EXPLORING THE LIVED EXPERIENCES OF SIBLINGS WHO GROW UP WITH A SIBLING DIAGNOSED WITH AUTISM SPECTRUM DISORDER

A Research Practicum
Submitted to the Faculty of Social Work
In Partial Fulfilment of the Requirements
For the Degree of
Master of Social Work
University of Regina

by
Amanda Day
Saskatoon, Saskatchewan
July, 2016

© 2016: Amanda Day
ABSTRACT

This research project explores the lived experiences of young adults who are living with a sibling diagnosed with Autism Spectrum Disorder (ASD) by asking one methodological question: What are the lived experiences of young adults who lived with a sibling diagnosed with ASD in Saskatchewan? The research practicum employs a phenomenological approach, which includes semi-structured interviews and participant derived photographs, involving 5 adult siblings in Saskatchewan. *A different relationship, but it is not one that is less* became the essence shared within the different lived experiences of the study participants. The essence was impacted by two major themes identified throughout the analysis, including *challenging* and *positive experiences*. Subthemes that emerged from the *challenging* theme include *the diagnosis* and *complex and layered*. *Positive experiences* subthemes include *reciprocity* and *bonding*. These themes are discussed, along with the implications for social workers and future research.
ACKNOWLEDGEMENTS

Time is one of the most precious gifts we receive, and each year time seems to move more quickly. As this journey comes to a close, I want to thank everyone who took the time to make sure I reached my finish line. The time I spent studying sibling relationships and Autism Spectrum Disorder has been challenging, rewarding, and has fulfilled my life in ways I cannot describe.

I am so thankful for the time participants took to share their stories. Your stories provided great insight into the value of sibling relationships. Your interviews were full of emotion, strength, and encouragement to seek out and connect with your sibling. I was moved by each story, and have great admiration for each participant.

My research project committee has also provided me a great deal of time. I am thankful to my supervisor, Dr. Randy Johner for her continued patience and thought-provoking questions. I am also thankful for the time Dr. Darlene Chalmers and Dr. Nuelle Novik spent reading and re-reading my work.

I am also thankful for my mom, dad, and mother-in-law's love and support. This project would not have been possible without your listening ears, or your words of encouragement. A deep thank you to my sister: thank you for helping me reflect on this journey. Sisterhood is an unbreakable bond and I cannot imagine my life without you. Thank you to my husband, who has provided me endless support and love. There were days where I wanted to quit, but you continued to cheer me on, and push me towards the finish line; I would not have finished were you not my number one cheerleader. Lastly, to my son: you inspire me to do great things in life. I hope that one day you too can understand the wonder and joy of a sibling relationship.
# TABLE OF CONTENTS

Abstract .......................................................................................................................... i

Acknowledgements ........................................................................................................ ii

Table of Contents ........................................................................................................... iii

List of Tables and Figures .............................................................................................. vii

Glossary ............................................................................................................................ viii

CHAPTER ONE: Introduction .......................................................................................... 1
  1.1 Personal Reflexivity ................................................................................................. 1
  1.2 Problem ..................................................................................................................... 2
  1.3 Purpose of the Research Project ............................................................................. 3

CHAPTER TWO: Literature Review ................................................................................ 4
  2.1 Introduction ............................................................................................................... 4
  2.2 Meaning of a Sibling Relationship ......................................................................... 5
  2.3 History of Sibling Literature .................................................................................. 7
  2.4 Current Sibling Literature ...................................................................................... 8
  2.5 Gaps in Sibling Literature ...................................................................................... 9
  2.6 Positive Experiences ............................................................................................... 11
    2.6.1 Sources of Comfort and Support ................................................................... 11
    2.6.2 Companionship and Friendship ................................................................... 12
    2.6.3 Sibling Warmth and Attachment ................................................................... 13
  2.7 Negative Experiences .............................................................................................. 15
    2.7.1 Responsibility and Blame .............................................................................. 15
    2.7.2 Stress and Conflict ......................................................................................... 16
  2.8 The Diagnosis of Autism Spectrum Disorder and the Sibling Relationship ............ 17
  2.9 Siblings and Autism Spectrum Disorder ................................................................ 20
  2.10 Current Literature on Autism Spectrum Disorder .................................................. 20
  2.11 Gaps in Sibling Literature ..................................................................................... 21
  2.12 Positive Experiences ............................................................................................. 24
    2.12.1 Helpful and Caring ....................................................................................... 24
    2.12.2 Closeness ...................................................................................................... 25
    2.12.3 Positive Attitude ........................................................................................... 25
  2.13 Negative Experiences ............................................................................................ 26
    2.13.1 Worry, Guilt and Responsibility .................................................................. 27
    2.13.2 Anger ............................................................................................................. 28
    2.13.3 Depression and Stress .................................................................................. 29
  2.14 Conclusion ............................................................................................................. 30
### CHAPTER FIVE: Discussion

5.1 Introduction ........................................................................................................... 73

5.2 A Different Relationship, but it is Not One That is Less ............................................ 73

5.3 Challenging Experiences ..................................................................................... 75
   5.3.1 The Diagnosis ................................................................................................. 75
   5.3.2 Complex and Layered ................................................................................... 76

5.4 Positive Experiences ......................................................................................... 81
   5.4.1 Reciprocity .................................................................................................... 81
   5.4.2 Bonding ......................................................................................................... 82

5.5 Strengths of the Research Project ......................................................................... 82

5.6 Limitations of the Research Project ...................................................................... 88

5.7 Implications for Social Work Practice .................................................................. 88

5.8 Future Research ................................................................................................ 90

5.9 Conclusion .......................................................................................................... 91

References .................................................................................................................. 93

APPENDIX A: Invitation to Participate ..................................................................... 112

APPENDIX B: Telephone Screening Guide ............................................................. 113

APPENDIX C: Letter of Invitation ........................................................................... 114

APPENDIX D: Counseling Services .......................................................................... 116

APPENDIX E: Interview Guide ................................................................................. 118

APPENDIX F: Participant Consent Form .................................................................... 120

APPENDIX G: Transcript Release Form ..................................................................... 123

APPENDIX H: Photography Release Form .................................................................. 124

APPENDIX I: Literature Review Chart ....................................................................... 125

APPENDIX J: Bronfenbrenner Ecological Systems Theory Diagram ....................... 136

APPENDIX K: Bronfenbrenner Ecological Systems Theory Diagram from a Sibling Perspective ................................................................. 137

APPENDIX L: Research Ethics Board Certificate of Approval ................................... 138

APPENDIX M: Research Ethics Board Certificate of Amendment of Approval ............. 139
APPENDIX N: Research Ethics Board Certificate of Amendment of Approval .......... 140
APPENDIX O: Research Ethics Board Certificate of Amendment of Approval .......... 141
APPENDIX P: Aaron's Interview Pictures ........................................................................................................ 142
APPENDIX Q: Charlotte's Interview Pictures .................................................................................................... 143
APPENDIX R: David's Interview Pictures ........................................................................................................ 144
APPENDIX S: Natalie's Interview Pictures ...................................................................................................... 145
APPENDIX T: Shawn's Interview Pictures ....................................................................................................... 146
APPENDIX U: Diagram of Study Themes ........................................................................................................ 147
List of Tables and Figures

Figure 1- Diagram of Study Themes .................................................................57

Figure 2- Bronfenbrenner Ecological Systems Theory Diagram: From a Sibling Perspective...............................................................77

Literature Review Chart........................................................................................................125

Bronfenbrenner Ecological Systems Theory diagram.........................................................136

Bronfenbrenner Ecological Systems Theory Diagram: From a sibling Perspective..........................137
Glossary

**Asperger Syndrome** - Asperger Syndrome is a form of Autism Spectrum Disorder that affects children and adults with social interactions. Individuals diagnosed with Asperger Syndrome may also exhibit a restricted range of interests and/or repetitive behaviours (Autism Speaks, 2015).

**Autism Spectrum Disorder (ASD)** - Autism Spectrum Disorder (ASD) is the most severe developmental disability that appears in the first three years of life (American Psychological Association, 2015). The disorder involves challenges in social communication, social interaction and restricted, repetitive patterns of behaviour, interests, or activities (Autism Consortium, 2011; American Psychological Association, 2015). ASD is a single spectrum; however, individuals vary in terms of the severity of ASD symptoms, patterns of onset and clinical course, etiologic factors, cognitive abilities, and associated conditions (American Psychiatric Association, 2013).

**Family-ecological systems theory** - Family-ecological systems theory focuses on entire system, not just parts of a system or an individual (Kothari, 2011; Whiteman, McHale & Soli, 2011).

**Phenomenology** - Phenomenology examines participants’ diverse stories, and explores central, common themes from participants' discussions (Creswell, 2007).

**Photo-production** - Photo-production is an inexpensive and effective method of gathering data from populations so that participants can discuss abstract ideas (White, Bushin, Carpena-Mendez, & Laoire, 2010).

**Receptive language** - Receptive language refers to one's ability to understand what is said or written (Autism Speaks, 2012).
**Sibling** - There are many definitions of a sibling relationship: (1) Biological siblings - Two or more people share a relationship and biological parents (Cicirelli, 1995), (2) Half siblings - Two or more individuals share a relationship and have one biological parent (Cicirelli, 1995), (3) Step siblings - Two or more individuals share a relationship without a biological parent in common (Sanders, 2004), (4) Adoptive siblings - Two or more people share a relationship because they are legally adopted into the family (Cicirelli, 1995), (5) Fictive siblings - Two or more people who share a relationship and are accepted into the family without any blood ties or legal criteria (Cicirelli, 1995).

**Sibling with Autism Spectrum Disorder (SWA)** - The individual in a family whose sibling has been diagnosed with ASD.
CHAPTER ONE: Introduction

1.1 Personal Reflexivity

When I was 4 years old, my mother had a blood clot in her jugular vein; at this time, she was also pregnant with my sister. It took a team of health providers to ensure my mother and sister remained alive, safe, and healthy. Although only four years old, I understood I had come close to losing my only sister. I can reflect back on this life-altering experience and realize that I may have never had the opportunity to develop a sibling relationship. My sister has always been an important piece of my life: she is the link to my past, where she and I share childhood memories. She is one of my best friends, and someone with whom I have the opportunity to talk and visit often. I look forward to the adventures that we will share in the future.

I have become a better social worker because of my relationship with my sister. My current social work practice involves working with children who have Autism Spectrum Disorder (ASD), a developmental disability that can cause significant social, communication and behaviour challenges (Facts about ASD, 2016). Part of my job is to provide parent coaching, and to assist children and youth who have ASD by establishing socially significant behaviours. These behaviours can include making requests for items, assisting with social skills, or working on safety concerns. Yet, due to the nature of the services I provide, I often do not include and provide support to the sibling because my job description and expectation focus on the sibling with Autism Spectrum Disorder.

Throughout my career, I have questioned what role a sibling plays in the life of a sibling diagnosed with ASD. I have observed a variety of families in my practice, and have discovered that siblings take on a variety of roles, such as a caregiver and teacher to
their ASD sibling, as well as a helper to their parents. I have also observed some siblings display aggressive behaviours and/or develop severe anxiety. I have a great passion for working with children and families who are affected by ASD.

1.2 Problem

As Autism Spectrum Disorder (ASD) diagnoses increase in North America, awareness and understanding of diverse support needs for persons with ASD and their family members is a growing concern among health care professionals (Bloch, & Weinstein, 2010; Boyd, Odom, Humphreys, & Sam, 2010). The sibling relationship is one of the longest relationships one will have; and when one sibling is diagnosed with Autism Spectrum Disorder (SWA), the sibling relationship can often become more complex (Tanaka, Uchiyama, & Endo, 2011) and may entail a long term commitment for their sibling, particularly as their parents age (Tozer, Atkin, & Wenham, 2013).

A research project that investigates the individual lived experience of young Saskatchewan adults, who live with a Sibling diagnosed with Autism Spectrum Disorder (SWA), could glean valuable insights into their support needs. In-depth semi-structured interviews with the use of photo production as a tool to encourage dialogue during the interview process will illicit rich data. It is anticipated that the project results will increase awareness and understanding of individual young adult sibling experiences with a SWA and their support needs.
1.3 Purpose of the Research Project

The purpose of this research project was to investigate individual experiences of young adults, who live with a Sibling with Autism Spectrum Disorder (SWA) in Saskatchewan. The objectives of this project were: (a) to understand individual experiences of siblings who live with or have lived with a SWA; and, (b) to understand how those individual experiences contributed to their individual support needs. According to Preece and Jordan (2007), social workers have a limited awareness and understanding of the lived experiences of young adults with a SWA. It is important to know what the support needs are of these young adults because these individuals may be involved in long-term support of their sibling with ASD, particularly as their parents age (Tozer et al., 2013).

According to Bishop (2012), sibling relationships with a SWA can be challenging and stressful; although, in contrast, Tozer et al. (2013) state that these sibling relationships can also be positive and supportive. Authors, Naylor and Prescott (2004) suggest that peer support groups, family awareness of support services, drop-in support services, and meeting individual needs (such as one-to-one counseling support) may have a positive impact on alleviating some of the support needs of siblings who have a SWA. Thus, in this project, the data collection method entails 2 semi-structured interviews with the use of participant derived photographs with each participant in an effort to gain an in-depth understanding of the individual lived experiences of the participants that contribute to their support needs. The information gleaned from this study will be beneficial to families and to the professionals who support them.
CHAPTER TWO: Literature Review

2.1 Introduction

This chapter will investigate 2 main literature themes: (1) siblings, and (2) siblings with Autism Spectrum Disorder (ASD). It is important to separate the two so that the reader can have a clearer understanding of what sibling relationships are, the history surrounding sibling relationships, what the literature discusses regarding sibling relationships, the gaps in the literature, as well as the strengths and challenges of having a sibling relationship. It is also important to focus on siblings and ASD because the reader must understand how the sibling relationship may change, the factors that influence a positive or negative relationship, as well as the current literature, history, and research gaps (Refer to Appendix I for a list of qualitative and quantitative sibling studies, years studies were published, number of participants and the number of theory-focused studies).

This chapter first provides an overview of the meaning of a sibling relationship, its uniqueness and history, the current literature on the subject, as well as current gaps, and research on positive and negative experiences of having a sibling. This chapter also discusses literature that concerns: ASD and the sibling relationship, ASD definitions and diagnoses, causes and treatment of ASD, the sibling relationship where one sibling has ASD, current literature and research gaps, and studies of the positive and negative experiences when one or more siblings have ASD.

A literature search focused on key words such as "history of sibling relationships," "siblings, sibling relationship," "sibling relationships," "sibling thesis" and "ASD, family and ASD," and "differential treatment". Electronic search databases
included ProQuest, Wiley-Blackwell Full Collection, Library Archives Canada, PubMed, Google Scholar, and JSTOR. The search revealed that prior to 1980, systematic research on siblings was virtually non-existent (Dunn, 1983). As a result, this review includes literature dating from 1980 to 2014.

The search process began by entering the term "sibling relationships" into the database. Many of the articles presented quantitative data from the parent perspective. Subsequently, the search advanced to “siblings and ASD,” which also overwhelmingly yielded quantitative studies from the parent's perspective. I then sought recent Canadian and worldwide theses. These theses were among the most relevant to my research, and included qualitative data from the siblings' perspective. The literature suggests that some siblings have positive sibling relationships, while other relationships are negatively impacted by the presence of an ASD sibling (Welsh, 2011; Wheeler, 2010). The positive and negative outcomes of these relationships are dependent on variables such as family stressors, sibling gender, sibling constellations, and 1- or 2-parent households (Stach, 2007; Whiteman et al., 2011).

2.2 Meaning of a Sibling Relationship

A sibling relationship is considered the strongest bond within families, as it is emotion-based from birth (Dunn & McGuire, 1992). The definition of a sibling has traditionally been discussed in the literature as two people who share a relationship and biological parents (Cicirelli, 1995). Although sibling relationships have been identified as sharing the same parent, Cicirelli (1995) states that the sibling relationship should also consider the inclusion of half siblings, step siblings, adoptive siblings and fictive siblings. A half sibling is defined as two individuals who have only one biological parent.
in common (Cicirelli, 1995; Sanders, 2004). Step siblings share a relationship because they have no biological parent in common (Cicirelli, 1995; Sanders, 2004). Adoptive siblings share a relationship because they are legally adopted into the family (Cicirelli, 1995). Finally, fictive siblings are accepted into the family without blood ties or legal criteria (Cicirelli, 1995). Dunn (1988) describes the sibling relationship as "distinctive in its emotional power and intimacy, its qualities of competitiveness and ambivalence, and its emotional understanding" (p.119). Intimacy is a distinct emotion shared among siblings compared to relationships between other family members (Perlman, 967 as cited in Sanders, 2004). When intimacy is established among siblings, a bond is created. This bond represents many things for each sibling relationship, including a tie that unites, an obligation or an agreement, as well as a connection or system of connections (Bank & Kahn, 1982).

The sibling relationship is unique, and is usually the first peer relationship a child has (Sanders, 2004; Jennings, 1998). The sibling relationship is thus considered one of the longest-lasting relationships in a person’s lifetime, often lasting 60-80 years in length, as siblings most commonly outlive their parents and other family members (Cicirelli, 1995; Garney, 2002; Milevsky & Heerwagan, 2013; Sanders, 2004). It is also among the most common relationships, as approximately 90 per cent of individuals in western society have a sibling (Milevsky & Heerwagan, 2013).

Siblings will usually spend more time with each other than with anyone else during their lifetimes, especially during childhood and adolescence, unless there are family changes, such as parent separation, death, and/or conflict within the home (Cicirelli, 1995; Pike, Coldwell & Dunn, 2005; Sanders, 2004). This time spent together...
may empower siblings to become confidants and companions with one another (Gass, Jenkins & Dunn, 2007; Goetting, 1986).

### 2.3 History of Sibling Literature

Research pertaining to the sibling relationship was relatively rare until 1980 (Dunn, 1983; Stach, 2007; Whiteman et al., 2011). Although sibling-focused studies have only developed in the last few decades, it is important to note how authors and playwrights have written about siblings for centuries (Feinberg, Solmeyer & McHale, 2012; Jennings, 1998). For example, discussions of sibling relationships date to the biblical era, as The Book of Genesis explores the power of sibling relationships when Cain and Abel are led into exile (Feinberg et al., 2012; Jennings, 1998). Sibling relationships are also discussed in Shakespeare's Hamlet, where rivalry and jealousy is explored between siblings when Claudius becomes king following his brother's death (Jennings, 1998).

In the last three decades, however, research interest in siblings has increased dramatically, and has focussed predominantly on childhood and adolescent relationships (Atkin & Tozer, 2013; Dunn, 2002). This increased interest in sibling research is likely due to changes in family dynamics. For instance, as a result of divorce and separation, a child today is more likely to live with another sibling than his or her own father (Green, 2013). Sibling relationship dynamics have also dramatically evolved since the early 1900s, when families were comprised of 6 or more children. The fact that American families currently have two-to-four children makes the sibling relationship more interdependent and intense; siblings not only grow up together, but they also have continued interactions into adulthood and old age (Herrick, 2008). It is important to note
that the average number of children at home per family in Canada is 1 (Statistics Canada, 2011). Thus, children who grow up in Canada may not have the same experience that children have in America because Canadian children may not have a sibling.

