EFFECTS OF AUTISM SPECTRUM DISORDER:  
A CLOSER LOOK AT  
THE TYPICAL SIBLING  

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EFFECTS OF AUTISM SPECTRUM DISORDER:
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THE TYPICAL SIBLING

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Thesis

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CHAPTER I

THE IMPACT OF AUTISM SPECTRUM DISORDER ON THE FAMILY

In the USA and UK, at least one in ten children and young people have special health, developmental and mental health concerns (Conway, 2008). One in sixty-eight American children receive a diagnosis of Autism Spectrum Disorder (ASD) (Autism Speaks, 2014). ASD is a chronic congenital neurological condition which is characterized by abnormal or impaired development in social interaction and communication and a restricted repertoire of activity and interests (American Psychiatric Association, 2000).

The spectrum of complex deficits and behaviors that accompany a diagnosis of ASD comes with unique and diverse implications for that individual. These deficits manifest in early development and are pervasive in nature, affecting individuals throughout their lifespan (Karst & Van Hecke, 2012). Often families find themselves in a complex world of treatment and medical options and needs. While there are increasingly more options for treatments for children with ASD, options are still staggering for the family members of these children that are impacted everyday by a diagnosis of ASD.

The Ecological Systems Theory of Urie Bronfenbrenner will be applied to examine how a diagnosis of ASD impacts the family dynamic, with a focus on typically developing siblings. The Ecological Systems Theory maintains that the environment
affects a child’s development, and that there is reciprocity in the child’s effects on his or her surrounding environment (Bronfenbrenner, 1979). A child’s primary environment that influences development in the early stages is the family environment, and the sibling relationship is among the first peer relationship formed. The sibling relationship is therefore of increased importance in families with ASD.

The purpose of the current study is to gain insight into the needs of the typically developing siblings of individuals that receive a diagnosis of ASD. While it is understood that similarities may exist related to the needs of children in families facing challenging situations the current study focuses specifically on the challenges and implications that ASD presents. It is the belief within this study that not enough attention and support is given to children who may be struggling to understand and cope with the situation that their family is dealing with due to a diagnosis of ASD.

The current study aims to address the following questions: (1) Are there specific coping mechanisms that have been utilized to assist typically developing children within families with a child with ASD, and have these mechanisms built resiliency within the family unit? (2) What forms of support have been useful in assisting siblings of children with ASD? (3) What do the parents believe are the key factors in maintaining and strengthening positive relationships between siblings when one sibling has a diagnosis of ASD?

Evolution of the Study

The concept for this study has advanced throughout my studies and career. Working with children with ASD began as a supplemental form of employment for me. It
quickly became an area of interest and passion, instead of simply a job. While working in the field of ASD, it became clear that this diagnosis affects not only the individual, but also the entire family of the individual. This led me to become interested in the specific ways that children who did not have a diagnosis of ASD were affected by living with a brother or sister with this diagnosis. I began reviewing the literature that was available on how family members of children with autism are affected. This led to researching the evolution of sibling support groups that were put into place to provide assistance to siblings and family members of children with ASD. Without the previous knowledge that these forms of support existed, this became an area of particular interest to me.

Conway and Meyer (2008) described sibling support groups, known as “Sibshops,” that had begun in Europe and had grown into a popular model in the United States. Sibshops evolved from the idea known as “Sibling Group.” Dyson (1998) describes the principles behind this program designed for typically developing children living with a sibling with a developmental disability. Within this program, children were afforded opportunities to interact with peers who were living in the same situations as themselves, and were able to learn more about their brother’s or sister’s disability through the assistance of professionals in the community, including counselors, social workers, or psychologists (Dyson, 1998).

The philosophy of “Sibshops,” described by Conway and Meyer (2008), incorporated the concept of providing a safe and enjoyable atmosphere for school-aged children to cope with their living situation of having a sibling with a disability. Gaining insight into these groups, formed specifically for school-aged to adolescent children,
brought up many questions for me regarding how many parents were familiar with this form of support for their children. This also led to the additional questions of whether or not parents are inclined to use this method of providing assistance to their children in coping with a difficult situation to understand and live with. If parents were not utilizing a method of a support group for their children, I was interested to learn which methods parents have applied to assist their typically developing children to cope effectively. The question still remains how parents have worked to build resiliency within their family when faced with the difficult situation of living with Autism Spectrum Disorder.

**Overview of Chapters**

The chapters that follow will describe the rationale, methods, results, and implications of this project. Chapter Two will focus on research literature regarding siblings’ perceptions of having a family member with ASD, as well as evaluations of programs that have been created to assist these children. Urie Bronfenbrenner’s (1979) Ecological Systems Theory on human development will be used as the theoretical foundation for this project, and a theoretical lens through which research results and resulting programming can be best understood. Chapter Three will discuss the research methods used in this project, providing a detailed description of the process of sampling, interviewing, and data collection. Chapter Four will describe my approach to analysis, as well as a summary of potential strengths and limitations to the project.
CHAPTER II
REVIEW OF LITERATURE

The following chapter discusses the complex characteristics that accompany a diagnosis of Autism Spectrum Disorder and the significance that this diagnosis has on other family members with a focus on siblings. Literature examining the relationships of typically developing siblings was reviewed to gain a better understanding of the significance of the sibling relationship within a family with a diagnosis of Autism Spectrum Disorder. Urie Bronfenbrenner’s Ecological Systems Theory is used to provide an explanation for the multiple impacts that a diagnosis of ASD can have on typically developing siblings in families.

Effects of Autism Spectrum Disorder

The early months and years of life are critical in human development according to Bronfenbrenner (1994), as this is when the process of progressively more complex reciprocal interactions between an individual and the persons, objects, and symbols in one’s immediate environment begin to shape development. A child that is growing up with a sibling with ASD will experience a very unique situation in his or her early life.

Autism Spectrum Disorder is a complex disability that has left many physicians and researchers with lingering questions regarding the origins and treatments for the
disability. There are several aspects of this puzzling and challenging range of disabilities that can make it very difficult at times for a family to function optimally and meet the needs of all its members. No one behavior or category of behaviors is diagnostic of ASD and instead it is the pattern or profile of symptoms that defines the condition (Carrington, et al., 2014). It is considered a heterogeneous condition, and although difficulties fall into core domains that are reliably measured and usually consistent across time, no two individuals will ever have the same behaviors (Lord et al., 2000).

