as well. She shared that her sister does not truly believe that their younger sister has a disability and believes her behavior is a way to seek attention. Thus, because of how her sibling and she view the situation, the relationship with the “normal” sibling was strained at times. Thus, her relationship
with her other sister within the family unit was negatively impacted by the sister with ASD. This is a real problem for Ella and causes dissention between them. She further clarified that,

However, it has had a severe impact with my relationship with my other sister. [She] and [my sister with Asperger’s Syndrome] are constantly fighting. It's hard for [her] to understand what ASD is and what it means for our sister. She sees it as being an excuse for bad behavior, and her refusal or inability to change her views has caused tension in our relationship. It is especially hard when my sister’s fight and I am forced to be the mediator between the two. I do my best to be fair, and [my sister with Asperger’s Syndrome] generally listens to what I say. [My other sister], on the other hand always gets upset whenever someone talks to her about her fights with [our sister with Asperger’s Syndrome]. She believes that because she takes it harder than [her], she is being unjustly punished, even when she isn't being punished at all.

Overall, Ella stressed that having a sibling with ASD has improved her family life. She contended that having a sibling with ASD can be frustrating at times and place financial and social strains on the family, but countered that despite this impact she would not change her sister. Overall, Ella’s story illuminated how having a sibling with ASD can impact the entire family unit, particularly if there are multiple siblings without the disorder that have different understandings of the disorder themselves. Additionally, it described the benefits and the disadvantages that can exist in the sibling relationship.
Ava

Ava is the oldest sibling in a house full of women as her father works out of town and comes home about once per month. Ava’s sister who is three years younger than her is diagnosed with Autistic Disorder and her younger sibling is diagnosed with PDD-NOS. When asked to describe her sisters in her own words, Ava uses a variety of words with a mix of both positive and negative connotations. Also, her descriptions of her two sisters are opposite. She characterizes her sibling with Autistic Disorder as “blunt, serious, smart, caring, closed, and emotional and stoic.” Individuals with Autistic Disorder have social and communication skills that are more impaired than children with other disorders on the spectrum (NIMH, 2009). She indicated that her sister with Autistic Disorder “doesn’t like spontaneity. She likes to know 10 steps ahead.” Ava characterized her sister with PDD-NOS as, “sweet, loving, extremely emotional, intense, passionate, and as a people pleaser.” She further stated that she, “does better with spontaneity and doesn’t mind things being unstructured.” Individuals with Autistic Disorder function better with structure and routine. Rapin (2001) asserted “[children with ASD] vehemently resist change in routines or the environment and have unusual tolerance for monotony” (p. 754). The researcher observed the strict adherence to routine. While interviewing the participant, Ava’s mother and youngest sister left the house so that Ava’s sister could keep her scheduled extracurricular activity.

When asked, do you think your sibling with ASD is different, and if so, when did you notice a difference? Ava indicated, “I don’t know. I can’t pinpoint it. I kind of grew up knowing. It became common knowledge because I knew that outbursts were not
normal.” Ava’s statement highlights the insight that siblings have regarding what is normal. Siblings interact with peers, friends, and other relatives. This interaction helps them to understand and identify normal behavior and recognize when behavior is not normal.

When asked about her relationship with her siblings, Ava stated that she and her sister with Autistic Disorder are very different from each other, and she and her sister with PDD-NOS are “a lot alike.” Ava further described her sister with Autistic Disorder:

Maybe [our relationship] is not most typical. [She] doesn’t like to go out, [to be around] too many people. She doesn’t like large groups, she becomes over stimulated.” [Because she doesn’t like to go be around large crowds], we rent movie, talk, and play card games. She likes structured things.

While interviewing Ava, the researcher noticed that Ava’s sibling with Autistic Disorder did not sit downstairs and offer or want to participate. She instead retreated to her room and remained there for most of the interview. It appeared that Ava has learned to be flexible in the activities that she engages in with her sibling. Ava recognized that her sister did not enjoy attending the football games due to the large crowds and thus adapted and found activities that she and her sister can enjoy together. Ava talked about the activities she does with her friends and it involves many of the activities she does not do with her sibling. She stated that [my friends and I] “we go shopping, to the movies, sporting events, and other activities at school.”

Ava said that she and her youngest sister were “close but not as close due to the age difference.” This was to be expected. The researcher found in her pilot study that
when siblings are further away in age, they do not interact and engage with one another as often as siblings who are closer in age. However, when asked about how having two siblings with a diagnosed Autism Spectrum Disorder, Ava stated that she is more patient, understanding, and open-minded. Additionally, Ava communicated that having two siblings with ASD has made her mature quickly and have a more mature mindset. Ava stated that her family is, “more open-minded, very giving, and that they are a more involved family.” This is evident in all of the time Ava spends volunteering or caring for other people. She volunteers with Big Brother, Big Sister, tutors children and babysits the neighborhood children. It is often characteristic for teenagers to be self-absorbed and involved in themselves. Ava does not appear to share that characteristic with her peers. When asked if there was anything that she thought could help her understand, and interact more with her siblings, she stated, “I don’t know...a decent understanding...maybe more knowledge about the disorders.”

Like Ella, Ava indicated that having siblings with ASD can be difficult at times. She conveyed it puts a strain on her parents’ relationships, and is time consuming for her mother. The researcher observed Ava’s mother and younger sister scurrying out the door for a scheduled activity while she was there. She also said, “It can be hard sometimes, it would be nice for them to be normal for a day.” However, she expressed that overall having siblings with ASD has made both her and her family better. In comparison to Ella, Ava has a large amount of responsibility as the older sister in the household. This could possible due to their gender as well as their family order. Still, Ava reaches beyond her family unit and utilizes the skills she has learned in the family unit to assist others as
well. Consequently, the impact of having a sibling with ASD has strengthened her ability to be compassionate with others and impact her outside work as a caregiver in her community at large.

John

John is just one year older than his sibling with PDD-NOS. He seems to be oblivious to the fact that his sibling is diagnosed with PDD-NOS even though his mother has told him. John stated that he and his brother are close and play together on a regular basis. While he noted that his brother has an “attitude problem,” outside of that he does not seem to think that ASD impacts him or his family negatively. John talked about helping his brother by trying to demonstrate how to communicate effectively. He stated, “Because whenever he says something that doesn’t make any sense, I always say it the right way so he can understand [how to say it properly.]” John appears to serve as a role model for his brother. This is not unique as siblings oftentimes serve in these capacity, especially older siblings. However, siblings of children with an ASD diagnosis may have to step up to these roles more often due to the communication and language barriers that their siblings face. When asked to describe his brother and their relationship he indicated, I would describe him as cooperative and not a loud person. We get along and [play together] a lot. We do chores together and we do sports together. Together we build things, anything that’s made of Legos. We play video games. We do not fight a lot, but yes we do argue.

During the interview, the researcher noted that John assisted his brother with cutting his food and making sure his brother was alright. John seemed to be protective and assisted
him when needed. When asked how having a brother with PDD-NOS has impacted him, John conveyed his feelings this way, “that's not the kind of attitude that he's supposed to have. He's supposed to have a good attitude. I can't find anything to make him stop acting like temporarily mad.” The researcher gleaned that John’s sibling displays some of the other deviant characteristics that are common with children with ASD. In turn, John as the elder, attempted to alter his behavior to more acceptable characteristics. In addition, John’s mother stated that his brother “[is] easily frustrated when he does not win.” Rapin (2001) asserted “[children with autism] are irritable and chronically unhappy.” She continued “some are excessively aggressive and may pinch or hit without provocation” (p. 755). The researcher did not note any aggressive behavior during the interview. John’s sibling sat quietly while the inquirer conducted the interview. When asked how having a sibling with ASD has affected the sibling relationship John asserted, “We have a good relationship because we both love each other.” John’s mother echoed John’s statement regarding his relationship with his brother. She contended that, “They’ve been very close, I mean, they’ve had to be. They share almost everything... They haven’t been away from each other for any length of time really. [On the other hand,] I think they’ve had typical sibling rivalry.” Despite John’s awareness of the personality disorder aspects of ASD that his brother demonstrates, John sought to support, and even challenge his brother despite his diagnosis of ASD. In other words, it did not alter their normal development as siblings within the family unit.