### 2.4 Current Sibling Literature

Family is the first relationship to which humans are exposed; yet many gaps remain within the literature (Herrick, 2008). For example, most family studies involve the mother-child dyad, with less attention paid to the sibling relationship (Milevsky & Heerwagen, 2013; Stach, 2007). A majority of the literature on siblings focuses on sibling bonds, family size and gender differences (Herrick, 2008). A review of literature found that birth order could affect sibling relationships (Furman & Buhrmester, 1985; Healey, 2008; Stach, 2007). More current sibling literature pertains to differential treatment, sibling warmth, and the transition process when the oldest child is no longer an only child (Brody, Stoneman, & Gauger, 1996; Buist, Deković, & Prinzie, 2013; Volling, 2012; Young, 2011). The literature also includes the differences between sibling pairs, and the connection between parent-child and sibling-child relationships (Dunn, 1988). In addition, the literature identifies the significance of connections with sibling relationships outside of the family (Criss & Shaw, 2005; Kramer & Kowal, 2005), conflict resolution (Shalash, 2011), and the quality of a sibling relationship as they experience higher stress levels within the family (Langeveld, 2010), parental financial difficulties (Criss & Shaw, 2005), death (Gass, et al., 2007), and divorce (Abby & Dallos, 2004; Jennings, 1998).
2.5 Gaps in Sibling Literature

There are several gaps in the literature on siblings. First, studies on siblings do not generalize to the entire sibling population due to small sample sizes that consist mainly of Caucasian, middle-class, 2-parent, and 2-child families (Connidis, 1992; Garney, 2002; Pike et al., 2005; Reechia & Howe, 2009). A second gap is that literature has chiefly centered on childhood, adolescence, and older adults; young adulthood is often ignored (Cicirelli, 1995; Dunn, 2002). Studies focusing on sibling ethnicity, low-income families, as well as sibling communication and division of labour are also lacking (Buist et al., 2013; Cicirelli, 1995; Criss & Shaw, 2005; Dunn, 2002; Kim, 2012). There is also limited research on family and community supports, as well as interventions that could enhance the research in sibling relationships (Campbell, 2011).

Another gap in the literature concerns methodology, in that studies are primarily conducted using quantitative methods. Researchers conduct natural experiments, quasi-experiments, longitudinal and postbirth studies in order to determine the quality of sibling relationships (Duis, Summer, & Summers 1997; Volding, 2012; Young, 2011). However, quantitative studies do not fully capture or enrich the sibling literature because they do not allow participants to speak freely about their experiences (Abbey & Dallos, 2004). Qualitative studies, on the other hand, attempt to capture the essence of one's experience, yet they remain limited in the sibling research (Abbey & Dallos, 2004; Bishop, 2012).

In addition to issues of methodology, many sibling studies also lack theoretical context (Caspi, 2011; Whiteman et al., 2011). Studies that are more theory-focused have the potential to strengthen empirical investigations into sibling relationships (Caspi,
2011; Whiteman et al., 2011), providing valuable insight into specific relationships, including changes in the environment (Campbell, 2011). Finally, longitudinal studies that explore the sibling relationship from birth to adulthood are lacking (Brody et al., 1996; Campbell, 2011; Herrick, 2008). Longitudinal studies could potentially generate information at each stage in the sibling's life (Campbell, 2011).

It is important to note that most sibling research focuses on the positive and negative experiences of having a sibling relationship. The results of such findings are significant because of the influence of variables on sibling relationships such as birth order, age difference, number of siblings within the family, family stress, marital status, gender, socio-economic status of the family, and culture (Buist et al., 2013; Cicirelli, 1995; Dunn, 1988; Kramer & Kowal, 2005; Langeveld, 2010).

Some sibling relationship studies reveal that siblings have positive relationships; siblings can assist in peer interaction, provide a source for support throughout life, assist in child development, and can create a secure base for younger siblings (Dunn, 1983; Dunn & McGuire, 1992; Whiteman et al., 2011). Although there are positive findings regarding sibling relationships, research has also explored negative findings, such as living in conflict, feeling inferior to the other sibling, and being competitive with one another (Stach, 2007; Whiteman et al., 2011). The next two sections of this report will discuss the positive and negative experiences that are found within the sibling literature.
2.6 Positive Experiences

Sibling-focused studies have been identified as positive experiences, using themes such as: siblings acting as sources of comfort and support, companionship and friendship, and sibling warmth and attachment. Each experience will be discussed further in detail in this next section.

2.6.1 Sources of Comfort and Support. Dunn (2002), Duis, Summer, and Summers (1997), as well as Gass, Jenkins, and Dunn (2007) note that stressful life experiences can result in siblings becoming sources of support and comfort to one another. For example, Abbey and Dallos (2004) examine the impact divorce has on sibling relationships. This sense of sibling support becomes especially strong when parents are in crisis, and cannot tend to their children's needs (Abbey & Dallos, 2004). Similarly, Connnidis (1992) found that life transitions during adulthood – including divorce, death of a spouse, and health problems of a family member – improve sibling relationships, as the sibling often provides emotional support and comfort during critical life events.

Langeveld (2010) examined 311 families with adolescent siblings, questioning if sibling relationships can alter the negative impact stress has on a child's well-being. Results revealed that siblings, especially sisters, are able to provide more support and exacerbate the negative effects of stress (Langeveld, 2010). Sibling constellation has also been studied. For example, McGowan, Beck and Hall (2009) researched the development of personality and relationships with the middle child. In their study, siblings reported high levels of support from family members, having the "best of both worlds" as they can seek comfort from the older sibling, while still being able to help the
younger sibling (McGowan et al., 2009, p. 4). At the same time, studies of the eldest siblings suggest that he or she can be a "teacher," and often manage the youngest siblings, while the youngest sibling is often the "learner" (Recchia & Howe, 2009; McElwain & Volling, 2005). In contrast, the eldest sibling is also more likely to intimidate or pressure their younger siblings into negative behaviours (McElwain & Volling, 2005).

2.6.2 Companionship and Friendship. Dunn (2002) states that, when children are good at understanding their emotions, they are more likely to be effective play companions, fostering imaginative play with their siblings. Sibling companionship is crucial, and is impacted by parental differential treatment (PDT), which refers to the differences between how parents treat a particular child in the same family (Young, 2011). Meunier et al. (2012) explored parental differential treatment, and indicated that siblings have more pro-social behaviour with their siblings if parents provide positive parenting to each sibling, and avoid favouring one child over the other (Meunier et al., 2012).

As already discussed, the eldest sibling has been studied a great deal in sibling literature. Dunn (1988) suggests that, if the eldest child experiences a peer relationship outside of the family prior to the second child’s birth, the sibling relationship can become more co-operative, friendly and empathetic. Kramer and Kowal (2005), and Kramer and Gottman (1992) explore peer relationships, with an emphasis on the eldest child, and their studies indicate that the eldest child can have a stressful transition following the birth of a new child, making it difficult to have a positive sibling relationship. However, the authors conclude that if the eldest sibling has a peer
relationship prior to the new baby, the sibling relationship can improve with positive social skills, better conflict management, and negotiation skills (Kramer & Gottman, 1992; Kramer & Kowal, 2005).

Finally, Yeh and Lempers (2004) used a 3-wave longitudinal study, and collected data from multiple informants (fathers, mothers, and target children) in 374 families to explore the potential effects sibling relationships had on adolescent development across early and middle adolescence. Participants reported having a better friendship and higher self-esteem, less loneliness, depression and delinquent behaviour, as they got older. From this, Yeh and Lempers (2004) concluded that positive social changes create more equality and connection among family members.

2.6.3 Sibling Warmth and Attachment. Buist and colleagues’ (2013) meta-analysis of sibling literature investigated the link between child and adolescent sibling relationships. Study results suggested that sibling warmth, less conflict, and less differential treatment are significant as there is less internalization and externalization of problem behaviour among children (Buist et al., 2013). They further proposed that having a positive attachment could thus increase sibling warmth, emotional security, and provide an increase in self-esteem (Buist et al., 2013). Howe Aquan-Assee, Bukowski, Rinaldi and Lehoux., (2001) also explored relationship warmth in a study that examined self-disclosure between early adolescent siblings, as well as emotional understanding and relationship warmth. The authors concluded that sibling relationships are warm if siblings can trust one another and disclose positive feelings to one another (Howe et al., 2001).
Age also impacts sibling warmth and attachment. For instance, siblings form stronger attachments towards one another when they experience a life transition (Milevsky & Heerwagan, 2013). Milevsky and Heerwagan (2013) state that, when one sibling moves to college, usually at the age of 18, siblings grow to appreciate one another more, an indication of increased maturity. Milevsky and Heerwagan (2013) also reveal that as siblings grow older, they are better able to resolve conflict. Participants reported developing a closer bond because their parents no longer resolved conflict for them (Milevsky & Heerwagan, 2013). Similarly, Roff, Martin, Jennings, Parker, and Harmon (2007) state that siblings would provide emotional support to one another, and often become closer when they begin providing care to their parents.

Bullock and Dishion (2000) explored adolescent sibling deviance, reporting that siblings will form coalitions that promote deviance and undermine parents. Although the authors suggest that deviance is a negative behaviour, study findings revealed that when siblings are closer in age, they have the ability to develop a close relationship in spite of this coalition development (Bullock & Dishion, 2000).

In this, gender is also an important aspect to sibling warmth and attachment (Herrick, 2008; Stach, 2007). While study findings among gender are inconsistent, Stach (2007) explored the sister dyad, questioning how sisters communicate intimacy. Study outcomes revealed that sisters share a unique relationship; they are closer because they communicate more than any other gender dyads and, if they possess similar interests, are able to quickly transcend rivalry and conflict (Stach, 2007). Rivalry and conflict are a few of the negative experiences described in sibling-focused studies; therefore negative experiences will be discussed in the next section.
2.7 Negative Experiences

Sibling-focused studies have also been categorized by negative experiences, using themes such as: responsibility and blame, as well as stress and conflict.

2.7.1 Responsibility and Blame. Much of the literature on responsibility for other family members and blame focuses on studies of the eldest sibling. For example, responsibility is often given to the eldest sibling of the family (Healey, 2008; Kim, 2012; Milevsky & Heerwagan, 2013; Roff et al., 2007). Healey's (2008) doctoral dissertation reviewed birth order and revealed that the first-born child is considered a people pleaser, and is often blamed for initiating fights with other siblings. Similarly, results from a qualitative study also found that the oldest sibling often resents the youngest sibling because parents are stricter with the older child (Milevsky & Heerwagan, 2013). The first-born was also explored in a dissertation by Kim (2012), which compared the East Asian and Euro-American sibling dyads. The study concluded that the first-born has more responsibility in the East Asian culture than in Euro-American culture.

Moving down the age scale, McGowan, Beck and Hall (2009) investigated the role of the middle child in a qualitative study that explored the personality and relationship of the middle child, reporting that middle children often feel a sense of responsibility, and are blamed if they cannot adhere to parental expectations, which are the result of standards set by the eldest sibling’s actions.

Finally, caring for a parent can cause concern for siblings, as there are some siblings who do not take any responsibility (Roff et al., 2007). One qualitative study suggests that the sibling who lives closer to the parent takes on the most responsibility
when providing care to that parent (Roff et al., 2007). This, as a consequence, can create conflict and stress among the sibling dyad.

2.7.2 Stress and Conflict. Stress can often cause negative emotions for siblings within the family (Dunn, 2002). For instance, the transition from one child to two children can impact the older sibling (Baydar, Greek & Brooks-Gunn, 1997; Baydar, Hyle & Brooks-Gunn, 1997; Dunn, 2002). Dunn (2002) reported that the eldest sibling may experience anxiety-like symptoms, lack of sleep, and may also exhibit more aggressive behaviours, coupled with a decrease in skill acquisition. Cicirelli (1995) and Ross, Ross, Stein and Trabasso (2006) noted that in these situations family disruption and sibling conflict is inevitable, so parents must communicate with the eldest sibling to ensure there is a successful transition from one child to two children, and more importantly, that a positive sibling relationship is built. Substance abuse can be another stressor that negatively influences the sibling relationship (Feinberg et al., 2012; Garney, 2002). The sibling literature suggests that one sibling’s substance misuse can negatively impact the quality of sibling closeness because there is a lack of trust and communication (Feinberg, et al., 2012; Garney, 2002).

Parental differential treatment can also create much stress on the sibling relationship (Meunier et al., 2012). Parental differential treatment begins when parents welcome the arrival of a second child; for example, Volling's (2005) research review used the ecological systems model to identify changes in family life, and the older child's adjustment following the sibling’s birth. Volling (2005) revealed that if the mother uses harsher treatment towards her oldest child, and has postpartum depression, the eldest sibling would likely develop problem behaviours that can impact the entire family.
system. The parent also may provide the eldest child with stricter rules compared to that of the younger sibling (Milevsky & Heerwagan, 2013). Differential treatment can also cause the eldest child to develop resentment and jealousy towards the younger sibling, which negatively impacts on the sibling relationship (Brody et al., 1996; Milevsky & Heerwagan, 2013).

Dunn (2002) identified that differential parent-child relationships are often associated with conflict among siblings. This is supported in findings from other studies, which suggest that parents who treat their children differently, or a family that includes children of a previous marriage of one spouse or both, may notice more conflict among siblings (Abbey & Dallos, 2004; Milevsky & Heerwagan, 2013; Pike, et al., 2005). Positive and negative experiences of a sibling relationship have been discussed. It is important to note that the sibling experience may change if there is one sibling diagnosed with Autism Spectrum Disorder (ASD). The next section will speak to the diagnosis of ASD, as well as the possible implications of a sibling relationship when there is one sibling diagnosed with ASD.

2.8 The Diagnosis of Autism Spectrum Disorder and the Sibling Relationship

Current literature suggests that the sibling relationship can become more complicated when there is a child with a disability and, more specifically, when the sibling is diagnosed with ASD (Tanaka et al., 2011). This complicated relationship results from the characteristics of ASD, including limited social interaction, communication, and aggressive and repetitive behaviour (Knott, Lewis & Williams, 1995).
Autism Spectrum Disorder (ASD) is the most severe developmental disability that appears in the first three years of life (American Psychological Association, 2015). The disorder involves challenges in social communication, social interaction, and restricted, repetitive patterns of behaviour, interests, or activities (Autism Consortium, 2011). ASD is a single spectrum; however, individuals vary in terms of the severity of ASD symptoms, pattern of onset and clinical course, etiologic factors, cognitive abilities, and associated conditions (American Psychiatric Association, 2013).

In the Diagnostic and Statistical Manual (DSM)-5 (2013), individuals with ASD must demonstrate symptoms from early childhood, even if the symptoms are not recognized until later in life (American Psychiatric Association, 2013). In addition, individuals who are assessed for ASD must meet the following criteria: challenges in social-emotional reciprocity, deficits in nonverbal communication used for social interaction, and deficits in developing and maintaining developmentally-appropriate relationships (Worley, 2012). Individuals must also meet at least two of the four restricted repetitive behaviours in order to receive an ASD diagnosis: (1) stereotyped or repetitive speech, motor movements, (2) use of objects, excessive adherence to routines, ritualized verbal or nonverbal behavior patterns, (3) excessive resistance to change, highly restricted, fixated interests that are abnormal in intensity and focus, and (4) hypo- or hyper-reactivity to sensory input or unusual interest in sensory aspects of environment (Worley, 2012). Finally, levels of support, etiology, and modifiers, such as language disorders must be determined in an ASD assessment.

Exact causes of ASD remain uncertain, yet research suggests that any of the following factors can contribute to a diagnosis: genetics, parental mental health, certain
types of infections, complications before, during or after birth, and environmental impacts (Center for Disease Control and Prevention, 2015b). There are no medications that can cure ASD; however, there are various treatments and therapies available, including Behavioral and Communication interventions, such as Applied Behaviour Analysis (ABA) and Speech and Language Pathology. There are also dietary approaches, such as biomedical interventions, as well as medications that can treat sleeping behaviours, and high energy behaviours; finally, there are Complementary and Alternative Treatments, such as special diets (Center for Disease Control and Prevention, 2015c; Coplan, 2010).

In the United States, ASD diagnosis has increased significantly in the last 15 years. In 2000, one in 150 people were diagnosed with ASD (Center for Disease Control and Prevention, 2015a). By 2008, ASD affected one in 88 people: one in 54 boys and one in 252 girls (Center for Disease Control and Prevention, 2015a). Currently in the United States, one in 50 children between the ages of six and 17 will be diagnosed with ASD (National Vaccine Information Center, 2013). In Canada, the prevalence of ASD is uncertain because recordings are different across provincial and territorial health care systems (Autism Speaks Canada, 2014). However, it is important to note that the reasons for the increase in ASD diagnosis remain uncertain; researchers believe that part of the reason is that there is more awareness of ASD among parents and health professionals, and that there is also an increase in access to diagnostic services (Center for Disease Control and Prevention, 2015a). Awareness and knowledge of Autism Spectrum Disorder (ASD) is important because this disorder impacts the way in which one
communicates, and socializes with individuals (Facts about ASD, 2016). This next session will discuss how the sibling relationship may change when one sibling has ASD.  

2.9 Siblings and Autism Spectrum Disorder  

While Autism Spectrum Disorder (ASD) affects each family member, the sibling relationship changes most drastically when the sibling without ASD will provide care to his sibling with Autism Spectrum Disorder (SWA) (Kaplan, 2013). When the sibling takes on a caregiver role, "power over" one sibling can occur. This "power over" one sibling creates a hierarchical relationship, instead of an egalitarian one (Burbridge, 2013). There are a number of illnesses and situations that may impact the family dynamics and sibling relationships; however, when one sibling has Autism Spectrum Disorder, (ASD) it can affect the family more than any other disability or disease, including Down syndrome, AIDS, cancer, and diabetes (Bayat & Schuntermann, 2013; Kaminsky & Dewey, 2001; Macks & Reeve, 2006). The following section will explore the current literature on Autism Spectrum Disorder (ASD).  

2.10 Current Literature on Autism Spectrum Disorder  

Current literature on Autism Spectrum Disorder (ASD) focuses on treatment and behaviour such as hitting, and repetitive actions (Coplan, 2010). Current literature also focuses on discussing coping strategies for parents, as well as how ASD may affect the marital dyad (Boushey, 2001; Hastings, et al., 2005; Latta et al., 2013). ASD literature has also studied higher stress levels, financial difficulties, and depression among mothers when there is a child with ASD in the family (Glasberg, 2000; Gray, 2003; Luther, Canham & Cureton, 2005; Rossiter & Sharpe, 2001). Other studies suggest that if family
and community supports are in place, families will encounter fewer negative experiences (Boushey, 2001).

Findings from studies examining parents’ marriages are inconclusive. Research findings addressed relationships between child, partner, and parent variables. Parents of 48 children with Autism Spectrum Disorder (ASD) (41 mother–father pairs) reported on child characteristics, as well as their own stress and mental health (Hastings et al., 2005). This study found that a child with ASD does not negatively impact marriage because there are extended family and community supports in place. In contrast, parents advise that having a child with a disability can increase marital stress for a number of reasons, including: the constant attention and care required by the child; an increased likelihood of maternal depression and paternal denial of the diagnosis; financial burdens due to treatment; and lack of time available to spend together as a couple (Hastings et al., 2005). This being said, however, there remains a dearth of literature exploring how a sibling diagnosed with Autism Spectrum Disorder (SWA) affects other siblings, particularly among young adults.

2.11 Gaps in Sibling Literature

Siblings’ voices lack representation in ASD literature as most studies about ASD focus on the parents’ marriage (Hastings et al., 2005), mother’s well-being (Gray, 2003), and the child who is diagnosed with ASD (Bishop, 2012; Coplan, 2010; Rivers & Stoneman, 2008). What siblings view as support systems also remains curiously absent in the literature (Boyd, 2002; Naylor & Prescott, 2004; Pitter, 2009; Smith, 2003), and studies that do pertain to siblings are primarily quantitative. Researchers have conducted interview surveys/questionnaires and/or experiments to examine how siblings, ages
seven to 18 years old, cope with living with a sibling with ASD (Knott, et al., 1995; Knott, Lewis & Williams, 2007; Macks & Reeve, 2006; Meyer, Ingersolle & Hambrick, 2011; O'Laughlin, 2006; Smith, 2000; Tanaka et al., 2011; Welsh, 2011; Wheeler, 2010; Williams & Piamiaiyakul, 2010). There are only a few quantitative studies that compare sibling relationships with ASD to sibling relationships with other disabilities, such as Down syndrome (Bagenholm & Gillberg, 1991; Kaminsky & Dewey, 2001; Knott et al., 1995). Sibling relationships are also compared when neither sibling has a disability (Bagenholm & Gillberg, 1991; Kaminsky & Dewey, 2001; Knott et al., 1995; Macks & Reeve, 2006). The comparative studies reveal that most siblings who have a Sibling diagnosed with Autism Spectrum Disorder (SWA) are less likely to form a strong bond than with those siblings who have Down syndrome, or those who do not have a disability. This inability to form a strong bond is due to ASD characteristics, where siblings with ASD present with limited communication, social skills, and have more aggressive or repetitive behaviours than siblings who have Down syndrome (Bagenholm & Gillberg, 1991; Macks & Reeve, 2006; Kaminsky & Dewey, 2001; Knott et al., 2005).