Significant characteristics of ASD include serious difficulties with the social use of language, along with impaired social functioning and ritualistic/repetitive behaviors (American Psychiatric Association, 2000). Deficits in social behaviors, including difficulties in the use of eye contact, facial expression, and social motivation, contribute to the complexity of forming relationships for an individual with ASD (Lord, et al., 2000).

Carrington et al. (2014) examined the distinguishing characteristics of Autism Spectrum Disorder as identified in the DSM-5. An essential item identified for diagnosis includes deficits in social-communication behaviors, particularly those related to social-emotional reciprocity. Deficits in the area of social-communication have significant effects on a child’s ability to form meaningful relationships with peers, which can transcend into the sibling relationship due to siblings often being similar in age groups. The sibling relationship is among some of the most important in an individual’s life since, unlike parent-child relationships, sibling relationships are not predictably
terminated by the death of one party while the other is still relatively young. Sibling relationships often last an entire lifetime (Lamb, 2014, p. 4). The significance of this relationship raises the questions of the implications of a diagnosis of ASD to the overall development of the relationship.

**Research on Sibling Relationships**

Research on the relationships between siblings in families of children with disabilities began with studies such as McHale and Gamble’s (1989), which compared siblings with disabled brothers and sisters, as well as nondisabled brothers and sisters. This research found that in many cases of siblings of disabled brothers and sisters, the typically developing children reported more time in caregiving activities than children without disabled siblings engaging in sibling activities. The additional household and caregiving responsibilities were found to be associated with negative experiences with their mothers (McHale & Gamble, 1989). Rodrigue et al. (1993) compared siblings of children with ASD to siblings of children with Down Syndrome or normal development siblings and found that having a sibling with ASD did not differ significantly on measures of self-competence or social competence.

Research has continued to evolve on the subject over the years as more information related to ASD became available. The relationships among siblings continued to be examined with Kaminsky and Dewey (2001) examining sibling relationships and comparing the findings of children with ASD to typically developing siblings. They found that siblings of children with ASD reported lower levels of
intimacy, pro-social behavior, and nurturance by their sibling compared to typically
strategies in siblings of children with ASD. Within this study they found that the
participating siblings predominantly struggled with internalizing difficulties, such as
dealing with aggressive behaviors with their sibling with ASD. Participants reported that
coping strategies such as “emotional regulation” and “wishful thinking” were common in
dealing with the difficulties of their relationships with their siblings with a diagnosis of
ASD.

**Theoretical Rationale**

Most of the research on Autism Spectrum Disorder (ASD) has centered on the
affected child, and focuses on assessments and treatment options for that child (Volkmar
et al., 2014). Autism Spectrum Disorder, however, is a condition that has ripple effects
throughout the family system. Thus, more recent research also examines the impact
Autism has on caregivers (Rivers & Stoneman, 2003) and other family members, such as
siblings (Hastings, 2003). Rivers and Stoneman (2003) found that a diagnosis of ASD
often led to higher levels of marital stress with parents and other caregivers. In this study
when marital stress was higher, typically developing siblings reported less satisfaction
with the sibling relationship, as well as more negative behaviors and fewer positive
behaviors directed by them toward their siblings with ASD. Hastings (2003) identified
the role of social support in families with children with ASD. In this study the impacts on
behavioral adjustments for the typically developing children were identified, as reported
by the mothers of the children. The study found that formal social support moderated the impact of the severity of symptoms of child with ASD on their siblings’ adjustment.

The attention to siblings is especially critical to understand, since some have expressed concerns that caregivers have finite time and resources to expend on caregiving, and therefore some siblings may be getting relatively less attention due having a relatively high-need sibling in the family. Siblings may, the logic goes, have unmet developmental needs, as the stress of parenting a child with ASD may make caregivers less available or responsive to typically developing offspring (Kaminski & Dewey, 2001).

The Ecological Systems Theory of Urie Bronfenbrenner (1977) can be beneficial in explaining the family dynamic of families who have a child with ASD, and the potential impact of the family system on typically developing siblings. The Ecological Systems Theory maintains that the environment affects a child’s development, and that there is reciprocity in the child’s effects on his or her surrounding environment (Bronfenbrenner, 1979). A child develops within multiple and interacting contexts, all of which exert a bidirectional impact on the child’s life. That is to say the child impacts his immediate environments, and those environments influence each other, to create a dynamic system of interacting elements (Bronfenbrenner, 1979).

Bronfenbrenner argued against the over-reliance on laboratory based research that completely divorced developmental outcomes from any natural context. He believed in and advocated for research to be conducted in naturalistic settings in order to better understand how development happens in “real life,” not just in the lab. He contended that
“the understanding of human development demands going beyond the direct observation of behavior on the part of one or two persons in the same place; it requires examination of multi-person systems of interaction not limited to a single setting and must take into account aspects of the environment beyond the immediate situation containing the subject (Bronfenbrenner, 1977, p. 514).”

Bronfenbrenner’s Ecological Systems Theory explains the different layers of environmental influence, or systems, that affect a child’s development (Bronfenbrenner, 1979). The primary system that a child is surrounded by is known as their microsystem. This includes individuals that the child interacts with the most often. In early years of life, the family is typically the primary environmental influence on a child. When a child is living in an environment with a sibling with ASD, this will likely influence the child in distinct ways. Research suggests that living with a brother or sister with a developmental disability such as ASD can leave a child with feelings of confusion, isolation, and frustration (Conway & Meyer, 2008).

Due to the fact that living with a sibling with ASD affects multiple environments of a child’s life, Bronfenbrenner’s Ecological Systems Theory can be employed to assist in explaining the numerous ways that a child is affected, as well as the various ways that these environments can be incorporated into methods of intervention. Bronfenbrenner’s theory acknowledges that the environment influences a child’s behaviors, while the child also plays a role in influencing his or her surrounding environment (Brendtro, 2006). This idea applies to relationships with others, as well as the behaviors and ideas that the child forms. This theory also focuses on the importance of changes over time with regard to an
individual’s development, rather than the importance of single and isolated events in an individual’s life (Bendtro, 2006).

