SIBLINGS OF PEOPLE WITH AUTISM: THE EXPERIENCES OF THE NON-AUTISTIC SIBLING

by

LAURA ELIZABETH MCNAMARA

B.A. S.W., Luther College, 2007

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SOCIAL WORK

in

THE FACULTY OF GRADUATE STUDIES

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

October 2012

© Laura Elizabeth McNamara, 2012
Abstract

Research shows that the relationships people have with their siblings have significant influence on their lives. This applies to sibling groupings of all sizes and constellations including ones where a sibling has a disability. The focus of this research is on the typically-developing siblings of persons with Autism Spectrum Disorders (ASD). Historically research on the siblings of people with ASD has focused on the impressions and evaluations of parents and teachers or used quantitative approaches to evaluate their experiences. This has left a gap regarding the stories of people with siblings who have ASD. The purpose of this study is to explore the experiences of having a sibling with ASD on a person’s life from a qualitative descriptive approach. Semi-structured interviews with five participants illuminate the experience of growing up with a sibling with ASD. The participants described experiencing relational closeness and contrasting distance, differential treatment, and specific roles like caregiver and teacher. Several themes emerged from participant stories including “a sense of normalcy”, difficulty, and feelings of loneliness, depression, anger, resentment, guilt, and fear.

Keywords: Autism Spectrum Disorder, siblings, qualitative, qualitative descriptive
Preface

This research required ethics approval from the UBC Behavioural Research Ethics Board (BREB). It received Full Board approval on February 3, 2012, as UBC BREB number H11-03175.
Table of Contents

Abstract .......................................................................................................................... ii
Preface ........................................................................................................................... iii
Table of Contents ......................................................................................................... iv
List of Tables ................................................................................................................ vi
Glossary ......................................................................................................................... vii
Acknowledgments ....................................................................................................... viii

Chapter One – Introduction ....................................................................................... 1
  Personal Reflexivity ................................................................................................. 1
  Research Question .................................................................................................. 4

Chapter Two – Review of Literature ........................................................................... 5
  Autism Spectrum Disorder ...................................................................................... 5
    Diagnosis and treatment ....................................................................................... 6
  Family Systems Theory ........................................................................................... 7
    Sibling relationships ............................................................................................ 8
  Attachment Theory ................................................................................................ 9
    Siblings attachment ............................................................................................. 10
  Siblings of People with Disabilities ....................................................................... 11
  Autism’s Effect on Non-Autistic Siblings ............................................................... 14
    Interpersonal relationships ............................................................................... 15
    Intrapersonal well-being ................................................................................... 19

Chapter Three: Research Outline ............................................................................... 25
  Data Generation ....................................................................................................... 30
  Data Analysis .......................................................................................................... 30
  Rigor .......................................................................................................................... 31
  Limitations ................................................................................................................ 32

Chapter Four: Research Results ............................................................................... 33
  Participant Introductions ......................................................................................... 33
  Participant Interview Conditions .......................................................................... 34
  Participant Stories .................................................................................................. 35
    Shannon ............................................................................................................... 35
    Mark ...................................................................................................................... 38
    Lydia ...................................................................................................................... 44
List of Tables

Table 4.1 – Participant Demographics .................................................................34
Glossary

Autism Spectrum Disorder (ASD)

A neuro-developmental disability characterized by “impairment in social interaction”, “impairments in communication”, and “restricted, repetitive, and stereotyped patterns of behavior, interests, and activities”. Classification includes Pervasive Developmental Disorders classified in the DSM-IV-TR: Autistic Disorder (299.00), Childhood Disintegrative Disorder (299.10), Asperger’s Disorder (299.80), Pervasive Developmental Disorder Not Otherwise Specified (299.80), and Rett’s Disorder (299.80).

Applied Behavioral Analysis (ABA)

Therapeutic intervention for children with autism developed by O. Ivar Lovass in the 1960s. Goal is to minimize challenging behaviors and increase appropriate communication by teaching social, motor, verbal, and basic reasoning skills through intensive treatment.
Acknowledgments

I extend my sincerest thanks to my faculty advisor, Dr. Richard Vedan, for his support and guidance throughout my academic pursuits especially the work done on this thesis. I also owe thanks to Dr. Vaughan Marshall for her assistance as I began my journey in her research course. She offered advice, encouragement and support as a key contributor and methodology specialist of my thesis committee. I must also thank Dr. Judy Illes for her time and energy given to me by agreeing to act as my external committee member.

I also thank my fellow learners in the UBC MSW program who offered much needed laughs and support throughout this process. I owe special thanks to Jana Malabuyoc for her continued support as I fought for motivation during the production of this thesis and for sharing a concern for individuals with ASD. Thanks as well to Sunny Kang, Rick Johal, Rachel Richer, Amy Schactman, and Karin McMorland with whom I shared this MSW experience and many meals of poutine.

I must also thank my parents, Mary Ann and Brian McNamara, who have taught me a love of learning. They have been my perpetual moral supporters and proof readers.

I offer special thanks to my husband, Andrew Filiposki, for his unwavering support as I endeavored to complete my MSW during our first year of marriage. He has been my loudest cheerleader. Without his love, patience, and creative cooking skills, this would not have been possible.
Chapter One – Introduction

The introduction to this paper begins with a brief outline of the subject and the need for this research. Next, I engage in a personal reflexivity in order to identify my biases and experiences related to the topic. Finally, the research question is introduced and I explain the need for further examination of the lived experiences of siblings of people with ASD.

Autism is a neuro-developmental disability that is of significant concern today because of the increasing rates of diagnosis. The Center for Disease Control and Prevention (2012) estimated in 2008 that the prevalence of autism was 1 in 88 children, up from 1 in 150 children in 2000. With this dramatic increase in diagnosis, more and more families are identifying a need for services from various providers. The whole family is impacted by the diagnosis which is discussed in more depth in the following chapter. The sibling relationship is a vital part of the family system. A person’s brother or sister serves as their first peer, and sibling relationships are often the longest relationships that people have. The brothers and sisters of a child with ASD are impacted by their sibling’s ASD in many ways that are discussed in the following chapter. There is a need for practitioners working with people with ASD and their families to understand the experience of growing up with a sibling with ASD in order to provide better services.

Personal Reflexivity

The topic of this research was selected for many reasons including my personal experiences. It is not possible for me, as the researcher to obtain complete objectivity, nor is it desired. It is important to identify what has led me to pursue this research. By engaging in this reflexivity, I attempt to identify the influences in my personal and professional experiences that have let me to investigate the experiences of siblings of people with ASD.

The focus on siblings of people with autism was chosen because I have a sibling with a
developmental disorder. In 1994, my younger brother was diagnosed with Attention Deficit Disorder after struggling in grade one. This diagnosis had a significant influence on my whole family because it had an influence on my brother. I can recall periods of my life during which I spent afternoons in the waiting rooms of the psychiatrist and psychologist offices, watching my mom try to manage my brother’s behaviors, trying not to upset him or set him off, and sensing the stress between my parents as they argued over medication. My brother’s ability to handle or not handle a situation made life complicated, and was a constant theme in all family activities and interactions. Dealing with transitions was very hard on my brother and my mother’s approach involved only telling him moments before we had to leave for an appointment or trip so his anxiety would not have time to build. As an adult, he is not magically better, and he still struggles with what is his natural way of functioning.

My brother’s condition has definitely had an impact on how I developed and how I describe my life. Not all of the impacts of my brother’s condition I experienced are bad. Because of him, I am more patient and understanding. These qualities have positively impacted my work and my other relationships. My older brother would pick on him and I would often act as my younger brother’s protector. I developed a desire to support and advocate for him and others who have extra struggles. I personally believe that having a sibling with a developmental disorder shapes one’s life and I wanted to see what other people’s experiences have been like.

I am focusing on the siblings of people with autism because I worked with adolescents with ASD for the past three and a half years. The individuals I worked with lived outside of Seattle in 24-hour staffed residential homes. The individuals in the program were placed there voluntarily, usually because of the family’s inability to manage the challenging behavioral and supervision needs of the child. As the manager for a home with four teenage boys with ASD, I
became familiar with the world of autism, the vernacular, and the common challenges of living with someone with ASD. During my tenure, I had the opportunity to observe the individuals interacting with their families. I was intrigued by the interactions between the individuals with autism and their siblings and how the non-autistic siblings seemed to react to them. From my observations, the typically-developing siblings were distant, cold, and uninterested. The majority of the siblings were adolescents and came to visit the individual less often than the parents. During the initial placement of one of the individuals, his sister expressed relief at not having her younger brother in the home much longer. She was ready for him to move out, and her frustration with him was evident. I was curious to see if others who grew up with a sibling with ASD would have similar feelings.

As a result of my personal experiences, I formed a number of assumptions about what it would be like to have a sibling with ASD. I assumed that siblings of individuals with autism eventually come to a place similar to me and become advocates for and supporters of their siblings. During adolescence, it is understandable that siblings have conflicts with their family members, and that when a sibling has autism, the struggles may intensify. I assumed that once a non-autistic sibling is out of the family home and is not residing with the sibling with autism, they develop a better understanding of their sibling with autism and the diagnosis and then change their perspective on their sibling. I assumed that their opinion about their sibling and the way that they reflect upon their life growing up with their sibling would also change from negative to positive over time. I acknowledge these assumptions in an attempt to set them aside and examine the lived experiences of siblings of people with ASD from as unbiased a perspective as possible.
Research Question

Families come in many shapes, sizes and constellations. When families have a member with ASD, it impacts everyone within the family system. The typically-developing siblings are especially impacted by their sibling with ASD, but often this is overlooked. This leads to the central question: How do people describe the experience and personal impact of having a sibling with ASD?
Chapter Two – Review of Literature

In this literature review, the current status of research concerning siblings of people with autism is discussed. First, the diagnosis of autism is defined and then the typical treatment prescribed for a child with autism is explored. Next is a discussion of family systems theory and attachment theory looking at typical family relationships specifically focusing on siblings. Information and research regarding siblings of people with disabilities are explored. Then, the scope is narrowed to examine the current literature on siblings of people with ASD specifically. Within that topic, the focus is on literature about relationships between autistic and non-autistic brothers and sisters, and then on research investigating the typically-developing sibling’s intrapersonal well-being.

Autism Spectrum Disorder

According to the *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, Text Revision (DSM-IV-TR)*, autism disorder is characterized by three specific areas: “impairment in social interaction”, “impairments in communication”, and “restricted, repetitive, and stereotyped patterns of behavior, interests, and activities” (American Psychiatric Association [APA], 2000, 299.00). Autism is one of a number of Pervasive Developmental Disorders (PDD) or Autism Spectrum Disorders (ASD) including Asperger’s Disorder, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), Rett’s Disorder, and Childhood Disintegrative Disorder (APA, 2000). The diagnostic criteria for Autistic Disorder and Asperger’s Disorder are very similar. The difference between Autistic Disorder, referred to sometimes as “classical autism”, and Asperger’s is that a person with Asperger’s does not experience “clinically significant delays” in language and cognitive development (APA, 2000, 299.00 & 299.80).

According to a report by the U.S. Surgeon General, autism “has roots in both structural brain
abnormalities and genetic predispositions” (U.S. Department of Health and Human Services, 1999, p. 163). ASDs can have varying degrees of impact on a person’s ability to function typically and live independently.

The symptoms of ASD are on a continuum and involve difficulties communicating and interacting with others. These difficulties can lead to challenging or inappropriate behaviors as an individual struggles to get their needs met in a socially acceptable way. For some individuals with ASD, communicating their emotions and getting their needs met in appropriate ways can be a challenge, and the resulting behaviors can range from yelling and Screaming, to self-harming and physical aggression towards others. There are also some stereotypical “autistic” behaviors that included rocking back and forth and hand flapping. These are often referred to as self-stimulation or “stimming”. Typically there is also a need for sameness including “ritualistic and obsessionaL behaviors” (Lovass, 1987, p. 3). This rigidity often leads to problems in dealing with change and managing transitions in everyday life. There are no physical markers of ASD and so it is often called an invisible disability.

In this research study, the terms “autism,” “autistic,” and “ASD” refer to all disorders included under the ASD label. When referring to the sibling of a person with ASD, they are identified as “non-autistic” or “typically-developing.”

**Diagnosis and treatment.** A diagnosis of ASD typically occurs early in life between the ages of three and five, but research shows that it is possible to diagnose ASD as early as twenty months (Charman et al., 1997). Typically, once a family has an ASD diagnosis they can then begin to develop an intervention plan to address the communication and behavioral issues.

The most common form of intervention is Applied Behavioral Analysis (ABA) therapy. According to the United States Surgeon General, this approach to behavioral therapy has yielded
positive outcomes for children as evidenced by thirty years of research (U.S. Department of Health and Human Services, 1999). ABA was developed by O. Ivar Lovass in the 1960s as an approach to minimize challenging behaviors and increase appropriate communication for individuals with ASD (Smith & Eikeseth, 2011). According to Lovass (1987), children with ASD are less likely than their typically-developing peers to learn in everyday situations and so specific interventions must be undertaken.

ABA programs are focused and intense. The intervention method involves upwards of 30 hours per week of treatment for several years (Hayward, Gail, & Eikeseth, 2009). It is recommended that ABA intervention programs be initiated as soon as possible after a child is diagnosed. Ideally, a diagnosis is made before a child reaches school age. It is also strongly believed that the programs should take place within the family’s home instead of a service centre (Smith & Eikeseth, 2011). ABA programs focus on teaching social, motor, verbal, and basic reasoning skills (Harris & Delmolino, 2002). This approach demands significant commitment and sacrifice from a family as well as a lot of time and energy from all of its members.

**Family Systems Theory**

Family Systems Theory was introduced by Murray Bowen during the 1960s and 1970s (Walsh & Harrigan, 2003). It marked a change in orientation of psychotherapy from the individual to the family, applying systems theory to the family structure. It is used in family services as a tool for assessment and intervention (Bowen, 1966; Walsh & Harrigan, 2003). Bowen (1966) explained, “The family is a system in that a change in one part of the system is followed by compensatory change in other parts of the system” (p. 351). Family systems theory focuses on “family dynamics, involving structures, roles, communication patterns, boundaries, and power relations” (Rothbaum, Rosen, Ujiie, & Uchida, 2002, p. 329). It recognizes that
families are not homogeneous and looks at the unique functioning of families in their own context.

Bowen (1966) noted that within the typical family system, there are other systems and subsystems at work, all functioning at different “levels of efficiency from optimum functioning to total dysfunction and failure” (p. 351). The different parts of the system compensate for other parts in order to find a balance between dysfunction and overfunction (Bowen, 1966). Family systems theory typically focuses on the triads within the family group (Rothbaum et al., 2002). Dyads are another division within the family system and the three primary dyads within families include “the spouse subsystem (husband and wife interactions), the parental subsystem (child-parent interactions), and the sibling subsystem (child-child interactions)” (Skrtic, Summers, Brotherson & Turnbull, 1984, p. 217). As noted by Skrtic et al. (1984), “it is important to remember that siblings affect, and are affected by, the other two systems” (p. 217). These subsystems made of parents and children can be complicated and can be made up of any combination of the members of the family group.

**Sibling relationships.** Family systems theory typically focuses on the adults in the system (Rothbaum et al., 2002). Meadan, Stone, and Angell (2010) highlight sibling relationships as very important and say they should not be ignored from the perspective of family systems theory. All people are born into some form of a family, and around 80 percent of people have at least one brother or sister (Dunn, 2000). Sibling relationships “serve as a prototype for later relationships with other adults” (Siegel & Silverstein, 1994, p. 17). Irish (1964) noted that the emotional ties shared by siblings are second in strength only to the emotional ties between a child and their parent. Also, sibling relationships are special because, for most people, the relationships they have with their brothers and sisters are the longest relationships they will ever
have. People’s siblings are their first peers and their foundational relationships.

Challenges in sibling relationships are typical, and can include complications due to an individual’s stage in life, or stressed relationships within the family. As young children, siblings can be each others’ first playmates and friends, or adversaries and competitors. Looking at the adolescent and young adult stages of life, Orsmond and Seltzer (2007) described the typical development of the sibling relationship noting “siblings experience decreased contact and intimacy as they establish their independent lives” (p. 313). Orsmond and Seltzer (2007) also noted that once siblings’ independent lives are established in middle and late adulthood, relationships between siblings become more prominent.

