


2016

# Experiences of Neurotypical Siblings of Children with an Autism Spectrum Disorder: A Qualitative Exploration

Stacie R. Keirse

Follow this and additional works at: <http://aura.antioch.edu/etds>

 Part of the [Clinical Psychology Commons](#), [Cognitive Psychology Commons](#), [Counseling Psychology Commons](#), [Developmental Psychology Commons](#), [Early Childhood Education Commons](#), [Family, Life Course, and Society Commons](#), [Other Social and Behavioral Sciences Commons](#), [Personality and Social Contexts Commons](#), [School Psychology Commons](#), [Social Psychology Commons](#), and the [Special Education and Teaching Commons](#)

---

## Recommended Citation

Keirse, Stacie R., "Experiences of Neurotypical Siblings of Children with an Autism Spectrum Disorder: A Qualitative Exploration" (2016). *Dissertations & Theses*. 332.  
<http://aura.antioch.edu/etds/332>

This Dissertation is brought to you for free and open access by the Student & Alumni Scholarship, including Dissertations & Theses at AURA - Antioch University Repository and Archive. It has been accepted for inclusion in Dissertations & Theses by an authorized administrator of AURA - Antioch University Repository and Archive. For more information, please contact [dpenrose@antioch.edu](mailto:dpenrose@antioch.edu), [wmcgrath@antioch.edu](mailto:wmcgrath@antioch.edu).

EXPERIENCES OF NEUROTYPICAL SIBLINGS OF CHILDREN WITH AN AUTISM  
SPECTRUM DISORDER: A QUALITATIVE EXPLORATION

A Dissertation

Presented to the Faculty of  
Antioch University Seattle  
Seattle, WA

In Partial Fulfillment  
of the Requirements of the Degree  
Doctor of Psychology

By

Stacie Keirse

December 2016

EXPERIENCES OF NEUROTYPICAL SIBLINGS OF CHILDREN WITH AN AUTISM  
SPECTRUM DISORDER: A QUALITATIVE EXPLORATION

This dissertation, by Stacie Keirse, has been approved by the committee members signed below who recommend that it be accepted by the faculty of Antioch University Seattle at Seattle, WA in partial fulfillment of requirements for the degree of

DOCTOR OF PSYCHOLOGY

Dissertation Committee:

---

Mary Wieneke, Ph.D.  
Chairperson

---

Steve Curtis, Ph.D.

---

Ned Farley, Ph.D.

---

Date

**Copyright by Stacie Keirse, 2016**

**All Rights Reserved**

## ABSTRACT

EXPERIENCES OF NEUROTYPICAL SIBLINGS OF CHILDREN WITH AN AUTISM  
SPECTRUM DISORDER: A QUALITATIVE EXPLORATION

Stacie Keirse

Antioch University Seattle

Seattle, WA

In recent years, the diagnosis of autism spectrum disorder (ASD) has been on the rise, prompting a simultaneous increase in scientific study regarding cause, impact, and intervention (Hughes, 2009; Ravindran & Myers, 2012). Research has proposed advances in the treatment of the individuals diagnosed and focused efforts on scholastic, parental, and professional intervention and supports. However, the siblings of ASD children have largely been neglected in this scientific investigation. The purpose of this hermeneutic phenomenological study was to explore neurotypical siblings' experiences in living with a child diagnosed with ASD. Seven adolescents were selected using criterion, convenience, and snowball sampling. Data were collected using semi-structured interviews and were analyzed using thematic reflection (van Manen, 1990). Data analysis uncovered seven themes: (a) personal impact, (b) familial impact, (c) social impact, (d) relational understanding, (e) socio-cultural influence, (f) future outlook, and (g) advice. Findings indicated neurotypical sibling experiences contain both positive and negative perceptions of living with a brother or sister diagnosed with ASD. Perceptions were often influenced by the cultural and societal value placed upon normal behaviors. The need for appropriate education regarding ASD etiology, symptomology, and treatment was deemed to be important for NTD siblings, parents, professionals, and society at large. Additionally, the development of social supports for NTD siblings was suggested. The electronic version of this

dissertation is at AURA: Antioch University and Repository Archive, <https://aura.antioch.edu/>  
and Ohio Link ETD Center, <https://etd.ohiolink.edu>

## Dedication

To the friends and family who remind me silver linings exist: I could not have done it without you. Thank you also to the professors, supervisors, and life teachers who inspired me to pursue knowledge. An additional thank you goes out to the participants who willingly gave their voices to this project.

Most importantly, I dedicate this work to my own siblings: Jamie, Rebbly, and David. I thank the universe every day for our relationships, and marvel that fate brought us together. I could not love you more.

<u>Table of Contents</u>	<u>Page</u>
Dedication.....	iv
List of Tables .....	vii
I: Introduction.....	1
Background.....	1
Statement of Purpose .....	3
Research Design Overview.....	4
Rationale and Significance .....	5
Premises.....	6
Definition of Terms .....	6
II: Literature Review .....	8
Mental Illness and the Sibling Relationship .....	9
Historical Context of the ASD-NTD Sibling Relationship .....	12
Research on ASD-NTD Sibling Relationships.....	14
Summary of Literature Review Findings .....	22
III: Methodology.....	23
Research Design .....	23
Recruitment of Subjects.....	24
Data Collection .....	29
Data Protection .....	30
Materials .....	31
Data Analysis.....	31
Data Quality.....	32
IV: Findings .....	34



Personal Impact .....	34
Familial Impact.....	39
Social Impact .....	43
Relational Understanding .....	48
Socio-cultural Influence.....	51
Future Outlook.....	56
Advice.....	58
Summary.....	62
V: Discussion.....	64
Addressing the Research Questions.....	64
Study Implications.....	79
Summary.....	87
References.....	88
Appendix A: Demographics Questionnaire .....	96
Appendix B: Interview Schedule.....	99

<u>List of Tables</u>	<u>Page</u>
1. Definition of Terms.....	7
2. Summary of Themes.....	64

## Introduction

In some ways my life is different from kids who have a normal brother, because most of my schedule revolves around Danny. . . . I think parents, teachers, and doctors should have more understanding for siblings, because they go through difficult experiences with their brothers or sisters.

-Jessica Kolber, age 9, sister to a child with an autism diagnosis<sup>1</sup>

## Background

The sibling relationship is unique in its shared experience. Siblings often have in common more genetic similarities, early childhood occurrences, and communal socio-cultural practices than with other family members or outside individuals. The duration of a sibling relationship can be longer than any other affiliation a person may have, and can persist with varying intensity throughout the lifespan.

Empirical evidence has recently begun to reveal that chronic physical childhood illness has a large, often negative impact on the “well” or “neurotypical” sibling: the brother or sister who does not have disease (Craft, Wyatt, & Sendall, 1985; Williams et al., 2003). This impact manifests through decreases in mental and physical health, well-being, and positive feelings toward the sibling relationship. Conversely, the experience of the neurotypical siblings of children with developmental disorders, such as autism spectrum diagnoses, has been largely unexplored.

An autism spectrum disorder (ASD) is a developmental disorder that may affect an individual’s ability to communicate, socially interact, or control behaviors (American Psychiatric Association, 2013). These difficulties are exhibited across a range of severity, and are present throughout the lifespan. A recent increase in the prevalence of this diagnosis within the United

---

<sup>1</sup> From Meyer, 2005

States has prompted a simultaneous raise in scientific study regarding cause, impact, and intervention (Hughes, 2009; Ravindran & Myers, 2012).

When examining familial impact, the most extensive body of research has been dedicated towards investigating parental influence on and reaction to childhood developmental disability, while disregarding the sibling relationship (Hughes, 2009; Karst & Van Hecke, 2012; White, McMorris, Weiss, & Lunskey, 2012). These findings implicate parents as both progenitors of autistic traits and as individuals significantly affected by the stress and difficulty of raising a child with a developmental diagnosis.

In 2008, approximately one in every six American children was diagnosed with a developmental disability (Boyle et al., 2011). One in 88 received an autism spectrum disorder (ASD) diagnosis. Concurrently, according to recent census data, 79% of children under the age of 18 live with at least one sibling (U.S. Census Bureau, 2004). This implies there are several million children with autism spectrum diagnoses; the majority of these likely have siblings.

The literature investigating sibling relationships in conjunction with ASD largely focuses on early detection of an ASD diagnosis within the family (Carayol et al., 2011; Deconinck, Soncarrieu, & Dan, 2013; Zwaigenbaum et al., 2007). Genetic predispositions of siblings, and early behavioral, communication, and social “warning signs” of a potential ASD diagnosis remain at the forefront of scientific investigation.

Few studies have been interested in the sibling experience of having a brother or sister with an ASD diagnosis. Those that have been conducted utilize quantitative methods that are not cohesive (Meadan, Stoner, & Angell, 2010; L. Smith & Elder, 2010). Survey measures are inconsistent, and have been administered to parents, teachers, or siblings, while behavioral observations vary in timing, setting, and observer. Oftentimes, these studies ask adult

participants to reflect on their past experiences, leaving research open to questions of longitudinal validity. Furthermore, the literature yields varying results regarding sibling health, well-being, and feelings toward the sibling relationship.

Due to the unclear nature of the experience of these siblings, few interventions have been designed to assist young siblings in adjusting to, managing with, or understanding their brother or sister with an ASD diagnosis. Largely, family resources have not yet been developed to promote positive sibling experiences, relationships between siblings, and the functioning of the household in its entirety. Through the neglect of this important topic, the mental health field is contributing to the belief that these siblings are unaffected and do not need support.

Contrary to this idea, some educators have responded to parent and sibling demand for assistance through the development and production of specialized trainings, books, and workshops dedicated to sibling support, education, and opportunities to share their experience. Don Meyer, Director of the Sibling Support Project, has recognized the need for sibling intervention, resources, and references, and has developed a globally-implemented curriculum for addressing the strengths and challenges of siblings of children with a disability diagnosis. His workshops and books have highlighted the unique ways in which siblings are affected, and emphasized the necessity for programs, services, and considerations for brothers and sisters of individuals with special health, mental health, and developmental needs.

### **Statement of Purpose**

This research sought to provide an understanding of what it is like to be an adolescent neurotypical sibling of a child with an ASD diagnosis. It attempted to illuminate how these siblings make meaning of their lived experience. To do this, five subsidiary research questions were addressed: (a) How do neurotypical siblings feel impacted by their brother or sister with an

ASD diagnosis? (b) How do neurotypical siblings perceive their relationship with the child diagnosed with ASD? (c) How do neurotypical siblings perceive their role and remaining relationships within the family? (d) What are the challenges of being a sibling of a child with an ASD diagnosis? and (e) What are some factors that contribute to resiliency in this population? Understanding the points of strength and areas of need in developing positive sibling experience within this population can offer important insight for clinical application.

Additionally, a qualitative method was utilized to investigate these research questions. The current literature focuses on quantitative measures that yield inconsistent results regarding sibling experience. By allowing participants to describe their experiences, rather than rely on outside observers or survey measures, this topic is openly explored in hopes of producing findings that can be used on greater scales in future studies.

Furthermore, a qualitative method was chosen to promote recognition of sibling challenges and successes for the participants themselves. The use of open-ended interview questions allows for the validation and authentication of participant experience, while providing an insider view of the life these siblings lead.

### **Research Design Overview**

Hermeneutic phenomenology is the methodology employed in this research study. In a phenomenological approach, the researcher is interested in the personal account of the lived experience of the participant. The meaning the participant creates from this experience is of particular importance to the study; the researcher attempts to capture these meanings in order to better understand what it is like to be the participant. In hermeneutic phenomenology, the researcher does not attempt to remove his or her personal biases or values from interpretation of these meanings, but rather divulges them freely.

This study looks at neurotypical children between the ages of 13 and 17 who have a sibling diagnosed with an autism spectrum disorder. These participants were recruited in a private practice, at several schools and hospitals, and via word-of-mouth. All data collection was conducted in a private setting within Washington State.

In this study, data was collected through the use of one-on-one interviews between the researcher and each participant. During these open-ended interviews, a series of questions was flexibly asked and the responses each participant gave were recorded. At the time of the interview, notes were taken while a tape recorder captured the entire exchange verbatim. The participants' verbatim responses were the data used for analysis, while notes aided in illumination of the researchers' values, biases, and assisted with interpretation of the results. Data analysis included organizing responses, discerning over-arching meanings, and establishing a hierarchy of themes related to the research questions.

### **Rationale and Significance**

A review of the current literature reflects conflicting quantitative evidence regarding the development of siblings of children with an ASD diagnosis. Research examining the effects of childhood physical illness on well or neurotypical siblings demonstrates negative effects on health, well-being, and quality of sibling relationship, raising concerns for neurotypical siblings of children with potentially comparable developmental difficulties. Current educators specializing in work with siblings of children with special developmental needs indicate that siblings often require intervention, education, and support. A scientific exploration of the specific concerns, challenges, and coping mechanisms that neurotypical siblings endorse is lacking in the current literature.

This project sought to address this dearth through qualitative interviews with adolescent neurotypical siblings of children with an ASD diagnosis. Understanding the consequences childhood ASD has on not only the diagnosed child or the parent, but also for the neurotypical sibling, provides important information regarding how clinical practice can better the psychological health of all parties.

Furthermore, investigating how neurotypical siblings experience having a brother or sister with an ASD diagnosis creates an enhanced understanding of the ways in which developmental disorders impact these children, and highlights the potential for mediation. Childhood experiences with siblings provide a possible context for developing social skills, emotion regulation, and practicing peer relationships (Parke & Buriel, 2008). The degree to which these interactions are positive or negative may have significant consequences for the development of healthy sibling and familial relationships. Establishing a greater awareness of the challenges and successes siblings face encourages future research for the development of interventions for this population.

### **Premises**

Based on a review of the literature and the current demand for interventions, this project has the following premises: (a) Neurotypical siblings of children with an ASD diagnosis are impacted by their sibling relationship in unique ways, both positively and negatively; (b) As adolescents who have lived with a special needs child for several years, these siblings are capable of describing a personal account of their lived experience; and (c) Common themes can be found amongst these accounts that speak to the unique ways these children are impacted.

### **Definitions of Terms**

The terms used for this study are defined in Table 1.



Table 1

*Definition of Terms*

Term	Definition
Autism Spectrum Disorder (ASD)	A Diagnostic and Statistical Manual, Fourth Edition, Revised (DSM-IV-TR) diagnosis of autism, Asperger's disorder, or pervasive developmental disorder; A Diagnostic and Statistical Manual, Fifth Edition (DSM-5) diagnosis encompassing developmental impairments across areas of social interaction, communication, or behaviors (American Psychiatric Association, 2013).
Pervasive Developmental Disorder (PDD)	A disorder usually identified in the early years of life, characterized by severe and pervasive impairment in several areas of development, such as social interaction, communication, or the presence of stereotyped behavior, interests, and activities (American Psychiatric Association, 2000).
Autistic disorder	A pervasive developmental disorder identified by "markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests" (American Psychiatric Association, 2000).
Asperger's Disorder	A pervasive developmental disorder identified by "severe and sustained impairment in social interaction (Criterion A) and the development of restricted, repetitive patterns of behavior, interests, and activities (Criterion B)" (American Psychiatric Association, 2000).
Neurotypically developing (NTD) sibling	An individual that does not exhibit developmental difficulties, and is also a brother or sister of an individual with a developmental diagnosis, such as an autism spectrum disorder.
Phenomenology	Research designed to investigate the lived experience of individuals to identify the core essence of this experience, as described by research participants (Bloomberg & Volpe, 2008).
Proband	An individual affected with a disorder who is the first subject in a study (as of genetic character in a family lineage) ("Proband," n.d.).

## Literature Review

Although a great deal of research has been dedicated towards understanding interparental relationships and their effects on the family unit, sibling dynamics within NTD-ASD pairs remain an underrepresented area of study. However, given the daily companionship and longevity of the sibling relationship, a growing number of researchers are beginning to document the developmental significance of this important bond.

A literature review conducted by Feinberg, Solmeyer, and McHale (2012) delineates ample evidence that sibling relationships impact individual development. Their findings indicate the quality of sibling relationships influences internalizing and externalizing behaviors for both members of the dyad. Sibling conflict or negative relationships are linked to increases in antisocial behaviors, substance abuse, depression, and anxiety. Alternately, positive sibling relationships have been correlated with increases in social competency and adaptive relationship skills. These manifestations have significant consequences for a child or adolescent in terms of school success, peer development, and personal adjustment (Barnett & Hunter, 2012; Morgan, Shaw, & Olino, 2012; Parke & Buriel, 2008; Tafoya & Hamilton, 2012; Yuan, 2009). Furthermore, these effects may be felt throughout the life span.

Given the influence of the sibling relationship on development, a review of the current literature is undertaken regarding: (a) childhood chronic mental illness and the sibling relationship (b) the historical contextualization of ASD-NTD sibling relationships, (c) NTD sibling health and well-being in ASD dyads, and (d) current interventions regarding the treatment of NTD siblings.

## **Mental Illness and the Sibling Relationship**

Historically, endeavors to include the family in childhood mental disorders habitually focused on the parents. Siblings were excluded in attempts to shield them from the consequences and burden of mental illness, without realizing this act often created psychological distress in these children (Abrams, 2009). However, as practitioners became more informed, much of the research on sibling relationships and mental illness was borne out of concern for the well or neurotypically developing sibling. Mental health professionals began investigating the impact mental disease had on the undiagnosed sibling, frequently using qualitative methods. The data gathered regarding chronic mental illness and the sibling relationship yields important comparisons for dyads involving developmental disorders.

In 1985, Riebschleger (1991) began to document the descriptive and emotional experience of well siblings who had lived with chronically mentally ill children. Using 20 individuals of broadly variant ages (20–65 years old), a medley of interview methods, and discussing schizophrenia, bipolar disorder, and organic mental illnesses, Riebschleger revealed revolutionary information about the viewpoint of the well sibling.

Far from being sheltered from mental illness, each sibling revealed feelings of anger, guilt, fear, and sorrow towards their sibling during childhood development. Thirteen of the 20 participants described incidents of encountering mental health professionals who would blame the family for the psychological problems of the ill sibling (Riebschleger, 1991). These negative experiences would in turn impair the ability of the well sibling to foster a positive relationship with the ill sibling. While the techniques used for this analysis were divergent from an appropriate scientific method, Riebschleger opened an avenue for the investigation of mental illness in sibling relationships.

Replications of these findings occurred on a more objective level a few years later. Greenberg, Kim, and Greenley (1997) administered four scaled assessments to 149 well siblings via a telephone interview. Recruitment of siblings came from their familial connections to a larger pool of 1,547 Wisconsin individuals with severe and chronic mental illness. The average age of the well siblings was 45, and 70% of them were female.

The researchers aimed to investigate feelings of subjective burden, stigma, fears, and worries about the future. One of the most important findings was that older well siblings (in comparison to the age of the ill sibling) felt less burden, perceived mental illness with a smaller amount of social stigma, and had fewer fears about their ill sibling's behavior than did younger well siblings (Greenberg et al., 1997). This finding has important implications for the socialization of siblings during childhood. If younger well siblings are indoctrinated with the same values taught older siblings, perhaps negative feelings surrounding sibling mental illness can be mediated to some degree.