The microsystem is the complex of relations between the developing person and environment in an immediate setting containing that person (Bronfenbrenner, 1977). In her discussion of resilience in childhood, Walsh (2004) discussed the importance of home and family as a microsystem, particularly in the early years of life. The situation at home could have many effects on a child’s development depending on the home situation, including whether or not there are two parents living in the household, the number of siblings, or the number of extended family members.

The relationships that children encounter among major settings outside of a child’s microsystem are known as the “mesosytem” according to Bronfenbrenner (1977). The way that a child’s family and life at home interact with other familiar settings such as peer groups and school, affect the child’s mesosystem. Children may miss out on typical activities with peers due to the demands presented by their brother or sister with a disability. Children also may have difficulties forming peer relationships due to feelings of embarrassment from their sibling and home life (Sage & Jegatheesan, 2010), or feelings that other children do not understand the situation that they are living in, causing feelings of isolation (Conway & Meyer, 2008).

Bronfenbrenner’s concept of the exosystem is also incorporated into Sibshops through the knowledge and assistance of professionals related to the fields of ASD and Child and Family Development. The exosystem comprises the linkages and processes taking place between two or more settings, at least one of which does not contain the
developing person, but in which events occur that indirectly influence processes within the immediate setting in which the developing person lives (Bronfenbrenner, 1977). In the setting of “Sibshops” professional assistance can be carried over into the home environment for children.

**Relevance to Child and Family Development**

Over the years, the number of children diagnosed with a disability has increased, and therefore Carpenter (2005) focused his research on what was needed to provide early-intervention programs that could lessen the impact of the disability on the family in the greatest way possible. The importance of incorporating all family members into early intervention processes and ensuring that each member feels valued and acknowledged was discussed as beneficial measures for early intervention programs. Carpenter (2005) looked at the development of programs that focus on early intervention. He found that interventions that use a trans-disciplinary method need to focus on family-centered approaches that are more responsive to the specific context for the individual family.

Karst and Van Hecke (2012) demonstrated the significance of the reciprocity of the impact on development that family members have when they proposed a model for interventions for individuals with ASD. This model proposed an intervention strategy that is transactional, and considers both the direct impact of intervention on the family, parents, and child with ASD, and takes into account how changes in each of these domains affect one another (Karst & Van Hecke, 2012). This research stresses the impact that each of the family domains has on one another, and therefore demonstrates the
importance of understanding how the home environment affects siblings without a diagnosis of ASD.

This research on successful models for early intervention programs may be of use when designing programs used to assist typically developing siblings. Increasing numbers of early intervention programs have been researched and created for varying family needs, including the needs of families with multiple children when one child has a diagnosis of ASD.

Research that has focused on how children deal with having a sibling with a disability such as ASD can assist in revealing how to best assist these children. With the increase in the numbers of children with diagnoses of a developmental disability, it is important to understand how to best assist these families in dealing with these situations. In the current study, the typically developing children in a family are the focus of the family unit. It is important to understand how these members of the family can best be assisted, and how support can be provided to the entire family.

**Shifting the Focus to Siblings**

Research on intervention strategies for children with ASD has identified the importance of the incorporation of family members (Karst & Van Hecke, 2012). The incorporation of siblings into intervention strategies has focused on the benefits for not only the child with ASD, but for the typically developing sibling as well. Shivers and Plavnick (2014) conducted a review of existing literature on intervention groups that included siblings, and found positive changes in the studies that reported on sibling relationships. Methods of intervention for the pairs of siblings may include the typically
developing sibling facilitating learning strategies through modeling or teaching skills (Shivers & Plavnick, 2014), or sibling play intervention may be beneficial (Tsao et al., 2012). Play intervention allows for the typically developing sibling to interact with the sibling with ASD in a preferred activity of the sibling’s, while being facilitated by an intervention specialist and parents. The key to success for this form of intervention requires taking the sibling’s motivation into consideration, and then creating play sessions with specific objectives for both children (Tsao et al. 2012).

The Development of Sibling Support Groups

To investigate the possible implications for peer relationships, research has focused on how children living in these situations can best be supported. Research on this particular mode of intervention began with programs known as Sibling Groups (Dyson, 1998). This program acknowledged the need for an intervention program designed for school-aged children who were in need of peer support, with an area to openly express feelings, as well as to gain coping strategies from professionals in the field on how to deal with having a sibling with a disability. This original form of intervention led to groups that met one day a week for two hours, and consisted of siblings of children with disabilities taking part in activities such as arts and crafts that provided interactions with peers that were in similar situations. It provided a time for learning and discussing siblings’ disabilities and sharing of experiences, and other recreational and social times (Dyson, 1998). This model incorporated the utilization of the child’s network of peers, through a supported environment that provided opportunities to learn through play and interact with others who experience similar lifestyles in the home. Children did report
positive outcomes from the experience; however, the model described in the current study did not incorporate the siblings with ASD or other close family members in the siblings’ lives.

Researchers have continued to analyze the effectiveness of sibling support groups. Smith and Perry (2005) organized a sibling support group for siblings of children with ASD, and found that siblings participating in the group reported a greater knowledge of ASD and better self-concepts at the conclusion of the eight-week session. It is the belief that sibling support groups providing opportunities for siblings to express their feelings in a structured environment are crucial for coping and dealing with their unique situations (Tsao et al., 2012).

Sibshops

One well-documented program for supporting siblings is Sibshops (Conway & Meyer, 2008). The importance of incorporating the multiple environments that a child interacts with regularly is promoted in the Sibshop model of sibling support. This program incorporates the important aspect of utilizing peer support in the assistance of siblings of children with disabilities, particularly those with a diagnosis of ASD. Fulfilling this need for children can positively affect other domains of their lives. At Sibshop groups, children can create distinct relationships with peers who are fully empathetic to the situation that they are living in, and can share in the frustrations, disappointments, or happiness and excitement that may accompany having a sibling with
autism. With the gaining of peer support, children are able to look at these programs as events that they look forward to attending (Conway & Meyer, 2008).