Another gap in sibling research is that qualitative studies where one sibling has ASD are limited (Bishop, 2012; Feiges, Weiss & Harris, 2004; Gray, 2003). There are few sibling studies that incorporate qualitative descriptive designs. Study findings suggest that quantitative research does not allow participants to respond to multifaceted issues; instead, quantitative studies restrict the researcher and participant to predetermined, close-ended research answers (Cridland, Jones, Magee & Caputi, 2013). Latta and colleagues (2013) indicate that young participants need meaningful ways, rather than a question and answer survey, to tell their story, suggesting that photo-
elicitation is a useful tool with which to gather qualitative data, allowing researchers to understand the human experience, and ensuring that participants feel comfortable sharing personal stories.

The generalizability of studies is also limited due to small population samples that consist of mainly Caucasian, middle-class families with both parents living in the same home (Bishop, 2012; O'Laughlin, 2006; Rivers & Stoneman, 2008; Smith, 2000; Welsh, 2011). What is more, there is a dearth of theory-focused studies in the literature of families where one sibling has ASD (Refer to Appendix I). Theory focused studies could strengthen the investigation of sibling relationships because having the same terminology, the consistency in terms of the actual framework, can improve the communication of findings, and identify emerging patterns (Cridland et al., 2013; Rossiter & Sharpe, 2001; Whiteman et al., 2011). There are also few literature findings that focus on family and community supports (Boyd, 2002; Campbell, 2011; Goehner, 2007; Kaplan, 2013; Naylor & Prescott, 2004; Pitter, 2009; Smith, 2003). Finally, longitudinal studies that explore the sibling relationship from birth to adulthood remain lacking. Longitudinal studies that examine life stages, such as childhood, adolescence, and adulthood, could provide insight into the stages of siblings' lives (Campbell, 2011; Green, 2013; Kaplan, 2013).

The last research gap in sibling literature is that study results that compare positive and negative experiences of growing up with a SWA are inconclusive. Some researchers have explored whether siblings of SWA’s have had an overall positive or negative experience (Reis, Collins & Bercheid, 2000; Welsh, 2011). While some studies denote positive experiences, where siblings without ASD are more compassionate,
protective, and helpful towards their sibling with ASD (Feiges, et al., 2004; Wheeler, 2010), others studies suggest that siblings are negatively impacted, as they experience a need to compete for parental attention. Siblings may also present with aggressive behaviours, can be bullied by peers, and lack social supports (Bishop, 2012; Smith, 2000; Wheeler, 2010). The next two sections of this chapter will focus on studies that explore the positive and negative experiences of having a sibling diagnosed with Autism Spectrum Disorder.

2.12 Positive Experiences

Sibling focused studies, when one sibling has ASD, are often divided by positive experiences, using themes such as: helpful and caring, closeness and intimacy, as well as positive attitude and increased self-esteem.

2.12.1 Helpful and Caring. Green (2013) conducted a literature review revealing that siblings are more empathetic towards others because of their experience. In Feiges, Weiss, and Harris’ (2004) study, 20 siblings were interviewed using narrative recordings. Study results indicated that respondents were comfortable living with their sibling because they had the opportunity to teach each other a variety of skills, such as patience and understanding (Feiges et al., 2004).

One of the few qualitative studies of adult siblings reported that most people accept the need to care for their siblings (Tozer et al., 2013). In this qualitative study, 21 siblings were interviewed, and indicated feeling the need to do the ‘right thing’ and become more involved with their sibling’s care as parents got older (Tozer et al., 2013). In these cases, the sibling learned to accept responsibility and care for their SWA; often, siblings saw this caring role as a way to re-establish a relationship in adulthood (Atkin &
In addition, siblings felt the need to re-locate, moving closer to their sibling with ASD so they could help care for him or her (Tozer et al., 2013).

2.12.2 Closeness. A quantitative study by Kaminsky and Dewey (2001) investigated sibling relationships of children living with ASD, compared to those who had typically developing siblings and those who had a sibling(s) with Down syndrome. The study outcomes suggest that the older sibling is closer to the reference sibling, and often provides a nurturing role to their sibling (Kaminsky & Dewey, 2001). The eldest sibling often demonstrated greater maturity and an ability to understand and appreciate the reasons for the SWA acting differently (Goehner, 2007; Kaminsky & Dewey, 2001).

A literature review by Travis and Sigman (1998) also discusses closeness and intimacy, indicating that a sibling relationship can become closer as siblings grow older and develop more cognitive awareness about their SWA.

A similar study in South Korea reported closeness and intimacy between siblings. Se Kwang (2009) interviewed nine siblings between seven and 5 years old, as well as their parents. This is one of few sibling studies focusing on non-western cultures; results indicated that although disabilities can be seen as shameful, and although discrimination and exclusion can take place, siblings still develop strong interpersonal ties of togetherness, and ASD is integrated into everyday life (Se Kwang, 2009). Part of the reason for this sense of inclusion is that, in non-western cultures such as South Korea, siblings learn to value a harmonious family life (Se Kwang, 2009).

2.12.3 Positive Attitude. Fourteen siblings of 13 children with ASD reported having a positive attitude towards their SWA in a qualitative study based on photo elicitation (Latta et al., 2013). Research studies, suggest that reasons for presenting with
a positive attitude may be due to the eldest sibling being mature, protective of his or her sibling with ASD, and having a good understanding of the sibling's diagnosis (Barr & McLeod, 2010; Green, 2013; Naylor & Prescott, 2004). Naylor and Prescott's (2004) mixed-method study assessed the needs of 55 siblings, ages eight to 18 years old using a peer support group in the United Kingdom. In this support group, siblings discussed their feelings regarding their SWA, and facilitators educated siblings about ASD (Naylor & Prescott, 2004). The study results revealed that siblings demonstrated a positive attitude, an increase in self-esteem, and had a basic understanding of ASD when they belong to a peer support group (Naylor & Prescott, 2004). The increase in self-esteem and positive attitude is likely due to parents educating siblings about ASD on an ongoing basis. As well, parents may include siblings in the intervention of choice, and may also ensure that the sibling has peer support so that thoughts and feelings are expressed (Boyd, 2002; Conway & Meyer, 2008; Naylor & Prescott, 2004). Unal and Baran's (2011) quantitative study and Beyer's (2009) literature review echoed these study findings, indicating that siblings establish positive relationships when they have knowledge about the diagnosis of the disability. Beyer (2009) stated that when siblings are in a group, and can share how they feel, they improve the intimacy and overall relationship with their sibling. Although there are several study findings that focus on positive sibling experiences, there are also negative experiences when one sibling has Autism Spectrum Disorder. The next section of this chapter will explore those negative experiences.

2.13 Negative Experiences

Research studies indicate that siblings report positive experiences when they have a Sibling diagnosed with Autism Spectrum Disorder (SWA). However, sibling focused
studies, where one sibling has ASD, have been divided into negative experiences using themes such as worry, guilt and responsibility, anger, and depression and stress.

2.13.1 Worry, Guilt and Responsibility. Bishop’s (2012) qualitative study investigated eight siblings' views when living with a brother or sister with ASD; finding primary themes of worry, guilt and responsibility. These themes were consistent with Feiges, Weiss, and Harris’ (2004) qualitative study, as well as Barr and McLeod's (2010) quantitative study. Siblings worried about being bullied, their sibling being bullied, what could happen to their sibling in the future, and what peers and strangers thought about their family (Barr & McLeod, 2010; Bishop, 2012; Ross & Cuskelly, 2006).

Siblings also reported feeling guilty because they were embarrassed to be with their sibling in front of their peers and in public (Barr & McLeod, 2010; Bishop, 2012; Feiges et al., 2004). For example, Barr and McLeod’s (2010) study analyzed 676 online sibling interactions. Siblings reported most often feeling guilty about being seen in public because strangers stare at them and their SWA (Barr & McLeod, 2010). Siblings were also embarrassed by bringing peers home, noting that peers do not understand what it is like to grow up with a SWA (Barr & McLeod, 2010).

Dodd (2004) also reported similar findings to Barr and McLeod's (2010) study. Participants, ages four to 11 in Dodd's (2004) qualitative study indicated that they worried about having friends come to their home, fearing that friends would not understand why their SWA is different (Dodd, 2004). They also feared being teased and bullied because they lived with a SWA (Dodd, 2004). Lastly, participants feared for their sibling’s future, worrying about what could happen when their parents were no longer able to care for their sibling.
Fears and issues remained even when siblings moved away from home, as some feel conflicted or guilty that they could no longer care for their sibling; however, these siblings also felt happy about moving away from home so that they could attend college. Siblings indicated that they were a "new person" because they were no longer in someone's "shadow," and because no one could judge them about their family life when they lived in a different city (Milevsky & Heerwagen, 2013; Tozer et al., 2013).

In many cases, siblings feel responsible for their SWA (Ferrailoli & Harris, 2010; Goehner, 2007; Macks & Reeve, 2006). Ferrailoli and Harris (2010) summarized studies which focused on the importance of sibling behaviour. The research indicates that siblings demonstrate more responsibility for the SWA, especially as adults (Ferrailoli & Harris, 2010). Study findings also indicate that, when the mother is more depressed, there is a higher expectation for the sibling to be more responsible, especially when the sibling is older and female (Feiges et al., 2004; Goehner, 2007; Roeyers & Mycke, 1995). Feiges, Weiss, and Harris’ (2004) qualitative study findings indicate that siblings felt responsible for parental and sibling well-being. The sibling may have engaged in parentification, as he or she protected the parents when the SWA was aggressive and/or cared for the sibling when the parents were unable to do so (Feiges et al., 2004).

2.13.2 Anger. Some siblings have exhibited anger as a result of having a SWA (Barr & McLeod, 2010; Dodd, 2004; Goehner, 2007; Latta et al., 2013). Goehner (2007) illustrated the difficulties siblings experience in grasping the concept and behaviour of ASD. For example, siblings may question why their SWA does not play with them (Goehner, 2007). Several quantitative research studies suggest that sibling relationships are compromised when one sibling has ASD (Barr & McLeod, 2010; Rivers &
Stoneman, 2008), a fact attributable to siblings believing that parents do not have time for them because they must pay greater attention and provide more care to the SWA (Barr & McLeod, 2010; Rivers & Stoneman, 2008). Although these siblings note negative experiences, research indicates that when siblings belong to peer groups they can release anger in a safe environment, become educated about ASD, and understand that they are not alone in their journey (Dodd, 2004; Feiges et al., 2004; Padilla, 2013; Tanaka et al., 2011).

2.13.3 Depression and Stress. Data were collected from 57 adolescents and mothers in a quantitative study (Orsmond & Seltzer, 2009). In this study, female siblings presented with more symptoms of depression and stress than male siblings (Orsmond & Seltzer, 2009). Researchers have suggested that this is the result of female siblings typically internalizing problems, and worrying more than male siblings (Green, 2013; Feiges et al., 2004; Sikora et al., 2013; Smith, 2000). Roeyers and Mycke (1995) and Bagenholm and Gillberg (1991) conducted comparative quantitative studies of siblings living without a disability and siblings diagnosed with ASD; and siblings who have intellectual disabilities. Siblings with a SWA were found to be at greater risk of depression, stress, and anxiety if the mother also presented with depressive symptoms (Bagenholm & Gillberg, 1991; Roeyers & Mycke, 1995). These studies also reported that children with ASD have more behavioural problems and lower cognitive functioning than children who live with any other disability; which may have a greater impact on the sibling relationship (Bagenholm & Gillberg, 1991; Roeyers & Mycke, 1995; Smith, 2000). Atkin and Tozer (2013) studied the impact of the sibling relationship when a sibling cared for the SWA during adulthood. Although there were positive aspects,
including the re-establishment of the sibling relationship, siblings questioned how they would care for their sibling and continue their own personal obligations to children, families, and employment. Study results revealed that some siblings experienced depression, low self-esteem, and anger.

Rivers and Stoneman's (2003) quantitative study investigated factors that could influence the quality of sibling relationships. For example, some siblings who have a SWA may not be well adjusted, and may have poor self-perception and problem solving behaviours (Rivers & Stoneman, 2003). The authors state that there is a need to focus on the entire family because marital stress and depression may contribute to the sibling's mental health and the quality of the sibling relationship (Rivers & Stoneman, 2003). Meyer, Ingersolle, and Hambrick (2011) also examined adjustment difficulties in siblings with ASD in a quantitative study. The authors concluded that there is a need to follow up with all family members when one member is ASD because everyone is affected (Meyer et al., 2011; Tozer et al., 2013).

2.14 Conclusion

This literature review explores the potential positive and negative implications that can occur for siblings who have a diagnosis of ASD. The literature review seeks to provide readers with an overview of the potential elements that can affect not only the parents and children when there is a diagnosis of ASD, but also the implications this can have for siblings.

This literature review has also identified the research gaps, including: the need for more qualitative data; studies that focus on diverse cultural backgrounds, (Bishop, 2012; Smith, 2000); the need for more creative study methods (Latta et al., 2013) and
longitudinal studies (Whiteman et al., 2011), and finally, the pervasive lack of theory-focused studies (Campebell, 2011; Whiteman et al., 2011). Most sibling studies focus on children who are 7 to 18 years of age (Refer to Appendix I), thus neglecting the adult population. However, young adults undergo significant transformation, seeking individuality and establishing independence from parents and siblings (Conger & Little, 2010). How these life transitions affect sibling relationships remains unanswered in the sibling literature (Cicirelli, 1996).

Because of such research gaps, this research project strives to address and redress some of the research gaps listed above. This project asks: what are the lived experiences of adult siblings who live with a sibling diagnosed with ASD in Saskatchewan? To answer this question, this research project, in addition to semi-structured interviews, employs photo-production as a tool with which to assist in dialogue during interviews and enrich each participant's story. Finally, the research project uses a family-ecological theoretical lens (Bronfenbrenner, 1995) that draws on siblings' experiences, and also looks at family variables, such as gender, sibling constellation, and parental involvement; all of which have the potential to impact the sibling bond (Volling, 2005). The next chapter will explore the research design, theoretical framework and methodology in further detail.
CHAPTER THREE: Research Design

This chapter will describe the theoretical framework, methodology, sampling and recruitment strategies, data collection procedures, data analysis, and ethical considerations for this study.

3.1 Theoretical Framework

3.1.1 Introduction. When conducting my literature review, I found that most sibling studies lacked a theory-based component (Refer to Appendix I). Theories provide valuable insight into how sibling relationships can change within one's environment over time (Campbell, 2011). Theory-focused studies are important to sibling literature because they have the potential to strengthen the investigation of sibling relationships, provide a model of organization, and offer perspective regarding the ways in which relationships function (Cridland et al., 2013; Whiteman, et al., 2011).

3.1.2 Family-Ecological Systems Theory. Bronfenbrenner (1995) believed that a child's development is influenced by those who surround the child's environment. It is important to note that in 1995, the family-ecological systems theory was renamed to bio-ecological systems theory (or bio-ecological paradigm) to emphasize that biopsychosocial characteristics, as well as the environment, fuel a child's development (Bronfenbrenner, 1995). In this project I continue to refer to Bronfenbrenner's family ecological systems theory as the 5 environmental systems, microsystem, mesosystem, exosystem, macrosystem, and chronosystem, play an intricate part in the way in which sibling relationships may evolve.
Family-ecological systems theory focuses on the entire system, not just parts of a system or on one individual (Kothari, 2011; Whiteman, et al., 2011). Families are hierarchically organized into interdependent, reciprocally influential subsystems (Whiteman, et al., 2011). The hierarchy includes: the individual, such as the child, mother, or father; the dyad, such as the marital or sibling relationship; and the triad, such as the parent-child relationship and the entire family system, which includes, but is not limited to, grandparents, aunts, and uncles (Whiteman et al., 2011). Subsystems, such as school and work, are other hierarchies that can have significant impact on the entire family (Whiteman, et al., 2011). It is important to examine all hierarchical levels as they can potentially affect family stability (Whiteman et al., 2011).

3.1.3 Systems Structures in Bronfenbrenner’s Theory. Family-ecological systems theory explores 5 circles, or layers that will impact a person's life. The layers are explored as 1) the person is responsible for his/her own actions within the environment 2) the person will adapt to each environment accordingly and 3) The environment consists of 5 different circles, including the micro system, mesosystem, exosystem, macrosystems and the chronosystems (Bronfenbrenner, 1977). These systems are significant to the sibling relationship and will be explored in further detail (Whiteman et al., 2011). (Refer to Appendix J).

3.1.4 Microsystem. The microsystem is a pattern of activities, roles, and interpersonal relations experienced by the developing person in a face-to-face setting (Bronfenbrenner, 1977). The relations between people happen in two ways: from the child, and towards the child. The parent may have influence on the child's behaviour; however, the child will also influence the parents' behaviour in a reciprocal exchange
(Harkonen, 2007). An example of a microsystem includes parents who incorporate both siblings into therapies when one child requires therapy, such as Speech and Language Pathology. When both sibling are involved, it is more likely that the sibling relationship will be close (Whiteman et al., 2011).

3.1.5 Mesosystem. The mesosystem is the second system of microsystems, and is comprised of a process that takes place when an individual is involved with two or more environments (Bronfenbrenner, 1977). These relations may include the home, school, and the workplace, where siblings adopt different ways of behaving towards one another in different settings (Whiteman et al., 2011). For example, in a therapy setting, a sibling may be forced to behave differently, acting as teacher to his or her Sibling diagnosed with Autism Spectrum Disorder (SWA). During this therapy time, the sibling complies with the rules of a therapy session, and treats his or her SWA with the utmost respect. However, during free time, the sibling may not comply with the rules and may avoid play with his or her SWA.

3.1.6 Exosystem. The exosystem is the third system of microsystems, and involves the linkage of one person to at least two or more different settings (Bronfenbrenner, 1995). For example, parents who work long hours may ask one sibling to care for a SWA. Although the sibling does not have direct contact with the parents’ workplace, the sibling is impacted because he or she must take on a caregiver role until the parent returns home.

3.1.7 Macrosystem. The macrosystem includes the micro-, meso- and exosystem characteristics of a given culture (Bronfenbrenner, 1995). For example, western culture focuses on individualism, where most people are competitive with one another
Due to this ideology, siblings may compete against one another for parental attention, and may become jealous of the other's experience (Whiteman et al., 2011). This impacts the entire system for the child, including the microsystem (the family relationships), the mesosystem (the school life where children may compete against one another for grades), and the exosystem (where siblings may compete against one another for their parent’s attention).

**3.1.8 Chronosystem.** The chronosystem extends the environment into a third dimension because it consists of individual change over time (Bronfenbrenner, 1995). For instance, a SWA may need to adapt to change within his or her environment when the older sibling moves away from home. The culture at home will change when the sibling leaves (change in one's microsystem). In turn, the mesosystem will change when siblings learn to do things on their own (such as going to school). The exosystem will also change, and parents may find that they need to hire someone to look after the sibling at home. Finally, the competition for parental attention will change as there is only one sibling living in the household. Furthermore, a spillover effect can occur when one system affects another system (Feinberg, Reiss, Neiderhiser & Hetherington, 2005; Pike et al., 2005). Spillover effects are based on the idea that, if one family member experiences stress, it will "spread and spill" to other family members, affecting each family relationship (Feinberg et al., 2005).