Through the lens of family systems theory, the relationships between siblings are influenced by the relationships that each sibling has with others in the family. If a parent shows favor to one sibling and not another, that will in turn have an influence on the non-favored sibling’s relationship with the favored sibling and the favoring parent. Dunn (2000) reported that differential treatment by parents can lead to “more conflicted, hostile sibling relationships, and with higher levels of aggression, difficult behavior and conduct disorder in the ‘unfavored’ sibling” (p.245). This is especially true in families experiencing stress due to having children with special needs like a disability (Dunn, 2000).

**Attachment Theory**

Another lens used to look at sibling relationships is attachment theory. Attachment Theory is the result of the work of John Bowlby and Mary D. Salter Ainsworth (Ainsworth & Bowlby, 1991; Bretherton, 1992). They theorize that attachment is “biologically rooted” and is necessary for the survival of the species (Ainsworth, 1989, p. 709). As Shaver and Mikulincer (2009) describe it, attachments to others “are viewed as products of evolution, [and] should be
associated with distinctive rewards and satisfactions” (p. 168). These rewards are typically feelings of happiness and enjoyable exchange of affection. Cancero (2008) notes that “all children are similar in their basic needs for affection, attention and acceptance” (p. 30). The type of attachment children have to their primary caregivers depends on whether or not their needs are met consistently, and this in turn affects whether a child has a sense of security or insecurity. The quality of parent-child attachment has a lasting impact on a person’s development and all future relationships (Ainsworth, 1989; Shaver & Mikulincer, 2009). People who have their needs met when they are young and have trust in their caregivers develop secure attachments. However, if one does not have a sense of safety and trust with their primary caregiver early in life, then they develop an insecure attachment. As noted in Brody, Stoneman, and Gauger (1996), “children develop internal representations of relationships from interactions with their primary caregivers, which they subsequently use in maintaining other relationships” (p. 1289).

**Siblings attachment.** Ainsworth (1989) states that “attachment theory is extended to pertain to developmental changes in the nature of children’s attachments to parents and surrogate figures during the years beyond infancy, and to the nature of other affectional bonds throughout the life cycle” (Ainsworth, 1989, p. 709). Surrogates can include siblings, and as Ainsworth (1989) explains, “older siblings may, on occasion, play a parental, caregiving role with one or more of their younger siblings and thus may become supplementary attachment figures for them” (p. 714). Ainsworth (1989) notes that while there has not been a lot of research in the area of sibling attachments, the relationship between siblings can be viewed through an attachment theory lens.

Siblings experience secure attachments with each other when a “symmetrical, cooperative, reciprocal, mutually trusting relationship” exists and such relationships often result
in friendships between siblings (Ainsworth, 1989, p. 715). But not all sibling bonds are viewed by attachment theorists as having the quality of friendships: “many sibling relationships are characterized by ambivalent feelings rather than mutual cooperation and trust, and yet are likely to constitute enduring affectional bonds” (Ainsworth, 1989, p. 715). The kin bond that siblings share is also described by Ainsworth (1989); she writes that siblings often “feel morally obliged” as well as biologically compelled to assist their siblings throughout life when needs arise (p. 715). While the closeness of the bonds between siblings vary, “siblings, who also share a relatively large proportion of genes, tend to promote the survival of their genes by promoting each other's welfare (and thus survival)” (Ainsworth, 1989, p. 715). Siblings’ attachments to each other typically endure over time because, as Ainsworth (1989) describes:

siblings have a background of shared experience over a relatively long period of time, which not only promotes similarities in their perception of situations and in value systems that influence their decisions, but also promotes mutual understanding, without necessarily requiring explicit communication. (p. 715)

This bond exists in sibling groupings of typically-developing individuals as well as those that include persons with disabilities.

**Siblings of People with Disabilities**

Research on siblings of persons with disabilities has been going on for decades and has focused on the roles that typically-developing siblings take as well as other impacts of having a sibling with disabilities on the non-disabled sibling. Siegel and Silverstein (1994) simply note that “having a developmentally disabled child puts an extra burden on any family, and everyone feels it” (p. 1). They also noted that there is no way to predict how any one particular person will react to or be impacted by having a sibling with a disability because not all families are alike
In fact, “families differ widely in their makeup or structure, and these differences lead to endless variations in the ways in which they function to meet the needs of their individual members” (Skrtic et al., 1984, p. 217). So the impact of having a sibling with a disability can vary dramatically depending on the individual and the family.

How a sibling reacts to having a sibling with a disability also depends on their age, birth order, gender, family size, and “temperamental characteristics” (Siegel & Silverstein, 1994, p. 27). As children develop, it is not unusual for the younger sibling to imitate the actions and behaviors modeled by the older child. When the older sibling has a developmental disability, the behaviors being modeled by them may not be appropriate and then the younger sibling, although typically-developing, may exhibit the same inappropriate behaviors (Siegel & Silverstein, 1994). This can be especially pronounced if the siblings are of the same gender. Also, younger siblings of children with disabilities are typically born into stressful situations where parents are already consumed with taking care of a child with a disability, and may not be able to appropriately attend to the needs of the newborn child and may even view the child “as an extra burden” (Siegel & Silverstein, 1994, p. 27). As siblings age and typically-developing siblings who are younger develop further than their sibling with a disability, there can come a time when the younger sibling takes the role of an older sibling (Siegel & Silverstein, 1994; Skrtic et al., 1984).

As typically-developing siblings move through adolescence and young adulthood, they sometimes become embarrassed by their sibling, distance themselves from the family, or make significant life choices regarding marriage and career based on their sibling with the disability (Siegel & Silverstein, 1994; Skrtic et al., 1984). Krauss, Seltzer, Gordon, and Friedman (1996) investigated “the inevitability of intergenerational transmission of caregiving” and the emergence of siblings as “the next generation of family caregivers” (p. 90). McHale and Gamble (1989)
also found that “children with disabled siblings reported that they spent more time in caregiving activities” than children with only typically-developing siblings (p. 428). Research indicates that approximately one-third of typically-developing adults whose sibling with mental retardation still resided at home with their parents anticipate having their sibling with a disability move in with them in the future (Krauss et al., 1996).

Research shows that female siblings, particularly older sisters of children with disabilities, experience more stress due to the typical gender roles assigned to them (Siegel & Silverstein, 1994). As females, they tend to be assigned caregiving duties, and as older children, they have increased family responsibilities (Siegel & Silverstein, 1994). In this situation, the caregiving sibling becomes a surrogate parent (Siegel & Silverstein, 1994; Skrtic et al., 1984). The relational experiences of brothers tend to differ in that “brothers sibling relationships are conditioned by the gender of their sibling” (Orsmond & Seltzer, 2007, p. 314). Therefore, male typically-developing siblings are closer to their sibling with disabilities than female typically-developing siblings (Orsmond & Seltzer, 2007).

Having a sibling with a disability can impact a person’s emotional well-being as they grow up. The differential treatment of the siblings with disabilities can be a source of pain for the typically-developing sibling, as a result of extra responsibilities and pressures being placed on the typically-developing child and special privileges being afforded to the disabled sibling (Siegel & Silverstein, 1994). McHale, Sloan, and Simeonsson (1986) found that the siblings interviewed for their study indicated some negative feelings towards their sibling when they perceived that their parents were favoring their autistic or “mentally retarded” sibling and when they felt rejected. It was the younger typically-developing siblings who experienced higher feelings of rejection towards their sibling with a disability (McHale et al., 1986). Verte, Roeyers,
and Buysse (2003) did not find differential treatment as a problem in their surveys of siblings and parents of children with high functioning autism, but that could be attributed to the fact that their participants were part of a “semi-residential treatment programme” (p. 202).

Typically-developing siblings often have extremely mixed feelings and views of their relationship with their brother or sister (Grossman, 1972; McHale et al., 1986; Gallagher, Powell, & Rhodes, 2006). Grossman (1972) found that some siblings of children with disabilities are negatively impacted by their role as a caregiver, but notes that others report benefitting from having such a role. It is possible that these varying responses by siblings are due to the varying levels of severity of their siblings’ disabilities (Benson & Karlof, 2007).

In their investigation of siblings of “severely handicapped” children and their siblings, Skrtic et al. (1984) note that sibling relationships are a vital part of the family system but emphatically declare that “isolating the sibling subsystem from family function, structure, and life cycle is artificial and may lead to faulty generalizations of research findings” (p. 241). Just as having a child with a disability impacts the parents, the siblings of that person are also affected by the effects that ripple through the whole family system. Benson and Karlof (2007) carefully note that “not all family difficulties emanate from the child with a disability” (p. 596).

It is important to note that in this literature about siblings of children with disabilities, authors do not always differentiate between whether the sibling has a physical, medical, or intellectual disability. Research related specifically to siblings of people with ASD is covered in the following section.

**Autism’s Effect on Non-Autistic Siblings**

A number of researchers have turned their attention to the non-autistic siblings and the ways in which they are impacted by their sibling’s ASD. There is a consensus among authors
that having a sibling with autism is not easy (Hastings, 2003a; Kaminsky & Dewey, 2002; Lainhart, 1999; Mascha & Boucher, 2006; Mates, 1990; Siegel & Silverstein, 1994; Smith & Elder, 2010). McHale, Sloan, and Simeonsson are seen as some of the first to have raised questions about the typically-developing siblings of children with autism (Smith & Elder, 2010). Typical “autistic” behaviors are marked by “abnormalities in reciprocal social interaction and communication and stereotyped, repetitive interests and behaviours” (Lainhart, 1999, p. 278). Even though communication can be a challenge between siblings with autism and those without autism, the amount of time spent together helps naturally form the relationship. In their research about siblings where one has ASD, Orsmond and Seltzer (2007) reported that siblings between 2 years and 12 years old spend “on average 40 minutes out of every hour together when observed at home” (p. 315). While growing up, autistic and non-autistic brothers and sisters may play together, but the games and activities are usually tailored to the interests of the brother or sister with autism.

Historically, research has yielded inconsistent results on the impact of having a sibling with a disability (Benson and Karlof, 2007; Macks & Reeve, 2007; Mascha & Doucher, 2006; Verte et al., 2003). Benson and Karlof (2007) found that although “most non-diagnosed siblings are not at heightened risk for maladjustment, it is clear that some siblings do have problems and that these problems are linked to child- and family stressors” (Benson & Karlof, 2007, p. 596).

**Interpersonal relationships.** As stated in the previous section, the people often had extremely positive, extremely negative, or extremely mixed views on their siblings with autism or mental retardation. Looking specifically at children with autism and their families, Lainhart’s (1999) findings supported the findings of McHale et al. (1986). Lainhart (1999) found “the autistic child requires a great deal of the parents’ time, leaving little time and attention for
siblings” (p. 296). Lack of adequate parental attention can lead to resentment towards the sibling with autism as well as the parent (Lainhart, 1999). Mascha and Boucher (2006) also noted that non-autistic siblings have some negative reactions to their siblings that “are largely related to the affected sibling’s aggressive or uncontrolled behaviour, and the embarrassment caused by such behaviour or by other autism-associated behaviours” (p. 27). The autistic-like behaviors can include acting and/or speaking impulsively, engaging in property destruction, becoming physically aggressive towards others, or throwing tantrums regardless of the audience or location. Lainhart (1999) reported “when autistic children, most of whom look normal physically, have severe emotional or behavioural outbursts in public, bystanders do not understand the situation” (p. 295) and this can result in sibling embarrassment. Dillenburger, Keenan, Doherty, Byrne, and Gallagher (2010) found in their survey of parents and professionals that typically-developing siblings experienced “feelings of being neglected, treated unfairly and isolated from their peers” (p. 19).

An autistic sibling’s behavior can also be described as destructive as “autistic children can be disruptive and may get into and damage the [sibling’s] special and personal belongings” (Lainhart, 1999, p. 296). This behavior can damage the sibling relationship. In their qualitative research, Angell, Meadan, and Stoner (2012) found that the children they spoke to who had siblings with ASD expressed complex and often conflicted feelings and emotions when talking about their sibling with ASD.

Although many non-autistic siblings struggle with their sibling’s challenging behaviors and their difficulty with typical communication, the non-autistic siblings can still have a positive relationship with their sibling with autism. McHale et al. (1986) noted “when children perceive their parents and peers as reacting positively to the handicapped child and when they have a
better understanding of the handicapped child’s condition, the sibling relationship tends to be more positive” (p. 412). Parents can help shape and reframe the experiences of non-autistic children to bring them to a realistic understanding of their brother or sister with autism, resulting in changed attitudes towards their sibling. Rivers and Stoneman (2003) reported that typically-developing children ages 7 to 12 with siblings with autism responded positively when asked about their relationship with their sibling with autism. Orsmond, Kuo and Seltzer (2009) found that unlike typical sibling relationships trends, both adolescent and young adult siblings of people with autism reported that they maintained a level of closeness with their sibling with autism, although this depended on the gender of the siblings. The characteristics of autism matter too; investigating the perceptions of relationship quality of the siblings of children with ASD, Kaminsky and Dewey (2001) found that “siblings of children with autism reported lower levels of intimacy, prosocial behavior, and nurturance by their siblings compared to children with Down Syndrome and normally developing children” (p. 407).

Like siblings of people with other disabilities, siblings of people with ASD can be put in caregiving and teaching roles. In their interviews with children ages six to fifteen with siblings with ASD, Angell et al. (2012) found that the siblings were often put in the role of modeling and teaching their siblings with ASD socially appropriate behaviors and “functional skills” with as well as how to manage challenging behaviors (p. 9). Fishbein (2010) found that typically-developing siblings with high levels of caregiving responsibilities experienced greater problems with their peers. The role of caring for their sibling with autism continues beyond childhood and as Benderix and Sivberg (2007) noted, siblings who are older feel “a form of mental responsibility for the child with autism and for his or her future” (p. 414).

Building a relationship with a sibling who has ASD is not easy, especially considering
that “failure to develop peer relationships appropriate to developmental level” and “lack of social or emotional reciprocity” are part of the autism disorder (APA, 2000). Autism brings with it difficulty with interpersonal interactions including interactions with their family. For the younger siblings of children with autism, their role model has unusual and often rigid ways of interacting and relating to the world around them (APA, 2000) and the younger sibling may learn these autistic-like behaviors. Some argue that the genetic components of autism also play a significant role in non-autistic siblings because although they may not have autism, they may have autistic-like traits as a result of the genetic material they share with their sibling (Orsmond & Seltzer, 2007).

The impact of having a sibling with autism goes beyond their relationship with that sibling, and can impact their relationships with others outside the family. In their qualitative research, Benderix and Sivberg (2007) noted that having a sibling with ASD negatively impacted the typically-developing siblings’ social life. They found that “many siblings describe their social life as poor, with few friends and a constant feeling of being prevented from bringing friends home when the child with autism is there” (p. 417). Fisman, Wolf, Ellison, and Freeman (2000) state that “sibling relationship issues are far more complex, and the adjustment of unaffected siblings is more closely related to sibling perceptions of being treated differently by their parents than to the siblings' relationship with one another” (p. 374). Differential treatment of siblings is not a surprising factor as it appears frequently in research on siblings of people with disabilities in general (Siegel & Silverstein, 1994).

In families with one child with autism and multiple typically-developing children, the typically-developing children tend to cope with stress better and have less pressure on them compared to the typically-developing siblings who do not have a typically-developing sibling
Taking a family systems perspective, this could be because the system is larger and the typically-developing siblings share the stress and form a strong dyad.

**Intrapersonal well-being.** In addition to looking at the interpersonal impact of having a sibling with autism, the current literature also includes information about the intrapersonal functioning or the well-being and adjustment of the non-autistic sibling. Research shows that having a sibling with ASD can have positive, negative, or no impact on typically-developing siblings’ adjustment and well-being. All findings are included in this literature review.