Additionally, the authors discovered that the further well siblings felt their ill counterparts could control the symptoms of their disorder, the greater the perceived burden, impressions of stigma, fear, and worry about the future. This result stresses the importance of accurate and timely dissemination of facts about the diagnosis to the well sibling. It demonstrates a correlation between a dearth of information or inaccurate conceptions about mental illness and a harmful psychological burden on the well sibling, thus creating a less positive sibling relationship.

While the findings of this study may be extrapolated to work with children, it is important to note this research was based on siblings who had maintained close relationships with their ill counterparts on average well into middle age. This may be reflective of certain family values or

experiences that may influence results. Work with younger individuals would help to alleviate this discrepancy.

In response to this precise need, a number of researchers have begun work on developing appropriate assessment tools for well siblings to be administered during childhood. Thus far, only moderate accomplishments exist. For example, the creation of the Impact on Sibling (IOS) scale, designed to determine the effects of childhood illness on the well sibling, has recently come under empirical scrutiny (Kao, Plante & Lobato, 2009). In a study that compared the IOS scale to a variety of other measures used to determine problematic functioning within children, results indicated the IOS was only somewhat effective at detecting negative impact in families of children with chronic physical illness, while proving unsuccessful with developmental disorders and autism. It could be one measure is not sufficient to gauge the influence of an entire spectrum of childhood chronic illness.

In contrast to this finding, mild accomplishment has been achieved in the formation of an assessment intended to establish the impacts of caring for siblings (and parents) of chronic mental illness (Joseph, Becker, Becker, & Regel, 2008). The recent development of the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) is an effort to ascertain and alleviate the potential psychological harm of well siblings living with an ill brother or sister. Investigators tested the scale on 410 United Kingdom children between the ages of six and 22, and validated it on 124 British school-aged children (Joseph et al., 2008). With further study, this scale could provide helpful information to pinpoint the beginnings of negative well sibling adjustment to mental illness; additionally these measures may well be extended to include neurotypical siblings of children with developmental disorders as well.

## **Historical Context of the ASD-NTD Sibling Relationship**

The diagnosis of autism has undergone several permutations since its conceptualization by Kanner in 1943 (Rutter, 1999; Wolff, 2004). In tandem with the progression of the diagnostic criteria, the role of the family and its influence has fluctuated as well. Historically, “bad parenting” was frequently assigned blame for causing the symptoms associated with an ASD diagnosis. Descriptions of “refrigerator parents,” as cold and unavailable caretakers alienated families and sparked interventions focused on ameliorating the supposed damage created by poor parenting. In contrast, early accounts of autism and the family neglected mention of the siblings; an interesting point, since many siblings of autistic children did not exhibit similar difficulties, despite having the same parents.

As genetics became increasingly popular in the late 1970s, causation turned from psychosocial factors towards biological underpinnings (Morgan, 1988; Rutter, 1999). Along with this shift, a divergence in the conceptualization of the family began to emerge. Scientific interests promoted the examination of genetics, brain-behavior correlations, and medical links within parents and siblings. Concurrently, a rise in family-systems perspectives began to describe childhood ASD as having mutually influencing effects on each family member and the family unit as a whole.

Early accounts of sibling health and well-being are limited when examining the impact of an ASD diagnosis in the family. Some authors attributed this dearth to the prevalence of developmental disorder diagnoses within these siblings (Morgan, 1988; Rutter, 1999). Within the literature, several descriptions of a Broad autism Phenotype (BAP), generated by genetic similarity, are used to explain symptom resemblance within siblings of children diagnosed with ASD (Meyer, Ingersoll, & Hambrick, 2011; Petalas et al., 2012; Rutter, 1999). As such, in some

research studies a demonstration of BAP is viewed as a confounding variable interfering with accurate analysis of sibling adjustment.

Literature reviews examining sibling adjustment have noted that the majority of contributions to the field have stemmed from international studies, rather than within the United States (Meadan et al., 2011; Orsmond & Seltzer, 2007). Alternately, the United States has been at the forefront of several of the biological and genetic studies regarding diagnosis and early detection of ASD in “at-risk” siblings (Carayol et al., 2011; Deconinck et al., 2013; Zwaigenbaum et al., 2007).

The focus on biological factors in terms of identification and treatment of ASD is consistent with a western emphasis on utilization of the medical model when considering psychiatric disorders (Ravindran & Meyers, 2012). This view is a departure from earlier cultural contextualization of ASD, which included analysis of family backgrounds by Kanner (1943), relational parenting influences popularized by Bettelheim (1967), and effects of technologic advancement described by Sanua (1984). Cultural differences in perspectives on etiology, intervention, and familial influence inform research focus and likely contribute to the current differences in literature regarding sibling health and well-being.

As such, the following investigation into the current literature regarding siblings of a child with an ASD diagnosis attempts to pull from studies conducted in the United States, but acknowledges that the majority of published research on the topic is conducted internationally. This is by no means an attempt to generalize the experience of these siblings, but rather, an effort to gain the maximum amount of data available regarding health and well-being in these individuals.

## **Research on ASD-NTD Sibling Relationships**

Much of the research surrounding sibling relationships in NTD-ASD pairs focus on genetics, examining the NTD sibling for ASD traits, or using the sibling in effort to enhance social skills in the proband (Castorina & Negri, 2011; Cebula, 2012; Ferraioli & Harris, 2011; Oppenheim-Leaf, Leaf, Dozier, Sheldon, & Sherman, 2011). Studies that focus on sibling health and well-being are predominantly quantitative in nature, often relying on parent survey measures to determine sibling relationship quality, externalizing behaviors, and the emotional adjustment of NTD siblings (Orsmond & Seltzer, 2007; Pollard, Barry, Freedman & Kotchick, 2013; Tomeny, Barry, & Bader, 2014). Results have been mixed; as compared to other siblings, NTD siblings of children with an ASD diagnosis are often reported as having both better and worse sibling relationships, demonstrating more and less social skills, and as exhibiting varying degrees of anxiety and depression (Dempsey, 2011; Hodapp & Urbano, 2007; Neely-Barnes & Graff, 2011; Orsmond & Seltzer, 2007). An in-depth examination of these studies seeks to outline the current predicament in research literature on NTD siblings, in hopes of illuminating the need for qualitative data in this field.

**Comparison to other sibling relationships.** There exists some evidence that the relationship between siblings of children with an ASD diagnosis is reported as more negative than the relationship between siblings of children with other developmental challenges. One study supporting this claim used a national web-based survey to poll adult individuals of siblings with Down syndrome and adult individuals of siblings with autism to examine sibling health, background, and the quality and closeness of sibling relationship (Hodapp & Urbano, 2007). Researchers utilized a survey measure designed for this study in particular: The Adult Sibling Questionnaire. The Adult Sibling Questionnaire is a Likert-style survey with 163 items examining demographics, sibling joint activities and interests, sibling relationship, respondent



health, and major life transitions. Results indicated siblings of individuals with Down syndrome reported more positive relationships. However, amount of contact between siblings was significantly correlated to positive attitude toward the relationship. Additionally, siblings of individuals with Down syndrome reported better health and lower levels of depression as compared to siblings of persons with an autism diagnosis.

This study used adults reflecting on their current relationship experience, neglecting childhood reports. A similar study, conducted by Pollard et al. (2013) also examined sibling relationships amongst brothers and sisters of children with an ASD or Down syndrome diagnosis. Online surveys were utilized as well, including a demographics questionnaire, the sibling portion of the Network of Relationships Inventory (NRI), and the Multidimensional Anxiety Scale for Children (MASC). One hundred and nineteen children between the ages of 11 and 17 were recruited. When results were examined, siblings of children with an ASD diagnosis reported lower levels of relationship quality than did siblings from the Down syndrome group. Additionally, increasingly negative perceptions of sibling relationship were correlated with higher ratings of anxiety across all individuals. Siblings of children with an ASD diagnosis appear to perceive their relationships with siblings as more negative than do siblings of children with Down syndrome, a developmental diagnosis often assumed as comparable in the literature.

**Sibling health and well-being.** The literature on sibling health and well-being in families where an ASD diagnosis exists is extremely varied. Often studies offer conflicting data, indicating results that range from reports of positive sibling relationships to increases in externalizing behaviors and anxiety. Several articles provide proposed mediators as explanations for negative reports. For the purpose of this review, studies will be loosely organized into (a) studies reporting positive gains in sibling health and well-being, (b) studies describing negative

impacts on sibling health and well-being, and (c) studies providing inconclusive or neutral evidence regarding sibling health and well-being.

**Positive impacts.** A study conducted in the United Kingdom by Hastings (2007) examined sibling behavior and well-being by asking mothers to fill out several surveys (demographics questionnaire, Vineland Adaptive Behavior Scales, and a Strengths and Difficulties Questionnaire) regarding both the child with an ASD diagnosis and the NTD sibling. Hastings discovered that, when compared to a national United Kingdom database, the siblings of the survey were reported as having no more difficulties in behavioral adjustment than the average child. Additionally, they were rated as having fewer hyperactive-type behaviors than the norm from the national database.

A literature review by Orsmond and Seltzer (2007) found that amongst qualitative studies investigating relationship quality between NTD-ASD siblings, that NTD siblings frequently describe the relationship in positive terms. The use of some survey measures have also found NTD siblings to rate their brothers or sisters with an ASD diagnosis as having greater admiration and respect for their siblings than typically developing sibling dyads. Additionally, children with an ASD diagnosis have been described as less aggressive and competitive by their NTD siblings than other typically developing dyads, increasing accounts of positive sibling relationships.

Despite limited discussion of positive sibling relationships, there exists a marked lack of research implicating positive benefits to the NTD sibling of a child with an ASD diagnosis. Although several studies have examined these siblings in comparison to national data, other siblings of children with developmental diagnoses, and using within-group measures, this review of the literature yielded no data regarding resiliency, coping mechanisms, or specific emotional

or health benefits correlated with having a sibling with ASD. Alternately, several studies reported negative impacts.

**Negative impacts.** Several researchers in recent years have utilized data drawn from the Simons Simplex Collection (SSC), a broad data pool with over 1,355 probands with an ASD diagnosis and 1,351 undiagnosed siblings (Brewton, Nowell, Lasala, & Goin-Kochel, 2011; Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012; Shivers, Deisenroth, & Taylor, 2013). Subjects were recruited in a variety of ways across 12 sites in the United States and parts of Canada, in attempts to yield heterogeneous data.

As part of this data, ASD diagnoses were confirmed using several measures, including the Autism Diagnostic Interview-Revised (ADI-R), the Autism Diagnostic Observation Schedule (ADOS), and the Vineland Adaptive Behavior Scales- II (VABS-II). Parents were also administered the Social Communication Questionnaire (SCQ), the Social Responsiveness Scale (SRS), and the VABS-II to establish that the sibling of the child with an ASD diagnosis had no apparent developmental disability. Parents additionally completed a Child Behavior Checklist (CBCL) for each child, detailing internalizing and externalizing behaviors (Brewton et al., 2011; Shivers, Deisenroth, & Taylor, 2013).

Various analyses of this vast pool of data generated several findings. Brewton et al. (2011) reported a positive correlation in prosocial behaviors, as reported by parents on the VABS-II, between ASD and NTD siblings. This trend was more significant in sibling pairs where the NTD brother or sister was younger. Brewton et al. declared this finding to be evidence that NTD siblings are effective social skills trainers for their brothers or sisters with an ASD diagnosis. However, alternate hypothesis may include a tendency for parents to report similar behaviors between siblings, a mutually influencing effect of prosocial behaviors within

family groups, or an increase in prosocial behaviors as a by-product of larger social and cultural influences. Unfortunately, it is difficult to generate causality from correlation.

Shivers et al. (2013) also used this data to complete an examination of anxiety within NTD siblings. Using the Anxiety subscale found on the CBCL, parental report indicated that, in general, NTD siblings do not reach clinical levels of anxiety any more or less than the norm. However, when divided into age and gender brackets, males and children in middle childhood (ages 6–11 years old) tended to report more anxiety than others. Additionally, when compared to the internalizing (e.g., behaviors indicative of depression and anxiety) and externalizing (e.g., aggression and hyperactivity) behaviors of the proband, a significant positive correlation was found between proband behaviors and sibling anxiety. This correlation was not prevalent when compared to severity of ASD diagnosis.

This finding has been replicated across several studies utilizing parent report on survey measures (Meyer et al., 2011; Petalas et al., 2011; Tomeny et al., 2014). In one study, birth order appeared to have an effect, with NTD siblings evidencing more behavior problems when the proband was older (Tomeny et al., 2014). In others, negative sibling behaviors were seen to additionally increase when the NTD sibling evidenced sub-threshold clinical traits similar to that of an ASD (Meyer et al., 2011; Petalas et al., 2011). These traits are often referred to in the literature as a “Broad Autism Phenotype” or BAP; BAP is consistently considered the “genetic liability” inherent within families where an ASD diagnosis is present.

A study conducted by Ross and Cuskelly (2006) investigated 25 NTD siblings with ASD brothers or sisters. The CBCL was administered to the mother of each family and NTD siblings also completed two questionnaires designed to rate their understanding of ASD and to identify challenges encountered and coping skills utilized when interacting with their ASD siblings.

According to an analysis of maternal completion of the CBCL, 40% of NTD siblings were identified as experiencing adjustment problems, most notably internalizing problem behaviors. Further, 84% of NTD siblings identified aggression (i.e., physical aggression, verbal aggression, destruction of property, and disruption) to be the most common stressor within interactions with their ASD sibling.

These studies all consistently relied entirely upon parental report for accurate data. None of this research used corollary data, such as two-parent report, teacher report, observer report, or self-report from either child involved. Thus, despite the concerning information regarding increases in anxiety and behavior problems, generalizability remains a concern.

**Inconclusive impacts.** In a study analyzing data from the 2006 National Health Interview Survey, researchers indicated there was no correlation between adverse mental health conditions and having a sibling diagnosed with a disability (Neely-Barnes & Graff, 2011). Although effect sizes were initially discovered between siblings of children with a disability diagnosis ( $n = 373$ ) and siblings of children without a diagnosis ( $n = 3,790$ ) on composites designed to analyze mental health status, use of mental health services, and generalized difficulties, once subjects were matched on demographic variables, effect sizes became insignificant. One large difficulty with this study is the lack of data regarding type of disability diagnosis; ASD diagnoses are not distinguished from other childhood disabilities in this study.

A study collecting data from 57 mothers and adolescent neurotypical siblings in NTD-ASD diagnosis groups yielded mixed findings regarding depression and anxiety (Orsmond & Seltzer, 2009). Results indicated that on self-report survey measures young males gave responses of anxiety and depression consistent with the general population. Females tended to self-report higher levels of anxiety; however, the researchers mediated these results with

indications of higher levels of maternal depression and having a history of an elevated number of stressful life events.

The largest sample of inconclusive results stems from literature reviews examining sibling health and well-being across a variety of domains. Similar to the evidence discussed above, methodologies, subjects, and findings are extremely inconsistent (Meadan et al., 2010; Orsmond & Seltzer, 2007; L. Smith & Elder, 2010). Similarities across reviews indicate a need within the field for continued research on the social, emotional, and behavioral adjustment of siblings of children with an ASD diagnosis. Focus could be generated towards rectifying inconsistencies in the field regarding methods, measures, tools, informants, and control-contrast groups; use of qualitative methodologies; and obtaining the perspective of the subjects themselves.

**Current interventions for siblings.** Siblings are often overlooked in the development of social supports and the treatment of individuals with developmental disabilities. Supporting the entire family and the relationship between neurotypical and special needs siblings is key in fostering positive, life-long connections (Conway & Meyer, 2008). Unfortunately, siblings are often neglected from conversation regarding diagnosis, symptomatology and its effects within daily living, as well as intervention strategies, planning, and individual or family treatment (Tsao, Davenport, & Schmiede, 2012). The limited research that exists regarding siblings in this important process indicates the neglect of siblings can lead to damaging the sibling relationship throughout the lifetime (Greenberg et al., 1997; Riebschleger, 1991).

An empirical study investigating a brief family-based intervention found after six sessions, siblings of children with chronic illness or developmental disorder demonstrated increased knowledge of their siblings' difficulties and elevated feelings of self-competence

(Lobato & Kao, 2005). Supporting this finding, a survey of 60 individuals discerned that siblings of individuals with mental illness endorsed increased education and assistance from professionals in understanding mental challenges. Results indicated these individuals believed this education resulted in providing more effective and willing care for their brother or sister (Hatfield & Lefley, 2005).

In addition to education, provision of a social support system may be integral in promoting sibling health and well-being. A study investigating the impact of applied behavioral analysis (ABA) found little significant changes across several areas of investigation; social support was demonstrated to evidence the largest impact on quality of sibling relationship (Cebula, 2012). Work by Conway and Meyer (2008) emphasizes the need for individual support for siblings of special needs children; they have found international success through implementation of workshops designed to directly support siblings.

A recent literature review regarding sibling intervention found a provision of parent support as well as sibling support to be of benefit to siblings of children with an ASD diagnosis (Tsao et al., 2012). Parent support groups, use of effective parent communication tools, and establishing firm boundaries regarding equivalent treatment between siblings all yielded positive results for supporting siblings. Additionally, use of sibling support groups, such as the ones proposed by Conway and Meyer (2008), and the additional provision of sibling interactive play therapy appeared to benefit these siblings as well. Tsao et al. (2012) lamented the lack of current literature surrounding sibling interventions, and strongly proposed further investigation into this field.

## **Summary of Literature Review Findings**

Studies examining childhood chronic physical and mental health disorders provide evidence that indicate a correlation between living with a child with a disorder and diminished physical and mental health within the undiagnosed sibling. This provides significant concerns regarding sibling health and well-being for children living with a child diagnosed with a developmental disorder, such as ASD. However, the findings regarding the experience of siblings of children with an ASD diagnosis offer mixed results. Variations in methods, tools, subjects, and comparison groups may contribute to the disorganization of the literature regarding this important topic. Historical and cultural influences of the Western medical model have encouraged examination of genetic and biological underpinnings, while largely neglecting the lived experience of siblings. Unfortunately, there are currently more questions than answers when considering how best to support the siblings of children with an ASD diagnosis. This highlights a need to hear the voices of these siblings by asking them directly for their perspective, attempting to understand their experience, and having them identify areas of strength and of needed support.



## **Methodology**

For the purpose of this study, a qualitative method was utilized to investigate the lived experience of neurotypical siblings of children with an autism spectrum diagnosis. This topic has been largely neglected in the current literature, relying on quantitative measures that yield inconsistent results regarding sibling experience. Through the use of the participants' own voices, rather than reliance on outside observers or survey measures, this topic was openly explored in hopes of producing findings that can be used on greater scales in future studies.