**3.1.9 Relevance of Family-Ecological Systems Theory.** This research project explored the dynamics within the participant's family (such as one parent households, and family stress) as well as environmental factors outside the family (agency supports and friendships) because they have potential to impact sibling relationships (Whiteman et al., 2011).
This project has highlighted important information for professionals to understand because individual psychological development, as well as behavioural adjustment, are not the only aspects to explore when working with a Sibling diagnosed with Autism Spectrum Disorder (SWA) (Whiteman et al., 2011). A practitioner who employs and understands the family-ecological systems theory approach could also focus on the school system, family system, and peer relationships when working with the sibling because there are circular rather than linear causes to an individual's support needs. As discussed before, there are few theory-focused studies in sibling literature, and much of the literature is quantitative in nature. The next section will emphasize the importance of choosing phenomenological methodology for this research project, given that phenomenology allows the nature of the problem to be investigated and provides an opportunity for participants to tell their story (Creswell, 2013).

3.2 Methodology

Sibling's voices lack representation in the literature on ASD (Bishop, 2012; Rivers & Stoneman, 2008). Siblings’ perceptions of support systems also remain unstudied (Boyd, 2002; Naylor & Prescott, 2004; Pitter, 2009; Smith, 2003). Examination of these two problem areas is best suited for a research approach that emphasizes the importance of understanding shared experiences (Landridge, 2007; van Manen, 1990).

I chose phenomenological methodology because I wanted to explore the nature of a particular experience for a group of individuals (van Manen, 1990). Questions in phenomenological inquiry are designed to maintain options for what will be discovered during the research process (van Manen, 1990). My research project focused on the
sibling relationship where one sibling is diagnosed with ASD. The lived experiences of siblings have not been captured within the existing research mainly because of the predominantly quantitative nature of studies (O'Laughlin, 2006; Welsh, 2011).

3.2.1 What is Phenomenology? Phenomenology examines participants’ diverse stories, and explores central and common themes from participants’ discussions (Creswell, 2007). This methodology involves the study of phenomena as they appear to individuals when they lay aside the customary understanding of that phenomenon (Gall, Gall, & Borg, 2007). Phenomenology draws on small sample sizes of approximately 5 to 20 people. The small sample size establishes a detailed and intensive analysis, which can focus on verbatim accounts (Larkin, Watts & Clifton, 2006).

Researchers approach phenomenology with two goals in mind. The first goal is to understand the participant's world, and describe how their experiences are meaningful. The second goal is to attempt to position the initial description within a wider social, cultural, and theoretical context in an attempt to provide “a critical and conceptual commentary upon the participants’ personal ‘sense-making’ activities” (Larkin, et al., 2006, p. 104). Two questions are answered through this process: 1) how is the phenomenon understood by the participant? 2) What does it mean for the participant to be part of the phenomenon? Researchers are provided with new insight into the phenomenon as questions are answered, and the essence of the phenomenon is captured.

Philosopher Edmond Husserl founded phenomenology (Richards & Morse, 2007). There are 5 main concepts Husserl formed about knowledge and how humans interact with the world. The first concept is intentionality, which looks at the underlying assumptions behind the focus of lived experience and perception in phenomenology
Langdridge (2007) stated that intentionality is the idea that when we are conscious, it is to be conscious of something; there is always an object of consciousness. The concept of intentionality leads to the phenomenological assumption that research should focus not on cognition, but rather on the interaction between internal perception and the experience of our world (Langdridge, 2007).

Noema (what is experienced) and noesis (the way it is experienced) is Husserl's second concept of phenomenological research. This concept argues that what is experienced will always be influenced by the way it is experienced, and that perceptions of experience will differ according to context (Husserl, 1963/1913).

The third concept is bracketing, or epoche. Bracketing refers to how researchers must suspend prior knowledge to clearly perceive a phenomenon (LeVasseur, 2003). Once researchers remove themselves, they can understand their own preconceptions and learn the participant's true meaning of experience (Larkin et al., 2006). Although it is believed that bracketing is beneficial to phenomenological research, some researchers believe that bracketing cannot be done because it is difficult to completely eschew one's knowledge (LeVasseur, 2003). As an aside, bracketing was quite difficult during the course of this research project. I was able to understand my participants’ views through the context in which they experienced it. However, I could not fully bracket my knowledge and perceptions due to my clinical experience and familiarity with current sibling literature.

The fourth concept that forms the basis of phenomenology is the reflexivity of the researcher. This concept holds that knowledge is co-constructed between the researcher and participant (Langdridge, 2007). As an active participant, the researcher
must continually evaluate one’s own biases, assumptions, and choices throughout the research process. As an active participant, it was difficult to put my biases aside when interviewing participants. Because of my role as a consultant at Autism Services, and considering the amount of sibling research I conducted, I continually evaluated my actions, and how I questioned my participants so that my participants' experiences were not misinterpreted.

To ensure that participants' experiences were not misinterpreted, they had the opportunity to review their transcripts and retract any statements that they felt might jeopardize their privacy. The ability to review their transcript document increased the credibility of this research study (Gall et al., 2007). In addition, participants had the opportunity to add more information to augment their transcripts if they wanted. All participants changed some aspects of their transcripts so that they were accurate. All participants signed a transcript release form after the first and second interviews. (Refer to Appendix G). Participants also signed a photography release (Refer to Appendix H) form so that pictures could be included as visuals in this research paper.

Essence is the final concept of phenomenology. Essence contends that the individual experience is not just a piece of information; the experience is an expression of the essence itself (Langdridge, 2007). Furthermore, phenomenology seeks the description of the essence of the phenomenon, focusing on common themes and experiences across participants (Creswell, 2007).

3.2.2 Max van Manen's Hermeneutic Phenomenology. Van Manen's phenomenological methodology is incorporated into this research project because it attempts to go beyond a descriptive focus, attaining a more interpretive understanding of
the phenomenon. Van Manen proposed 6 basic steps to phenomenological research, including: (1) studying a phenomenon that seriously interests us and commits us to the world; (2) investigating an experience as we live it rather than as we conceptualize it; (3) reflecting on essential themes that characterize the phenomenon; (4) describing the phenomenon through the art of writing and rewriting; (5) maintaining a strong and oriented relation to the phenomenon; and (6) balancing the research context by considering parts as whole (Landridge, 2007).

Phenomenology was an appropriate methodology within which to frame this research project because phenomenology allows the nature of the problem to be investigated, allows the researcher to discuss her personal experience, and provides an opportunity for participants to discuss their story (Creswell, 2007). During the interview process, I was able to become more knowledgeable about the sibling phenomenon. I also used photos as a tool with which to provide richness to my understanding of each sibling relationship. For example, in conducting the first set of interviews, it was difficult for some of the participants to open up about their experiences. However, by the second set of interviews, participants brought photographs that reflected their sibling story. This provided me more knowledge and insight into the sibling relationships. Participants also opened up and disclosed more personal stories as they spoke about how their photographs reflected their sibling relationships.

3.3 Sampling and Recruitment Strategies

Participant recruitment occurred over a 6-month period between February 26 and August 26, 2014. The following discussion outlines how I recruited 5 participants, three men and two women ranging in ages from 19 to 26 years.
3.3.1 Sampling Strategies. The population of interest for this research project was defined as individuals who currently live, or have lived, with their sibling diagnosed with Autism Spectrum Disorder (ASD). There were two required criteria to participate in this study. The first requirement was that the participant must be 18 to 30 years of age. Second, the participant must have lived with their sibling, who is diagnosed with ASD.

In the first few months of recruitment, no participants came forward. On April 21, 2014, the Regina Ethics Board approved my study criterion to include adults of any age (Refer to Appendix M). Adults were selected for this study because I wanted to ensure that my participants would be able to reflect on their past experiences. The reflection process was an important feature of this project; participants were asked to talk about their past, both verbally and through the use of pictures, so that I could develop a greater understanding of what it is like to grow up with a Sibling diagnosed with Autism Spectrum Disorder (SWA).

Relatively small samples are generally used in phenomenology due to the time consuming nature of the analytic process (Langdridge, 2007). In keeping with the research method, I used purposive sampling because it is necessary to gather participants who have experienced a specific phenomenon (Langdridge, 2007). Purposive sampling occurs when a researcher believes that a particular group or population will represent the research goals (Rubbin & Babbie, 2005). For example, I included only adult siblings who have a SWA in the recruitment for this study because there is a dearth of research around this population. I also wanted to include participants who could reflect on their sibling relationship in a mature manner.
3.3.2 Recruitment Strategies. In order to recruit 4-8 participants who satisfied the criteria for the research project, a poster invitation was designed and displayed at the University of Saskatchewan campus, the University of Regina campus, as well as various health agencies’ bulletin boards. Health agencies included Child and Youth Mental Health Services, Mental Health and Additions Services, Alvin Buckwold Child Development Center, and Autism Services Adult Group Homes (Refer to Appendix A). Health professionals within these agencies were also asked to provide information about the study to clients; however, clients determined if they wanted to participate by contacting me directly once they had been provided with the information about the study. Recruitment at Autism Services, Saskatoon Autism Intervention Program was prohibited, as I currently work for said agency, and recruitment through this department of Autism Services, Autism Intervention Program was considered a conflict of interest. Because I identified only two participants via poster invitation, on July 3, 2014, the University of Regina Ethics Review Board once again approved my study amendment so that I could include on-line recruitment (Refer to Appendix N). This recruitment strategy provided me with more opportunities to seek participants for my study.

Once participants initiated contact via email or telephone, I contacted the potential participants via telephone, and administered a screening interview (Refer to Appendix B) in order to ensure that the individual met the criteria. At first, I found it difficult to plan and schedule interviews because participants wanted to communicate via text or email. I needed to ensure that participants’ confidentiality was protected as per the ethics approval process, and therefore decided that texting and email would be eliminated prior to conducting this study. However, avoiding technology is difficult, and
as the process continued the University of Regina Review Ethics Board approved the amendment to my research project to include correspondence with participants via texts and e-mails (Refer to Appendix O). Participants were notified that e-mails and texts might not always remain confidential. If a breach of confidentiality occurred, I advised participants that I would immediately make efforts to address the issue by contacting the individual who had mistakenly received the confidential information. That individual would be asked to delete the text or e-mail immediately. At this time, I would contact the participant directly to inform them of the breach of information. It is important to note that throughout the recruitment and participation process, there was no breach of confidentiality that occurred where I was required to follow the steps outlined above.

3.4 Data Collection

During recruitment, participants were informed of two tools that would be used to collect the data: interviews and participant derived photographs.

3.4.1 Interviews. The most common method of data collection in phenomenological research is the verbal interview (Langdridge, 2007). A semi-structured interview (Refer to Appendix E) was conducted at a time and place that was convenient for each participant. Participants were interviewed on two occasions, and interviews lasted approximately 30-90 minutes. During the first interview, participants were asked to share their stories about their Sibling with Autism Spectrum Disorder (SWA). The first interview allowed me to capture the participants’ experience; however, during the second interview, I was able to obtain richer and more meaningful data regarding the experiences of growing up with a Sibling with Autism Spectrum Disorder (SWA). The second interview also afforded opportunities for both the participants and I
to reflect on the first interview. I was able to ask questions about the first interview, and participants were able to share deeper and more nuanced insights about their stories. With participants’ permission, an audio recording device was used to record the interviews, so as to ensure that their words and experiences were accurately captured. Research questions focused on individual participant’s experiences, feelings, beliefs, and attitudes about growing up with a SWA.

3.4.2 Photo-production. Photo-production is an inexpensive and effective method of gathering data from populations that can create unique opportunities for participants to discuss abstract ideas (White, et al., 2010). During the first interview, participants shared information about their sibling experiences. At the end of this interview, participants were provided with photo-production "homework" prior to the second interview. As part of this homework assignment, participants were asked to take approximately 10 photographs that they believed captured the meaning of their sibling relationship. Each participant was provided with a disposable camera, or, if preferred, used their personal camera to take photographs. Participants were also asked to print their pictures, or email them to me so that I could print the pictures for discussion during their second interview. Participants were reimbursed for any costs associated with printing photographs. As part of the research project consent process, participants provided consent to have the pictures included in the final report as a way to enrich the exploration of their stories and other information that they shared for the purposes of the project.

Photo-production for this research project was used solely as a tool in the interview process, and the photographs, were not analyzed in the data. The photographs were used strictly to encourage dialogue during the interview process, and to enhance
rapport-building between researcher and participant. I chose photo-production as a tool after I read Latta and colleagues’ (2013) article on sibling relationships. In their work, they used photo-elicitation to facilitate communication between children and health-care professionals (Latta et al. 2013). In this way, this process in this research project is similar to their process because participants in their study also took pictures that depicted the essence of their sibling relationships (Latta et al., 2013). This creative strategy acted as a tool to encourage the participants to open up about their experience, and for the researcher to develop a richer understanding of their stories.

Photo-production can be an important aspect of the research process because it enhances the relationship between researcher and participant (Rose, 2012). For example, photo-production can prompt discussion about a variety of topics, in different ways, and also can assist participants in discussing and reflecting on everyday activities. This process allows participants to articulate thoughts and feelings that typically remain unspoken (Prosser, 2011; Rose, 2012). Lastly, photo production empowers participants to be the 'expert' of the interview, because their voices explain images to the researcher thus enhancing their power position in the process (Prosser, 2011; Rose, 2012).

It is important to note that photo methods have been previously used in other studies in conjunction with phenomenological inquiry to evoke emotions, abstract ideas, and a shared human experience (Hodges, Keeley & Grier, 2000). Researchers view photographic methods as a means by which to contribute to, and develop, knowledge that matters to participants and to one's practice (Hansen-Ketchumew & Myrick, 2008; Macarow, 2010). This is further illustrated in Macarow's (2010) study, where she writes about photo essays that capture the experience of the lives, roles, resilience, migration,
and opportunities for victims of the holocaust in the Jewish Diaspora. This section explored the data collection process; the next section will explore how I analyzed the data collected throughout the interview process.

3.5 Data Analysis Process

In a hermeneutic phenomenological study, analysis and data generation occur simultaneously (van Manen, 1990). As a result, I manually transcribed the interviews in order to allow for ongoing analysis and reflection on themes throughout the data generation process. As each interview was manually transcribed, participants were provided with copies of their written transcripts in order to review for accuracy, either physically or by mail if they lived out of town. A self-addressed stamped envelope was provided to participants so they could mail any changes or additions to their transcript. Finally, each participant signed a "release of information" form once they were satisfied with their transcripts that were manually transcribed (Refer to Appendix G).

During the data analysis process, I read and re-read each transcript. Significant phrases and quotes were noted in the margin of the paper so that I could begin to identify categories (Langdridge, 2007). Emerging themes were then noted in the margins of the paper so that I could pull together the "greater meaning" of this phenomenon (Langdridge, 2007). Stage three involved listing several sub-themes so that I could organize and re-organize the similarities and differences within each category (Langdridge, 2007). Finally, a master diagram was designed that was representative of all of the participants. The next section, thematic analysis, will go into further detail of the analysis process.
3.6 Thematic Analysis

The purpose of a thematic phenomenological analysis is not to describe the specifics of each individual’s account, but rather to decipher meaning from all of the accounts collectively (van Manen, 1990). This process has been described as exploring the essence of one situation (van Manen, 1990). In this research project, the aim of the thematic analysis was to discover themes from the participants’ stories which best represent the overarching meaning of their experience of having a sibling with ASD.

Data analysis within this research project took a holistic approach to discover themes and parts as a whole (van Manen, 1990). I completed the thematic data analysis without the use of qualitative software, such as Nvivo10 in order to develop fluency with each participant's story (Ziebland & McPherson, 2006). First, I used a selective approach by reading and re-reading the data, and searching for similar sentences (van Manen, 1990). During this process, I found several thematic sentences in each participant's data set, and overarching themes began to emerge. After themes emerged, I re-read the data to examine any phrases that might capture the meaning of each story (van Manen, 1990). Third, I manually analyzed each sentence using a reflective journal during the interview process and asked, "What does this reveal about the phenomenon?" (van Manen, 1990). Last, I took notes and penned ideas in my journal throughout the transcripts, rather than at the end of the analysis as a way to reflect and gain insight into this phenomenon (van Manen, 1990).

The process of analysing and re-analysing appealed to me because I was able to clarify ideas and develop a clearer understanding of the phenomenon. The data analysis process was time-consuming and tedious; however, it allowed me to gain an appreciation
for each participant’s story. In addition, I started to understand that there were more complexities and layers within each individual story, and within each theme that emerged. I reviewed the data numerous times to reach an understanding of the overall essence of this phenomenon, the sibling experience of having a Sibling diagnosed with Autism Spectrum Disorder (SWA). The participants were important during the data analysis process. I paid careful attention to the participant's feelings because the memories that they reflected on seemed difficult to talk about. I ensured that participant's thoughts and feelings were kept confidential. The ethical considerations of this project will be discussed in further detail in the next section.

3.7 Ethical Considerations

There were several important ethical considerations to consider throughout this research project. The ethical considerations were pertinent when considering participants, research methods, and data analysis. The next section will speak to the participants of this study, including the process for recruitment, as well as safety precautions.

3.7.1 The Participant. In accordance with the research requirements of the University of Regina, an ethics application was submitted for approval to the Behavioural Ethics Review Board. The University of Regina Ethics Review Board approved this study on February 26, 2014 (Refer to Appendix L). All information regarding conflict of interest, participant recruitment, informed consent, data storage, and safety precautions taken throughout the study are outlined in more detail in the ethics application. Prior to the initial interview, participants were asked to sign a consent form (Refer to Appendix F) and were advised that they could decline participation, or
withdraw from the research project at any time. Participants were informed that they did not need to answer questions about which they did not feel comfortable. I paid close attention to the participants, ensuring they did not show signs of discomfort potentially related to this during the interview process. I also provided study participants with information about counselling services in the event that they experienced emotional hardship as a result of their participation in the study (Refer to Appendix D). Prior to any data collection, informed consent was obtained from participants (Refer to Appendix F), and participants were provided with the opportunity to ask questions about the research and the research process. Ethical considerations about photographs, a tool used during the interview, will be emphasized in the next section.

3.7.2 Photographs. Any research study using visual research methods must be appropriately developed in an ethical manner (Rose, 2012). Therefore, I paid considerable attention to what was required to protect the participants' right to confidentiality and anonymity. In order to protect such rights, participants were asked to refrain from taking pictures of people and items that may infringe copyright. For example, if a participant took a picture of their sibling or their house, it may not protect the privacy of the participant. Infringing copyright is a broad term, but it can be an ethical issue because copyright owners may be the only individuals who legally have access to re-produce the desired item (Canadian Intellectual Property Office, 2015). Therefore, participants were asked to cover up any logos when taking photographs. When participants shared their photographs with me, they signed a consent form so that the photographs could be included for visual purposes in the final report (Refer to Appendix H).
3.7.3 Confidentiality. Confidentiality is defined as the ability to keep information private, whereas anonymity is the ability to keep an individual unidentifiable (Canadian Association of Social Workers (CASW), 2005b). There are ethical considerations regarding anonymity within this proposed research study because the Autism Spectrum Disorder community in Saskatchewan is small, and individuals could recognize who the participant is once his or her story is told. When I met with participants, we discussed that anonymity may be difficult to maintain, as some readers may recognize the participant's stories. Thus, in an attempt to maintain confidentiality, participants were provided with pseudonym names, and pictures of people – including participants, their friends, family, siblings, and strangers – were prohibited. Participants were also asked to refrain from taking pictures of their houses and streets in which they live or have lived because these pictures could have the ability to identify study participants.

Confidentiality was important for me to maintain because of my employment. However, when it came to recruitment of the participants, my biggest concern was the potential for a conflict of interest. Conflict of interest is highlighted in the next section.