In their investigation of the “psychosocial adjustment in siblings of children with autism,” Kaminsky and Dewey (2002) found that the impact of having a sibling with autism does not predispose a person to experience “adjustment difficulties or loneliness” (p. 231). They also reported that the brothers and sisters of children with autism felt that they had “received high levels of social support in their lives” (Kaminsky & Dewey, 2002, p. 225). When looking at non-autistic sisters in two-child families, Mates (1990) found no connection between having an autistic sibling and poor school performance or behavior when examining ratings from parents, teachers, and the sibling themselves. He noted evidence of a connection between having a sibling with autism and having “positive self-concept, interpersonal, and caretaking skills” (Mates, 1990, p. 51). Non-autistic siblings reported average levels of loneliness and social support compared with their peers without siblings with autism (Mates, 1990). Ormond et al. (2009) found no increased rates of reported depression in their investigation of siblings of people with ASD; however, the siblings closest in age to the sibling with ASD did score higher on the depressive symptom scale used.

Macks and Reeve (2007) also found that “siblings of children with autism appeared to have a more positive self-concept than did siblings of non-disabled children” and lower levels of
depression when they rated themselves on the Piers–Harris Children’s Self-Concept Scale and Children’s Depression Inventory-Short Form (p. 1065). This response from the siblings did not match the responses of their parents who rated the siblings as having social and emotional adjustment levels lower on the Behavior Assessment System for Children–Parent Rating Scales than the control of parents without a child with ASD (Macks & Reeve, 2007).

Rodrique, Geffken, and Morgan (1993) also noted that “siblings of developmentally disabled children in general, and siblings of autistic children in particular, are not especially vulnerable to adjustment difficulties” (p. 671). However, they did note that older siblings of people with autism exhibited “higher rates of both internalizing and externalizing behavior problems” (Rodrique et al., 1993, p. 672). Faber (2010) found that the siblings of children with autism reportedly experienced high levels of depression and hyperactivity but reported lower levels of anxiety.

Hastings (2003a) indicated that there is a connection between having a sibling with autism and poor adjustment as measured by the Strengths and Difficulties Questionnaire (SDQ) and the Developmental Behavioral Checklist. Hastings (2003a) reported that the younger brothers of siblings with autism “engaged in fewer prosocial behaviors” compared to a standard sample (p. 99). It is also important to note that the participating families in Hastings’ (2003a) study had children with both autism and mental retardation. Dillenburger et al. (2010) also found that parents and professionals thought that typically-developing siblings “felt worry, anxiety and general sensitivity, but also at times resentment” (p. 19).

According to Lainhart (1999), siblings of people with autism, among other family members, have an increased chance of developing major depression compared to people without a family member who has autism. Meyer, Ingersoll, and Hambrick (2011) found a positive
correlation between the severity of their sibling’s ASD symptoms and adjustment problems in typically-developing siblings, especially when mothers displayed more depressive symptoms and when the sibling themselves displayed some autistic traits. In her study of siblings of boys with autism, Gold (1993) found that children with autistic siblings scored higher on the Children’s Depression Inventory than children without autistic siblings. The results indicated that although siblings of boys with autism had higher rates of depression, they did not have problems with social adjustment as measured by the Parent Report form of the Child Behavior Checklist (Gold, 1993). These studies typically focused on siblings who were in the adolescent stage of life.

In their research comparing siblings of children with PDD, Down Syndrome, and “normal” children, Fisman et al. (1996) found that “siblings of PDD children were found by their teachers to have higher levels of internalizing problems compared with DS and control children” (p. 1539). They related this to the stress of having a child with PDD on the mother’s ability to provide for the emotional needs of the typically-developing sibling; they state that “this lack of availability may be a factor that directly accounts for both the internalizing and externalizing behavior manifestations in the healthy sibling” (Fisman et al., 1996, p. 1540). In a three-year follow up to Fisman et al. (1996), Fisman et al. (2000) found that having a sibling with PDD put the typically-developing sibling at risk for adjustment problems.

In their research on siblings of people with high functioning autism, Verte et al. (2003) used input from parents as well as responses from typically-developing siblings on a Self-Description Questionnaire. They found that “brothers and sisters between 6 and 11 years old, had more internalizing and externalizing behaviour problems than children of the control group” (Verte et al., 2003, p. 201). However, they also found that the self-reporting sisters of children with high functioning autism described themselves as having “higher social competence” and
sisters age twelve to sixteen “had a more positive self-concept” compared to the control group (Verte et al., 2003, p. 201).

Some researchers have speculated about the impact of the typical ABA interventions on typically-developing siblings. In Hastings’ (2003b) study, mothers rated the adjustment of siblings of children with ASD who were receiving intensive ABA therapy. Results obtained from the Strengths and Difficulties Questionnaire indicated “no evidence for a negative effect on sibling adjustment” (p. 147). In her study, Cebula (2012) did not find that ABA interventions for children with ASD had any negative impact on the adjustment of their typically-developing siblings and that “parents and siblings perceived improvements in sibling interaction since the outset of ABA” (p. 847). They reported, “It is perhaps surprising that the ABA intervention for the children with autism did not translate into substantial benefits for the siblings, particularly when parents on the whole perceived it to be an effective approach for their child” (Cebula, 2012, p. 858). The overall result of ABA interventions was neutral for the sibling of the child with ASD (Cebula, 2012). Not all studies have found such positive results when looking at the adjustment and functioning of typically-developing siblings of people with autism.

Having a child with ASD impacts the entire family. As Benson and Karlof (2007) explain:

Families of children with autism deal with the same problems and stressors as do other families, though the impact of these difficulties are often amplified in the context of contending with a family member or members with a severe developmental disorder. (p. 596)

Often the stress of having a child with ASD results in a great deal of attention being directed towards the child with ASD. Because children with ASD are delayed in reaching their
developmental milestones, that child “has a prolonged infancy, the period of dependency in self-care” (Cancro, 2008, p. 30). The typically-developing sibling is often not given as much attention as they go through their developmental stages and this can have detrimental results on their emotional development (Siegel & Silverstein, 1994). A person can experience feelings of jealousy as their sibling with autism receives unequal amounts of attention and care (Cancro, 2008).

Reflecting on his own experiences growing up with a brother with autism, Dr. Stuart Silverstein remarked that “there was little, if any, room left over for me and my problems. I was an emotional orphan” (Siegel & Silverstein, 1994, p. 7). Parents may brush off the problems of the typically-developing sibling as trivial, which can have lasting effects on the sibling as they grow up. A child who grows up having their problems and feelings ignored learns to internalize that response and continues it into their adulthood (Siegel & Silverstein, 1994). In his account of his own experiences, Silverstein talked of the complexity of his emotions regarding his parents and growing up with a sibling with ASD, saying “my feelings are a mixture of forgiveness and understanding, as well as anger” (Siegel & Silverstein, 1994, p. 13). The conflicting emotions are common in people with siblings with ASD.

Having a sibling with autism has an impact on the mental and emotional well-being of the non-autistic sibling, even after the non-autistic sibling leaves the family home. Typically-developing siblings also feel an internal pressure—the burden of worrying about their sibling’s future (McHale et al., 1986). Once aging parents are no longer able to care for the person with autism due to age, illness, or death, the responsibility of managing the care of the person with autism falls to the siblings. Fear and uncertainty regarding the future of a sibling with disabilities are common themes in surveys of their non-autistic siblings (Meyer, 2010). Worry
over the uncertain future of their brother or sister with autism is a stressor that people without siblings with autism do not typically face.

Current literature has looked at the interpersonal effects on relationships between autistic and non-autistic siblings and the intrapersonal effects of having a sibling with ASD on the non-autistic siblings in terms of adjustment and loneliness. Studies have also examined these questions by means of asking the parents or teachers to help evaluate non-autistic siblings (Cebula, 2012; Dillenburger et al., 2010; Hastings, 2003a; Hastings 2003b; Fisman et al., 1996). There have been a few authors who have investigated it from the perspective of the non-autistic siblings themselves. Multiple studies have identified a need for further study of the autistic and non-autistic sibling relationship (Angell et al., 2012; Cebula, 2012; Mascha & Boucher, 2006; Meadan et al., 2010; Meyer et al., 2011; Orsmond & Seltzer, 2007; Smith & Elder, 2010; Verte et al., 2003).
Chapter Three: Research Outline

In this chapter, the qualitative methods and qualitative descriptive approach to investigating the proposed research question are discussed. Then, the approaches used for sampling, for data generation, and for data analysis are discussed.

Qualitative Description

A qualitative approach has been chosen for this research study in order to elicit stories of the participants’ experiences that could not be accessed through a quantitative study. In using a qualitative approach, several specific methodologies were considered: phenomenology, case study, grounded theory, narrative research with categorical content analysis, and qualitative descriptive (Sandelowski, 2000). The decision to use a qualitative descriptive method came after the exclusion of the other methods.

In a phenomenological study, a researcher may review the lived experiences of participants and describes an invariable “essence” of what is experienced by people experiencing the phenomenon with descriptive phenomenology or go beyond description and bring out meaning embedded in the experiences of the phenomenon with interpretive phenomenology (Lopez & Willis, 2004). A descriptive phenomenological approach requires that a researcher ensures scientific rigor by “bracketing” their own experiences, biases, and preconceptions so as to achieve objectivity and neutrality as they conduct their research. A descriptive phenomenological method would be more applicable to the topic of this study had the participants been a more homogeneous group; however, the participants varied in age, sibling diagnosis, family structure, and overall experience. With this research study, coming to a universal “essence” of what it is like to have with a sibling with ASD is not possible. An interpretive phenomenology does not assume that bracketing is possible, necessary, or beneficial.
to the research and goes beyond describing the phenomenon and looks “for meanings embedded in common life practices” (Lopez & Willis, 2004, p. 729). The interpretive phenomenology approach could have been applied to this study investigating the phenomenon of having a sibling who has ASD. It was not chosen because the origins of this study were rooted in a qualitative descriptive design and the purpose in choosing qualitative descriptive was to avoid claiming methods not used in the research.

A case study method applies to investigation of a specific issue within a bounded system and utilizes multiple sources of data collection (Creswell, 2007). Using a case study methodology was not appropriate for this research due to the varied experiences of the participants and the lack of a definite bounded system. Use of a grounded theory method is meant to generate or discover a new theory at the conclusion of the study (Creswell, 2007). It is presumptuous to assume that a new universal theory could be drawn from the result of a study on such a limited scale and it has not been the intention of the researcher to come up with a theory but rather to simply describe a shared features of an experience and give voice to the siblings of people with ASD.

A narrative research has to do with the study of peoples’ lives and the stories that people create in order to communicate their experiences. In narrative research, the stories told by participants are retold by the investigator and then analyzed using one of many forms of narrative analysis. Hiles and Čermák (2008) list six different approaches to analysis within narrative research that can be combined or used singularly: sjuzet-fabula, holistic-content, holistic-form, categorical-content, categorical-form, and critical narrative analysis. The method out of these narrative research options that could have been best applied to this research was the categorical-content analysis which is “involves breaking the text down into relatively self-
contained areas of content, and submitting each to thematic analysis” (Hiles & Čermák, 2008, p. 158). This approach was not used in this research because creating a narrative and examining how participants told their stories was not seen as a goal at the beginning of this research and so narrative approaches were not considered. Thus a qualitative descriptive method is the approached used in this research study.

A qualitative descriptive approach, as described by Sandelowski (2000), is used in this study. According to Sandelowski (2000), “qualitative descriptive studies offer a comprehensive summary of an event in the everyday terms of those events” and uses language as “a vehicle of communication, not itself an interpretive structure that must be read” (p. 336). A qualitative descriptive method was chosen because it is stays close to the surface of the participants’ words, places an emphasis on the description of an experience in the least invasive way, and yields “low-interference” interpretations (Sandelowski, 2000, p. 335). The words used by participants are highly valued and are presented with direct quotes in the retelling of their experiences. While not as interpretive as phenomenology or other research approaches, a qualitative descriptive does require the researcher to “make something of their data” (Sandelowski, 2010, p. 78). Neergaard, Olesen, Andersen, and Sondergaard (2009) note that within a qualitative descriptive approach the “descriptions depend on the perceptions, inclinations, sensitivities and sensibilities of the describer” (p. 53). This describer is the participant as well as the author as they retell the stories of the participants. A completely neutral retelling of the participants’ stories is not possible, nor is it desirable. Sandelowski (2010) notes that qualitative descriptive analysis as the “readings of lines as opposed to into, between, over, or beyond lines” (p. 78).

The aim in using this approach is to describe the experiences of the participants using their own language and offering interpretations of what they share. As stated by Sandelowski
(2010), the boundaries between different methods are not always clearly definable as black and white but are “highly permeable” (p. 81). The influences of other methodologies can appear in any study, including this one. The choice to classify this research as qualitative descriptive reflects the origin of the investigation of this topic as well as the desire to not presume to classify this research as something it is not.

**Sampling**

An illustrative (Mason, 2002) and purposive sampling technique was utilized in this study. Participants who meet the specific study criteria were intentionally sought out. The participants for the study had to have a sibling diagnosed with an autism spectrum disorder, be over the age of nineteen, which is the age of consent in Canada, be able to speak and understand English, live in the greater Vancouver area, and be willing to participate in a face-to-face interview and have that conversation recorded. Only a small number of participants were sought because the focus is on their specific experiences and the intention is not to generalize these experiences over a broader population. A recruitment poster was developed indicating these participant criteria.

The recruitment poster (see Appendix A) was circulated through the UBC School of Social Work Listserv as well as through an organizer with Sib Link, a group of adult siblings of people with disabilities in the Vancouver area. Two personal contacts of the researcher provided assistance in the recruitment process. One of the researcher’s colleagues sent the recruitment poster to his connections within the special education community and a friend of the researcher who has a son with ASD posted information about the study on the Families for Early Autism Treatment of British Columbia (FEAT BC) classifieds. Several email responses were received from individuals responding to the recruitment posters and seven people were interested in
participating but only five met the criteria. Those five people were interviewed.

After the respondents contacted the researcher by email, the study was described and they were pre-screened against the participant criteria outlined above. The respondents who met the criteria were sent a copy of the consent form by email for their review and encouraged to ask any questions (see Appendix B). The participants were invited to pick a place and time for the interview. Participants were offered the option to meet in-person or communicate by phone to discuss the study in person before committing to participate. Four of the five participants chose to be interviewed in their own home. One of the participants was out of the country and requested to conduct the interview over Skype.

At the beginning of the initial interviews, the participants were thanked for being willing to participate in the study and the consent form was reviewed. The participants were informed that only the principal investigator and co-investigators will have access to the data in the form of audio recordings, research notes and transcripts. Participants were informed that their interviews would be audio recorded and would be transcribed by the interviewer. They were reminded of their right to stop the recording at any time and that if they wanted to withdraw from the study at any time, any data generated would be kept secure and eventually destroyed. They were also informed that their identities would be protected and given the opportunity to choose pseudonyms for themselves and other people in their story whose names would appear in the study. All participants deferred to the researcher for pseudonym assignment. They were offered the option of contacting the researcher after the interview if they had any further questions or comments. The participants were also offered a list of free and/or low-cost counseling supports available in the area if the interview brought up any difficult feelings. They were given the opportunity to ask any questions before signing the consent form.
**Data Generation**

The participants were interviewed using a semi-structured interview style for approximately forty-five minutes to one and one quarter hours. Specific open-ended questions were used to elicit sharing of their experiences related to the topic under examination. Other open-ended questions and prompts were also used to encourage the participant to share more. The interview questions included: “Tell me about your family?”; "How did your parents explain your brother/sister’s autism?”; "What did you understand about your brother’s autism?”; "What was it like growing up with a brother with autism?"; "What was your life like when you were in elementary school?"; "What was life like for you as a teenager?"; "Have your attitudes towards your brother changed over time?"; and "Has your relationship with your brother changed over time?". Various other questions were added during the interview as the conversation progressed and the participants shared information. The purpose of these questions was to investigate how they experienced growing up with a sibling with ASD.

**Data Analysis**

Data analysis was approached informed by the work of Auerbach and Silverstein (2003) and Sandelowski (2000). The analysis process involved processing the raw data, reading and rereading transcripts, identifying relevant text, observing repeating idea, and clustering themes.