John’s mother also noted how important routine is in his brother’s life. She stated, “It’s much more helpful for him to be on routine. If he has to change, sometimes that can
be...he will express that it’s difficult for him, that he doesn’t like it or he doesn’t want to do it.” This is similar to Jordan’s, Ava’s, and Ella’s story. John’s brother also has a difficult time making friends. His mother conveyed, “but I think sometimes they [peers] don’t understand his language and the way he talks, so they kind of shy away from him.” When asked about his communication style, his mom illuminated his abilities; She recalled, “he can’t get the right words, he’s frustrated and he might just [shut down]...squinting his eyes really closed, tightly closed.” Consequently, as a family unit the sibling with ASD was supported by the families’ understanding as a unit of his disorder and they worked as a unit to support his development, particularly John as the sibling, despite his disability.

In all, it appeared that having a sibling with ASD affected John only socially. He did not speak to any other frustrations, or concerns. He spoke about playing and interacting with his brother, and ASD did not seem to impair that aspect of their relationship in any manner. In fact, it may have made them even closer as John illuminated how he had become his brother’s advocate. While not a negative impact, it was still an impact on John’s interactions with not just his sibling with ASD, but the larger social atmosphere in which children interact.

*Jordan*

Jordan is the oldest son of three children. His twin younger brothers are both diagnosed with Asperger’s Syndrome. His description of his siblings is below. Jordan described Twin #1:
He’s the funny one. He’s always the person who likes to make other people laugh. He’s taller and bigger [than his twin brother].” Fun, funny, [and] annoying sometimes. Like sometimes...he’s funny sometimes when it’s not in a funny atmosphere. He really loves to scream and...I’m like...I’m right next to you; you don’t have to scream to talk to me.

On the other hand, the other twin even as a twin is different in personality. Jordan described twin #2.

He’s more of the serious one. Serious, whiny...he really likes to dance. [He] is usually...like at first he’d be the person who’d introduce people to [his twin brother]. So it was like he was the leader of the group.

When asked how his siblings were different from him, Jordan talked about his siblings having tantrums. He thought, “They need to pay attention and solve things without crying. My mother just started something with Twin #1 where if he doesn’t cry for a week she’ll give him a prize.” This is similar to Ella’s and John’s mother’s comment regarding the challenges faced when presented with new or different tasks. According to Rapin (2002), children with ASD have an unusual tolerance for monotony, so new tasks or different routine can be expected to cause a significant disruption to the lives of children with ASD. Jordan was there when his mom talked to the doctor about her suspicions about the siblings having autism. He recalled,

I remember when we were at the doctor’s office with the [doctor], she explained to him she thought they were autistic because she was going through nursing classes and they had a lot of the symptoms of autism. He didn’t think they had it at first, and then she kept...so then after a while she kept recording the things they
would do and then...got them...toys. [Twin #1] would always organize his toys and if it was unorganized he would freak out.

Jordan’s mother discussed the signs that she observed with the twins and how she had to advocate for the doctor to even test the children for the disorder. She recalled the experience,

So I went to the doctor with my husband and I told him, ‘I think something is wrong with the twins.’ And he was like we’ll check them out. But I told the doctor, ‘I think they’re autistic.’ He was like, ‘no, no they have perfectly fine [communication skills] and they can talk. I was like ‘well there’s a type of autism...it’s called Asperger’s, it’s more common in boys and it’s just pretty much social.’

Parents are usually first to note the abnormality in their child (Filipek et al., 2000). They may notice that the child is not meeting developmental milestones or that the child has a quirky way of behaving and interacting. Once parents notice these things, they typically ask the pediatrician to address their concerns. Sometimes, parents have to serve as an advocate for their child to receive an appropriate diagnosis and proper treatment and services.

During the interview, the twins were in their parent’s room watching a movie. While the researcher did not observe the interaction of John with his brothers, the information that he relayed and the compassion that he displayed, appeared to help John understand his brother’s challenges. When asked how having a sibling with ASD has impacted him, Jordan said, “sometimes I understand and others don't.” Jordan like John
as males appear to have been more impacted socially by the sibling with ASD and others understanding or lack thereof concerning the disability. Also, Jordan discussed how having brothers with ASD has affected the relationship between them and how he interacts and communicates with him. He conveyed,

Having brothers with ASD has affected me by having to understand some things I say to them, they take it literally. I can't say things like ‘Oh I cut myself with a piece of [glass] and I am bleeding’ and them not thinking I am going to bleed to death. I have to keep being reminded they are different from other children when it comes to loud noises, touch, and smells.

Children with Asperger’s Syndrome have difficulty with understanding social cues and many times take things literally. This can be challenging for children in play because joking is a familiar activity. Overall, Jordan has mixed emotions about how he has been affected by having brothers that are diagnosed with Asperger’s Disorder. He summarized it as,

Having siblings with ASD has impacted my family in regards to making people aware that the disease is a real one, and not just being spoiled, bad behaved children. My family and I have [gone] to an autism conference in Ohio before and I learned more about my brothers. My family and I were given a blessing and a curse; you just have to find the good in blessing, and roll with the bad. My parents have patience, and understanding with my brothers. My family works very hard to try and live a normal life but sometimes I ask myself what is normal.
Jordan’s experiences highlight the role that siblings may take in becoming advocates for their sibling with ASD. This experience was similar for Ella, Ava, and John who either educated other siblings within the family unit or people outside of the family unit. Moreover, Jordan’s experiences further indicated the role that education can play in supporting the understanding of ASD by the sibling without the disorder and the family unit in general. Educational experiences can strengthen their resolve to support not only the sibling, but also heighten their role as not just a sibling, but as advocates within the larger social community for children with ASD through their interactions with others.

Chris

Chris is the next to the youngest son of five brothers. His youngest brother is diagnosed with Autistic Disorder. Chris described his brother as:

[He’s] very energetic, lots of energy, never runs out of energy. [He’s] intelligent, clever, rhythmic...lots of rhythm. Outgoing socially, likes to be around people but is language impaired, laughs a lot, has tantrums and gets mad and he is physically strong.

When asked to describe his relationship with his brother with Autistic Disorder, he stated that, “it’s great.” He indicated that he and his brother play ball (bouncing the ball) and have a good time together. Chris articulated that his relationship with his other siblings is different. He discussed that with his typical brothers that they have a “brotherly relationship” and pick on each other, whereas, he does not pick on nor fight with his younger brother with Autistic Disorder. One of the features of children with ASD is that they do not understand teasing. Chris chuckled when I asked him about arguing and
fighting with his brother with autism. He attested that, “In brotherly relationships, we pick on each other. [With my brother with autism] we can’t really pick on each other. I mean he wouldn’t understand if I did fight with him.” In addition, Chris recalled how he is more responsible for the care of his brother and more protective of him. Also, he talked about being more emotional about his brother with Autistic Disorder. He stated, “I get defensive if someone says something about my brother, but not my older brother. I get more protective because he has autism and it’s serious, [much] more serious.”

Similar to other participants in the study, Chris discussed his brother’s tantrums. He recalled, “He has tantrums and gets mad. Like when he wants food or sometimes we don’t even know why he is having the tantrum because he is [non-communicative]. Sometimes it’s because there’s too much going on, distractions or noise and he gets mad.” Behaviors such as this were an indication to Chris that his brother was not “normal.” Chris stated that he has always known that his brother was different. It was not one particular thing that stuck out, but a combination of characteristics and attributes.

In the back of my mind, I’ve always known. [My brother] never talked or spoke the language. That was the biggest hint. [He] needed a lot, he also used to rock to music. [It] was kind of different than what people usually do. As far as I can remember [I’ve always known]. In 5th grade I asked my mom. I guess I never really paid any attention but as I got older, I began to wonder and she told me he has autism.

Chris is similar to Ava in this regard. Both of these siblings recognized that their siblings were different. Unlike Ava, Chris had other siblings to compare to concerning the
normal development of sibling relationships, whereas Ava did not. When asked how having a sibling with ASD has impacted him, Chris stated that he “Wouldn’t be as sympathetic and [have] respect for a lot of things. [For instance,] I don’t make fun of people with mental or physical disabilities.” He further indicated that having a brother with Autistic Disorder has “made my personality better.”

Chris indicated that having a brother with ASD has made him more responsible and that he constantly has to watch his brother. This, according to Chris, is a negative side to having a brother with ASD. Chris believed that having a brother with ASD has made his family better and opined that they spend more time together. He conveyed that, They feel the same way as I do. It has made them better. [Having a family member] helps [us] understand how other feel. It’s rare to have someone in your family with ASD and we embrace it. It brings us closer. We all pitch in to help and since we are all going through the same thing, we understand it.