3.7.4 Conflict of Interest. I was very concerned with the possible conflict of interest when interviewing participants because I currently work with individuals who have ASD, and thus I needed to be very cautious when recruiting participants. For example, I ensured that I had not provided support or services to any of the participants prior to carrying out any research with them. During the research process, I did not share emerging study results with colleagues and friends, because I worried that someone may know one of my participants. I attempted to maintain the confidentiality of study participants at all times.
3.8 Conclusion

This chapter described the theoretical framework, methodology, sampling and recruitment strategies, data collection procedures, data analysis, and ethical considerations for this research project. It was important for me to ensure that there was a theoretical framework in place, as several sibling studies lack theoretical context (Cridland et al., 2013; Rossiter & Sharpe, 2001; Whiteman et al., 2011). It was also important for me to utilize a methodology that captured the essence of the phenomenon so that participant's voices were represented (Bishop, 2012; Rivers & Stoneman, 2008). I was able to remain close to the data throughout the analysis process by manually transcribing the interviews. The ability to manually transcribe this data allowed me to become more aware of the potential themes and categories of each phenomenon. Lastly, I paid careful attention to the participants of this project by following ethical guidelines during recruitment. I ensured it was not a conflict of interest to interview the participants, and I maintained their confidentiality at all times. The next chapter will refer to the results of the research project using the individualized stories of the participants.
CHAPTER FOUR: Research Findings

4.1 Introduction

The purpose of this research project was to investigate individual experiences of young adults, who live with a Sibling with Autism Spectrum Disorder (SWA) in Saskatchewan. This chapter discusses the results of the research using the individualized stories of the 5 participants. This data will be presented in two separate sections. The first section presents the context of the individual participants' stories; the second section discusses themes and subthemes that provide meaning to the lived experiences of growing up with a SWA. Pseudonyms are used throughout to protect the confidentiality of the 5 participants. All participants were given the opportunity to choose a pseudonym name; four individuals chose their own pseudonym name, while one individual did not; thus I chose a pseudonym for that individual participant.

4.2 Context

Phenomenology places emphasis on providing in-depth detailed accounts of individual experiences (Smith, Larkin, & Flowers, 2009), with the goal of uncovering the essence of the experience. Thus, a brief description of each of the 5 participants will be provided in order to determine whether or not the specific elements of the phenomenon, the experience of living with or have lived with a Sibling with Autism Spectrum Disorder (SWA), are similar across each participant’s life contexts.

4.2.1 Participant 1: Natalie. "I can't imagine my life without my sibling" (Natalie). Natalie is 26 years old and is the eldest sibling in her family. She has one younger brother who was diagnosed with Autism Spectrum Disorder when he was 5 (Natalie was 12).
Natalie describes her relationship with her brother as strong now; however, she found it difficult while growing up. Natalie indicates that her brother’s adoption was a difficult transition, as previously it had been just her and her parents. Natalie reported that she experienced several family changes when she was younger, including her father moving out of the home, and a stepfather coming into her life. Natalie said that it was difficult to find time alone with her mother due to her brother's high medical needs.

As Natalie matured, she found that she became closer to her brother. Natalie often advocated for her brother's needs, protected him like her own child, and coached her brother through various activities such as shopping, ordering food, and self-care skills. Natalie proudly reported that her brother is "the most caring person in the entire world," and that he provided a different perspective of the world and of the people that lived in it.

4.2.2 Participant 2: Aaron. "He's always been part of my life" (Aaron). Aaron is the youngest sibling in his family. He has two older brothers; at a young age, the eldest brother by six years was diagnosed with Asperger syndrome, a form of Autism Spectrum Disorder that affects children and adults with social interactions (Autism Speaks, 2015). People who are diagnosed with Asperger Syndrome often have one of the following behaviours: limited or inappropriate social interactions, "robotic" or repetitive speech, challenges with nonverbal communication (gestures, facial expression, etc.) coupled with average to above average verbal skills, tendency to discuss self rather than others, inability to understand social/emotional issues or non-literal phrases, lack of eye contact or reciprocal conversation, obsession with specific, often unusual, topics, one-sided conversations, and awkward movements and/or mannerisms (Autism Speaks, 2015).
Aaron lived with his mother and father in a city in Saskatchewan, prior to attending university in Ontario. His father worked out of the home, while his mother took care of the home and the children. Aaron describes his relationship with his oldest brother as "surprisingly normal" indicating that he and his brother "just do things together like guys".

4.2.3 Participant 3: Charlotte. "It's not an easy sibling relationship, I don't know what one [sibling relationship] looks like" (Charlotte). Charlotte is the eldest of two children. Charlotte’s younger sister was diagnosed with Autism Spectrum Disorder at a young age. Charlotte goes to school in Winnipeg, where she currently studies Social Work. Prior to beginning university, Charlotte lived in a rural Saskatchewan community with her mother and father. Charlotte's father worked out of the home, while Charlotte's mother looked after the children. Charlotte describes her sibling relationship as difficult and different, noting that her sister would often become aggressive because she did not have the ability to vocally express herself. The aggressive behaviours became too much for the family after one incident where a family member was hospitalized. Following this situation, the family decided it would be best if Charlotte's sister moved into a group home. Charlotte said that she now has a good relationship with her sister, despite her sister's aggression and tantrums. Charlotte expressed that even though she and her sibling have limited vocal communication, they still have a sibling relationship, and she helps her sister as much as possible: "We love each other the best we can."

4.2.4 Participant 4: Shawn. "There's no way I would be the person that I am today without having grown up and having [my] sibling in my life" (Shawn). Shawn's mother and father adopted Shawn and his three siblings, and Shawn is the second eldest
of four children. He has one older brother, one younger brother, and one little sister. His mother and father lived in a rural Saskatchewan community, and both worked outside of the home when Shawn was growing up. Shawn's younger brother was diagnosed with Autism Spectrum Disorder at a young age. Shawn indicated that when his brother was younger, the sibling relationship was difficult due to his brother's behaviour; however, as Shawn matured, their relationship evolved.

The more challenges that I tackle, or help [my] sibling tackle, the cooler it is for me because I just have more notches on the story belt, to be like hey, don't underestimate any kid with a disability because their potential is ridiculous! (Shawn).

4.2.5 Participant 5: David. David was born in the United Kingdom and moved to a mid-sized city in Saskatchewan when he was eleven with both of his parents. David's father worked out of the home, while his mom worked in and out of the home, while caring for both children. David was born with cerebral palsy, spastic diplegia feature with a hint of ataxia. Cerebral palsy is a neurological disorder that appears in infancy or early childhood and permanently affects body movement and muscle coordination (National Institute of Neurological Disorders and Strokes, 2015). There are nine forms of Cerebral Palsy, and David's form affects his coordination, where balance and posture are involved (My Child, 2015). David is two years older than his sister. His sister was diagnosed with Autism Spectrum Disorder when she was younger. David reports that he went to several medical appointments for himself, as well as for his sister.

David indicated that when he was younger, it was difficult having a relationship with his sister because of her tantrums; he also expressed that he experienced difficulties
coming to terms with his own disability. Over the years, David developed a friendship with his sister, reporting that "My sister is my sister, and it is my job to be a good brother when I'm around."

In summary, the brief descriptions of the 5 participants helped to determine whether or not the specific elements of the phenomenon, the experience of living with a Sibling with Autism Spectrum Disorder (SWA), were similar across each participants’ life contexts. Although each experience was unique, all participants had similar themes and subthemes found in the data analysis. The next section will discuss the themes and subthemes that emerged from the data.

4.3 Being the Sibling Diagnosed with Autism Spectrum Disorder

As participants shared their individual stories, primary themes and subthemes emerged from the data. In hermeneutic phenomenology, the word “theme” is used to represent the many pieces of meaning, which come together to form human experience (Wood, 2010; van Manen, 1990). A different relationship, but it is not one that is less became the central underlying meaning of the experience, or the essence, shared within the different lived experiences of the study participants (Creswell, 1998). The essence was impacted by major themes identified throughout the analysis, including: (1) Challenging experiences, and (2) Positive experiences (Refer to Figure 1). Two subthemes that emerged from the major Challenging experiences theme were the diagnosis and complex and layered. Two additional pieces of meaning or common elements within the diagnosis subtheme include: when participants were 'younger’ and ‘communication’. The complex and layered subtheme also contained three additional pieces of meaning or common elements: ‘the family composition,’ ‘sibling birth order,’
and ‘paid employment;’ these three common elements are integral to the understanding of how the subtheme of complex and layered may have impacted the sibling relationship (Refer to Appendix U). The other major theme, Positive experiences included two subthemes: reciprocity and bonding (Refer to Figure 1).

Figure 1. Diagram of Study Themes. This figure illustrates the themes and subthemes that emerged from the data.
4.4 A Different Relationship, but it is Not one That is Less

"A different relationship, but it is not one that is less" emerged as a common thread among all participants. Each participant expressed that although their sibling relationship was different, due to communication challenges, it was never less valuable than other sibling relationships; in fact, the sibling relationships were explained as positive. Aaron, for example, said that his brother had difficulty interacting with other people. However, as Aaron got older, he believed that despite the communication challenges, the relationship was "pretty normal" (Aaron).

Natalie, like Aaron, admitted that her sibling relationship was different. Natalie reported that when she was younger, her brother had difficulty communicating his needs. Natalie also did not understand why her brother was resistant to change. For example, Natalie recollected a time where she and her family went for supper. When they went for supper, they could only go to one restaurant because her brother would become distressed with any changes in his regular routine. Natalie's understanding of her brother's behaviours became more accepting as she got older, and Natalie reported that with time, she and her brother became close friends.

Shawn echoed Natalie and Aaron's message during his interview, indicating that he and his brother had a complex relationship when they were younger; and as Shawn got older, he was able to form a positive relationship because he understood more about the diagnosis of Autism Spectrum Disorder. Shawn also had positive support from family, friends and peer support groups. During one of the interviews, Shawn was asked to explain how a picture of his brother's hands (Refer to Appendix T), was a metaphor to
that of his sibling relationship; *it is a different relationship, but it is not one that is less* because:

It’s like hands, you can't ... there's not another relationship like me and [my] sibling's. There's ones that have certain similarities, but there's no relationship that's exactly like me and [my] sibling's, and there will never be anybody who can take that away from us. And it's a beautiful thing (Shawn).

Charlotte and David also indicated that they had a unique and beautiful relationship with their siblings. Both of Charlotte and David's siblings were younger sisters, who had limited vocal communication. Despite the communication challenges, Charlotte and David developed meaningful relationships with their siblings with Autism Spectrum Disorder (SWA). Charlotte said that although her sibling could not vocally communicate her needs and wants, they were still able to participate in the same activities as other siblings might: "We still would do that [play in the playground] together, even though [it] may not be the same as others [relationships]. We still used to play together and have our times of hanging out like normal kids would" (Charlotte).

Similarly, when David was asked about some of the positive aspects of having a sibling with Autism Spectrum Disorder (SWA), he responded by saying that it "changes the dynamic immensely, but you still have a sister." David understood that his sibling relationship was different, and noted that although his sister may never be able to live on her own, he believed that he and his sibling shared a meaningful bond, and appreciated the fact that he had a sibling.

*A different relationship, but it is not one that is less* emerged as the essence in this research project. All participants echoed that their sibling relationship was difficult
when they were children. When reflecting on the difficult relationship, participants spoke of the challenges they had socializing and communicating with their sibling. Participants also spoke about their siblings restricted and repetitive behaviours. The participants also had difficulty understanding the diagnosis of Autism Spectrum Disorder (ASD) when they were young. As the participants matured, they began to more fully understand and accept the ASD diagnosis of their siblings. The participants’ ability to self-reflect found each of them describing their relationship as different, but overall, a positive experience. Thus, two major themes emerged from this research project: (1) *Challenging experiences* and (2) *Positive experiences*. These major themes, as well as the subthemes within the major themes and the corresponding common elements within specific subthemes will be discussed in further detail.

### 4.5 Challenging Experiences

Throughout the course of the interviews and during the data analysis process, it became evident that participants described their sibling relationship as *challenging*. What struck me about the *challenging experiences* was how participants reflected on the challenges, as well as how they worked through their challenges with family members and friends.

Subthemes that emerged from the major *challenging experiences* theme were the *diagnosis* and *complex and layered*. Two common elements within the *diagnosis* subtheme included: ‘when participants were younger’ and ‘communication.’ The *complex and layered* sub theme contained three common elements: ‘the family composition,’ ‘sibling birth order,’ and ‘paid employment;’ these three common
elements are integral to the understanding of how the theme of *complex and layered* may have impacted the sibling relationship.

4.5.1 The Diagnosis. Participants reported that when they were young, they did not understand Autism Spectrum Disorder (ASD), and how ASD could impact their relationship with their sibling. This lack of understanding created challenges for them in learning how to bond and communicate effectively with their siblings.

Autism Spectrum Disorder (ASD) is the most severe developmental disability that appears in the first three years of life (American Psychological Association, 2015). The disorder involves challenges in social communication, social interaction and restricted, repetitive patterns of behaviour, interests, or activities (Autism Consortium, 2011; American Psychological Association, 2015). ASD is a single spectrum; however, individuals vary in terms of the severity of ASD symptoms, patterns of onset and clinical course, etiologic factors, cognitive abilities, and associated conditions (American Psychiatric Association, 2013).

The participants experienced difficulty socializing and communicating with their sibling. They also did not understand why they had to complete the same routine, such as going to the same restaurant, or why their sibling only spoke of their interests and activities, such as gaming systems. Charlotte and her sibling appeared to have the most difficulty communicating, as she mentioned that one of the only ways she was able to communicate was by saying "hi" and giving her sister a high-5 (Refer to Appendix Q). Charlotte also reported that her sister had aggressive behaviours, where she would bite her shirt, or bang her head against the wall as a way of expressing her needs. Charlotte
reflected during the interview, saying that she often asked her family why her sister could not "get better."

Aaron echoed Charlotte's question, wishing that he would have known more about Autism Spectrum Disorder (ASD) when he was younger. Aaron spoke about his brother’s restricted behaviours and how they impacted their sibling relationship. Aaron indicated that his brother was smart; however, Aaron found that having a conversation with his brother was a challenge. For instance, Aaron said that their conversations usually revolved around logical things, such as math or science, and that he could not joke around with his brother because his brother usually did not understand the joke.

As the participants got older, they advised that they became more knowledgeable about Autism Spectrum Disorder (ASD). Natalie reported that her mother told her why her brother had ‘quirky’ behaviours on a daily basis, while Charlotte and Shawn expanded their knowledge of ASD when they participated in sibling support groups. Charlotte indicated that during one group session a video was played, and this is when she began to fully understand what ASD meant.

Understanding ASD helped the participants learn how to communicate in a different manner with their sibling. For instance, when Charlotte and her parents visit her sister, her sister smiles and says, “Mom, Dad, Charlotte, fries" (Charlotte) (Refer to Appendix Q). Charlotte expressed that this form of communication indicates that her sister is happy. She explained that, "Even though she can’t say I love you, there's times when she's excited to see me so that's always a plus" (Charlotte).

David also reported that although it was difficult to communicate with his sister, he learned that you do not need to use vocal communication to develop a sibling
relationship. David reflected about a time where he admired his sister's receptive language:

One day, I had split up with my girlfriend, and she walked over and I looked sad, I guess. It was funny because you think of autistic kids as not having a perception of facial stuff. She took her fingers and was trying to push my muscles into a smile (David).

In summary, although participants developed other ways of communicating with their sibling, their sibling relationship was still challenging due to the characteristics of Autism Spectrum Disorder (ASD). ASD is a challenging diagnosis and it impacts an individual's ability to socialize and communicate (Autism Consortium, 2011). As individuals develop awareness, like the participants of this study, they are better able to adapt and explore unique ways to communicate with someone who is diagnosed with ASD (Autism Society, n.d). Furthermore, participants found that as they matured, they were able to overcome the communication challenges with their siblings; this enabled them to be able to develop and maintain a positive sibling relationship.

4.5.2. Complex and Layered. The sibling relationship was challenging because the family was complex and layered. Within this subtheme, three common elements of ‘family composition’, ‘sibling birth order’ and ‘paid employment’ (Refer to Appendix K) are explored. These three common elements are integral to the understanding of how the theme of complex and layered may have impacted the sibling relationship.

'Family composition' is the first common element of the complex and layered subtheme. One participant expressed that he was adopted, and one participant said that her brother was adopted. For example, Natalie explained that she had the most difficulty
accepting her brother in her family, indicating that the transition was challenging, and that she did not receive the attention from her parents that she was used to. Thus, Natalie developed jealousy and resentment towards her brother, and these feelings impacted her sibling relationship. It is important to note that jealousy is a common feeling for siblings, especially when a family welcomes a second child (Volling, 2005). Jealousy can occur if the sibling is adopted or enters the family via birth (Volling, 2005). Natalie not only found that her parents spent more time with her brother during this transition, but she also found that her parents focused on her brother's medical needs. Natalie, at this time, did not understand what her brother's medical needs were, and this lack of awareness further cemented the negative feelings Natalie had about her brother.

David, like Natalie, also did not form a strong bond with his sister initially because he had to overcome his own challenges, and accept his own disability before he could truly understand his relationship with his sister. David noted that his parents took him to various doctor appointments, and suggested that his parents did “double duty” because they had to help both of their children. David said that when he was younger he was not able to develop a positive relationship, nor reflect maturely about his relationship with his sister until he was able to understand and accept his own diagnosis: “I think I could probably reflect on it better now. I don't think I could have had this conversation at 15 or 16” (David).

‘Sibling birth order’ is the second common element within the subtheme of complex and layered. Charlotte, Natalie, Shawn and David reported that they were the eldest sibling in their family. Being the eldest added to the complexity of their sibling relationships because they took on more responsibility for their sibling, and worried
about the care of their sibling, as well as their siblings’ future. Natalie and Shawn advised that they cared for their sibling, and this responsibility impacted their ability to connect with their peers. Natalie, Shawn, Charlotte and David also worried about their sibling, advising that they worried about the care of their sibling, if their sibling could find employment in the future, and questioned who would look after their sibling when their parents were no longer able to. Furthermore, these participants found it very difficult to formulate a bond that was reciprocal in nature because they acted as parents. Aaron, on the other hand, was the youngest sibling, and reminisced that his sibling relationship was relaxed because he did not take on a caring role for his brother when he was younger.

‘Paid employment’ is the third and final common element within the subtheme, complex and layered, that influenced the sibling relationship. Both Natalie and Shawn's parents worked outside of the home, while Charlotte, David and Aaron's mom worked at home, while their fathers had paid employment outside of the home. Shawn and Natalie advised that because their parents worked, they provided care for their sibling. Charlotte, David and Aaron's mothers stayed at home, and consequently they had fewer caring responsibilities for their sibling. The notion of ‘parents' paid employment' make the dynamics of the sibling relationship more complex because it may have an impact on older siblings’ care giving responsibilities for their younger brothers and sisters and thereby promote complementarity rather than egalitarianism in sibling roles (Whiteman et al., 2011). These sibling roles will be discussed further in Chapter 5 (Refer to Appendix K).
In summary, *complex and layered* is the second subtheme within the major theme of *Challenging experiences* that created an often demanding sibling relationship for each of the participants. The complexity and layered aspect of the individual participant challenging experiences of having a Sibling with Autism Spectrum Disorder (SWA) was situated within the three common elements of ‘family composition,’ ‘sibling birth order,’ and ‘paid employment.’ It is important to understand that families have different complexities and layers; however, the uniqueness of each participant's story demonstrates how participants view their sibling experiences as *challenging* and *positive*. *Positive experiences* are the second major theme that is shared amongst the participants, and this theme will be discussed in further detail.