First, the audio tracks of the interviews were downloaded from the recording device and put into separate, password-protected computer folders identified by the date of the participant’s interview. Then, in a Microsoft Word document, the recorded interviews were transcribed verbatim with the omission of non-word fragments, like “ummm,” “uhh,” and throat clearing. Any notes made during each interview were recorded in a Microsoft Word document and saved within the individual participant folder.
Next, the transcripts were read off of the computer screen and relevant text sections were identified related to what the participants’ experiences of growing up with a sibling with ASD. Quotes of interest were highlighted in a bold text in a Microsoft Word document and memos were made using the Comment function. Each transcript was reread multiple times. Before further analysis, the life stories of the individual participants were described chronologically in order to give a clear context for their experiences. These descriptions of what they experienced and how they experienced it are included in chapter four. They are preceded by a brief description of the differing settings in which the interviews occurred and are separated into the individual participants’ life stories.

The next step in the data analysis was further review of the relevant quotes. A cumulative list of quotes was made and then the quotes were organized into specific themes. Not every theme was present in the experiences of every participant. In chapter five, the identified themes are described and connections are made between the themes and other research cited in the literature review.

**Rigor**

In order to ensure rigor during this study, the interviews were transcribed verbatim to preserve the stories and experiences of the participants. The author also attempted to give voice to the participants and allow them to speak through the writing by using direct quotes from the interviews. Interpretive comments are given and direct quotes from the participants are used to illustrate a point. Member checking was also used by asking the participants to review the transcripts of their interviews to verify the accuracy of the transcription and to correct any misunderstood or misspoken statements.
Limitations

I acknowledge that there are limitations to this study. The stories and experiences shared are impacted by the circumstances of the interview and the interviewer-interviewee relationship. As I am utilizing qualitative methods, my goal is to capture the experiences of the participants and recognize that the results are not representative of all siblings of people with ASD. The themes and topics that ultimately emerged were the result of the individuals’ responses to the questions and were colored by their own concerns with respect to the questions asked. Geographic and time constraints served to limit study participants to five in total.
Chapter Four: Research Results

In this chapter, the results from the interviews with the five study participants are explored and discussed. A brief demographic discussion is followed by a description of the differing contexts of the interviews. Then each individual is introduced with a synopsis of their life story in the context of their family relationships, particularly highlighting their relationship with their sibling with ASD. Direct quotes from the individual participants are used to highlight their experiences growing up with a sibling with ASD. The chapter concludes with a discussion of some of the similarities and obvious differences between the individuals.

Participant Introductions

The five participants range in age from 19 years old to 37 years old. Each participant has a sibling with Asperger’s Disorder and two of the participants also had an additional sister with Autistic Disorder. Three of the five participants do not currently reside with their sibling with ASD. The other two participants reside with at least one of their siblings with ASD. Two of the participants are the youngest in their families. The other three participants are considered to be the middle children of their family. Two participants who are in the middle have one sibling with ASD older and one sibling with ASD younger than they are. The other participant who is in the middle of their family is older than their sibling with ASD. The age differences between participants and their siblings with ASD range from one year to eleven years. Two of the five participants have full-time paid employment. Two of the participants have their own children, or will very soon. All of the participants have resided in the Lower Mainland in the past year. One was not born in Canada and one is currently not residing in Canada.
Table 4.1 – Participant Demographics

<table>
<thead>
<tr>
<th>Name</th>
<th>Shannon</th>
<th>Mark</th>
<th>Lydia</th>
<th>Melina</th>
<th>Danielle</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>36</td>
<td>35</td>
<td>37</td>
<td>25</td>
<td>19</td>
</tr>
<tr>
<td>Occupation</td>
<td>On Maternal leave</td>
<td>Unemployed</td>
<td>Stay-at-home Mom</td>
<td>Nurse</td>
<td>Psychology Student “Working with kids with autism”</td>
</tr>
<tr>
<td>Birth Order</td>
<td>Youngest</td>
<td>Youngest</td>
<td>Middle</td>
<td>Middle</td>
<td>Middle</td>
</tr>
<tr>
<td>Sibling’s Name</td>
<td>Aaron</td>
<td>Sean</td>
<td>Juan Antonio</td>
<td>Erin</td>
<td>Erin</td>
</tr>
<tr>
<td>Sibling’s Age</td>
<td>40</td>
<td>38</td>
<td>26</td>
<td>17</td>
<td>17</td>
</tr>
<tr>
<td>Sibling’s Age</td>
<td></td>
<td></td>
<td></td>
<td>27</td>
<td>27</td>
</tr>
<tr>
<td>Sibling’s Diagnosis</td>
<td>Asperger’s</td>
<td>Asperger’s</td>
<td>Asperger’s</td>
<td>Autism</td>
<td>Autism</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Asperger’s</td>
<td>Asperger’s</td>
</tr>
</tbody>
</table>

**Participant Interview Conditions**

The conditions of the interviews varied between participants. Shannon’s interview was the first conducted and analyzed. It occurred in her living room over a cup of tea and the preliminary themes that emerged from Shannon’s interview shaped the direction of the other interviews. The interview with Mark was conducted over Skype because he is traveling outside of Canada for an extended period of time. Interviewing over the computer with only voice communication posed a few challenges because the nonverbal indicators like facial expressions and body posture were not observable. The argument could be made that it allowed Mark to speak more candidly as if it was a confessional.

Lydia’s interview had several challenges. There were unavoidable distractions because of the limits on time and place availability for the interview. Her son, who has ASD, was finishing
an ABA therapy session and her daughter had to play outside where the interview was taking place so as to not disrupt the ABA session. Another challenge with Lydia’s interview was the fact that English was not her first language. There were occasions where she seemed to struggle to find the “right” word to communicate her message.

The two participants, Melina and Danielle, requested to be interviewed together at their family’s home. The researcher permitted this because of the limited availability of the two participants. During that interview, we were interrupted twice. The first interruption was the late arrival of the eldest sister and the second interruption was from their mother who was returning home. Upon the mother’s arrival, their sister with ASD came into the area where the interview was taking place prompting the interview to change locations. One concern during the interview was that the two sisters would simply say the same thing, but both women shared their own individual and differing opinions and experiences.

**Participant Stories**

While sharing the experience of having a sibling with ASD, each participant has a unique story of their experiences. As briefly depicted in Table 4.1, the participants are not a homogeneous group. In the following section, I tell the stories of the five individuals who participated in this research. These are the stories of their lived experiences and are told using direct quotes to illustrate their experiences in their own words.

**Shannon.**

Shannon is a thirty-six year old Caucasian woman who lives in Vancouver, BC. Her older brother, Aaron, has Asperger’s. Shannon’s brother Aaron is five years older than she is and she has always known that he had some sort of “mental retardation”. She grew up in Halifax until the age of ten and describes her early childhood as “really good.” Reflecting on her relationship
with her brother at that time, she says “I was lucky in that because his mind was at a younger age, I had him as a playmate for a really long time.” She noted “he loved playing Barbies with me which was great. And, you know, watching a lot of the same programs and stuff together.”

She talked about a time where she and her brother were out at a water park:

Kids used to tease him all the time. Like, we would go to... we lived in Tsawwassen so we would go to Splashdown Park and then he, you know, would have other kids bug him, but for the most part my brother stood up for himself. He's a really, he's very tall, he's like six foot something and he's a solid guy, and, you know, there were a couple times when he'd give a good swift kick when somebody ticked him off.

Shannon reflects very positively on her childhood relationship with Aaron.

Shannon and Aaron went to the same high school but she described that “I had my group of friends that I hung out with at lunch time and I hardly ever saw my brother.” Even though she did not have a lot of contact with him during school, he was still a part of her life. She talked about her friends and their interactions with Aaron saying, “For the most part my friends were pretty accepting of Aaron. Because he had such a good personality that they, you know, they would laugh with him as opposed to laugh at him.” Reflecting on their relationship, she said “Our relationship as teenagers was probably like a normal brother and sister during their teenage years, you fight a lot. And obviously weren't playing as much together.” Reflecting back on that she said:

I think maybe where the fighting stemmed from me not understanding, um, really understanding Aaron and why he would do the things that he would do and react the way he does and then me getting angry or frustrated with him and then him getting angry or frustrated with me. That's probably where the fights would stem from here. Or I would
tell him to do something and he wouldn't do it. But I mean who wants their younger sister telling them what to do.

Shannon describes her high school years as being pretty “normal”. In her last few years of school, her brother went to live with her father while he finished high school. Shannon and her brother lost contact during the couple of years he lived with their dad in Vernon. But after her mother got remarried, her mother and step-father moved to the Sunshine Coast and Aaron came back to live with them. Shannon stayed in the Lower Mainland to finish high school and “by the time I moved out to the Coast, then my brother was ready to not be living with his parents anymore and he went and lived in a group home in Sechelt.” Then after finishing high school, Shannon moved to the Okanogan to go to college. Reflecting on her relationship with Aaron, she says that “it continued to be really distant.” She reports, “I would see my brother when I would come home, you know, whether it be for reading break or something like that or a holiday and I would see my brother then. But we didn't keep in touch on the phone or anything.”

After her time at college in the Okanogan, Shannon moved to London, England. She lived and worked there for three years. She reports that she only came home once during that three year time period. During her time in London, her mother and step-father stayed on the Sunshine Coast but her brother moved from his group home in Sechelt to live with a family in North Vancouver. He has lived with the same family for over twelve years and Shannon reports that her family considers them as part of the family now.

After moving back to BC, she would often travel to go see their parents on the Sunshine Coast. She says it was on those trips that she would see her brother. They did not spend time with each other outside of those family visits. Her relationship with her brother has changed in recent years and Shannon has been spending more time with her brother outside of their visits to
see their parents. She describes the change saying:

So maybe as little as probably three or four years ago is when I started to arrange dates with him, I guess, to go out and do stuff. And try to make a better effort of being a part of his life more in the things that he does on the side like whether it's going to one of his Special Olympics games or track meets.

She now takes a special interest in her brother and says that she makes specific efforts to continue their relationship and improve it.

The change in her relationship with her brother has been a positive change in her life. Shannon and her husband, Trevor, make a special effort to spend time with Aaron. She says, “it's now that I'm older I definitely make the time more... He'll come over and stay with Trevor, my husband and I, you know, for a night and we'll watch a movie or we'll go out and watch a movie or grab dinner or something like that. Make more of an effort to do things with him.” The relationship that Shannon shares with her brother she hopes will continue into the future but may change with the approaching birth of her first child. Thinking about what will happen after her parents pass away, Shannon mentions some fear around her brother saying “like, yes he still may be living with somebody else but the fact that I'm going to have to be looking out for, you know, his sort of everyday needs and that come his way is a little bit scary.” Even in the face of uncertainty, Shannon has hope and optimism about her brother and her future.

Mark.

Mark is a thirty-five year old man who grew up in Vancouver, BC. Mark is currently out of the country and so the interview was conducted over Skype. Mark grew up with a brother, Sean, with Asperger’s Disorder who is two and a half years older than he is. Mark describes himself as the “normal one” in his family and describes his childhood as not easy. His mother
was a therapist and his father was a lawyer. She had a Master’s degree in counseling psychology and was a very intelligent woman. Mark describes his mother as “somewhat Borderline Personality” and as someone who always “wanted very much to be in control of things.” She passed away earlier this year. About his father, Mark said that “he considers himself also [to have] Asperger’s but he’s much more normal” compared to Sean. With his father’s family history of having the hidden “crazy” family member, he got the impression that “my dad actually always felt guilty about... He thought it was his fault my brother was the way he was.” When asked if his dad talked about the guilt, Mark replied, “Not in an overt way. But I could see the guilt in his eyes.” As a lawyer, he focuses on “very technical aspects of law” and he has an affinity for “learning things and focusing on little details.” Mark also mentions that his father is very uncomfortable with any expression of feelings and that “if anything emotional comes up, he just wants to end the conversation.”

Growing up, Mark was an active child who enjoyed playing sports and had a number of friends early on in school and then things changed. Because of his brother, Mark often was not able to do all of the activities he wanted to because “things came a lot slower physically” for Sean. He recalled that “my mom tried to keep a bike away from me because she knew just how frustrated my brother would get if I learned to ride the bike earlier than him, being two and a half years younger.” Both of them did eventually learn but Sean struggled and got very “frustrated.” Mark did not “think about ‘why is he having these problems?’” because it was just his brother. He recalled wanting Sean to play with him “but that rarely happened.” As they got older, “we sort of went into domains” with his brother focusing intensely on chess and Mark mastering the computer.

After his mother went back to school and earned her Master’s degree, his parents “started
fighting a lot because he... he [his father] couldn’t stand her trying to counseling him.” Mark’s parents divorced when Mark was about seven. Mark and his brother went to live with their mother and their father moved to a place five blocks away. Mark remembers going to his father’s house once a week “the same evening every week for the next ten years.” Mark noted that the visits were very scheduled for the benefit of his parents not having to communicate as well as for his brother’s need for routine and “there wasn’t anything unplanned.”

After the divorce, his mother was incredibly focused on her sons. However, Sean reacted severely to the attention she would give him and so his mother would focus nearly entirely on Mark and then “in a roundabout way, my brother.” He even described the intensity of her focus as “on the obsessive side” towards him because “there was very little hope about him [Sean] being warm to her.” He reported that “with my mum being more obsessed about me, I actually started pushing people away myself” including his friends in school. She was very overbearing and over-reacted to any sign of emotional expression. Mark described her as having “too much general anxiety” and remarked that “the only thing she knew how to do was to act more aggressively and try to fix it.” Mark recalled that “if I displayed a lack of warmth towards her, she would really freak out.” She also “used her counseling to deflect any responsibility away from her.” She did not respect privacy and had no sense of emotional boundaries.

The first few years after the divorce, the emotional environment of his father’s house was more relaxed compared to the “more tense” emotional environment of his mother’s house. Mark remembered initially enjoying his visits with his dad because he was able to “relax a bit around my dad because he didn’t want anything” from him. He only wanted to “see me from a distance.” He remarked that his dad “wasn’t as easily freaked” by eight-year-old Mark’s emotional expressions. At first, his father put effort into doing things with Mark and his brother,
“But after a while, it just got so that we did very little” because his brother would refuse to do the things that Mark wanted to do. His brother’s limited interests meant that “if I did stuff, it was alone,” and in the rare occurrence of a shared activity, it was usually Mark who was “forced” to do what Sean wanted to do because “usually he would have the trump card.”

Mark described his brother’s power over the family as frustrating. When he was younger, Sean “would freak out more and do nasty stuff” in order to get his way. This decreased when Sean got older but he still held the “power” and he knew it. About Sean’s influence, Mark said:

He knew that... that he could say no and just say no and be absolutely stubborn and unyielding and people would give in. Because he was absolutely fine having no dinner.

Staying in his room the whole time staring into a blank wall.

Mark reports that “both my parents never wanted to look at how my brother’s condition affected me, effectively silencing any questioning I had.” Mark did not share any closeness with his brother. He reported that he “never really felt like I had a brother because there’s nothing to talk to, talk with about nothing.” He said “how I describe myself sometimes, is in some ways an only child and some ways youngest, and in some ways an oldest.” It was very difficult to relate to his brother in any way. Mark got the sense that his brother had “no empathy” for anyone and was very calculating in his behaviors. Mark recalls receiving “really cold stares” from Sean and the feeling of an “utter lack of warmth” from him. Because of his mother’s psychology background, he had an understanding of his brother’s diagnosis, but that technical information did not have an impact on their relationship.

Mark recalled feeling very alone and different from the rest of his family members. Sean “was always the one with issues” and his family was “never really been able to talk about it.” His parents would just say “Oh, he’s Sean. You have to be the strong one.” If Mark ever wanted
to talk about Sean, he said “my dad would end the conversation or my mom would potentially try to say, ‘Well, you have to understand that Sean is going through this. He’s this... He’s, you know, a lot of issues. And you just have to live with it.’” He reports that his parents had a definite dilemma “because they were very much focused on him, but also trying to not get too close for fear of, like, upsetting him. So there was definitely a big ball of worry about him.”

In high school, Mark was involved in music which offered him a venue to do “emotionally expressive things.” With his brother and father’s lack of emotions and his mother’s hovering, he could not express them at home and had to “end up blocking myself with music... or writing because she would want to talk about everything.” Mark recalled feeling the pressure from his family. “They were like ‘hey, you’re the healthy one. Just, you know, live with it. You’re... you’re, you know... you should be glad you’re not like Sean.’” The pressure to succeed and the lack of healthy emotional support led to Mark “feeling really depressed and isolated” in high school. Over time Mark internalized the negative feedback he’d receive if he revealed his emotions and so he had to control it because “there was this big feeling of walking on eggshells” at home. Any emotion expressed in body posture or facial expression had to be controlled or he would have to explain and have it analyzed by his mother. So it was easier to not show anything.