This is a positive aspect because Chris noted that he knows more about his brother and gives his brother more attention. Also, Chris stated that having a brother with ASD has cost more money, time, effort, and patience. Overall, Chris seems to have a positive outlook on his sibling relationship, and the affect that it has on him individually, and his relationship with his brother, and his family.

The Impact of ASD on Sibling Relationships

Through the interviews and subsequent data analysis, commonalities across all participants were found. These commonalities will be discussed below.
Whereas the literature contends that sharing information with siblings can be beneficial (Glasberg, 2000), my participant’s stories demonstrated that this was not happening. One commonality in most interviews was that the siblings did not remember a time that their parents talked with them about their brother’s or sister’s disorder. Most participants do remember a time when the conversation took place; however, it was either initiated by the participant or they just happened to be present when the topic was being discussed. Once the sibling found out, it appeared that some of them sought more information so that they could better understand their siblings’ disability as well as support their development socially. According to Ella, her awareness of her siblings’ disability “wasn’t a ground breaking event. It just feels to me like I’ve always known that she had this label.” Ava indicated that “I can’t pinpoint it. Kind of grew up knowing...became common knowledge.” When I asked Chris when did he find out about his brother’s disability he said, “In the back of my mind, I have always known.” The participants had experiences with peers and relatives and understand normal play and interaction. They have had the opportunity to be socialized to what normal is and recognized the differences in their siblings. Clearly, as informed by the literature, the participants ascertained their understanding of their sibling with ASD through the sibling relationship further indicating the significance of the impact of ASD on the siblings and the sibling relationship.

While many of the participants spoke about always knowing things with their sibling were different, some participants wanted to educate themselves about the specific disorders. Ella, Jordan, and Ava recalled obtaining specific resources to understand the
disorder and its characteristics. Ella indicated that she went to the Autism Society of America’s website because she wanted to know more. Jordan stated that he attended an Autism Conference to learn more about Asperger’s Disorder. Ava read the book, *The Curious Incident of the Dog in the Night Time* to help her understand the challenges that her siblings face.

Another similarity across most sibling interviews was that participants talked about the tantrums that their brother or sister have. Jordan recalled his brothers’ inability to handle different situations. He asserted that, “If Twin #1 needs more time, he’ll start crying.” Ella discussed what happened when her sister was faced with challenges. She recalled, “When she meets something that’s difficult, she has a meltdown, kind of throw herself on the floor and start screaming and crying.” Chris says, “He has tantrums when he gets mad.” Children with ASD have difficulty expressing themselves and articulating their feelings. This is especially evident when faced with new tasks or challenges.

In addition to the tantrums, many of the participants discussed how inappropriate their siblings words or conversations can be at times. Ella stated, “Like if there is someone just passed away. I’d know maybe if that person wouldn’t feel like talking about it right now, but [she], she’d jump in and talk about how much she misses them and when are they going to see each other again.” John described his brother’s tactlessness a little bit differently. He stated, “We have to give him consequences for having that attitude. He has a rude attitude and that’s not the kind of attitude he is suppose to have. He’s supposed to have a good attitude and I can’t find anything to make him stop acting like temporarily mad.” John recognized that his brother’s attitude is not typical. He also understood that
discipline was used to correct his brother’s “attitude”. The researcher noticed that John used the word “we” implying that he too serves as a disciplinarian for his brother. Jordan talked about how his brother’s communication style was different. “[Twin #1] he always likes to scream I guess...scream what he is saying. I’m like...I’m right next to you, you don’t have to scream to talk to me.” Jordan continued, “He’s just funny sometimes, when it’s not a funny atmosphere.” Ava says that her sister with Autistic Disorder is, “blunt...she doesn’t mean to be mean.” This speaks to the social impairment that children diagnosed with ASD experience. Failure to understand social cues is a cardinal feature and most of the participants spoke of this. Children with ASD are unable to comprehend the feelings of others and have difficulty seeing things from other people’s perspective. In addition, children who have a disorder on the autism spectrum do not understand sarcasm or jokes (Johnson, 2004).

Additionally, many of the participants express great concern and protectiveness over their sibling with ASD. Sibling’s talk about feelings of helplessness and frustration in regards to assisting their sibling feel normal, even if only for a day. Ella stated,

I’d change the part that some things are just so incredibly hard for her.

Of course I would prefer that [she] didn’t have to go through the struggles that she has to face daily- the taunts, the anxiety, the frustration at not being understood.

The hardest part of ASD is feeling absolutely helpless as I watch my little sister become so distressed that she makes herself sick and being completely unable to help her. It's hard for me to see [her] as an autistic child. I see her as an incredibly
loving, intelligent, creative, amazing human being who inspires me more than anyone I know.

Additionally, Ava supported this contention. She asserted, “It’s hard sometimes. It would be nice for them to be “normal” for a day.” This is an impact of the disorder on the sibling relationship.

The siblings in the study appear to be more aware of the distress that their brother or sister experiences as a result of having ASD. The siblings are less selfish and absorbed in their own lives and wish they could improve the lives of their brother or sister. In addition to wanting to change the situation for their siblings, one participant explained how he is uncomfortable with the behaviors his brothers display. Jordan stated, “Many times their behavior embarrasses me. They can be loud, running around or just crying over something small. I feel like many times I have to do things I don't want just to make them happy.” Again, this shows the giving and selfless attributes of the siblings in this study. Some researchers have stated that siblings of children with disabilities may be resentful because of the restricted activities (Macks & Reeves, 2006). However, the researcher did not observe resentment, but frustration as Jordan and others were able to participate in several activities and maintain a typical life outside of his family unit.

Yet, another parallel that emerged from participant interviews was the closeness of the relationship with their sibling with ASD. Individuals described spending more time with their siblings. Oftentimes, it was to assist their parents with the care of their sibling. Furthermore, some participants shared that they were more knowledgeable about their sibling. The overarching message was ASD made the relationship closer, and more
intimate. Chris indicated, “Our relationship is better. We spend more time together and I know more about him.” Ava stated, “It’s closer in a way. I am very protective over [my sister with autism]. I am involved in her life.”

Typical sibling relationships usually involve some form of sibling rivalry (Downey & Condron, 2004). Siblings fight, argue, and bicker. Participants in this study illuminated that their relationship with their sibling with ASD was less quarrelsome than other sibling relationships and even when they do argue or fight, it does not last as long as it would with other siblings or friends. Jordan relayed, “I think I’m nicer than other people. My sibling rivalries don’t last as long as their [my friends] do.” Chris communicated, “We can’t really pick on each other. He wouldn’t understand it if I did.” A classic feature of children with ASD is that they have trouble with verbalizing their feelings and comprehending sarcasm, jokes, and teasing. The siblings in this study have recognized this and therefore do not provoke their sibling with ASD whereas typical sibling relationships would have an element of this behavior.
### Table 5.1

**Common Themes Among Participants**

<table>
<thead>
<tr>
<th>Name</th>
<th>“Always Known”</th>
<th>“Meltdowns”</th>
<th>“Inappropriate Communication”</th>
<th>“Closeness”</th>
<th>“Positive Impact”</th>
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</thead>
<tbody>
<tr>
<td>Ella</td>
<td>“I’ve always known that she had this label”</td>
<td>“kind of throw herself on the floor &amp; start screaming &amp; crying”</td>
<td>“I’d know maybe if that person wouldn’t feel like talking about it right now, she’d jump in”</td>
<td>N/A</td>
<td>“I believe having a sibling with ASD has actually impacted my life for the better”</td>
</tr>
<tr>
<td>Ava</td>
<td>“kind of grew up knowing”</td>
<td>N/A</td>
<td>“Blunt”</td>
<td>“It’s closer in a way.”</td>
<td>“I’m more patient, understanding &amp; open-minded because of my siblings.”</td>
</tr>
<tr>
<td>John</td>
<td>N/A</td>
<td>N/A</td>
<td>“He has a rude attitude”</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Jordan</td>
<td>N/A</td>
<td>“He’ll start crying”</td>
<td>“Funny, when not a funny atmosphere”</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Chris</td>
<td>“I’ve always known”</td>
<td>“He has tantrums, when he gets mad”</td>
<td>N/A</td>
<td>“Our relationship is better”</td>
<td>“It definitely made my personality better.”</td>
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</tbody>
</table>
A final parallel that was discovered through analysis of the data collected was positive ways that having a sibling with ASD has impacted each participant. Chris stated, I probably wouldn’t be sympathetic. It’s different when you know someone or have been affected by autism. I have respect for a lot of things. I don’t make fun of people with mental or physical disabilities. Usually people who don’t have a sibling or family member or know someone are the ones who make fun of people with disabilities. It has definitely made my personality better than if he didn’t have autism.