This model also continues to focus on the importance of providing children with information about their siblings’ disability, as well as providing them with information on how to best assist their sibling provided by professionals from the community. It is important for the children to receive information from community members and professionals who are trained in the area specific to their sibling’s condition. This also allows the child to gain information about the concerns and opportunities that are frequently experienced by other siblings of people with special needs (Conway & Meyer, 2008). This important quality within the Sibshop model assists the children in gaining feelings that they are not alone in their situations. At Sibshops, children learn information about coping strategies that have been successful for others, and that could be applicable to their own situation. Thus, multiple systems of both peer and family social systems are used by children in the development of their own coping strategies. Programs that incorporate helpful information and strategies to assist siblings and maintain healthy relationships within families are extremely important in building resiliency within the child.

Finally, the Sibshop program is very beneficial to young siblings of children with disabilities in that it incorporates the people who are within the social setting that is closest to their everyday lives. The parents and family members play extremely important roles in assisting children to cope with the difficult situations that they find themselves in, and in exploring the tools and resources to assist them. Parents are a key part of the
Sibshop program (Conway & Meyer, 2008). Not only is it important for typically developing children to understand that they have the support of their parents, but it is also important that the parents are able to understand their children’s needs, and how they can best assist their typically developing children. As professionals explore the ways that siblings can improve the relationships between the typically developing child and the child diagnosed with a disability in the family, the parents can assist in continuing to foster and develop these relationships in the home. This provides support for the child, explained in the Exosystem with the Ecological Systems Theory (Bronfenbrenner, 1979), through the interaction of two settings in which at least one does not contain the developing person, but in which events occur that indirectly influence processes within the immediate setting in which the person lives.

This current study focuses on an area related to ASD that has not received significant attention. Research on children with ASD has focused primarily on the individuals that receive the diagnosis, without adequate examination the immediate family members surrounding the child. The earliest years of life are the most crucial to a child’s development, and the available literature suggests that having a brother or sister with a diagnosis of ASD can affect a typically developing sibling in crucial ways. Research has focused on siblings’ perceptions of their brother or sister with autism, but often fails to identify how siblings have been assisted in dealing with stress, lack of attention, negative perceptions, or even how positive perceptions of siblings may have been formed.
In the proposed study, it was hypothesized that families that have participated in sibling support groups will report that their children are having an easier time coping with the situation of having a brother or sister with ASD when compared to a matched sample of families that have reported that they have not engaged in any community resources specifically targeted to their typically developing children. The reasoning for this hypothesis include the fact that community resources have been able to provide children with information regarding their sibling’s diagnosis so that the children are able to better understand the reasons for their siblings’ actions and what that sibling is going through. Sibling groups have been able to provide children with this information in a way that is easier for the children to understand, and easier to apply to their own situations. These groups also afford opportunities for the siblings to learn ways to positively interact with each other, and at the same time provide opportunities for the siblings to have time to spend time alone with their parents, which they may not regularly get to do. All of these reasons lead to the hypothesis that families that have participated in these sibling groups will report children that are better adjusted to the family’s situation. For families that report that they have not participated in these sibling groups as a resource, then any methods or resources that the family have engaged will be identified. Other coping mechanisms believed to be successful by the family will be identified through the discussion of alternate resources.
CHAPTER III
METHOD OF INQUIRY

Participants

The sample size for the current study was five parents who have a child with a diagnosis of ASD, and at least one other child who is typically developing with no known disabilities. Both children fell within the school-age group, ranging from ages 7 to 17. Participants were recruited through the assistance of mothers of children with ASD that I have pre-existing relationships with. I have worked closely with the children of both of the mothers assisting me and have provided tutoring services to their children in their home. Both mothers have a child with ASD and have at least one other typically developing child. They are both very involved with other parents in the ASD community, and used these connections to assist me in finding participants that met my criteria for the current study.

The goal for the current study was to involve both parents in the interview process in order to allow for the possibility of a broader viewpoint coming from the parents in combination. For all of the participants, only the mothers were available to be interviewed, and therefore the responses come from the viewpoints of one parent. All interviews were conducted individually. Three of the five interviews were conducted in
the family home, while the other two interviews were conducted in a location agreed upon by the participant and interviewer. A brief description of each participant will be provided in the following paragraphs. All participants and their responses are described using pseudonyms for the privacy of the families.

Ashley

The first participant was married and had two children, both male. The sibling with a diagnosis of ASD, David, was 11 years old, while the typically developing sibling, Tyler, was 12 years old. Ashley described Tyler’s experience of being in school with David as mostly negative, due to the regression that had occurred with David at the time they were attending elementary school together. The siblings currently do not attend school together.

Kathy

The next participant was also married and had two children. This family represented one of the two families interviewed with a “typical” female sibling. The sibling with a diagnosis of ASD, Dylan, was 10 years old, and the typically developing sibling, Erica, was 11 years old. Erica and Dylan attended pre-school classes together, but were not attending the same school at the time of the interview. Kathy described her children’s relationship as positive and constantly changing, based on the needs of Dylan. When describing their relationship she explained, “we all evolve with Autism, she has to evolve as a sibling whether she wants to or not.”

Kelly
This participant was married and had three children. The sibling with the diagnosis of ASD, Tommy, was 17 years old and male, and has a twin brother, Tanner, who is typically developing. The third sibling in the family, DJ, was 15 years old and male as well. Since both of the typical siblings fell within the age range for the current study, both siblings were discussed throughout the interview. Tanner and DJ do not attend the same school as Tommy; however all of the brothers did attend school together for a brief time during the pre-school years.

Linda

The next participant represented the only family involved in the study in which the parents were divorced. The sibling with a diagnosis of ASD, Alex, was 15 years old and male, and his sister Katie was 13 years old. Alex and Katie attended an integrated pre-school together initially, but do not currently attend the same school. Linda described the sibling relationship as growing more distant over the years as it became more difficult for the siblings to find commonalities.