The practice of self editing and the “defensive reactions to tension” carried over into Mark’s other relationships and made it difficult for him to get “real friends.” Because his brother is “the way he is” and his father, Mark is “not sure how to act around guys” and has difficulty making and maintaining friendships with other men. He reports that he is comfortable having “fun and joking around” in certain settings like parties or when acting. He does not feel relaxed in family situations and certain social settings but rather experiences “a sense of separation” and “hardness.” This was especially pronounced in high school when he reported being “more
uncomfortable” saying that “it just felt worse socializing” because he always had to “watch what I was saying about what was emotional.”

Mark described holidays and birthdays as being stressful times in his family. His brother, Sean, “insisted on getting absolutely nothing for his birthday” because “he didn’t want any day to be different from any other” and would get angry if any one did. Christmas time was another source of tension in his family. Because of his brother, Mark was used to restrained holiday celebrations but when his father remarried and his step-mother wanted to implement her traditions, he felt uncomfortable. This proved problematic because when Mark tried to express how he was feeling about the changes, he was told to “shut up and pretend” and that he was being “selfish.”

As a young adult, Mark went to university and pursued a promising career in the technology and computer fields. He found great success professionally and financially but was suffering. It was not until Mark went to pursue post-graduate studies that, as he puts it, “I realized just how stuck I felt emotionally.” Growing up in a family where emotions were not easily processed has left a lingering impact on him. As he describes it, “it’s hard to get to the point where I feel completely relaxed and just feeling. Just expressing what’s there, not analyzing things, not having to think about things before expressing them.” It was at that point that he pursued creative expression through the arts. “In some ways it was a release to be able to just give that one time where I could vent or just give full voice to... to some sort of emotion which was... of course, was the opposite to my family.” Even after using the arts as an outlet for emotions, he began experiencing a lot of troubling physical symptoms. He was eventually diagnosed with Chronic Fatigue Syndrome which he attributes to decades of emotional tension and his emotionally reactive family.
Mark’s last interaction with his brother was at his mother’s funeral earlier this year. As Mark moves into his mid-thirties, he has no desire to have a relationship with his brother. He is working towards mental and spiritual health and finding a place of emotional safety. He says “it’s something I yearn for to... to... to just relax and not really think too much about what I say before I say it. And it’s something... it’s fairly ingrained still... [having to be] self edited.” He has come to the point where he is realizing that “hey, if anything is gonna get better, it has to come from me.” He is attempting to work through his Chronic Fatigue Syndrome by learning to relax and to experience his emotions without jumping to suppress them while on a meditation retreat in Mexico. The lingering influence of his family has impacted Mark’s ability to engage in intimate relationships. He puts a lot of effort into creating and sustaining relationships with healthy boundaries.

Mark has an awareness of his brother’s influence on his life and the obvious “chain reaction” that having a brother with ASD has caused throughout his family. He has no desire to have a close relationship with his brother and “very little interest in actually seeing my brother.” He admits that “I don’t enjoy his company now – and haven’t since I was a small child.” Mark feels he is reaching a place where he can be unedited around his brother and “stop acting like I ‘should’ towards him.”

**Lydia.**

Lydia is a thirty-seven year old woman who lives with her husband and two children in a home in the suburbs of Vancouver, BC. She has a younger brother with Asperger’s as well as a young son with autism. Lydia has two older sisters who are also typically-developing. She grew up living with her parents and sisters in Venezuela. Her father worked outside of the home as a professor and her mother was a stay-at-home mom. As the youngest, she enjoyed being the baby
of the family for twelve years before her brother Juan Antonio was born. She talks about his birth saying he was “the best gift that my mom and my dad could give me because I was the youngest.” She recalled that he was healthy and hit the expected developmental milestones: “He talked, he crawled. He walked at the time he was supposed to.” He was her own personal doll. She described him as “this doll that I could take care, that I can bathe, that I can put the baby powder, everything!” She talks of the great amount of love that her family had for him. She shared about how she “had a bicycle and I put him on the bike and I took him everywhere.” She was very involved with him and says that “I even took him to the school and I picked him from the school.” Her relationship with him was very parental.

Lydia remembers knowing Juan was different when he was three years old. The doctors just said that he was “hyper.” She shares that “when he was little, he was verbal, he looked quite normal, but he has a lot of sensory processing things like movement.” It was the sensory movements like jumping and stimming behaviors that made him stand out. She also noted that he spoke “super fast” and that as “he was at the end of one word he was beginning the other one.” Looking back, she remembers that he had difficulties socially in school and that it “was very difficult for him because all the other kids, they didn't want to approach him because he was doing things different.” She says, “Many people say many things, ‘oh you know, look at him. He looks weird!’ But my mother always believed in him.” She touts her family’s support of Juan as the reason that he has been successful so far. Lydia remembers a game that she played with her brother. It was “a game about patterns, about logic thinking.” During their play time together Lydia helped lay the foundational skills typically accomplished through ABA interventions. “I was doing therapy without realizing it. I was doing therapy with my brother.”

Lydia had a typical adolescence. They lived in a small town in Venezuela and there were
not many teenagers in her area. She babysat for her brother a lot and did so willingly to help out her mother. She said “that was my entertainment, to take care of my brother.” She described the other teenagers in her area as “not good for me and not good influence.” She enjoyed studying, spending time in nature, and hanging out with her family.

Ultimately Lydia and her family moved from Venezuela to Colombia when Juan was about thirteen. Lydia recalled the process of trying to get Juan diagnosed. Her parents had taken Juan to doctors in Venezuela but were not satisfied with the treatment there. So when they moved to Colombia where “the education is better,” they were disappointed again to be told that he was hyper and have the neurologists recommend Ritalin and black coffee. After graduating high school, Lydia was working and studying at the university. Lydia remembered Juan having a hard time in high school and having other children pick on him a lot. She notes that their relationship changed in that “he was not as open as when he was little.” Lydia said that it was around that point in time as he was in high school that he stopped attending school. Her father retired, and began homeschooling him and focusing him on subjects that he was interested in.

Lydia lived with her brother and her parents until she was twenty-six when she moved to Canada. Lydia met her husband Charlie and fell in love. They married and have celebrated the birth of two beautiful children, Eva and Tyler. Eva is six years old and is typically-developing, and Tyler is four years old and is diagnosed with autism. She is involved in the autism community of greater Vancouver. It is a family affair because, like Lydia did when her brother was younger, Eva acts as a therapist for Tyler and also works/plays with another child with ASD for therapeutic purposes. Lydia is very proud of her daughter.

Because of Lydia’s own experiences as the sister of someone with ASD, she has paid specific attention to the way that she parents Eva. Lydia’s own experience was quite different
than her daughter’s because the age gap between her and Juan was twelve years and between Eva and Tyler it is only two. Lydia had already grown up a lot and spent twelve years as the “baby” of the family. She recalls a moment after Tyler was first diagnosed and there was an influx of therapists and social workers coming into the home. Eva came up to her and “she was like ‘why everybody wants to play with Tyler and nobody wants to play with me?’ And my heart was broken.” The services and assessments for Tyler were important but Lydia started making special time for outings with just Eva and planning special activities for them to do without Tyler so that Eva can be the one in the spotlight.

With the knowledge from her own experiences and from observing her daughter, she speaks to other parents with children with ASD and typically-developing children saying:

They need to be aware that even though your kid was diagnosed, you need to also look for the other ones. It’s important. Don’t think that just because they are fine doesn’t mean that they need love that they need to feel that attention…. even I told the Moms, “don’t forget your daughter,” when I know families. Don’t forget the brother and the sister.

She also has an understanding of what having a sibling with ASD could become in the future as parents age. Because the sibling “relationship is longer than [the] mother and father,” she is mindful of what that means for Eva. Lydia’s parents are getting older; her father is eighty-two and so she thinks about the inevitability of his death. She says, “I know that even though I’m not in this world, I know that Eva, she will look after Tyler.” She doesn’t want Tyler to “be a weight on her shoulders” and is thinking about that even though he’s only four.

Being so far from her family in Colombia is difficult but she says that she is still very close with her family. Her sisters, one of whom is a doctor and the other an engineer, still live in
Colombia with their families. She makes visits to Colombia to visit her family every two years and has regular phone contact with them. She has regular contact with Juan through emails, Facebook, and the occasional phone call. She talks about how intelligent he is. He speaks five languages fluently and is still studying at the university. Lydia says that she is still the one that the family uses to talk to him “if there is any problem”. She tried to understand what his reasons were for doing the things he did. She explained, “I understand why, because always there is a reason for a behavior.” Then when she talks, “he listens” because she understands him and she can communicate in a way that he understands. Lydia tries not to judge him for his choices.

Their family knew early on that Juan was not developing normally but they did not know Juan had autism until very recently. Once Lydia’s son was diagnosed a year ago and she learned about ASD, she told her parents to get her brother assessed. It was around that time that her parents asked her “could you please take care of Juan Antonio?” She was overwhelmed because she did not know what her son would be like when he grew up. The thought of having to look after her own son and her brother was overwhelming. Her feelings about being asked have changed because “my son has changed a lot.” His intensive ABA treatment has increased his communication skills and decreased his challenging behaviors. She now looks at it as “a privilege because they didn’t ask my other two sisters… I know that they want me because I could understand him better because I have my son and I know that I will understand him better.” The relationship Lydia has with her brother now is an especially important one because he was officially diagnosed with Asperger’s Disorder just two months before the interview. And on her trip, just days after the interview, she will be helping her family and her brother to understand the diagnosis better.
Danielle.

Danielle is a nineteen year old woman who lives just outside of Vancouver, BC. Danielle comes from a large family. She has two siblings on the autism spectrum. Her younger sister, Erin has been diagnosed with Autism and her older brother, Kevin has Asperger’s. She recalled that “Kevin didn’t have any responsibility whatsoever!” Being the eldest son and also having ASD, “he really couldn’t have handled that responsibility.” She has five siblings, including Erin and Kevin. Her two oldest siblings, Steve and Terry, are from her father’s previous relationships. Danielle grew up with her three full siblings with her parents with intermittent contact with Steve, but she did not meet Terry until she was fourteen.

Growing up, Danielle has always known that her older brother, Kevin, had problems, even though he was eight years older than she was. It was just normal for her. Danielle’s relationship with her older sister, Melina, was impacted in that she had “the parental role of me and Erin” and in certain ways was the “replacement parent.” Danielle described that she had a very happy childhood and that early on was often unaware that her family was different.

Danielle describes her younger sister, Erin, saying “she’s the baby.” She said she remembers when they were young that Erin “wouldn’t hug” and “wouldn’t make eye contact.” Erin did not get diagnosed with autism until she was five and getting ready to start Kindergarten. Danielle said that Erin “missed out on a lot” of intervention time because the diagnosis was so “very delayed.” She attributes the delay in diagnosis and therapy as the reason for “how severe she is now.” From the time she could remember, “a lot of focus was on Erin.” After Erin’s diagnosis, Danielle’s family jumped into the world of autism treatment. Danielle remembers when she was eight having her dad force her to watch videos about Lovass’s ABA treatment. Her parents would take her and her sister to workshops put on by various autism groups. She
remembered that one whole room of their house, their former family room, became Erin’s full time therapy space. Danielle said that she only worked with Erin as a therapist “only a few times. It was weird, just ‘cause I was so close in age. Mom was just like ‘no, she can’t do that.’”

Reflecting on her primary school years, Danielle remembers that Erin “had a hard time in elementary school.” Erin had to switch schools multiple times and “was home schooled for a while.” This had a significant impact on Danielle because she also had to switch schools. She recalled having to switch schools after the first day of grade six with “no warning”. She was not thrilled about it but did not express her objections saying, “you know, I repress my emotions.” She said she did not get really upset about the switch until she was unable to make friends at the new school. She “had no idea how to make new friends” felt “like the total freak.” She said that “once I went into high school, I was like, ‘Oh my god, I’m so glad I moved schools.’ ‘Cause then you actually, like, know more people and you realize how like different it was.” So while the year was difficult, in the long run it was not a bad change.

Danielle was a very obedient child. She said “up until like a couple of years ago, I really just happily listened to anything anybody told me just ‘cause that was the way that I was, right.” Danielle described herself as a child as a bit oblivious and a bit of a “space case.” She is “easygoing,” possibly to the extreme. She said “people just kinda made decisions for me and I would go along with it, just ‘cause, you know, that’s the way it was.” She also describes herself as being a “professional” at emotionally disassociating from the chaos of her family.

Growing up, Danielle said that she “totally” noticed differences between her family and the families of her friends. She made a comment immediately afterwards saying, “Just kidding, I didn’t even go out. I didn’t even see any other families. I didn’t know we were weird.” She was referring to the isolation that she experienced having two siblings with ASD. Danielle
acknowledged that it was hard because “my mom had four kids and she was doing it basically by herself,” noting that her father was not involved with the kids. She remembered doing swimming classes with all her siblings because it was ASD-friendly “it was convenient for them” but she did not get the opportunity to do any other extracurricular activities as a teenager.

After Melina moved out, Erin became Danielle’s responsibility and she describes herself as “being the total parent of Erin.” She described it as “comfortable” saying that “it’s just my temperament” and that she has a “motherly instinct.” As a teenager, looking after her sister became her main activity: “it was come home, look after Erin.” Danielle reports that she has a lot of love for her sister and that with Erin, “I feel more like a mother.” She does not hold resentment towards Erin for not being “thankful” for all of the care she provides for her and understands that she is not capable of it. Danielle says it can be difficult going out in public with Erin because of her unpredictable behaviors but she does not have a problem going out in public with her. Erin’s behaviors “barely faze” her but she noted that her dad was “obsessed with the idea of, like, us looking normal.” Generally, she says she has “no embarrassment any more at this point.” She said she knows that “If I want to go out and look good, I’m not going to bring Erin.”

Danielle moved to Kelowna for a year and a half to attend the University of British Columbia at Okanagan (UBC-O). She said that she had had enough of the “hippy-raver” environment and moved back home. She returned home in February only to find that her sister had taken over her bedroom. Things changed when she got home and she slipped into a parental role. Danielle said that Erin had “all the freedom she wanted. And I came back and I’m just like, ‘This is not acceptable! Like, she cannot be wearing these clothes like ten days in a row. Like, you can’t let her do that.’” From Danielle’s description, her parents are “done” raising kids
and do not have the energy to handle Erin because she’s “not easy.”

Danielle describes her relationship with her parents as being “decent” at this point in time, but she still struggles with frustration and resentment. There is still an expectation placed on her to look after her sister. Her frustration was evident when she said “with us it was just expected, you know, ‘you take care of Erin. You cancel all social plans.’” Her childhood friendship opportunities were impacted. She said, “I didn’t go out. I didn’t have a social life. I just didn’t, in high school and elementary school.” This upset her because she is “a very, very social person.” Her parents have “relaxed” since she’s come home citing that her mom “actually has started to be like ‘do you have anything or will you be able to take care of Erin?’ And that is a huge step.” But she knows that “I’ll be guilted if I don’t.” She acknowledges the difficult position her mother is in because she works full time with kids with disabilities in schools and her father does not help at all with Erin. So if Danielle says no to looking after Erin, then her mother is the only one left. Although she has some “resentment” towards her parents for the expectations placed on her, she understands that she “can’t hate them for it…What happened, happened. That’s it.” Danielle admits that she is not as independent as her older sister and still has expectations of care-giving placed on her, but as she says, “I’m still working on that.” Danielle admits being “resentful” of other siblings of people with ASD who do not have as much responsibility and involvement with their siblings as she does. She speculated that the expectations were due to the cultural influence of their parents’ Middle Eastern heritage.

Having to be responsible for her sister has had an impact on Danielle’s relationships with other people. She shared that her eldest sister, Terry, sometimes invites them over but that “when she’s inviting us over, she’s like, ‘Yeah but I don’t know, maybe don’t bring Erin this time.’” Danielle knows why, saying that “it is hard… because the whole time we’ll be babysitting
basically.” She also noted that Terry works in psychiatry “so she works with people like that” all day and the interactions are more professional than familial. It limits her ability to just relax and spend time with Terry and her family. The fact that Erin is her sister also impacts how she chooses her friends. When she meets people who are unaware that she has a sister with ASD, she pays attention to how they speak about other people with disabilities. If she hears them people speaking in a way that is “degrading” towards people with disabilities, then they just “can’t be friends anymore.”