Jordan indicated, Having brothers with ASD has affected me by having to understand some things I say to them, the take it literally. I can't say things like" Oh I cut myself with a piece of and I am bleeding" and them not thinking I am going to bleed to death. I have to keep being reminded they are different from other children when it comes to loud noises, touch, and smells. Sometimes I understand and others I don't. Ella communicated, “I believe that having a sibling with ASD has actually impacted my life for the better. I see people walking around either completely oblivious to what Autism is, or with a gross misconception about it, and I feel anger and pity for their ignorance.” Ava stated “I am more patient, understanding, and open-minded because of my siblings.” Participants identified some unexpected benefits of having a sibling with ASD. They discussed positive characteristics that have been developed and they attributed this development to having a sibling with ASD.

In summary, each participant lends a voice to the phenomenon of having a sibling with ASD. While all stories and experiences are unique, commonalities across all stories
were discovered. None of the participants remembered a time when their parents had a conversation with them to discuss their sibling’s disorder, its characteristics or symptoms. Some of the participants expressed the desire to know more about ASD. In wanting to have more knowledge, some of the participants sought out information regarding ASD. Also, most of the participants discussed that there sibling had tantrums. These tantrums range in the causes, frequency and duration, nevertheless tantrums are present. A final commonality across the participants was the positive impact having a sibling with ASD had on each participant. Many of the participants stated their personality is better because of their sibling. The next chapter will identify the lessons that were learned by the researcher as a result of the siblings sharing their stories.
CHAPTER 6: LESSONS LEARNED

Introduction

This study revealed the impact of Autism Spectrum Disorders on the sibling relationship from the siblings’ perspective. As siblings discussed their story and perspective, four themes emerged and each theme was named using the participants own words. Through each voice, a deeper understanding of each participant was discovered. Moreover, information regarding how they perceived their sibling and identified what impact having a sibling with an ASD has had on them personally, their family unit, and the sibling relationship was gained. In addition, each participant’s nuances and uniqueness were uncovered. The previous chapters reported the findings gleaned from this qualitative case study. This chapter will discuss the lessons learned from the participants.

Four themes emerged from this inquiry. These themes were: “The hardest part of ASD is feeling absolutely helpless,” “That’s just the way our family is”, “Having a sibling with ASD has actually impacted my life for the better”, and “It’s a blessing and a curse.” This chapter will provide a discussion and interpretation of the lessons learned.

Table 6.1

<table>
<thead>
<tr>
<th>Lessons Learned</th>
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<tr>
<td>Theme #1 “The hardest part of ASD is feeling absolutely helpless”</td>
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<tr>
<td>Theme #2 “That’s just the way our family is”</td>
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<tr>
<td>Theme #3 “Having a sibling with ASD has impacted my life for the better”</td>
</tr>
<tr>
<td>Theme #4 “It’s a blessing and a curse”</td>
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Theme 1: “The hardest part of ASD is feeling absolutely helpless”

The siblings in this study conveyed that they were frustrated and felt helpless regarding the attitudinal barriers their siblings faced on a regular basis. Attitudinal barriers are the negative, misleading, and deceiving thoughts, words, and phrases that society uses to describe individuals with disabilities. These thoughts, attitudes, words, and phrases reveal a gross misconception about individuals with disabilities. Some of these attitudinal barriers are: fear, denial, ignorance, inferiority, or the hero effect. Pivik, McComas, and LaFlamme (2002) reported, when discussing the barriers that students with disabilities faced that “parents singled out attitudinal and social barriers as the biggest difficulty for their children, including inappropriate comments, lack of knowledge, or rude behavior by both adults and children” (p.99) Siblings in this study also identified this as challenging.

Ella discussed this frustration. She reflected that, “I see people walking around either completely oblivious to what autism is, or with a gross misconception about it, and I feel anger and pity for their ignorance.” Ignorance is a common attitudinal barrier people with disabilities face. Largely due to people failing to understand the abilities that individuals who have a disability possess. Oftentimes, people dismiss individuals with disabilities and do not provide the opportunity for people with disabilities to showcase their skills and abilities.

Another attitudinal barrier that was faced by individuals with disabilities is denial. People deny that the disability exists and that any type of accommodation is needed. This is especially true for hidden disabilities and diseases such as learning disabilities,
psychiatric disabilities, epilepsy, cancer, arthritis, and heart conditions. ASD is not an exception to this. Jordan conveyed that people do not believe that ASD is a real disability. He indicated that, “having siblings with ASD has impacted my family in regards to making people aware that the disease is a real one and not just being spoiled, bad behaved children.” Siblings serve as teachers to the outside world and offer an inside perspective on ASD. Because children diagnosed with ASD display aberrant behaviors and the disability may not be seen physically, members of society often make inaccurate judgments about the children, their parents, and their families. Some people think that parents are not providing appropriate discipline; some people think that the children are just not well-behaved, and some people believe it is a combination of both poor parenting and misbehaving children. The attitude that is displayed towards their sibling and their family causes frustrations, and increased stress with siblings, individuals with ASD, and the parents. Consequently to avert this societal criticism, siblings serve as educators to people outside of the family unit while serving as mediators for their sibling with ASD.

Stereotypes are overgeneralizations. Society has many stereotypes about individuals with disabilities. Often, individuals with disabilities share widespread troubles of stigma and discrimination with ethnic and racial minorities (Marinelli & Dell Orto, 1999). Chris does not allow his friends to have these misconceptions. He stated, “I just show them my brother and let them learn firsthand. Some things are hard to describe [or explain].” It is not uncommon for siblings of children with ASD to be asked about the behaviors of their siblings or for people to come up with their own answers based upon incorrect information.
Attitudinal barriers are the most common barriers that individuals with disabilities face and the most difficult to overcome. Pivik, McComas, and LaFlamme (2002) in their study of inclusiveness of schools for students with disabilities indicated that, “Attitudinal barriers were identified by our students as the most deleterious of their school experiences. All of the participants experienced negative comments, teasing, staring, and isolation” (p. 104). This experience was challenging as well for siblings of children with disabilities because the disability impacted the entire family. Siblings frequently feel frustrated and helpless to educate people about their sibling’s disability. More awareness and education about ASD will help individuals, siblings, and families overcome attitudinal barriers. Ava talked about being an advocate for her siblings and all people with ASD. Ava wears an autism awareness bracelet daily to try to raise awareness about autism. Pivik et al. contended that “The main suggestion for improving this situation was the integration and inclusion of individuals with disabilities within all aspects of society” (p.99). In order to overcome the unjust condemnation from society, siblings and family members must continue to push for inclusion of their siblings and other individuals with ASD into society to help raise awareness and improve society’s perception of individuals with ASD.

Another aspect of the helplessness for the participant is their inability to fix things for his or her brother or sister. Siblings in this study recognized the challenges that come along with a diagnosis of ASD. These challenges can range from meeting new people and making friends, to completing demanding homework, or handling the spontaneity that can come with daily life. Whether their enhanced understanding of these difficulties
come from research about ASD or experiences with their sibling, the participants realized that it is not easy for their brother or sister to participate in the regular activities of being a child.

Many participants expressed the longing to have their siblings become normal if only for a day. The participants recognized the difficulty for their brother or sister to “fit in” with peers and do things that typical children their age do. Participants wished they could make their sibling’s ASD disappear, even if only momentarily, so their sibling could participate in usual daily activities. The typical sibling wanted their sibling to be able to experience the joy of childhood without the communication difficulties and the social awkwardness. The participants acknowledged that their brother or sister will have to deal with ASD for the rest of their lives and there is not taking that away. In addition, siblings realized this will continue to be a challenge for their sibling, their family and for them. Along with the realization that ASD is forever, siblings also understand that if life is going to be different, they (the family and the participant) will be the ones who will need to be flexible and adapt. The next theme discusses how the family has adapted to the dynamics of having a family member with ASD.