Jill

The final participant in the study was married and had three male children. The sibling with a diagnosis of ASD, George, was 8 years old, and had a 10 year old brother, Anthony, as well as a 5 year old brother, Henry. The responses from the interview included in the current study focused on the experience of the 10 year old brother, Anthony, who fell within the age range requirements. George represented the only child in the interview process that attends a public school. Currently George and Anthony
attend school together. Jill described multiple structured activities that the siblings all participate in together, including “Tae-Kwon-Do” classes and summer sports camps.

Methods

Five families with a child with ASD as well as a typically developing child that were willing to meet with me and participate in the study were contacted. A questionnaire was formulated for use with the interview process, which was based upon the findings of previous research relating to the topic, as well as finding answers geared towards the research questions within the study. The questionnaire consisted of approximately 26 questions (see Appendix A) that refer to the parents’ experience of how the typically developing children in the family have adjusted to having a sibling with ASD, and the coping mechanisms that have been employed to assist the children. The questions assisted in discovering if parents have taken any steps in the past to strengthen relationships between siblings such as taking them to support groups, or having any form of assistance, such as behavior specialists, come into the home to facilitate activities between the siblings.

Based on the availability of each of the participants, I met with each participant individually to complete the interview process. Three of the interviews were conducted in family homes, while the other two interviews were conducted in public locations chosen by the parents. All of the interviews were conducted with the mothers of the siblings, only due to the fathers work schedules. Open-ended, semi-structured interviews were
conducted with each participant, allowing the researcher to gain more personal insight into the individual experiences of the families and sets of siblings in the study. The interviews were recorded using a voice recorder, and were saved for transcribing.

Interpretative Phenomenological Analysis (Smith & Osborn, 2003) was employed in the interview process. It explores in detail how participants are making sense of their personal and social world. This is done through detailed examinations of the participants’ life and is concerned with an individual’s personal perception or account of events, as opposed to producing objective statements of the events.

Qualitative research methods through the use of semi-structured interviews allows for the participants to feel more comfortable and open, which results in better, more detailed responses. Creswell (1998) defined qualitative research as a “process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem whereby the researcher builds a complex, holistic picture, analyzes words, and reports detailed views of informants” (p. 15). Also, qualitative inquiry “is focused on discovery, insight, and understanding from the perspectives of those being studied” (Merriam, 1998, p. 1). Phenomenology is a qualitative method that gives descriptions from the perceptions and experiences of the participants (Kvale & Brinkmann, 2009). The use of Interpretative Phenomenological Analysis was preferable in the current study because this method allows for in depth examinations of participants’ accounts within small, homogenous samples (Smith & Osborn, 2003).
Analysis

The analytical process begins during review of many cases of qualitative research (Pope et al., 2000). As Pope et al. (2000) describes, the analytical process begins during data collection as the data already gathered may shape the ongoing data collection. As interviews were conducted, the data of participants’ responses constantly affected the analytical process, which allowed for themes to begin to emerge in the interview process, and continued to develop throughout the project.

All interviews in the current study were audio recorded and transcribed. The transcriptions were broken down into specific categories that the parents brought up in the conversations. The method of “coding” was used to separate the responses into categories. Through the process of coding, the researcher fractures the data and organizes it by the ideas contained within (Jacelon & O’Dell, 2005). Through this process themes emerged from each of the parents’ responses, including discussions of the sibling relationship, qualities observed by the parents as being demonstrated by the typical sibling, and coping strategies and useful methods employed to assist the siblings.

As categories and themes were discovered through the process of coding, the data was then examined and identified within the categories with a process called constant comparison (Pope et al., 2000). This process involved checking and comparing the rest of the data to determine which category each of the parts of data fell into. This method was useful in the current study due to the process of conducting open-ended interviews, which allowed the parents’ ample room for discussing and elaborating on the topics that were
most relevant to their families’ experiences. Topics within each parents’ discussion were identified to determine the patterns of shared experiences among the families.

Pope et al. (2000) also discusses a five-stage framework for data analysis, which was used in the current study. The first stage is “familiarization,” which is the initial immersion into the data to locate recurrent themes. In the current study, the recurrent themes observed throughout the responses involved the topics of sibling relationships, qualities of the siblings, and coping strategies and alternate methods.

The next stage is “identifying a thematic framework.” Within this stage, the objectives of the study were focused on, and the concepts and themes identified from the responses were incorporated into developing the overall framework and outcomes of the study. “Indexing” was incorporated to assist in developing the framework, which was completed in the current study by numerically identifying the themes and sections of information.

All of the data were then re-organized based upon the themes they fell under, using a process known as “charting.” This allowed for a better understanding of the differences of views and experiences in the responses received, and it also provided concise direction for organizing the data to provide responses to the original research questions. Finally, the associations between themes were identified and used to provide explanations for the findings of the research through the process of “mapping and interpretation.”
Limitations of the Study

The recruitment methods and sample characteristics make it impossible to generalize the results of this study to a larger population. The data in the current study were collected from a very small sample size of five families. These convenience samples were recruited from the same geographic area. All of the participants were middle class, Caucasian families. All participants came from similar educational backgrounds. Although the research was limited to the perspectives of five participants, the objective of the current study was to gain an in-depth look at the experiences of these families, with the purpose of generating hypotheses to guide future, larger-scale studies with randomly selected samples.

Another limitation of the current study was the variability in the functioning level of the children with ASD, and how this impacts the relationships with the other siblings in the family. Based on the small sample size, it was not possible to determine whether or to what degree the differing functioning levels of the children with ASD may have affected the experiences of the siblings, parental expectations, or the overall quality of the sibling relationship. Future studies should control for level of functioning to better account for how this variable may contribute to observed outcomes.
CHAPTER IV
RESULTS

The chapter discusses the unique implications facing a child living in an environment with a brother or sister with Autism Spectrum Disorder. The following chapter addresses the original research questions (1) Are there specific coping mechanisms that have been utilized to assist typically developing children within families with a child with ASD, and have these mechanisms built resiliency within the family unit? (2) What forms of support have been useful in assisting siblings of children with ASD? (3) What do the parents feel are the key factors in maintaining and strengthening positive relationships between siblings when one sibling has a diagnosis of ASD?

The results of the study will be discussed with in light of positive and negative effects on the typically developing sibling, according to the parental interviews. Three themes have emerged from the participants’ responses: the sibling relationship, qualities of the typical siblings, and coping strategies. Data that led to these themes will be described in detail in this chapter.

