

The Psychosocial Effects of Having a Sibling with Autism Spectrum Disorder

Norah Jesseca Perlman

A Thesis

In

The Department

Of

Education

Presented in Partial Fulfillment of the Requirements

For the Degree of Master of Arts (Child Studies) at

Concordia University

Montreal, Quebec, Canada

August 28, 2019

© Norah Jesseca Perlman, 2019

CONCORDIA UNIVERSITY

School of Graduate Studies

This is to certify that the thesis prepared

By: Norah Jesseca Perlman

Entitled: The Psychosocial Effects of Having a Sibling with Autism Spectrum
Disorder

and submitted in partial fulfillment of the requirements for the degree of

Master of Arts (Child Studies)

complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the final Examining Committee:

_____ Chair

Chair's name

_____ Examiner

Miranda D'Amico

_____ Examiner

Hariclia Petrakos

_____ Supervisor

Nina Howe

Approved by _____

Chair of Department or Graduate Program Director

_____ 2019 _____

Dean of Faculty

ABSTRACT

The Psychosocial Effects of Having a Sibling with Autism Spectrum Disorder

Norah Jesseca Perlman

As siblings play an important role in one another's cognitive, affective, behavioral, and social development, the sibling relationship is an important subsystem within the family unit. However, in families where one child has an Autism Spectrum Disorder diagnosis, the dynamics between family members may be different due to the associated deficits in communication. Therefore, the purpose of this mixed method study was to explore the perceptions of six typically developing children with a sibling with autism and their parents. Semi-structured interviews and questionnaires were used for both parents and the typically developing child, which allowed for an in-depth investigation into the sibling relationship. Identification of major themes followed by focused coding was conducted in order to capture the essence of what was said and to categorize the most frequent themes. Overall, both parents and typically developing children had positive and negative things to say about the relationship. Additionally, typically developing children seem to be at a loss for coping strategies that they consider helpful, perhaps due to their own poor emotional regulation skills. This study emphasizes the need to support typically developing children and their development, as well as parents. Parents also identified other themes beyond the sibling relationship such as the perceived poor quality of public services received, the school experience, and their reactions towards the diagnosis.

Acknowledgements

I would first and foremost like to thank my supervisor, Dr. Nina Howe, for her continuous support, encouragement, motivation, and optimism throughout this process. Without her dedication to her students, and guidance this past year would not have been the same. I am truly grateful and appreciative. I would also like to thank my committee, Dr. Hariclia Petrakos and Dr. Miranda D'Amico, for their support and advice.

A special thank you goes to all participating families, without whom this study would not be possible. It was a pleasure meeting and speaking with parents and siblings of children with autism, as it was a learning experience I could not have achieved any other way. Their stories and experiences deserve to be heard, and I am thankful to be the one to voice it.

Last, but certainly not least, I would like to thank my family and friends for standing by my side and supporting me constantly. Again, this would not have been possible without your love and commitment.

Table of Contents

List of Tables.....	vii
List of Figures.....	viii
List of Appendices.....	ix
Introduction.....	1
Theoretical Perspectives.....	1
Peer Modeling Theory.....	1
Family Systems Theory.....	2
Positive Psychology.....	3
Review of the Literature.....	4
Understanding Autism Spectrum Disorder.....	4
The Impact of ASD on Parents.....	6
The Importance of Siblings.....	7
The Siblings Influence on the Child with ASD.....	8
The Sibling Relationship in Families with a Child with ASD.....	10
The Experiences and Perceptions of Typically Developing Siblings.....	11
The Adjustment of Siblings of Children with ASD.....	12
Birth Order.....	13
Gender.....	14
Positive Adjustment.....	15
The Broad Autistic Phenotype.....	16
Coping Strategies of Typically Developing Children.....	17
The Present Study.....	18

Method.....	19
Participants.....	19
Procedure.....	23
Materials.....	24
Questionnaire and Thematic Analysis.....	28
Results.....	31
Descriptive Information.....	31
Perspective of the Child with ASD.....	38
Focal Child’s Perspective of Sibling Relationship.....	43
Parent Interview.....	52
Discussion.....	69
How Typically Developing Children Describe Their Sibling Relationship.....	70
Birth Order.....	74
Emphasis.....	75
Coping Strategies Used by Typically Developing Children.....	75
Adjustment of the Typically Developing and Sibling with ASD.....	77
Parents Reactions Towards Public and Private Services.....	79
Limitations and Future Directions.....	80
Role of the Researcher.....	82
Conclusion.....	82
References.....	84
Appendices.....	93

List of Tables

Table 1. Ranges, Means, Standard Deviations, and Percentages for Parent Demographic Information.....	29
Table 2. Ranges, Means, Standard Deviations, and Percentages for Child and Sibling Demographic Information.....	30
Table 3. Ranges, Means, and Standard Deviations on the Sibling Relationship Questionnaire (SRQ)	36
Table 4. Ranges, Means, and Standard Deviations on the Daily Events Scale for Siblings of Children with a Disability or Illness (DES)	36
Table 5. Ranges, Means, and Standard Deviations on the KIDCOPE.....	37
Table 6. Ranges, Means, and Standard Deviations on the Parental Expectations and Perceptions of Sibling Relationship Questionnaire (PEPC-SRQ).....	37

List of Figures

Figure 1. Focal Child Analysis of their Sibling with ASD..... 39

Figure 2. Focal Child Analysis..... 44

Figure 3. Parent Analysis 53

List of Appendices

Appendix A.....	93
<i>Ethics Form</i>	
Appendix B.....	106
<i>Recruitment Forms</i>	
Appendix C.....	110
<i>Parent Consent Form and Child Assent Script</i>	
Appendix D.....	114
<i>Demographic Questionnaire for Parents</i>	
Appendix E.....	117
<i>Parental Expectations and Perceptions of Sibling Relationship Questionnaire (PEPC SRQ)</i>	
Appendix F.....	122
<i>Parent Interview Questions</i>	
Appendix G.....	123
<i>Sibling Relationship Questionnaire (SRQ)</i>	
Appendix H.....	125
<i>Daily Events Scale for Siblings of Children with a Disability or Illness (DES)</i>	
Appendix I.....	129
<i>KIDCOPE</i>	
Appendix J.....	130
<i>Child Interview Questions</i>	

The Psychosocial Effects of Having a Sibling with Autism Spectrum Disorder

Introduction

In 2015, the prevalence of Autism Spectrum Disorder (ASD) diagnoses in Canada was 1 in 66 children between the ages of five and seventeen (Government of Canada, 2018). Due to its high prevalence in our society, the associated social and communication deficits, as well as idiosyncratic behaviors, it is vital to understand the impact such disorders have on the family members of these children. As children's first playmates and social partners are their sibling(s) (Dunn, 2007), it is crucial to understand the dynamics between siblings when one has an ASD diagnosis. The following literature review will discuss theoretical perspectives used to frame the experiences and outcomes of siblings of children with an ASD diagnosis. Findings from empirical research will be reviewed to shed light on the impact a child with ASD has on the family unit. This review forms the basis for the current investigation of typically developing children's perceptions and experiences of having a sibling with autism.

Theoretical Perspectives

Peer modeling theory. Peer Modeling Theory's central notion is that one's own behavior is learned through the observation of others and is later strengthened and reinforced by engaging in said behavior (Richard, Heathfield, & Jensen, 2010). Ideally, the model would demonstrate appropriate behaviors, although peer modeling can foster change in one's comportment for the good and the bad. For instance, Habelrih, Hicks, and Vanstone (2018) hypothesized that siblings of children with autism would fare worse compared to siblings of typically developing children in their social, emotional, and academic efficacy. While the siblings' of children with autism emotional and social skills were lower than control siblings, their academic performance was comparable. As there are several risk factors in the homes of the

ASD-sibling group (e.g., parental stress, extra responsibilities), the authors attributed the sibling's academic success to observing the study methods and work habits used by their classmates and friends. By seeing school-aged peers succeed, siblings may have been motivated to do well, thus increasing their perception of their own academic abilities and performance.

As siblings are children's first play partner they serve as important developmental models for one another (Dunn, 2007). Jones and Schwartz (2004) explored the effectiveness of peer, sibling, and adult models in improving the language acquisition of children with autism. Their study demonstrated that children with autism responded positively to all three models, although many displayed a preference for similar-aged teachers. The study further supported the concept that children are effective models for teaching children with autism various language and behavioral skills. Due to the significant amount of time siblings spend together as children, the authors argued that siblings might learn the most from each other, thus demonstrating the importance of the sibling relationship.

Family systems theory. Family Systems Theory has several assumptions: (a) family characteristics are inputted into the system, producing a response, (b) the family as a whole is affected by the relationship between its members, and (c) boundaries exist between family subsystems and the outside world (Cridland, Jones, Magee, & Caputi, 2014). Essentially, the psychological wellbeing of one family member influences the wellbeing of all other family members, and vice versa. Also, the relationship between a subsystem within the family (e.g., parent-child, sibling) impacts the rest of the family unit. A review of the empirical literature concerning the socioemotional and behavioral adjustment of siblings of children with autism revealed mixed results (Meadan, Stoner, & Angell, 2010). Some children reportedly benefited from their family circumstances (i.e., heightened self-concept and social skills), whereas others

reacted more negatively to their experiences (i.e., increased internalizing and externalizing problems, lower levels of prosociality). It is reasonable to propose that behaviors evident in other subsystems within the family, such as parenting style, marital satisfaction, and the presence of extended family, may in part contribute to the outcomes of typically developing siblings.

Positive psychology. Positive psychology at the subjective level focuses on one's experiences: individual's wellbeing, satisfaction, hopes for the future, and happiness. At the individual level it is about the individual's positive traits, be it interpersonal skills, romantic relationships, wisdom, courage, originality, or any characteristic that contributes to an individual's wellbeing (Seligman & Csikszentmihalyi, 2000). The mission of Seligman and Csikszentmihalyi was to remind professionals that psychology is not solely about weakness and mental illness, but involves the study and development of virtue and strength as well. Much of the disability research focuses on difficulties experienced by family members, thus it is equally important to understand the positive aspects and gains experienced by family members of children with disabilities, which is largely missing in the extant literature. Bloch and Weinstein (2009) assert that professionals have to identify personal and family strengths when developing treatment or intervention programs for families of children with autism, so as not only to focus on what needs improving. To maintain a positive and warm relationship in a somewhat difficult circumstance, the focus cannot be on only the struggles, but has to include and develop the more favorable features.

While this concept is not a theory of development, it is useful in the everyday lives of individuals. It is important for parents, family members, teachers, and clinicians to keep this in mind to instill values, happiness, and positivity in children. Seligman's (Seligman & Csikszentmihalyi, 2000) theory of wellbeing can perhaps help explain the different outcomes of

siblings of children with special needs. This theory emphasizes positive emotions, engagement in enjoyable activities, relationships with family, friends, and a larger network, meaning and purpose, and accomplishments, which in families with children with disabilities is not always valued to the extent that it might be in families with typically developing children.

By looking at the family as a single unit one can ascertain the degree of warmth, positive and negative feedback, and other information to increase one's knowledge of family functioning. This is useful in families where a child has a disability as it can help in understanding individual roles and guide future intervention techniques. Family systems theory and peer modeling theory are helpful in understanding the importance of family in the context of socioemotional and behavioral development. While family systems theory considers the family as a whole, peer modeling theory emphasizes the importance of siblings as a driving force in development. The two concepts together create a more complete picture in understanding child development of all children when one has an ASD diagnosis.

Review of the Literature

Understanding Autism Spectrum Disorder

Autism spectrum disorder is defined and diagnosed by the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, hereafter referred to as the DSM-V (American Psychiatric Association, 2013). The DSM-V characterizes autism spectrum disorders as the abnormal development of social communication and interactions across various settings, as well as the use of restricted and repetitive behaviors, interests, or activities. The severity of diagnosis is determined by the level of impairment in the two psychopathological domains. The essential features to obtain an ASD diagnosis are (1) persistent impairment in reciprocal social communication and social interaction, (2) restricted, repetitive patterns of behaviors, interests, or

activities, and (3) the symptoms are present from early childhood and impair or limit everyday functioning (American Psychiatric Association, 2013).

Symptoms are often seen within the second year of life, however, if severe enough, signs can be detected before 12 months of age. Infants may demonstrate little to no eye contact and joint attention, or an overall lack of social interest. Over time delayed language development or regression is common, as well as odd play patterns, unusual communication patterns, and continued little social interest in others. During the second year of life, these odd and repetitive behaviors become more apparent as described in the DSM-5 manual (American Psychiatric Association, 2013).

Researchers have set out to examine how children with ASD play in both solitary and dyadic settings. Observational methods have been used to identify at what frequency several play behaviors occur, such as prosocial and agonistic acts, initiations, and responses within the sibling dyad. Children with autism are less likely to initiate play and are more likely to ignore others' initiations towards them than typically developing children (Knot, Lewis, & Williams, 1995; MacDonald, Hatfield, & Twardzik, 2017). When children with autism do react to another child, it is often in an agonistic and negative manner (Bontinck, Warreyn, Paelt, Demurie, & Roeyers, 2018). Their lack of communication skills may be frustrating, causing an outburst as their means of expressing themselves.

Alternatively, their lack of communication skills might explain why children with an ASD diagnosis seem to prefer solitary play (Holmes & Willoughby, 2005). Holmes and Willoughby evaluated the social level of play that children with ASD engage in at school and at home. They found that their kindergarten-age sample of children with an autism diagnosis preferred solitary and functional play. Essentially, these children used toys and objects the way

they are supposed to be used and preferred to do so independently. Since children with ASD had a harder time engaging in constructive, exploratory, make believe, and dyadic play it can be said that imaginative and creative play is more difficult for these children. Overall, it seems that children with autism communicate less than typically developing individuals during play (Kaminsky & Dewey, 2002; Knot, Lewis, & Williams, 2007; Ward, Tanner, Mandelco, Dyches, & Freeborn, 2016).

The Impact of Autism on Parents

After an ASD diagnosis is received the entire family unit has to readjust. At first parents may be in denial and feel depressed, angry, helpless, and fearful, which impedes optimal family functioning as not everyone's needs are being met (Bloch & Weinstein, 2009). It is commonly found that mothers of children with autism report feeling more stressed (Hastings, 2003b; Rao & Beidel, 2009; Walton & Ingersoll, 2015) and depressed (Hastings et al., 2005) than their partners and mothers of typically developing children. This is possibly due to mothers spending more time with their children and often tackling daily responsibilities concerning their children (Hastings, 2003b). Alternatively, in a Canadian study on the needs of families of children with autism, families reported they received little information about the various programs and services available to them, social activities suitable for their child, and community services (Brown, Oullette-Kuntz, Hunter, Kelley & Cobigo, 2012). This may augment parental stress, as now they have to dig to find information. The physical health of mothers of children with autism is also poorer than mothers of typically developing children (Rao & Beidel, 2009). Despite the negative toll a child with ASD seems to have on mothers, Hastings et al. (2005) found that their perception of their child with special needs tends to be more positive than that of their spouses. Bloch and Weinstein (2009) suggested that fathers struggle with not being able to "fix the

problem” while simultaneously feeling that they have to be strong for their family. Such disregard for their emotional wellbeing may leave fathers feeling isolated and bitter towards the situation. In line with family systems theory, parents experiencing stress may influence their child’s emotional, cognitive, and social development in a negative manner.

The Importance of Siblings

As siblings share parents, space, and property their relationship is considered intense and intimate. Siblings provide each other with their first social experiences and act as important developmental influences on one another (Dunn, 2007; Howe, Ross, & Recchia, 2011). Cognitive, affective, behavioral, and social skills are practiced through their continuous interactions, which allows them to share and experience friendship, loyalty, support, and rivalry (Buhrmester, 1992). Due to the significant amount of time siblings spend together in childhood and their individual personalities, their exchanges can involve positive, negative, and ambivalent affect. Both positive and negative interactions are important for their cognitive and socioemotional development (Howe et al., 2011), as different skills, behaviors, and emotions are developed and strengthened through play and conflict.

Play is a complex social activity that requires partners to collaborate and negotiate to reach a common and agreed upon framework (Göncü, 1993). For play to occur, children have to determine the play theme, interpret play actions, and establish guiding rules. In order to develop and maintain such shared understandings children will use internal state language, or references to their cognitions (Dunn, 1998). By using such language play partners are able to express their perspectives, beliefs, thoughts, and feelings, as well as understand those of their play mate (Howe, 1991; Howe, Petrakos, & Rinaldi, 1998). By school-age, children are more able to express their cognitions to their sibling, perhaps due to their shared history (Leach, Howe, &

Dehart, 2017). The use of prosocial behaviors, such as teaching, sharing, and laughing further contribute to the development of shared understandings (Göncü, 1993; Howe, Rinaldi, Jennings, & Petrakos, 2002), as their interactions are more likely to be of a positive nature and be more engaging than acts of antagonism (Howe & Recchia, 2005).

However, sibling conflict is a normal part of sibling relations as children's goals and desires are not always compatible with one another. Through conflict resolution children develop social understanding as they process another's perspective, while further learning about themselves through defending their own position (Howe et al., 2011). Brody (2004) states that younger siblings who engage in conflict tend to be more socially competent and better equipped to maintain positive peer relationships, as skills such as managing one's emotions, understanding their partner's emotions and viewpoints, and conflict resolution skills are generalized to peers. Excessive fighting and aggression, however, is associated with poorer adjustment. Dunn (2007) postulates that relationships consisting of high hostility and low warmth increase one's risk for internalizing and externalizing difficulties. In a literature review on sibling relationships, Dirks, Persram, Recchia, and Howe (2015) reported moderate associations between sibling conflict and internalizing and externalizing symptoms. While sibling disputes are normative, it is clear that some are harmful at both the dyadic and individual level. Moreover, the negative behaviors acquired during sibling conflict are likely to be generalized to peers, which can be harmful to children's social success. When conflicts are repeatedly unresolved, children do not have the opportunity to practice empathetic and prosocial behaviors. Consequently, their emotional regulation and social understanding skills are limited.

Siblings' Influence on the Child with Autism

Studies reveal that the presence of a neurotypical sibling can have a positive impact on

children with autism. Specifically, the presence of a typically developing older sibling is associated with less severe deficits in their sibling with ASD. Ben-Itzhak, Zukerman, and Zachor (2016) found that children with autism had less severe communication impairments and were less likely to engage in negative affect when there was a typically developing older sibling in the home. Similarly, Knot et al. (2007) in their longitudinal study found that children with autism demonstrated a decrease in their use of agnostic behaviors whereas the rate of positive reactions increased towards their sibling over a 12-month period. Perhaps the older sibling acts as a model for their sibling with autism. Through observing, learning from, and practicing with their socially adept sibling there is a positive influence on their own abilities.

Researchers have further assessed the use of siblings in intervention studies, which have yielded positive results. In a study conducted by Tsao and Odom (2006), four sibling dyads participated in which one sibling in the dyad had an ASD diagnosis. The typically developing siblings were given lessons on how to facilitate play with their sibling with ASD, such as skills to initiate conversation, suggest activities, offer or ask for help, and make eye contact. After training, increases in the quality and quantity of interactions between siblings were seen. Three of the typically developing siblings interacted more with their sibling with ASD and were able to generalize these prompts outside of the home environment. The children with autism demonstrated improved joint attention, social behaviors and responses, and overall engagement after their siblings' training, as well.

Similar results were found by Oppenheim-Leaf, Leaf, Dozier, Sheldon, and Sherman (2012), in which three typically developing siblings were given skills training on how to enable play and how to gauge the appropriate times to implement such strategies. All of the typically developing children increased their use of verbal requests, physical and verbal prompts, and

praise for appropriate behavior towards their sibling with ASD. Likewise, their siblings engaged in more cooperative and parallel play after their typically developing sibling received training. One child further demonstrated a decrease in negative interactions after his sibling's training. Evidently, the social skills of children with autism can be enhanced with the proper strategies in place.

The Sibling Relationship in Families with a Child with ASD

As children, siblings spend an ample amount of time together allowing them to develop a deep understanding of one another and strong ties. This is not always the case in ASD-afflicted families, as studies have demonstrated that typically developing siblings spend less time with their sibling with autism compared to siblings with Down Syndrome (Knot et al., 1995; Stoneman, 2001) or other typically developing siblings (Walton & Ingersoll, 2015). Ferraioli and Harris (2010) proposed that siblings of children with autism spend less time together because of a widening gap in development. While the child with autism remains at a young developmental level the typically developing sibling matures, and perhaps loses interest in their sibling. Alternatively, the odd, ritualistic, and aggressive behaviors and poor communication skills of children with autism may deter their sibling from playing with them.