Thinking about the future of her siblings with ASD, she is not worried about her older brother. He’s employed and works in IT. He will be able to survive on his own. But in terms of Erin’s future, she says that they “Don’t even have a clue, like, five years from now.” Danielle’s “just kinda hoping that funding won’t be cut for group homes and stuff and she’ll be happy there.” It is so uncertain at this point that she jokingly said “maybe she’ll get married.” If Danielle gets married and has children, she is somewhat concerned. She said, “what’s also a big thing for me is the chances of us having kids with disabilities.” She thinks about it every once in a while and she said that because of her experiences she has “been much more supportive of abortion.” Having her own child with autism “would be hard” but she has a lot of her own experiences that have been both positive and negative.

Danielle says “I definitely wouldn’t be who I am now if it wasn’t for Erin.” Because of Erin, she says she is more “humble,” “hospitable,” and “empathetic.” Having grown up with attention-demanding siblings, she is still not comfortable being the center of attention and even remarked during the interview that “this is very, very weird for me to have, like, all this attention.” Danielle has enjoyed finding out that “we [the non-autistic siblings] actually are important too.”
Danielle’s natural care-giving temperament has carried over into her career choices. Currently, Danielle works as a tutor and also works with kids with autism. She says it is hard because “it’s like, you go to work, kids with autism. You come home, more autism.” She does not plan on making that her permanent career but is pursuing a degree in psychology. She commented, “I find the way that people think and just the way people do things just absolutely fascinating” and attributes this to having grown up in a family like hers.

Melina.

Melina is a twenty-five year old woman who lives in the metro Vancouver area. She is Danielle’s older sister. She has close relationships with her older half-siblings, Steve and Terry. She remembers that Terry’s mom and her parents had a “falling out” when she was seven and so she lost contact with Terry until she was twenty-one. Steve lived with his mom and was in and out of Melina’s life growing up. He moved to Montreal when Melina was twelve but moved back to BC when she was twenty-two. She described her home life with her three full-siblings as kind of chaotic but “comfortable.” She described herself as a very “obedient” child. She said that “we were kinda taught, like, you know, somewhat submissive roles.” As the oldest daughter in the home, she was quickly put into a care-giving role as a young child.

When asked about her primary school years, Melina replied that “It was not easy.” Her brother Kevin was a “late talker” and “didn’t start speaking until he was four and he had lots of difficulties around school.” She recalled that “Kevin used to have lots of repetitive stimming behaviors.” She recalled that “a lot of the focus and attention was on him” and “all of the talk was around Kevin and, like, Kevin and his behaviors at the dinner table or when he went to school and coming home.” She explained that “I was supposed to be, like, kind of the one who took care of him.” There was a lot of responsibility placed on Melina. She recalled her parents
telling her “’Melina, you should make sure Kevin behaves himself. You should be with Kevin at lunchtime. You should be with him at recess.’ And... and... and, you know, like, ‘make him not do his silly behavior’, and stuff like that.” Melina described her parents’ reaction to Kevin’s difficulty saying that “there was a lot of denial about Kevin as well. It was like ‘oh, he’s a late talker but he’s fine.’” Even though the school was wanting to give him teacher’s aides and have him evaluated, their parents were resistant because “if he has an aide then he won’t be integrated in the class and... he would have been excluded.”

At one point, her parents were putting Kevin into counseling “because when he was ten, he wrote a letter saying ‘I have no friends and nobody likes me.’” Unfortunately for Melina, that meant that she had to move schools to better facilitate her brother’s counseling appointments. She reported that the school they moved into was “awful,” the principal “was a jerk” and neither of them made any friends there. Melina was at that school for one year before being transferred to a third elementary school.

When Melina was six, Danielle was born and then at eight, Erin was born. She describes that “it was like a totally different family system.” Melina described that Danielle was not that much of a burden for her. She described Danielle as “my little side kick who helped me out, kind of, with Erin especially.” Melina described their relationship saying that “we were like best buddies.” She recalled that her brother did not have a lot of responsibilities saying “he, like, was not capable of it.” She said that she was “the built-in babysitter.” She remembered knowing something was different about Erin early on. She remembers that Erin “used to smile and talk. And she started speaking at like one… and then she stopped.” She characterized Erin having “very rigid behaviors.” Melina remembered people saying that Erin was just going to be a “late talker” like Kevin but when “four came around and it was like... ‘She’s still not talking yet.’”
Erin was only “echolalic” in her speech. Melina’s parents put pressure on her saying “You need to talk to Erin... You talk to Danielle too much and that’s why Erin’s not talking. So you have to talk to Erin more. And, you know, just speak with her and she’ll start speaking.” But after they got the autism diagnosis for Erin and her parents jumped into finding out more about autism, Melina also was involved. She attended numerous workshops with her parents and became their primary therapist for Erin.

Describing her life as a teenager, Melina says that “all it was, basically, was come home, look after Danielle and Erin and, like, if I had the opportunity to get homework done.” She described the expectations placed on her saying “I had my role and it was really supposed to be just, like, helping my mother and it was supposed to be helping the kids, kind of thing.” She had no “personal life”. Melina became very involved in the autism community and was a member of Autism Community Training (ACT) and FEAT BC. She got training and “learned about Lovass” ABA interventions. Melina was not only working with her sister but she recalled, “I was doing it with other kids as well. Like, way involved in the autism kind of community.” Looking back, her whole adolescence was full of autism: “that’s what I did when I was a teenager!” She even remarked “Why didn’t I have a normal adolescence? Oh! Because I was like frickin’ bombarded with autism jobs and information.”

Caring for her siblings has always been her primary responsibility within the family. She described that when she chose to do something else she was viewed as “very selfish.” She remembered being “shocked” seeing other people who had siblings with ASD not being as “hyper involved” as she was. She admits that she might be “pissed off that they didn’t take care of their own kids and they were totally irresponsible.” She compared herself to other friends and noted that “I had no extracurricular activities” and that “Erin was the one who had all the
extracurricular activities happening.” Every activity that Melina was involved with was because Erin or Kevin could do it too. They could only do what was “convenient.” She acknowledges that it must have been difficult to do with four children and two with ASD. But she remembers “being younger and seeing families and they got to go on lots of vacations. They got to go on trips and it wasn’t always a hullabaloo.” She was referring to the possibility of Erin having a temper tantrum when out in public.

Erin’s behavior impacts family get-togethers as well. Melina says “any time we go out somewhere, somebody has to keep an eye out on her” because she was likely to get into trouble. She notes that at Steve’s wedding Erin got away for a moment and put her fingers in the wedding cake. Steve invited Erin to the wedding and has “more to do with Erin… than Terry does.” Going out with Erin is stressful in that “it’s just like, ‘for the love of god, I hope we don’t have a scene when we go to this restaurant.’” But when she lived at home and her friends were around Erin, there was a response of “that’s Erin, just doing her thing” and “it was totally fine and it was much more relaxed.” Unlike her sister, Danielle, Melina is still “mortified if Erin makes a big scene” in public. She draws the distinction between two possible situations saying, “if you want to look cool, don’t bring Erin. If you don’t care how you look, you can bring Erin.”

Having siblings with ASD has had a definite impact on who she chooses as her friends. They need to be accepting of the fact that her siblings have ASD. If people make any sort of comments that are “discriminating in any way shape or form” then they become “somebody who I don’t really want to get to know”. She notes this as especially important in choosing boyfriends. She says that they have to be ready because “it’s gonna get dirty and you have to be prepared to… to get dirty along side with whoever you’re with.”
The expectations changed after she graduated from high school. She recalled that “it was like, ‘okay, you don’t have to look after them anymore.’ But, yeah. Danielle started to take over my role for taking care of Erin. And Kevin was, like, an adult by that time.” Around that time, she moved into the basement of the family home and her relationship with her family “had changed.” But it wasn’t until she completely moved out of the home to live with her boyfriend at twenty-two that her relationship with her parents really changed “because I was, like, no longer, kind of, living this conservative, like, submissive lifestyle.” She referred to this “rebellious stage” as a “very traumatizing.” When she broke up with her boyfriend, she said she “really started to kind of look at my relationship with my parents and I was so... mad at them.” She reported fighting with her parents a lot during this time period. She was experiencing “feelings of inequality among the siblings and, like, you know, some were treated better than others. There some were taken care of or focused on more than others and… a lot of throwing people under the bus at the expense of others.”

Melina describes her frustration and resentment towards her mother and Erin, citing what happened during a trip to Australia recently. She had to come back early from her trip because her mother just left due to the stress saying that she “could not handle being with the family anymore.” She came back because her mom burned out and so she “had to look after Erin and at that point in time she was having really severe behaviors.” Melina had a hard time with this and said that she got to a point with Erin where she “just hated her.” She even said that she believed “she would sell our souls, basically, just for ice cream.” She remarked about having Erin as her sister saying:
This was not like some wonderful, like, you know, blessing. And she was not some angel that God had blessed us with or something like that. She was just like a child and she had autism and it was really, really, fucking difficult.

This time period served as an “eye-opener” for her in relation to her siblings as well as her relationship with her parents. Melina says that she has “done a lot of counseling” and it has helped her work through her experiences and establish healthy boundaries in relationships.

Melina describes her relationship with her parents now as “healthier.” She says “it’s a lot more open and we’ve had to have a lot of fights and arguments and boundaries have been drawn. Because before there really weren’t any boundaries.” She notes that “I don’t have that expected role to take care of anybody now” and so she is in control and has a “choice” of her relationships with her siblings as opposed to having them dictated to her. She is still in a bit of a difficult situation in that her brother, Kevin, lives with her. It was supposed to be a temporary situation with him sleeping on the couch in her one bedroom apartment, but he has been there for two years. It’s a “huge problem” for Melina at the moment because with Kevin, “I’m still expected to be responsible for him in a certain way, and I do not want to be and I should not be.” She is battling feelings of guilt over having him move out but having him live with her is “detrimental” to their relationship. He gets angry with her when she brings up wanting him to move out.

Growing up with siblings with ASD has had an impact on Melina. She said that it has made her more “thoughtful” and “empathetic.” She says, “I mean I didn’t choose nursing for no reason, I don’t think. I think I’d already learned how to look after people, so it was, at that point, second nature.” While her experiences with her siblings has had a positive impact on her character, Melina admits that “sometimes, though I find I almost have less patience” for other people. She says that sometimes she wants to tell people who “impede” her in some way to
“‘just be fucking normal’ and just like, ‘leave me alone.’ Like, ‘I don’t want.... I don’t want to deal with it right now.’” She acknowledges that there is “still a little bit of anger there” after years of dealing with her brother and sister.

Looking to her future, Melina is not worrying about her brother. She says he can live on his own and has a job and will be fine. But with Erin, it’s “a different situation.” She says that her parents’ have not done anything to plan or prepare for when she turns nineteen. She recalls that her “mom has said she wants to live with Erin until she dies.” Having multiple typically-developing siblings has been helpful. She has no doubt that all of the siblings will help them financially at that point but does not know what will happen long term. She expressed concern about long term care homes saying “a lot of them are really awful” and “group homes for disabled is they... constantly hearing of them closing and shutting down.” Melina knows that Erin will not end up helpless and homeless because “she does have a lot of siblings and a lot of family that are here. But where is she gonna go and how is it gonna work and whose life is gonna be compromised in what way, I’m not sure.” She is hopeful that no one’s life will be “fully sacrificed” and is confident in that “we’ll do what it takes to, you know, have her happy.”

Reflecting on the possibility of getting married and having children of her own someday, Melina said, “If I had a kid with autism, I wouldn’t have a kid. So, like, I.... Like honestly, I just don’t think I... like... it is so frickin’ difficult.” Growing up with Erin and Kevin and seeing what her parents have gone through she wonders “is it worth it? And I honestly, I don’t... I don’t have an answer.” She said, “I’m not being like, ‘The silver liningblah blah blah.’ It’s like, ‘Okay how hard is this actually going to be.’” Having a child with autism would not be bad necessarily but it would be hard and at this point in her life, Melina does not know if it is something she would want.
Summary

It is important to note that the life stories of these individuals are unique in many ways. The stories that they shared were shaped by the conditions of our interviews including me as the interviewer, the questions asked, the way in which the questions were asked, the surrounding environment, and any other variable of the day. Given the opportunity to repeat these interviews with another investigator, it is possible that what they share and how they share would be different. So these stories are a snapshot of their experiences from the day and time of the interview.
Chapter Five: Discussion

Having described the individual contexts in which the participants experienced having a sibling with ASD, this chapter serves to illuminate the many different themes that emerged from the lived experiences of this study’s participants. The themes are clustered under two overarching topics: “what was experienced” and “how it was experienced.” Within each theme, parallels are drawn between the experiences of the participants of this study and the findings of other researchers cited in the review of literature.

What Was Experienced

From the lived experiences participants shared with the researcher, themes of closeness and distance, differential treatment, and roles emerged.

Closeness and distance. In the interviews, the participants reported experiencing various types and degrees of closeness and distance with their sibling with ASD. Lydia highlighted that her relationship with her brother, Juan, “is very close.” She described that there was a distance that developed when he became an adolescent, but that as adults, they are closer. She noted that her brother does not have any close friends who he can “go out to eat pizza with” or go to the movies with, making her one of his closest friends, even though she is thousands of miles away. Shannon shared a similar experience with her brother, Aaron. When they were younger, they played frequently but, as Shannon described, “it was probably when I got into my teenage years… that is when that relationship sort of distanced itself.” She has made efforts to be closer to her brother now that they are adults. They are closer and spend time together frequently. Danielle did not describe relational closeness with their siblings with ASD but only talked about their closeness in terms of age and intense involvement.

In his family, Mark said “there wasn’t any sense of real closeness.” When he and his
brother were younger, they would “bike around the neighborhood” together but that “after about age nine, the actual interaction I had with him was minimal.” The distance he has with his brother continues as Mark explains that, “I have very little interest in actually seeing my brother” and that he does not see them reconnecting in the future. Melina expressed similar experiences saying that “Because of how much I had been with her throughout my whole, like, childhood and adolescence and as an adult, I just did not want to have a lot to do with her.” According to Melina, her relationship with Erin has been “not easy” and does not have a very close relationship because, as she describes it, Erin “would sell our souls, basically, just for ice cream.” She also noted that “whatever I give her, I am never going to receive the same amount back in like love or care or affection or anything like that. And she demands a lot and does not… reciprocate.”

Both Lydia and Shannon experienced a shift from closeness to distance and then back to closeness in their relationships with their brothers with ASD from childhood to adolescence and young adulthood to their thirties. This is not unusual, according to Orsmond and Seltzer (2007). Mark and Melina’s distance and decreased involvement with their families echo one of the findings of Orsmond et al. (2009). Kaminsky and Dewey (2001) found that typically-developing people with siblings with ASD reported experiencing less intimacy and nurturance with their sibling with ASD. This was apparent in the experiences of Mark, Melina, and Danielle and their descriptions of the lack of closeness they experience with their siblings with ASD.

It is also important to mention the role of distance in their experiences as it related to travel. Each of the five participants has engaged or will soon engage in extended travel. This would not be a surprise to Melina who commented on siblings of people with ASD saying, “I think... yeah....you’ll find, like, all of us are obsessed with traveling.” Shannon spent three years
living in London, England, during which time she had very limited interactions with her family and only visited home once. Mark’s travels brought him from Canada to Thailand for retreats as well as to where he is now on retreat in Mexico. Ten years ago, Lydia moved from her home country to Canada and only returns back every two years. Danielle spent a year and a half studying in Kelowna and she talked excitedly about her upcoming trip to India and Nepal. Melina discussed her various travels including a long trip to Australia. For Melina, the trips served to help her be more independent and gain a better perspective on her family. But even physical distance could not separate her from family obligations and when her mother had reached her limit and left the family for a brief period of time, Melina had to return from her trip to Australia early in order to take care of her sister, Erin. The distancing of one’s self from the family is not unexpected as people with siblings with ASD mature and seek individuation (Siegel & Silverstein, 1994; Skrtic et al., 1984).