Theme 2: “That’s just the way our family is”

There is literature that highlights the positive effect on the relationship when children have siblings with disabilities (Cuskelley & Gunn, 2003; Fisman et al., 1996, McHale & Gamble, 1989; Roeyers & Mycke, 1995). Many of the participants discussed that they were closer to their ASD siblings. Not only did the participants attest that their relationship is improved, but they also highlighted how their family was close knit as a
result of having a sibling with ASD. Ava discussed her relationship with her sibling with autism, “We have a strong relationship since we have gotten older. We have bonded. I am very protective over [her] and involved in her life.” She further attested that “[I am] protective but not as close [to her youngest sister with PDD-NOS] mainly due to our age difference.” Chris further illuminated the impact of ASD on him and his sibling’s relationship. He stated that,

I am more protective [of my brother with autism]. I am more emotional about him. I get defensive if someone says something about my younger brother but not if they say something about my older brother. I get more protective because autism is serious and so it’s more serious.

Ella communicated that “[She] and I are very close. She often comes to talk to me about anything that is on her mind, if she is having trouble with something. I also feel like I can talk to her. We share lots of passion for books and for writing and for animals.”

In this research, the positives explicated by the participants were that they shared a more warm relationship with their siblings and felt more bonded to their sibling with ASD. In addition, siblings reported that their families were more devoted to one another and quick to help one another.

On one hand, siblings identified that their relationship is closer. On the other hand, siblings described hanging out with their friends, going to the movies, and going to school activities. When asked about the activities they do together with their sibling with ASD, in comparison to their friends, the relationship appears less interactive. However, the relationship is not less interactive but these siblings have fewer activities that they can
participate in together. This is most likely due to the difficulty in identifying mutually enjoyable activities (Knott, Lewis, & Williams, 1995; Stoneman & Brody, 1984).

Siblings discussed the complexity in identifying activities to do with their brother or sister with ASD. Most siblings seemed to take their cues for recreational activities from their sibling with ASD. For example, Ava talked about how she and her friends like to go to the football games and hang out on Friday evenings. She thought it would be a good idea to bring her sister along. However, her sister did not have fun at these events. In fact, Ava reported that her sister was uncomfortable and over-stimulated in large crowds. Ava explained, “She [sister with autism] doesn’t like to go out, [with] too many people. She gets over-stimulated when there is a lot of things going on and too many people.” She continued, “She [sister with autism] likes structured things. She likes this game called Apples to Apples so we play that. We go to the movies and rent movies.” To illustrate further, Chris described, “[he] likes to run around the house and play tag, play with the drums. I will drum and then he will drum. If I clap, he grabs my hands and claps them.” In both of the examples, the interviewees made accommodations to find activities to interact with their sibling with ASD. While the literature addressed the difficulty normal children have while playing with their ASD siblings, these individuals were creative and flexible and found games and other enjoyable activities to do with their sibling. Consequently, the sibling with ASD dictated what activities their sibling could participate in with them. Thus, overall the relationship may be closer, but less interactive in terms of how activities are chosen and participated in. This signifies the importance of providing information and support to siblings. This information could assist siblings with
identifying equally rewarding activities for both children. Increased knowledge of mutually beneficial activities can increase the quality time siblings spend together.

**Theme 3: “Having a sibling with ASD has actually impacted my life for the better”**

Adolescents often try hard to fit in with peers. Any difference, however slight, may cause disruption to the peer relationship. Siblings of children with ASD may be embarrassed because their sibling displays improper language skills and unusual behaviors which may cause both children to be ostracized. Rapin (1991) stated “with the pressure of fitting in, the siblings may not want their sibling with ASD to play nor communicate with friends.” However, this contention was not supported in this research.

When asked, “What do you tell your friends about your sibling with ASD?,” the siblings stated that they were up front and honest with their friends about their siblings and their disorder. Chris recalled that, “Most of the time I just tell them that he has a language impairment and he can’t communicate like we communicate.” In addition, Chris stated, “I show them my brother and they can learn firsthand because some things are hard to describe. If asked, I tell them he has autism.” This was not unique to Chris. Ava indicated she had similar actions. “I am upfront and honest with my friends. I am not embarrassed at all...I usually wear an autism awareness bracelet.” Furthermore, Ella stated,

Most of my friends I think I just told them even before they met [her]. Like in our psychology class we talk about it a lot, we talk about what autism is and my other good friends that I’m not in psychology with...for some reason autism became part of our conversation...then they came over to my house and met [her]...To tell
you the truth, some of them are like, ‘oh I had no idea that there was anything wrong with her.’ That drives me crazy that they say that.

While some siblings were open and honest with their friends, others stated that their siblings are not part of the conversation with their friends. For instance, Jordan indicated that, “we don’t really talk about them... the last thing on my mind is the twins when I’m at school, when I’m hanging out with my friends.”

In addition to not being embarrassed, many of the participants felt that their lives had been enriched. Many siblings highlighted the positive changes that have occurred within themselves. These changes, range from them being more patient and understanding, to them being more giving. Chris stated, “I’d probably wouldn’t be sympathetic or have respect for a lot of things. [Having a brother with ASD] has made my personality better than if he didn’t have autism.” Ava believed that she is, “I am more patient, understanding, and open-minded [because of her siblings].” Ella concurred when she indicated that, “I believe that having a sibling with ASD has actually impacted my life for the better. I realize if not for Abby, I could have ended up just another judgmental, uncaring bystander, and the thought sickens me.”

**Theme 4: “It’s a blessing and a curse”**

It is widely known that children with a diagnosis of ASD struggle in the area of communication, social interactions, and repetitive behaviors (APA, 1994; Rapin, 2001). However, there are other aberrant behaviors that are common when interacting with children with ASD. These other symptoms include: hyperactivity, aggression, self-abusive behavior, temper tantrums, irritability, and lability of mood. These symptoms are
associated features of autistic disorder. Moreover, these behaviors can interfere with daily functions and cause interruption in routine and schedules. The participants in this study spoke of the tantrums and hyperactivity and discussed the impact on the family system.

Ella stated, “Like when she meets something that’s difficult, she has a meltdown, kind of throw herself on the floor and start screaming and crying. That’s probably the hardest part.” Jordan experienced something similar with his sibling. He stated, “I think just as their skills as of needing to pay attention and solving things without crying.” Chris attested that his brother, “bursts into sudden tantrums and I don’t know why.” Ava talked about her sister with autism has, “fits and outbursts if she doesn’t do well.” John experienced disruptive behavior a little bit differently. He recalled, “That’s not the kind of attitude he’s supposed to have. He’s supposed to have a good attitude. I can’t find anything to make him stop acting like temporarily mad.” Whether it was a result of meeting difficulty with new tasks or for reasons unknown, siblings expressed that these behaviors, these tantrums, are difficult to deal with and manage. It may be expected that siblings would be embarrassed by the actions of their siblings. However, the study did not find that embarrassment was a common feeling. In fact, many participants were frank about their sibling and their disorder with others.

Many researchers agreed that having a child with a disability has a great impact on the family system (Burke & Cigno, 2000; Case-Smith, 2008; Soresi et al., 2006). This impact ranges from emotional and financial costs to stress and strain on the parental relationship. However, Dunn et al. (2001) asserted that families of children with autism have higher rates of dissatisfaction than families of children with other disabilities. Some
of the participants in the current study discussed what impact having a sibling with ASD have had on their family. Participants cited economic, as well as, social challenges and feelings of frustration and feelings of helplessness because of their inability to improve their siblings’ lives. Ava identified some of the struggles or challenges that accompanied having a sibling with ASD. She contended that, “It puts a strain on my parents’ relationship. My mom is constantly in meetings and [it’s] time consuming.” I observed her mother in the middle of her busyness. While conducting the interview, Ava’s mother had to leave to ensure her sibling’s schedule remained intact. Also, Jordan’s mother talked about the initial strain that was placed on her and her husband prior to the twins’ diagnosis of Asperger’s Syndrome. She discussed the differing opinions regarding the reasons behind the twins’ behaviors. Her husband thought more discipline would solve the bad behavior problems, whereas, she believed the twins had autism. Ava continued, “It’s hard sometimes. It would be nice for them to be normal for a day.” Chris stated, “It can cost more money, [takes more] effort, time, and patience.” Ella conveyed a similar point, “Having a sibling with ASD can present challenges, both economically- through expensive therapy bills, and socially- through the ignorance of others...”

While participants stated that there are some challenges that families face when they have a child with ASD, for them, the benefits seemed to outweigh the challenges. Some of the common benefits identified were a tight knit family, being more open-minded, being and more accepting. Ava addressed this benefit. “I think we are more open-minded, very giving, more involved family.” Chris concurred that, “[having a brother with autism] has made [us] better. It’s rare to have a family member with autism
and we embrace it.” Ella elucidated “I also know that encountering ASD in the way that we have has caused my family to be more open-minded and accepting of others' differences than many families are, and for this, I am almost grateful.” The impact of ASD on the sibling and family can be best summed up with Jordan’s comment, “My family and I were given a blessing and a curse, you just have to find the good in blessing and roll with the bad.”