Kaminsky and Dewey (2001) examined the sibling relationship of children with autism compared to siblings of children with Down Syndrome and typically developing siblings through the use of various questionnaires. Researchers found that the ASD-sibling group reported lower levels of intimacy, nurturance, and acts of prosocial behaviors relative to siblings of children with Down Syndrome and typically developing children. Such findings are not surprising, as children with autism have deficits in emotional regulation, perspective taking, expressive language, and engage in odd behaviors. However, not all results were of a negative nature. The

ASD-sibling group also reported lower levels of quarreling, competition, and increased admiration for their sibling compared to typically developing dyads.

Rivers and Stoneman (2008) attributed persistence to sibling's positive relationship quality. In their study, typically developing siblings who demonstrated high levels of persistence were reported by parents as being more empathetic and concerned for their sibling with ASD, as engaging in fewer unkind, negative, or avoidant behaviors toward their sibling. Perhaps the trait of persistence in difficult situations buffers the negative effects of their family context.

The Experiences and Perceptions of Typically Developing Siblings

By the time siblings of children with ASD reach school age they have a decent understanding of autism and its implications within their family system (Ross & Cuskelly, 2006), partially due to the amount of time they have spent together. Like any sibling relationship, typically developing children are often conflicted between the positive and negative aspects of their relationship (Baumann, Dyches, & Braddick, 2005; Orfus & Howe, 2008; Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Rao & Biedel, 2009; Verté, Roeyers, & Buysse, 2003; Ward et al., 2016).

Ward and colleagues (2016) and Petalas and colleagues (2012) interviewed the brothers and sisters of children with ASD in order to gain perspective into their experiences. Although Petalas et al.'s sample consisted of adolescents and Ward et al. had a broader age range of school-aged and adolescent siblings, the studies yielded similar conclusions. Both studies identified positive and negative themes regarding having sibling with ASD. The positive aspects of having a sibling with autism were parallel in both studies – the positive disposition and character of their sibling, and what they had learned and gained from their circumstances were highlighted by almost all siblings. As for the more arduous aspects, both studies revealed that the

aggressive and odd behaviors of their sibling with ASD was difficult at times. Ward et al. (2016) further discerned that the challenging aspects revolved around not just their sibling, but their family dynamics as well. Siblings were frustrated at times with the extra responsibilities they had to assume, as well as receiving less parental attention than their sibling. Petalas et al. (2012) heard from their sample of typically developing siblings that they often felt embarrassed by their sibling in social situations. Moreover, the responses or reactions of their peers were often unhelpful and caused anger, frustration, and disappointment.

Studies demonstrate associations between parental stress and poor child adjustment (Hesse, Danko, & Budd, 2013) and delays in social skill development (Pilowsky, Yirmiya, Doppelt, Gross-Tsur, & Shalev, 2004) in the typically developing younger sibling. As parental treatment of the younger child is largely influenced by the older child's characteristics (Brody, 2004), neurotypical younger siblings seem to be negatively impacted by parental stress associated with having a child with ASD. Differential treatment of children often occurs in times of stress and can leave the responsible child feeling jealous or angry (Dunn, 2007; Rivers & Stoneman, 2003). Bauman et al. (2005) learned through their study of typically developing siblings that they often felt that they received less attention from their parents and had to assume a caregiving role, which stopped them from engaging in social activities or outings. Perhaps not engaging in pleasurable activities or developing social relations can further explain the negative adjustment of the typically developing sibling. However, Kaminsky and Dewey (2002) found that typically developing children of parents who attended support groups did not experience less perceived support, which was associated with low levels of loneliness and enhanced academic performance and social satisfaction.

Adjustment of Siblings of Children with Autism

Several studies have assessed sibling's psychosocial outcome when one child has an ASD diagnosis, which have yielded contradictory findings. Family systems perspective (Cridland et al., 2014) posits that the psychological wellbeing of one family member influences the wellbeing of all other members within the system. As such, siblings of children with autism are considered to be at an increased risk for poor psychosocial adjustment. For example, studies have found that typically developing siblings of children with autism have a greater chance of experiencing externalizing and internalizing problems (Brewton, Nowell, Lasala, & Goin-Kochel, 2012; Rodrigue, Geffken, & Morgan, 1993; Ross & Cuskelly, 2006; Vaudrey, 2015; Verté et al., 2003). Moreover, these children demonstrate higher levels of social problems when compared to siblings of typically developing children (Habelrih et al., 2018; Hastings, 2003a; Kaminsky & Dewey, 2002). Such social deficits may stem from not having a partner to practice play, conflict, and conflict resolution skills with, which may render children less socially skilled when they reach school age. Alternatively, typically developing children might adopt certain behaviors from their sibling with ASD. Rao and Beidel (2009) assessed the impact of high-functioning autism on parents and non-ASD siblings alike. These families scored lower than control families in family independence, personal growth, and engagement in social and recreational activities. This lack of individuality, freedom, and interaction with non-ASD peers incurred by some siblings may further explain their adjustment difficulties.

Birth order. Verté et al. (2003) found that siblings who are younger than the child with ASD were more likely to experience internalizing and externalizing difficulties than siblings who are older. This was especially true for children between the ages of 6 and 11. Perhaps siblings at this age are becoming more aware of parental differential treatment and act out as a means of attaining additional attention. Additionally, at this age children may be more aware of their

siblings' oddities due to their increased interaction with peers. However, with age siblings also seem to become more empathetic toward their sibling with ASD (Pilowski et al., 2004). Orfus and Howe (2008) uncovered that siblings focus on different stressors related to their sibling with ASD at different ages. Their study revealed that younger children are more self-focused, in that they felt most stressed when they were not able to do something because of their sibling with ASD. That coupled with their immature coping and expressive abilities may help explain the adjustment difficulties seen in younger siblings.

Older siblings, however, seem to be other-focused in their thinking, especially towards their sibling with ASD (Orfus & Howe, 2008; Ward et al., 2016). Orfus and Howe found that typically developing older siblings react more negatively when something affects their sibling with ASD, be it emotionally, physically, or health wise. As such, older siblings reported more daily hassles due to their sibling with ASD and fewer positive interactions. This may partially explain why some studies have found that older brothers seem to be at risk for behavioral problems (Hastings, 2003a; Rodrigue et al., 1993; Walton & Ingersoll, 2015). Older siblings seem to put family first, which may contribute to such behaviors.

Gender. There seems to be apparent gender differences in the outcomes of children whose siblings have an ASD diagnosis. Sisters, both younger and older than their sibling with autism, are more socially competent and have a more positive self-concept when compared to siblings of typically developing children (Kaminsky & Dewey, 2002; Pilowski et al., 2004; Rodrigue et al., 1993; Verté et al., 2003). Orfus and Howe (2008) revealed that sisters were more likely to seek out social support to cope with their struggles, whereas brothers were more likely to engage in wishful thinking, which is a possible mechanism to explain such gender differences. Sisters' tendency to express themselves may contribute to their social skills and self-perception,

whereas wishful thinking separates one from reality.

On the other hand, typically developing brothers tend to focus on the aggressive behavior of their sibling with ASD (Ward et al., 2016). While aggression was described as one of the more common stressors among typically developing siblings, brothers increased attention to it may explain why they are at a greater risk for increased hyperactivity, poor peer relations (Walton & Ingersoll, 2015) and prosociality (Hastings, 2003a), and internalizing problems compared to sisters (Rodrigue et al., 1993; Ross & Cuskelly, 2006). Rodrigue et al. (1993) attributed the higher rates of externalizing behaviors to the change in family dynamics that occurred when the sibling with ASD arrived, including having to take on a nurturing role.

Positive adjustment. Several studies have found no difference in adjustment or ill effects between siblings of typically developing children and siblings of children with autism (Kaminsky & Dewey, 2002; Pilowski et al., 2004; Walton & Ingersoll, 2015). Beyond no difference, some siblings demonstrate increased competencies in certain domains. A common finding is that typically developing siblings experience a heightened self-concept (Bloch & Weinstein, 2009; Ferraioli & Harris, 2010; Macks & Reeve, 2007; Rao & Biedel, 2009; Verté et al., 2003). This may be from a sense of pride and competence siblings acquire from taking care of their sibling with special needs and being present for joyous moments. Walton and Ingersoll (2015) reported that prosociality was higher among siblings of children with autism. Perhaps counterintuitively, social skills are documented as better among siblings of children with autism than of typically developing siblings (Bloch & Weinstein, 2009; Rodrigue et al., 1993; Verté et al., 2003). Macks and Reeve (2007) proposed that siblings of children with autism have to mature faster than some other children, and because of their competencies at home they have a more positive view of their abilities and themselves outside of the home. Alternatively, perhaps

these parents emphasize diverse values, such as the importance of family but also the importance of individuality. Maybe by maintaining a strong sense of family ties and existence outside of the home these children are well-rounded.

The broad autistic phenotype. Hartup (1989) alleged that both individuals within an interaction are developing, perhaps along different paths, but nonetheless are simultaneously developing. The maladjustment of siblings of children with autism may be associated with their sibling interactions, as studies show that infant siblings of children with autism show similar symptomology without receiving an ASD diagnosis. This has been termed the broad autistic phenotype, which can be said to have been first recognized in Folstein and Rutter's (1977) landmark study. In assessing monozygotic twins where only one had an ASD diagnosis, the authors noticed that their sibling demonstrated similar social and cognitive deficits. Specifically, the neurotypical twin siblings exhibited delayed language and speech development, a lack of social interest, and emotional difficulties. Numerous studies have since confirmed this broad autistic phenotype in sibling dyads.

During the face-to-face-still-face task, infant siblings of children with ASD smiled significantly less and remained neutral during the entirety of the task compared to infant siblings of neurotypical children (Cassel et al., 2007). Moreover, siblings smiled less and were more likely to cry during the face-to-face component and smiled more often during the still-face component. This speaks to their preference to be undisturbed and remain unsociable, much like their sibling with ASD. Similarly, siblings of children with autism score significantly lower in receptive and expressive language and symbolic play (Toth, Dawson, Meltzoff, Greenson, & Fein, 2007) and engage in more negative behaviors during play (Bontinck et al., 2018). Bass and Mulick (2007) described that children with autism fail to exhibit eye contact and joint attention,

among other behaviors, which can also be seen in their neurotypical siblings as well. Moreover, studies report that siblings initiate joint attention and respond to joint attention less when there is a child with ASD in the home (Cassel et al., 2007; Toth et al., 2007). As relationships are bidirectional perhaps the sibling with ASD acts as the model for the younger typically developing sibling until an age where the roles can be reversed.

Coping Strategies of Typically Developing Children

As children have had fewer life experiences than adults they may be at an increased risk for experiencing stress, perhaps due to lesser cognitive abilities to recognize available resources. Not only are their cognitions a factor, but their emotional level of development further impacts their appraisal and reaction to stress (Lazarus & Folkman, 1987). Gamble and McHale (1989) classified several coping styles into four general categories. Other-directed behavior, which can be thought of as problem-solving, consists of seeking social support or trying to deal with the problem head-on. Other-directed cognitions occur when blame is placed on someone else or something in the environment. Self-directed behaviors are essentially avoidance or withdrawal, in that activities are done so as to not think about the problem. Lastly, self-directed cognitions are attempts at emotional regulation, such as trying to calm down or thinking of one's own role in the situation. It is important to be aware of whether a child is avoiding or facing a problem, as it can help explain variability in adjustment.

Ross and Cuskelly (2006) examined coping strategies used by siblings of children with ASD. They indicated that the most common coping strategy was wishful thinking, followed by emotional regulation. Similarly, Orfus and Howe (2008) studied the coping strategies of siblings of children with disabilities and came to a parallel conclusion; wishful thinking was the most commonly used mechanism followed by trying to fix the problem. Petalas et al. (2012)

documented that typically developing siblings had many wishes, including having a sibling relationship similar to those of their peers by having a typically developing sibling, or that the birth order was reversed. The high use of wishful thinking can imply that typically developing siblings want things to be different, either for them, their family, or their sibling with special needs. The use of emotion-focused and solution-focused coping further implies that siblings are cognizant of their emotions and circumstances and have to work within the realm of possibilities. Spending time with others and trying to fix the problem were considered to be the most helpful strategies (Orfus & Howe, 2008), although they were not the most used.

The Present Study

Family cohesiveness and unity can be understood through the lens of family systems theory and peer modeling theory, as both are integral in understanding family functioning. When a child is diagnosed with autism, the effect is felt not only by parents, but by the other children in the family as well. Previous research demonstrated that the effects on the typically developing child of having a sibling with ASD can be positive, negative, or a combination of the two. Moreover, there are various factors that come into play when looking at the adjustment of typically developing siblings, such as parental stress, gender, and birth order, just to name a few. To my knowledge, studies have yet to look at adjustment and relationship quality in the context of coping strategies. Thus, the purpose of this mixed-method study was to explore various coping strategies (Gamble & McHale, 1989) used by typically developing siblings, their reports of sibling relationship quality, and psychosocial adjustment. The qualitative aspect of the study takes on a phenomenological research design, as the goal is to understand how and what each sibling experienced by having a sibling with autism (Creswell, 2013). The questions of this study are four-fold: (1) how does the typically developing sibling describe their sibling relationship?

(2) how do the descriptions of the sibling relationship differ relative to birth order and gender? (4) what aspects of their sibling relationships do typically developing siblings emphasize most (i.e., positive, negative)? and (4) what coping strategies are regularly used by the typically developing sibling? As a form of triangulation, parents were also asked questions pertaining to the sibling relationship: (1) can you tell me about your children's relationship? (2) can you describe the behaviors of your child with autism? and (3) how do you think (name of child with autism) behaviors impacts your typically developing child or their sibling relationship?

Method

Participants

Families including at least one child with autism spectrum disorder and at least one neurotypical child were recruited in a large, urban city in Canada by word of mouth and online support groups. Recruitment lasted for three months, at which time a total of six families agreed to participate. Demographic information can be seen in Tables 1 and 2 at the end of the Method section.

Partaking families had between two and four children ($M = 2.83$, $SD = 2.06$). Focal (neurotypical) children were between the age of six and 12 ($M = 8.5$, $SD = 2.07$), five of whom were female, and one was male. Four children were older than their sibling with autism. In families where there was more than one child with autism ($n = 3$), the focal child was asked to focus on the sibling with whom he or she had the closest relationship. Each child will be described in more detail below.

Siblings with autism were between the ages of four and 12 ($M = 8.33$, $SD = 3.50$), four of whom were male. Three siblings attended the same school as their neurotypical sibling(s), and all were receiving services for various aspects of their diagnosis.

All participating parents were biological mothers of the children, with a mean age of 38.16 years ($SD = 4.44$). Two fathers were present at the time of the interview, but did not contribute. Fathers had a mean age of 42.33 years ($SD = 3.20$) and were all employed. Three of the mothers were employed out side of the home (50%). One mother had high school education, one mother attended CEGEP, and three mothers attended university and obtained one degree or more. One family each reported an annual income below \$20,000, between \$35,000 – \$50,000, between \$50,000 – \$75,000, and three families above \$75,000. All families were Caucasian and of various religions; two Catholic families, two Christian families, one Jewish family, and one non-practicing family. Parents were also asked to indicate other stressful events that had occurred over the last 12 months. One mother reported moving, one mother reported divorce, one mother reported loss of an extended family member, two mothers reported loss of an immediate family member, and one mother reported illness or injury to an immediate family member.

Child 1. Child 1 was an 8-year-old boy, living at home with his mother and three sisters, two of whom are autistic. Child 1 is the eldest, followed by a 7-year-old neurotypical sister, and two sisters with autism who were three and four years old. The sister he decided to talk about was the 4-year-old, as she is verbal, which allows for a stronger bond. She was diagnosed with ASD and global developmental delays. He does not go to the same school as his sister, which may be because he is in elementary school and his sister goes to daycare, nor does he receive any services. His mother reported that she and her partner had divorced within the last year.

Child 2. Child 2 was a 9-year-old girl living at home with both of her parents, and her 11-year-old brother with Pervasive Developmental Disorder Not Otherwise Specified. He is considered high functioning and attends the same school as his sister. He was diagnosed at 22

months of age. Child 2 has never received services, although her brother did receive ABA therapy and is currently attending a social group. Her mother indicated that an immediate family member had fallen ill within the last year.

Child 3. Child 3 was a 12-year-old girl living at home with both of her parents, twin 10-year-old brothers who are both on the spectrum, and a younger neurotypical sister. The sibling of focus was diagnosed with ASD, Attention Deficit Hyperactive Disorder, sensory disorders, and learning disabilities at the age of three. As children, the two boys with autism received services in and outside of the home, through both private and public means. However, the family is no longer receiving services. The daughters never received services, and all four children attend the same school.

Child 4. Child 4 is a 6-year-old girl living at home with both of her parents and her 4-year-old brother with ASD and comorbid language impairment. The sibling received his diagnosis at the age of two. Neither child is currently receiving any services, although the sibling with autism is on a waitlist to receive public assistance. The children do not go to the same school, as the sibling with autism is still in day care and his sister is in elementary school. Their mother indicated the loss of both an immediate and extended family member within the last year.

Child 5. Child 5 was a 7-year-old girl living at home with both of her parents and two siblings with autism spectrum disorder; a 12-year-old-sister and a 10-year-old brother. Both siblings were diagnosed with severe ASD, intellectual impairments, and language impairments of varying degrees. Her brother is considered more high functioning than her sister, as he is verbal, and was therefore the sibling of interest. He received his diagnosis at the age of four. The two siblings with autism both attend the same school for children with special needs. Various services were given to both siblings with autism, although presently only the brother is receiving

social skills training. Their mother reported that they moved family residence within the last year.

Child 6. Child 6 was a 9-year-old girl living at home with both of her parents and her 8-year-old brother with ASD and specific learning impairments in reading, written expression, and mathematics. The children are currently in the same school, although the sibling with autism will be transferring to a special needs school in the upcoming academic year. The sibling received his diagnosis at the age of seven. The sibling with autism is currently receiving services, such as occupational therapy and ABA therapy. The mother reported that within the last year they had lost an immediate and extended family member.

Public assistance. Some families received public assistance from two major community centers in Montreal: (1) Local Community Service Centers (CLSC), and (2) a re-adaptation Center. CLSC's are free clinics run by the provincial government of Quebec and offer various services to children and adults. There are currently 147 CLSC's in the province, which offer routine health and social services, preventative and medical services, rehabilitation and reintegration services, and public health activities. The re-adaptation center, also run by the provincial government of Quebec, is geared towards children and adults with ASD's, PDD-NOS, and intellectual disabilities. They offer residential and community integration services, rehabilitation, and habilitation services.

Special needs schools. Two siblings with ASD attended a special needs school in Montreal. Both are subsidized private schools for individuals between the age of four and 21. The school attended by sibling 5 is geared towards individuals with intellectual disabilities, ASD, and psychopathological disorders. They provide instruction in both English and French, and established their curriculum based on the Education Program for Students with Profound

Intellectual Impairments, Preschool Education Program, and Competency-Based Approach to Social Participation (CASP). The other school, which sibling 6 will begin in the upcoming academic year, educates children and adults with intellectual disabilities, ASD, and behavioral and emotional disturbances in English. Here, they offer preschool, a modified primary program, a modified secondary program, CASP, and post-secondary programs.

Procedure

After ethical approval was received (Appendix A), the primary researcher began the recruitment process. Participants were recruited through word of mouth and online support groups (Appendix B). All parents made initial contact with the primary investigator, who then followed through and set up a time to discuss further the aims of the study, the procedure, and answer any questions over the telephone. Once a parent agreed to participate, a time was established to meet. All families were studied in their homes.

Upon meeting the participants, written consent and oral consent was received from the mothers and children, respectively (Appendix C). Parents were given a demographic questionnaire and the Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire (PEPC-SRQ; Kramer & Baron, 1995). Before administering questionnaires to the children, some ice-breaker questions were asked to make the focal child feel more comfortable. The purpose of the study, how participants can help, and the procedure was also explained, at which point they were encouraged to ask any questions. Throughout the process, children were reminded that they were able to take a break, not answer a specific question, or stop entirely at any time. Children were first given a revised version of the Sibling Relationship Questionnaire (SRQ; Buhrmester & Furman, 1990), followed by the Daily Events Scale for Siblings of Children with a Disability or Chronic Illness (Giallo & Gavida-Payne, 2008), and lastly the

KIDCOPE. (Spirito, Stark, & Williams, 1988).