Additionally, a qualitative method was chosen to promote acknowledgement of sibling challenges and successes for the participants themselves. The use of open-ended interview questions allowed for the validation and authentication of participant experience, while providing an insider view of the life these siblings lead.

## **Research Design**

A qualitative hermeneutic phenomenological design was utilized for this study. The aim of this research was exploratory, and designed to investigate the lived experience of siblings with a brother or sister diagnosed with an autism spectrum disorder. As the research question is exploratory, or "bottom-up" in nature, a qualitative approach was recommended by Creswell (2009). In particular, a phenomenological study was suggested when examining a subject's lived experience.

A hermeneutic phenomenological approach stems from the philosophies of Husserl and Heidegger (Creswell, 2009). In phenomenology, the researcher is interested in understanding the participant's personal perception of a lived event. Informed by hermeneutics, an emphasis emerges, concerned with situating this perception within appropriate linguistic, social, historical, and cultural contexts (J. Smith, Flowers, & Larkin, 2009). Rather than portray an objective

stance on experience, research becomes a dialogue between examiner and subject, imbued by meaning from both. In this way, phenomenological research may be considered “double hermeneutic” in nature: the researcher is interpreting the participant’s interpretation of a particular experience.

In utilizing a hermeneutic phenomenological approach to research, the investigator must acknowledge the influence of personal bias and sociohistorical context when collecting, analyzing, and interpreting data (J. Smith & Osborn, 2003). Rather than attempt to bracket away these prejudices, as is suggested in the phenomenological approach by Moustakas, the author attempts to be aware of the influences cultural context may impart during analysis of qualitative information (Creswell, 2009). Further, the assumptions of the researcher are considered an integral part to the interpretive process; these influences are considered key contributors to the research process as a whole (Laverty, 2003). Biases, assumptions, and influences may be directly stated, and discussed during any or all of the stages of research. In this way, the researcher interprets the participants’ experiences through the lens of the researcher’s own theoretical and personal knowledge.

### **Recruitment of Subjects**

This study was limited in recruitment by geographical location, as participants were required to attend in-person interviews in the Greater Seattle area. The participant pool was additionally limited by specified criteria for participation. A summary of the sampling strategies employed, participant limitations, and participant biographies is detailed below.

**Sampling strategies.** Within hermeneutic phenomenological research, the aim of participant selection is to recruit participants who have lived experience of the phenomenon studied, who are willing to talk about their experience, and who are diverse enough that each

might offer distinctive stories of the experience (Laverty, 2003). As such, criterion sampling was employed, with the intention of recruiting individuals who have lived as the sibling of a brother or sister diagnosed with an autism spectrum disorder.

Convenience and snowball sampling were also employed. Participants were gathered via distributed flyers and word of mouth. Each flyer featured a brief description of the study, including specificities regarding subject recruitment and research intent. Additionally, the incentives for participation offered were detailed (two \$10 gift cards to a nationwide retail company), as well as contact information for enrolling in the study.

Flyers were posted at a private practice location in Bellevue, Washington, that provides neuropsychological assessment and treatment to children and their families. Flyers were also distributed via email to schools and hospitals in the Greater Seattle area, in hopes of recruiting a more diverse population.

Once a potential participant accessed the contact information for the study, the researcher engaged with the participant to provide appropriate screening data (e.g., age, living situation, sibling diagnosis). Guardian involvement was required for completion of the demographics questionnaire and the screening measure.

**Sample size.** Qualitative phenomenological research does not seek to generalize results; thus a small sample size is sufficient to gain initial responses regarding the research questions proposed (Creswell, 2009; J. Smith & Osborn, 2003). However, in an attempt to gain answers from diverse perspectives, this study gathered seven adolescents for participation.

**Participant criteria.** Subjects were recruited based upon a number of specific variables, including: age, living situation, sibling diagnosis, and lack of current developmental diagnosis.

Additionally, participants were asked to participate in two individual meetings with the researcher.

***Age and developmental stage.*** Children recruited ranged in age from 13 to 17, in effort to obtain subjects with similar developmental experiences. Restriction of the age range to an adolescent level sought to encompass individuals in comparable school grades, who were still living with their guardians, and who were capable of describing their lived experience verbally.

Importantly, this research study takes a relational psychotherapeutic stance on lifespan development. In many models, a child's age is of import; when examining any relationship, being mindful of what is developmentally appropriate must always be considered, both within objective measures and qualitatively. In a relational and hermeneutic approach, when addressing developmental level, it is important to avoid making an assumption of relative value (Altman, Briggs, Frankel, Gensler, & Pantone, 2002). This could include making subjective judgments of a child's social interactions without appropriately considering individual and cultural diversity. Instead, addressing family norms, gender, and the specific environment to which a child is adapting contextualizes the individual, without making reportedly "objective" judgments in appropriate stage development.

***Living situation.*** All subjects were living in the same household with their diagnosed sibling for the period of at least two years. This was in effort to ensure adequate exposure and influence for a relationship study.

***Sibling diagnosis.*** Guardians were asked to provide a statement regarding the diagnoses of their children. On the demographics questionnaire (see Appendix A), a section is dedicated to the diagnosis of the sibling who is not participating, including: type of diagnosis (e.g. PDD, Asperger's, autism, ASD) and date of diagnosis. Additionally, the guardian was asked to

confirm that the prospective subject has never received a developmental diagnosis. No participants were reported to have received a developmental diagnosis prior to study participation.

**Screening for ASD.** Additionally, the parents of prospective subjects were asked to complete a screening survey measure for the potential participant. This survey measure was intended to identify signs of developmental disability within the potential subjects; ensuring participants meet the identifier of “neurotypically developing.” The Social and Communication Questionnaire (SCQ), Lifetime version was chosen for this study. The SCQ is a measure administered to caregivers and frequently used throughout the literature to confirm or rule out developmental diagnoses within the proband and the sibling studied. No participants met criteria for a developmental disability according to the SCQ.

**Demographics.** Although certain variables, such as sibling order, gender, ethnicity, socioeconomic status, and religious background were not controlled for, an attempt was made to gather subjects from diverse backgrounds.

**Participant biographies.** A short description of each participant is included to contextualize the data presented, aid in interpretation of experience, and orient the reader to each voice included within this study. For this study, one male and six females participated. All participants identified as White.

**Sam.** At the time of interview, Sam was a 17-year-old Jewish male whose younger brother was diagnosed in 2010 with an autism spectrum disorder. Sam lived with his mother and younger brother. Sam and his younger brother also spent time with their father.

**Riley.** Riley was a 15-year-old female. Her younger sister was diagnosed with autism spectrum disorder three years prior to interview. Riley lived with her mother, father, and younger sister.

**Julia.** Julia was 13 years old at the time of interview. She was a female whose older brother had been diagnosed with Asperger's disorder in 2006. Julia lived at home with her father, mother, and older brother at time of interview.

**Esther.** At the time of interview, Esther was a 14 year-old female. Esther had two older brothers and three younger brothers. Her second oldest brother was diagnosed with pervasive developmental disorder in 2007, while her youngest brother was diagnosed with autism spectrum disorder in 2016. Esther lived at home with her mother, father, and younger brothers. Her older brother had started boarding school in the year she was interviewed, and returned home for holidays and summer vacations.

**Tiffany.** Tiffany was a 14-year-old female whose older sister had been diagnosed with Asperger's Disorder in 2006. Tiffany lived at home with her mother, father, older sister, and younger sister.

**Michele.** Michele was a female who was 14 years old at the time of interview. Her younger sister was diagnosed with autism spectrum disorder in 2016. Michele lived with her father, mother, and younger sister.

**Abby.** Abby was a 17-year-old female whose younger brother had been diagnosed with autism spectrum disorder in 2015. She and her younger brother split time between their divorced parents' households.

## Data Collection

Prior to interviews, interested parents were asked to complete a demographics questionnaire and the aforementioned screening measure to gain background information and ensure appropriateness of participation for potential subjects. These forms were all completed in-person.

All subsequent meetings were conducted in a private setting. The subject and the interviewer were in a room alone, while parents and guardians waited nearby. The first meeting began with an introduction to the researcher, an explanation of the study and its immediate and larger aims, and the completion of an informed consent document. Verbal review of the consent form ensured participant understanding. This portion of the meeting took approximately 15 minutes. Following verification of consent, the initial interview process began. The first interviews ranged in time from 34 to 67 minutes.

During the initial semi-structured interview, the researcher asked specific open-ended questions regarding sibling experience (see Appendix B). The second meeting, designed for validity checks, ranged in time from 15 to 25 minutes, and allowed subjects to examine the emergent themes for acceptance or correction. At this time, the subjects were asked to review transcripts of the previous interview, make edits as needed, and allowed to add information they felt was not communicated in the initial interview.

Hand-written notes were documented and a digital tape recorder was running each session. A verbatim transcript was generated from each audio recording, and hand-written notes were utilized to draw attention to important points noted by the researcher during each session.

Interview questions were chosen to elicit direct and indirect relational experiences of siblings with a brother or sister with an autism spectrum disorder diagnosis. These questions

were formed from a review of the literature, with particular emphasis on queries taken from *The Sibling Slam Book: What It's Really Like to Have a Brother or Sister with Special Needs* (Meyer, 2005).

The questions covered were designed to gain a better understanding of the lived experience of siblings of children diagnosed with an autism spectrum disorder. As such, questions addressed five subsidiary research points. (a) How do neurotypical siblings feel impacted by their brother or sister with an ASD diagnosis? (b) How do neurotypical siblings perceive their relationship with the child diagnosed with ASD? (c) How do neurotypical siblings perceive their role and remaining relationships within the family? (d) What are the challenges of being a sibling of a child with an ASD diagnosis? (e) What are some factors that contribute to resiliency in this population? An informal and open-ended interview schedule was devised to address these questions (Appendix B).

### **Data Protection**

Upon consenting to participate, each subject chose a code name that was utilized throughout data description. Additionally, each participant was assigned a number. All consent forms, demographics questionnaires, and screening measures were marked with the assigned number and contained in a sealed envelope. All hand-written notes were contained within similar envelopes, marked solely with the identifying number. All paper materials were kept in a locked filing cabinet within a secure office. Access to these materials was granted to the researcher and a designated site supervisor.

Digital recordings were made on a password-protected device. Immediately following each session, recorded interviews were uploaded via encrypted files to a password-protected storage device and subsequently deleted from the recorder. Each encrypted file was marked with



the assigned subject number, as well as the date. All data will remain in these secured locations for at least one year after analysis, and up to seven years should this study be publicized.

### **Materials**

Equipment used included a password-protected digital tape recorder, a computer for uploading files, and a user-only storage device for holding encrypted files. A locked filing cabinet was also utilized for data storage.

**Incentives.** Two \$10 gift cards to a nation-wide retail store were offered to participating subjects. These gift cards were offered at the expense of the researcher and were not sponsored by outside parties of any kind. In general, one \$10 gift card was distributed at the start of each meeting with the subject. Additionally, incentives were distributed to participants regardless of their commitment to the research project.

### **Data Analysis**

This study employed the use of a hermeneutic phenomenological analysis. In implementing hermeneutic phenomenology, the researcher first read, then reread the initial interview, making primary annotations directly on the transcript (J. Smith & Osborn, 2003; van Manen, 1990). Afterwards, the data was examined again; the researcher then marked emergent themes that became apparent through annotation and direct verbiage. Once complete, the emergent themes were analytically interpreted to discern connections, wherein super- and subordinate connections became clear.

This process was completed for each transcript, requiring an iterative analysis of each set of data (J. Smith & Osborn, 2003). From the subsequent themes generated, a final table of superordinate themes and subsets evolved, intertwining results emergent from each participant's

account. This table was then transformed into a narrative account, accented by case examples and quotations from the original data.

Additionally, when applying hermeneutic phenomenology, the researcher attempts to make clear when biases and subjective judgments based on personal experience occur during the process of analysis. Rather than attempt to bracket away these opinions, as is popular in some forms of phenomenology, hermeneutic phenomenology insists on the impossibility of the removal of one's own perspective (J. Smith et al., 2009). Thus, the researcher attempted to be aware and made note during each stage of analysis when personal assumption and interpretation may have entered into the methodological discourse.

### **Data Quality**

When performing qualitative studies, one method of ensuring the validity and reliability of the data analysis is by conferring with the original participants (J. Smith & Osborn, 2003). During the second meeting, the author presented the transcription of their personal account to each participant, discussed the emergent themes, and asked for their insights regarding the accuracy of the results. Participants offered feedback on the data, the themes presented, and on some occasions shared further information regarding the research questions upon reflection of the initial interviews. Data collected during this stage was useful in revising thematic organization and ensuring the authenticity of transcriptions and meaning making. This second data collection was thus used to inform and confirm thematic development.

A second method of maintaining data quality was through peer review. Presentation and discussion of themes with colleagues, aids in finding congruence between data and the interpretations that emerge. Use of peer review was implemented throughout the development of

research methods, within the initial stages of data analysis and after the generation of thematic findings.

In addition to these measures, use of an audit trail to detail researcher decisions regarding thoughts, methods, and procedures highlights potential bias and values that influence the research proceedings (Patton, 2002). A research journal was utilized throughout the course of the study to document emotions, interpretations, and influences that arose. This was of benefit when participating in peer review, understanding the emergence of themes, and for reporting findings at the conclusion of the study.

## Findings

Findings from a hermeneutic phenomenological study on adolescents' experience of living with a brother or sister diagnosed with an autism spectrum disorder are reviewed in this chapter. Within this study, participants were asked to describe their experiences from five main questions, including: (a) How do neurotypical siblings feel impacted by their brother or sister with an ASD diagnosis; (b) How do neurotypical siblings perceive their relationship with the child diagnosed with ASD; (c) How do neurotypical siblings perceive their role and remaining relationships within the family; (d) What are the challenges of being a sibling of a child with an ASD diagnosis; and (e) What are some factors that contribute to resiliency in this population?

Data were analyzed using continuous thematic reflection (van Manen, 1990). Seven themes emerged from this analysis: (a) personal impact, (b) familial impact, (c) social impact, (d) relational understanding, (e) socio-cultural influence, (f) future outlook, and (g) advice.

Each of these themes and their subthemes are described in this chapter and illustrated by direct quotations from participants' interview transcripts. Chosen pseudonyms, brackets, and replacement of sibling names for phrases such as "my brother" or "my sister" are utilized to ensure anonymity.

### Personal Impact

Participants described feeling personally impacted by living with a sibling diagnosed with ASD. In this context, "personal impact" is used to describe an effect more directly related to the individual, implying an internalized influence on the participant's way of being. Within this study, personal impact was discussed in terms of: (a) emotional tolls, (b) a sense of increased personal responsibility, and (c) personal enrichment.

**Emotional tolls.** Participants identified experiencing a number of negative feelings in response to sibling behaviors. Embarrassment and fear were most often reported. One participant also shared feelings of anger, while another mentioned sadness. Though these emotional experiences were often framed in a dismissive way, they appeared to greatly impact participants, affecting their environment and subsequent behaviors.

Five of the participants expressed feelings of embarrassment following sibling interactions with strangers and friends. Abby reported, “And he’ll say stuff and do stuff that feels embarrassing to me. Like, ‘[Brother], stop it! Oh my God, why won’t you stop doing that?’” Of particular note, participants were adamant that they did not blame their diagnosed siblings for their socially awkward behaviors, and understood that social interaction was difficult for them. Tiffany gave voice to this feeling: “[My sister] doesn’t really know when she’s doing something wrong. It’s not self-centered, because she can’t control it. It’s totally her Asperger’s, but it’s kind of in a self-centered manner.”

Though all participants voiced understanding regarding their siblings’ embarrassing actions, the social implications for these feelings of mortification were also evident. Sam shared, “I find him to be, kind of an embarrassing little brother, so I don’t very often like it when my friends meet him.”

Fear was another prominent emotion endorsed by participants. Subjects reported feeling both fearful of and fearful for their siblings. All of the diagnosed siblings were described as participating in verbally and/or physically aggressive behaviors at some point in their lives.

Esther recalled how pervasive her brother’s aggression seemed:

I grew up with lots of yelling and violence. I mean he would just kind of, you know, hit, and he was just that kind of person. There was never a day when there was not constant, you know, rants, and bickering, and that kind of stuff. I don’t know, I’ve never really known anything else, so it’s kind of—yeah. He would go on rants for, like, three hours

and throw things, and like, call the police because he wanted—you know what I mean? That kind of stuff. Like he would get in a rant for three hours and then be like, “I’m calling the police,” and he would call the police.

Thus, a culture of fear often became pervasive in the environment. However, the constant nature of the emotional experience seemed to become normalized and accepted by the participants. As Julia said, “The fights [my brother] would get into with my parents sometimes were scary for me. But I like, got over it, and then he stopped.”

Fear was also expressed in relation to concern for ASD siblings. Four participants reported worries that their sibling would have difficulties socially interacting to the extent that they might find themselves in danger, either physically or emotionally. Tiffany said, “I always get nervous because she always wants to approach people who don’t really know her. And, she wants to like, give them hugs and stuff. She’s really a hugger. And so, then, I get really stressed out.”

Abby shared her brother’s experiences with aggression within his school environment:

And that was another thing, was at school, if he got really mad and hit another kid, you know, a kid could hit him right back. And there were times when he was like, “Oh, this kid scratched me. Oh, this kid hit me. Oh, I got punched, you know, here.” And he would come home from school and I would be like, “Why is he going there? Why is that happening?”

Abby, Sam, Tiffany, and Esther all drew from previous experiences in which their sibling had engaged in social interactions that had placed them in harm’s way.

**Personal responsibility.** All but one of the participants endorsed a heightened sense of personal responsibility. Subjects frequently described assuming the role of family caretaker. As an extension of this role, participants reported undergoing an intensive and constant process of self-monitoring.

Subjects identified with the role of protector, advice-giver, or coach for their diagnosed sibling. This sense of responsibility was prevalent regardless of participants' age and birth order.

For example, Esther shared:

Well, with my older brother, he just got back and this is my first time I've ever been responsible for him. . . . Since he has no friends, since he had to ditch all of his friends because they are all drug addicts, it's kind of my responsibility to keep him busy and like, do things with him.

Occasionally, siblings reported feeling as if they were the only one who could support their sibling, and as such, felt obligated to fulfill this role. Riley said, "Sometimes [my sister] can't understand when daddy or momma are trying to help her, but I am good at understanding her and helping so she can understand what the work is."

This role of caretaker was extended to other siblings in families with larger than two children. Both Esther and Tiffany provided examples in which they attempted to help their neurotypical siblings better interact with their diagnosed siblings. Tiffany said, "[My diagnosed sister] has little problems with our little sister, who's 11, and they get in conflicts quite a bit. But I'm normally the peace-settler with them."