The Sibling Relationship

The majority of the participants’ viewed the relationship between siblings as a positive relationship, yet often a challenging relationship. Most of the mothers described their children as attempting to find commonalities with the diagnosed sibling through
shared interests, such as video games. When asked about the sibling relationship, the majority of the participants referred to the fact that the typical siblings did not know anything different outside of a life with ASD. Kathy described Erica’s view of Dylan as very matter-of-fact, “That’s just my brother. He just has Autism.” Ashley also described the fact that Tyler has never known anything different:

I think it’s harder for Tyler than a kid that has many years between you and your sibling. Because they’re so close in age Tyler has just always grown up with it, he’s never known anything else.

Two of the five mothers interviewed described the sibling relationship as currently being “distant” or “negative,” and described the sibling relationship as more positive in the younger years than at the time of the interview. Linda described the changing relationship between her two children:

When she was younger, she embraced it a little more, a little differently, she was the big sister in her mind and rallied for him. I think as she got older and as his chronological age and developmental age widened, it’s harder for her to relate anymore.

Ashley explained her viewpoint on Tyler’s feelings towards his relationship with Dave:

I think when he was younger it was more frustration and I think he’s really sad that his brother has to go through this. I think he mourns the loss that he doesn’t have a typical brother.

Kathy also stated that previously she “pictured Erica to feel more like an only child more than anything else, and that Dylan just happened to be in the house.”

Many of the typical siblings were described as being “cheerleaders” for their sibling, and as taking joy in the successes that they watched their sibling accomplish. Kelly described:
Tanner and DJ are really thrilled when Tommy’s doing something great. When he’s doing something out of the ordinary or something he wouldn’t typically do, everybody’s like, come here you’ve got to see this. So I think they share in his success a lot.

Kathy described Erica as being a cheerleader for Dylan, “she gets excited when he gets something.” She also described Erica as being more of a “defender” of Dylan:

I’ve seen instances where maybe a cousins giving him a little bit of a hard time and she’ll be like, nope you’re not gonna do that, he’s gonna play.

Incorporating siblings into everyday functions such as learning social skills through guided play also seemed to foster positive relationships among the children described in the study. Participants described the importance of the time that the siblings spent together, from unstructured activities such as watching television together, to structured activities that the typical siblings are able to provide peer modeling for. Ashley described activities that Tyler and Dave participate in together:

Now a level playing field for them is video games. Dave will say, Tyler come watch this video! And Tyler will sit down next to him and they’ll bond that way.

Kelly also described the use of electronics as a means of bringing the siblings together, “They hang out more, they’ll have the I-Pad and play Tommy’s bowling game with him.”

Jill described the structured activities her children participated in such as tae-kwon-do classes or structured times of playing games facilitated by an in-home aide or therapist. When referring to the role of Anthony she explained:

We really say to him, you are your brother’s best therapist, so I think the praise has really helped Anthony feel special.

Even when the parents described the quality of the sibling relationship as “positive” overall, all of the participants still discussed challenges that accompany the
sibling relationship. The difficulties with social reciprocity that accompany a diagnosis of ASD were discussed as a challenge within the sibling relationship. Ashley explained,

> It can’t be easy when your only sibling has special needs and can’t interact with you the way you would like to interact. They can’t have that typical sibling relationship, especially when it’s only two of them, Tyler doesn’t have anybody else to go.

The participants all discussed the challenge of being “fair” between the siblings, and this aspect causing feelings of anger or resentment in the typically developing sibling. All of the parents described instances where the typically developing sibling did not receive the same treatment as their sibling with ASD. In some cases this included the amount of chores expected to be completed in the home, or the amount of time that each child is permitted to play electronic games. Kathy stated, “Dylan lives in a different world than Erica does. It’s not fair, but it is what it is.”

**Qualities demonstrated in siblings**

As the families discussed the unique qualities accompanying the sibling relationship, this led to the discussion of the personal qualities that the typical siblings exhibited, which often were believed by the parents to be unique to siblings of children with ASD. All but one of the participants discussed their children being more independent at younger ages. As the majority of the attention from parents is often forced to be focused on the child with ASD, the participants discussed their observations that their other children learned to do things and care for themselves quickly in life. Linda described Katie as extremely independent, even when she was very young. Due to the high needs that her brother required, she had to learn to vocalize her needs very quickly,
and had to contribute what was presumed to be more than kids her age when she was younger.

The majority of the parents’ interviewed also described their typical child as being more sensitive and accepting of other individuals with disabilities. Two of the five mothers gave specific examples of their children standing up to bullies at school picking on other kids, and also befriending kids at school with special needs. One of the most unique examples came from Kelly:

There was a kid with special needs helping to manage the basketball team, and this kid was savvy enough to want his picture taken with the cheerleaders. We see the kid get off the bench and go stand to get a selfie with the cheerleaders and he immediately looks to Tanner, who immediately smiles and gives him the thumbs up, so I just think they’re much more compassionate people.

The parents believed that the exposure to having a sibling with ASD gave their children a more open-minded view of the differences in people, and they all felt that this was a positive quality that their children would maintain throughout their lives.

Qualities observed in the siblings also exposed some of the ways that the siblings viewed their roles with their brother with ASD. Many of the typical siblings were described as being a “protector” or “caretaker” of their sibling. Linda discussed Katie’s role with Alex:

She’s the first to tell on a babysitter if she doesn’t like what they’re doing with him. I know she has it in her head to watch over him if we’re not there kind of thing.

While all of the parents stated that they did not want their typical children to have the responsibility of being caretaker for their other children, the majority of the parents felt
that if it were needed, the typical siblings would assist in caretaking roles. Kelly explained that DJ had expressed his vision of his future role with Tommy:

DJ has said, well he’ll come live with me someday, and I’ve said, no he will have his own life. Your role will be to go pick him up and take him for ice cream, take him out to dinner, or to a baseball game. Do fun things, but you will not be his primary caretaker.

When asked about the siblings’ roles for later stages of life into adulthood, all of the parents responded that they wanted their typical children to lead their own lives, and to interact with their siblings in a supportive, “typical” sibling relationship rather than having the responsibility of caring for the sibling.