In families where the focal child was older and could answer the questionnaires without assistance, the parent interview took place simultaneously. Then, while the focal child was interviewed, their mother completed her set of questionnaires. In other families, the investigator stayed with the child in order to help explain or read items. Under those circumstances, parents completed their questionnaires at the same time, and the parent interview occurred when the child requested a break. All child interviews took place after the questionnaires were completed. Families were able to choose whether the parent would be present for the child interview. In all families, the mother stayed. All interviews were tape recorded and later transcribed onto Microsoft Word. All data from the questionnaires were entered into SPSS for descriptive information.

Parent Measures

Demographic questionnaire. Parents completed a brief demographic questionnaire related to their home and family environment (See Appendix D). Mothers answered questions such as their marital status, age, gender, religious and cultural affiliations, education level, type of employment, and annual income. Information was also asked concerning their child with special needs and the participating child, such as age, birth order, gender, and other relevant information for the purposes of this study (i.e., services received, extracurricular activities).

Parental Expectations and Perceptions of Children's Sibling Relationships

Questionnaire. The Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire (PEPC-SRQ; Kramer & Baron, 1995) was administered to parents (see Appendix E). Only the second part of this measure was used, which assesses parental appraisal of their children's sibling relationship. The PEPC-SRQ consists of 28 items assessing the degree of

warmth, antagonism, and rivalry and competition. Warmth consists of pride, protectiveness, comfort, loyalty, kindness, help, respect, affection, sharing of worries, talking to and playing with each other, sharing and teaching, and affection. Antagonism consists of behaviors such as fighting over objects or territory, arguing, aggression, anger, threats, unresolved conflicts, and controlling sibling behaviors. Lastly, rivalry, competition, and jealousy make up the final scale. Parents were presented with 27 behaviors and were asked to indicate (a) how frequently each behavior occurs in the sibling relationship, (b) if the behavior is a problem within the sibling relationship, (c) how easily they could improve that aspect of the sibling relationship, and (d) how much help they would need in improving that aspect. The frequency of behaviors is rated on a 5-point Likert scale (1 = *never*, 2 = *rarely*, 3 = *sometimes*, 4 = *usually*, 5 = *always*). The parent's perception of how problematic each behavior is within the relationship is indicated on a 4-point Likert scale, where 1 = *it is not a problem*, 2 = *it is a small problem*, 3 = *it is a big problem*, and 4 = *it is a very big problem*. The parent's ability to improve each aspect is rated on a 5-point Likert scale, where 1 = *very difficult*, 2 = *difficult*, 3 = *neutral*, 4 = *easy*, and 5 = *very easy*. How much help they would like in improving each aspect is rated on a 3-point Likert scale, with 1 = *no help*, 2 = *a little help*, and 3 = *a lot of help*. Lastly, parents were asked to provide an overall rating of the perceived quality of the sibling relationship on a 7-point Likert scale ranging from *very poor* to *extremely well*. The PEPC-SRQ has moderate test-retest reliability and construct reliability; there is also agreement on responses by parents completing the questionnaire separately (Kramer & Baron, 1995).

Parent interview. The parent interview consists of questions related to their perceptions of the sibling relationship quality as well as information regarding the child with ASD and the typically developing child. The interview is semi-structured as it consists of open-ended

questions, with prompts if needed. See Appendix F for the list of interview questions.

Focal Child Measures

The Sibling Relationship Questionnaire. The Sibling Relationship Questionnaire (SRQ; Buhrmester & Furman, 1990) was completed by the participating child, which assesses their perception of their sibling relationship (see Appendix G). A modified version (12 items) was developed from the 49-item SRQ, to assess intimacy/closeness and conflict. For the purposes of this study the power and rivalry scales were removed. The intimacy/closeness factor consists of items assessing the degree of prosociality, companionship, similarity, admiration of their sibling, admiration by their sibling, and affection (i.e., how much do you and your brother/sister tell each other everything?). The conflict factor consists of items assessing the degree of quarreling, antagonism, and competition (i.e., how much do you and your brother/sister insult and call each other names?). The focal child was asked to indicate how much each item is characteristic of their sibling relationship on a 5-point Likert scale (1 = *hardly at all*, 2 = *not too much*, 3 = *somewhat*, 4 = *very much*, 5 = *extremely much*). A higher score is indicative of a greater level of that characteristic. Buhrmester and Furman (1990) reported moderate to high internal consistency coefficients for children in 3rd, 6th, 9th, and 12th grade ranging from .71-.81. The SRQ also has moderate to strong correlations with other family members' reports of the sibling relationship.

The Daily Events Scale for Siblings of Children with a Disability or Chronic Illness.

This scale assesses the content and frequency of daily hassles and uplifts experienced by the participating sibling relative to their sibling with special needs (Giallo & Gavidia-Payne, 2008; see Appendix H). The focal child was asked to rate events on two dimensions: how often each event occurs and how stressed or happy that event makes them feel. A modified version of the

measure was given, in which 18 items were related to stressful events, such as “when my brother or sister with a disability cries or gets upset”, and 15 items were related to uplifts, such as “when my brother or sister with a disability tries hard at something”. The frequency of an event is indicated on a 5-point Likert scale, with 0 = *never*, 2 = *sometimes*, and 4 = *always*. The subjective outcome of the event is also indicated on a 5-point Likert scale, with 0 = *not at all*, 2 = *a bit*, and 4 = *very much*. For both scales the option to circle “1” or “3” is there, although no direct indication is provided for what the numbers represents. For clarification purposes symbols (i.e., sad faces and happy faces) were added to the questionnaire to demonstrate the level of each number. Higher scores are indicative of a greater frequency of the event and associated affect. The measure has high internal consistency with alpha coefficients ranging from .89-.94 (Giallo & Gavidia-Payne, 2008).

KIDCOPE. The KIDCOPE (Spirito et al., 1988) for ages 7-12 was administered to the participating sibling (see Appendix I). The KIDCOPE is a 15-item self-report measure, which assesses ten common behavioral and cognitive coping strategies: distraction, social withdrawal, wishful thinking, self-criticism, blaming others, problem-solving, emotional regulation, cognitive restructuring, social support, and resignation. Examples of some of the items are “I just tried to forget it” or “I yelled, screamed, or got mad”. Focal children were asked to recall and describe a recent problem they experienced (within the last month or so) and indicate by circling *yes* or *no* if any of the 15 coping strategies for that particular stressor was used, and how much it helped by circling *not at all*, *a little*, or *a lot*. The KIDCOPE has moderate test-retest reliability over short periods of time, as well as concurrent validity demonstrated by moderate to high correlations with other coping measures, such as the Coping Strategies Inventory and the Adolescent Coping Orientation for Problem Experiences Inventory (Spirito et al., 1988).

Sibling interview. The sibling interview consists of the participating child answering several questions related to their sibling relationship and coping strategies. The interview is semi-structured, consisting of open-ended questions, with prompts or probes to gain further insight and detail into the child's experiences. See Appendix J for the list of interview questions.

Questionnaire and Thematic coding

Due to the small sample size, information from the questionnaires yielded only descriptive statistics as reported in the Results section. Child and parent interviews were coded separately, so that all child interviews were coded together, followed by all parent interviews. The transcribed interviews were coded in stages. First, the identification of themes was done separately by two coders to capture *what* the units of analysis were about and to summarize what was said. The language of the participants was largely maintained. This method seemed appropriate due to the phenomenological nature of the study (Saldaña, 2016). Upon comparison of the themes developed by the coders and reconciling any differences in this first step, the primary researcher used focused coding. This was done to sort the most frequent codes into categories consisting of sub-categories (Saldaña, 2016).

Table 1. Means, Standard Deviations, and Percentages for Parent Demographic Information

	Mother	Father
Age Range	33 – 45	37 – 45
Mean Age (SD)	38.16 (4.44)	42.33 (3.20)
Employed : Unemployed	3:3	6:0
Mean Number of Children (SD)	2.83 (0.98)	
Level of Education (%)		
High School	1 (16.77)	1 (16.77)
CEGEP	2 (33.33)	1 (16.77)
University	3 (50)	3 (50)
Annual Income		
< 20, 000	1 (16.77)	
20, 000 – 35, 000	0 (0)	
35, 000 – 50, 000	1 (16.77)	
50, 000 – 75, 000	1 (16.77)	
> 75, 000	3 (50)	
Religious Affiliation		
Catholic	2 (33.33)	
Christian	2 (33.33)	
Jewish	1 (16.77)	
None	1 (16.77)	
Married : Single	5 : 1	
Other Stressful Life Events (%)	5 (83.33)	

Table 2. Means, Standard Deviations, and Percentages of Child Demographic Information

	Non-ASD sibling	Sibling with ASD
Age range – years	6 – 12	4 – 12
Mean age (SD)	8.33 (2.06)	8.33 (3.50)
Older sibling (%)	4 (66.7)	2 (33.3)
Number of Females : Males	5:1	1:5
Attend the same school (%)	3 (50)	3(50)
Receive services within the home	0	4 (66.7)
Receive services outside the home	0	3 (33.3)

Results

Descriptive Information

Due to a small sample size, only descriptive statistics were obtained for the parent and child questionnaires. It is important to note that child 4 did not complete any of the questionnaires due to her young age and associated developmental level. Therefore, all data from the sibling questionnaires were yielded from a sample of five children.

Sibling Relationship Questionnaire. Descriptive data from the Sibling Relationship Questionnaire are presented in Table 3 (tables are placed at the end of the descriptive information section of the Results). The frequency of negative events had a mean of 3.20 ($SD = .82$), and the frequency of positive events had a mean of 3.0 ($SD = .48$). The most highly rated items were “how much do you and your sibling care about and love each other?” and “how much do you and your sibling argue or get mad with each other?”. Most children reported those events occur *very much* or *extremely much*, respectively. The lowest rated event amongst focal children was “how much do you and your sibling tell each other everything or share secrets?” with most children reporting *hardly at all*.

Focal children who were younger than their sibling with autism seem to experience a considerably greater occurrence of negative events than older siblings, with a mean of 4.13 ($SD = .17$) and 2.58 ($SD = .52$), respectively. Second-born focal children rated being mean, getting angry, and picking on their sibling as occurring more often than first-born focal children. Similarly, younger focal children appear to experience a greater occurrence of positive events than older siblings, with a mean of 3.25 ($SD = .35$) and a 2.71 ($SD = .50$), respectively. Younger siblings reported that they share secrets with their sibling with autism more often than older siblings, as well as spend more free time with their sibling.

Daily Events Scale for Siblings of Children with a Disability or Chronic Illness.

Descriptive data from the Daily Events Scale for Siblings of Children with a Disability or Chronic Illness can be seen in Table 4. Specifically, disability related hassles and uplifts were analyzed. A mean frequency of daily hassles of 2.46 ($SD = .26$), with a negative emotional response mean of 2.07 ($SD = .52$) was reported. The most highly rated items were “when my sibling goes into my room without asking, takes things, or makes it messy” and “when my sibling embarrasses me at home or in public”. The least common hassle was “when people ask questions about my siblings’ disability”. Although rated as occurring less often, “arguing with my parents” and “when my sibling hurts me verbally or physically” were identified as causing the most stress as reported by the focal child.

First-born focal children did seem to experience slightly more daily hassles ($M = 2.51$, $SD = .22$) than second-born focal children ($M = 2.39$, $SD = .38$). A rare occurrence for younger siblings was being asked about their sibling with autism, which seemed to happen more often to older siblings. However, second-born focal children reported a greater occurrence of arguing with their sibling than first-born focal children. Similarly, older children seem to have more intense reactions to daily hassles ($M = 2.18$, $SD = .70$) than younger children ($M = 1.92$, $SD = .03$). More specifically, being asked by parents to do a job, talking to friends about personal things, when siblings do not do what they were asked, people not understanding things about the diagnosis, and being embarrassed at home or in public were rated as causing high levels of stress in older focal children.

The mean frequency of daily uplifts was 2.51 ($SD = .46$) with a mean positive emotional reaction level of 3.3 ($SD = .24$). Two items that were rated as occurring most often were “when my parents help me with something” and “spending time with my parents at home or going out”.

Four uplifts were rated as occurring least often: (1) when my sibling learns something new, (2) when my sibling tries hard at something, (3) when my sibling shares something with me, and (4) when my day runs smoothly without interruptions from my sibling. Four items were rated as producing a great deal of happiness by the focal child: (1) when my sibling learns something new, (2) having friends over, (3) being able to do what they want, and (4) hearing good news about their sibling. Spending time and playing alone was rated as causing the least amount of happiness in focal children.

Once again, first-born focal children experienced slightly more uplifts, with a mean of 2.61 ($SD = .58$) than second-born focal children ($M = 2.37$, $SD = .33$). Older siblings rated “spending time or playing on my own” and “spending time and playing with my sibling” as occurring more often than younger siblings. Younger siblings did, however, indicate that hearing good news about their sibling occurred more often. Emotional intensity was similar between the groups, with a mean of 2.28 ($SD = .30$) for older siblings and 2.30 ($SD = .24$) for younger siblings. For older siblings, “when my sibling does funny things” was associated with high levels of happiness, whereas for younger siblings, “when my sibling tries hard at something” was associated with high levels of happiness.

KIDCOPE. Several coping strategies were noted by all focal children: (1) I stayed by myself, (2) I tried to fix the problem by doing something or talking to someone, (3) I tried to calm myself down, (4) I tried to feel better by spending time with others like family, grownups, or friends, (5) I wish the problem had never happened, and (6) I wished I could make things different. The least often used strategy ($n = 1$) was “I blame someone else for causing the problem”. All first-born focal children reported that they “just tried to forget it”, while none of the second-born focal children reported using this strategy. The mean number of strategies used

was 10.8 (1.09) and is presented in Table 5.

Parent Expectations and Perceptions of Sibling Relationship Questionnaire. All six mothers completed this form about the sibling relationship of the focal child and the child with ASD. Higher scores are associated with events or behaviors occurring more frequently, being a greater problem, ease of improving them, and the amount of help needed to improve them. Means and standard deviations can be seen in Table 6. Parents rated that positive events and behaviors occur somewhat more frequently than negative ones, with means of 3.22 ($SD = .28$) and 3.06 ($SD = .48$), respectively. Similarly, negative events and behaviors were rated as more problematic than positive events and behaviors between siblings ($M = 1.90, SD = .56$ vs. $M = 1.50, SD = .28$). The ability to improve positive behaviors was rated easier to do than improving negative behaviors ($M = 3.73, SD = .84$ vs. $M = 3.20, SD = 1.11$ respectively). Lastly, parents marked needing more help in improving negative than positive behaviors ($M = 1.53, SD = .56$ vs. $M = 1.31, SD = .19$).

A roughly similar number of negative and positive behaviors were rated by mothers as *always* occurring. The most frequently occurring positive behaviors were loyalty and sticking up for one another, feeling proud of one another, helping one another, affection, being kind and nice to one another. Of the negative behaviors, arguing, fighting over objects, trying to control each other's behaviors, and teasing and annoying each other were rated as most frequently occurring. Two positive behaviors, "going to each other for advice or support" and sharing inner secrets and feelings, and four negative behaviors (i.e., physical aggression, competition, fighting where the problem never gets worked out, and threatening) were rated as *never* occurring between dyads.

Some positive behaviors were rated as *big problems* by mothers, such as playing together and respecting each other's property. Arguing, fighting over objects, and teasing or annoying

each other were also rated as *big problems*. Competition and threatening one another were the only negative behaviors rated as *not a problem*. On the other hand, many positive behaviors were considered *not a problem*: protectiveness, feeling proud of one another, helping one another, and teaching.

Of the positive items that were rated *easy to improve*, many of them were not considered to occur often or be a problem, such as comforting one another, protectiveness, feeling proud of one another, and helping one another. Talking to each other and having conversations with each other was rated as difficult to improve by mothers, as was trying to control each other's behaviors and arguing. Similarly, loyalty and sticking up for one another, protectiveness, feeling proud of one another, helping one another, and affection were rated as needing *no help* to improve. Playing together, angry feelings, and teasing or annoying each other were rated as needing *a lot of help* to improve.

Table 3. *Ranges, Means, and Standard Deviations on the SRQ*

	Mean (SD)	Range (min. – max.)
Frequency of negative occurrences	3.20 (0.26)	2 – 4.5 (1 – 5)
First-born focal children	2.58 (0.52)	
Second-born focal children	4.13 (0.17)	
Frequency of positive occurrences	3.00 (0.48)	2.25 – 3.5 (1 – 5)
First-born focal children	2.71 (0.50)	
Second-born focal children	3.25 (0.35)	

Table 4. *Ranges, Means, and Standard Deviations on the Daily Events Scale*

	Mean (SD)	Range (min. – max.)
Frequency of daily hassles	2.46 (0.26)	2.11 – 2.72 (0 – 4)
First-born focal children	2.51 (0.22)	
Second-born focal children	2.39 (0.38)	
Intensity of reaction to hassles	2.07 (0.52)	1.77 – 3.0 (0 – 4)
First-born focal children	2.18 (0.70)	
Second-born focal children	1.92 (0.03)	
Frequency of daily uplifts	2.51 (0.46)	2.13 – 3.26 (0 – 4)
First-born focal children	2.61 (0.58)	
Second-born focal children	2.37 (0.33)	
Intensity of reaction to uplifts	3.30 (0.24)	2.93 – 3.47 (0 – 4)
First-born focal children	2.28 (0.30)	
Second-born focal children	2.30 (0.24)	

Table 5. *Ranges, Means, and Standard Deviations on the KIDCOPE*

	Mean (SD)	Range (min. – max.)
Strategies used	10.8 (1.09)	10 – 13 (0 – 15)
Degree of helpfulness	1.87 (0.17)	1.73 – 2.06 (0 – 3)

Table 6. *Ranges, Means, and Standard Deviations on the PEP-C-SRQ*

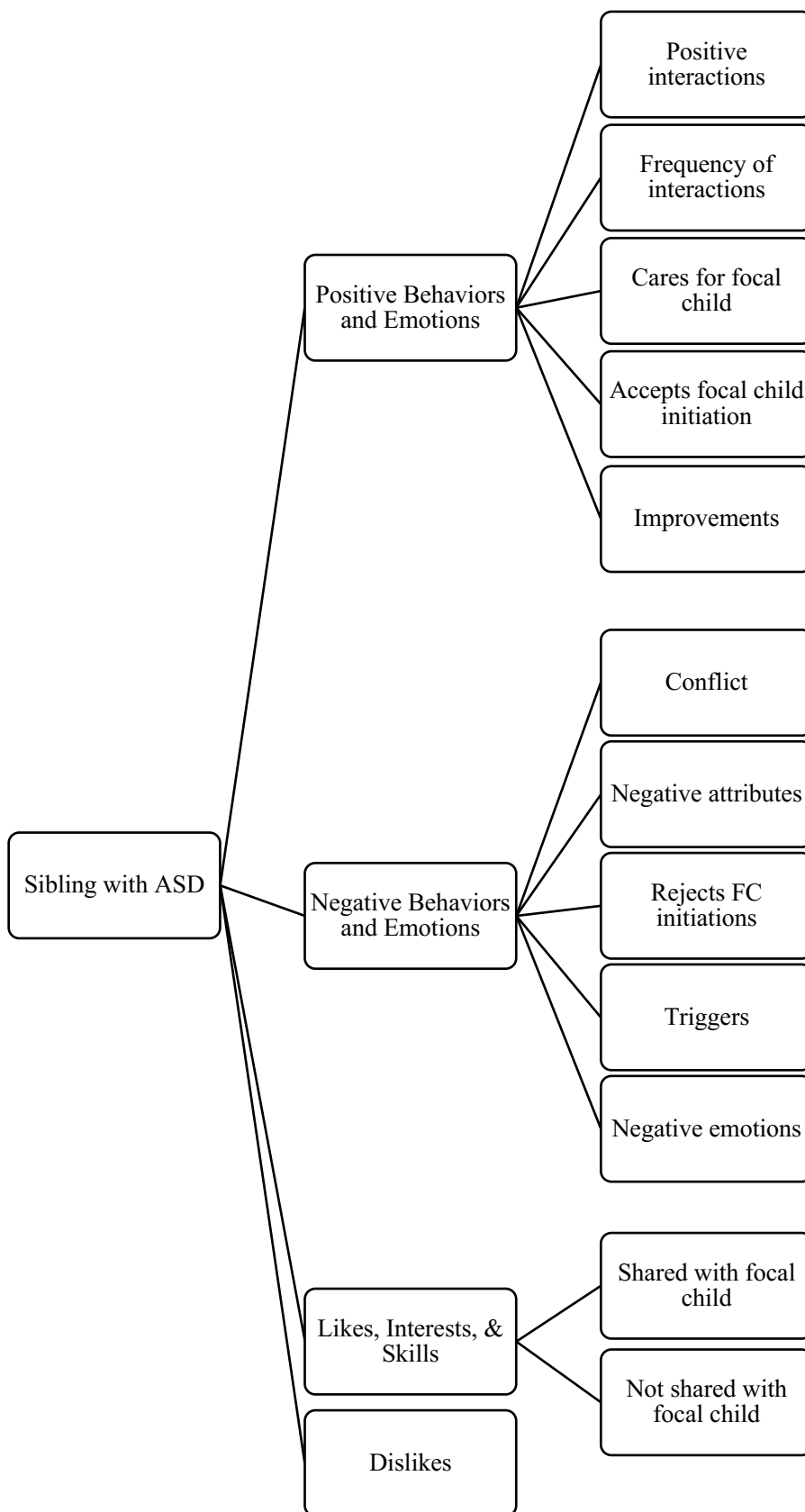
	Mean (SD)	Range (min. – max.)
Frequency of negative events	3.06 (0.48)	2.5 – 3.58 (1 – 5)
Frequency of positive events	3.22 (0.28)	2.66 – 3.40 (1 – 5)
Severity of negative events	1.90 (0.56)	1.25 – 2.75 (1 – 4)
Severity of positive events	1.50 (0.28)	1.06 – 1.86 (1 – 4)
Ability to improve negative events	3.20 (1.11)	1.83 – 5.00 (1 – 5)
Ability to improve positive events	3.73 (0.84)	2.53 – 4.80 (1 – 5)
Help needed for negative events	1.53 (0.56)	1.00 – 2.33 (1 – 3)
Help needed for positive events	1.31 (0.19)	1.00 – 1.53 (1 – 3)

Qualitative Finding in the Interviews

The following section will explore the themes of the child and parent interviews. First, themes relating to the character and personality of the sibling with autism through the eyes of the focal child will be discussed, followed by the focal child's perception of themselves and their sibling relationship. Lastly, themes from parent interviews will be reviewed.