In addition to assuming a caretaking role, participants also offered numerous instances in which they were careful to monitor their own behaviors. This tendency appeared tied to a desire to reduce inflammatory situations involving their diagnosed siblings. Abby noted, "What keeps me calm is that I know that I have to stay calm. Because otherwise, it's just going to get so much worse, and it's going to escalate, and make it harder for everyone." Esther shared a similar viewpoint:

But, we've had a lot of discussions over the years on how to deal with it, and how we need to act with [older brother], and how we just need to stay calm, and if something starts, we just can't react, no matter how much it frustrates us. We have to not yell back, because it's just going to make it worse. We just have to be like, "Okay [older brother],

you're right, I probably shouldn't do that," or whatever, and then just go upstairs and go to your room.

Thus, participants focused on changing their own behaviors, accepting that their siblings would not adjust theirs'.

**Personal enrichment.** Five of the participants reported feeling as if they had learned several lessons from interacting with their diagnosed siblings. The growth of personal traits, such as being calm or tolerant was frequently endorsed. When asked what was the most important thing she had learned in helping her sister, Riley replied, "Patience."

At times, the participants had difficulty putting into words what exactly they had learned, because the experience of living with a diagnosed sibling was so impactful. Esther shared, "I feel like that's the most important thing that's happened in my life. I really do believe that. It's like, the most crucial thing in my life. I don't know, because it's just affected everything. My entire way of thinking is based off of that."

Participants most often described personal enrichment experiences immediately following descriptions of difficult interactions with their diagnosed sibling. For example, when talking about living with her brother, Abby said:

Um, you know, it changes all of our lives. And, I think it's made things a lot harder. But, we also want nothing more than for [my brother] to be happy and thriving in his environment. And, as hard as it can be, I really think it's helped all of us. And, we've all learned from it.

In this way, participants appeared to defend the behaviors of their siblings (or make allowances) by offering the "silver lining" of lessons learned. Thus, though participants acknowledged the challenges that living with their ASD siblings posed, these difficulties were accepted because they yielded personal growth within the participants.



## **Familial Impact**

The family system was a significant topic of discussion as well. Subjects indicated that their siblings' behaviors affected family dynamics. Participants often described their families in oppositional terms, offering feelings of discontent paired with admiration and a sense of connectedness. As such, the most prominent subthemes were: (a) family conflict, (b) a chaotic family environment, and (c) familial bonding.

**Family conflict.** When discussing their families, all seven of the participants described experiencing family conflicts, with regards to their siblings' behaviors. Conflicts occurred at every level of the family system: between siblings, between parents and siblings, and between parents.

Participants shared feeling as if they constantly argued with their diagnosed sibling. Abby reported, "Yeah, and you know, my parents, I think, don't think that I understand [my brother] or like, give him enough credit. Because him and I fight, like, all the time. I can't stand him." Michele felt similarly, reporting, "So, I'd say most of the time we either ignore each other or there's fighting. There's not a lot of good that happens."

In addition, conflicts regarding how to treat the diagnosed sibling frequently occurred. Esther, whose oldest brother is neurotypical, described fighting with him on how best to treat her diagnosed brothers: "And with [oldest brother] and I, we have a lot of like, arguments on how we should be handling [our diagnosed brothers], because we handle our brothers differently. We have a lot of arguments in that kind of way."

Arguments regarding treatment of diagnosed siblings frequently extended to altercations with parents as well. Sam shared an example of conflict with his brother, which led to an argument with his mother:

A perfect example: Awhile back, [my brother and I] were fighting. I don't remember what it was about. And it got out of hand. I tackled him against the counter, or something like that. And my mom did freak out. She yelled at me, and I kind of retreated into my room. And then she yelled at him a lot too. And I'm so used to being on the other end of that, where he's being the unreasonable one, and I'm getting a lot of disciplinary feedback. . . . And I confronted my mom about that. I said, "You shouldn't have yelled at him. I was being unreasonable in that situation. This is why I'm frustrated when you take his side in our arguments."

Six participants shared experiences in which they engaged in disagreements with their parents regarding how best to treat their diagnosed sibling. Many conflicts stemmed from disputes regarding differential treatment between participants and the diagnosed sibling. As Riley noticed, "At one point I was jealous, because I had been making my own lunch since I was in third grade, and she was still getting her lunch made." Other conflicts were generated when participants felt they knew how best to handle their ASD sibling. Michele stated,

So, again, the main thing that me and my parents fight about is parenting strategies. Because I'm like, "If you keep on letting her keep on like this, she's only gonna get worse." And they're like, "Well [Michele], she's special needs." And I was like, "That doesn't mean she gets away with everything that happens in the house!"

Two participants reported increased parent to parent arguments due to sibling behaviors.

Michele shared:

Um, [my sister] is tearing this family apart. Like, actually 90% of the fights between mom and dad are because of her. Um, my mother is—I've never seen her worse. She's driving, she never has time off, and she's like depressed, and it's because of [my sister]. Because [my sister] is screaming at her 24/7, and she is like always with [my sister], so she's always getting the brunt of all of [my sister's] stuff. And then, dad, he doesn't spend time with [my sister] because he's out working, and then he'll travel for work. But then when he gets back, mom's already so stressed out, that she like, snaps at him. And then he's stressed out, because of work, so he snaps back, and then

The amount of conflict contained within the family system appeared to contribute to an overall sense of a chaotic family environment, the second subtheme of this section.

**Chaotic family environment.** Five participants illustrated their home life as stressful, tiresome, and hectic. In order to best support the diagnosed sibling, families were described as

endlessly driving to appointments, switching schools, and involving professionals into the family system. Abby said, “It really changes everyone’s schedule. Before I was driving, having to take him to all of his appointments, and having to go to this and that. I would get annoyed, because I didn’t want to sit in the car while he had a therapy appointment.” Sam shared that his younger brother had switched schools so many times, that he did not know which one his brother was currently attending: “It’s a little embarrassing. Because people ask me like, “How old is your brother? Where does he go to school?” And I don’t really answer these simple, simple questions. I mean, he has bumped around schools a lot, recently, so that’s part of it.”

Participants reported feeling as if oftentimes, the family schedule revolved around their ASD siblings’ needs. Tiffany said,

Okay, when [my sister] switched to her new school, mom has to drive her, and she has to do this and that, and she has to go places, and she’s gone a lot from home. Um, and that’s one of my biggest things, is when she first went to this school, I learned that my mom was going to be driving her, and I’m like, “But what about me? I’m going to go places too.

In many of these circumstances, once participants were old enough to drive, they also gained the responsibility of transporting their siblings to various locations.

The hassle of added appointments and distant school drives appeared to mingle with the frustration of family conflict to create an emotionally draining atmosphere. Abby shared this perception of her family environment:

It’s never calm. There’s always stuff going on; [my brother] is always running around. Well, I guess that’s not true. If you put him in front of the TV, he’s fine. I hate that electronics is like, the only way to calm these kids down. That really annoys me, but at the same time, you’re exhausted, and you’re like, “Just sit in front of the TV please. Just—go do something.” . . . It just, you know, causes tension, a lot. And, I get the: “Don’t be the parent” all the time. And the: “He has special needs!” And he’s still an annoying little brother! Um, just, and you know, it does cause conflict in everyday life. And, you know, constantly having to be like, “Don’t yell at the nanny. Don’t be mean. Be nice. Do this, do that.” And it’s constantly like—it’s never just existing with him.

It's like, "[Brother], watch out. [Brother], stop this. [Brother] stop that." That's really difficult.

The stress of conflict and external demands on family time appeared to take an emotional toll on not only the participants, but on their family systems as well. Michele said:

I just wish that, like, my family, in just general, had more energy kind of thing. Because, you know, we're all just so tired. And I'm so tired too, kind of deal. As far as my family goes, I've just definitely noticed over the past few months, just like, I generally (without even knowing it), I've like shut down. By the time, I like, get in the car to go from school, I think the most conversation that goes down is like: "How was your day?" and I'm like, "Good." . . . Because everyone's tired, everyone's like—my family just seems depressed right now.

**Family bonding.** Despite conflicts and a stressful home environment, all but one of the participants shared that they had good relationships with their family members. This was particularly true of their ASD siblings. For instance, Julia described her brother in a positive light: "Um, he's really nice. Like, he's always there for me. Um, he has a good sense of humor. I just enjoy being around him." Participants portrayed their families in terms of connection, cooperation, and collaboration.

Six of the participants indicated that one of the most integral pieces to managing the balance of the family system was sharing information about family decisions regarding their diagnosed sibling. Tiffany provided this perspective:

I know everything because my parents share everything with the family because we're really, quite an involved family. You kind of have to be, with [my sister]. You have to be involved with her. . . . I think if my parents would have kept it more hidden, it just wouldn't have been as easy. But, when we're so involved, and I know everything, I can help, instead of just like, being confused.

The emphasis on family involvement and collaborative understanding of sibling diagnosis, behaviors, and supports was repeatedly conferred. Participants spoke frequently of the desire to be included in these conversations so that they might be helpful to the family as a whole.

In addition, four participants reported admiration for their parents' abilities to work together to meet the needs of their diagnosed sibling. Abby, whose parents were divorced, described learning about cooperation from her parents:

I mean, and [my parents] have to completely put their differences aside when they have to, when it's for the common good of their kid. And, they get annoyed with each other, and they piss each other off, but they have to work together for the good of [my brother]. And that's something that I've really learned about them. About just working with other people for, you know, the same goal. Which is to keep [my brother] happy, and safe, and thriving in his environment.

Perhaps fueled by the need to resolve and reduce conflict, four of the participants described feeling as if managing their diagnosed siblings' needs caused the family system to grow closer to one another. Esther communicated this sense of familial bonding:

But it's like, when I go to other people's houses, I feel like we're a lot closer than other families are. We're so open with each other, and we know each other so well. We fight all the time, but we also love each other really passionately. . . . I feel like we're all very very close, compared to other families, I really do think that we're close. I think that we all—since we all kind of had that really big, traumatic experience with our brothers, I think that it brings us closer. And it kind of—I feel like we know things that other people don't, and so, we can have these conversations, you know? We went through that together, and I feel like we just have that bond, you know?

Thus, the sense of family connectedness is not “in spite of” conflicts and a chaotic environment, but may instead be born “because of” these types of experiences.

### **Social Impact**

Six of the participants described experiencing social sequelae, as a result of having a sibling with an ASD diagnosis. In this theme, the impact on the participants' social realm is described. Social impacts were discussed with regards to (a) social sacrifice, (b) isolation, and (c) seeking understanding.

**Social sacrifice.** Four of the participants shared stories of social sacrifice. In these examples, “sacrifice” is used to denote a social expense, generally regarding friendships.

Frequently, participants reported instances in which their diagnosed siblings had targeted their friend groups, causing social distress. Esther described a typical interaction with her brother when she had friends over to her house:

[My brother] only likes a certain kind of person, so he doesn't like a lot of my friends. So, he can kind of be rude to my friends. Like, if we come in the game room, he'll be like, "You can't be in here." And they'll be like, "Wow, what a jerk." But, he just doesn't like to be around people. He doesn't have that, like, self-control, to say like, "Oh, it's fine, you can be in here." He just kind of like, yells.

In this manner, Esther had to place her brother's desires above the comfort of her friends. She defended his actions, indicating that he was unable to socially interact in an appropriate manner. This type of defensiveness appeared in many participants' descriptions.

Occasionally, the social expense was unintentional, but caused distress nonetheless. Sam provided an example: "[My brother will] sit there, and he'll hum, and he doesn't even realize he's doing it most of the time, but I'll have friends that will come over, and it will drive them crazy!"

In other examples, the social sacrifice was more apparent. Three of the participants described specific instances in which they placed their diagnosed siblings before their social connections. Abby shared her personal rule: "If I ever had someone over who is like, "You're brother is so weird," I'd be like, "Get out of my house." I'm not going to be friends with someone that can't appreciate him or can't understand him."

Abby additionally illustrated her feelings with an example in which she prioritized her brother over other social relationships:

[My brother] came to a swim meet of mine, when I was still on the team, and he just refused to leave without wearing his Spiderman costume. And one of the kids on my team was making fun of him, and I said, "We're gonna go outside." I made the kid cry, I came back inside, and [my brother] said, "Why is that boy crying?" And I said, "Don't worry, sweetie. I took care of it." It's like, you don't mess with my family. You don't mess with my brother because you don't get it. You don't understand, and you have no

right to speak that way. And, so if anyone tries to do anything to him, I go full momma bear, and I'm like, "Don't touch my little brother." I will get like, really pissed.

Thus, the sense of personal responsibility described in the subtheme above appeared to socially affect participants as well. Tiffany recalled a year in which she organized her recess around her older sister:

That was one of the biggest things, is when we were in elementary school she had a lot of trouble making friends. It was really hard for me and I would normally be the only one that would play with her at recess. Because I didn't like that she didn't have anyone to play with, because she would try to make friends, but all these people were just jerks, and it like, broke my heart that they were so mean.

Tiffany's prioritization of her sister's emotional and social needs inadvertently resulted in a sacrifice of her own opportunity for engaging in peer relationships.

**Isolation.** In addition to prioritizing their siblings' over other social relationships, participants illustrated their experiences with feelings of isolation. Participants described multiple instances in which they were ostracized from social interactions due to the nature of their diagnosed siblings' behaviors. Six participants endorsed this subtheme.

Limited social ventures were one way in which participants felt isolated. Michele shared, "Um, I feel like, you know, there's always that one weird family that you see in public, and you're like, "What the heck?" I feel like we're that family. Like, we don't go to restaurants often. Heaven forbid." Michele went on to describe why her family avoided outings such as going out to dinner:

Usually there's like, some sort of scene and it's embarrassing for everyone involved, except [my sister]. . . . We can't have dessert, so she starts screaming, and like, banging the table. Stuff like that, in a family restaurant. Or, she's done, but we're not, so again: screaming, banging table. She's just like—she gets very physical.

As in Michele's illustration, subjects reported avoiding situations in which they knew their ASD sibling would become dysregulated.

In some cases, participants described engaging in social ventures, but then needing to leave partway through, as their diagnosed sibling became emotionally activated. This most frequently occurred in situations that were filled with sensory stimulation, such as amusement parks. Many participants noted that their ASD siblings had difficulty with this type of environment. Julia shared, “If there’s a situation where it’s like really loud or crowded, [my brother] doesn’t like it.”

Another form of social isolation came in the form of the self-containment of problems. Six of the participants described feeling as if there were limitations on sharing their personal challenges with other people. Esther became tearful when she attempted to portray how isolating the experience of living with her brothers seemed:

Yeah, it’s definitely hard with friends. I don’t like explaining things to them. Because it’s like, you can’t really explain how it is, because they would never understand, right? They would never understand how that is. It would never be as bad as they think, right? Like, people think it’s not as bad as it actually is, right? You can’t really explain to someone who doesn’t have any actual experience with that, in any way. Because it’s just so—you cannot understand it. You know, because we barely understand it ourselves. There’s no way. Like, I never even try to, because it’s like, “What’s the point?”

Though participants seemed to feel it was not beneficial to internalize their experiences, they also appeared unsure how else to manage these feelings. When asked how she dealt with challenges, Julia replied, “I don’t know. I guess it’s probably not very good, but I just kind of keep it to myself.”

**Seeking understanding.** Perhaps in an attempt to minimize their social isolation, four participants reported experiences in which they sought out other individuals with connections to ASD. These connections were twofold. Some participants made bonds with individuals who had a family member on the autism spectrum as well. Other participants specifically searched



for individuals who were diagnosed on the autism spectrum, or who had general challenges with socially relating to others.

Those who described seeking out relationships with others who had similar family situations reported a feeling of mutual understanding. Sam illustrated this sense, sharing, “It’s almost a bonding thing. There are other kids at my school who also have siblings with autism, and they’ll joke that we have a club.” Tiffany’s best friend also had a sibling on the autism spectrum:

I feel like it’s easier for kids who have siblings or family members on the Spectrum to understand. Like, my best friend, her little sister can’t speak, and she just makes noises. Um, I don’t know what kind of autism she has, but it’s more farther up there. And one of the reasons why she’s my best friend is that she totally understands that. But, um, like, people like her and me understand the kids in the learning center and are more compassionate and nice to people because we know and understand.

Not only did her best friend appreciate Tiffany’s own experience, but also there was a sense that both girls better understood those with personal challenges. Additionally, they actively sought out those individuals to offer this opportunity for shared understanding.

This desire appeared shared by several other participants. Abby revealed that she worked at a summer camp for teenage girls who were diagnosed as on the autism Spectrum. She reported that she felt she had a unique perspective and approach to dealing with these adolescents, due to the time spent with her diagnosed brother. She said:

But, last summer I worked as an intern . . . and I had no idea what I was doing. But, I loved going to work everyday. And I love working one-on-one with kids. . . . But, every other kid with special needs, I can figure it out. And I don’t know everything, I don’t know what I’m doing a lot of the time, um, but I’ve observed and I’ve learned and I know the compression, and the hug, and different ways to, you know, interact with them, and figure out how to talk to them when they’re upset. Um, and you have to just be very observant to how they’re feeling and how, you know, their needs show up.

Esther felt the same way. In addition to volunteer work that she completed at an Autism Awareness program, she described seeking out individuals who appeared socially isolated. She

said, “Most of the time, I go around at lunches and I find people who are sitting alone, and I sit with them. And I get to know them and most of them . . . have some sort of autism, or some sort of you know, difference.” Esther went on to describe how she felt a shared understanding with these individuals: “I get really attached to people who are alone or sad. So, I don’t know how I’d be without my brothers, but it’s definitely made me understand people more like that. It’s like, I do it to help them, but they help me, you know?”

### **Relational Understanding**

The experience of living with a sibling diagnosed with an autism spectrum disorder appeared to affect the manner in which participants understood relationships and interacted with the people in their lives. The term “relational understanding” here indicates the manner by which participants perceive and exist within the framework of a relationship between themselves and another person. It includes how participants approach relationships, how they manage conflicts within them, and the manner by which these relationships are sustained. Living with a diagnosed sibling appeared to perpetuate 2 disparate approaches to relationships: (a) emotional attunement and (b) withdrawal.

**Emotional attunement.** In this instance emotional attunement constitutes the ability to perspective take, enhanced communication skills, and emotional sensitivity to the feelings of others. All of the siblings expressed this ability. Most of them related their emotional sensitivity and conflict management approaches to their experiences at home. Abby observed that her family interactions influenced her style of conflict management:

It really teaches you to be aware at all times, and be understanding of how you’re speaking to them, and hearing them, and interacting with them. And, you know, tough situations like [with my family], have helped me with tough situations just like, with my friends. Instead of freaking out and being like, “I can’t believe you did this!” I’m kind of like, “You know, it kind of annoyed me when you did this, and this is upsetting to me.” And staying calm and not getting, you know, upset.

Sam also described a similar approach, offering an example of a conflict with a peer:

It would be very convenient if I could make clear to everyone that I am being sincere almost all of the time. My sarcasm goes completely misunderstood very often, and that's I'm sure, because of this communication style that's been brought into our family. I had a run-in with a girl last year. We were arguing about something inane. I had a bad hairstyle at the time and she said something bad about it later, and it started this huge argument that was blown way out of proportion. I, during that argument, tried to be very understanding to her side, and like, sympathetic about her frustrations with me. And she thought I was being completely sarcastic the entire time, because she couldn't possibly believe that anyone would approach it like an argument or discussion in that way.