Coping Strategies

The importance of providing the typically developing sibling with individualized attention away from their siblings with ASD was echoed throughout the responses of the participants. Many of the parents described activities that the typical siblings participated in individually with their parents, or with extended family members and groups of friends, and found this time to be crucial for assisting their children with coping. Ashley described “mother-son” vacations that she plans exclusively for Tyler every year. Kathy described special activities that assisted Erica in bonding with her father:

She started to go fishing with him and do some other kinds of things and I think he found some of those things as part of his relationship with her and this is part of the reason they are as close as they are.

The majority of the families indicated that they felt a strong sense of support from extended family members and close groups of friends and then reported less time that their typical children spent receiving professional services from a Psychiatrist or Counselor. Three of the five participants in the study reported that their typical children
had received professional services, and all responded that they thought these services were very beneficial in coping. Linda described the importance of Katie having “multiple sounding boards that she knows she can go to.”

When discussing coping methods with each of the families, the topic of the use of Sibshops came up in each of the interviews. Only one out of the five families interviewed had participated in a formal “Sibshop” group as discussed in Chapter II. Ashley described the Sibshop that Tyler had attended which took place over the course of twelve weeks. The participants attended one night per week on weeknights. Ashley said that at first Tyler had trouble opening up, and “didn’t want to talk about his feelings; I don’t care that my brother has Autism.” She stated he just did not find it helpful. The remaining parents gave examples of why they did not choose to have their children participate in Sibshops, including the expense of formal groups and the parents’ feelings that their children were still getting the support they needed from other sources, including informal exposure to other siblings, or family and friends.

The majority of the parents had enrolled their children in integrated school settings comprising typical children as well as children with disabilities as early as the pre-school years. The typical siblings were not only able to get exposure to other children with disabilities outside of their siblings, but also were able to see that there were other siblings living with the same “situation” and that “they weren’t alone.” The majority of the parents described the continued exposure and opportunities to interact with other siblings with ASD and other disabilities, such as summer camp activities, events held at the school of the sibling with ASD, and even specially designed social groups to
incorporate siblings. Kathy explained that when Erica is able to interact in non-formal settings with other siblings of kids with ASD, “she has a lot of energy and feedback. It’s very reinforcing for her to be around other typical siblings.” This theme of the importance of the sense of “comradery” found in the presence of other siblings of children with ASD was recurrent in each of the interviews as a beneficial coping strategy.

In summary, this chapter described the overall themes that emerged from the parent interviews. The themes underscore the unique developmental niche that the siblings of children with ASD occupy. In response to the first research question regarding coping mechanisms, the participants reported that their typically developing children found sources of comradery from other siblings of children with ASD to be beneficial. Informal settings where the children were able to befriend other siblings and know that they were not alone in their situations assisted the children in coping. The importance of being able to lead their own “typical” lives outside of their sibling was another factor that parents believed helped their typically developing children to cope and be resilient. Finally, parents reported that assuring that the siblings always had people to whom they could turn to, talk to and express feelings to was invaluable for coping. This may include family members, groups of friends, or professional supports such as counselors.

In response to the second research question as to what forms of support have been useful in assisting siblings, none of the participating families referred to formal Sibshop groups as useful for the children, as hypothesized. Support from family members and friends was discussed as useful, as it afforded the siblings opportunities for individualized attention that otherwise might be difficult to achieve.
Finally, parental guidance and encouragement with regard to interaction between siblings assisted in strengthening the sibling relationship. All of the participants described aides coming in to the home who would incorporate the sibling into games, and therefore work on social skills. The limitations in social reciprocity that accompany a diagnosis of ASD have been observed as less evasive with the guidance of aides or behavior therapists. Also, parents believed that siblings’ joint participation in activities of mutual interest helped to strengthen the sibling relationship.

The next chapter will discuss the important theoretical implications of the current study’s findings. The chapter will also discuss future directions for research and practice based in this study’s findings.
CHAPTER V
CONCLUSION

The current study, I believe, gives significant insight into the experiences of siblings of children with ASD, and offers contributions to the current body of knowledge of how to best assist these siblings. Research on the topic up to this point has demonstrated limited resources for siblings outside of formalized sibling groups such as “Sibshops.” Therefore, it was hypothesized in the current study that the majority of families that revealed positive experiences for their typical children would have engaged their children in a formal sibling support group. While the families provided ample examples for why they chose not to utilize these services such as cost, or accessibility of the groups, many alternate methods for assisting siblings were revealed that led to positive experiences when growing up with a sibling with ASD.

According to Bronfenbrenner’s Ecological Systems Theory (Bronfenbrenner, 1979), there are multiple environments that affect a child’s growth and development. This is true for all children, including those living with a sibling with ASD. Bronfenbrenner (1994) stated that human development takes place through processes of progressively more complex reciprocal interaction between an active, evolving bio-psychological human organism and the persons, objects, and symbols in its immediate environment. Thus the initial environment that a child is exposed to when living with a sibling with
ASD has implications for development that are often unique in comparison to typical siblings living together. Bronfenbrenner (1979) also stated that a child develops within multiple and interacting contexts, all of which exert a bidirectional impact on the child’s life. The responses of each of the mothers who participated in the study demonstrate the ways that multiple environments in a child’s life impact their development and ability to effectively cope with living with a sibling with ASD.

From the perspective of the Ecological Systems Theory, the responses demonstrated how the home environment within all of the participants’ microsystems (Bronfenbrenner, 1979) have transcended into other systems of the children’s lives, thus affecting their behaviors at school and other settings. It is also important to note that the parents felt that these would be defining qualities that their children possessed throughout their lifetimes. This demonstrates Bronfenbrenner’s theories maintaining that the qualities developed in their primary environments will continue to impact their relationships and development as they encounter multiple environments throughout their lives.