### 4.6 Positive Experiences

The major theme of *Positive experiences* was echoed by all participants, suggesting that just having a sibling is positive in and of itself. Participants expressed that there still are challenges with their adult sibling relationship, but the *positive experiences* definitely outweighed any of the negative experiences that they recalled having as children with a Sibling diagnosed with Autism Spectrum Disorder (SWA). The major theme, *Positive experiences* has two subthemes that will be explored: (1) *reciprocity*; and (2) *bonding*. The subtheme of *reciprocity* refers to how each sibling developed a new perception about life, and an appreciation and understanding for their sibling. The subtheme of *bonding* speaks to how participants spent time with their sibling so that they could foster a positive sibling relationship.

#### 4.6.1. Reciprocity

All participants found ways to help their siblings, and this assistance appeared to foster positive relationships. Aaron and Natalie, for example, were able to help their brothers by providing life skills, such as building collegial relationships.
and developing comfort in various social settings. Aaron said that one summer he and his brother worked at the same employment center so that he could teach his brother to socialize in the work place. As Aaron reminisced, he smiled and said that he has been able to help his brother in social settings; however, the relationship was very much reciprocal in nature because Aaron's brother's strengths helped Aaron understand challenging concepts, such as math, science, and more importantly, Autism Spectrum Disorder (ASD).

In-between interviews, Aaron asked his brother to explain what it is like to have ASD. Aaron reported that his brother provided him with a diagram, and was able to describe the meaning of the diagnosis (Refer to Appendix P):

What I was meaning to get at with this picture was just that he's very technical and he'll want to reduce things to understandable concepts and he's very logical. What I was saying here is although sometimes it can be a little bit too much, he'll just ask why about something, but a lot of time I actually find it really helpful. I wish a lot of other people would do it too. Sometimes when they're explaining something and it doesn't seem like they know what they mean. If it’s [my] sibling he'll be able to tell you in a very clear way, and he'll realize if what he's saying isn't clear or something. I regard that as a positive aspect of ASD. It's called disability, but in some ways it increases abilities it seems (Aaron).

Natalie, like Aaron fostered a positive relationship with her brother. She explained that she often coached her brother through various social outings, and as she and her brother spent more time together, Natalie's view of the world, as she had
understood it, began to change. For example, Natalie reminisced about a time in her life where she had difficulty accepting her stepfather into the family. Natalie's brother was able to provide a new perspective, suggesting that they were lucky because they had two moms and two dads:

  He always changes your perspective on things too, right? Which is kind of nice, you get to look at it. Some days I'd like to put on [my] sibling's glasses and see how he sees things because he'll always have a different spin on [it]...

  Yeah, I never really thought about it that way (Natalie).

In summary, the subtheme of *reciprocity* refers to how each sibling developed a new perception about life, and an appreciation and understanding for their sibling, thus creating a positive relationship. It is important to note that through *reciprocity*, participants found new meaning in their sibling relationship and that they felt they then became more caring and compassionate about the world and the people in it. Interestingly, these sibling relationships have had a direct influence on how each participant chose their career path. For instance, Natalie, David, and Shawn have worked in schools as educational assistants. Charlotte is currently studying social work, and Aaron is studying international development. Both of these studies, social work and international development will further their careers of supporting others and advocating for their needs. The reciprocal nature of the participant's relationship motivated the participants to not only help their siblings, but to help those within their community.

4.6.2 Bonding. The second subtheme with the major theme of *Positive experiences* is *bonding*. Many people diagnosed with Autism Spectrum Disorder (ASD) have difficulty developing relationships because of their ability to communicate and
socialize (Autism Speaks, 2015). Each participant found it challenging to vocally communicate with their sibling. However, in both interviews, participants shared many unique memories about how they formed a bond over time with their sibling (Refer to Appendix P-T); and felt that their sibling relationships were like typical sibling relationships where there is no diagnosis of ASD. Each participant expressed how positive their bond was, and how they looked forward to visits with their sibling. Shawn, for instance, said that he was able to bond with his sibling by eating pizza, and driving around in his car. Shawn advised:

[He] and I have spent so many road trips together where he's had me laughing and we've just had a blast. And there's so many good memories that tie into that car, which is just another reason why I'll probably never get rid of that car. It's me and [my] sibling's portal to so many awesome things (Shawn).

For Aaron, he and his sibling bonded by enjoying activities together, including using the computer:

This is a site where lots of things between us happened playing together, learning, helping, fighting over the computer time... but this one was more showing to some extent the normalcy of the relationship since presumably, I'm guessing, this is what most people would do on computers with their siblings (Aaron).

Aaron expressed that he and his sibling enjoy typical activities, including playing computer games, video games, board games, and travelling together as a family (Refer to Appendix P).
David also explained how he and his sister bonded, understanding that his sister was different, yet they were able to have a typical sibling relationship by doing things like wrestling and play-fighting:

I'd been watching WWF, which is a stupid decision for any 8-year-old. I decided, who's my biggest test subject? My sister. We were wrestling at the top of the stairs. She decided she wanted my keys. I ended up going down the stairs.... (David).

David said that as he got older, he and his sister watched movies and went for walks. Through this, they were able to spend time together, and learn to appreciate one another for who they are.

As each participant talked about their memories, and how they bonded with their sibling, they expressed a sense of pride. Participants also believed that having opportunities to bond with their sibling diagnosed with Autism Spectrum Disorder (ASD) were key in helping them establish a positive experience.

4.7 Summary

This chapter explored the experiences of 5 participants who grew up with a Sibling with Autism Spectrum Disorder (SWA). According to the theoretical underpinnings that inform Hermeneutic Phenomenology, it is possible to learn about a phenomenon, such as the impact of growing up with a SWA, by exploring the lives of individuals who have direct contact with that phenomenon. Although everyone’s experience is unique, participants shared common experiences that focus on the essence of a different relationship, but it is not one that is less.
The essence wove throughout all participants’ narratives, and was impacted by two major themes identified throughout the analysis, including: (1) Challenging experiences, and (2) Positive experiences. Two subthemes that emerged from the major theme of Challenging experiences were the diagnosis and complex and layered. Two common elements within the diagnosis subtheme were: ‘when participants were younger’ and ‘communication’. The complex and layered subtheme contained three common elements: ‘the family composition,’ ‘sibling birth order,’ and ‘paid employment;’ these three common elements are integral to understanding how the subtheme of complex and layered may have impacted the sibling relationship. In terms of the major theme of Challenging experiences, participants shared how their sibling relationship was difficult when younger as a result of a lack of community and peer supports, ASD awareness, and because of siblings’ aggressive behaviours and/or lack of verbal communication. Participants discussed that with more parent and peer supports, they became more educated about Autism Spectrum Disorder (ASD), and their sibling relationship, over time, evolved from one of challenging to one of positive.

Two subthemes that emerged from the second major theme of Positive experiences were reciprocity and bonding. Reciprocity was the first subtheme. Participants believed that they not only taught their siblings skills, such as socializing, but their siblings taught them life lessons; these life lessons assisted in the development a new perception about the world, and participants became more compassionate to those around them. Being more compassionate about others was evident as all participants had worked in, or were educating themselves to work, in the helping profession. Participants also discussed that their sibling experience was positive because they found a way to
bond (the second subtheme) with one another. The ability to develop a bond strengthened each sibling relationship and it developed meaningful insight into their lived experiences. In Chapter 5, I will revisit the research project results from chapter 4 as part of a broader discussion of the available literature pertaining to siblings who live with a SWA.
CHAPTER FIVE: Discussion

5.1 Introduction

This research project explored the individual experiences of young adults, who live with, or have lived with, a Sibling with Autism Spectrum Disorder (SWA) in Saskatchewan. The objectives of this study were: (a) to understand individual experiences of siblings who live with a SWA; and, (b) to understand how those individual experiences contributed to their individual support needs. In this chapter, I revisit the research project results as part of a broader discussion of the available literature pertaining to siblings who live with a SWA. I will first discuss the participants’ experiences, and will then connect those experiences to the research lens of the family-ecological systems theory. The strengths and limitations of this research project, followed by implications for social work practice, and suggestions for future research will also be discussed.

5.2 A Different Relationship, but it is Not One That is Less

The overarching theme, a different relationship, but it is not one that is less, was found among all participants. All participants understood that they had a sibling diagnosed with Autism Spectrum Disorder (ASD), and that their sibling was different from many other children. This difference was accepted and was evident when Aaron stated that his sibling relationship was "surprisingly normal”. Each participant echoed the word “normal” as they accepted and valued their relationship with their sibling, regardless of the challenges the family faced. Charlotte, for instance, appeared to have more family challenges due to her sister's behaviours; that said, Charlotte maintained a close relationship with her sister, and thought that even if it was a different relationship,
one must love "the best [one] can" (Charlotte). Study findings suggest that this "normalized" view of the sibling relationship may result in part from the maturity and growth that each participant exhibits (Green, 2013). In addition, each participant was able to describe feelings of closeness to their sibling. This was reflected when the participants described how positive their relationship was, the reciprocity between the siblings, and the ability to bond.

One’s ability to maturely reflect on their sibling relationship was examined in Kaminsky and Dewey’s (2001) study. The authors suggest that the eldest sibling is more likely to be close and intimate than the youngest sibling of a SWA (Kaminsky & Dewey, 2001). The eldest sibling often demonstrates greater maturity, and an ability to understand and appreciate the reasons for the sibling with Autism Spectrum Disorder (SWA) acting differently than a non-SWA (Goehner, 2007; Kaminsky & Dewey, 2001). Travis and Sigman (1998) also suggest that close sibling relationships can develop as siblings grow older and develop more cognitive awareness about their SWAs. Focus on the eldest sibling is specific to this research project because Natalie, Charlotte, Shawn, and David were the eldest siblings in their families. However, differences amongst participant experiences were also evident. Aaron had a close sibling relationship that was very comparable to other participants, except that Aaron is the youngest sibling in his family, and is male. Because Aaron is a young adult, he was able to reflect maturely about his sibling relationship. This ability to reflect maturely may also be due in part to Aaron’s understanding of Autism Spectrum Disorder (ASD). Green (2013), Barr and McLeod (2010), and Naylor and Prescott (2004) found that the sibling relationships became closer when they had more support. For example, Charlotte and Shawn found
peer support when they attended sibling groups, and all participants had supportive parents who provided more education and awareness to them (the non-SWA). Education, according to Naylor and Prescott (2004), as well as Tanaka, Uchiyama, and Endo (2011), is an important factor that allows the SWA’s sibling to adapt to the diagnosis, and develop a close sibling relationship (Refer to Appendix K and U).

In summary, this research project examined the lives of 5 participants who had a Sibling diagnosed with Autism Spectrum Disorder (SWA). The experiences were similar as each participant believed that their sibling relationship is different, but it is not one that is less. Thus, two themes emerged from this study: (1) Challenging experiences; (2) Positive experiences. These themes, as well as the subthemes will be discussed in further detail.

5.3 Challenging Experiences

The theme challenging experiences was the first theme explored in this project. This theme was consistent with all of the participant's experiences because participants said that it was difficult to understand the diagnosis of Autism Spectrum Disorder (ASD) at such a young age. Within the Challenging experiences theme, there were two subthemes: the diagnosis and complex and layered. Two common elements within the diagnosis subtheme include: ‘when participants were younger’ and ‘communication’.

The complex and layered subtheme contained three common elements: ‘the family composition’, ‘sibling birth order’, and ‘paid employment’; these three common elements are integral to understanding how the theme of complex and layered may have impacted the sibling relationship.
5.3.1. The Diagnosis. Participants spoke of how challenging their sibling relationship was, describing that it was harder when they were 'younger' because they could not initially understand, nor internalize, the implications of an ASD diagnosis. Although all participants cited difficulty in their younger years, anger was not a common expression.

Natalie was the only participant who expressed feelings of anger towards her sibling when she was younger. Natalie explained that she often had to go to the hospital, requiring that she missed birthday parties and school because her brother was sick. These feelings of anger are relevant to current research because younger siblings tend to have more unanswered questions, and lack awareness of ASD (Barr & McLeod, 2010; Bishop, 2012; Goehner, 2007). Although Natalie expressed negative experiences of having a SWA during childhood, she also highlighted that her sibling had become one of her best friends. As Natalie and the other participants matured, they began to understand how ASD may impact their sibling relationship. Participants also reflected that there were many more positive memories that outweighed any of the negative experiences.

5.3.2 Complex and Layered. The findings in this project also suggest that each participant's story was uniquely complex and layered based on the ways in which each family functioned. Through the use of family-ecological systems theory, I was able to consider how ‘the family composition,’ ‘sibling birth order,’ and ‘paid employment’ impacted the participants' sibling relationship (Refer to Appendix K). Family-ecological systems theory proposes multiple levels of influence on individual development, including the microsystem, mesosystem, exosystem, macrosystem, and chronosystem (Whiteman et al., 2011). These levels of influence examine how major changes in one's
life alter family relationships, and are particularly relevant to sibling relationships (Whiteman et al., 2011; Bronfenbrenner, 1977). These levels of influence will now be discussed in further detail (Refer to Figure 2).

Figure 2. Bronfenbrenner Ecological Systems Theory Diagram: From a Sibling Perspective. This figure illustrates the 5 levels of influence and how the people within each system may potentially impact the sibling relationship.

Bronfenbrenner's first level of influence is the microsystem, which is described as a pattern of activities, roles, and interpersonal relations experienced by the developing person in various face-to-face settings (Bronfenbrenner, 1977). Each participant in the study had different roles and interpersonal relationships within his/her family, which related directly to their sibling experience. Natalie, for example, experienced many challenges when she was younger, including her brother's adoption. Natalie advised that
at first, the sibling relationship was difficult to develop because she had resentment and anger towards her brother. However, Natalie's role with her sibling changed with time, where she became a mother-like figure for her brother. This mother-like figure is due to her parent’s ability to maintain a close relationship with both children, as well as help educate and support Natalie about Autism Spectrum Disorder (ASD). Thus, the sibling relationship over time changed from challenging to positive.

Charlotte also experienced many challenges, including moving her sibling to a group home, and Aaron went through challenges when he helped his brother with employment. Regardless of the challenges within each family, participants appeared to have developed positive relationships with their siblings. These positive relationships may be due to the parents’ ability to educate and support the participants (Goehner, 2007).

'Sibling birth order' was another layer of complexity involved with sibling relationships, and it correlates directly with the mesosystem, the second level of influence – which refers to connections between the microsystem contexts (Whiteman et al., 2011). Norms about age and gender segregation may be consistent as siblings move from family and neighbourhood to school, or siblings may have to adopt different ways of behaving toward one another in different settings (Whiteman et al., 2011). For example, Shawn, Natalie, Charlotte and David were the oldest siblings in their family units, and often provided care for their younger sibling. However, their relationship with their siblings changed when they moved away from home. David, for example, indicated that he and his sister spend more quality time together when he returns home from university, and he provides less care-responsibilities for his sibling.
Aaron, as the youngest sibling, had a different experience than the other participants. Aaron found that as he got older, his relationship with his sibling changed when he took on a mentoring role. Although Aaron's role changed with his sibling, all participants worried about their sibling's future. Charlotte, for instance, questioned if she would have to make decisions on behalf of her sister when her parents were no longer able to. Natalie and Aaron worried about their brothers' future, and they hoped that their siblings could find employment. Worry about the future is directly correlated with the sibling literature, where studies indicate that as siblings get older, they develop a different responsibility for their sibling, often worrying about the sibling's future and parent's ability to care for their sibling (Feiges et al., 2004).

In summary, the changes to the participants' environments, the mesosystem, allowed each sibling to become interconnected with one another. The siblings were able to establish social connections with peers, develop their own identity, bond through various family activities, and provide support to their sibling as their lives evolved. The opportunity for change within each environment allowed for a rich sibling experience.

The third level of influence is the exosystem. Bronfenbrenner (1995) explains how a sibling relationship may change indirectly if parents work long hours (Whiteman et al., 2011). Participants in this study spoke of the challenges they face in caring for their sibling if their parents worked. Shawn, for example, took on more sibling-care and household responsibilities because both of his parents worked outside of the home. These responsibilities can create more layers of complexity within the family system because the sibling relationship becomes more hierarchical, rather than egalitarian. This hierarchal relationship can lead one sibling to have more parent-like responsibilities and
be more protective of the other sibling. When this occurs, it can be difficult for the sibling to find ways to relate or share an interest with their Sibling diagnosed with Autism Spectrum Disorder (SWA) (Goehner, 2007).

The fourth level of influence is the macrosystem, which speaks directly to the broader societal context, and western culture focuses more on individualism (Whiteman et al., 2011). Study participants agreed that when they were younger their sibling relationship was more difficult. Some felt alone, as they did not have peer support, professional support, or time with which to discover their own identities. Charlotte, David, and Aaron stated that they wished there would have been more sibling support. Participants also noted that if it were not for their parents, they would not have learned about ASD, and thus would not have developed meaningful sibling relationships. When participants reflected on the wider context, they expressed the need for more government and professional support so that families do not feel isolated. Feelings of isolation stem from western culture’s belief that the immediate family should be the main source of support; in contrast, Eastern cultures provide more communally orientated support (Whiteman et al., 2011).

The last level of influence is the chronosystem, and extends the environment into a third dimension, consisting of individual change over time (Bronfenbrenner, 1995). Study participants highlighted that their sibling relationships evolved over time into mature, reciprocal, and positive relationships. Participants worked through family and personal challenges, learned to accept who they were as individuals, and developed awareness and understanding of Autism Spectrum Disorder (ASD). As the participants grew up, they found that their siblings were more than family members – they were also
friends in whom they could confide, and people they felt proud to know. The positive outlook participants hold about their sibling relationship can be attributed to parents including the sibling in interventions, explaining what ASD is on an ongoing basis, and ensuring that the typical sibling has peer groups within which to express opinions and attitudes (Conway & Meyer, 2008; Glasberg, 2000; Naylor & Prescott, 2004; Rivers & Stoneman, 2008; Tanaka et al., 2011). Based on these study findings, it is important that mental health professionals encourage parents to communicate with siblings on an ongoing basis. When siblings are younger, their relationship may be more difficult; however, as siblings grow and evolve, they can develop a lasting bond and friendship as long as there are parental and educational supports in place (Refer to Appendix K and U).

5.4 Positive Experiences

The chronosystem demonstrated that participants' views of their sibling relationships evolved from being challenging when 'younger,' to a positive experience. The positive theme explored two subthemes: reciprocity and bonding.

5.4.1 Reciprocity. Participants believed they had learned much from their siblings and that they wanted to choose a meaningful career path as a reflection on these experiences. The participants’ experience with their sibling allowed them the opportunity to become more empathetic to others, thus choosing the meaningful career path (Green, 2013). The decision to choose a career in the human services field, such as social work or education later in life, is also a feature of the sibling literature, where siblings suggest that their past experiences make them better persons because they are more empathetic and understanding of other individual's needs. The experiences assist the siblings in
“paying it forward” in the community (Feiges et al., 2004; Goehner, 2007; McHale & Gamble, 1989), and are best reflected as the participants of this study say that their sibling taught them how to be patient, understanding, and more empathetic when helping other people.

5.4.2 Bonding. Participants reflected on their bonding experience, saying that it was unique, but that the ability to bond was positive. Some sibling pairs had limited vocal communication. As a result, the participants were able to find different ways to connect with their sibling. The ability to bond can increase sibling warmth, emotional security, and provided an increase in self-esteem among the sibling pair (Buist et al., 2013).

It is important to note that the participant's ability to bond strengthened over time; especially when the participants left the family to pursue their careers. Milevsky and Heerwagan (2013) stated that, when one sibling moves to college, usually at the age of 18, siblings appreciate one another more, indicating that they become more mature. Furthermore, bonding strengthened with time and change within each participant's environment. The participants believed that the supportive environments helped create a meaningful sibling relationship.