In this case, Sam's thoughtful and sensitive approach to conflict management was misinterpreted by his peer as disingenuous.

In addition to conflict management, all of the participants described a desire to understand others, their behaviors, and their motivations. Each pointed out the importance of perspective taking. Tiffany put this desire eloquently, saying, "My biggest thing is just: don't judge people, because you don't always know what's happening at home."

**Withdrawal.** All of the participants expressed engaging in withdrawal as a response to conflict management. This was particularly prevalent when discussing familial conflicts. When asked about these conflicts, the similarity in response was easily seen and highlighted by Abby, Riley, and Julia. Abby said, "Um, but, even if there's stuff going on in the house that I don't think is the right thing, I kind of just stay out of it." Riley reported, "I just stay out of it." Julia shared, "I normally just stayed out of it and let my parents deal with it."

Additionally, the participants described actively avoiding interactions with their family members, particularly when under intensive stress. Michele illustrated this avoidance, "I like, you know, just kind of hide out. I like watching TV and doing homework—well I don't like doing homework—but I do it, so. I just kind of like, lock myself in a dark room and—[laughs]."

Sam appeared to agree, adding, “[My brother’s] a lot to handle sometimes. I mean I also get home and kind of retreat into my room a little bit after an overwhelming day.”

Abby and Esther shared moments in which they removed themselves from the house when feeling overwhelmed. Abby stated:

Sometimes it’s like, if [my brother] gets on my nerves and my parents are annoyed, I’m just like, “Can I come over to your house? I just don’t want to go home.” It’s hard to deal with him. You know, during finals, he stays at my dad’s, because I can’t have him around when I’m studying. Because, I mean, I just can’t. It’s way too much. Um, and, you know, if he’s really pissing me off, I’ll go downstairs and get away from him. Like, I’ve learned how to—you know if he’s getting on my nerves, just, get away from him.

Esther’s story was similar:

Like when the rants would used to happen, I would just go on a walk. Like I would leave the house, because I couldn’t be around that, you know? And like, when [my brothers] came for Christmas and they got into a humongous fight or something, I just had to leave. I was just like, “I cannot do this again. I can’t just sit and watch,” right?

Additionally, two participants reported efforts to engage in an individuation process, in which they separated and distinguished themselves as “their own person,” separate from their siblings and family. Riley and Michele emphasized the importance of personal growth outside of the family system. Riley stated, “Like, try to help as best you can, but don’t make it your entire time. . . . Like, I have soccer and track, so I do that. I bake, and I just do things that I like to do, and stuff like that.” Michele added, “I’m always at the barn, or at a friend’s house, or, you know, at school (because school takes up a lot of energy and also meetings with teachers and stuff like that). Then, if I did an after-school sport, I’d get even more time off.” In this manner, the participants engaged in activities related to their own interests and which removed them from the familial environment.

## Socio-cultural Influence

The experience of each of the participants is situated within the broader context of societal and cultural influence. The manner in which society and culture understand and portray autism spectrum disorder led to significant effects on all of the participants. Each of them spoke to various sociocultural values and customs that framed the way in which their experiences were interpreted and felt. The influences most discussed by participants were: (a) education and (b) the construct of normalcy.

**Education.** The broad category of education encompasses the process of gaining and imparting knowledge about autism spectrum disorder. Five of the participants described actively seeking to educate themselves about autism spectrum disorders. Sam shared his experience, in which his family all focused on learning more about ASD:

Um, just the endless books that have come streaming into the house, with what you're supposed to do with the situation. I mean, I think that's where all these classes are going, is how to figure out how to deal with [my brother]. And then, as soon as that language from the books starts getting circulated, everyone has to learn how to deal with him differently, and that affects how we talk to each other differently.

Esther described a similar desire to learn more about ASD. She said:

I want to understand [people with ASD]. And, like I said, I'm really interested in it. And, I really like people. I like understanding people. So, my teacher . . . would recommend stuff to me. . . . And when you read the books, you just learn more and more and more about them. You understand them more, and how to be around them more, and how to react when they do some things, you know?

In some circumstances, participants reported greater knowledge of ASD through their personal experiences, as opposed to more formal means. Abby illustrated this approach: "I mean, I didn't know anything about the autism spectrum or sensory processing disorder, and I never, like sat down at the computer and like researched about it. I just kind of figured it out and learned about it just from living with [my brother]."

The other two participants reported that knowing more about ASD would not change their perspective on their siblings, and so, felt no need for further education. Riley observed her own feelings on the matter, stating, “At some point, my mom was like, ‘I’m gonna have [your sister] tested, but don’t tell her.’ And, I don’t know. I’m still not really sure about it. . . . I don’t really care. I don’t think it would change anything.”

Whether participants expressed a desire for further information on ASD or not, all participants reported that their first educational experience regarding ASD came from their parents, when they were told of their siblings’ diagnosis. Abby recalled the moment she discovered her brother was diagnosed as on the autism spectrum:

I don’t remember specifically if there was a sit-down, specific conversation, but I remember that it was just kind of like, “Why are we pulling [my brother] out of school? What’s going on?” My mom was like, “We had him tested. He’s on the autism spectrum. You know, this school isn’t good for him.” . . . I always had a suspicion, and it kind of made sense. And you know, it like, didn’t change anything. I like, like I said, it wasn’t like, “Oh! Well that makes sense now. He does this; it makes sense now.” I mean it didn’t really change anything. It’s just like, okay, that’s another thing that we have to be aware of.

As Abby illustrated, many of the participants seemed unsurprised by their siblings’ diagnosis. Julia remembered when she was told: “Well, my mom kind of told me and I just noticed that sometimes he would just act—different.” Michele added a similar experience, reporting, “My parents sat me down and talked to me about it, obviously. Which was definitely like a: “Okay, so this is a thing. . . . They were just kind of like, well, like, ‘As you may know already, [your sister] is very special needs, so—just don’t piss her off.’”

In addition to learning about autism spectrum disorder, five of the participants described assuming the role of educator, in order to inform others about ASD. Most frequently this role was assumed in order to correct misperceptions about ASD. Tiffany reported these types of experiences as one of her greatest frustrations:

Yeah, um, that's like, one of my things, like at school, when they are trying to teach us or show us [about ASD], they just don't know how to explain it because they don't know how to say, "Here's what it is," because they don't have any experience! And someone like me, who has experience, and is like, "Okay, this is actually what you do when you are around a person [diagnosed with ASD]. And they're not that different, so you don't need to treat them like they are young, or like they are not as high as you." And that's kind of what they teach you at school: is like, "Oh, you need to be nice to these kids." But, if you just need be nice to them, you're not going to end up being their friend. And so I feel like at school they kind of take the wrong approach. And so I'll always educate my friends and stuff like that.

Esther had similar complaints about the understanding and treatment of ASD individuals within the school environment. She also felt the desire to educate school officials about ASD. She shared this story regarding the interactions between her diagnosed friend and her math teacher:

My friend has autism and is pretty different—and [my teacher] just doesn't know how to act with him. Like, on the teacher's side [my friend] would be really frustrating, and really hard to be around, and really tough. I know how the teacher feels, and I know how the kids around him feel. But if [my teacher] were just to reach—I wish that I could just like, talk to him sometimes, and just tell him, "That's not how you are supposed to respond."

**Normalcy.** The construct of *normalcy* was discussed frequently by all of the participants. Normalcy was described as a state of standard, typical, usual, expected, or average way of being. In this subtheme, normalcy was discussed in terms of understanding ASD differences, making comparisons, expectations of normalcy, and achievement of homeostasis.

With regards to the diagnosis of ASD and the behavioral sequelae that accompany it, the label of ASD appeared to indicate that diagnosed individuals were in some way "not normal." Esther spoke to this difficult concept, sharing, "I mean, there's things that [younger brother] does. Like, he'll just come to the hot tub and strip down naked in front of all my friends and just get in. And it's not weird to him. And he's in fourth grade. That's not normal, right?" Tiffany observed:

[My sister] doesn't try to be normal, and she knows she's not normal. But, I've had her say to me, many times, "I wish I wasn't—sometimes I wish I was not on the Spectrum." She'll be like, "[Tiffany], sometimes I wish I wasn't on the Spectrum." And I'll say, "Why, [sister]?" And she'll be like, "I just—I want to be normal." I'm like, "Are you sure, because normal is not as fun as you think it is." Um, and no one is normal; everyone is odd.

In addition, the sociocultural description of normal family or sibling interactions caused participants to engage in comparisons between themselves and other families. Five of the participants reported differences between their family experience and those of "normal" families. Sam compared his relationship to his brother to those of other families he knew:

Um, the thing where I really notice where our relationship is different from that of siblings that I see around school is that I can't mess with him. I can't push him. Because he freaks out, and it's because mom is very protective of him. But, I feel like that's a bonding thing that a lot of siblings do that I'm kind of missing out on. And I wish that I could have conversations with him about things in my life, things that are going on. Brothers seem like they are supposed to be able to do that on some level. But I suspect that I will never be able to have conversations with him about drugs, or alcohol, or girls. I just don't see that happening. I don't see those things influencing his life.

Similarly, Tiffany opened up about the other sibling relationships she knew of, describing:

There's just some things, you know, I wish. All my friends, their older sisters drive them around. And they'll like, just drive them to the mall and do stuff like that together. Like, they'll go to the movies together or they'll go shopping together. Or just go do special stuff together. But [my sister] just refuses to drive, and it's harder to do that with [my sister] because she doesn't like public places as much.

In contrast, two participants stated that their siblings and families as a whole were fairly normal, and emphasized the commonalities over the differences. Julia's beliefs were reinforced when she encountered a classmate who had also been diagnosed with ASD: "Um, there was a kid in my grade for a couple years that had [autism spectrum disorder]. It was a lot more severe. I used to think [my brother] was like way more different, and then once I saw the way more severe [diagnosis], he was like almost normal. Which he is."



In addition to the comparisons regarding normalcy that the participants made themselves, two of the subjects described feeling as if there existed an expectation that they would fulfill the role of “the normal ones” within the family. This expectation appeared to be generated by their parents. Esther reported:

It’s different with my dad. He expects a lot of me, because I’m one of the normal ones. So I’m expected to—like if I ever do something, he’ll be like, “I’m not doing this again,” or something like that. Like, if he were to ever find out that I tried drugs or something like that, he would be like, “Oh my god, you’re going to become a drug addict!” You know what I mean? He kind of compares everything that I do to everybody else.

Michele expressed a similar theme, saying, “I feel like, if [my sister] was normal, then [my parents would] be fine. But, like, they need a perfect child now, because their other one is not doing so well.”

Regardless of comparisons, all of the participants described feeling as if a “normal” or homeostatic state had been achieved within their family environments. The sense that “things have always been this way” was pervasive. Sam illustrated this point when he attempted to recall when his brother received the ASD diagnosis: “I have no idea [when it happened]. It’s been kind of an always thing. Huh. We are five, no we’re three years different? No, four or five. And, so that’s about when you start remembering stuff, when you’re four or five. And that’s about right when he showed up.” Abby reported a similar feeling. She said, “I mean, I was six when we got [my brother], so I don’t remember everything about his—baby time. But, yeah, from what I can remember he’s always been pretty high strung.”

The frame of reference for understanding what is considered normal appeared to impact the participant’s beliefs about the family environment. Esther described her experience and belief that screaming and arguments were the normal part of having a brother:

Well, [my brother has] always been weird. So, there was like, never a time, other than far back when we were little, and it was normal right? Ever since I was in, like, second

grade, it would be like, right when I got out of school, screaming. And like, “I’m not going to do my guitar lessons,” and “I’m not going to do my homework,” and it would be this humongous thing, right? And it was kind of like normal; it was kind of like that’s what happens after school. It wasn’t weird.

She later added, “Like, I didn’t realize that that wasn’t as normal, until later, like once I started growing up and going over to friend’s houses, and it just doesn’t happen [there].”

### **Future Outlook**

Six participants engaged in discussion regarding their prospective prognosis for their siblings and themselves. Interestingly, all of the participants focused on the future of their diagnosed siblings, rather than on themselves. Five of these participants shared feelings of hope for the development and positive progress of their siblings. One participant reported a negative outlook regarding the future. However, all six of these participants stated that they would care for their siblings in the future, should their parents be unable to.

**Temporal projections.** The five participants that endorsed this subtheme acknowledged that they could not predict the future, but the descriptions of the outlook they had for their siblings was generally quite positive. Tiffany illustrated:

Well, we’re hoping [sister] can go to community college. Um, like, [specific college] or something like that. My parents think she could go there, um, they’re not sure—she wants to go to [specific college], but I don’t know. . . . But, I know that she’ll be successful and I know that she will find a job and probably get married, you know, because I know she can.

Julia added a similar belief, sharing, “Um, 10 years from now, I don’t know. I guess, I could picture [my brother], like, living in his own house, with like, a cat, because he likes cats. I don’t know, just like, I have no idea, having a job or something.”

Esther acknowledged her brother’s deficits, but also believed that he could have many of the same things:

So, of course, [my brother] can just be successful and kind of have his own place. It probably won't be far from my family; I don't think he'll ever be able to live far from mom and dad. Like, just have his own little place near my family, have like, a job, that, you know, he enjoys, and it's not crazy big and stressful, but it's, you know, something he can do. And have like a dog. And I don't know if he'll be able to—you know, he wants to have a wife and stuff like that.

As Esther's description illuminates, the emphasis on future "success" was present in all of the descriptions. The manner in which success was measured appeared to vary divisibly between career, living independently, owning a pet, and having a romantic partner.

In contrast to the visions of success expressed by other participants, Michele articulated concerns for her sibling's future. She shared her worries:

I foresee a lot darker route than I think my parents do. I see [my sister], kind of like, slowly, either tearing this family apart or when she gets to high school, finding stress too much and then like, running away or committing suicide. Which is awful to think about, but, like, the way she's very "angsty" and sad all the time—and she's in fifth grade—and, like, it worries me how much she's always sad.

**Sibling caretaking.** Regardless of predictions regarding success, all of the participants that spoke of the future indicated that they would be willing to care for their diagnosed siblings, if needed. Tiffany expressed a definite desire to assist her sibling in the future, going so far as to share that she believed the process would be enjoyable. She stated:

I will definitely still be close with her. As we get older, I will stay near her; I'm not going to go let her be alone. I'm feeling she'll probably be living with our parents for a while, because it's harder for her to function. But, um, when I get out of college, she'll probably come live with me, if my parents want to go move somewhere else or something. Because I want what's best for her, and if I have to take care of her, it would be a blast living with her because I love her a lot. It would be so much fun.

Riley expressed doubt that her sibling would need aid, but still endorsed a willingness to provide care, saying:

Well, probably we'll still be close. She'll be—I don't know—doing something creative and amazing. I don't know. But, yeah. I'll help if she needs help. I think she won't need it. . . . Cuz, I don't know, she's just—she's mostly able to get things done for herself.

And, even when she struggles, she fights to make sure she gets it. So, I think she'll be doing good.

In contrast, Abby described motivating her brother to care for himself. She shared:

I would take [my brother]. It would really annoy me, and I'd be like, "Are you kidding me; can't he live with [my parents] in the nursing home?" Um, but I think, you know, at the end of the day he's still my brother. If I have to take care of him, I'm going to take care of him, and I'm going to do what I have to do to get him out of my house. Not because I want him out, but because I know he's capable of doing it on his own. I'm not going to sugarcoat it and be like, "Oh, sweetie, you can stay here as long as you need. It's fine, I'll cook for you." It's like, "You gotta cook, you gotta learn how to clean. I'm gonna make you pay, because you gotta get a job, because you can do it."

Despite Michele's perspective regarding her sister's future, even she believed that she would care for her sister one day. However, this desire appeared to be pressured by her parents:

I constantly enter the conversation when it's like, "Well, I mean, when we get old, you have to take care of her" kind of thing. They don't say it like that, but it's like, "You'll have to look out for her!" And I'm just like, that means when [my sister gets older]—that's going to cost a lot of money and time and she's gonna be all on me.

## Advice

In this section, all participants responded to prompts asking them to provide suggestions to parents, professionals, and siblings with a similar experience to themselves. Three main subthemes were identified when participants suggested advice: equality, collaboration, and understanding.

**Equality.** In this subtheme, equality refers to finding commonality, dividing time and attention evenly between children, and emphasizing the importance of the neurotypical sibling's experience. This advice was almost always directed towards parents. Three participants endorsed this subtheme.

Riley made this suggestion to parents:

Um, just make sure that they spend time with [the neurotypical siblings]; that not all their efforts are put toward the [diagnosed] sibling. . . . Like, if they really needed it, they

could have a day a week or night or something where they like, have an activity with that one kid.

Riley's advice included finding opportunities to make the neurotypical sibling feel included.

Tiffany vocalized why this was important, saying, "All kids want to be paid attention to, myself included. Because, especially in our teenage years, we want attention. . . . Um, so, if [parents] are always focusing themselves on the Autistic kid, then the other kids are just going to get frustrated."

Tiffany later provided an example from her own life to illustrate the importance of equal time and attention:

Um, but, I think that if you're going to talk to the brothers and sisters, you have to make them feel good about it, and tell them, it's okay and that there is nothing wrong with them. Um, and just that, you're important too, because a lot of the times, when you have your Autistic sibling, you're like, "Oh, I'm not important anymore." And, I mean, that's what I did feel, sort of, at first, is "Oh, I won't be important anymore," or something happens with [my sister] and I'm like, "Oh, I'm not important anymore," but, that's not true. . . . Mom started doing things with me. My dad too. They both started doing things with me. And I'd say, "Hey, can we do a special dinner, just the two of us?" or something like that. Or like, "Oh, mom, can I go shopping with you? Just us?" And then she started to get more connected with me, and it was all good.

In Tiffany's description, she was able to advocate for herself in order to maintain the relationship between her parents and herself, thereby restoring feelings of value and care.

**Collaboration.** Three participants discussed the importance of working together in order to support their diagnosed siblings. This advice was primarily directed to caregivers and other neurotypical siblings; however, one participant also asked professionals to be willing to collaborate in order to support families as a whole.

Abby shared her beliefs on familial collaboration, saying, "As hard as it is for [parents] and for the siblings, everyone understands, and you all are working towards the same goal, and

you have to work together. And you know, just keep that in mind.” Tiffany agreed, and exemplified her opinion with the cooperation in her family:

That’s how our family works. It’s like a vote. So we all get our say. . . . Um, and so, we kind of all pitch in our ideas, and if we don’t like it, we won’t do it. And so, that’s kind of how it works. It’s good.