**Differential treatment.** As the participants shared what they have experienced growing up with siblings with ASD, experiences of differential treatment were described. Shannon and Lydia did not mention being aware of their siblings receiving different treatment than they did during their interviews but it occurred frequently in Mark, Melina, and Danielle’s stories. The differential treatment was also observed by the researcher during one of the interviews. For Mark, the differential treatment was apparent as he described the influence and power that Sean, his brother with ASD, held within the family. The activities that they engaged in as a family depended greatly on whether or not Sean wanted to do something and it had to pass the question “what would Sean be ok with?” Mark noted how from his perspective as the “normal” one, that “with an autistic brother, it just became commonplace for everyone in the family to just not think of me.” Mark also noted, “I was the lowest person on the totem pole, and even when I’d
expressed something was important to me, it was clear that my brother’s veto would always be considered more important.” Mark was treated differently by his mother and he described how she would hover over him because his brother was so reactive to her attention.

The differential treatment that Danielle experienced was extremely obvious during the interview. Although she may not have mentioned and discussed it as much as Melina or Mark, it became clear when her mother arrived home during the interview and brought a big marshmallow on a stick with chocolate and sprinkles home for Erin but had nothing for Danielle. Danielle asked her mother “oh, what’s that?” To which she was told that it was for Erin, leading to Danielle’s disappointed comment, “oh, for her.” Another instance in which the differential treatment came up was when talking about who was responsible for what and she remarked “Kevin didn’t have any responsibility whatsoever!” She qualified her outburst saying “I don’t know if that’s ‘cause he was the oldest male or just ‘cause he really couldn’t have handled that responsibility.” But it was clear that a lot of responsibility was put on Danielle and her sister, Melina.

Melina also noted the differential treatment she experienced and the amount of attention her brother got compared to her. Talking about growing up, Melina noted that with her brother, Kevin, “a lot of the focus and attention was on him, and… like all of the talk was around Kevin.” As soon as she was in school, it was her task to watch him at school. As a teenager, if she ever wanted to do something for herself instead of taking care of her siblings, she was told that she “was very selfish.” For her, it became more obvious after she moved out of the family home. It was at that point that she was able to get perspective on the family dynamics at work. She explained that she had “a lot of, like, feelings of inequality among the siblings.” She went on to note, “Some were treated better than others. There some were taken care of or focused on more
than others and... a lot of throwing people under the bus at the expense of others, a lot of times.” Her realization, and the conversations she had with her parents, forced “a change in dynamics,” because her family was forced to examine what had been the pattern. It may not have changed the amount of attention or the special treatment that the other got, but it has changed her attitude towards it. In a way, Melina is still perpetuating the differential treatment by not kicking Kevin out of her apartment, even though it is damaging their relationship, causing her to feel “resentment towards him,” and she feels “he’s like totally taking advantage” of her.

The differential treatment that these participants described is not dissimilar to the findings in studies of people with siblings who have other disabilities (Siegel & Silverstein, 1994) and with siblings with ASD in particular (Fisman et al., 2000). Because of the demands from children with ASD on parental time noted in Lainhart (1999) and Cancro (2008), typically-developing siblings like Mark, Melina, and Danielle experienced less positive attention which can lead towards resentment.

Roles. In their lived experiences, several participants described having to fill certain roles within their family. The roles that each participant took was experienced and expressed differently but three common roles emerged. Participants described being their siblings’ caregivers, teachers, and protectors in various ways.

Caregiver. Three out of five participants described having specific caregiving roles. This can be attributed to the fact that these three participants were elder female siblings, and siblings in that position take on more caregiving roles in families, especially when there are siblings with a disability (Siegel & Silverstein, 1994).

In their stories, Lydia, Danielle, and Melina all talked about their role of being a primary caregiver for their siblings with ASD. Lydia talked about the fact that her mother would be busy
cooking and doing things around the house and so she would have the responsibility of watching her brother. She described an instance when she said to her mother “how come I have to be responsible for him all the time?” Reflecting on her role as her brother’s caregiver, she “was glad to do it” and attributes the closeness they have now as being a result of her being his primary caregiver and in many ways a surrogate parent. Discussing her role, Melina described herself as “the built-in babysitter” noting that “always there was the expectation that I was supposed to look after Erin.” For Melina it was clear that “I had my role and it was really supposed to be just, like, helping my mother and it was supposed to be helping the kids, kind of thing.” Melina’s parents had also assigned her the responsibility of watching her brother, Kevin, at school. Similar to the findings of Skrtic et al. (1984), Melina had the duty of “explaining the handicap to peers” and “being responsible for the sibling at school” (p. 239). When it comes to her older brother Kevin, Melina’s caregiving role continues today, and she finds that she is “still expected to be responsible for him in a certain way.”

For Melina and Danielle it was not a solo task. Melina remarked that “Danielle was my little side kick who helped me out, kind of, with Erin, especially.” When Melina moved out, Danielle was the only one to fill the caregiving role for Erin and she ended up “being the total parent of Erin” for several years having “to take responsibility for Erin.” Even after returning from being away at university, Danielle quickly fell into the caregiver role again.

Melina and Danielle also mentioned the impact of their caregiving roles on their social life. Danielle explained what she experienced saying:

With us it was just expected, you know, “you take care of Erin. You cancel all social plans.” I didn’t go out. I didn’t have a social life. I just didn’t, in high school and elementary school, which was hard because I’m naturally a very, very social person.
Her experience of having her social life impacted by having to care for her sister is also reflected in the findings of Benderix and Sivberg (2007) and Dillenburger et al. (2010). Melina and Danielle both talked about having to take Erin out in public during their caregiving duties and being embarrassed. Melina specifically mentioned that she would be “mortified if Erin makes a big scene.” Danielle said that it “used to drive me crazy” but that at this point Erin’s behaviors in public “barely faze me.” Behavior management duties can fall within the sibling caregiver role (Angell et al., 2012).

The demands placed on them as the older female siblings to fill a caregiving role are consistent with the findings of researchers that place the sister of the person with disabilities in that specific role (Fishbien, 2007; Grossman, 1972; Krauss et al., 1996; McHale & Gamble, 1989; Siegel & Silverstein, 1994; Skrtic et al., 1984). Their role in being “the responsible ones” for their siblings also corresponds to the findings of other research about siblings who have to take on increased responsibilities related to their sibling with a disability (Skrtic et al., 1984). Siegle and Silverstein (1994) mention the instances of typically-developing siblings being “denied the carefree days of childhood and adolescence” and being called upon to be “little adult[s]” (p. 13).

Looking to the future evolution of her caregiving role, Lydia discusses that she is expecting to be responsible for her brother after her parents pass away, and she views this as a “privilege.” Melina and Danielle discuss the communal approach all of their siblings will take for taking care of Erin after their parents pass away. For Melina, she is working to establish new boundaries around this role announcing that “I don’t have that expected role to take care of anybody now” but that when she does, it is out of a “desire to be a part of the family and to care for whoever, my sister or whatever.” It is not out of obligation but now, “it’s my choice.” The
experiences of these three participants echo the findings of Benderix and Sivberg (2007) who noted that the older siblings develop “a form of mental responsibility for the child with autism and for his or her future” (p. 414). Shannon and Mark did not anticipate any changes to the type of role they have in the lives of their brothers.

**Teacher.** The same three participants also described their role as a teacher for their sibling with ASD. Lydia was and still is a teacher for her brother in many ways. She talked about a game she would play with Juan in order to help teach him new skills as being similar to the work that she does with her son who has ASD. She talked also about going back to Colombia to visit her family and teach them more about Asperger’s now that her brother has an official diagnosis. Melina and Danielle both talked about getting training so that they could act as therapists and peer teachers for their sister, Erin. Each of their experiences includes a time when they were taking active roles teaching and instructing their siblings. This echoes what was found in the research describing how typically-developing siblings play instructor roles with their siblings with autism (Angell et al., 2012).

Shannon and Mark did not fill a role as caregiver or teacher with their siblings. Their roles with their brothers were not instructive but they both described being their siblings’ “playmate” at one point when they were younger. The difference between Shannon and Mark and the other three can be attributed to the fact that both Shannon and Mark were younger than their sibling with ASD.

**Protector.** Another role that siblings often took was that of the protector. Four of the five participants mentioned having or wanting to protect their sibling with ASD from others. Participants mainly talked about how who they chose to associate with socially was a way for them to protect their sibling and advocate for people with disabilities.
Shannon used the word “protection” to talk about her relationship with her brother on a few occasions. She described that “I was always protective over him.” She described his ability to defend himself but she also said that “I think if somebody ever said something or had a problem with him, I probably would've knocked them out.” Her role as protector for her brother impacted her relationships with other people. Shannon said “I know that if I had a friend or a boyfriend who was uncomfortable with Aaron, then it ended… I can't have somebody who's going to be weirded out or uncomfortable around my brother.” She is very protective of him and talked about how little tolerance she has for intolerant people. For Shannon, noted that “in high school, if anybody, or if I overheard somebody not necessarily making fun of Aaron specifically, but somebody that was mentally challenged or using the word 'retarded' or something, then I would freak out on them.” Shannon was the most explicit of all participants when sharing about her protector role with her brother, but most of the others also shared her position on choosing friends.

Danielle explained being protective over Erin saying that she remembers when she was very young that she “used to get so defensive about it.” Melina filled the role of protector for Kevin at school. Like Shannon, Melina has zero tolerance for her friends being “discriminating in any way, shape, or form.” Melina wants to protect her siblings and make sure that any boyfriend she has is “accepting of Erin and Kevin and the culture and everything.” In order to protect her family, Danielle also talked about how she would end friendships with people after hearing them talk in a way that was discriminating or “degrading” to people with disabilities. Danielle takes this protective stance because “this is who we are. We have this family” and if someone cannot accept that, then she will have nothing to do with them.

For Lydia, the protection of her brother was a function performed by her whole family.
As a family, they made home a safe place, a sanctuary where Juan was not picked on and was given complete support. She noted that her family’s inability to protect him outside of the home was “painful for them.” She talked about how her brother faced “bullies” as a teenager. She said that “there were kids that were hitting him at school and they were asking him [for] money. If he didn't, so they will punch him.” She described how she wanted to help him but that he did not talk about it with anyone. When he was experiencing this bullying, she was working full time and so her “availability for him was limited due to the circumstances.”

For Mark, the role of protector featured very differently. Mark did not feel protective over his brother, Sean. In Mark’s experiences, he had to protect himself from his family. He talked a lot about his home not being a safe place emotionally. Mark had to protect himself from the emotionally reactive attacks from other family members.

**How It Was Experienced**

Similarly to the previous section about what was experienced by the participants, how the participants experienced growing up with a sibling with ASD is very important. As the participants discussed their experiences of having a sibling with ASD, the researcher noted how they described the experience. Several themes emerged from the interviews includes “a sense of normalcy”, difficulty, and feelings.

**A sense of normalcy.** As the participants shared their unique experiences of growing up with a sibling with ASD, four out of five specifically described living with their siblings and the way their family functioned as normal to them. Lydia did not describe it as “normal” explicitly. She was twelve when her brother was born and so having a baby brother was very novel and exciting. Shannon noted early on “I hate using the word ‘normal’” but she conveyed a feeling of life as “normal” with her brother. She indicated that she did not see that having a brother with
autism made her life that much different from others. Aaron was Aaron and her parents never really explained him as being different because “that's all I knew Aaron to be, it was the normal for me.” Shannon even described her relationship with Aaron “like a normal brother and sister during their teenage years” with occasional disagreements and fights. Mark described the feeling of life with his brother just being normal noting that “it’s just sort of what you’re used to and I don’t remember… things being really odd or weird. It’s just what was.” For Danielle, she was born into a family that already had one child with ASD and so she knew nothing else. As she described it, “you grow up with autistic lifestyle where it’s constant repetition and you don’t see it as abnormal.” When Erin was born, “it was normal for her to be like that.”

Like Danielle, Melina felt her life was normal. She only became aware of the differences between her life and others’ as an adult and while reflecting back during the interview she asked herself, “why didn’t I have a normal adolescence? Oh! Because I was like frickin’ bombarded with autism jobs and information.” She just assumed that every sibling of a person with ASD would be as involved as she was in therapy and caregiving because that was what had been expected of her. Danielle said she never really noticed the differences between herself and her family and her friends and their families when she was younger saying “I didn’t know we were weird.” She has accepted it saying “this is who we are. We have this family, whatever.”

Shannon also commented about the love, acceptance and support for her brother modeled for her by her family as being “the norm.” Having grown up with Aaron, Shannon was “never fazed” to be with him in public and “wouldn't think twice about really doing anything” with him even when he engaged in his unique autistic behaviors. Like Shannon, Danielle’s sister Erin’s autistic behaviors do not “faze” her even in public. Both Melina and Danielle commented on was their father’s desire to have the family appear to be “normal” and not autistic in public.
Danielle noted that saying “Dad’s obsessed with the idea of, like, us looking normal which is hilarious.” For Melina, going out with him and the rest of the family was stressful because of this unrealistic expectation.

**Difficulty.** While their experiences were “normal” to them, there was also a clear acknowledgment that growing up with a sibling with ASD is difficult. Having a sibling with ASD is a challenge for a family system. Lydia described the difficulty of watching her brother struggle socially and in school, but did not describe her own experiences as difficult. Reflecting on his overall experience growing up, Mark noted the hardship and “the difficulty of growing up with it.” On the systematic impact of his brother’s ASD, Mark commented that “It haunts me.” He noted that “Most people, of course, have very little idea, like, what it’s like growing up with a very different family.” The concept of family was difficult for him to relate to emotionally the way others did noting that “It’s more of a technical... ‘hey, I’m related to these people.’”

Melina’s experience of having two siblings with ASD was also very difficult. Speaking specifically about Erin, she said, “This was not like some wonderful, like, you know, blessing. And she was not some angel that God had blessed us with or something like that. She was just like a child and she had autism and it was really, really, fucking difficult.” Melina spoke frankly when she said “I’m not being like, ‘The silver lining blah blah blah.’” Both Melina and Danielle noted multiple times throughout the interview just how “hard” it was for all of the family members dealing with so much autism in the family. But even though the difficulty of growing up with a sibling with ASD, Danielle noted that “I definitely wouldn’t be who I am now if it wasn’t for Erin.” As difficult as it was, Melina explained “You have no choice. This is what you’re with, so you better appreciate the little things because, otherwise there’s gonna be very little to appreciate.”
Feelings. Each of the participants discussed how they were impacted by having a sibling with ASD, and the impact on their emotions was evident. As was found in the research, the experiences of participants varied and were often mixed. The emotions described in this section reflect those that emerged most notably as they described how they experience growing up with a sibling with ASD. The specific feelings under exploration are loneliness, depression, anger and resentment, guilt, and fear.

**Loneliness.** The concepts of loneliness and isolation came up in several of the interviews as the siblings described their experiences growing up with their siblings with ASD. The loneliness and isolation were experienced as physical and social isolation as well as emotional isolation. Mark experienced loneliness and isolation within his family system. He expressed this saying that “I had no one to talk to after a while” and that “if I did stuff, it was alone.” This pervasive relational isolation from his brother and his father had massive impact on him in that “I felt sort of unimportant.” Mark spoke of extreme emotional isolation and overwhelming feelings of “loneliness.”

Both Danielle and Melina discussed the isolation they experienced from their peers because of their autistic siblings’ inability to do activities. Comparing her family to her friends families, Melina noted that “there was big differences. It was very isolating.” She was unable to do the same activities as her friends and had her whole social life controlled by her caregiving responsibilities. When they went out, they often had to take their siblings and the activities they did as children, like swimming lessons, always involved their siblings with ASD. Danielle remarked more than once that she is naturally an outgoing person but that because of her siblings, she was unable to be as social as she always wanted to be. Dillenburger et al. (2010) found that the typically-developing siblings of children with ASD have experienced being
“isolated from their peers” (p. 19). Lydia did not report loneliness and isolation as the others did. She explained, “We lived in a small town in Venezuela. And there not many kids around. Not many teenagers around.” The area she lived in limited her social options, not her brother.