Child with autism. Four major themes relating to the focal child's perception of the sibling with autism were pulled from the interviews: (1) positive behaviors and emotions, (2) negative behaviors and emotions, (3) likes, interests, and skills, and (4) dislikes. Figure 1 presents a visual representation of the themes, which can be found on the following page.

Figure 1. Focal child analysis of their sibling with autism.



Positive behaviors and emotions. All focal children referred to their sibling with autism in a positive light, such as being nice, caring, and respectful. For example, child 6 stated: “he cares about me and will always be there for me” speaking about her brother. Child 2 expressed that her brother cares about her “too much”. Child 3 included: “people that don’t know [him] very well might have the wrong impression of him, but, once you get to know him, he’s a pretty cool guy. He can be very sweet, caring, sensitive, and very protective”.

Furthermore, most children expressed that their sibling accepted their initiations for joint activities. For example, child 3 explained how she and her siblings will play outside, ride their bikes, and go swimming together. Child 2 said: “we love to have fun together”, which she said is often in the form of playing board games. In addition to joint activities, several siblings with autism appear accepting of the focal siblings’ teaching and assistance. According to child 6, her brother will seek her help when he does not understand something, especially schoolwork. Similarly, child 1 indicated that he was helping his sister learn how to go up and down stairs properly.

Although only child 6 described her brother as being “happy”, based on the positive behaviors and interactions shared by other sibling dyads, it seems that the sibling with ASD all appear happy according to the focal child. Nevertheless, negative aspects of their sibling relationship were repeatedly mentioned, as well.

Negative behaviors and emotions. All children reported there were negative interactions between them and their sibling with autism. For instance, although few children used the word “angry” to describe their sibling, many referred to negative behaviors that can be considered an expression of anger. For example, child 1 explained that when he watches something on the television that his sister with ASD does not like, she will “turn off the TV, get pissed, and throw

things on the floor”. Other children said their sibling will scream when angered, such as child 2 who reported that her brother screams when he is told to turn off his tablet.

Other children described some of their siblings’ behaviors as bothersome. Child 6 explained that her brother will sometimes touch and play with her belongings, which she does not like. Alternatively, child 3 described her brother’s lack of social understanding as difficult when she stated:

Sometimes when I have friends over, we sleep in the basement and I ask them (two brothers with ASD) to clean up their mess, because it's really messy down there...it takes them a while...and I tell them, you’d understand if you ever had friends over.

A common occurrence reported by most children was their sibling with autism rejecting their initiations for joint interactions or ignoring them. Child 4 recalled when she wanted to help her brother with a toy car, he rejected her advances. Similarly, child 5 explained: “I find it hard how I can’t get [his] attention. And, like, if I’m like, “look, look” he's like “ahhh” and he goes away...he's like looking at his tablet and then he walks away and sometimes running”.

Some children also suggested that their sibling’s behaviors is, at times, unpredictable. For example, child 6 stated, “...he wants to ask me for help sometimes so that I can help him but sometimes it doesn’t work, sometimes it works”. She later commented: “...after maybe it can go well, maybe it can go bad. We don’t know” in relation to her brother’s emotional wellbeing after a tantrum. This concept was furthered by child 3 who, in an attempt to explain ASD to her grade four classmates, made a PowerPoint presentation, in which she wrote:

Every second is unpredictable. He could wake up happy in the morning and then, all of a sudden, he can have an extreme emotional outburst...This can be caused by seemingly normal day to day occurrences (someone accidentally bumps into him, or someone looks at

him the wrong way).

It appears that many focal children pointed out both positive and negative aspects of their sibling's personality, which, as will be discussed, affects the sibling relationship.

Likes, interests, and skills. All focal children inferred their sibling enjoys spending time with them. Child 4 exclaimed: "in the bath we do bubbles. And one time I put it on his face and then he laughed". Other children mentioned doing arts and crafts, playing Lego, board games, and other interactive activities. Child 5, for example, said the following:

What he likes about me the most is that when...what he likes from me is definitely me spending time with him and chasing him. And also, I think his favorite thing that I play with him is playing on roadblocks (i.e., computer game).

Some children included that their sibling enjoys peer interaction, as well. Child 6 claimed: "he likes to play with me, and he likes playing with his and my friends". Similarly, child 2 explained that her brother likes talking on the telephone with his friends, having sleepovers, as well as playing with his sister.

Most children made a reference to technology when speaking about their sibling's likes. Some went further to indicate that their siblings are at times *consumed* by electronics. For example, child 2 stated: "he loves playing on electronics, like going on his iPad, going on his computer or iPad, watching YouTube. He's addicted to electronics. Like he *really* loves it." Child 3 mentioned that her brother at times refuses to play with her because he does not want to stop playing videos games, nor will he let her have a turn because it is "still his turn". Similarly, child 5 said that her brother will often ignore her advances because he is preoccupied with his tablet, and that it is extremely difficult to get him to stop playing on it.

In line with technology, almost all children inferred that their sibling enjoyed solitary

play. For example, when asked what activities dyads engage in, child 2 and child 5 referred to computer games where face-to-face interaction is unnecessary. In addition, focal children seemed to indicate that their advances are rejected more often than accepted, further indicating a desire to be alone.

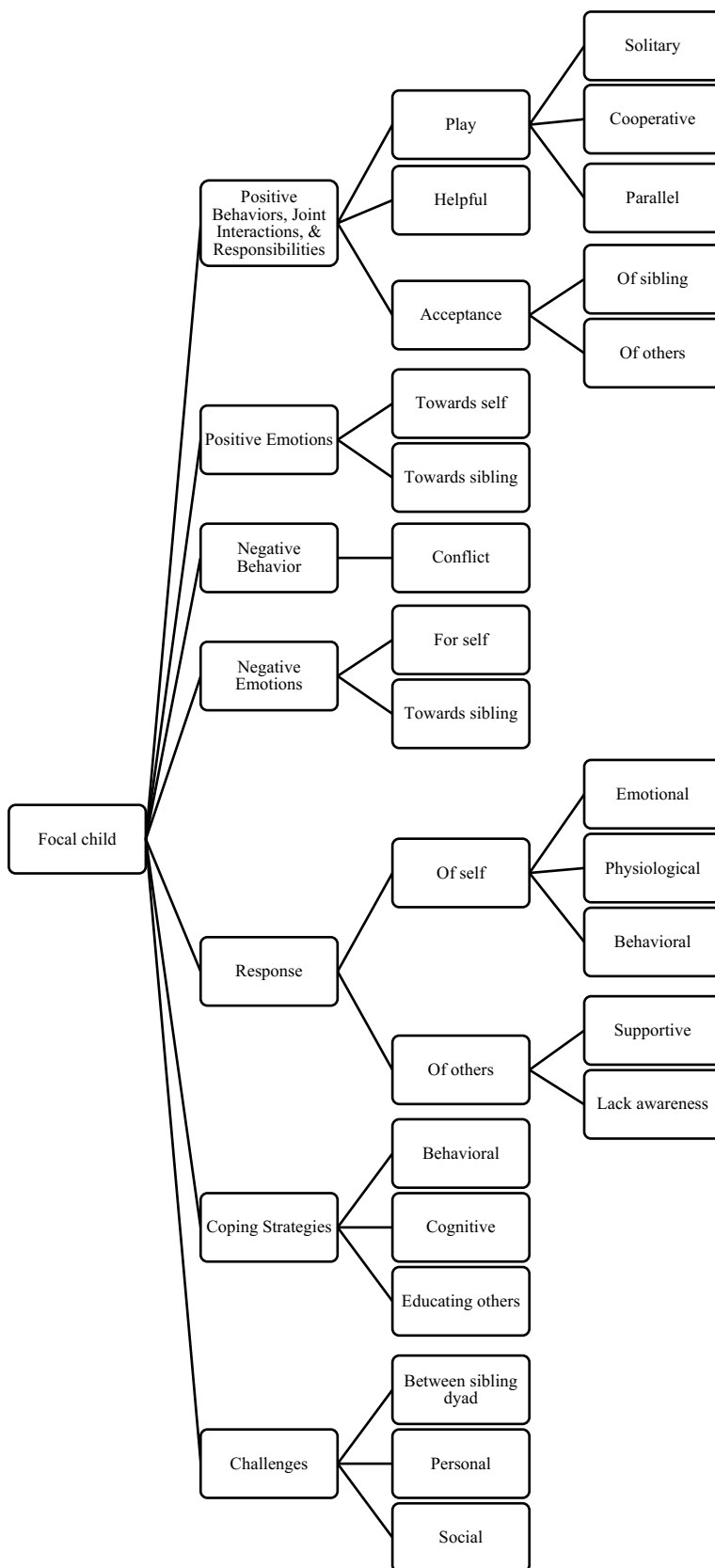
Dislikes. Many children included activities that their sibling does not enjoy. A common dislike was not being able to use technology when they wanted. Child 2 and child 5 explained that an outburst often occurs when their sibling with ASD is asked to turn off their tablet. For child 3 and child 4, an outburst occurs when the TV is turned off. For instance, child 4 remembered when: “I tell mommy if he's crying or if he's mad, and if my daddy's bothering him...When [dad] leaves, he puts the TV off” and then the child with ASD screams.

Child 6 stated that her brother does not like things “he can't do...math, gymnastics, all kinds of stuff”. Similarly, child 2 and child 3 explained that their brothers do not like to do homework, especially when they do not understand the material. In the same vein, child 2 added that her brother does not like being told what to do or trying new things.

It appears that many of the siblings' dislikes mentioned by focal children are in line with the symptomology of autism, while others may be common among many typically developing children. Nevertheless, it causes a rift between members of the family as discussed later.

Focal child. Seven major themes were pulled from child interviews in terms of their own behaviors, emotions, and perspectives of their sibling relationship: (1) positive behaviors, joint interactions, and responsibilities, (2) positive emotions, (3) negative behaviors, (4) negative emotions, (5) response of self and others, (6) coping strategies, and (7) challenges. Figure 2 represents the themes outlined by the focal child.

Figure 2. Focal child analysis.



Positive behaviors, joint interaction, and responsibilities.

Play. All children stated that they play with their sibling with autism. Activities such as Lego, hide and seek, board games, art, and computer games were mentioned. Child 1 stated: “Uhm, I like doing arts with [my sister] and building Legos with her... We build Lego a lot together”. Child 2 explained how she and her brother had to come to a compromise on who gets to pick the board game they would play. She stated: “Like when I ask him to go play this game...like we have a deal if he says, ‘you play this game with me’ then I say, ‘fine but then you play this game with me’”. This prevents a great deal of conflict as they play board games frequently together. Child 5 was reminded of a time when she and her brother would run and chase after each other, as well as play hide and seek together.

Acceptance. Some children spoke of actions and behaviors associated with accepting their sibling and their condition. For example, child 2 mentioned: “I don’t care if he doesn’t understand something, I’ll just go help him”. In addition, child 3’s acceptance of differences extends to others, not just her brother with autism. She spoke of another boy in her school, who “...says a bunch of random things but he's really nice and really cute. He just runs up to anyone and starts singing and dancing. It's just super cute”. Child 3 identified this boy’s behavior as “cute” rather than negatively, which may stem from the experience of having a sibling with autism.

Helpful. Most children spoke of helping their sibling in various ways. One commonly referenced behavior was through acts of teaching. For example, child 4 explained how she tries to teach her younger brother numbers and makes the “5” a different color so he can recognize it easily. Similarly, child 1 mentioned how he helped his little sister learn how to walk up and down a flight of stairs. In addition, child 2 mentioned that “I love when he doesn’t understand

something so I can go help him”.

Child 6 made several references to caring for her brother’s emotional well-being and trying to help him calm down:

...I just want to help him, and I don’t want him to be emotional like that... I talk to him about good things; and take a deep breath and let it out for five seconds, and don’t feel that way, think about happy things in your life that you did. And think about your friends doing good things to you.

In a similar vein, child 2 mentioned that she tries to protect her brother’s feelings when they argue, by making a conscious effort to not say something mean that may hurt his feelings.

Such behaviors were considered acts of caring and demonstrated that many children feel a sense of responsibility toward their sibling with autism.

Positive emotions. All children made reference to experiencing positive emotions towards their sibling with autism. Child 1 recalled a time when his sister drew a picture of their family and gave it to him, which, according to him, made him happy. Two children also stated that they feel happy when their sibling accepts their invitation for a joint activity. Child 2 said:

I like...when I ask him ‘do you want to do this with me?’ he sometimes says yes, and he sometimes says no. And when he says no, I say ‘ok I’ll go read a book’ but then when he says yes, I feel really happy.

Alternatively, child 6 mentioned feeling happy for her sibling, rather than for herself: “...he likes playing with his and my friends. That doesn’t happen often but when it does, he feels happy inside. And I like that – when he feels happy”.

Child 5 mentioned she feels happy for and proud of her brother, especially his knowledge on how to work a computer. She also mentioned she feels proud of herself when she is able to

help him with something. Others expressed similar feelings of enjoying their role as a sibling. For example, child 4 said she likes making things for her brother, such as drawings. Child 6 stated: "...I just love having a little sibling...". Such a statement seems to capture many of the children's perceptions toward their sibling.

Empathy was also referenced by two children. Child 6 implied that she is quite empathetic towards her sibling, in that her emotions are often related to his. She expanded this sentiment by explaining that when her brother shows his *mad face* she feels "sad because I just want to help him, and I don't want him to be emotional like that". Child 3 expressed feeling empathy towards other children who may be struggling. She mentioned that she finds it rude when her peers laugh at someone who is crying or struggling, because "they don't know what they're going through". She also explained how her friends are sympathetic towards her and her brother, for which she expressed gratitude. She recalled an incident from a few months prior, in which she and her friends saw her brother playing outside alone. Her friends then went and invited him to join their activity. She recalled thinking it was "really nice of them".

Negative behaviors. Most children mentioned conflict with their sibling. Several pointed out that they often argue over objects. Child 4 ruminated about when "I take something that is his and I want to play with it, and then he gets mad...". Similarly, child 6 explained how her brother often "fools around" with her possessions, which she does not like. Child 2 said her mother had bought her a punching bag, as she was experiencing anger and needed an outlet, but it resulted in the children fighting over who got to use it, so neither of them could. Comparable experiences were shared by child 1 with the television. He explained how if his sister does not like what he is watching she will throw a tantrum and turn off the TV. This leads to him putting on her favorite TV show in an attempt to calm her down. Likewise, child 3 and her brothers argue over the TV

and video games, as they commandeer the devices and do not let her have a turn. As a result of such interactions, focal children also mentioned experiencing negative emotions.

Negative emotions. All children spoke of experiencing negative emotions, such as anger. Child 2 mentioned: “it’s annoying when he tells me what to do...I get annoyed a lot”. Another incident that seems to annoy child 2 is when her brother “babies” her. For instance, she stated: “...its annoying because he cares about me too much...cause like I’m older now and I can handle stuff like when I’m upset...”.

Some children offered a different root cause for their anger, namely, lack of a playmate. Child 4 mentioned that it is sometimes hard when she tries to play with her brother, because he rejects her initiation and continues to play by himself. Similarly, child 5 pointed out that her brother’s favorite activities are solitary ones, while hers are not. Although she tries to get her brother’s attention and interact with him, more often than not her efforts go unnoticed and ignored, which is difficult for her.

Feeling embarrassed was mentioned by some children, as well. For example, child 5 mentioned: “it kind of feels weird”, when asked about her sibling relationship. She further stated: “I feel a lot different. Really different compared to others...that I have an autistic brother and sister and that they don’t know how to talk to friends and stuff”. In addition, child 3 recalled a time when her peers would stare at her when they heard her brother having a meltdown at school, which made her uncomfortable.

Response of self and others. Due to the various ages and unique experiences of all focal children, it is not surprising that they react to their sibling differently and perceive others’ reactions distinctively. Some children made reference to how they react to their sibling, while some explained others’ reactions.

Responses of self. The first type of response that will be discussed is children's physiological reaction to their emotions. Some children reported reacting to their emotions in a physical manner. For instance, child 1 said he feels it in his legs and needs to kick something, whereas children 2 and 5 said they feel it in their hands and want to punch something. Child 3, on the other hand, stated: "I get butterflies... I usually get really sweaty and stressed out and my head hurts a little".

In terms of behavioral responses, two children said they often have to concede to their sibling in an attempt to make the situation better. As mentioned, child 1 will stop watching his TV show or movie to put something on that his sister prefers to stop her tantrum. He also stated that he often has to monitor his reactions as his mother tends to get angry at him. Similarly, child 4 explained:

When I take something that it his and I want to play with it and then he gets mad and mommy says '[your sister] wants to play with it'...he cries and then mommy says I will give it back to him and I give it to him.

Child 2 described how she at times will give her brother a taste of his own medicine, and not let him do something if he previously did not let her do it. She told a story from earlier in the same day as the interview:

...when we bake, he wants to do the thing he's doing and when I ask him if I could try, he doesn't really respond – he kind of like ignores me. It's like he doesn't know what I said or if I said it or not...And when I'm baking and I'm doing my stuff uhm he says, 'can I have a turn?' and I'm like 'but can I just finish...can I just do this?' and then he's like 'ok but...' but then I keep doing it and I don't really let him because he didn't let me.

Responses of others. Friends of focal children also seem to be introduced and integrated

into the family context differently. For example, child 1 explained when he has friends over “they often do their own thing” in order to not have to interact with his sister. Alternatively, some children spoke of having supportive friends who interact kindly with their sibling. Child 3 and child 6 explained how their friends will sometimes include their sibling in what they are playing. When asked what his (sibling with ASD) interests are, child 6 mentioned that he likes playing with her friends, as well as his own. Similarly, child 3 recalled when her friends invited her brother to play with them, and he joined happily.

Coping strategies. Common coping strategies, used by five of the children, consisted of various behavioral techniques. Punching pillows and kicking their bedframe was mentioned by three children. Child 2 stated: “I feel it in my hands like I need to punch something”, which inspired her mother to buy a punching bag. Similarly, child 5 mentioned that she often feels the urge to punch something. Child 1 explained he lets out his anger by kicking various things in his bedroom.

Withdrawing was also mentioned by three participants. Most children implied they withdraw by going into their bedroom, thereby removing themselves from the situation. For example, child 1 explained that when he gets angry, “I go in my room sometimes”. Similarly, child 3 stated: “I go to my room and go on my phone and play games, or watch TV, or I go outside and play sports” when she is upset. Child 3 said that she would not go check on her brother at school when she heard him having a meltdown, which represents a form of withdrawing, that is avoidance.