In addition to working as a family unit to support one another, Abby advised professionals to value family input when providing care for diagnosed siblings. She shared her own family’s experience in working with a school that did not appear to appreciate familial insight:

And, you know, hearing about stuff that went on at school really pisses me off. Because that’s, I mean, I don’t want to talk badly about a school—they weren’t, they weren’t accommodating. And everything that we said [my brother] needed, they said that was wrong. And they didn’t listen to what we thought because they’re, you know, “the professionals.” They know what they’re doing, and we’re just the family. And it’s like, we live with him everyday. We see how the diagnosis shows itself in his everyday life. . . . I think part of, you know, helping and assisting kids with special needs is to listen. You need to be understanding and listen to what the people who live with them have to say. . . . You have to have an open conversation and understanding. You have to work together, not work against each other.

**Understanding.** The most frequently given advice by participants was a request for developing understanding. This understanding was not only of the challenges of their diagnosed siblings’, but also of the challenges that accompany being the brother or sister of a diagnosed sibling. Six participants reported the subtheme of understanding as the advice they would give to professionals, parents, and siblings in similar situations.

All six participants endorsed the suggestion that others attempt to perspective take and develop an understanding of the difficulties of being diagnosed with an autism spectrum disorder. Julia advised parents, “To explain it to the one that doesn’t have it so they understand it, and for the one that does have it I would just, if you don’t understand what it is, figure out what it is and how to help them.”

Tiffany expanded upon this idea, and detailed how understanding ASD might better the sibling relationship:

I definitely think that if I knew a parent that had an Autistic kid with a sibling, I would definitely recommend to them that they um, tell their kid when they think their kid is mature enough and can sort of understand it. Because it's much easier than judging your sibling like, "Why are they different?"

Sam agreed with this reasoning, and provided an example of his own understanding of his diagnosed brother:

The big one that I had to learn about [my brother], and I don't know that I have yet, is—he really can't help it. Even if it looks like he's calm all the time, even if that's what you see of him in the house because he's just in his room being mellow. He actually can't help freaking out sometimes, breaking down. And it's not his fault, it's not aimed at you, that's just who he is, as an Autistic person.

Similarly, Esther argued that all individuals that know and interact with those diagnosed with ASD have a responsibility to work to understand the disorder. She stated:

Probably just to try and understand them as much as possible. Because, I feel like, people with autism, one of their main struggles is like, not being understood, you know? Like nobody understands them; and it's like, nobody can fully understand them. But I feel like the most important thing is trying to, the best that you can, you know? Like, really trying to understand them. Because I feel like their lives are just so hard, you know, and just so frustrating. And so, I feel like that's the most important thing, is just try to be as understanding as possible, and just try to be there. I feel like you should—I feel like it's your responsibility if you're a friend, or even like a teacher, or a parent, or sibling, I feel like it's your responsibility to research about it, and not be so ignorant about it. Because, like, if your child has cancer, or your brother has cancer, you're going to know about it, you know? Like, with autism, I feel like it should be treated the same way, like you should be researching about it and knowing about it. Because they're not going to be successful if you can't understand it and you can't help them through it, you know?

Here, Esther makes the comparison of ASD to a childhood cancer, advocating for the education of all related parties.

Finally, Michele also tentatively suggested that siblings attempt to understand their diagnosed counterparts. However, she was hesitant in her response, given her own experience.

When asked for her advice to neurotypical siblings in dealing with their ASD brothers and sisters, Michele replied:

Don't. [laughs] I don't know; it's different for all kids. I know stories of kids on the autism spectrum who are really sweet and quiet and just need warming up to. And I'm just like: not mine. Also, I've heard other stories where they are even more violent and worse than [my sister]. So, I guess it really depends on your situation, because like, when we say autism spectrum disorder, there's a reason it says, like, "Spectrum." So, it really depends. If you've got a shy, quiet kid, then like, I don't know, take the time to get to know them, and like, who knows? . . . But, then, other ones, if they're like really violent (especially if they're older), like if you have an older sibling on the autism spectrum disorder, and they acted like my sister? I mean, I don't know what you would do, because they are bigger than you. When they punch you, it's gonna hurt.

Though most participants gave advice regarding increased understanding for the diagnosed sibling, Abby made the suggestion to parents that they attempt to have better understanding of the neurotypical sibling as well. She explained:

Give them credit. Because, they don't go through the same thing you go through, but, you know, for parents that work nine to five jobs, you're not there in the middle of the day. You know, you sit, and you go on conference calls, and you have a really stressful day, and your employee quits. But, you know, your kid's going to school and having a stressful time and then they come home to a sibling that's you know, difficult. And you have to come home from work to a child that's difficult and another one that's annoyed by them. But you know, they experience the kid just like you experience them, in different ways, and you know, they've observed stuff about that kid. And you know, it's affected them. Not in the same way, but as it's affected you. And so you've gotta give them credit, for understanding about that kid, because they can't live with them for as long as they have, and not know anything about them.

## Summary

This chapter presented the findings of this hermeneutic phenomenological study on the lived experience of the neurotypical siblings of a child diagnosed with an autism spectrum disorder. The data were analyzed utilizing thematic reflection and presented using the participants' own voices. The seven main themes that emerged from the data were: (a) personal impact, (b) familial impact, (c) social impact, (d) relational understanding, (e) socio-cultural influence, (f) future outlook, and (g) advice. These themes and their subthemes are presented in



Table 2. Chapter V will undertake a hermeneutic investigation of these themes and discuss the implications of this of this study to the research and treatment of families with a child diagnosed with ASD.

Table 2

*Summary of Themes*

Main Themes	Subthemes
Personal Impact	<ul style="list-style-type: none"> <li>• Subtheme 1: Emotional Toll</li> <li>• Subtheme 2: Personal Responsibility</li> <li>• Subtheme 3: Personal Enrichment</li> </ul>
Familial Impact	<ul style="list-style-type: none"> <li>• Subtheme 1: Family Conflict</li> <li>• Subtheme 2: Chaotic Family Environment</li> <li>• Subtheme 3: Familial Bonding</li> </ul>
Social Impact	<ul style="list-style-type: none"> <li>• Subtheme 1: Social Sacrifice</li> <li>• Subtheme 2: Isolation</li> <li>• Subtheme 3: Seeking Understanding</li> </ul>
Relational Understanding	<ul style="list-style-type: none"> <li>• Subtheme 1: Emotional Attunement</li> <li>• Subtheme 2: Withdrawal</li> </ul>
Socio-cultural Influence	<ul style="list-style-type: none"> <li>• Subtheme 1: Education</li> <li>• Subtheme 2: Normalcy</li> </ul>
Future Outlook	<ul style="list-style-type: none"> <li>• Subtheme 1: Temporal Projections</li> <li>• Subtheme 2: Sibling Caretaking</li> </ul>
Advice	<ul style="list-style-type: none"> <li>• Subtheme 1: Equality</li> <li>• Subtheme 2: Collaboration</li> <li>• Subtheme 3: Understanding</li> </ul>

## **Discussion**

This chapter is separated into three sections to form a discussion based on the findings of this study. The first section focuses on the how the results address the research questions guiding this analysis. The second section details the implications of the study and suggests directions for future research. The final section provides a summary.

### **Addressing the Research Questions**

The research undertaken in this study sought to address the overarching question: What is the lived experience of neurotypical adolescent siblings who have a brother or sister diagnosed with an autism spectrum disorder? Five subsidiary questions were developed in hopes of illuminating this primary inquiry: (a) How do neurotypical siblings feel impacted by their brother or sister with an ASD diagnosis? (b) How do neurotypical siblings perceive their relationship with the child diagnosed with ASD? (c) How do neurotypical siblings perceive their role and remaining relationships within the family? (d) What are the challenges of being a sibling of a child with an ASD diagnosis? (e) What are some factors that contribute to resiliency in this population?

In this section, the researcher attempts to make clear how the results address the research questions identified. Importantly, when utilizing a hermeneutic phenomenological approach, it is also critical to situate the thematic results within a sociocultural and historical framework (Lavery, 2003; J. Smith & Osborn, 2003). As such, the themes provide a story for the reader that reflects the research questions; a hermeneutic interpretation seeks to provide suggestions for why these stories make sense, given the particular social, cultural, and historical underpinnings the stories are developed in.

In review of the results, it becomes clear that each theme and research question is interrelated with one another. Thus, the responses to each of the subsidiary research questions are examined first, to build scaffolding in understanding the overarching research question. Hermeneutic interpretations are offered within the response to the primary research question.

**Subsidiary Question 1: How do neurotypical siblings feel impacted by their brother or sister with an ASD diagnosis?** The findings revealed in this study suggest that participants are impacted across three broad areas: personally, within their family units, and within their social lives. Further, the impacts discussed held both positive and negative outcomes.

The breadth of impact highlights the widespread and interwoven influence of sibling relationships with individuals diagnosed with ASD. The pervasive effects generated by familial relationships with diagnosed individuals have been reflected in literature conducted with parents of ASD children (Hoogsteen, 2011; Robinson, York, Rothenberg, & Bissel, 2015). In these studies, parents described feeling as if, in many ways, their lives revolved around the diagnosis of autism. As such, their time was consumed by educating themselves about ASD, focusing on the diagnosed child's needs, and managing treatment options.

Similarly, several participants in this study indicated that their sibling's behaviors and the subsequent methods of managing these behaviors led to impacts across most areas of their lives. Some adolescents described their entire way of life as being affected by the experience of living with their diagnosed siblings.

The mixed nature of the valence of impact reflects the findings discussed within the literature review: NTD siblings were reportedly impacted positively in some studies and were impacted negatively across others (Meadan et al., 2010; Orsmond & Seltzer, 2007; L. Smith & Elder, 2010). The seemingly disparate results generated from quantitative studies appear to have

overlooked the nuanced nature of the sibling experience. Reliance upon single data points, cross-sectional measures, and outside reporters does not appear to have captured the perspective of adolescent siblings of children diagnosed with ASD.

In this study, participants frequently reported negative experiences in living with their diagnosed siblings (e.g., increased family conflict, feelings of stress and chaos, emotional tolls) that were then quickly paired with positive outcomes (e.g., familial bonding, personal enrichment, emotional attunement). In this way, it is not that neurotypical siblings are only positively or negatively impacted by their experience, but instead feel impacted in a myriad of ways.

Thus, the effects of living with a brother or sister diagnosed with ASD do not fit easily into all-or-nothing categories. Instead, the impacts are seen as pervasive, diverse, and flexible. The findings suggest that living with a diagnosed sibling is a complex, dynamic, and evolving process, not easily quantifiable.

**Subsidiary Question 2: How do neurotypical siblings perceive their relationship with the child diagnosed with ASD?** The majority of the participants described the relationship with their diagnosed siblings as largely positive. Participants portrayed their siblings as nice, creative, funny, and a joy to be around. They repeatedly shared that they would not change the personality of their siblings and valued their siblings for the many challenges that they have overcome. These descriptions mirror findings within the literature that suggest NTD siblings often reflect the relationship with their ASD counterparts as a positive one (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004; Orsmond & Seltzer, 2007).

Despite the positive overtones, many instances of conflict and turmoil were also reported. All of the participants described their diagnosed siblings as engaging in high levels of physical or

verbal aggression. Participants shared daily experiences of hitting, thrown objects, shouting, and cursing. Arguments erupted between themselves and their siblings, themselves and their parents, or their siblings and their parents. Familial experience of aggressive behaviors by children diagnosed with ASD is well documented within the literature (Kanne & Mazurek, 2011; Ross & Cuskelly, 2006).

In this study, some NTD siblings also mourned the loss of “typical” or “normal” sibling relationships. They compared the relationships with their diagnosed siblings to that of other known sibling relationships, and subsequently expressed disappointment for missing aspects. Some of these aspects included: inability to communicate about personal interests and meaningful social situations, missed opportunities for casual outings (e.g., being driven, going to the mall, seeing movies), and a lack of playful or teasing interactions.

In addition, many participants detailed feelings of personal responsibility for the wellbeing of their siblings. They assumed the role of protector, advice-giver, or coach for their diagnosed sibling. This personal responsibility manifested regardless of age or birth order. Some participants reported assuming this role because they felt they were the only person capable of providing assistance to their ASD sibling. Further, NTD siblings in this study all endorsed willingness to care for their diagnosed siblings in the future, should it be needed. In contrast to the perceived burden of care identified by adult siblings of individuals diagnosed with chronic mental illness, it would seem NTD siblings of NTD-ASD dyads willingly assume the role of caretaker for their diagnosed sibling (Riebschleger, 1991).

The findings from this study indicate that the NTD siblings perceive the sibling relationship in a multifaceted manner. While fraught with conflict and connected to the burden of care, participants situated the relationship in a positive and enriching manner. The emphasis

was placed on personal gain and benefit from sharing a sibling relationship with an individual diagnosed with ASD.

**Subsidiary Question 3: How do neurotypical siblings perceive their role and remaining relationships within the family?** Findings from this study indicate NTD siblings' roles and remaining relationships within their families reflect similar positions fulfilled when interacting with their ASD siblings. A maintenance and extension of relationships and roles appeared thematic. That is, families were described in positive terms, family conflict and chaos was acknowledged, and an increased sense of personal responsibility within the family was endorsed.

Similar to sibling descriptions, participants portrayed their families in terms of connection, cooperation, and collaboration. The majority of participants reported feeling valued and cared for by parents, despite the intensity of time and devotion that their diagnosed siblings required. Most frequently they discussed working together as a family to support the needs of the child diagnosed with ASD. The effectiveness of collaborative problem solving, communication, and equivalent treatment between siblings is suggested in other literature sources (Tsao et al., 2012).

Participants also denoted multiple instances of intense familial conflict. NTD siblings admitted to engaging in arguments with their other NTD siblings and with parents on how best to treat their diagnosed sibling. Discussions on parenting strategies appeared to stem from both a desire to support their diagnosed sibling and from efforts to advocate for equal and fair treatment.

Chaotic family environments were also reported. NTD siblings illustrated their households as revolving around treatment strategies for their diagnosed siblings, including

specialized school programs, therapeutic appointments, and involvement of outside professionals giving varied advice. In tandem with family conflicts, home life was reported as stressful, tiresome, and draining.

However, conflict and chaos appeared to increase the sense of family bonding rather than separate family relationships in most cases. One participant described the sense that the family had survived a traumatic experience in navigating their diagnosed sibling's behaviors. As survivors, the family members were bonded and connected through events others could not understand. A collective sharing of emotions and problems was thus established, removed from the challenges typical families face.

Finally, commensurate with their role of personal caretaker for their diagnosed siblings, participants often discussed assumption of caregiver roles within the entire family environment. This was evident in coaching other neurotypical siblings to respond more appropriately to their diagnosed siblings' behaviors, advocating for collaborative family problem solving, and discussing parenting strategies with their parents.

**Subsidiary Question 4: What are the challenges of being a sibling of a child with an ASD diagnosis?** In addition to the family/sibling conflict and chaotic family environment mentioned above, participants also cited multiple social tolls. Social sacrifice, social isolation, and withdrawal were reported. Additionally, a burden or expectation of normalcy appeared to cause significant stress to NTD siblings.

Participants often indicated that the sibling relationship was valued above other social relationships. They described episodes in which their diagnosed siblings would engage in behaviors that caused disruption to peer relationships. Behaviors on the part of the diagnosed sibling were both indirect (e.g., socially awkward/inappropriate actions, annoying behaviors,



lack of friendships) and direct (e.g., targeted physical or verbal aggression). Regardless of intention, NTD siblings indicated repeatedly that they accepted the social burden that resulted. Participants educated friends, rejected peer relationships in which an individual was unwilling to understand ASD, and neglected their own social advancement in order to reduce the emotional distress of their siblings.

In conjunction with social sacrifice, participants detailed examples of social isolation. Due to the needs of their ASD siblings, typical family outings were often avoided. Rather than overstimulate or dysregulate their diagnosed siblings, participants and their families refrained from attending firework displays, theme parks, and light shows. Some participants shared that their families were unable to dine out.

Further, participants described feeling unable to share their challenging experiences with others. Here, a pervasive sense of being misjudged existed. Participants reported frustrations with the lack of education, understanding, and appropriate treatment of ASD individuals. An extension of this misunderstanding included inaccurate beliefs about ASD families and NTD siblings. Therefore, NTD siblings reported a distinct dearth of social supports.

Concurrently, participants often spoke of the expectation of normalcy. The findings of this study indicated that ASD siblings were expected by society members to behave typically, NTD siblings were pressured to exceed normalcy, and aspects of normalization within siblings, families, and familial relationships were emphasized wherever possible. The areas in which expectations of normalcy were not met caused stress, tension, and negative emotionality within the NTD siblings of this study.

**Subsidiary Question 5: What are some factors that contribute to resiliency in this population?** The coping skills employed by participants in this study were varied. However,

many themes emerged that appeared to highlight some commonality between responses. Most participants valued development of relational skills, such as emotional attunement. Employment of avoidance techniques or withdrawal from conflict was also reported. Finding commonality and support amongst other individuals (whether they be family members or others who have undergone similar experiences) was also important. Family strategies, such as ensuring equal treatment of siblings and collaborative problem solving, were commonly given advice.

NTD siblings valued the development of relational skills, such as perspective taking, communication skills, and emotional sensitivity to the feelings of others. Participants reported appreciation for these skills in managing the relationship with their ASD siblings. Many credited this understanding with maintaining peace within the household. Further, NTD siblings recognized the benefits of these skills within their relationships with peers.

Often, when overwhelmed, participants engaged in withdrawal. They avoided joining in or witnessing conflict that involved their ASD siblings by going to their rooms, on walks, or to the houses of their friends. Stepping away from conflict was most frequently reported when NTD siblings were already experiencing stress (e.g., exams, challenging work days). Both emotional attunement and withdrawal as coping mechanisms correlate with previous research that reported NTD siblings most often respond to conflict with either emotion regulation or withdrawal (Ross & Cuskelly, 2006).

Likely in response to the social isolation described above, NTD siblings indicated that seeking understanding from those with similar experiences was particularly supportive. Some individuals reported establishing relationships with peers whom also had a brother or sister diagnosed with a developmental disorder. Other participants described offering a relationship to children similar to their diagnosed siblings. This effort to find commonality in the social realm

coincides with research that indicates social support is the greatest benefactor in promoting NTD sibling well being (Cebula, 2012; Conway & Meyer, 2008).

Participants consistently promoted family collaboration in resolving challenges within the household. NTD siblings asked to be informed about ASD and sought to be educated on etiology, symptomology, and treatment. With informational support, NTD siblings felt more equipped to contribute to family decisions and to accept the behaviors of their ASD siblings. This finding supports research in the literature suggesting that educating NTD siblings decreases psychosocial distress (Hatfield & Lefley, 2005; Lobato & Kao, 2005).

**Primary research question: What is the lived experience of neurotypical adolescent siblings who have a brother or sister diagnosed with an autism spectrum disorder?** The findings of this study indicate that the experience of participants may vary in many ways from typical sibling dyads. In particular, all participants consistently spoke of their experiences in comparison and contrast to that of “normal” siblings, families, and environments. Here we can explore the social, cultural, and historical implications of the development of expectations for normality, and how these allusions may impact neurotypical siblings and their experiences.