5.5 Strengths of the Research Project

There are several strengths to this project. First, the project contributes to the literature in an area that has been identified as lacking (Bishop, 2012; Rivers & Stoneman, 2008). Specifically, current research focuses primarily on quantitative studies, which do not allow participants to respond to multifaceted issues, or to capture the nuance or texture of responses. I chose to conduct a qualitative research project so as to
capture experiential depth of what it is like to grow up with a sibling with ASD. The participants of this project were young adults, who were able to reflect maturely on their sibling relationship, and were also able to capture photographic images that were representative of their experience. In addition, this sample selection choice of young adults fills a current gap in the literature, as young adult siblings are not well represented (Campbell, 2011; Green, 2013; Kaplan, 2013).

Theory-focused analyses are also not common in sibling studies (Cridland et al., 2013; Rossiter & Sharpe, 2001; Whiteman et al., 2011). By incorporating family-ecological systems theory, I was able to develop a better understanding of the family systems, and investigate emerging patterns and themes from each participant's story. In addition, I wanted to understand the individual support needs of the participants that could be linked to family and community agency supports to siblings who do not have Autism Spectrum Disorder (ASD), as this is another area of limited research (Boyd, 2002; Naylor & Prescott, 2004; Smith, 2003). Throughout the research process, I was able to capture the meaning of growing up with a Sibling with Autism Spectrum Disorder (SWA) as participants understood this, as well as discover how those individual experiences contributed to their support needs.

A second strength to this project was photo-production. Adding photo-production as a method to encourage dialogue enhanced this research project, as each participant took pictures and told me their unique stories. Picture methods are another underused tool in research studies (Latta et al., 2013), but can effectively encourage dialogue between participants and researchers. During my first set of interviews, for example, I felt there were a lot of unanswered questions with some of my participants. I
did not know how participants were able to bond with their siblings, nor was I able to fully capture the participants’ beliefs, values, or viewpoints regarding their sibling relationship. During the second set of interviews, many of my questions were answered when participants presented their pictures. This visual tool provided a creative opportunity for individuals to talk about different topics, in different ways, and allowed participants to articulate thoughts and feelings that typically remain unspoken (Prosser, 2011; Rose, 2012).

A third strength to this research project was the inclusion of multiple strategies throughout the study in order to ensure its trustworthiness; criteria that speak to trustworthiness include credibility, transferability, confirmability, and dependability (Lincoln & Guba, 1985; Morrow, 2005).

Credibility refers to external checks of the accuracy in a research study (Lincoln & Guba, 1985). In order for the study to be deemed credible, I completed member checks, which confirmed the accuracy of categories and themes derived from participants (Merriam, 2002). Participants were able to confirm if their words reflected what they intended to say (Lincoln & Guba, 1985; Lincoln & Guba, 1986). Therefore, as previously discussed, participants were asked to review the accuracy of their transcripts. After interview two, participants were asked to sign a transcript release form authorizing their consent to use their data for the purpose of my research project.

I also maintained credibility through the use of triangulation. Triangulation refers to how the investigator reduces bias and cross-examines the integrity of participants' responses (Anney, 2014). I used multiple methods such as a semi-structured interview, photo-production, and family-ecological systems theory to enhance the quality through
different sources of data (Anney, 2014). An additional strategy used to increase the credibility of my project was debriefing (Lincoln & Guba, 1985; Lincoln & Guba, 1986; Merriam, 2002). I consulted with my supervisor on various occasions. My supervisor provided expertise in qualitative research and in my study findings.

Transferability refers to the degree in which the results of qualitative research can be transferred to other contexts with other respondents (Anney, 2014). The goal of my study was to obtain information from experts in the field; individuals who were young adults that grew up with a Sibling with Autism Spectrum Disorder (ASD), and to allow my readers to arrive at their own judgements regarding the “degree of fit” (Lincoln & Guba, 1986) of my research. In order to facilitate this, ‘thick’ descriptions of the data are provided. The goal of providing thick descriptions of the data is to enable the readers’ understanding of my interpretations and reporting of the results. These rich descriptions involve the themes derived from the data.

Dependability and confirmability can both be evaluated through the use of an audit trail (Lincoln and Guba, 1986). An audit trail examines the inquiry process and product to validate the data, accounting for all research decisions and activities to show how the data was collected, recorded and analyzed (Bowen, 2009; Li, 2004). The audit trail, for the purpose of this project, consisted of journal notes during the data analysis which were beneficial; they allowed me to gather my thoughts, ideas, and ask pertinent questions that aided in reaching my study conclusions.

The impact that this research has left on me as a researcher and as a clinician is the last study strength. First, as a researcher, conducting the literature review at times almost hindered my ability to hear the participants' experiences. The current literature on
sibling relationships is generally divided into positive and negative experiences; therefore, I felt it was pertinent to ask participants about the negative and positive experiences of growing up with a Sibling with Autism Spectrum Disorder (SWA). To my surprise, most participants reported few negative experiences, especially while younger. Participants believed that positive experiences far outweighed the negative, and some laughed when I asked what some of the potential negative experiences would be growing up with a SWA. The message I took from each participant was that the SWA was still his or her sibling, regardless of any disability. When conducting the interviews I found that I had to put my personal bias aside. My personal opinion was that there were negative implications that outweighed positive aspects of having a sibling with Autism Spectrum Disorder (SWA). This personal opinion stems from the literature review I conducted for this study. In addition, I thought about my social work practice and found that siblings often were upset, or had significant behaviours because their SWA received more attention. When I asked participants about the negative experiences, I felt the question was not appropriate and I had to eschew any personal bias I had. The participants moved me to understand that there were far more positive experiences than negative, and it was the "small" things that counted such as going to the park together, going for a drive, or simply playing a video game.

Participants did not report any major signs of resentment or anger towards their parents. Participants truly were mature adults who described their siblings and their experiences in optimistic ways. In addition, participants all described a team-like family relationship, which added to the positive sibling experiences. This finding was
enlightening, and as I continued to interview participants, I forced myself to suppress my experiences with the literature so that it would not impact my interviews.

As a clinician, I found the interviews informative. Participants said they had a great family experience, and felt much support from their immediate and extended families (Refer to Appendix U). The revelatory moment was when participants talked about a lack of community supports. Charlotte and Shawn, for example, both spoke about the need for more sibling groups. Coming from a rural community, Charlotte and Shawn said they felt isolated, and wished for a sibling group so they could converse with others who understood their situations (Refer to Appendix K). Shawn noted that it is not always about talking through experiences with a counsellor, but also is about siblings being able to get together to cathartically share stories, and identify with one another so that they do not feel alone.

As a professional currently working in the field of Autism Spectrum Disorder (ASD), it is important to understand that those who live in rural areas need to be able to access support so they can avoid feeling socially isolated. Aaron, Natalie, and David could access ASD resources because they reside in a city. I think that further evaluation of support systems should be conducted in rural areas, as people need to have the opportunity to access a variety of supports. Shawn put the matter succinctly when he highlighted the importance of finding commonalities among peers so that one does not feel alone. As a professional, I have always felt that it is important to ensure that every family member’s needs are met; however, that does not always mean through talk therapy. For some, it is about professionals making connections for their clients so they have a peer with whom to talk – someone who understands their situation.
5.6 Limitations of the Research Project

The experiences shared by the 5 participants in this project offer another perspective or understanding; yet is a small glimpse into the essence of having a sibling with ASD. By learning from these individuals, greater understanding of the human experience is gained, but only within the unique context of these participant’s life stories. This project thus only represents one tiny piece of the puzzle: young adult siblings. This project does not incorporate older adults, who may be caring for their siblings. The research project also does not demonstrate what it is currently like for a child to live with their Sibling with Autism Spectrum Disorder (SWA), nor does it examine cultural differences. Finally, this project does not consider current community supports available to those who have a SWA.

5.7 Implications for Social Work Practice

Exploring siblings’ lived experiences and potential support systems is relevant to health care services delivery, and the social work field. Social workers promote social inclusion of people with disabilities (CASW 2005a; CASW, 2005b). With this in mind, social workers must strive to respect and provide services to the entire family, especially siblings who can be negatively or positively impacted by living with a sibling with Autism Spectrum Disorder (ASD).

How social workers perceive and understand the sibling dyad when one sibling has ASD impacts the ways in which they assess a child’s needs, and the ways in which services and interventions are provided to families (Preece & Jordan, 2007). Social workers need to be cognizant of all family members affected by an ASD diagnosis; however, most literature pertaining to ASD focuses on treatments for children with ASD,
the mother’s mental health, and marital status (Bayat & Schuntermann, 2013; Boushey, 2001).

In my social work practice, I have observed that treatment and services for the child with ASD is pertinent. I have also observed that most parents that live in the urban settings have access to various support services, such as counselling and parent support groups. The sibling, on the other hand, does not always receive the same treatment or services, and is often the forgotten family voice. As a social worker in Saskatchewan, I have difficulty referring siblings to support services because there are few therapeutic services available to support siblings of SWAs. In the United States, as well as in other Canadian provinces (such as Ontario), there are Sibshop groups that attempt to empower siblings. Sibshops afford opportunities for brothers and sisters of children with special health and developmental needs to obtain peer support and education within a recreational context (Sibling Support Project, n.d.). The participants in this project echoed the importance of implementing support groups. Participants believed that having peer support and education within a recreational context was valuable, and prevented siblings from feeling isolated. The peer support groups also provide participants with a greater understanding of ASD, which can mitigate, if not eliminate, feelings of jealousy and resentment.

This research project is also pertinent for social workers because of its focus on family-ecological systems theory (Bronfenbrenner, 1979). Bronfenbrenner’s theory allows one to consider numerous environmental factors, and numerous persons in different interactional relationships, roles, actions, and processes (Harkonen, 2007). A family systems framework directs attention to the larger context in which sibling
relationships develop, and it is within this holistic perspective that families are best understood (Whiteman et al., 2011). When social workers can provide treatment and services to the entire family, the family can develop perseverance, creativity, and love. In addition, the sibling relationship may be stronger when one is educated and understands the diagnosis of Autism Spectrum Disorder (ASD). Lastly, social work services that encourage courageous conversation within families ultimately increase a family’s capacity and connectivity (Pitter, 2009). As social workers, it is truly important to respect the inherent dignity and worth of all persons (CASW, 2005a). This means that social workers must understand that each family is different and that each family member has support needs and may require services.

5.8 Future Research

The prevalence of Autism Spectrum Disorder (ASD) continues to increase, as one in 50 children are currently diagnosed with Autism (National Vaccine Information Center, 2013). With this statistic in mind, it is recommended that qualitative research be conducted from the perspective of the sibling who lives with a Sibling with Autism Spectrum Disorder (SWA), as sibling voices lack representation in ASD literature (Bishop, 2012; Rivers & Stoneman, 2003). Qualitative research could be further expanded to include comparison studies – for example, across different ethnicities. Most studies include participants that are Caucasian, upper-middle class citizens (Campbell, 2011; Rivers & Stoneman, 2003). It would thus be interesting to use an ethnographic methodology, where the researcher observes families of different cultures and socioeconomic contexts to explore sibling relationships. This research could use a mix-methods approach to draw comparisons between cultural values and beliefs; in addition,
this research could potentially benefit practitioners who need to be culturally sensitive to how families interpret ASD diagnoses.

It would also be interesting to complete a case study that compares younger and older siblings. It appears that younger siblings have negative feelings toward their SWA because they do not understand what ASD is, while older siblings have the ability to reason and understand the diagnosis (Glasberg, 2000). A case study that examines education directed at the sibling's level of development could ultimately improve positive feelings of younger siblings toward their SWA. In addition, it would be beneficial to have further research incorporate photo-production as an interview tool so that researchers can develop a better understanding of the sibling relationship, and encourage dialogue between researcher and participants.

5.9 Conclusion

Having a child with a disability is not easy as there are often family disruptions, perceived inequality, and emotional distress (Weiss, 2004). It is important that families ensure a safe and positive environment for one another, where communication is ongoing so that the sibling relationship can thrive in a positive and healthy manner.

This research project used a qualitative approach to better understand how the sibling relationship can change when one sibling is diagnosed with Autism Spectrum Disorder (ASD). The sibling relationship is important, and is one of the longest lasting relationships one has (Cicirelli, 1995; Garney, 2002; Milevsky & Heerwagan, 2013; Sanders, 2004). It is also the one relationship that evolves over time. For example, during childhood the sibling relationship is often quite close; however, the sibling relationship will change once individuals move away from home (Tozer, et al., 2013).
The participants interviewed for this project were mature young adults with a positive outlook on their sibling relationship. Participants provided great insight into their sibling relationship.

On a personal level, the participants moved me in such a way as to realize that although the current literature suggests there are negative and positive sibling experiences, in this particular research, positive experiences significantly outweighed the negative experiences. The overarching theme *it is a different relationship, but it is not one that is less* was echoed among all participants. Through this research project, I was able to discover that although everyone’s journey is different, the sibling journey is challenging and positive, regardless of the ASD diagnosis of one sibling.
References


Facts about ASD. (2016, March 28). Retrieved from
http://www.cdc.gov/ncbddd/autism/facts.html

brother or sister on the Autism Spectrum.* Overland Park, KS: Autism Asperger
Publishing Company.

association of family subsystem negativity on siblings' maladjustment: Using
behavior genetic methods to test process theory. *Journal of Family Psychology,*
19 (4), 601-610.

Feinberg, M., Solmeyer, A., & McHale, S. (2012). The third rail of family systems:
Sibling relationships, mental and behavioral health, and preventive intervention
in childhood and adolescence. *Clinical Child Family Psychology Review,* 15 (1),
43–57.


http://cerebralpalsy.org/about-cerebral-palsy/types-and-forms/


http://digitalcommons.pcom.edu/cgi/viewcontent.cgi?article=1151&context=psychology_dissertations.

http://scholarworks.csun.edu/bitstream/handle/10211.2/3185/autism.pdf?sequence=1.


Retrieved from:


*Journal of Undergraduate Research, 10* (1), 1-15.


APPENDIX A

Invitation to Participate

Do you have a Sibling with Autism Spectrum Disorder?

If you are an individual who is over the age of 18 and has lived with or are currently living with a sibling or siblings diagnosed with Autism Spectrum Disorder, you are invited to participate in a research study entitled *Exploring the lived experiences of siblings who grow up with a sibling diagnosed with Autism Spectrum Disorder*.

I am a University of Regina graduate student in the School of Social Work program, looking for individuals to participate that meet the following criteria:

- Are 18-30 years of age
- Have lived with or currently live with a sibling who has Autism Spectrum Disorder
- Willing to share your experience as a sibling living with or lived with a sibling with Autism Spectrum Disorder
- Willing to participate in two 90 minute interviews
- Willing to take approximately ten photographic images that symbolize the nature of your sibling relationship

The purpose of this study is to: 1) Explore the perceptions of siblings, who have lived or are living with a sibling with Autism Spectrum Disorder (2) Understand how siblings view potential family and community supports.

If you have any further questions about this study, please contact myself by email or telephone: klimm11a@uregina.ca, 1-306-291-9416; or Dr. Randy Johner (Supervisor): Randy.Johner@Uregina.ca or 1-306-585-4549. This research project was reviewed and approved on ethical grounds through a harmonized review process by the University of Regina and the University of Saskatchewan Research Ethics Boards.
APPENDIX B
Telephone Screening Guide

R: Thank you for expressing interest in the research study. I would just like to confirm that you meet the participation criteria for the study. First, I need to confirm that you are willing to participate in the study and are able to commit to two interviews that will last no longer than 90 minutes each?

R: Are you willing to participate in this research study by capturing photographic images that symbolize the nature of your sibling relationship? Instructions on this task will occur after the first interview. I ask that you refrain from taking pictures of your neighbourhood, house, and people to protect confidentiality, as well as logos that may infringe copy write. Please note that taking images will occur between the first and second interview.

R: Are you currently living with or have lived with a sibling diagnosed with Autism Spectrum Disorder?

R: Lastly, are you currently between the ages of 18-30 years?

R: Great. Now that we covered the participation criteria, I would like to set up a time to meet with you and hear about your experiences.
APPENDIX C

Letter of Invitation

Experiences And Views Of Social Support For Siblings Who Live With Siblings With ASD

Dear Participant,

You are invited to participate in a research study entitled Exploring the lived experiences of siblings who grow up with a sibling diagnosed with Autism Spectrum Disorder. I am currently a Social Work Master's student at the University of Regina, Saskatoon, Saskatchewan campus. The main aim of this research project is to explore the lived experiences of siblings who live with siblings diagnosed with Autism Spectrum Disorders (ASD). In addition, I would like to understand what siblings view as available supports. In order to complete this study, I require participants who are over 18 years of age, who have lived with or are currently living with a sibling diagnosed with ASD. This research project was reviewed and approved on ethical grounds through a harmonized review process by the University of Regina and the University of Saskatchewan Research Ethics Boards.

If you are interested in participating in this project, your commitment will include two face-to-face interviews. Each interview will take no more than 90 minutes to
complete. The two interviews will be scheduled at a time and place that is convenient for you. This interview is voluntary and you can opt out of this research at any time. The information you share with me will not be included in the study if you opt out. However, your information will remain in the study once I have analyzed your information shared.

My passion for sibling research stems from my own personal sibling relationship, in addition to my professional work experience with families and individuals diagnosed with ASD. It is hoped that learners will gain a better understanding of sibling relationships when there is one sibling with a diagnosis of ASD. ASD continues to become more prevalent in North America. Therefore, one should be aware of the positive and negative aspects to sibling relationships as well as community and family supports currently in place.

Your participation in this study will be a valuable tool and learning opportunity for those who want to understand more about sibling relationships. If you or someone you know would like to participate in this pilot project, please contact me at: 2014swa@gmail.com, or 306-291-9416. You may also reach my supervisor, Dr. Randy Johner at: Randy.Johner@Uregina.ca or 1-306-585-4549. Thank you for your time and for your willingness to participate in this project.

Sincerely,

Amanda Day
Master of Social Work Student
University of Regina
Mobile: 306-291-9416
Email: klimm11a@uregina
APPENDIX D

Counseling Services

Should you experience any emotional anxiety or distress as a result of our interviews, below is a list of agencies in Saskatoon that may be a support service for you.

**Saskatoon Family Service**
506 25th Street East
Saskatoon SK S7K 4A7
Phone: (306) 244-0127
Website: www.familyservice.sk.ca
Fee: sliding scale (dependent upon income)

**Saskatoon Christian Counselling**
617 3rd Ave. N.
Saskatoon SK S7K 2J8
Phone: (306) 244-9890
Website: http://www.saskatoonchristiancounsellingservices.com
Fee: $90/hour; however subsidy may be available

**Adult Community Services**
4th Floor
715 Queen Street
Saskatoon SK S7K 4X4
Phone: (306) 655-7950
Website:
http://www.saskatoonhealthregion.ca/your_health/ps_mh_adult_community.htm
Fee: No charge

**Catholic Family Services**
200 - 506 - 25th Street East
Saskatoon, SK. S7K 4A7
Phone: (306) 244-7773
Fax: (306) 244-8537
Email: staff@cfssaskatoon.sk.ca
Fee: No charge
Prairie Therapists and Trainers
910 Queens Street
Saskatoon, SK
S7N 0N2
Phone: (306) 665-6242
Toll-Free: 1 (877) 772-9933
Fee: Unknown

The Family Counselling Center
Phone: (306) 652-3121
603-3rd Ave. N.
Saskatoon SK
S7K 2J8
inquire@family-counselling.ca
Fee: Unknown

Student Health and Counselling Services
University of Saskatchewan campus
306-966-4920
3rd floor of Place Riel
Fee: Free to University of Saskatchewan students
APPENDIX E

Interview Guide

Questions and Probes

**General question asked to all participants:**

1. Please share with me your experience of what it is like to live with (or have lived with) a sibling diagnosed with Autism Spectrum Disorder.

**Interview One - Guiding questions** (used only if the participants have difficulty articulating their experiences):

1) How old were you when you first found out about your sibling's diagnosis?

2) Tell me about your family and what roles they had (or have) within your home.

3) Tell me about your relationship with your sibling who has ASD

**Probe question:**

How has your relationship with your sibling changed over the years?