Child 6, who is older than her brother, uses more cognitive coping techniques, such as taking deep breaths and letting them out for five seconds, “letting it out in [her] head” and thinking of positive things. Another strategy that was used by child 3 was to make a PowerPoint

Presentation on autism and present it to her grade four class. The presentation was entitled *How to explain what living with an autistic sibling is like: My experience*, and covered general information about autism, her brother's experiences and perceptions, as well as her own experiences.

Challenges. Through the interview and analysis process, it became evident that certain questions were harder for some children to answer than others. Several children eluded to not having appropriate or effective coping skills. Child 2, who claimed to hit her pillow or kick her bed when angry, stated: "I think it *doesn't* help but it helps myself. But would you rather me hit my pillow or say something mean?". Similarly, child 1 said: "...and [my mom] told me to go to my room, and I went to my room and I just started kicking stuff, and then she got mad cause she told me to stop but I wouldn't stop". He continued to explain that he found kicking things helpful until his mother got mad, at which point he felt the need to react physically again. Although child 6 did not mention using any behavioral coping strategies, only cognitive ones as noted above, she did say that they were self-taught.

In a similar vein, emotional regulation seemed to be problematic for some children. For example, child 2 claimed: "I feel like my head and my anger gets out and I can't hold it because there's too much... I say some mean stuff, but I can't control it because he gets me so angry". Child 5 also seemed to struggle in this area. She explained that when she becomes irritated "...the first thing I want to do is definitely scream. Everybody wants to scream. And the second thing that I really want to do is punch something or someone". She continued to explain that she does scream and punch things until her parents are able to calm her down.

Others seemed to have a difficult time thinking of positive things to say about their sibling dynamics, even when prompted by the interviewer or parent. Child 1, for instance,

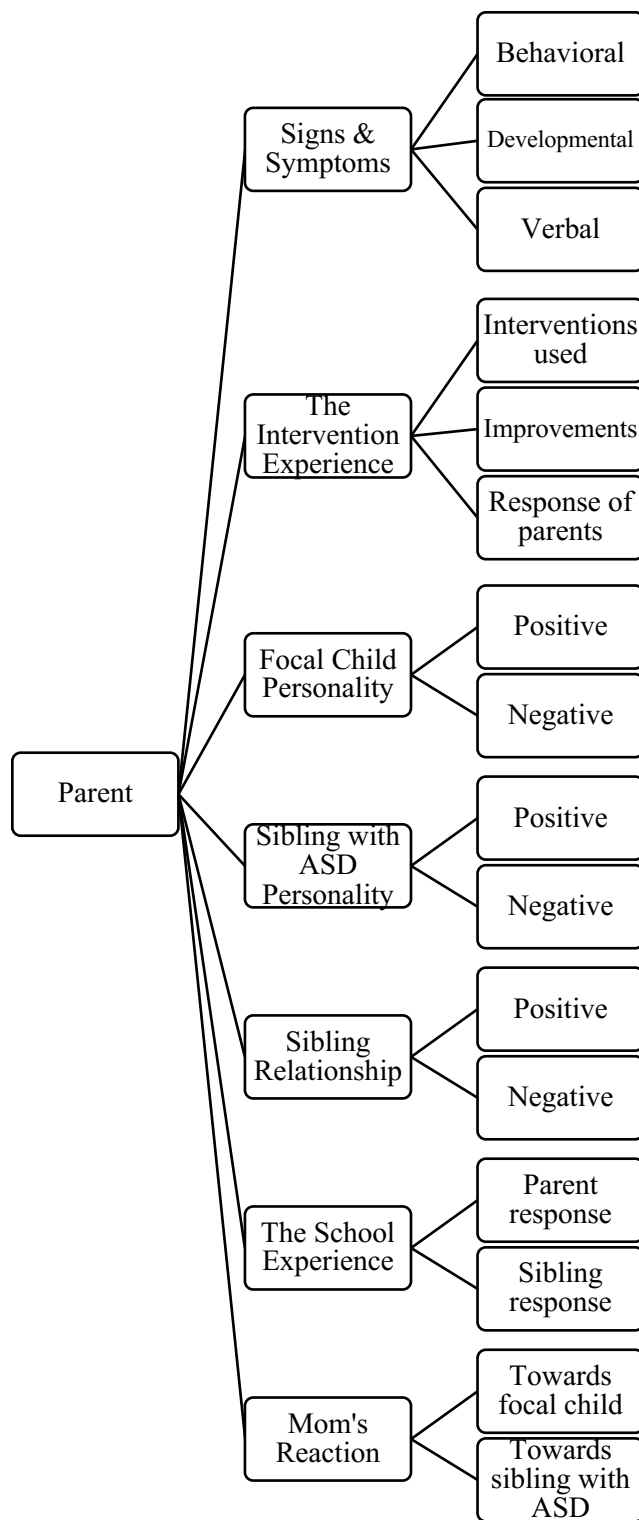
replied: “I got nothing” several times when asked about the good in his sibling relationship. It was not until his mother reminded him of a story that he was able to provide an answer. Similarly, child 3 repeated that “[she] was not sure” what was good about her sibling relationship. While child 2 was sharing positive memories between her sibling and herself, she had a difficult time staying on track, and the memories often ended with a negative interaction. She had to be reminded several times to focus on the positive parts, which she said was quite difficult to do.

Another aspect that seemed challenging to some focal children was the lack of knowledge and acceptance, either by themselves or others. After her class presentation on autism and how it affected her, she stated: “I think some people were a little confused maybe”. Although her immediate friend group seems to be supportive and understanding, she explained that she has a difficult time at school, as not everyone is as compassionate.

In conclusion, all sibling relationships seem to include positive and negative aspects; love, acceptance, frustration, annoyance. Child 2 stated: “we love each other, but sometimes we don’t act like we do, but we always will. And if we say we hate each other in our hearts we don’t”. Such a statement can be said to describe the other typical sibling relationships, categorized by love and conflict (Howe et al., 2011).

Parent interviews. Seven major themes were pulled from parent interviews: (1) signs and symptoms, (2) the intervention experience, (3) focal child personality, (4) sibling with ASD personality, (5) the sibling relationship, (6) the siblings’ and parents’ school experience, and (7) parent reactions, which is portrayed in Figure 3.

Figure 3. Parent analysis.



Signs and symptoms. As symptoms and severity varied within the participating families, parents were asked to describe their child's tendencies and behaviors. Some parents also included the behaviors that triggered them to have their child assessed, as well as improvements in their child's functioning.

Parent 1 simply described her daughter's symptoms, which included extreme meltdowns, not being aware of danger, difficulty communicating, poor adaptive and self-help skills, and poor emotional regulation. She continued to explain that there are "certain simple rules that she doesn't understand". In addition, she is not able to "do all the things that [she's] supposed to do", which makes going out with her quite difficult. This is especially true in stores, as "if she wants something, she'll have a meltdown right there if she wants it... when she's not happy there's the crying and...and you can't always know why... she's so upset and she can't verbalize".

Parent 2 started by explaining what she first noticed in her son's development that was cause for concern:

The repetitive behaviors... because [he] used to be very infatuated with hoses, vacuums, wires... anything along those lines. Those were all signs for us obviously. The eye contact, there was a lot of lack thereof... That was the other sign, the lack of hugging. We weren't allowed to touch him or anything.

Through the use of ABA therapy, she explained that many of his symptoms have since improved. According to his mother the "repetitive behaviors have stopped for the most part, and eye contact is there, affection is there". She explained that he still does have a subtle stim, which he mostly engages in when nervous, as well as difficulty communicating. Both are things that they are working on improving.

Parent 3 explained "We knew something was up... we couldn't put our finger on it

because we didn't know what *it* was". She explained that her son presented sensory issues, rigidity in many behaviors, and lack of affection. He has become more affectionate, as his parents tried very hard to break that barrier. Parent 3 explained that when her son would not allow his parents to hug and kiss him before bed, she decided

This isn't going to happen, you will be kissed every night at least, before bed. So, we forced ourselves on him basically, I don't know if psychologically that's the best parenting move, but he's the first to come hug us, he hears me say *ow* from the next room he's the first to come check on me.

He still struggles with sensory issues, and poor self-help and adaptive skills, as well as being quite literal. In addition, emotional regulation is a problematic area as "he goes from medium to extreme emotion there's no middle. It's quick..." Nevertheless, parent 3 mentioned that "he's come a long way" especially in his rigidity. As a young child, she remembered "he had to have the blue cup, sit in a certain spot, have a certain bowl...", but they worked very hard to "pull him out of that".

Parent 4 first became concerned when at 18-months of age her son was not speaking. She further mentioned the presence of sensory issues and poor emotional regulation, but repeatedly spoke of his progress, especially in communicating. She explained that:

...Now with ABA therapy we have someone working with him one-on-one, and he speaks a lot more. Like, he used to say 'water' but now we won't give him water unless he says, 'I want water' or 'can I have water'... Because, initially, he would only point. Now, he's saying more.

She also mentioned that her son became toilet-trained, which was difficult, but with the help of his ABA therapist he was able to learn. In addition, his sensory issues have lessened. Parent 4

stated:

... We did have a big sensory issue. We worked a lot on that. He wouldn't wear anything long sleeve, he wouldn't touch anything. We worked very hard with an occupational therapist. He wouldn't touch sand, now he does he loves it.

Parent 5 mentioned that her son struggles with self-help skills, aggression, and poor emotional regulation. She explained that when her son has a meltdown:

I have to hold him because he'll go after everything, everybody in the house. He'll throw things, rip leather off chairs. After it's done, he feels bad and apologizes, but in the moment, he has no control, so I have to physically hold him.

Even still, parent 5 was very quick to provide examples of the progress he has made over the years. For example, at 9-years-old he was able to speak in full sentences and is doing very well in school. His communicative improvements have allowed him to develop a friendship with his sister over the last two years, which their mother is very happy about.

Parent 6 described her son's behaviors from a few years ago, which included "turning in circles, wondering what's going on...he's kind of lost". She also mentioned that he will ask the same question several times within a very short time frame, as well as other forms of rigidity, which was concerning to her. Her son still struggles with being "very literal and will freak out at noise".

The intervention experience. A variety of interventions were sought out by parents, including Applied Behavior Analysis, speech therapy, occupational therapy, food therapy, and social skills training. Parent 4 began the intervention process before receiving an official ASD diagnosis, as she did not want to wait. Her son received speech therapy and occupational therapy before he was diagnosed, followed immediately by ABA therapy.

Although parents found the interventions helpful, they had their own feelings about the process itself. For example, parent 2 stated:

We were doing it privately – we weren't being picked up by the system obviously because it takes a really long time. But at the same time, yes it was a fortune, but it was the best money that was spent because it really helped him.

It seems that parent 2 became frustrated waiting for public services and decided to go private, which was costly. Similarly, parent 3 explained, “our system sucks...we rushed and went private so we could get that early intervention.” Parent 4 shared a similar experience:

We decided to do everything privately. So, we skipped a lot of the waiting lists, but at a cost... And [the system's] not doing anything to help with that. Nothing. Like, the local CLSC, I have a social worker, never met her. They accepted to do services on him as of January 2020. So, what do I do in the meantime? I let him do nothing? No, I can't. But we had to sell a property to help him.

It appears that dissatisfied parents found a way to get their child the services they needed at personal cost.

Focal child's personality. Parents made reference to several positive traits they see within their typically developing child. For instance, many parents inferred that their child has a sense of responsibility towards their sibling with autism. Some, for example, were said to take on a protective role. Parent 1 stated that her son is “very very over protective” of his sister with autism. Parent 2 described her daughter showing her protective side in a different way. She explained that her daughter will do her brother's chores and clean up after him to avoid him getting in trouble, but he has a poor reaction to her help. Parent 3 explained when her daughter finds out after the fact her brother had a negative peer interaction at school, she states “I wish I

would have seen that I would have taken care of that...”. Similarly, parent 4 described a time in daycare where her daughter stood up for her brother when a peer was making fun of him. She continued by saying: “She’ll speak for him, she’ll come to his defense with other kids. She’s always defended him.”

Some parents explained how their children are helpful in day-to-day activities with their sibling with ASD. Parent 1 explained that “With [his sister] he helps a lot because he gets to her for some reason” in terms of getting dressed in the morning and eating. Parent 5 described a similar experience with her daughter, who likes to help her brother out with his shoes and jacket.

Parents also commented on the maturity of their typically developing children, and how their sibling circumstances allowed for the development of certain characteristics. For example, parent 1 and 3 described their typically developing children as mature and patient towards their siblings. In addition, some of them were said to have strong characters. Parent 2 reminisced:

[Focal child] for a while didn’t know how to necessarily react towards [her brother with autism], and then finally basically got the backbone and started sticking up a little bit more for herself and kind of slapped it in the face.

Alternatively, parent 5 explained her daughter has always had a backbone, and was never afraid to stand up for herself:

I think it's a great thing that she has [siblings with autism]. Yes, it's hard now but I think in the long run...and it's also made her have a strong character. She doesn't put up with bullying, she doesn't put up with anything. You know, she's tough, she says her opinion and that's the way it is.

Although they might be strong willed, they are not without their loving side. Most parents mentioned that their children are loving, caring, and empathetic towards their sibling with

autism. Parent 1 mentioned that her son “was always a big fan of his sisters”. Parent 4 described her daughter as “sad...when [sibling with autism] is sad she gets sad”.

Some parents divulged that progress made by the sibling with autism is celebrated, and the focal child seem especially proud of their sibling. Parent 1 stated that her son “gets really excited to see the little progress that they make”. In addition, parent 4 described her daughter’s reaction to her sibling learning something:

... so, we try to ask, ‘what did you learn today?’ and with [focal child], I’ll tell her what he did, and she’ll go ask him. When he was doing interviews at school, because [teacher]she would send the recording, so she would watch them with me, and [focal child] would ask him the same questions. She’s very involved. And even when we go somewhere, and we tell people ‘[sibling with autism] did this or that’ she’ll try and show them what he did.

Parent 5 explained that her daughter is often caring to those with autism outside of the family home:

Well I think it's amazing how...when we go anywhere, to a park, to the play grounds and stuff she always finds the autistic kid and plays with them. She just knows how to get into their bubble and play with them. And then you see the parents’ faces just glow because someone is *actually* paying attention to their child and knows how to get into their bubble. So, she’s very much accepting of everybody.

That being said, parent 5 did mention that her daughter does have difficult peer interactions. She explained how

[Focal child] gets really excited to have friends because at home she doesn’t have the interaction... So, a lot of times she plays with kids at school it's roughhousing and things

like that, the way she would with her brother. And I have to explain to her that's not how things go.

While it can be said that many of the focal children try hard with their sibling, negative attributes were mentioned by several parents, as well. Parent 4 explained how her daughter became jealous of the amount of time her mother and brother were spending together. She expanded by saying:

I need speech therapy, occupational therapy, ABA therapy, and for her was the hardest cause she was also young, so I'd be taking him to an appointment but in her head, it was an activity. So, it was an activity that I was doing with my son. But it wasn't really an activity it was an appointment, right? So, there was a lot of jealousy at the beginning.

According to parent 5, it seems that her daughter also had a difficult time adjusting. She explained that her daughter "has a lot of anger issues", as well as poor emotional regulation skills. For example, parent 5 stated:

Her as well she doesn't know how to self-soothe. She doesn't know how to calm herself down. She's never learnt that skill... the only way to calm her down is I have to go in there and physically hold her and hug her to calm her down. Because she can't do it on her own. She'll scream for 2 hours... when [sibling with autism] has a meltdown, I have to hold him because he'll go after everything...so, I guess she sees that as soothing and that's what she wants as well.

Moreover, it seems that the focal child has feelings of resentment towards her sibling with autism. Parent 5 said that her daughter has made comments in the past as "it's hard being the youngest. Really hard. They should be taking care of me, not me of them." In addition, child 5 expressed to her mother that it is unfair that "[her siblings with autism] get away with things that

she's not able to". While this child in particular seems to be struggling, her mother is under the impression that "it's hard now, she's little, but I think it will make her an amazing young woman one day", which may be the case for many of the focal children.

Personality of Sibling with Autism. The sibling with autism was also talked about in a positive light by many parents. For example, parent 3 described her son as affectionate and caring as noted above: "he's the first to come hug us, he hears me say *ow* from the next room he's the first to come check on me". In addition, parents 3 and 6 described their sons as sensitive, in that they become emotional quickly. Parent 2 described her son as protective towards his younger sister as he "always looks out for her" as he tries to fulfill his role as a big brother.

Some parents described their child's temperament, as well. Parent 1 described her daughter with autism as "easy going". Similarly, parent 3 mentioned that the focal child "has a good group of friends and they're all really nice with him. Even one of them said 'your brothers [twins with ASD] are cooler than the boys in our grade'. Parent 3 attributed that to him being calm, unlike some of the other boys his age.

Some parents mentioned that their children with autism try hard, perhaps in order to gain independence. For instance, parent 3 stated that her son knows the right thing to do in certain situations. She recalled an event where her son was being bullied at school. Her son first asked the boy to stop several times, and when the boy continued, he then went to a teacher. When this boy still bullied him, child 3 took matters into his own hands and reacted aggressively. Although the outcome was not ideal, parent 3 was proud that he did not involve his neurotypical sister and attempted handle it.

Alternatively, some children with autism were said to lean on their siblings for social support. For example, parent 6 explained "he will attempt to socialize. But he does use his sister.

He uses her as a crutch. She kind of leads and he follows”. For parent 3, she sees her son with autism leaning on his twin brother, who is also on the spectrum, rather than his neurotypical sibling when she stated: “[sibling with autism] leans on [twin brother] a lot but when [twin brother] is not there you see the other side.

Parent 3 mentioned that her son is in a constant state of struggle, as “his actually IQ is like higher than most people. So, it seems like a constant... it’s like a fight in his head sometimes”. Some parents also described more negative personality traits that their child with autism exhibits. Parent 2 described her son as controlling, whereas parent 4 described her son as stubborn. An example she provided was:

Now, what he started doing when he doesn’t get his way, he’ll run in his room. And the thing is, if he needs to pee he’ll do it on himself... But that has nothing to do with autism that’s more him being stubborn.

Parent 6 described her son as very “on edge and irritable”, as well as passive. She explained how he can be passive with school work, but also with decisions. For instance, she stated:

He’s able to play alone but it’s the interest of his sister that either he adopted or...it's like he can’t make up his mind for himself. We always have to impose things on him and see if he likes it.

The sibling relationship. The sibling relationship described by several parents seems to resemble that of any sibling dyad; there is positive and negative. Four parents stated that their children are very close and love each other. Some said they have a nice bond, or simply a great relationship. Parent 6 described her children as being “best friends”. Parent 2 described a special bond between her children:

when [focal child] was born was the reason that allowed [sibling with autism] to start

being affectionate. The first person he ever hugged or kissed was [focal child] when she was a baby. So, that's also a really nice story... we tell it to them when they fight. And that kind of, having that sibling kind of changed him a little bit.

This bond is further demonstrated by the playful interactions the dyads share. For example, parent 1 stated "he plays with her...he likes to play with her...and she loves her big brother". Parent 5 also explained that her daughter and son have only recently started interacting with one another, and that it is very nice to see them play together.

In two families, the younger child seems to model their older sibling's behavior, regardless of the diagnosis. Parent 5 explained that her neurotypical daughter took on the interests of her older brother with autism, and prefers to play with logic games and puzzles, rather than with dolls and make-believe. Alternatively, parent 6 described how the sibling with autism adopted the interests of his older sister. She stated: "whatever she's doing he's interested... Other than the electronics that's what interest him... being around her and doing like her. Even his interests sometimes, he'll play alone but with things that she liked".

Parents also mentioned conflict between their children. For example, when asked about the sibling relationship, parent 1 stated "Well she gets on his nerves...it's more annoyance". Parents 3, 4, and 6 mentioned that the levels of conflict between their children are comparable to other typically developing sibling dyads. However, parent 2 stated she believes her children argue more than other dyads, "...they can be at war more than I would think a brother and a sister would be." This may stem from conflicts that escalate, as they "have difficulty communicating, how to direct problems that they might have with each other. So, their reaction is a little bit more verbal, where it would be harsh on emotions". Even so, parent 2 mentioned more than once "they do still really fight... they really do genuinely love each other. You can see

it based on how...what they do for each other and how affectionate they can be”.

The school experience. Due to the varying ages and symptom severity of the children with autism, the type of schooling they are receiving varied as well. Of the six children, two went to daycare, three were mainstreamed in regular classrooms, and one went to a special needs school. Interestingly, one child being mainstreamed will be attending a special needs school in the upcoming academic year. Parents whose children were mainstreamed spoke about their child’s school experience. Parents 2, 3, and 6 all said their children have made friends at school and are good at certain subjects, while they struggle in others. Parents 3 and 6 put their children on a modified curriculum and spoke quite negatively about their sons’ and their own experience with the school.