The ideal of normalcy appeared to influence the manner in which participants interpreted their experience as a sibling of a child diagnosed with ASD. Despite their being no specific “prescription” for achieving normal sibling, family, and social relationships, all participants expressed knowledge of so-called typical behaviors and interactions. The perpetuation of this standard of life stems from social, cultural, and historical influence that generates a picture of what “normal” means to these participants and to society at large. Further, the values embedded within our culture deem that being normal is a universally positive attribute that everyone should strive for (Thorne, 1993).

The NTD siblings in this study also placed value on being normal. As such, participants either lamented the lack of normalcy within their sibling interactions, family relationships, and home environments or they emphasized the aspects of normalcy that they saw evident within these realms. In reviewing the findings of the study, observational comparisons were frequently made between the participants' lives and those of their associates.

By concentrating on the ways in which their families are normal, NTD siblings are decentralizing the differences that exist within their lives. This reinterpretation may allow participants to better adjust to the challenges of having an ASD sibling. It may promote acceptance and help NTD siblings to become more involved with the treatment of the diagnosed siblings. Further, it may offer hope to NTD siblings that positive changes are possible, within their sibling, family, and home environment.

The focus on normalcy was not unique to participants alone. Several participants spoke of experiencing pressure from their parents to fulfill the role of "the normal child." In this manner, participants discussed parental expectations for NTD sibling success within many arenas of their lives, including: socially relating, behavior management, academic prowess, and emotion regulation. Thus, the participants felt expected to excel at the aspects in which their diagnosed siblings had greater difficulty.

The genesis for this expectation remains unclear. It may be that participants placed these expectations on themselves, in order to stabilize the family environment. As discussed earlier, participants frequently assumed the role of caretaker for not only their siblings, but for the family as a whole. In succeeding in the areas that their siblings struggle, participants may be attempting to compensate and balance the family dynamics. Alternately, they may be striving to reduce the strain placed upon their parents, who already exert significant amounts of effort to manage the

diagnosed child. In yet another scenario, the participants may be excelling in these arenas in attempts to conform to the idealized view of a normal family.

In contrast, parents may indeed be placing increased expectations on participants. They might also hold fast to an idealized version of a normal family, pushing their capable child to fulfill roles that the diagnosed sibling is not able to. Rather than a normal dispersion of success, the burden is instead placed upon the neurotypical child. Perhaps in efforts to portray themselves as “successful” parents, they hold exceptionally high expectations for their neurotypical children. We see the socio-historical genesis of the fear of bad parenting reflected in the early interpretations of the causes for autism, when we recall the “refrigerator parents” of the 1940s (Rutter, 1999; Wolff, 2004). Unfortunately, the stigma associated with poor or neglectful parenting as a causation of autism spectrum disorder behaviors still occurs, despite advances in etiology, understanding, and treatment of ASD (Kuhn & Carter, 2006; Robinson et al., 2015).

Participants felt the negative effects of social stigma as well. NTD siblings often alluded to the invisibility of an ASD diagnosis. Without visible physical clues, cultural expectations are often high for ASD siblings to adhere to typical behaviors. Therefore, when an ASD sibling behaves in an unexpected and societally unacceptable manner, social stigma easily results. The judgments passed often regard the family as a whole, causing fear and embarrassment in NTD siblings.

In response to this social stigma, participants frequently described assuming the role of educator. NTD siblings shared multiple examples in which they informed peers about the ASD diagnosis, including associated behaviors, potential triggers for emotional dysregulation, and appropriate treatment. Additionally, participants lamented the lack of proper education and understanding of ASD individuals by laypeople and professionals alike. Their concern is

reflected in research studies that find there are multiple misconceptions and confusion regarding the ASD diagnosis in latency-aged children, college students, and various medical professionals (Campbell & Barger, 2011; Gillespie-Lynch et al., 2015; Heidgerken, Geffken, Modi, & Frakey, 2005).

Participants also expressed a limited emotional range of feelings regarding sibling behaviors, family relationships, and environmental opportunities. Amongst most participants, there existed a distinct lack of sadness, anger, and frustration when describing emotional aspects of their lives. Despite discussing high levels of family conflict, participants consistently reported employing relational strategies that involved either intensive emotional attunement or avoidance of conflict.

In this manner, NTD siblings consistently described themselves as constantly attempting to perspective-take, understand the emotions and motivations of others, and withdrawing from situations that would create conflict. While in many ways, this approach demonstrates maturity beyond their years, it also seems that participants have been instructed (either directly or indirectly) to ensure that their own emotions take a back seat to others'. Despite encountering several challenging situations that would make many individuals angry, frustrated, or sad (e.g., experiencing daily sessions of screaming and ranting, enduring consistent physical abuse from one's sibling, denial of family experiences in order to manage the emotions of another person) participants rarely expressed these emotions during interview.

What drives this emotional denial? One hypothesis may again, be tied to the idea of normalcy. This idea puts forth that, although autism spectrum disorder does not consist of "typical behaviors," it does generate "typical behaviors for autism spectrum disorder." As such, participants have been informed (often beginning at a very early age), that the behaviors of their

brother or sister “cannot be helped.” Frequently, participants suggested during interview that their siblings struggled to fulfill typical expectations as a result of their diagnosis. As such, there was a pervasive sense that neurotypical siblings must accept the behaviors of their sibling as part and parcel of the disorder with which they were diagnosed. Therefore, if the neurotypical sibling was upset or angry at the diagnosed sibling because of their behaviors, this produces a negative reflection on the neurotypical sibling, due to their “lack of understanding” regarding their siblings’ diagnosis. An analogy would be to become angry with a blind person for being unable to see. To be angry in this situation would be nonsensical; one would infer that the angered person lacks understanding, kindness, or compassion. Thus, the participants, in order to avoid stigma of this nature, may have learned to deny themselves the full range of emotions when discussing their diagnosed sibling and their behaviors. This approach may be considered an adaptive response to relational interactions within the family environment (Altman et al., 2002).

The belief that children diagnosed with autism spectrum disorder are unable to accomplish tasks and exhibit a variety of appropriate behaviors is an idea that is prevalent in today’s Western society. The participants in this study frequently brought up this concept when speaking of the lack of education regarding ASD. The results of this study imply neurotypical siblings constantly encountered situations in which there were misperceptions regarding ASD and the ability structure of their diagnosed siblings. Further, at times these misunderstandings resulted in the, often unintended, mistreatment of children diagnosed with ASD.

These misperceptions of ASD and their ability structure may be in response to the emphasis on the genetic and biological underpinnings of this disorder. As reviewed in the literature, the Western approach to interpretation of ASD is one that highlights medical detection, brain based behaviors, and behavioral genetic links. Early neurobiological research

linked ASD to enlarged head size, localized differences in brain structure, and sought to connect behavioral deficits with corollary neurobiological deficits (Acosta & Pearl, 2003; Tager-Flusberg, 2008). In tandem, the manifestation of these impairments was thought to be categorical, fixed, and often accompanied with intellectual deficit (Charman, 2010; Constantino & Charman, 2016).

However, the participants in this study, as well as research and direct work with ASD individuals, indicate that most diagnosed children are able to learn, mature, and compensate for many of their difficulties (Bishop-Fitzpatrick, Minshew & Eack, 2013; Bradshaw, Steiner, Gengoux, & Koegel, 2015; Dawson & Bernier, 2013). While typical tasks may be much more challenging for those diagnosed with ASD, it would be incorrect to assume that a diagnosis of this nature equates with complete inability to interact socially, exhibit appropriate behaviors, or communicate adequately. Current research on ASD is also beginning to generate developmental models with increased sensitivity to environmental factors (Charman, 2010; Constantino & Charman, 2016).

Finally, the manner in which participants interpreted their experience living with a diagnosed sibling was largely positive. This is consistent with previous literature reviews, which have attempted to ascertain the relationship between NTD-ASD dyads (Orsmond & Seltzer, 2007; Pilowsky et al., 2004). As detailed above, despite the multitude of negative impacts that participants consistently described (e.g., increased family conflict, feelings of stress and chaos, emotional tolls), participants primarily reported their overall experience as positive, meaningful, and personally enriching. How and why do participants translate their difficult experience in this manner?



One possibility is that participants find meaning in this experience as a method of coping. The emotional and environmental tumult that the majority of participants describe experiencing is one that would be challenging for any individual to manage. The findings of this study suggest that the participants not only are able to manage their lives, but to achieve success in many arenas, and to find positive and affirming aspects of their experience that appear to motivate and sustain them. More than once, participants expressed that they felt their lives were traumatic, stressful, or tiring, and yet many of them voiced that they would not exchange their experience for that of another's. Perhaps meaning-making is a needed process that allows these participants to continue with their lives, sustain the status quo, and continue to strive for normalcy within their lives.

Of note, one participant was adamant in expressing anger, fear for the future, and a strong desire that her family environment was different. This participant appeared similar across many demographic variables; however, her description of the family unit appeared to vary somewhat from other participants. In particular, she constantly described feeling as if her parents favored her younger sister, such that the participant did not feel a valued or connected family member. In contrast to the advice given by other participants, who touted collaboration, understanding, and attachment, this participant expressed feelings of withdrawal, avoidance, and separation from her family. Perhaps because of her perceived isolation and persecution within the family unit, this participant felt able to express "abnormal" emotions and thoughts often associated with negativity (e.g., anger, dissatisfaction, doubt regarding her siblings' abilities).

### **Study Implications**

The findings for this study might be used in application with other neurotypical siblings, with parents of neurotypical-ASD dyads, and with professionals who work with diagnosed

individuals and their families. Further research can expand upon the findings produced here to overcome limits, investigate related questions, and continue to explore this understudied phenomenon.

**Application.** The results produced in this study have implications for neurotypical siblings of children diagnosed with an autism spectrum disorder. The findings here offer suggestions for ways in which these siblings might better manage the relationship with their diagnosed sibling, their roles within the family environment, and their interactions with the community at large. Provision of informational support, emotional support, and social support are recommended.

In particular, the findings of this research suggest that seeking out education from reliable sources regarding the manifestations, challenges, and abilities of those diagnosed with ASD is of particular benefit for NTD siblings. Informational support can increase understanding of ASD behaviors, thereby allowing for increased acceptance and diminished judgments from NTD siblings. Education could also provide skills that might better interactions between ASD-NTD dyads.

Additionally, the participants of this study advised that neurotypical siblings connect with other individuals who have similar experiences. The social isolation and misperceptions that can be generated from living with a sibling diagnosed with ASD appear difficult to manage. Participants reported feeling more at ease sharing challenging familial experiences with peers undergoing analogous situations. Engaging other adolescents in discussion may yield additional resources, strategies for managing stress, and provide an emotional outlet to engage in expressing feelings they may be uncomfortable divulging with others.

The findings from this study also have implications for parents of neurotypical-ASD dyads. Several participants reported feeling that they could not share their problems with their parents. Though these results are difficult to generalize, it may be that many neurotypical siblings have similar challenges. Thus, parents may gain important insights regarding their own children in reviewing the findings of this study.

Participants gave many suggestions to parents. Firstly, they indicated a desire that parents understand that living with a child diagnosed with ASD also impacts the neurotypical child. While parents might become frustrated, fatigued, and experience great amounts of stress while managing the child diagnosed with ASD, the neurotypical child often feels these same emotions. As such, acknowledgement of the struggle each member of the family undergoes is important to the growth and development of all.

In tandem with this realization, participants requested that parents dedicate time and effort to their neurotypical children as well. Participants expressed the need for care and attention from their parents, while understanding that their diagnosed siblings often require more devotion. Parents might use this information to develop methods for ensuring each of their children feels appreciated. Several participants suggested that parents might dedicate one night or a special activity that they engage in alone with the neurotypical siblings.

The need for education was also highlighted. Participants described feeling more integral and helpful to the family as a whole when informed about sibling diagnosis, challenges, and decisions regarding sibling care. Collaboration and dissemination of information were emphatically suggested. As such, parents should carefully consider what knowledge to impart to their children, and when this should occur. The findings from this study, as well as from

literature regarding chronic mental illness, indicate that early education sustains more positive sibling relationships later in life (Hatfield & Lefley, 2005; Lobato & Kao, 2005).

In speaking of education, the findings from this study suggest that professionals who work with children diagnosed with ASD should make efforts to inform themselves about this disorder. Several participants lamented the difficult challenges their brothers and sisters experienced, particularly within the academic environment. They reported frequent occasions in which their diagnosed siblings were misunderstood, mistreated, or labeled in an inappropriate manner. While the origins of these misconceptions are explicable in context of the social and cultural realm, professionals should strive to stay abreast of the latest advancements in understanding ASD. Reflecting the advice of the participants, it may be that correct information needs to be disseminated more widely to parents, siblings, and those that work with children diagnosed with ASD.

Further, it would prove beneficial to view individuals diagnosed with ASD in a strength-based manner. Often, the focus for intervention and treatment lies in training ASD individuals to better adhere to societal expectations and norms, highlighting yet again the cultural value in universality (Bishop-Fitzpatrick et al., 2013; Ravindran & Myers, 2012; Siegel & Beaulieu, 2012, Thorne, 1993). The participants in this study instead tended to highlight the unique strengths and assets their diagnosed siblings possessed. Viewing ASD as a variation of normality and an adaptive response to environmental factors allows for a reconceptualization of expectations and expands treatment options. Further, as opposed to simply acknowledging differences, greater effort should be placed on valuing neurodiversity.

Participants described feeling directly impacted by societal misinformation. At times, this occurred when participants recognized teachers misunderstanding peers. At others,

participants were expected to engage in academic curriculum that portrayed ASD in a manner that was not commensurate to their own experiences. Social stigma was also frequently experienced, as a result of misinformation.

These examples highlight the need for appropriate education of the public. Informational support should also be provided to professionals, particularly those working in academic settings. Consideration of educational training programs for school staff on the manifestations and appropriate treatment of individuals diagnosed with ASD may prove beneficial. Careful thought should also be undertaken when deciding to implement academic curriculum regarding complex diagnoses, such as ASD. Special deliberation concerning how those directly impacted by ASD might view these curriculums is needed.

Other professionals working with children diagnosed with ASD and their families should take care in valuing the experience of the family. Some participants expressed instances in which they felt as if professionals were mandating prescriptions without taking into account the input families had to offer. Thus, professionals should recognize the expertise in life experiences that family members possess, and may consider utilizing this information when working with these families.

Professionals should also formulate options for inclusion of NTD siblings during care planning for ASD siblings. Specialists might consider collaborating with caregivers regarding the appropriate information (e.g., type, mode, amount) to disseminate to NTD siblings. Assessing the needs of the NTD sibling might also contribute to treatment plans for families with children diagnosed with ASD.

Work might also be done in developing outreach programs for NTD siblings. Creation of programs that allow NTD siblings to access education about ASD and families in similar situations might also address the need for informational support.

Counselors and therapists who may work directly with the neurotypical siblings of children diagnosed with ASD may also benefit from the findings of this research. In many ways, the participants in this study displayed success across most areas of their lives. However, they also expressed feelings of stress, emotional repression, and pressure to live up to high expectations from their parents. Understanding the unique challenges that impact these individuals, while appreciating the myriad ways in which they manage their lives could be helpful when working with these adolescents.

Finally, continuing to develop sibling support groups, such as those advocated for by Conway and Meyer (2008) may be extremely beneficial to these individuals. Creating opportunities for peers to join with one another and openly explore their experiences without judgment appears important. Professionals may use the findings from this study to aid in structuring these meetings or in generating group curriculum.

**Future research.** This study aimed to begin dialogue in a largely unexplored field: investigating the experience of neurotypical adolescent siblings of children diagnosed with an autism spectrum disorder. Given the relatively small amount of literature written on this important topic, this research was exploratory and qualitative in nature. Future research may wish to expand upon the limits of this study or investigate related questions. Some suggestions for further study are related below.

**Size.** As a qualitative study, this research only produced findings from 7 participants. While suitable for a qualitative and exploratory study, future research may wish to build upon the

thematic results reported in this research to develop studies integrating a broader number of individuals.

***Demographics.*** Further, though this study sought to incorporate individuals of diverse backgrounds, due to the small sample size and geographical location of the study, demographics did not vary widely. The majority of participants were reportedly White and from an upper-middle class family. The similarity in demographic information limits the scope of this study and may have impacted the findings generated.

Future studies could integrate individuals with greater differences in demographic background. They may also compare or contrast participant experiences using particular demographic variables. Variations in race, socioeconomic status, and geographical location may yield divergent findings. As discussed previously, social and cultural norms appear to impact participants' interpretations of their lived experience. Therefore, it may be the experiences of NTD siblings in diverse cultures are varied as well. In particular, investigating NTD-ASD dyads in non-Western societies may yield findings that differ from this study.

***Gender.*** Within this research study, 6 participants were female; only 1 was male. However, the gender of their diagnosed siblings was more evenly distributed, with 5 being male and 3 being female. Gender plays an interesting role in autism spectrum disorder research, as the majority of individuals diagnosed tend to be male (Constantino & Charman, 2016). Examining the sibling relationships between variously gendered dyads may further illuminate the experience of these siblings.

***Severity of diagnosis.*** At the time of this study, the introduction of the diagnosis of autism spectrum disorder was being undertaken. The diagnosis of ASD is now used to replace previous diagnoses, including: Pervasive Developmental Disorder, Asperger's Disorder, and

Autistic Disorder. Several participants emphasized the differences between diagnoses, particularly when describing their siblings to outsiders. This tendency derived from a desire to underscore the level of severity (or lack thereof) within sibling diagnoses.

Future research may seek to separate participants based upon level of severity associated with an autism spectrum diagnosis. Though the new heading of ASD was designed to become more inclusive, participants in this study were adamant about distinguishing diagnostic differences and the severity levels associated with them. Future studies may discriminate between levels of severity to discern whether this affects sibling experiences in a different manner.

***Supporting neurotypical siblings.*** The findings from this research implicated several factors that contribute to increased challenges for NTD siblings. Social effects, such as isolation, experiences of stigma, and social sacrifice were frequently reported. Future studies might investigate methods to reduce these difficulties for NTD siblings and their families.

NTD siblings might also be supported in acquiring education regarding ASD etiology, symptomology, and treatments. Research could be conducted that focuses on dissemination of informational supports to NTD siblings. Methods of deliverance, discrimination of useful education, or effects of informational supports are some areas that could be investigated.

Longitudinal studies might also be considered to document the experience of NTD siblings over the course of development. Life is not static; NTD siblings may express differing thoughts, needs, and emotions over time. Tracking stable and mutable themes might help parents and professionals better understand how best to support NTD siblings during their lifespan.



## Summary

The purpose of this hermeneutic phenomenological study was to investigate the lived experience of neurotypical siblings of children with an autism spectrum disorder. This study found NTD sibling experience to contain both positive and negative perceptions of living with a brother or sister diagnosed with ASD. NTD siblings were affected personally, within their family relationships, and socially. Perceptions were often influenced by the cultural and societal value placed upon normal behaviors. The need for appropriate education regarding ASD etiology, symptomology, and treatment was deemed to be important for NTD siblings, parents, professionals, and society at large. Additionally, the development of social supports for NTD siblings is suggested.