**Probe question:**

What are some positive aspects to having a sibling with ASD?

**Probe question:**

What are some negative aspects to having a sibling with ASD?

**Probe question:**

What are your wishes for your sibling who has ASD?

**Probe question:**

Have you learned anything from your sibling?
What would you have like to have known when you were younger about ASD? About your sibling?

Support system

4) What or who do you view as supportive individuals to you?

5) What or who do you view as supportive individuals to your family?

Probe question:

What type of supports did you have when growing up with your sibling?

Probe question:

What type of supports would you hope to have if you were to repeat childhood?

Probe question:

Who were/are currently your primary supports?

Probe question:

What wishes do you have for siblings who currently live with a sibling who has ASD?

Interview Two:

1. Have you had a chance to read over the copy of your transcript from the previous interview? Is there anything you would like to add, alter or delete from the transcript?

2. During today’s interview I would like to discuss with you the photographic images you have taken to symbolize your sibling relationship. As we go through the photographs, please consider HOW these images reflect on your relationship, both positively and/or negatively. (Researcher will use the questions in interview two at this time if necessary to see how individuals capture the nature of their sibling relationship.

3) Is there anything you feel we have not discussed in regards to your experience with your sibling relationship?
Project Title: Exploring the lived experiences of siblings who grow up with a sibling diagnosed with Autism Spectrum Disorder

Researcher:
Amanda Day
Graduate Student
Faculty of Social Work
University of Regina
1-306-291-9416
klimm11a@uregina.ca

Supervisor:
Dr. Randy Johner
Faculty of Social Work
University of Regina
1-306-585-4549
1-306-664-7131 (f)
Randy.Johner@uregina.ca

Purpose(s) and Objective(s) of the Research: The purpose of the research is to explore the perceptions of siblings, who have lived, or are living with, an SWA, and to understand how siblings view potential family and community supports.

Procedures: Your participation in the study will involve two interviews; each interview will be approximately 90 minutes in length, and will take place at a time and place convenient for you. In addition, you will take approximately ten photographs that capture
and symbolize the nature of your sibling relationship. Instructions regarding photography will occur during the first interview.

**Funded by:**

This research project is not funded.

**Potential Risks:** There are no known or anticipated risks to you by participating in this research. If you experience any feelings of discomfort during and/or after the research, the researcher will make a referral for you to speak with a counsellor.

**Potential Benefits:** The potential benefits of this research are to: 1. Provide social workers with knowledge that could assist in strengthening interventions, such as counselling or sibling support groups, and 2. Assist in establishing more information and knowledge to the topic of sibling relationships and ASD. Please note that these benefits are not guaranteed.

**Compensation:** There is no compensation for participants of this study.

**Confidentiality:** Due to the nature of this study, confidentiality will be limited. To ensure as much confidentiality as possible, your name will NOT be used and a pseudonym (false name) will be assigned when the interviews are transcribed and reported. In addition, it will be asked that you refrain from taking any photographs that infringe on copyright or confidentiality, such as labels, people, your house or neighbourhood. Also, care will be taken that no identifying information will be included in direct quotes. At times, the research may make slight alterations to a situation or context to conceal the identity of the participant. Due to the unique nature of the environments that the participants may be describing, complete confidentiality cannot be guaranteed. For example, there is a chance that participants could be identified by their speech patterns or by persons who support them.

I give permission:

Individual interview (audio-recorded)

YES…………….. NO……………….

To share my photographic pictures

YES…………….. NO……………….

**Storage of Data:** The data will be stored in a locked cabinet by the researcher and computer files are protected by a password. Once the study is complete, data will be stored in a locked cabinet by Dr. Randy Johner, at the University of Regina for five
years. After the required five years, the audio-recordings will be erased and destroyed, and the transcripts, including computer files, will be deleted or shredded and discarded.

**Right to Withdraw:** Your participation is voluntary and you may answer only those questions with which you feel comfortable answering. You may withdraw from the research project for any reason, without explanation or penalty of any sort up to one month following your interview. After one month your data may be integrated into the analysis or part of the final report.

**Follow up:** A summary of the final report will be available by request from the researcher.

**Questions or Concerns:** Contact the researcher using the information at the top of page one (1). This research project was reviewed and approved on ethical grounds through a harmonized review process by the University of Regina and the University of Saskatchewan Research Ethics Boards. Any questions regarding your rights as a participant may be addressed to that committee through the U of R Research Ethics Office research.ethics@uregina.ca (306) 585-4775. Out of town participants may call collect.

**Consent**

In-Person Individual:

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Researcher’s Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

_A copy of this consent will be left with you, and a copy will be taken by the research_
APPENDIX G

Transcript Release Form

I, ____________________________________, have reviewed the complete transcript of my personal interview in this study, and have been provided with the opportunity to add, alter, and delete information from the transcript as appropriate. I acknowledge that the transcript accurately reflects what I said in my personal interview with Amanda E. Day. I hereby authorize the release of this transcript to Amanda E. Day to be used in the manner described in the Consent Form. I have received a copy of this Transcript Release Form for my own records.

_________________________  _______________________
Name of Participant         Date

_________________________  _______________________
Signature of Participant     Signature of Researcher
APPENDIX H

Photography Release Form

Exploring the lived experiences of siblings who grow up with a sibling diagnosed with

Autism Spectrum Disorder

Photography Release Form

The photographs used in this study may be incorporated for visual purposes in this research project. There will be no photographs used in this study that may breach confidentiality or infringe copyright. I understand that the purpose of the photographic images is to enrich the study and provide a visual to those interested in the sibling phenomenon.

I,__________________________________, hereby authorize the release of my photographic images to Amanda E. Day to be used in the manner described in this form. I have received a copy of this Photography Release Form for my own records.

_________________________  ________________________
Name of Participant  Date

_________________________
Signature of Participant

_________________________
Signature of Researcher
## APPENDIX I

### Literature Review Chart

<table>
<thead>
<tr>
<th>Authors, Year &amp; Article</th>
<th>Qualitative or Quantitative</th>
<th>Participants</th>
<th>Theory incorporated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Atkin, K., &amp; Tozer, R. (2013). Personalisation, family relationships and Autism: Conceptualising the role of adult siblings. Journal of Social Work, 0(0), 1-18.</td>
<td>Qualitative</td>
<td>21 adult siblings, aged 25 to 67, with Autism plus a learning disability from 17 families.</td>
<td>No</td>
</tr>
<tr>
<td>Bagenholm, A., &amp; Gillberg, C. (1991). Psychosocial effects on siblings of children with Autism and mental retardation: A population-based study. Journal of Mental Deficiency, 35 (4), 291-307.</td>
<td>Quantitative</td>
<td>60 children and young adults aged 5 to 20, 20 of whom had siblings with Autism, twenty of whom had siblings with developmental disabilities, and 20 of whom had siblings who did not have a disability.</td>
<td>No</td>
</tr>
<tr>
<td>Barr, J., &amp; McLeod, S. (2010). They never see how hard it is to be me: Siblings' observations of strangers, peers and family. International Journal of Speech- Language Pathology, 12 (2), 162-171.</td>
<td>Inductive thematic analysis</td>
<td>676 contributions to a children’s Internet sibling support site were analysed.</td>
<td>No</td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Description</td>
<td>Discussion</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>---------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------</td>
</tr>
<tr>
<td>Baydar, N., Hyle, P., &amp; Brooks-Gunn, J. (1997). A longitudinal study of the effects of the birth of a sibling during preschool and early grade school years. <em>Journal of Marriage and Family, 59</em> (4), 957-965.</td>
<td>Quantitative</td>
<td>Sibling cohort of preschool aged children over 2 years. 673 non-Black, non-Hispanic children, aged 3 to 5 years at the time of the 1986 assessment. The sample was limited to children for whom reliable reports of date of birth or age were available (16 children were excluded), and for whom assessments in 1988 were available. Among these, 64% (433 children) were interviewed again in 1990.</td>
<td>No</td>
</tr>
<tr>
<td>Researcher</td>
<td>Year</td>
<td>Title</td>
<td>Methodology</td>
</tr>
<tr>
<td>------------</td>
<td>------</td>
<td>-------</td>
<td>-------------</td>
</tr>
<tr>
<td>Bullock, B., &amp; Dishion, T. (2000).</td>
<td>Sibling collusion and problem behavior in early adolescence: Toward a process model for family mutuality.</td>
<td>Journal of Abnormal Child Psychology, 30(2): 143–153.</td>
<td>Quantitative</td>
</tr>
<tr>
<td>Reference</td>
<td>Title</td>
<td>Methodology</td>
<td>Findings</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>-------------</td>
<td>----------</td>
</tr>
<tr>
<td>Dodd, L. (2004).</td>
<td>Supporting the siblings of young children with disabilities. <em>British Journal of Special Education, 31</em> (1), 41-49.</td>
<td>Article discusses the need and value for siblings support groups.</td>
<td>No</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Type of Study</td>
<td>Description</td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------------------------------------</td>
<td>---------------</td>
<td>-----------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Green, L. (2013).</td>
<td>Review article</td>
<td>Fourteen articles were accessed.</td>
<td></td>
</tr>
<tr>
<td>Goetting, A. (1986).</td>
<td>Review of research</td>
<td>No</td>
<td></td>
</tr>
<tr>
<td>Gray, D. (2003).</td>
<td>Qualitative analysis</td>
<td>One member of 33 families where there was a child with Asperger’s.</td>
<td></td>
</tr>
<tr>
<td>Herrick, P. (2008).</td>
<td>Quantitative</td>
<td>263 total 112 (42.6%) male and 151 (57%) female.</td>
<td></td>
</tr>
<tr>
<td>Author</td>
<td>Title</td>
<td>Methods</td>
<td>Sample Description</td>
</tr>
<tr>
<td>--------</td>
<td>-------</td>
<td>---------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Kaplan, L. (2013).</td>
<td>Sibling relationships with an Autistic Sibling (Master's thesis, St. Catherine University).</td>
<td>Quantitative and qualitative data methods</td>
<td>Two of the children with Autism were twins with a typical twin. Three out of the six children with ASD were girls, which is not typical of Autism.</td>
</tr>
<tr>
<td>Knott, F., Lewis, C., &amp; Williams, T. (1995).</td>
<td>Sibling interaction of children with learning disabilities: a comparison of Autism and Down's syndrome. Journal of Psychology and Psychiatry, 36 (6), 965-976.</td>
<td>Quantitative</td>
<td>15 sibling dyads in which one child had Autism and the other was developmentally normal, and 15 dyads in which one child had Down’s syndrome and the other was developmentally normal.</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Description</td>
<td>Relevant Data</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td>Latta, A., Rampton, T., Rosemann, J., Peterson, M., Mandleco, B., Dyches, T., &amp; Roper, S. (2013). Snapshots reflecting the lives of siblings of children with Autism spectrum disorders. <em>Child: Care, Health and Development,</em> 40 (4), 1-10.</td>
<td>Qualitative</td>
<td>14 siblings of 13 children with ASD received disposable cameras and captured images that were important to them.</td>
<td>No</td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Participants</td>
<td>Findings</td>
</tr>
<tr>
<td>-----------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------</td>
</tr>
<tr>
<td>Naylor, A., &amp; Prescott, P. (2004).</td>
<td>Qualitative</td>
<td>Participants were non-disabled siblings and their parents, between the ages of eight and 18 years.</td>
<td>No</td>
</tr>
<tr>
<td>O’Laughlin, K. (2006).</td>
<td>Quantitative</td>
<td>12-18 years old siblings who had sibling with ASD.</td>
<td>No</td>
</tr>
<tr>
<td>Orsmond, G., &amp; Seltzer, M. (2009).</td>
<td>Quantitative</td>
<td>57 siblings ages 12–18 during the fourth wave of an ongoing longitudinal study of families with adolescents and adults with an ASD.</td>
<td>No</td>
</tr>
<tr>
<td>Padilla, C. (2013).</td>
<td>Project PowerPoint</td>
<td>Padilla created a power point explaining the importance of support groups for families of children with Autism to teachers and school administration.</td>
<td>No</td>
</tr>
<tr>
<td>Pitter, J. (2009).</td>
<td>Supporting siblings newspaper article</td>
<td>Supporting siblings newspaper article</td>
<td>No</td>
</tr>
<tr>
<td>Rivers, J., &amp; Stoneman, Z. (2008).</td>
<td>Descriptive analysis</td>
<td>Fifty families participated in the study. Families had a child with ASD between the ages of 4 and 12, as well as a typically N zero.</td>
<td>No</td>
</tr>
<tr>
<td>Author(s)</td>
<td>Title</td>
<td>Study Type</td>
<td>Participants</td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>-------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Ross, H., Ross, M., Stein, N., &amp; Trabasso, T. (2006).</td>
<td>How siblings resolve their conflicts: The importance of first offers, planning, and limited opposition. <em>Child Development, 77</em> (6), 1730 – 1745.</td>
<td>Quantitative</td>
<td>64 sibling dyads (4 – 12 years old; 61% males; 83% European-American) 58 families with four participating family members (mother, father, older child, and younger child) and 6 families with three participating family members (mother and 2 children) provided data. Older siblings (34 boys and 30 girls) were 8.9 years of age on average (SD 1.17, range 56.2 – 12.4 years). Younger siblings (44 boys and 20 girls) were 5.8 years of age (SD 0.93, range 53.6 – 7.9 years).</td>
</tr>
<tr>
<td>Se Kwang, H. (2009).</td>
<td>Same but different: A visual ethnography of the everyday lives of siblings with autistic children in South Korea (Doctoral dissertation, Durham University). Retrieved from <a href="http://etheses.dur.ac.uk/2117/">http://etheses.dur.ac.uk/2117/</a>.</td>
<td>Visual ethnography</td>
<td>Nine children, aged between aged 7 and 15, in two South Korean cities were Social psychological, young carers, the new sociology of</td>
</tr>
<tr>
<td>Reference</td>
<td>Methodology</td>
<td>Participants</td>
<td>Cultural Context</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------</td>
<td>---------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Volling, B. (2012). Family transitions following the birth of a sibling: An empirical review of changes in the firstborn’s adjustment. Psychological Bulletin, 138(3), 497-528.</td>
<td>Literature review summarizes research examining change in firstborns’ adjustment to determine whether there is evidence that the TTS is disruptive</td>
<td>30 studies</td>
<td>No</td>
</tr>
<tr>
<td>Study</td>
<td>Participants</td>
<td>Methodology</td>
<td>Abstract</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>--------------</td>
<td>-------------</td>
<td>----------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Yeh, H. &amp; Lempers, J. (2004).</strong> Perceived sibling relationships and adolescent development. <em>Journal of Youth and Adolescence</em>, 33 (2), 133-147.</td>
<td>3-wave data longitudinal, 374 families studied the potential effects of sibling relationships on adolescent development across early and middle adolescence.</td>
<td>Quantitative</td>
<td>No</td>
</tr>
</tbody>
</table>
APPENDIX J


APPENDIX K

Bronfenbrenner Ecological Systems Theory Diagram: From a Sibling Perspective
APPENDIX L

Research Ethics Board Certificate of Approval

University of Regina

Research Ethics Board
Certificate of Amendment Approval

PRINCIPAL INVESTIGATOR:
Amanda Elia Day
9 – 410 Kawarli Crescent
Saskatoon, SK S7N 4R6

SUPERVISOR:
Dr. Randy Johnson – Faculty of Social Work

DEPARTMENT:
Social Work

RZB#:
2014-021

FUNDER(S):
Unfunded

TITLE:
Exploring the Lived Experiences of Siblings who Grow Up with a Sibling Diagnosed with Autism Spectrum Disorder

AMENDMENT APPROVAL OF:
February 26, 2014

ORIGINAL DATE of APPROVAL:
February 26, 2014

CURRENT EXPIRY DATE:
February 26, 2015

Date of Amendment Approval:
April 21, 2014

Full Board Meeting
Delegated Review

AMENDMENT CERTIFICATION:
The University of Regina Research Ethics Board has reviewed the changes to the above-named research project in your e-mail memo dated April 16, 2014, and they are approved.

ONGOING REVIEW REQUIREMENTS:
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/REB/main.shtml

Dr. Lelana Hoobler, Chair
University of Regina
Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775 Fax: (306) 585-4893
research.ethics@uregina.ca
APPENDIX M

Research Ethics Board Certificate of Amendment of Approval

<table>
<thead>
<tr>
<th>PRINCIPAL INVESTIGATOR</th>
<th>DEPARTMENT</th>
<th>REBs#</th>
</tr>
</thead>
<tbody>
<tr>
<td>Amanda Ellis Day</td>
<td>Social Work</td>
<td>2014-021</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>SUPERVISOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. Randy John – Faculty of Social Work</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FUNDER(S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unfunded</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TITLE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exploring the Lived Experiences of Siblings who Grow Up with a Sibling Diagnosed with Autism Spectrum Disorder</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>AMENDMENT APPROVAL OF</th>
</tr>
</thead>
<tbody>
<tr>
<td>To Recruit on-line</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ORIGINAL DATE of APPROVAL</th>
<th>CURRENT EXPIRY DATE</th>
<th>Date of Amendment Approval</th>
</tr>
</thead>
<tbody>
<tr>
<td>February 26, 2014</td>
<td>February 26, 2015</td>
<td>July 3, 2014</td>
</tr>
</tbody>
</table>

- Full Board Meeting
- Delegated Review

AMENDMENT CERTIFICATION
The University of Regina Research Ethics Board has reviewed the changes to the above-named research project in your e-mail memo dated June 26, 2014, and they are approved.

ONGOING REVIEW REQUIREMENTS
In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: http://www.uregina.ca/research/REB-main.shtml

Dr. Larissa Hurley, Chair
University of Regina
Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
Research and Innovation Centre 109
Regina, SK S4S 0A2
Telephone: (306) 585-4775
Telefax: (306) 585-4803
research.ethics@uregina.ca
APPENDIX N

Research Ethics Board Certificate of Amendment of Approval

University of Regina

Research Ethics Board
Certificate of Amendment Approval

PRINCIPAL INVESTIGATOR
Amadeo Elias Dav
5 – 410 Ross Hall
Saskatoon, SK, S7N 3Z6

DEPARTMENT
Social Work

REB #
2014-021

SUPERVISOR
Dr. Randy Johnson - Faculty of Social Work

FUNDING:
Unfunded

TITLE
Exploring the Lived Experience of Siblings who Grow Up with a Sibling Diagnosed with Autism Spectrum Disorder

AMENDMENT APPROVAL

Rationale: The research project seeks to expand the age range of the study to include participants who are 18 years old and above.

In light of this expansion, the Research Ethics Board (REB) has reviewed and approved the amendment to the study.

Please refer to the following website for further instructions: http://www.uregina.ca/ethics/amend.html

Dr. Laura Hebert, Chair
University of Regina Research Ethics Board

Please send all correspondence to:
Office for Research, Innovation and Partnership
University of Regina
100 Wiggins Road, Grace Hospital Centre 108
Saskatoon, SK, S7N 5A9
Telephone: (306) 585-4775 Fax: (306) 585-4990
research.ethics@uregina.ca
APPENDIX O

Research Ethics Board Certificate of Amendment of Approval

[Content of the certificate is shown with details such as Principal Investigator, Department, REB#, Title, AMENDMENT APPROVAL OF, ORIGINAL DATE of APPROVAL, CURRENT EXPIRY DATE, Data of Amendment Approval, and signatures.]
APPENDIX P

Aaron’s Interview Pictures

Aaron, personal communication, June 28, 2014
APPENDIX Q

Charlotte’s Interview Pictures

Charlotte, personal communication, July 19, 2014
APPENDIX R

David’s Interview Pictures

David, personal communication, July 9, 2014
APPENDIX S

Natalie’s Interview Pictures

Natalie, personal communication, July 17, 2014
APPENDIX T

Shawn’s Interview Pictures

Shawn, personal communication, August 15, 2014
APPENDIX U

Diagram of Study Themes