**Depression.** Depression was reported very prominently in the experiences of one participant. The feelings of depression shared were closely related to the participant’s family system. Mark noted plainly, “I was obviously depressed as a teen.” The social isolation he experienced as well as the autistic, emotionally-stifled home environment caused a lot of internalization of his feelings. His mother’s solution to his experience was “to blame everything on my father and the divorce, or simply that I was intelligent and intelligent people just have problems with depression.” But at his father’s house, it was not any better, in fact he noted that there, he “usually felt more depressed.” He was often told that the solution was to just “love and appreciate my brother.” In the literature, Faber (2010), Gold (1993), and Lainhart (1999) found that the siblings of children with autism were at higher risk for depression and also experienced higher levels of depression.

Depressive descriptors did not emerge in the interviews with Danielle, Melina, Lydia, or Shannon as explicitly as they did in Mark’s interview. Danielle admitted that she may not be fully in touch with her emotions, noting “you know, I repress my emotions.” Melina noted that in order for her and Danielle to deal with their experiences, “We’ve done a lot of counseling.”

**Anger and resentment.** As Mark, Melina, and Danielle described their experiences growing up with a sibling with ASD, feelings of anger and resentment emerged. For Mark, his household was an emotionally unsafe environment and he had to “try to not really show emotion” because of the reactions of his brother, Sean. He said “I didn’t realize just how frustrated I was and angry about the situation until afterwards because I wasn’t really allowed to
express it.” Melina and Danielle shared anger towards their father as they described how he refused to help with their sister, Erin. They also expressed anger when they talked about having to change schools because of their siblings with ASD and having their lives disrupted. For Danielle, she experiences anger but not specifically at any one family member. As she talked about how she feels about her parents, she said:

I don’t know if it’s really anger... it is resentment but it’s like, I can’t hate them for it. I mean it happened. What happened, happened. That’s it. And that’s who they are and I can’t... you can’t change them.

Melina admits that she has “a little bit of anger” about having to deal with the difficulties of people’s disabilities. Melina also talked about how she “was really angry” with her parents once she realized how consumed her life had been with caring for her brother and sisters. She said that when she “really started to kind of look at my relationship with my parents and I was so mad at them.” When talking about other siblings who are not involved with their sibling with ASD, Danielle emphatically said “I’m resentful about that.” Danielle admitted that she represses a lot of her emotions but she was vocal about her resentment. Melina also talked a lot about her feelings towards her brother and sister with autism and the “resentment” she feels. She admitted that at one point when she had to return early from her trip to Australia to care for her sister, Erin, that she “just hated her.”

**Guilt.** Feelings of guilt were expressed by several participants as they reflected on their experiences of having a sibling with ASD. Shannon talked about feeling guilty for not spending time with her brother saying, “I think it always sort of played on the back of my mind as I got older the fact that I'm not spending enough time with him. I mean, and I felt bad about it.” She said, “I started to feel bad that I wasn't doing stuff with him, you know, like something normal
that I would be doing whether it’s going to a movie or going out to dinner with friends and having him come along or something like that.” Shannon’s guilt was resolved as she acted on it and now she says, “I don’t feel guilty anymore. I don’t have a weight laying on me that I’m not spending enough time with my brother, and it’s again, it’s not because I didn’t want to do it. I think I just got caught up in my own life.” The resolution of her guilt is attributable to her choices to reconnect and make specific efforts to spend time with her brother.

The experience of guilt for Melina and Danielle revolves around their obligations to take care of their siblings with ASD. Melina says, “It’s a bit of a struggle right now because I still have a lot of guilt in that I want to... I feel like I should be taking care of him [her brother with ASD].” She also said, “I feel a lot of guilt in... in separating myself from him and wanting to kick him out.” Danielle commented that when her mother asks her to look after her sister with ASD, “I’ll be guilted if I don’t.” Melina used to experience this guilt from her mother as well, but the guilt she experiences with her brother is internalized and no longer requires maternal prompting.

**Fear.** Elements of fear came forward in the experiences of several individuals. For Shannon, the theme of fear appeared as she talked about her future in relation to her brother. While this is not her predominant feeling about her brother’s future, it was important to acknowledge her feelings around this topic because it echoes the feelings of other siblings of people with autism whose parents are aging (Meyer, 2010). Shannon says, “One of the things that frightens me is when my parents pass away, is the fact that, obviously I definitely am going to step up to the plate, but the fact that Aaron will be my responsibility really, or mine and Trevor's responsibility.” Although Aaron has the support of organizations in the community
supporting him, after his parents die, Shannon will get the burden of making decisions on his behalf and worrying about any issues that come up as he ages.

Danielle and Melina do not worry about their brother, Kevin, but have some concern over Erin’s future. Melina said that she is “hoping when the time comes, everyone will be willing to put in enough, kind of, so that no body’s life is fully sacrificed and we’re just, you know, bound to Erin, like a shackle, kind of thing.” There is hope, but concern, because there is no plan in place for Erin when she turns nineteen in two years. For Lydia, she was afraid early on when her parents asked her to take care of her brother after they die, but she is hopeful and confident that it will not be a problem. Fear is not uncommon for people with siblings with ASD as they think about the future of their sibling (McHale et al., 1986; Meyer, 2010).

Summary

The themes that emerged from the interviews spanned from what was experienced by these siblings of people with ASD and how they experienced it. In their relationships, they felt closeness and distance. They also shared a propensity for traveling and putting physical distance between themselves and their families. They experienced differential treatment from their siblings with ASD and filled a number of roles in their family. For these siblings, their lives had a feeling of normalcy even though they faced many challenges and difficulties. Their emotions were also impacted by having a sibling with ASD in their family and they expressed loneliness, depression, anger, resentment, guilt and fear as they talked about their experiences.

The findings of this study validate the findings of other researchers who have investigated typically-developing siblings of people with autism. These other researchers primarily utilize parent and teacher evaluations using quantitative methods and only occasionally investigated the subject with the typically-developing siblings themselves. Taking a qualitative
approach to topic has served to give these siblings of people with ASD an opportunity to voice their side of the autism experience and have their stories heard. This research fills that gap in current literature in addition to offering more questions to be investigated in future research.
Chapter Six: Conclusion and Implications

In the previous chapters, the need for investigating the topic of having a sibling with ASD has been introduced, the methodology has been described, and a thorough description has been offered of the lived experiences of five individuals with siblings with ASD. In this chapter, what participants have shared is connected to findings of other researchers in the area. The chapter concludes with a discussion of the implications for future research and social work practice in the area of siblings of people with ASD.

Connections to Current Research

The lived experiences of participants described in this study are consistent with the findings of previous research done in the area of siblings of people with ASD and other disabilities. The depression reported by some of the participants confirm the findings of Faber (2010), Gold (1993), and Lainhart (1999) who determined that siblings of people with ASD were at higher risk for and experienced higher levels of depression. Not all participants reported experiencing depression which also supports the findings of Macks and Reeve (2007) and Orsmond et al. (2009) who found no increased risk or level of depression in siblings of people with ASD.

Kaminsky and Dewey (2002) had also found that when there are multiple typically-developing siblings in a family with a child with ASD, the typically-developing siblings cope with stress better, and the experiences of Lydia, Melina, and Danielle support that. The experiences of Melina and Danielle also indicated that they expressed conflicted feelings about their siblings with ASD which is in line with the findings of Angell et al. (2012). Lainhart (1999) and Mascha and Boucher (2006) report that siblings can be embarrassed by their siblings with ASD and several participants confirmed this finding in their lived experiences. Also, the
lack of closeness that several of the participants reported having with their sibling with ASD is in line with the findings of Kaminsky and Dewey (2001).

The impact that having a sibling with ASD had on the social lives of Melina, Danielle, and Lydia echo the findings of Benderix and Sivberg (2007), as does the sense of responsibility these participants expressed. The role of caregiving feature prominently in several participant stories and this affirms the research of Fishbein (2010), Grossman (1972), Krauss et al. (1996), McHale and Gamble (1989), Siegel and Silverstein (1994), and Skrtic et al. (1984).

The overall positive experiences Lydia and Shannon had growing up with brothers with ASD supports the findings of Kaminsky and Dewey (2002) and Rodrigue et al. (1993), who determined that having a sibling with ASD does not predispose a person to emotional or adjustment issues. As found by Benson and Karlof (2008), “the quality of the family climate contributed significant unique variance in explaining prosocial behavior among siblings without a diagnosed disability or disorder” (p. 595). The better equipped the parents were to help the child with ASD, the better the adjustment of the non-disabled sibling. According to Mark’s shared experiences, his family experienced a lot of conflict and stress and were not able to manage it. So Mark was negatively impacted by this in addition to his brother’s ASD. The experiences of Lydia support the other end of the spectrum as they worked hard to help her brother and manage life’s challenges. This could be linked to her more positive reflection on her life experiences.

In confirmation of what was discussed by Siegel and Silverstein (1994) and Skrtic et al. (1984), multiple participants in this study reported that their siblings had influence over significant life decisions like choosing a partner or career. Fear and concern for the future of
their sibling with ASD have been reported by participants and echo the findings of McHale et al. (1986) and Meyer (2010).

Because of the demands from children with ASD on parental time noted in Cancro (2008), Lainhart (1999), and Siegel and Silverstein (1994), typically-developing siblings like Mark, Melina, and Danielle experienced less positive attention which can lead towards resentment and other emotional reactions. The differential treatment and social isolation experienced by the participants in this study echo the findings of Dillenburger et al. (2010), Fishman et al. (2000), Siegel and Silverstein (1994), and Skrtic et al. (1984).

**Implications for Future Research**

A number of questions emerged from this investigation. One that could be pursued is the differences between siblings of people with Asperger’s Disorder and siblings of people with Autism Disorder. Of the participants in this study, only two had a sister with Autism Disorder in addition to a brother with Asperger’s. In their experiences, the impact of their sister featured more prominently than that of their brother, and it could be argued that it was because their sister’s diagnosis yielded increased behavioral challenges and caregiving requirements. These differences are worth further investigation.

Another area that could benefit from more investigation is the experiences of siblings who are younger than their sibling with ASD and close in age. Shannon and Mark were both younger than their sibling with ASD. Mark was significantly closer in age to his brother than Shannon was to hers, and he demonstrated a more negative influence from his brother. This topic has been investigated in quantitative form in previous research on the subject (Hastings, 2003a) but requires investigation from a qualitative method. Because a person’s siblings are
their first peers, a child with an older sibling with ASD who is close in age may be more impacted by their sibling’s ASD as an influence on their social behaviors.

Another avenue of research that might shed more light on the experiences of siblings of people with ASD would be to conduct an investigation of the whole family system. The siblings are not the only family members impacted by a child with ASD and ASD interventions. How the parents are impacted has an effect on their relationships and interactions with the typically-developing siblings. Taking a family systems approach could expand the understanding of the phenomenon of having a sibling with ASD. It could also reveal avenues for better intervention and support for the whole family and the non-autistic siblings in particular.

**Implications for Social Work**

Social workers have many opportunities to have a positive influence in the lives of people with siblings with ASD. As social workers provide supports for families of people with ASD, as well as other disabilities, it is important not to ignore the typically-developing child. As the child with ASD has higher needs, the other siblings can be overlooked and the resulting differential treatment can have lasting effects on the typically-developing siblings as they become adolescents and adults. Social workers can teach parents to set realistic boundaries so that their typically-developing child gets the individual positive attention they need for healthy emotional development. Social workers can help families access support groups for siblings of people with ASD so the typically-developing child can have a safe place to talk about their lives and learn about how other people deal with having a brother or sister with autism. Resources should also be made available to offer respite care so that parents can attend groups with the typically-developing child and not have to worry about providing care for the child with ASD.
As people with autism and their parents age, often the burden of care falls onto the non-autistic sibling. As those siblings take the role as primary care givers, supporters and/or decision makers in the lives of those with autism, social workers will need to have an increased understanding about how having a sibling with autism has impacted the lives of the typically-developing siblings. It may impact the plans and supports that are arranged for people with autism. This understanding will help social workers to build effective alliances and create better relationships with the siblings helping to support their sister/brother with autism.

In addition, knowledge of experiences of people growing up with a sibling with autism may be useful in a clinical setting. The results of this study could indicate possible relationship challenges or complex family dynamics for which siblings of people with autism may seek out clinical support. The complex emotional issues discussed indicate that this population may need professional support in order to work through these emotions. It is clear that this area requires additional research and investigation in order to further give voice to this population.
Bibliography

doi: 10.1037/0003-066X.44.4.709


doi:10.1176/appi.books.9780890423349

doi:10.1155/2012/949586

http://site.ebrary.com/lib/ubc/docDetail.action?docID=10078435&p00=auerbach


Appendix A
THE UNIVERSITY OF BRITISH COLUMBIA

RESEARCH PARTICIPANTS NEEDED

Do you have a brother or sister with Autism?

I am a Master of Social Work student at the University of British Columbia. As part of my thesis and a graduate-level research course, I am conducting a study entitled “Siblings of People with Autism: The Experiences of the Non-Autistic Sibling.” I am interested in the experiences of non-autistic siblings of people with autism who grew up in Canada.

You are eligible to participate in this study if:
- You are a sibling of a person with autism
- You are over the age of 19
- You live in the Lower Mainland of BC
- You speak and understand English
- You are willing to provide 2-3 hours of your time to be interviewed.

Total time commitment will not exceed 3 hours.

This study is being supervised by Dr. Richard Vedan, Associate Professor, UBC School of Social Work, (604) 822-3520.

No compensation is offered for participation in this study.

Interested? Please contact:
Laura McNamara, MSW Student
Phone: 778-708-0584
Email: mcnala01@interchange.ubc.ca
Appendix B

THE UNIVERSITY OF BRITISH COLUMBIA

School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
Tel: (604) 822-2255  Fax: (604) 822-8656
www.socialwork.ubc.ca

Siblings of People with Autism:
The Experiences of the Non-Autistic Sibling

Principal Investigator:  Dr. Richard Vedan, Associate Professor, School of Social Work, University of British Columbia, 604-822-3520

Co-Investigator:  Laura McNamara, MSW Student, School of Social Work, University of British Columbia, Telephone: 778-708-0584; Email: mcnala01@interchange.ubc.ca

This research is being conducted as a requirement for a thesis, a semi-public document. You will be informed regarding the use of and access to the information provided. All identifying information will be removed from information collected during interviews.

Purpose
The purpose of this study is to explore the experiences of adult siblings of people with autism in Canada.

Study Procedures
You will be asked to participate in a one to two hour initial interview and an optional follow-up interview of up to one hour. In the initial interview, you will be asked about your life experiences including several questions pertaining to growing up with a sibling with autism. At the conclusion of the initial interview, you will be asked if you would like to be contacted for an optional follow-up interview after the interview has been transcribed. If you consent to participate in the optional follow-up interview, you will be contacted following the transcription of the interview, be given a copy of the transcribed initial interview, and be invited to schedule the optional follow-up interview. During the optional follow-up interview, you will be offered the opportunity to provide feedback on the transcript of the initial interview. The interviews will be conducted by Laura McNamara, co-investigator. Maximum total time commitment is three hours.

Confidentiality
Your identity will be kept confidential. Any personal identifying information will be removed from interview transcripts. Interview audio recordings and written transcripts will be kept in a locked file box in a locked office. Any electronic study documents stored on the computer will be password-protected. You will not be identified by name in any completed study reports.
Risks
The topic of this research study is personal and potentially sensitive. While I, Laura McNamara, do not anticipate any risk, I will attempt to minimize any possible emotional risks to you by reminding you of your right to stop the interview at any time should you feel distressed or uncomfortable, or if you feel you are unable to continue.

Remuneration/Compensation
No remuneration or compensation is offered for participation in this study.

Contact for information about the study
For further information regarding this study, you may contact Laura McNamara by phone at 778-708-0584 or via email at mcnala01@interchange.ubc.ca, or you may contact Dr. Richard Vedan at 604-822-3520

Contact for concerns about the rights of research participants
Any concerns about your rights or treatment as a participant may be directed to the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia at 604-822-8598.

Consent
Your participation in the study is entirely voluntary. You may decline to participate or drop out of the study at any time without consequence.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature below indicates that you have had the opportunity to ask questions regarding confidentiality and consent.

Your signature below indicates that you consent to participate in this study.

Signature:  

Printed Name:  

Date:  