Parents 3 and 6 explained their sons are experiencing both academic and social difficulties. For example, parent 3 stated:

...For instance, he’ll retain only a small percentage of what’s being told to him and he doesn’t understand...but he, for instance, the teacher will say or explain something and tell him ‘ok, do pages 11-15 in your book’ he can’t be left alone. He really needs someone next to him to help him. He doesn’t work at all... almost every day, he doesn’t feel motivated to go to school.

Parent 3 expressed that she sees her son as passive in his education and unmotivated to try.

Parent 6 articulated similar sentiments when she said, “...he notices at school that he's behind and that’s where the issues are right now. He refuses to do work. His last report card in French, it wasn’t like the mercy 60%, it was blank”. She continued to explain that her son is beginning to become aware of the differences between him and his peers, as he is “not at the same point as everyone”, which makes him embarrassed.

These parents additionally talked about the social aspect of school, which they see as difficult for their children. Parent 3 explained that her son "... has a group of friends that they play manhunt or tag.... And the kids he plays with kind of get him. But then there are kids at school who go after his emotions". Parent 6 similarly explained that she sees her son as stigmatized:

Kids his age, they're like 7- or 8-years-old, they're not necessarily mean, they don't do it intentionally, but they'll say things like, 'why aren't you doing [your work] and it just hurts his feelings, you know? There's been a few times that he actually maybe even was bullied.

Parent 6 continued to explain the social dilemma she believes her son has, as "he's able to develop relationships...but still there's something lacking. He's misunderstood, he doesn't get the social cues".

Parents also mentioned the lack of school resources as a problem within the education system. Parent 6 explained that the school has a child care worker who her son can use as needed, however, she is an aid for other children, as well. This mother continued to explain that when her son needs her, she is often unavailable or cannot stay with him for a long period of time. Parent 3 voiced similar criticisms about her son's school, as well as her dissatisfaction; she seemed to feel that the school is not offering enough support and assistance to her son:

...We have to work on it, but we can't always pinpoint what *that* is. So, we look to the professionals at school but they're not giving you that. So, I don't know... The principal is really quick to send him home for anything, when he should be working with his aid in a resource room working on his tools that we had been doing with our [re-adaptation center] psychoeducator.

Parent 3 continued to say that their psychoeducator, who had provided the family with many tools and recommendations, was also experiencing resistance from the school in implementing some of her ideas.

Mom's reaction to diagnosis. Parents seemed to respond differently to their child's diagnosis and have different perceptions of what should be done. The parents' response towards the diagnosis and sibling with autism will be discussed, followed by their reaction towards the focal child.

Reactions towards the diagnosis. Some parents seemed to be accepting of the diagnosis and open about autism with their family and with others. Parent 3 said that they talk about autism and the day-to-day struggles as a family "a lot". She continued by saying:

... The first time we told him he was like 'ok' it doesn't change anything. It doesn't mean...all of a sudden there's a diagnosis and you've got a different child. It doesn't do that. That's what I'm trying to tell other parents...

Similarly, parent 4 stated: "I'm very open to say it to people, I have nothing to hide. You know, it is what it is". She continued by explaining that she will "cut people off" who are unwilling to accept her son and his diagnosis. Parent 5 mentioned similar feelings in that she has nothing to hide. When in public, she explained, she will not deny her son his *chewie* if he wants it, and if people stare, she simply smiles at them. She continued to say they "aren't embarrassed or ashamed of the word *autism*" and use it freely.

Parent 6, on the other hand, as she has yet to tell her child with autism and his neurotypical sibling about the diagnosis. According to her, they use "special needs" rather than autism. Similarly, parent 3 explained: "... the thing is when you get diagnosed you don't have to tell anyone, you don't even have to tell the school. It is really your choice". It seems some

parents have chosen to be more private about the diagnosis than others.

One mother mentioned how difficult it was immediately after the diagnosis due to her lack of knowledge. Parent 4 described obtaining a diagnosis that “you know nothing about”:

They throw you into a river and they say go swim with these sharks... Then, I finally learned what to do cause really when we got the diagnosis, we were just like...you know my husband was working so I was just ‘what do I do now?’

It seems as though there was a sense of shock and urgency to find the next step, without knowing what the step is or how to go about finding out.

Responses towards their child with autism. Several parents seemed to take a proactive stance, however, parent 1 seemed to be constantly on edge, as her daughter with autism is still young and does not understand certain rules. She expanded by saying, “...going outside is very difficult, you know, so I constantly have to be there and watch for...one doesn’t stay put, one doesn’t want to know nothing”.

Alternatively, parent 3 described how she taught her son proper social conduct when he was younger. She explained having two large Bristol Boards; one was green with pictures of positive actions (i.e., sharing, smiling), the other red with negative actions (i.e., biting, hitting). Over time “he would know if he did any of those [negative things] it was agreed he was going upstairs, and it was for a calm down period”. Other behavior aids were used as well, such as prepping him before an outing or transition, reminding him of his options when he feels overwhelmed, and “pulling him out of” his rigid habits. Parent 5 mentioned that they have had several therapies for her son at home, which they still practice today. Parent 2 stated: “the key towards it is following it at home and ensuring that we practice it. So, we worked really significantly hard”, which seems to be the strategy adopted by other parents. Most parents

demonstrated that they were proactive and heavily involved in helping their child with autism.

The need for and lack of support. While no focal children or parents were members of support groups or the like, some parents had considered it. Parent 3 said: "...we looked into it, and you know, when things are going well that's when you don't, but that's really when you should. But it's just hectic". Similarly, parent 5 stated: [focal child] never had any intervention on her to deal with anything. There's been times where she probably needed it and it just kind of...didn't happen". Parent 4 expressed her strong belief in and need for support:

The beginning is very hard because you're getting a diagnosis that you know nothing about. And, I find if you don't have the support there's no way you can get through it. Because, when we got our diagnosis all my friends were like, 'it'll be ok' and I find that the 'it'll be ok' that's coming from someone who doesn't know what you're going through means nothing. If you don't live it, you don't know it. Just the fact that you're telling me this is what *I did* with my son, I know you went through it and I can trust you.

Parent 4 does have an informal support group, which was organized by an acquaintance of hers who "created a group and we get together every once in a while. So, we rent out a gym and we all bring our kids with special needs and their siblings, and they just play, we share stories. I've learnt a lot from that". As the neurotypical children get older they will perhaps be able to turn to each other for support, advice, and companionship, which is the hope of parent 4.

Responses towards the focal child. Some parents, such as parents 1 and 4 expressed feeling fortunate to have the focal child in their family. For example, parent 1 stated: "I'm pretty lucky to have him to deal with everybody because he's pretty good and patient". Parent 3, on the other hand, said that her other children are lucky to have the focal child as a sibling.

Parent 4 explained that her daughter became very jealous of her brother with autism, due

to the amount of time he was spending with their mother. As a result, parent 4 created “mommy and focal child] days”, where they spend quality time together to compensate for all the time parent 4 spends on her son with autism.

Some parents also mentioned the harder aspects of parenting a special needs child and neurotypical child. For example, parent 5 described how it is difficult to discipline her daughter, as she has often said to her mother: “I wish I was autistic so I could be like them and go to special needs school and not have homework and I don’t have to do hard school work”. Her mother believes that her daughter does not understand that her brother with autism has his own struggles and his life is not necessarily easier than hers.

Discussion

The purpose of this mixed method study was to investigate typically developing children’s perceptions of their sibling with autism and the nature of their sibling relationship, as well as parental perceptions of the sibling relationship and the experience of having a child with ASD. Through questionnaires and semi-structured interviews, mothers and typically developing children expressed their perceptions of the sibling relationship and family context. Information shared by typically developing children was shaped around four main research questions: (1) how does the typically developing sibling describe their sibling relationship?; (2) how do the descriptions of the sibling relationship differ relative to birth order and gender?; (3) what aspects of their sibling relationships do typically developing siblings emphasize most (i.e., positive, negative)?; and (4) what coping strategies are regularly used by the typically developing sibling? Parents offered information on their perception of the sibling relationship, the intervention and school experience, as well as their reaction to the diagnosis. Parent interviews were used to support information provided by the focal children as a form of triangulation. Many aspects

reported during the parent and child interviews were consistent with one another, although some differences were noted. The various themes will be discussed and tied to relevant empirical research and theory in the following sections. First, the four major questions will be addressed, as well as unanticipated themes that emerged from the analysis process. Information from all participants has been integrated within the subsequent sections. This will be followed by implications, limitations, and future directions stemming from this study.

How Typically Developing Children Described Their Sibling Relationship

The first research question aimed at investigating how typically developing children describe their sibling with autism and their sibling relationship. Questions about their sibling's personality, likes, interests, dislikes, and comportment were asked to obtain such information. A main finding common to focal children was a description of their sibling with autism that contained both negative and positive behaviors, which is in line with previous findings (Baumann et al., 2005; Orfus & Howe, 2008; Petalas et al., 2012; Rao & Biedel, 2009; Verté et al., 2003; Ward et al., 2016). All focal children used adjectives such as nice, caring, understanding, respectful, and affectionate to describe their sibling with autism. In support of the interview data, the highest rated item on the SRQ by children was "how much do you and your sibling care about and love each other?", indicating a sense of closeness. Mothers added to the picture by including additional qualities, such as protective of their typically developing sibling, sensitive, and hard working. Similarly, loyalty towards each other, feeling proud of one another, protectiveness, helping one another, affection, and being kind to one another were rated as frequently occurring by parents on the PEPC-SRQ.

Nonetheless, undesirable behaviors were also discussed by focal children and mothers. Children described their siblings' behavior as at times unpredictable, aggressive, bothersome,

and rude when they felt ignored or rejected. For example, child 3 explained that when she invites her brothers with autism to play with her, their response is often “no, we’re too busy [playing video games]”. In addition, focal children rated being embarrassed and interrupted by their sibling with ASD as often occurring on the Daily Events Scale and arguing and getting mad with each other on the SRQ. Similar results were found by Knot et al. (1995), who reported that siblings with autism were less likely to initiate play and more likely to ignore their typically developing siblings’ advances for joint interaction. Mothers spoke more generally about their child with autism, and used terms such as controlling, stubborn, passive, and irritable. This was supported by their ratings on the PEPC-SRQ, in which arguing, fighting, trying to control each other’s behaviors, and teasing and annoying were rated as often occurring.

Nevertheless, all focal children expressed that they had opportunities for joint interactions with their sibling with autism in various forms. Play was a common occurrence within sibling dyads, in the style of solitary, parallel, and cooperative play. This was supported by the Daily Events Scale, in which “spending time with my family” was rated as occurring most often by focal children. Moreover, some focal children rated “how much do you and your sibling like the same thing?” as occurring on the SRQ, which was expanded on during the interview. Some focal children mentioned enjoying arts and crafts, Lego, and other games with their sibling with autism. As some of the siblings with autism in this study are high functioning, it is not surprising that there was cooperative play amongst them. However, some play was in the form of board games or computer games, where interaction with their playmate is limited. As children with autism have low communication, imaginative, and creative skills (Holmes & Willoughby, 2005; Kaminsky & Dewey, 2002; Knot et al., 2007; Ward et al., 2016), it stands to reason that they prefer structured games-with-rules and little interaction rather than pretense or more creative

play. Solitary play, especially with technology, was mentioned by almost all focal children as consuming much of their siblings' time. This is in line with findings from Holmes and Willoughby (2005), in that solitary play was preferred by children with autism.

Focal children also engaged in various forms of helping and teaching their sibling with autism. Unlike Kaminsky and Dewey (2001), who reported that prosocial acts among children with siblings with autism were relatively low, this sample seemed to be quite helpful. Focal children mentioned helping their siblings with day-to-day tasks (i.e., getting dressed, transitions), teaching, and supporting their emotional well-being. This was supported by findings from the parent questionnaire and interview. On the PEPC-SRQ, the most frequently occurring events highlighted by parents were teaching, helping, protectiveness, and being kind to each other. This was expanded during the interviews, where mothers went into detail about the behaviors of the focal child. All expressed that their typically developing child is protective of and helpful with their sibling with autism. Perhaps the child's involvement has allowed them to see their siblings' progress, as well as instilled a sense of maturity, acceptance, and patience within the focal child, which were other positive qualities expressed by mothers about their typically developing children during the interviews.

Naturally, such positive exchanges were linked to positive emotions experienced by the focal child. Many described themselves as happy when they have pleasant interactions with their sibling, being proud of their sibling, empathetic towards their sibling, and appreciating time spent with their sibling. Relatedly, "when my sibling learns something new" was rated by focal children as triggering the highest levels of happiness on the Daily Events Scale. Mothers agreed, by describing their typically developing child as loving, caring, proud, and empathetic towards their sibling with autism. Empathy is a common finding among typically developing children of

siblings with disabilities (i.e., Pilowski et al., 2004), as are acts of prosociality directed towards their sibling with disabilities (Walton & Ingersoll, 2015). Thus, the present findings are in line with the literature.

Another common finding reported by all participants was a high rate of conflict between these sibling dyads, which is a behavior also characteristic of typically developing sibling relationships (Howe et al., 2011). Focal children rated arguing with and getting mad at their sibling as the most frequently occurring negative event on the SRQ. This was supported by the interviews, where children were able to voice the specifics of their conflicts. For example, fighting over objects, such as toys, the television, and video games was mentioned by several children and was rated as most frequently occurring by parents on the PEPC-SRQ, findings in line with the literature (Howe et al., 2011). Additionally, focal children rated “when my sibling goes into my room without asking, takes something, or makes it messy” as most often occurring on the Daily Events Scale. Child 6 specifically mentioned her brother taking her belongings in the interview, and how it upsets her.

Teasing and annoying each other was rated by parents on the PEPC-SRQ as occurring most often and being a big problem amongst siblings, as well as something they would need a great deal of help to improve. This is in line with findings from Kramer and Baron (1995), in which agonism was perceived by parents as a larger problem than deficient level of warmth, and was rated as needing more help to improve than warmth. While some parents expressed that the levels of teasing between their children are comparable to that of other families, parent 2 disagreed. She seemed to believe her children argue and are mean to each other more than most siblings. This may be due to the poor communication and expressive skills of her child with autism, which may have been adopted by her typically developing child, as well. Moreover,

playing together, respecting each other's property, and arguing were rated by mothers as big problems, indicating that they often occur and cause turmoil. As play requires a great deal of communication and shared understanding about materials and goals (Dunn, 1998; Göncü, 1993, Howe et al., 1998), it may be difficult for these dyads, as one child struggles with language and communication abilities and their typically developing sibling may not. In line with such findings, children rated "how much do you and your brother/sister tell each other everything or share secrets?" as least often occurring, as did parents on the PEPC-SRQ.

Birth order. The second research question set out to explore if descriptions differ relative to birth order and gender. As only one focal child was male, gender could not be considered. First-born and second-born focal children seemed to respond differently to having a sibling with autism, which is in line with previous studies (Orfus & Howe, 2008; Pilowski et al., 2004; Verté et al., 2003). Results from the SRQ indicated that second-born focal children rated experiencing more negative and positive events than first-born focal children, perhaps due to similar developmental levels. Interestingly, the same cannot be said for the Daily Events Scale, as first-born focal children reported more daily hassles and daily uplifts than second-born focal child. A potential explanation for this is that the SRQ focuses on day-to-day events between siblings, whereas the latter measure is focused on specific events related to the sibling with the disability. As in the study conducted by Orfus and Howe (2006), the results suggest that older siblings experience more responsibilities and frustrations related to having a sibling with autism. However, during the interviews, the two younger focal children spoke of taking care of their older sibling with autism and looking out for them. Perhaps, in families with a non-typically and typically developing child, birth order plays less of an important function in determining children's roles compared to families with only typically developing children. Typically

developing children by nature of their development may take on certain jobs, such as teaching or helping, even when they are second-born (Howe et al., 2011). Baumann et al. (2005) found that typically developing children often take on a caregiving role towards their sibling, as well as assume more responsibilities. However, the aspect of birth order requires further investigation.

Emphasis. The third research question centered around what aspects of the sibling relationship focal children emphasized more than other aspects. As mentioned, focal children highlighted their siblings' negative behaviors and conflict more than positive aspects of their relationship. This was supported by the SRQ results, in which siblings rated negative events as occurring more often than positive events. Not only were negative aspects discussed more, but focal children often had little to say when asked about happy memories, positive qualities of their relationship or own development. Parents, on the other hand, spoke more about the positive traits of both their children, as well as how the sibling context has and will continue to strengthen their typically developing child's character. It may be that while parents were quick to describe the benefits of the sibling context to the primary researcher, they may not consistently do so with their typically developing children. A main tenant of positive psychology (Seligman & Csikszentmihalyi, 2000) is the focus on one's interpersonal skills that positively contribute to their development and well-being, which all focal children have demonstrated having in the interviews and questionnaires. Perhaps if positive aspects of interactions, such as moments of growth or happiness, were accentuated by parents, children would become more cognizant and aware of them, as well. While Kaminsky and Dewey (2002) found that children of parents who went to support groups reported certain benefits, perhaps the inclusion of positive psychology pillars would allow for this additional benefit. This may be a useful area for future researchers.

Coping Strategies Used by Typically Developing Children

The fourth research question investigated the various coping strategies used by focal children. Of the types of coping strategies listed by Gamble and McHale (1989), this sample seemed to engage in all of them. Other-directed behaviors (i.e., problem-solving) were evident on the KIDCOPE, where all focal children responded as using them. Specifically, trying to fix the problem by thinking of answers, and spending time with others such as family members, friends, and grownups, were used by most focal children. In addition, a class presentation was used by child 3 to help educate her peers and perhaps stop them from staring at her when her brother(s) had a meltdown at school. Self-directed behaviors (i.e., avoidance, withdrawal) were commonly reported coping strategies by focal children in the interview, as well as on the KIDCOPE. This may be partially explained by half of the participating families being a four-child household, where two children have an ASD diagnosis. Here, the focal child may enjoy some quiet time by withdrawing to their bedrooms.

Physical acts were also described by many children, such as kicking, punching, and screaming. As some studies have found that typically developing children with siblings with autism are at an increased risk for externalizing behaviors (Brewton et al., 2012; Rodrigue et al., 1993; Ross & Cuskelly, 2006; Vaudrey, 2015; Verte et al., 2003), their reactions could be understood and may be in line with this literature. As these children may not often have opportunities to practice conflict resolution with their sibling with autism, they may resort to physical acts to calm themselves down and express their frustrations. Self-directed cognitions were also used by focal children, specifically wishful thinking, which all children marked as a heavily used strategy on the KIDCOPE. Otherwise, cognitive techniques were not commonly rated as being used. During the interview, only child 6 acknowledged using cognitive techniques to calm herself down, such as breathing exercises and thinking happy thoughts. The least

common strategy reported by focal children was other-directed cognitions, such as blaming someone else. Overall, these findings are in partial support of previous studies, which found high levels of wishful thinking and problem-solving (Orfus & Howe, 2006), but also high levels of emotional regulation (Ross & Cuskelly, 2006).

A potential reason for the lack of emotional regulation within this sample can be drawn from Richard et al's. (2010) peer modeling theory. Essentially, typically developing children may observe the lack of self-expression from their sibling with autism and, therefore not attempt it for themselves, but instead focus on more negative expressions. Such findings and explanations are in line with results from Habelrih et al. (2018), who indicated that even typically developing siblings had low levels of emotional regulation when their sibling had a disability.

An alternative explanation for the low levels of emotional regulation in this study is the family context. In two families where the neuro-typical child is the eldest, there are two other siblings with autism. This context may amplify conflicts and negative emotions experienced by the typically developing sibling, and outbursts from the siblings with autism, which in turn takes attention from parents away from the typically developing child. The remaining eldest focal child in this study is still quite young and may not be at a developmental level to recognize and express her coping methods. Moreover, child 5, who is a second-born sibling, was said to not have emotional regulation skills by her mother. She attributed this to observing her two siblings with autism extreme tantrums that involved screaming, aggression, violence, and the being physically held to calm down.