As discussed by Bronfenbrenner (1979), the direct impacts on the children within their primary environments was affected by outside factors including social support from extended family members and friends, and the use of professional supporters such as psychiatrists or therapists. Outside of the home and family environment, school is presumably the next most prominent environment in a child’s early stages of development. The school setting for the siblings was important to all of the participants, and allowed for an environment that exposed the children to other individuals living in similar situations. This environment positively impacted the sibling relationship, and
therefore the experiences of the siblings at home. This also allowed for siblings to gain
the understanding and empathy towards others that is believed by parents to be vital
qualities that will remain with the children throughout their lives. This follows
Bronfenbrenner’s description of how the multiple systems in an individual’s life interact
to shape development throughout the lifespan.

After examining the information gathered from the interviews, it is apparent that
siblings of children with ASD face very similar situations. The information gathered
demonstrated that living with a sibling with ASD can have both positive and negative
effects on typically developing siblings in the home. Three primary themes emerged from
the responses of the participants, including the sibling relationship, qualities of the typical
siblings, and coping strategies. These themes were useful in addressing the original
research questions.

The support of close networks, such as family and friends and groups, helped
provide siblings with opportunities to interact with other siblings in similar situations and
were prominent ways used to successfully assist the siblings. These findings support the
findings of Rivers and Stoneman (2003) who found that in families who actively sought
informal social support, the typically developing siblings reported higher levels of
positive behaviors in the sibling relationship. Hastings (2003) also found that social
support moderated the impact of the severity of symptoms of children with ASD on their
siblings’ adjustments. In the current study, allowing time for individualized attention, and
the opportunity for the siblings to lead individual lives separate from their siblings also
provides assistance for successful coping.
None of the families in the current study used Sibshops as a successful method for assisting their children. In response to the original research questions, the families instead seemed to use methods that gave the children a more natural and realistic setting for learning to interact and cope effectively. This included the use of aides or therapists coming in to the home and working on social skills between the siblings in all of the participating families. Other methods that proved to be the most successful in assisting the typical siblings included involving the siblings in integrated settings beginning with academic classrooms and continuing into social groups and structured shared activities.

The utilization of these supports and coping strategies into the experiences of the children led to many positive qualities in the siblings of children with ASD. All of the children were described as being independent beginning at early ages, and also as being more sympathetic and kind towards others with disabilities. They also demonstrated qualities of often being protective over their sibling, and assuring that their sibling was being properly cared for.

As the numbers of individuals affected by ASD has grown over the years, it is becoming increasingly important to identify ways to address the needs of the family members of these individuals. Future research should assess the impact that the functioning level of the sibling with ASD has on the sibling relationship. The participants in the current study had children that fell on multiple areas of the Autism spectrum. The extent to which the functioning level of the sibling with ASD affected the sibling relationship was unable to be determined, and would be beneficial to examine. Future research would also need to compare the experiences of siblings of children with ASD to
the experiences of siblings living in a household in which all of the children are typically developing.

The participants in the study shared their unique experiences of raising children growing up with a sibling with ASD. These children are affected daily by the implications of their siblings’ diagnosis. With the amount of support required by the sibling with ASD, it is important for other siblings in the family not to be overlooked. The siblings in the current study demonstrated resilient and remarkable qualities as a result of their experience of living with a sibling who has ASD. It is important for the proactive measures discussed by these families to be utilized in assisting other siblings of children with ASD.
REFERENCES


APPENDIX

Demographics:

1. In what year were you born?

2. What is your current marital status?
   [married, living with partner, single, divorced, widowed]

3. What is your current occupation?

4. Did you or anyone in the household ever have to switch occupations to assist your child with autism?

5. What is your highest level of education? Did the diagnosis of Autism cut your educational plans short?

6. Please tell me the first name, gender, and age of each of your children. Please specify which child has been diagnosed with ASD. Are all of the children still at home?

7. How old was {child’s name} at the time of the diagnosis?

8. How old was/were your other children/child at the time of the diagnosis
9. What was your initial reaction to the original diagnosis of Autism for your child? [What initial feelings did you experience, can you elaborate?]

10. Where on the spectrum would you say {child’s name} falls? What is his/her placement in school, is he/she in a self-contained classroom at school?

11. Do they attend the same school all together? If so, do you see/have you ever observed this affecting your children in the ways that they interact, etc?

12. What services is {child’s name} currently receiving? How long has he/she been receiving these services? [Speech pathology, occupational therapy, etc.]

13. Have there been any other services that {child’s name} has received over the years? Have you ever thought about ways that you feel these services could be improved? [Speech pathology, occupational therapy, etc.]

14. Did you or your family receive any professional assistance in coping initially? [Clarify if needed: Assistance for you/the parent, not the children.]

15. What steps at the time were taken to assist {child’s name} with coping? [Did {sibling’s name/s} attend sibling support groups? Receive home based services?]

16. When did you first talk to {sibling/s’ names} about {name}’s diagnosis? How did you go about explaining the diagnosis to {sibling/s’ name}?

17. Did you receive any professional support in explaining to {sibling’s name} what Autism is, and what to expect? If so, please explain.

18. How much of an understanding or knowledge base would you say {sibling’s name} currently have about Autism?

19. How would you say the language difficulties that accompany Autism have affected the relationship between {child’s name} and {sibling’s name}? How would you say social deficits that accompany a diagnosis of Autism has affected {sibling’s name}? How have the repetitive behaviors that accompany a diagnosis of Autism affect {sibling’s name}? [Prompt if needed: Embarrassed in school, difficult to be home? Can you elaborate more on that?]
20. Have ritualistic/repetitive behaviors and social deficits affected the environment and everyday functioning of the family at home, and therefore affected {sibling’s name}? Can you describe this to me?

21. In what ways do you think having a sibling with Autism has shaped {sibling’s name} behaviors and development? [Prompt if needed: More accepting and caring towards others? More responsible/independent? Can you elaborate more on that?]

22. Can you describe the relationship between {sibling’s name} and {child’s name}? [Positive or negative, can you explain? Do they seem to enjoy spending time together? Is there much conflict, and how is it resolved?] Can you estimate about how much time the siblings spend together on a typical day?

23. Are there any structured activities they participate in together? [swim class, basketball, etc.] Do they participate in unstructured activities together?

24. You mentioned that {child’s name} engages in {name behaviors associated with his/her Autism}. How does this affect {sibling’s name}? [melt-downs, aggressions, repetitive behaviors, etc.]?

25. Is there anything else you would like to tell me?