## References

- Abrams, M. S. (2009). The well sibling: Challenges and possibilities. *American Journal of Psychotherapy*, 63(4), 305–317.
- Acosta, M. T., & Pearl, P. L. (2003). The neurobiology of autism: New pieces of the puzzle. *Current Neurology and Neuroscience Reports*, 3(2), 149–156. doi:10.1007/s11910-003-0067-0
- Altman, N., Briggs, R., Frankel, J., Gensler, D., & Pantone, P. (2002). *Relational child psychotherapy*. New York, NY: Other Press.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Barnett, R. A., & Hunter, M. (2012). Adjustment of siblings of children with mental health problems: Behaviour, self-concept, quality of life, and family functioning. *Journal of Child and Family Studies*, 21(2), 262–272. doi:10.1007/s10826-011-9471-2
- Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of self*. New York, NY: Free Press.
- Bishop-Fitzpatrick, L., Minshew, N. J., & Eack, S. M. (2013). A systematic review of psychosocial interventions for adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 43(3), 687–694. doi:10.1007/s10803-012-1615-8
- Boyle, C. A., Boulet, S., Schieve, L. A., Cohen, R. A., Blumberg, S. J., Yeargin-Allsopp, M.,...Kogan, M. D. (2011). Trends in the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 127(6), 1033–1043. doi:10.1542/peds.2010-2989
- Bradshaw, J., Steiner, A. M., Gengoux, G., & Koegel, L. K. (2015). Feasibility and effectiveness of very early intervention for infants at-risk for autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders*, 45(3), 778–794. doi:10.1007/s10803-014-2235-2
- Brewton, C. M., Nowell, K. P., Lasala, M. W., & Goin-Kochel, R. P. (2011). Relationship between the social functioning of children with autism spectrum disorders and their siblings' competencies'/problem behaviors. *Research in Autism Spectrum Disorders*, 6(2), 646–653. doi:10.106/j.rasd.2011.10.004
- Campbell, J. M., & Barger, B. D. (2011). Middle school students' knowledge of autism. *Journal of Autism and Developmental Disorders*, 41(6), 732–740. doi:10.1007/s10803-010-1092-x

- Carayol, J., Schellenberg, G. D., Dombroski, B., Genin, E., Rousseau, F., & Dawson, G. (2011). Autism risk assessment in siblings of affected children using sex-specific genetic scores. *Molecular Autism*, 2(17). n.p. doi:10.1186/2040-2392-2-17
- Castorina, L. L., Negri, L. M. (2011). The inclusion of siblings in social skills training for boys with Asperger syndrome. *Journal of Autism and Developmental Disorders*, 41(1), 73–81. doi:10.1007/s10803-010-1023-x
- Cebula, K. R., (2012). Applied behavioral analysis programs for autism: Sibling psychosocial adjustment during and following intervention use. *Journal of Autism and Developmental Disorders*, 42(5), 847–862. doi:10.1007/s10803-011-1322-x
- Charman, T. (2010). Developmental approaches to understanding and treating autism. *Folia Phoniatica Et Logopaedica*, 62(4), 166–177. doi:10.1159/000314032
- Constantino, J. N., & Charman, T. (2016). Diagnosis of autism spectrum disorder: Reconciling the syndrome, its diverse origins, and variation in expression. *The Lancet Neurology*, 15(3), 279–291. doi:10.1016/S1474-4422(15)00151-9
- Conway, S., & Meyer, D. (2008). Developing support for siblings of young people with disabilities. *Support for Learning*, 23(3), 113–117. doi:10.1111/j.1467-9604.2008.00381.x
- Craft, M. J., Wyatt, N., Sendall, B. (1985). Behavior and feeling changes in siblings of hospitalized children. *Clinical Pediatrics*, 24(7), 374–378. doi:10.1177/0009922885024007 02
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches*. (3rd ed.). Los Angeles, CA: Sage.
- Dawson, G., & Bernier, R. (2013). A quarter century of progress on the early detection and treatment of autism spectrum disorder. *Development and Psychopathology*, 25(4), 1455–1472. doi:10.1017/S0954579413000710
- Deconinck, N., Soncarrieu, M., & Dan, B. (2013). Toward better recognition of early predictors for autism spectrum disorders. *Pediatric Neurology*, 49(4), 225–231. doi:10.1016/j.pediatrne urol.20 13.05.012
- Dempsey, A. G., Llorens, A., Brewton, C., Mulchandani, S., & Goin-Kochel, R. P. (2012). Emotional and behavioral adjustment in typically developing siblings of children with autism spectrum disorders. *Journal of Autism and Development Disorders*, 42(7), 1393–1402. doi:10.1007/s10803-011-1368-9
- Feinberg, M. E., Solmeyer, A. R., & McHale, S. M. (2012). The third rail of family systems: Sibling relationships, mental and behavioral health, and preventative intervention in childhood and adolescence. *Clinical Child and Family Psychology Review*, 15(1), 43–57. doi:10.1007/s10567-011-0104-5

- Ferraioli, S. J., & Harris, S. L. (2011). Teaching joint attention to children with autism through a sibling-mediated behavioral intervention. *Behavioral Interventions*, 26(4), 261–281. doi:10.1002/bin.336
- Gillespie-Lynch, K., Brooks, P. J., Someki, F., Obeid, R., Shane-Simpson, C., Kapp, S. K., . . . Smith, D. S. (2015). Changing college students' conceptions of autism: An online training to increase knowledge and decrease stigma. *Journal of Autism and Developmental Disorders*, 45(8), 2553–2566. doi:10.1007/s10803-015-2422-9
- Greenberg, J. S., Kim, H. W., & Greenley, J. R. (1997). Factors associated with subjective burden in siblings of adults with severe mental illness. *American Journal of Orthopsychiatry*, 67(2), 231–241. doi:10.1037/h0080226
- Hastings, R. P. (2007). Longitudinal relationships between sibling behavioral adjustment and behavior problems of children with developmental disabilities. *Journal of Autism and Developmental Disorders*, 37(8), 1485–1492. doi:10.1007/s10803-006-0230-y
- Hatfield, A. B., & Lefley, H. P. (2005). Future involvement of siblings in the lives of persons with mental illness. *Community Mental Health Journal*, 41(3), 327–338. doi:10.1007/s10597-005-5005-y
- Heidgerken, A. D., Geffken, G., Modi, A., & Frakey, L. (2005). A survey of autism knowledge in a health care setting. *Journal of Autism and Developmental Disorders*, 35(3), 323–330. doi:10.1007/s10803-005-3298-x
- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings with down syndrome versus with autism: Findings from a large-scale U. S. survey. *Journal of Intellectual Disability Research*, 51(12), 1018–1029. doi:10.1111/j.1365-2788.2007.00994.x
- Hoogsteen, L. (2011). *The lived experience of parenting a child with autism in a rural area: Making the invisible, visible* (Order No. MR77344). Available from ProQuest Dissertations & Theses Global. (1025745629).
- Hughes, J. R. (2009). Update on autism: A review of 1300 reports published in 2008. *Epilepsy & Behavior*, 16(4), 569–589. doi:10.1016/j.yebeh.2009.09.023
- Joseph, S., Becker, S., Becker, F., & Regel, S. (2008). Assessment of caring and its effects in young people: Development of the Multidimensional Assessment of Caring Activities Checklist (MACA-YC18) and the Positive and Negative Outcomes of Caring Questionnaire (PANOC-YC20) for young carers. *Child Care, Health, and Development*, 35(4), 510–520. doi:10.1111/j.1365-2214.2009.00959.x
- Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders*, 41(7), 926–937. doi:10.1007/s10803-010-1118-4

- Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child*, 2, 217–250.
- Kao, B., Plante, W., & Lobato, D. (2009). The use of the Impact on Sibling scale with families of children with chronic illness and developmental disability. *Child Care, Health, and Development*, 35(4), 505–509. doi:10.1111/j.1365-2214.2009.00944.x
- Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review*, 15(3), 247–277. doi:10.1007/s10567-012-0119-6
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry*, 76(4), 564. doi:10.1037/0002-9432.76.4.564
- Laverty, S. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods*, 2(3), 21–35. doi:10.1177/160940690300200303
- Lobato, D. J., & Kao, B. T. (2005). Brief report: Family-based group intervention for young siblings of children with chronic illness and developmental disability. *Journal of Pediatric Psychology*, 30(8), 678–682. doi:10.1093/jpepsy/jsi054
- Meadan, H., Stoner, J. B., & Angell, M. E. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities*, 22(1), 83–100. doi:10.1007/s10882-009-9171-7
- Meyer, D. (2005). *The sibling slam book: What it's really like to have a brother or sister with special needs*. Bethesda, MD: Woodbine House.
- Meyer, K. A., Ingersoll, B., & Hambrick, D. Z. (2011). Factors influencing adjustment in siblings of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(4), 1413–1420. doi:10.1016/j.rasd.2011.01.027
- Morgan, J. K., Shaw, D. S., & Olino, T. M. (2012). Differential susceptibility effects: The interaction of negative emotionality and sibling relationship quality on childhood internalizing problems and social skills. *Journal of Abnormal Child Psychology*, 40(6), 885–899. doi:10.1007/s10802-012-9618-7
- Morgan, S. B. (1988). The autistic child and family functioning: A developmental-family systems perspective. *Journal of Autism and Developmental Disorders*, 18(2), 263–280. doi:10.1007/BF02211952
- Neely-Barnes, S. L., & Graff, J. C. (2011). Are there adverse consequences to being a sibling of a person with a disability? *Family Relations*, 60(3), 331–341. doi:10.1111/j.1741-3729.2011.00652.x

- Oppenheim-Leaf, M. L., Leaf, J. B., Dozier, C., Sheldon, J. B., & Sherman, J. A. (2011). Teaching typically developing children to promote social play with their siblings with autism. *Research in Autism Spectrum Disorders*, 6(2), 777–791. doi:10.1016/j.rasd.2011.10.010
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism spectrum disorders across the life course. *Mental Retardation and Developmental Disabilities Research Reviews*, 13(4), 313–320. doi:10.1002/mrdd.20171
- Orsmond, G. I., & Seltzer, M. M. (2009). Adolescent siblings of individuals with an autism spectrum disorder: Testing of a diathesis-stress model of sibling well-being. *Journal of Autism and Developmental Disorders*, 39(7), 1053–1065. doi:10.1007/s10803-009-0722-7
- Parke, R. D., & Buriel, R., (2008). Socialization in the family: Ethnic and ecological perspectives. In W. Damon & R. M. Lerner (Eds), *Child and adolescent development: An advanced course* (pp. 95–138). Hoboken, NJ: John Wiley & Sons, Inc.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Petalas, M. A., Hastings, R. P., Nash, S., Hall, L. M., Joannidi, H., & Dowey, A., (2011). Psychological adjustment and sibling relationships in siblings of children with autism spectrum disorders: Environmental stressors and the broad autism phenotype. *Research in Autism Spectrum Disorders*, 6(1), 546–555. doi:10.1080/13668259800033591
- Pilowsky, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. S. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry*, 45(4), 855–865. doi:10.1111/j.1469-7610.2004.00277.x
- Pollard, C. A., Barry, C. M., Freedman, B. H., & Kotchick, B. A. (2013). Relationship quality as a moderator of anxiety in siblings of children diagnosed with autism spectrum disorders or down syndrome. *Journal of Child and Family Studies*, 22(5), 647–657. doi:10.1007/s10826-012-9618-9
- Proband. (n.d.). In *Merriam-Webster online*. Retrieved from <https://www.merriam-webster.com/dictionary/proband>
- Ravindran, N., & Myers, B. J. (2012). Cultural influences on perceptions of health, illness, and disability: A review and focus on autism. *Journal of Child and Family Studies*, 21(2), 311–319. doi:10.1007/s10826-011-9477-9
- Riebschleger, J. L. (1991). Families of chronically mentally ill people: Siblings speak to social workers. *Health & Social Work*, 16(2), 94–103. doi:10.1093/hsw/16.2.94

- Robinson, C. A., York, K., Rothenberg, A., & Bissell, L. J. L. (2015). Parenting a child with asperger's syndrome: A balancing act. *Journal of Child and Family Studies, 24*(8), 2310–2321. doi:10.1007/s10826-014-0034-1
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual & Developmental Disability, 31*(2), 77–86. doi:10.1080/13668250600710864
- Rutter, M. (1999). The Emmanuel Miller Memorial Lecture 1998: Autism: Two-way interplay between research and clinical work. *Journal of Child Psychology and Psychiatry, 40*(2), 169–188. doi:10.1111/1469-7610.00431
- Sanua, V. D. (1984). Is infantile autism a universal phenomenon? An open question. *International Journal of Social Psychiatry, 30*(3), 163–177. doi:10.1177/002076408403000301
- Shivers, C. M., Deisenroth, L. K., & Taylor, J. L. (2013). Patterns and predictors of anxiety among siblings of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 43*(6), 1336–1346. doi:10.1007/s10803-012-1685-7
- Siegel, M., & Beaulieu, A. A. (2012). Psychotropic medications in children with autism spectrum disorders: A systematic review and synthesis for evidence-based practice. *Journal of Autism and Developmental Disorders, 42*(8), 1592–1605. doi:10.1007/s10803-011-1399-2
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretive phenomenological analysis: Theory, method and research*. London, UK: Sage.
- Smith, J. A., & Osborn, M. (2003) Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods*. (pp. 51–80). London, UK: Sage.
- Smith, L. O., & Elder, J. H. (2010). Siblings and family environments of persons with autism spectrum disorder: A review of the literature. *Journal of Child and Adolescent Psychiatric Nursing, 23*(3), 189–195. doi:10.1111/j.1744-6171.2010.00240.x
- Tager-Flusberg, H. (2008). Cognitive neuroscience of autism. *Journal of the International Neuropsychological Society, 14*(6), 917–921. doi:10.1017/S1355617708081423
- Tafoya, M. A., & Hamilton, M. A. (2012). Relational dynamics and the expression of aggression and comforting between siblings. *Journal of Language and Social Psychology, 31*(1), 49–74. doi:10.1177/0261927X11425035
- Thorne, S. E. (1993). *Negotiating health care: The social context of chronic illness*. Newbury Park, CA: Sage.

- Tomeny, T. S., Barry, T. D., & Bader, S. H. (2014). Birth order rank as a moderator of the relation between behavior problems among children with an autism spectrum disorder and their siblings. *Autism, 18*(2), 199–202. doi:10.1177/1362361312458185
- Tsao, L., Davenport, R., & Schmiede, C. (2012). Supporting siblings of children with autism spectrum disorders. *Early Childhood Education Journal, 40*(1), 47–54. doi:10.1007/s10643-011-0488-3
- U. S. Census Bureau. (2004). Retrieved from the U.S. Census Bureau Newsroom website: (<http://www.census.gov/newsroom/releases/archives/children/cb08-30.html>)
- van Manen, M. (1990) *Researching lived experience*. Albany, NY: SUNY Press.
- White, S. E., McMorris, C., Weiss, J. A., & Lunskey, Y. (2012). The experience of crisis in families of individuals with autism spectrum disorder across the lifespan. *Journal of Child and Family Studies, 21*(3), 457–465. doi:10.1007/s10826-011-9499-3
- Williams, P. D., Williams, A. R., Graff, J. C., Hanson, S., Stanton, A., Hafeman, C., . . . Sanders, S. (2003). A community-based intervention for siblings and parents of children with chronic illness or disability: The ISEE study. *Journal of Pediatrics, 143*(3), 386–393. doi:10.1067/S0022-3476(03)00391-3
- Wolff, S. (2004). The history of autism. *European Child & Adolescent Psychiatry, 13*(4), 201–208. doi:10.1007/s00787-004-0363-5
- Yuan, A. S. V. (2009). Sibling relationships and adolescents' mental health: The interrelationship of structure and quality. *Journal of Family Issues, 30*(9), 1221–1244. doi:10.1177/0192513X09334906
- Zwaigenbaum, L., Thurm, A., Stone, W., Baranek, G., Bryson, S., Iverson, J., . . . Sigman, M. (2007). Studying the emergence of autism spectrum disorders in high-risk infants: Methodological and practical issues. *Journal of Autism and Developmental Disorders, 37*(3), 466–480. doi:10.1007/s10803-006-0179-x



Appendix A  
Demographics Questionnaire

## PARTICIPANT DEMOGRAPHICS

Please note: you are not required to answer these questions; however any information will be helpful for our interview and for the research project.

Please answer these questions as they pertain to the child participating in this study.

### STUDY: ADOLESCENT SIBLINGS OF CHILDREN WITH AN ASD DIAGNOSIS

**Date:** \_\_\_\_\_

**Child's Gender Identity:**    F            M

**Child's Age:** \_\_\_\_\_

**Child's Grade Level:** \_\_\_\_\_

**Child's Race/Ethnicity:** (Which does your child most closely identify with? Check all that apply)

- \_\_\_\_\_ First Nations/Native American  
(Tribe[s]: \_\_\_\_\_)
- \_\_\_\_\_ Asian
- \_\_\_\_\_ Black or African American
- \_\_\_\_\_ Native Hawaiian or Other Pacific Islander  
(please specify) \_\_\_\_\_
- \_\_\_\_\_ Caucasian (European descent)
- \_\_\_\_\_ Hispanic/Latino
- \_\_\_\_\_ Middle Eastern (please specify) \_\_\_\_\_
- \_\_\_\_\_ More Than One (please check all that apply)
- \_\_\_\_\_ Other: \_\_\_\_\_

**Socioeconomic Status:**

My family makes approximately \$ \_\_\_\_\_ each year

**Birth Order:**

The child participating in the study is the number \_\_\_\_\_ of \_\_\_\_\_ children

My child diagnosed with ASD is the number \_\_\_\_\_ of \_\_\_\_\_ children

**Participant diagnosis:**

The child participating in this study has never been diagnosed with a developmental disability, such as: Pervasive Developmental Disorder (PDD), Asperger's Disorder, Autistic Disorder, or Autism Spectrum Disorder (ASD)

\_\_\_\_\_  
Parent signature

**Sibling diagnosis:**

One of my children was diagnosed with a developmental disability (check all that apply:

\_\_\_\_\_ Pervasive Developmental Disorder (PDD)

\_\_\_\_\_ Asperger's Disorder

\_\_\_\_\_ Autistic Disorder

\_\_\_\_\_ Autism Spectrum Disorder (ASD)

Date (or year) of diagnosis: \_\_\_\_\_

Appendix B  
Interview Schedule

### **Interview Schedule**

1. How long have you known about your sibling's diagnosis?
2. What has it been like to have a sibling with a disability diagnosis?
3. Do you think being a sibling of a child with a disability diagnosis has affected you personally?
4. How would you describe your current relationship with your sibling?
5. How would you describe your current relationship with the rest of your family?
6. What are some of the challenges of being a sibling with your experience?
7. What strengths have helped you deal with your experience?
8. What would you recommend to other siblings with a similar experience?
9. Is there anything else you want to say?
10. Do you have any questions?