Adjustment of the Typically Developing Sibling and Sibling with Autism

An interesting theme that emerged from the parents' and focal children's data offered

insight into the adjustment of both siblings. As mentioned, both children exhibit positive and negative behaviors towards each other. Some parents, however, attributed behaviors and tendencies to the specific sibling configuration of their family. For instance, parents 3 and 5 attributed their daughters' acceptance of others to their relationship with their sibling with autism. While child 3 explained how she is perhaps less judgemental of others than her peers, parent 3 stated "because [focal child has] been exposed to it, and we talk about how you never know what someone is going through". Similarly, parent 5 expressed how her neurotypical daughter interacts with children with disabilities in playgrounds, as "...that's her life, right? ... She just knows how to get into their bubble". Other mothers spoke of their children's maturity, protectiveness, caregiving, and other prosocial acts that have been strengthened through their family context. Additionally, some mothers expressed how their children have taken on each other's interests. For instance, parent 5 expressed:

[Focal child] likes technology, she likes puzzles, mind games. Not just regular puzzles but puzzles that are 3-D and you have to put it together and stuff like that. She's really into logic, and I think that comes from her brother and sister [with autism]. That's what they've always been interested in.

Parent 5 explained how her daughter behaves similarly with her peers as she does with her siblings with autism; "it's hard too, [focal child's] best friend when she comes over, they butt heads because she wants to do this and the other wants to play house". Alternatively, parent 6 expressed how her son with autism adopted the interests and likes of his typically developing sibling, inferring that the influence is bi-directional.

Some mothers also spoke of their child's negative adjustment. Parent 4 expressed how her daughter became jealous of the time and attention her brother with autism requires from their

mother. Moreover, child 5 was said to have poor emotional regulation techniques, which her mother also thinks she learned from her brother. Parent 5 explained how her son with autism needs to be held in order to calm him down, which her neurotypical daughter also requires, otherwise “she’ll scream for two hours”. She continued to say: “[Focal child] needs some way to get out her frustration...because it's not a normal upset child. It's extreme”.

Parents Reactions Towards Public and Private Services

Another theme that emerged from the data related to parents’ experiences was in obtaining services for their child with autism, which most mothers spent a great deal of time discussing. Many mothers expressed their discontent with the public services they received, or did not receive in some cases, as well as with the education system. After waiting several months and not getting anywhere, most families chose to purchase private help for their child with autism. Mothers mentioned that it was taking too long to hear back about receiving public services, or being told that they would have to wait over a year to receive the assistance. Such perceptions are in line with findings from Rivard, Lepine, Mercier, and Morin (2015). In this study, parents ranked accessibility as one of the most important quality determinants of public services, but also as the least implemented. As early intervention is crucial for a child’s prognosis, it is not surprising that families felt let down by the social service and educational systems. In the Quebec public health and service system, families have to go through several steps before being seen by a specialist, and as expressed by several mothers in this study, the process is not efficient enough to handle all demands.

A similar complaint related to the lack of school resources was expressed by mothers who mainstreamed their children with autism. Mothers mentioned that their child rarely saw or rarely had a substantial amount of time with their case worker, as their time is divided among

many other students. This is in support of Brown et al's., (2012) study, where parents described their child's needs as being "unmet" at school. In the current study, mothers felt dissatisfied with what the school was doing as it went against professional advice and undid much of what they tried to instill in their child with autism through the use of various therapies they had received privately. Relatedly, Brown et al. reported that parents found a lack of consistency and follow through from the school, which was expressed in this study, as well. As school-age children are no longer eligible for early intervention services, the discontinuity may be more likely to occur. However, as expressed by several parents and highlighted in previous literature, it is extremely important for the development and prognosis of their child with autism that rules, responses, and expectations be consistent across different contexts (Brown et al., 2012; Rivard et al., 2015). Clearly, this requires coordination between early intervention services and school intervention.

This lack of continuity may partially explain some of the difficulties experienced by children with autism at school. Mothers reported that their children with autism have become passive, unmotivated, and anxious when it comes to school and the associated social and academic expectations. Mothers felt that their children had become aware of the differences between themselves and their peers, which may discourage them academically and socially. This is supported by Ashburn, Ziviani, and Rodger (2010) in that teachers described their students with autism as having low adaptive functioning because they were anxious, depressed, withdrawn, and socially and academically delayed. Moreover, students were considered inattentive, oppositional, aggressive, and withdrawn, which can further explain the poor academic achievement and social problems reported by mothers in the current study.

Limitations and Future Directions.

Although the study produced rich findings, it is not without its limitations. First, the small

sample size is problematic. The study was based on the interviews of six typically developing children and their mothers, all living in an urban city who speak English. As a result, the findings may not be representative of others, as it is bound by culture of the setting. As perceptions are shaped by cultural beliefs and values, it would be beneficial to replicate this study with families from diverse backgrounds. In addition, more remote locations may not have as easy access to services mentioned by these families and may experience a different sibling dynamic. By replicating this study with a more diverse and larger sample taken from a larger geographical area, individual's cultural influences and accessibility would be taken into consideration when researching autism and its impact on the family unit.

Secondly, the information collected from participants was through self-report measures, which presents a further limitation. When answering questionnaires and interview questions, the information provided by parents and typically developing children may not have been completely accurate. For instance, they may not have been able to remember events that happened in the past, and either minimized or exaggerated certain facts simply based on how they were remembered. Alternatively, participants may not have been entirely forthcoming and withheld certain details that they did not want publicized for reasons of social desirability. Nevertheless, based on the length of several of the parent and child interviews, it seems that participants were open and did not shy away from the questions.

Lastly, the timeframe of the current study did not allow for longitudinal information on the sibling relationship, which could prove to be useful. While research shows that sibling dynamics change over time (Howe et al., 2011), the relationship of a typically developing and non-typically developing sibling will also change. It would be interesting to see if such changes follow a similar trajectory as other sibling dyads, such as two typically developing siblings, or a

sibling with a different disability than autism, or follow a different course of transformation. This is related to the previously mentioned idea of birth order and sibling roles, which is another possibility for future research. In the current study, both older and younger siblings had a sense of responsibility towards their sibling with autism, indicating that birth order may be less important in such families, or that the children's cognitive development plays a larger role in these families. A final area of future research is the implementation of strategies from positive psychology. While none of the families in the current study were members of a formal support group, the shift in behavior from focusing on the negative to the positive may ameliorate some of the difficulties seen, and is an avenue for future research.

Role of the Researcher

In order for this study to develop, the primary researcher investigated the previous literature to ascertain what seemed to be missing, as well as her values, beliefs, interests, and ideas. Once questions were developed, the primary researcher started the recruitment phase of the study. While having experience working with children with autism and their families, it is very possible that my past experience allowed me to be mindful, understanding, and empathetic towards families that participated in this study. On the other hand, the same experiences may have influenced certain emotional responses and biases while conducting the interviews and analyzing the data. Efforts were taken to ensure that the information presented is neutral, such as convenient sampling, having two coders, and the awareness to remain impartial throughout the process in order to maintain validity and allow the participants voices to be heard.

Conclusion

This study revealed some of the struggles typically developing siblings may be facing in families with another child(ren) with ASD. Through the use of semi-structured interviews and

questionnaires, children and mothers were able to open up about the day-to-day challenges and uniqueness of having a family member with autism. While children and parents were more likely to be in agreement than not, it became clear that different aspects of the sibling relationship are noticed and focused on by each. Similarly, the questionnaires provided triangular support for the reports of children and parents more often than not. Needless to say, the sibling and family dynamics of children with autism needs further investigation to advance our understanding of this phenomenon. The implications of the findings highlight the need to provide support to the families of children with autism, through both formal and informal methods.

References

- American Psychiatric Association. (2013). *The diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: Author.
- Ashburn, J., Ziviani, J., & Rodger, S. (2010). Surviving in the mainstream: Capacity of children with autism spectrum disorders to perform academically and regulate their emotions and behavior at school. *Research in Autism Spectrum Disorders, 4*, 18-27. doi: 10.1016/j.rasd.2009.07.002
- Bass, J., & Mulick, J. (2007). Social play skill enhancement of children with autism using peers and sibling as therapists. *Psychology in the Schools, 44*, 727-735. doi: 10.1002/pits.20261
- Baumann, S., Dyches, T., & Braddick, M. (2005). Being a sibling. *Nursing Science Quarterly, 18*, 51-58. doi: 10.1177/0894318404272108
- Ben-Itzhak, E., Zukerman, G., & Zachor, D. (2016). Having older siblings is associated with less severe social communication symptoms in young children with autism spectrum disorder. *Journal of Abnormal Child Psychology, 44*, 1613-1620. doi: 10.1007/s10802-016-0133-0
- Bloch, J., & Weinstein, J. (2009). Families of young children with autism. *Social Work in Mental Health, 8*, 23-40. doi: 10.1080/15332980902932342
- Bontinck, C., Warreyn, P., Paelt, S., Demurie, E., & Roeyers, H. (2018). The early development of infant siblings of children with autism spectrum disorder: Characteristics of sibling interactions. *Plos One, 13*, 1-19. doi: 10.1371/journal.pone.0193367
- Brewton, C., Nowell, K., Lasala, M., & Goin-Kochel, R. (2012). Relationship between the social functioning of children with autism spectrum disorders and their siblings'

- competencies/problem behaviors. *Research in Autism Spectrum Disorders*, 6, 646-653.
doi: 10.1016/j.rasd.2011.10.004
- Brody, G. (2004). Siblings' direct and indirect contributions to child development. *Current Directions in Psychological Science*, 13, 124-126. doi: 10.1111/j.0963
7214.2004.00289.x
- Brown, H., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an Autism Spectrum Disorder. *Journal of Applied Research in Intellectual Disabilities*, 25, 497-508. doi: 10.1111/j.1468
3148.2012.00692.x
- Buhrmester, D. (1992). The developmental courses of sibling and peer relationships. In F. Boer, & J. Dunn (Eds.), *Children's sibling relationships: Developmental and clinical issues* (pp. 19-40). Hillsdale, NJ: Erlbaum.
- Buhrmester, D., & Furman, W. (1990). Perceptions of sibling relationships during middle childhood and adolescence. *Child Development*, 61, 1387-1398. doi: 10.2307/1130750
- Cassel, T., Messinger, D., Ibanez, L., Haltigan, J., Acosta, S., & Buchman, A. (2007). Early social and emotional communication in the infant siblings of children with autism spectrum disorder: An examination of the broad phenotype. *Journal of Autism and Developmental Disorders*, 37, 122-132. doi: 10.1007/s10803-006-0337-1
- Creswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed). Thousand Oaks: Sage.
- Cridland, E., Jones, S., Magee, C., & Caputi, P. (2014). Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism: The*

- International Journal of Research and Practice*, 18, 213-222. doi:
10.1177/1362361312472261
- Dirks, M., Persram, R., Recchia, H., & Howe, N. (2015). Sibling relationships as sources of risk and resilience in the development and maintenance of internalizing and externalizing problems during childhood and adolescence. *Clinical Psychology Review*, 42, 145-155. doi: 10.1016/j.cpr.2015.07.003
- Dunn, J. (1988). *The beginning of social understanding*. Oxford: Blackwell.
- Dunn, J. (2007). Siblings and socialization. In J. E. Grusec & P. D. Hastings (Eds.), *Handbook of socialization: Theory and research* (pp. 309-327). New York, NY: Guilford.
- Ferraiolo, S., & Harris, S. (2010). The impact of autism on siblings. *Social Work in Mental Health*, 8, 41-53. doi: 10.1080/15332980902932409
- Folstein, S., & Rutter, M. (1977). Infantile autism: A genetic study of 21 twin pairs. *Journal of Child Psychology and Psychiatry*, 18, 297-321.
- Gamble, W., & McHale, S. (1989). Coping with stress in sibling relationships: A comparison of children with disabled and non-disabled siblings. *Journal of Applied Developmental Psychology*, 10, 353-373. doi: 10.1016/0193-3973(89)90035-X
- Giallo, R., & Gavidia-Payne, S. (2008). Evaluation of a family-based intervention for siblings of children with a disability or chronic illness. *The Australian e-Journal for the Advancement of Mental Health*, 7, 84-96. doi: 10.5172/jamh.7.2.84
- Göncü, A. (1993). Development of intersubjectivity in the dyadic play of preschoolers. *Early Childhood Research Quarterly*, 8, 99-116. doi: 10.1016/S0885-2006(05)80100-0
- Habelrih, E., Hicks, R., & Vanstone D. (2018). A study of the wellbeing of siblings of children with autism spectrum disorders: Sibling efficacy, positive and negative affect, and coping

- strategies. *International Journal of Psychological Studies*, 10, 102-113. doi:
10.5539/ijps.v10n2p102
- Hartup, W. (1989). Social relationships and their developmental significance. *American Psychologist*, 44, 120-126. doi: 10.1037/0003-066X.44.2.120
- Hastings, R. (2003a). Brief report: Behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disability*, 33, 99-104. doi:
10.1023/A:1022983209004
- Hastings, R. (2003b). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research*, 47, 231-237. doi: 10.1046/j.1365-2788.2003.00485.x
- Hastings, R., Kovshoff, H., Ward, N., Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions on mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35, 635-644. doi:
10.1007/s10803-005-0007-8
- Hesse, T., Danko, C., & Budd, K. (2013). Siblings of children with autism: Predictors of adjustment. *Research in Autism Spectrum Disorders*, 7, 1323-1331. doi:
10.1016/j.rasd.2013.07.024
- Holmes, E., & Willoughby, T. (2005). Play behavior of children with autism spectrum disorders. *Journal of Intellectual and Developmental Disability*, 30, 156-164. doi:
10.1080/13668250500204034
- Howe, N. (1991). Sibling-directed internal state language, perspective taking, and affective behavior. *Child Development*, 62, 1503-1512. doi: 10.1111/1467-8624.ep9202105176

- Howe, N., & Recchia, H. (2005). Playmates and teachers: Reciprocal and complementary interactions between siblings. *Journal of Family Psychology, 19*, 497-502. doi: 10.1037/0893-3200.19.4.497
- Howe, N., Petrakos, H., & Rinaldi, C. (1998). "All the sheeps are dead. He murdered them": Sibling pretense, negotiation, internal state language, and relationship quality. *Child Development, 69*, 192-191. doi: 10.1111/j.1467-8624.1998.tb06142.x
- Howe, N., Rinaldi, C., Jennings, M., & Petrakos, H. (2002). "No! The lambs can stay out because they got cozies": Constructive and destructive sibling conflict, pretend play, and social understanding. *Child Development, 73*, 1460. doi: :10.1111/1467-8624.00483
- Howe, N., Ross, H., & Recchia, H. (2011). Sibling relations in early childhood. In C. Hart & P. K. Smith (Eds.), *Wiley-Blackwell handbook of childhood social development* (2nd edition, pp. 356-372). New York, NY: Wiley.
- Jones, C., & Schwartz, I. (2004). Siblings, peers, and adults: Differential effects of models for children with autism. *Topics in Early Childhood Special Education, 24*, 187-198. doi:10.1177/02711214040240040101
- Kaminsky, L., & Dewey, D. (2001). Siblings relationships of children with autism. *Journal of Autism and Developmental Disorders, 31*, 399-410. doi: 10.1023/A:1010664603039
- Kaminsky, L., & Dewey, D. (2002). Psychosocial adjustment in siblings of children with autism. *Journal of Child Psychology and Psychiatry, 43*, 225-232. doi: 10.1111/1469-7610.00015
- Knott, F., Lewis, C., & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and down syndrome. *Journal of Child Psychology and Psychiatry, 56*, 965-976. doi: 10.1111/j.1469-7610.1995.tb01343.x

- Knott, F., Lewis, C., & Williams, T. (2007). Sibling interactions of children with autism: Development over 12 months. *Journal of Autism and Developmental Disorders, 37*, 1987-1995. doi: 10.1007/s10803-006-0347-z
- Kramer, L., & Baron, L. (1995). Parental perceptions of children's sibling relationships. *Family Relations, 44*, 95-103. doi: 10.2307/584746
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York, NY: Springer.
- Leach, J., Howe, N., & Dehart, G. (2017). "I was my people can be like ducks": Children's references to internal states with siblings and friends from early to middle childhood. *Infant and Child Development, 26*, 1-12. doi: 10.1002/icd.2015
- MacDonald, M., Hatfield, B., & Twardzik, E. (2017). Child behaviors of young children with autism spectrum disorder across play settings. *Adapted Physical Activity Quarterly, 34*, 19-32. doi: 10.1123/APAQ.2016-0028
- Macks, R., & Reeve, R. (2007). The adjustment of non-disabled siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 1060-1067. doi: 10.1007/s10803-006-0249-0
- Meadan, H., Stoner, J., & Angell, M. (2010). Review of literature related to the social, emotional, and behavioral adjustment of siblings of individuals with autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 22*, 83-100. doi: 10.1007/s10882-009-9171-7
- Oppenheim-Leaf, M., Leaf, J., Dozier, C., Sheldon, J., & Sherman, J. (2012). Teaching typically developing children to promote social play with their siblings with autism. *Research in Autism Spectrum Disorders, 6*, 777-791. doi: 10.1016/j.rasd.2011.10.010

- Orfus, M., & Howe, N. (2008). Stress appraisal and coping in siblings of children with special needs. *Exceptionality Education International, 18*, 166-181.
- Petalas, M., Hastings, R., Nash, S., Reilly, D., & Dowey, A. (2012). The perceptions and experiences of adolescent siblings who have a brother with autism spectrum disorder. *Journal of Intellectual and Developmental Disability, 37*, 303-314. doi: 10.3109/13668250.2012.734603
- Pilowski, T., Yirmiya, N., Doppelt, O., Gross-Tsur, V., & Shalev, R. (2004). Social and emotional adjustment of siblings of children with autism. *Journal of Child Psychology and Psychiatry, 45*, 855-865. doi: 10.1111/j.1469-7610.2004.00277.x
- Rao, P., & Beidel, D. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment and family functioning. *Behavior Modification, 33*, 437-451. doi: 10.1177/0145445509336427
- Richards, L. C., Heathfield, L. T., & Jenson, W. R. (2010). A classwide peer-modeling intervention package to increase on-task behavior. *Psychology in the Schools, 47*, 551-566. doi:10.1002/pits.20490
- Rivard, M., Lepine, A., Mercier, C., & Morin, M. (2015). Quality determinants of services for parents of young children with Autism Spectrum Disorder. *Journal of Child and Family Studies, 24*, 2388-2397. doi: 10.1007/s10826-014-0041-2
- Rivers, J., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*, 383-394. doi: 10.1023/A:1025006727395

- Rivers, J., & Stoneman, Z. (2008). Child temperaments, differential parenting, and the sibling relationships of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 38*, 1740-1750. doi: 10.1007/s10803-008-0560-z
- Rodrigue, J., & Geffken, G., & Morgan, S. (1993). Perceived competence and behavioral adjustment of siblings of children with autism. *Journal of Autism and Developmental Disorders, 23*, 665-674. doi: 10.1007/BF01046108
- Ross, P., & Cuskelly, M. (2006). Adjustment, sibling problems and coping strategies of brothers and sisters of children with autistic spectrum disorder. *Journal of Intellectual and Developmental Disability, 31*, 77-86. doi: 10.1080/13668250600710864
- Saldaña, J. (2016). *The coding manual for qualitative researchers*. Los Angeles, CA: Sage.
- Seligman, M. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *American Psychologist, 55*, 5-14. doi:10.1037/0003-066X.55.1.5
- Spirito, A., Stark, L., & Williams, C. (1988). Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology, 13*, 555-574. doi: 10.1093/jpepsy/13.4.555
- Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardation and Developmental Disabilities Research Reviews, 7*, 134-142. doi: 10.1002/mrdd.1019
- Toth, K., Dawson, G., Meltzoff, A., Greenson, J., & Fein, D. (2007). Early social, imitation, play, and language abilities of young non-autistic siblings of children with autism. *Journal of Autism and Developmental Disorders, 37*, 145-157. doi: 10.1007/s10803-006-0336-2

- Tsao, L., & Odom, S. (2006). Sibling-mediated social interaction intervention for young children with autism. *Topics in Early Childhood Special Education, 26*, 106-123. doi: 10.1177/02711214060260020101
- Vaudrey, B. (2015). *Effects of sibling quantity and birth order on problem behaviors in children with autism spectrum disorder and their typically developing siblings* (Doctoral dissertation). Retrieved from ProQuest. (3737075)
- Verté, S., Roeyers, H., & Buysse, A. (2003). Behavioral problems, social competence and self-concept in siblings of children with autism. *Child: Care, Health & Development, 29*, 193-205. doi: 10.1046/j.1365-2214.2003.00331.x
- Walton, K., & Ingersoll, B. (2015). Psychosocial adjustment and sibling relationships in siblings of children with autism spectrum disorder: Risk and protective factors. *Journal of Autism and Developmental Disorders, 45*, 2764-2778. doi: 10.1007/s10803-015-2440-7
- Ward, B., Tanner, B., Mandleco, B., Dyches, T., & Freeborn, D. (2016). Sibling experiences: Living with young persons with autism spectrum disorders. *Pediatric Nursing, 42*, 69-76.