Unique Findings

*Ella*

Family dynamics play an important role in families. These dynamics shape how siblings interact with one another. Ella is African American and her mother, both of her siblings and her maternal uncle with whom the family resides is Caucasian. This has impacted the relationship with her sister with Asperger’s Syndrome. Ella stated,

In the beginning we lived with [her] father, and he refused to accept the fact that [she] had Asperger’s. [He thought] that she does it to get attention...something like that. That’s why [my other sister] has always been the favorite...he never like me...so [my sister with Asperger’s Syndrome] and I just kind of banded together. I guess we have that bond for kind of being outsiders. We’ve always [had] trouble with life and I’ve just kept to myself, so that’s another reason that we’ve bonded together.

Research has shown that individuals with disabilities share similar experiences of prejudice, discrimination, and bias (Rubin & Roessler, 2001). Both Ella and her sister
with ASD experienced this and were able to relate to one another because of it according to Ella’s understanding of their shared experience as outsiders.

_Ava_

Again, family dynamics are important to family functioning. These dynamics can have both a positive and negative impact on the family. Ava informed the researcher that her father lives out of state due to his job. She indicated, “[Having a sibling with ASD] puts a strain on [my parent’s relationship]. Mom is constantly in meetings and is time consuming.” While the strain on her mother is evident, there are multiple variables that may add to her stress. Her father’s absence may play a vital role in the increased stress and strain her mother experiences. More research to explore how often this dynamic occurs and what impact, if any, it has on the children would be beneficial.

_Jordan_

Jordan’s perspective was unique because his siblings were twins. There is literature to discuss the likelihood of both twins having ASD if one is diagnosed. However, this researcher did not find any literature regarding if there is an amplified effect on the sibling because both siblings have ASD. This should be explored further to identify if specialized services are needed for these siblings.

_John_

John appeared to have more of a nonchalant attitude regarding his brother with PDD-NOS. He did not have feelings on one extreme or the other. He appeared to be fairly neutral regarding the topic. This may have been due to the closeness in age to his
brother. It could be that he has not begun to be aware of the differences that the other siblings acknowledged.

Chris

Chris was the only participant that discussed assisting in the discipline of their sibling. He stated that he has helped restrain his brother. Assisting in the formal discipline of siblings can shift the roles. Siblings who assist with this may feel more like a parent rather than a sibling. While it did not seem to, it would be interesting to explore if this has an impact on his view of his brother or the sibling relationship.

Discussion of Themes

The research question that was explored in this study was, “how does a diagnosis of Autism Spectrum Disorders impact the sibling relationship?” Four findings were identified and will be discussed below. The findings were: (a)”The hardest part of ASD is feeling absolutely helpless” (b) “That’s just the way our family is” (c) “Having a sibling with ASD has impacted my life for the better”, and (d) “It’s a blessing, and a curse.” All of these findings were found to impact the sibling relationship when a one of the siblings has been diagnosed with an ASD.

Theme1: “The hardest part of ASD is feeling absolutely helpless” describes sibling’s feelings of lack of control. This lack of control includes the inability to fix or change their sibling’s behavior, social interaction, or the way society views their sibling and family. Siblings express heartache over their powerlessness to help their siblings be normal and reduce the amount of stress and trouble with everyday activities such as homework. It is extremely difficult for siblings to sit back and watch their sibling
struggle with tasks and things such as spontaneity. Many of the participants wanted to offer assistance but do not know what type of support they can offer to alleviate the anxiety that their sibling feels.

In addition to the desire to ease the anxiety and frustration their siblings feel, participants also want their siblings to enjoy more activities. Participants talk about wanting their siblings to accompany them to sporting events, school activities and other places and feel helpless to achieve that. Siblings identified failed attempts to do so and feel discouraged. This reflects the traditional idea that sibling relationships include shared interests. Oftentimes siblings are able to engage in social activities together. In this study, they do interact, but are unable to engage in typical activities and this has caused some stress for participants.

Finally, siblings were extremely frustrated by society’s many misconceptions about Autism Spectrum Disorders. One source of frustration was the negative view people held about their siblings and their family. Siblings know that people made comments and held viewpoints that were contradictory to the truth. For instance, members of society think that their brother and sister are misbehaving, need more discipline, or uncontrollable. This is upsetting for siblings as they know these thoughts are inaccurate. Siblings express the desire to educate others about ASD, so that their sibling and family would not be unfairly judged, scrutinized, and criticized. This confirms the need for awareness about Autism Spectrum Disorders. Awareness is one of the best ways to help people change their negative viewpoints and evidentially improve the prejudice and discrimination individuals with ASD and their families encounter.
Siblings are able to see firsthand the attitudinal barriers their siblings face and that it improves the way they treat their sibling and ultimately relate to their sibling.

Parents recognized the challenges of attitudinal barriers on their children with disabilities. Their point of view is addressed in the literature (Pivik et al., 2002); however, the sibling’s perspective is not. Siblings in this study recognized the impact of attitudinal barriers on their siblings as well as their family unit. These obstacles actually enhanced the sibling relationship as it drew them closer to one another in order to overcome these hurdles.

Theme 2: “That’s just the way our family is” emphasized participants close relationships with their brother or sister with ASD and also stressed the lack of interaction with one another. Participants conveyed that they spent more time with their siblings, were more involved in their sibling’s lives, and were more protective of their siblings. This is commonly due to increased care responsibilities. Wolf et al. (1998) discussed that non-disabled siblings may have increased care responsibilities for their sibling with a disability. This research confirms this finding. Siblings may have to babysit their brother or sister or entertain them. This can be challenging if the typical sibling is not aware of the likes and dislikes of their brother or sister with ASD. A way to overcome this challenge for participants in this research was to discover mutually interesting tasks and leisure activities for their sibling with ASD and engage in those.

Children diagnosed with ASD have impairment with communication. Siblings recognized the communication deficits experienced by their brother or sister. In doing so, participants identified that their relationship is less quarrelsome. Some siblings do not
fight with their brother or sister because of the sibling’s inability to understand or communicate effectively. They felt as if the fight would be one-sided and see no point in that. Others stated that even when they do argue or fight it does not last long.

The literature contends that sibling conflict prepares siblings to resolve conflict with others (Brody, 1998). Since siblings of children with ASD in this research stated that they do not fight or fight less often, their conflict resolution skills may need further development. Siblings of children with ASD will have to practice their play, communication, and interaction skills with their peers.

Siblings of children with ASD are flexible. They have learned to be adaptive to the needs of their brother or sister with ASD and find appropriate activities to engage in. Wolf, Fisman, Ellison, and Freeman (1998) found that typical siblings were at an increased risk for poor peer relations and lower levels of participation in outside activities. However, this research did not support this finding. In fact, the siblings in this study were quite active and participated in a variety of school, and extracurricular activities. The researcher contends this was due to families being linked to appropriate resources and thus families spent less time trying to access these resources and had more time for recreation. Moreover, most of the siblings in this study were teenagers and less dependent upon their parents for care and transportation. This increased their freedom and ability to participate in activities outside of their home.

Siblings discussed how interactive and reciprocal their relationships were with their peers; however, this was not the same with their siblings. Most often participants engaged in activities that their siblings take pleasure in, not necessarily activities that they
would initiate. This is due to the restrictive and repetitive nature of the child with ASD. Participants, instead of participating in these activities with their sibling, they engaged in these hobbies, and interests with their peers. In essence, participants recognized the barriers to interacting with their sibling and identified ways to overcome them. In summary, siblings learned to be caring, protective, flexible, and understanding in their relationship with their brother or sister diagnosed with ASD. These acquired characteristics help them to feel closer with their sibling and lessen the likelihood of fighting with one another.

Theme 3: “Having a sibling with ASD has actually impacted my life for the better” discusses the positive influence that having a sibling with ASD has had on them and ultimately their sibling relationship. Siblings are more open, understanding, patient, and giving. Not only are these qualities beneficial to them in the sibling relationship, they are advantageous for all they encounter. Siblings confirmed that because of the social and communication impairments, they have to be more tolerant of differences and can empathize with others who experience disability within their family unit. Many participants indicated that without the increased responsibilities and care of their sibling, they would not be as patient or understanding. The literature is inconclusive regarding whether or not having a sibling with a disability has positive or negative outcomes (Bagenholm & Gillberg, 1991; Hastings, 2003; McHale, Sloan & Simeonsson, 1986). This study’s results indicated a positive impact on siblings.

In addition, having a sibling with ASD has had an effect on the family system. Many siblings stress the togetherness they feel as a family. Participants communicated
spending more time as a unit. They talked about having a bond due to understanding the daily struggles each member faced. This bond tied them together and pushes them to assist one another.

The improvements in character that siblings cited enhanced their interactions with their brother or sister and the overall family unit. This allowed for increased quality time together and positive feelings towards the sibling. Had siblings expressed negative attributes, the relationship would likely be impoverished and not flourishing as it was here.

Theme 4: “It’s a blessing and a curse” described the tumultuous feelings that siblings have regarding their siblings with ASD. Siblings clearly identified positive aspects to having a sibling with ASD. These included being more open to differences, more patient with people, and more understanding of diversity. Many participants recognized that there were positive aspects to having a sibling with ASD.

Also, siblings spoke to the challenges of having a brother or sister with ASD. Siblings cited financial strains, familial dissent, time constraints, and social stigma as common trials. This finding was consistent with the literature, but added the dimension of the sibling perspective on the impact of a family member with ASD from a phenomenological perspective. Turnbull and Turnbull (1997) discussed the financial challenges that families with children with disabilities encounter and the impact of the family system. Norton and Draw (1994) also cited the increased parental and sibling responsibilities as it related to caring for the child with a disability. Siblings talked about needing money for therapy and medications. There was increased stress when a family
member believed the child’s behavior was a result of lack of discipline and does not respect the child’s diagnosis. There can be discord when one of the parents does not have time for the other children, or the spouse.

While these trials were mentioned, none of the participants focused on these challenges for long. This seems to be supported in the literature. Naylor and Prescott (2004) found that siblings were hesitant to talk about negative feelings relating to their sibling with a disability. Many simply stated what they felt and moved on. It appeared that the benefits outweighed the disadvantages and siblings learned to adapt.

In summary, siblings of children with ASD have mixed emotions regarding their sibling and the impact on their relationship. Siblings cite numerous advantages to having a sibling with ASD, but also identified some disadvantages. While siblings were able to give a balanced viewpoint of the impact of ASD on their sibling relationship, it seems that overall the experience is positive and life changing. Overall, these four emergent findings captured the siblings’ perspective of the essence of having a sibling with ASD. The experience is like a journey with many twists and turns, but also with smooth patches along the way. The bumps in the road are similar to the bumps experienced when their sibling displays inappropriate or disruptive behavior. The smooth patches can be equated to the enhancement in personal characteristics, in the quality of the relationship with their sibling, and in the enrichment to their family unit. However, one cannot get to the smooth patches without encountering some of the rough spots. Siblings, while traveling on this journey, adapt to the bumps in the road, and learn how to go around or travel right over the barriers. Adaptation is essential to siblings who learn to be flexible with their time,
activities, and sense of normalcy. While this journey is tumultuous, it is also without destination. Siblings of children with ASD recognized that their brother or sister may never experience a “normal” life and the journey that they are on with them will last a lifetime.
CHAPTER 7: IMPLICATIONS AND RECOMMENDATIONS

Purpose

The purpose of this study was to understand from the sibling’s perspective the impact that Autism Spectrum Disorders has on the sibling relationship. The research question for this study was: How does ASD impact the sibling relationship? Interviews and observations were conducted with five siblings of children diagnosed with an ASD. The data was analyzed using phenomenological and systems theory lens and four themes emerged: “The hardest part of ASD is feeling absolutely helpless”, “That’s just the way our family is”, “Having a sibling with ASD has impacted my life for the better”, and “It’s a blessing and a curse.”

Theme 1: “The hardest part of ASD is feeling absolutely helpless” was related to siblings feeling helpless to assist their brother or sister become “normal” and to alleviate the attitudinal barriers faced by their sibling and family. Theme 2: “That’s just the way our family is” emerged from the siblings and family making adjustments to adapt to having a child with ASD. Theme 3: “Having a sibling with ASD has impacted my life for the better” materialized from the personal growth that siblings experienced as a result of having to become more mature and more responsible to assist with the care of their sibling with ASD. The final theme, “It’s a blessing and a curse” became apparent out of siblings discussion on the positive and challenging aspects of having a sibling with ASD. The information uncovered from the sibling perspective will help improve the identification of services for siblings, parents and families with children diagnosed with ASD. This chapter will discuss the implications for clinical work as well as make
recommendations for counselors working with families of children with ASD, and parents and siblings of children with ASD.

Implications for Clinical Work

This study highlights the adaptability of siblings of children with ASD. The participants in this study exhibited a selflessness that is not typical of adolescents. Many of the participants discussed the sacrificing of “normalcy” and changing their activities so they could include and engage their sibling with ASD. Some participants even gave up some of their free time to assist with the care of their sibling. This increased responsibility for their sibling is one way in which siblings relinquished some of their freedom. In addition, many talked about seeking out information in an effort to further understand the abilities and limitations of their brother or sister. This understanding of the characteristics of ASD helped the participants become more flexible and allowed them to be interactive and engaging with their sibling. As a result of having a sibling with increased needs, the participants, in this study, appeared to have a heightened awareness and understanding of compromise. They compromised their wants in order to help their sibling be more socialized. In sibling relationships, many times children barter or negotiate the play activities. However, in the relationships studied, the siblings with ASD drive the recreational activities. Siblings were also more in tune to their needs and to the needs of their brother and sister as well.

Participants in this study recognized that their relationship with their brother or sister was different than typical sibling relationship. Siblings identified that their relationships were less quarrelsome and they did not fight or argue much. Participants
with higher functioning siblings fought more than participants with lower functioning siblings. This is largely due to the fact that children with ASD may not understand the sarcasm or teasing put forth.

In addition to being compromising and selfless, siblings serve as educators to others about autism and the other disorders on the spectrum. Siblings educate their friends, classmates and others about ASD and how it impacts their siblings and their lives. This helps participants introduce ASD and their siblings to individuals outside of the family unit.

Siblings of children with ASD experience unintended benefits. One of the benefits is an enhanced sense of compassion, understanding and patience. Siblings are more compassionate to individuals with disabilities and less tolerant of jokes, teasing and discrimination directed at individuals with disabilities.

The first implication of this study is that families need information about ASD, resources and services to make informed decisions. Families who have children with a chronic illness or disability have increased stress and deal with complex situations. It is imperative that health care workers, counselors, social workers and other service providers recognize the need for support and information for these families. The knowledge that is helpful details the chronic illness or disability, appropriate services, and techniques for all of the children in the family, ways to address familial concerns or issues, and ways to balance it all (Jokinen & Brown, 2005; Seltzer, Floyd & Hindes, 2004; Soresi et al., 2006). This can be accommodated by counselors, and other service providers in a variety of ways. One way is to provide psychoeducational groups for
families and siblings of children with ASD. While this is an emerging concept, it’s important to ensure that a major component of the group is education about the disorders. This will answer some of the many questions regarding the sibling with ASD’s behavior. Moreover, it may assist with communication techniques that will ultimately enhance the relationship among the siblings and families.

Also, this research highlights the importance of operating from a family systems perspective. It confirms the idea that counselors and service providers should not be singularly or narrowly focused on the person with a disability or solely on the parents of that person, but should instead provide information and services to the entire family. The participants in this study discussed how the sibling with ASD not only impacted them personally, but also impacted their family unit. This qualitative phenomenological case study research underscores the importance of the family system approach because all members are impacted by disability. Furthermore, it is imperative for parents to get assistance to help them have the conversation with other children and family members about the disorder, its symptoms, and the impact it may have on the sibling relationship, the family unit and the parents. Literature speaks to how important this conversation is, yet the findings of this research suggest that this conversation is not occurring.

Specific support groups for siblings of children with ASD are needed. An important component of these groups should focus on activities and approaches that have been beneficial in building the sibling relationship. While each participant identified some activities that they are able to enjoy with their sibling, many also stated that their sibling relationship was less interactive as others they have witnessed. Discussing
approaches that have been positive for other siblings may provide ideas for them and eventually lead to an improved relationship with their sibling.

Based upon the implications that have been identified, specific recommendations for counselors, parents and siblings of children with ASD follow.

Recommendations for Counselors

- Identify effective and appropriate treatment interventions for siblings of children with disabilities. Information sessions and support groups have been shown to enhance children’s psychological state, their knowledge of disabilities, and their understanding of the family situation (Wamboldt & Wamboldt, 2000).

- Be knowledgeable about necessary and appropriate services for families of children with ASD and other disabilities.

- Empower families to make informed decisions about their child’s and their family’s care.

- Assist parents with the conversation with family members regarding the child’s disability and potential impact on the family.

Recommendations for Parents of Children with ASD

- Have a planned and purposeful conversation with your typical child(ren) about the disability, symptoms, and behaviors.

- Plan activities so that all members of the family are able to participate.

- Be open and available for your children to discuss concerns, and/or frustrations with you. Have planned time to spend with the typical child as well.
• Be knowledgeable about appropriate resources available to you, your children, and your family.

• Be an advocate for your family.

Recommendations for Siblings of Children with ASD

• Participate in a support group. This will allow you to discuss any concerns, fears, and frustrations with individuals who have similar experiences. In addition, this will allow you to gather information regarding activities that other siblings engage in with their brother or sister with ASD.

• Participate in extracurricular activities. This will allow you to maintain a sense of normalcy in your life.

• Seek out information regarding ASD. Ask your parents, teachers, or conduct your own research. This will help you understand the disorder, its characteristics and manifestations.

• Talk with your parent(s) about your needs, concerns, and feelings. This will assist your parents in making appropriate decisions for your family.

Recommendations for Future Research

While this study offers a glimpse of the impact that ASD has on the sibling relationship from the perspective of the sibling without ASD, more research is needed to understand the impact further. The research should continue to employ a qualitative methodology to allow for deep understanding of the sibling’s perspective. Four recommendations for future research came out of this study.
More research is needed to understand the impact that birth order has on the sibling’s perspective of the impact of ASD on the sibling relationship. A majority of the siblings in this study were the eldest and this may influence their perception of, and interaction with their sibling.

While there is significant research on the impact that having a child with a disability has on the parental relationship, future research should explore the impact that having a child diagnosed with an ASD has on the parental-typical child relationship. The research should be qualitative and be designed to gain an in-depth understanding of the relationship and the changes that may occur.

Finally, research is needed to identify how socioeconomic status impacts the family system of children diagnosed with an ASD. While this was not the focus of this research, the researcher observed the lifestyles of each family and observed how access to adequate resources benefited the family unit and ultimately the siblings. Moreover, additional research is need to understand what role race played in the acquisition of services which assists the family unit as well as the siblings and the many differences associated with rearing a child with an ASD.
REFERENCES


The following research study has been approved by the Institutional Review Board at Ohio University for the period listed below. This review was conducted through an expedited review procedure as defined in the federal regulations as Category(ies): 7.

Project Title: A Phenomenological Case Study of the Impact of Autism Spectrum Disorders on the Sibling Relationship

Primary Investigator: DeAnna Henderson
Co-Investigator(s): 

Faculty Advisor: Mona Robinson
(if applicable) 

Department: Counseling & Higher Education

Rebecca Cale, AAB, CIP 
Office of Research Compliance

Approval Date: 11/24/09
Expiration Date: 11/23/10

This approval is valid until expiration date listed above. If you wish to continue beyond expiration date, you must submit a periodic review application and obtain approval prior to continuation.

Adverse events must be reported to the IRB promptly, within 5 working days of the occurrence.

The approval remains in effect provided the study is conducted exactly as described in your application for review. Any additions or modifications to the project must be approved by the IRB (as an amendment) prior to implementation.
APPENDIX B: IRB AMENDMENT APPROVAL

The amendment, detailed below, and submitted for the following research study has been approved by the Institutional Review Board at Ohio University.

**Project:** A Phenomenological Case Study of the Impact of Autism Spectrum Disorders on the Sibling Relationship

**Amendment:** Change Age Range to 11 - 18; Change Sibling Age Difference to 5 years

**Primary Investigator** DeAnna Henderson

**Co-Investigator(s):**

**Advisor:** Mona Robinson

**Department:** Counseling & Higher Education

Rebecca G. Cale, AAB, CIP
Office of Research Compliance

**Protocol Expiration Date:** 11/23/2010

02/26/10 Date
APPENDIX C: CONSENT FORM

Ohio University Consent Form


Researchers: DeAnna Henderson

Your child is being asked to participate in research. For you to be able to decide whether you want your child to participate in this project, you should understand what the project is about, as well as the possible risks, and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used, and protected. Once you have read this form, and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study

This is a research study to understand the impact that Autism Spectrum Disorders (ASD) has on the sibling relationship. This study will utilize participants ages 12-18 who have a sibling with an ASD. The researcher will observe the interaction of the siblings, and family. This observation will be brief, 2-3 hours in length, and take place in your home. This observation will be documented with h, and written notes. Next, the researcher will ask questions of the sibling without ASD, and audio-record those questions, and answers. This will take approximately 1-2 hours.

Risks, and Discomforts

There is, however, minimal risk that sometimes, for some people, talking about relationships, and family can be upsetting. If this happens, your child can stop the interview or I can refer your child to receive help.

Benefits

The benefits of your child participating in the study are that your child might learn some new things about themselves, their sibling, and their relationship. In addition, your child’s participation in this study may help me, and others better understand how to help adolescents have an improved relationship with their siblings with Autism Spectrum Disorder, and to offer services to siblings of children with Autism Spectrum Disorder.
Confidentiality, and Records

Your child’s participation is voluntary, and will be kept confidential within the limitations of the law. The names that will be shared with the researcher will not be used in the written part of the study. All names will be fictitious (i.e. made-up).

The audio tapes will be destroyed approximately in June 2012 (2 years) after dissertation completion.

Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:
* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU;

Compensation
Each participant will be given a ticket to the Columbus Zoo. The ticket price (general admission-age 9, and over) is $11 child (ages 2-9) admission is $6.

Contact Information
If you have any questions regarding this study, please contact DeAnna Henderson at dh110007@ohio.edu or Mona Robinson at robinsoh@ohio.edu 614-352-9362.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

By signing below, you are agreeing that:

• you have read this consent form (or it has been read to you), and have been given the opportunity to ask questions
• Known risks to your child have been explained to your satisfaction.
• you understand Ohio University has no policy or plan to pay for any injuries your child might receive as a result of participating in this research protocol
• you are 18 years of age or older
• your child’s participation in this research is given voluntarily
• your child may change their mind, and stop participation at any time without penalty or loss of any benefits to which your child may otherwise be entitled.
You are invited to participate in a research study to understand the impact that Autism Spectrum Disorders (ASD) has on the sibling relationship. This research is being completed as a part of my program as a doctoral student at Ohio University.

I am asking you to participate because I believe that your ideas, and feelings about having a sibling with an Autism Spectrum Disorder would help me to better understand the impact that having a sibling with ASD has on the sibling relationship. The benefits of you participating in the study are that you might learn some new things about yourself, your sibling, and your relationship. In addition, your participation in this study may help me, and others better understand how to help siblings have an improved relationship with their siblings with Autism, and to offer services to siblings of children with Autism. There is, however, a risk that sometimes, for some people, talking about relationships, and family can be upsetting. If this happens, you can stop the interview or I can refer you to receive help.

I will be the only person (other than your family) who knows that you are participating in this study. Anytime I use the information you give me, I will always identify you with a fake name (if you like you can choose the name I use for you). When I interview you I would like your permission to tape-record our interviews, and also take notes to remind me about what we talked about. After I have finished with the study, all the tapes will be destroyed.

As a part of your participation in this study, I will spend time with you, and talk with you over the course of two weeks. I will first spend time with you, and your family observing the interaction. This means that I will watch you, and your family at your house, and take notes about what I see. This observation will last about 2-3 hours. Next I will talk with you by yourself, and ask you questions about you, and your sibling. This will take approximately 1 to 2 hours.

When the study is complete, I will give a ticket to all of the participants to the Columbus Zoo. This will be my way of saying thank you for participating in my study.

The most important thing for you to remember while you are participating in this study with me is that there is no right or wrong answers to the questions I ask you. All I am looking for is your opinion or ideas or feelings. If I ask you to tell me more, or explain your answer, it is because I want to be really sure I understand what you are telling me. Always remember that in this situation you are the expert, or teacher, and you are explaining to me what the relationship with your sibling with an Autism Spectrum Disorder is like for you.

You should also know that you can decide to not participate in this study or stop doing it at any time after you have started-this is your decision. You may decide to stop doing the study at any time without any penalty.

Please sign & date if you want to participate.