Appendix A

Ethics Form



SUMMARY PROTOCOL FORM (SPF)

Office of Research – Research Ethics Unit – GM 900 – 514-848-2424 ext. 7481 – oor.ethics@concordia.ca – www.concordia.ca/offices/oor.html

IMPORTANT INFORMATION FOR ALL RESEARCHERS

Please take note of the following before completing this form:

- You must not conduct research involving human participants until you have received your Certification of Ethical Acceptability for Research Involving Human Subjects (Certificate).
- In order to obtain your Certificate, your study must receive approval from the appropriate committee:
 - Faculty research, and student research involving greater than minimal risk is reviewed by the University Human Research Ethics Committee (UHREC).
 - Minimal risk student research is reviewed by the College of Ethics Reviewers (CER; formerly the “Disciplinary College”), except as stated below.
 - Minimal risk student research conducted exclusively for pedagogical purposes is reviewed at the departmental level. **Do not use this form for such research.** Please use the Abbreviated Summary Protocol Form, available on the Office of Research (OOR) website referenced above, and consult with your academic department for review procedures.
- Research funding will not be released until your Certificate has been issued, and any other required certification (e.g. biohazard, radiation safety) has been obtained. For information about your research funding, please consult:
 - Faculty and staff: OOR
 - Graduate students: School of Graduate Studies
 - Undergraduate students: Financial Aid and Awards Office or the Faculty or Department
- Faculty members are encouraged to submit studies for ethics by uploading this form, as well as all supporting documentation, to ConRAD, which can be found in the MyConcordia portal.
- If necessary, faculty members may complete this form and submit it by e-mail to oor.ethics@concordia.ca along with all supporting documentation. Student researchers are asked to submit this form and all supporting documentation by e-mail, except for departmental review. Please note:
 - Handwritten forms will not be accepted.
 - Incomplete or omitted responses may result in delays.
 - This form expands to accommodate your responses.
- Please allow the appropriate amount of time for your study to be reviewed:

- UHREC reviews greater than minimal risk research when it meets on the second Thursday of each month. You must submit your study 10 days before the meeting where it is to be reviewed. You will normally receive a response within one week of the meeting. Please confirm the deadline and date of the meeting with the staff of the Research Ethics Unit.
- CER reviews, and delegated reviews conducted by UHREC generally require 2 to 4 weeks.
- Research must comply with all applicable laws, regulations, and guidelines, including:
 - The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)
 - The policies and guidelines of the funding/award agency
 - The [Official Policies of Concordia University](#), including the [Policy for the Ethical Review of Research Involving Human Participants, VPRGS-3](#).
- The Certificate is valid for one year. In order to maintain your approval and renew your Certificate, please submit an Annual Report Form one month before the expiry date that appears on the Certificate. You must not conduct research under an expired Certificate.
- Please contact the Manager, Research Ethics at 514-848-2424 ext. 7481 if you need more information on the ethics review process or the ethical requirements that apply to your study.

ADDITIONAL INFORMATION FOR STUDENT RESEARCHERS

- If your research is part of your faculty supervisor's research, as approved, please have him or her inform the Research Ethics Unit via e-mail that you will be working on the study.
- If your research is an addition to your faculty supervisor's study, please have him or her submit an amendment request, and any revised documents via e-mail. You must not begin your research until the amendment has been approved.

INSTRUCTIONS FOR COMPLETING THIS FORM

- Please make sure that you are using the most recent version of the SPF by checking the OOR website.
- Please answer each question on the form; if you believe the question is not applicable, enter not applicable.
- Do not alter the questions on this form or delete any material. Where questions are followed by a checklist, please answer by checking the applicable boxes.
- The form can be signed and submitted as follows:
 - Faculty research submitted on ConRAD will be considered as signed as per section 16.
 - SPFs for faculty research submitted via the faculty member's official Concordia e-mail address will also be considered as signed as per section 16.
 - Both faculty and student researchers may submit a scanned pdf of the signature page by e-mail. In this case, the full SPF should also be submitted by e-mail in Word or pdf format (not scanned).
 - If you do not have access to a scanner, the signature page may be submitted on paper to the OOR.

ADDITIONAL DOCUMENTS

Please submit any additional documents as separate files in Word or PDF format.

I. BASIC INFORMATION

Study Title: The Psychosocial Effects of Having a Sibling with Autism Spectrum Disorder

Principal Investigator: Norah Jesseca Perlman

Principal Investigator's Status:

- Concordia faculty or staff
- Visiting scholar
- Affiliate researcher
- Postdoctoral fellow
- PhD Student
- Master's student
- Undergraduate student
- Other (please specify):

Type of submission:

- New study
- Modification or an update of an approved study.
- Approved study number (e.g. 30001234):

Where will the research be conducted?

- Canada
- Another jurisdiction:

2. STUDY TEAM AND CONTACT INFORMATION*

Role	Name	Institution [†] / Department / Address [‡]	Phone #	e-mail address
Principal Investigator	Norah Jesseca Perlman	Department of Education/ 1610 Saint-Catherine St. West, Montreal, Quebec, H3H 2S2	514-984-0822	Jesseca.perlman@gmail.com

Faculty supervisor [§]	Dr. Nina Howe	Department of Education/ 1610 Saint-Catherine St. West, Montreal, Quebec, H3H 2S2	514-848-2424, ext: 2008	Nina.howe@concordia.ca
Committee member [†]	Dr. Hariclia Petrakos	Department of Education/ 1610 Saint-Catherine St. West, Montreal, Quebec, H3H 2S2	514-848-2424, ext: 2013	Hariclia.petrakos@concordia.ca
Committee member [†]	Dr. Miranda D'Amico	Department of Education/ 1610 Saint-Catherine St. West, Montreal, Quebec, H3H 2S2	514-848-2424, ext: 2040	Miranda.damico@concordia.ca

Additional Team Members [°]				
Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

Notes:

* If additional space is required, please submit a list of team members as a separate document.

†For team members who are external to Concordia only.

‡For individuals based at Concordia, please provide only the building and room number, e.g. GM-910.03.

§For student research only.

‖For research conducted by PhD and Master's students only.

°Please include all co-investigators and research assistants.

3. PROJECT AND FUNDING SOURCES

Please list all sources of funds that will be used for the research. Please note that fellowships or scholarships are not considered research funding for the purposes of this section.

Funding Source	Project Title*	Grant Number [†]	Award Period	
			Start	End
Not applicable	Not applicable	Not applicable	Not applicable	Not applicable

Notes:

* Please provide the project title as it appears on the Notice of Award or equivalent documentation.

† If you have applied for funding, and the decision is still pending, please enter "applied".

4. OTHER CERTIFICATION REQUIREMENTS

Does the research involve any of the following (check all that apply):

- Controlled goods or technology
- Hazardous materials or explosives
- Biohazardous materials
- Human biological specimens
- Radioisotopes, lasers, x-ray equipment or magnetic fields
- Protected acts (requiring professional certification)
- A medical intervention, healthcare intervention or invasive procedures

Please submit any certification or authorization documents that may be relevant to ethics review for research involving human participants.

5. LAY SUMMARY

Please provide a brief description of the research in everyday language. The summary should make sense to a person with no discipline-specific training, and it should not use overly technical terms. Please do not submit your thesis proposal or grant application.

This mixed method study seeks to examine the psychological, social, and behavioral effects of having a sibling with autism for their typically developing sibling. Moreover, possible associations between these outcomes and coping strategies will be investigated.

Siblings are an integral part of any family as they provide each other with their first social experiences. Through their continuous interactions, children practice and strengthen their cognitive, affective, behavioral, and social skills, allowing them to experience friendship, loyalty, support, and rivalry (Buhrmester, 1992; Dunn, 2007). However, in a home where a child is diagnosed with autism these interactions may not be so common.

Autism Spectrum Disorder is a pervasive developmental disorder, whose main characteristics are impaired social communications and interactions and the use of restricted or repetitive behaviors (American Psychiatric Association, 2013). During dyadic play, these children are less likely to initiate play or reciprocate another child's initiations (MacDonald, Hatfield, & Twardzik, 2017). That being said, the literature demonstrates that typically developing siblings have a positive impact on their sibling with autism. For instance, less severe communication impairments, increased positive affect, and decreased negative affect have been documented.

Moreover, in cases when intervention training has been given to the typically developing sibling, engagement from the child with autism increases and negative affect decreases (Tsao & Odom 2006). However, over time, potentially due to poor communication skills, aggressive behaviors, or a widening developmental gap, typically developing siblings spend less time with their sibling with autism compared to children with other disorders (Stoneman, 2001).

As such, previous studies have documented the positive and negative experiences of typically developing siblings and they indicated that their siblings' positive disposition and learning from their upbringing were positive aspects. Nevertheless, aggressive and odd behaviors were categorized as difficult, as was receiving less parental attention, having extra responsibilities, and at times feeling embarrassed by their sibling (Petalas, Hastings, Nash, Reilly, & Dowey, 2012; Ward, Tanner, Mandleco, Dyches, & Freeborn, 2016).

Past research has demonstrated that typically developing siblings adjust to having a sibling with special needs on a spectrum, ranging from maladjusted to well-adjusted. Siblings of children with autism are at an increased risk for experiencing internalizing and externalizing symptoms, as well as social deficits. This may stem from not having a similar aged peer to practice with at home, or perhaps they have adopted their siblings' weaker social skills. Beyond this, personal growth, and engagement in recreational activities also suffer in ASD-afflicted homes (Ross & Cuskelly, 2006). On the other hand, other studies have found that typically developing siblings demonstrate a heightened sense of self, prosociality, and general social skills. This may be due to caring for their sibling with autism and the associated early maturation these children undergo (Kaminsky & Dewey, 2002).

Although there are a number of possibilities as to why some siblings adjust better than other (e.g., personality, parenting styles), the focus of the current study is on children's coping strategies and their effectiveness. Studies have found that siblings engage in wishful thinking, emotional regulation, and focusing on a solution (Orfus & Howe, 2008; Ross & Cuskelly, 2006). No study, to my knowledge, has assessed the effectiveness of such strategies related to the child's adjustment and sibling relationship quality.

The current study addresses four questions: (1) how does the typically developing sibling describe their sibling relationship?; (2) how do the descriptions of the sibling relationship differ relative to birth order and gender?; (3) what coping strategies are regularly used by the typically developing sibling?; and (4) what aspects of their sibling relationship do typically developing siblings emphasize most (i.e., positive, negative)?

6. RISK LEVEL AND SCHOLARLY REVIEW

As part of the research, will participants be exposed to risk that is greater than minimal?

Minimal risk means that the probability and magnitude of the risks are greater than those to which participants would be exposed in those aspects of their daily lives that are pertinent to the research.

Yes

No

Has this research received favorable review for scholarly merit?

Scholarly review is not required for minimal risk research.

For faculty research, funding from a granting agency such as CIHR, FQRSC, or CINO is considered evidence of such review. Please provide the name of the agency.

For student research, a successful defense of a thesis or dissertation proposal is considered evidence of such review. Please provide the date of your proposal defense.

- Yes Funding agency or date
of defense: Thursday,
November 15, 2018
- No
- Not required

If you answered no, please submit a Scholarly Review Form, available on the OOR website. For studies to be conducted at the PERFORM Centre, please submit the Scientific Review Evaluator Worksheet.

7. RESEARCH PARTICIPANTS

Will any of the participants be part of the following categories?

- Minors (individuals under 18 years old)
- Individuals with diminished mental capacity
- Individuals with diminished physical capacity
- Members of Canada's First Nations, Inuit, or Métis peoples
- Vulnerable individuals or groups (vulnerability may be caused by limited capacity, or limited access to social goods, such as rights, opportunities and power, and includes individuals or groups whose situation or circumstances make them vulnerable in the context of the research project, or those who live with relatively high levels of risk on a daily basis)

a) Please describe potential participants, including any inclusion or exclusion criteria.

Potential participants will be a typically developing child (no diagnosis of any disorder) with a sibling with autism spectrum disorder and a parent. The gender, age, and birth order will not be controlled, although siblings should be school-aged (8-14 approximately). Factors such as SES, culture, or religion will not exclude possible participants.

b) Please describe in detail how potential participants will be identified, and invited to participate. Please submit any recruitment materials to be used, for example, advertisements or letters to participants.

Participants will be recruited through snowball, convenience, and criterion methods. Centers for children with autism and their families will be contacted in order to see if they have clients who fit the requirements and may be interested in participating. Families interested in participating will be able to contact the primary researcher directly via e-mail.

c) Please describe in detail what participants will be asked to do as part of the research, and any procedures they will be asked to undergo. Please submit any instruments to be used to gather data, for example questionnaires or interview guides.

Potential participating families will first be presented with a brief description of the study. If parents agree to participate, the researcher will reach out to them and find an appropriate time to meet. Prior to this meeting, a letter describing the study, parental consent forms, and the demographic questionnaire will be sent to the family's homes. The demographic questionnaire can be completed before or during the interview. Before the interview takes place, the researcher and parents will find an agreed upon time for the researcher to meet the child. A short activity or game will be played to build rapport with the child. Afterwards, the questionnaires will be administered, and the interviews will be conducted.

Parents will be asked to complete the demographic questionnaire and the Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire, which assesses parental appraisal of their children's sibling relationship. Copies are included in the appendix. Parents will also be asked to partake in a brief interview with the researcher in order to gain insight into their perspectives of the sibling relationship quality. The interview will be audio recorded. A list of interview questions can be found in the appendix.

Once verbal assent is received, the participating child will be asked to complete modified versions of the Sibling Relationship Questionnaire, assessing warmth and conflict within the sibling relationship, and the Daily Events Scale for Siblings of Children with a Disability or Chronic Illness, which assesses daily hassles and uplifts of the typically developing child. The child will also be asked to complete the KIDCOPE, which assesses the use and effectiveness of 10 coping strategies. An interview consisting of 13 questions will also be done with the typically developing sibling and will be audio recorded. The interview should take approximately 10-15 minutes. Breaks will be given to the child when he/she seems restless, hungry, or asks for one. Copies are included in the appendix.

d) Do any of the research procedures require special training, such as medical procedures or conducting interviews on sensitive topics or with vulnerable populations? If so, please indicate who will conduct the procedures and what their qualifications are.

No.

8. INFORMED CONSENT

a) Please explain how you will solicit informed consent from potential participants. Please submit your written consent form. In certain circumstances, oral consent may be appropriate. If you intend to use an oral consent procedure, please submit a consent script containing the same elements as the template, and describe how consent will be documented.

Please note: written consent forms and oral consent scripts should follow the consent form template available on the OOR website. Please include all of the information shown in the sample, adapting it as necessary for your research.

On the day of the interview, the parent(s) will be asked to provide signed consent for their child to participate in the study. The primary researcher has prepared a verbal assent script which will be read aloud to all participating children, which explains the purpose of the study in terms they can understand. It also informs them that all information is confidential and that they can stop at any time or choose not to answer a question without any consequences. They will then be asked to provide verbal agreement to participate. A copy is provided in the appendix.

b) Does your research involve individuals belonging to cultural traditions in which individualized consent may not be appropriate, or in which additional consent, such as group consent or consent from community leaders, may be required? If so, please describe the appropriate format of consent, and how you will solicit it.

No.

9. DECEPTION

Does your research involve any form of deception of participants? If so, please describe the deception, explain why the deception is necessary, and explain how participants will be de-briefed at the end of their participation. If applicable, please submit a debriefing script.

Please note that deception includes giving participants false information, withholding relevant information, and providing information designed to mislead.

There will be no deception in this study.

10. PARTICIPANT WITHDRAWAL

a) Please explain how participants will be informed that they are free to discontinue at any time, and describe any limitations on this freedom that may result from the nature of the research.

The consent form will include a section on withdrawal, which the researcher will go over with each of the participating parents. Moreover, verbal reminders will be given to the parents and child about their right to withdraw on the day of the interview.

b) Please explain what will happen to the information obtained from a participant if he or she withdraws. For example, will their information be destroyed or excluded from analysis if the participant requests it? Please describe any limits on withdrawing a participant's data, such as a deadline related to publishing data.

If a participant decides to withdraw, their information will be destroyed. Families will have one month after the interview to withdraw from the study.

11. RISKS AND BENEFITS

a) Please identify any foreseeable benefits to participants.

There are no direct benefits for the individuals participating in this study. However, the participants may gain knowledge about the sibling relationship, its strengths and weaknesses, and how this impacts the family unit.

- b) Please identify any foreseeable risks to participants, including any physical or psychological discomfort, and risks to their relationships with others, or to their financial well-being.

There are no risks to participating in this study. However, if a child becomes nervous, anxious, or uncomfortable a break will be given, and the child will be reminded that they can stop the interview if they would like. If the child wishes to continue, the researcher will follow his/her pace to ensure their comfort.

- c) Please describe how the risks identified above will be minimized. For example, if individuals who are particularly susceptible to these risks will be excluded from participating, please describe how they will be identified. Furthermore, if there is a chance that researchers will discontinue participants' involvement for their own well-being, please state the criteria that will be used.

A game or activity will be done with the child and researcher before any questions are asked, to build rapport. If a child wishes to stop the interview, their request will be granted.

- d) Please describe how you will manage the situation if the risks described above are realized. For example, if referrals to appropriate resources are available, please provide a list. If there is a chance that participants will need first aid or medical attention, please describe what arrangements have been made.

As this study does not include any physical strain, medical issues should not arise. If they do, the parent of the child will be present and will be notified.

12. REPORTABLE SITUATIONS AND INCIDENTAL FINDINGS

- a) Is there a chance that the research might reveal a situation that would have to be reported to appropriate authorities, such as child abuse or an imminent threat of serious harm to specific individuals? If so, please describe the situation, and how it would be handled.

Please note that legal requirements apply in such situations. It is the researcher's responsibility to be familiar with the laws in force in the jurisdiction where the research is being conducted.

In the unlikelyhood that such a circumstance arises, my supervisor, Dr. Nina Howe, and committee members, Dr. Hariclia Petrakos and Dr. Miranda D'Amico, will be consulted immediately. Drs. Petrakos and D'Amico both have expertise in working with families in which there is an individual with a special need.

- b) Is there a chance that the research might reveal a material incidental finding? If so, please describe how it would be handled.

Please note that a material incidental finding is an unanticipated discovery made in the course of research but that is outside the scope of the research, such as a previously undiagnosed medical or psychiatric condition that has significant welfare implications for the participant or others.

To my knowledge, this is no such risk in this study, however should such a situation arise Drs. Petrakos and D'Amico will be consulted.

13. CONFIDENTIALITY, ACCESS, AND STORAGE

a) Please describe the path of your data from collection to storage to its eventual archiving or disposal, including details on short and long-term storage (format, duration, and location), measures taken to prevent unauthorized access, who will have access, and final destination (including archiving, or destruction).

All the data, which consist of audio recordings, notes, and transcripts, will be stored electronically on a password protected computer in Dr. Howe's research lab. The questionnaires will be kept in a locked filing drawer in Dr. Howe's lab, as well. All participating individuals will be assigned a numeric code, as to not disclose their identity. Once the study is completed and published, all the data will be destroyed within 5 years.

b) Please identify the access that the research team will have to participants' identity:

<input type="checkbox"/>	Anonymous	The information provided never had identifiers associated with it, and the risk of identification of individuals is low, or very low.
<input type="checkbox"/>	Anonymous results, but identify who participated	The information provided never had identifiers associated with it. The research team knows participants' identity, but it would be impossible to link the information provided to link the participant's identity.
<input type="checkbox"/>	Pseudonym	Information provided will be linked to an individual, but that individual will only provide a fictitious name. The research team will not know the real identity of the participant.
<input type="checkbox"/>	Coded	Direct identifiers will be removed and replaced with a code on the information provided. Only specific individuals have access to the code, meaning that they can re-identify the participant if necessary.
<input type="checkbox"/>	Indirectly identified	The information provided is not associated with direct identifiers (such as the participant's name), but it is associated with information that can reasonably be expected to identify an individual through a combination of indirect identifiers (such as place of residence, or unique personal characteristics).
<input checked="" type="checkbox"/>	Confidential	The research team will know the participants' real identity, but it will not be disclosed.
<input type="checkbox"/>	Disclosed	The research team will know the participants' real identity, and it will be revealed in accordance with their consent.
<input type="checkbox"/>	Participant Choice	Participants will be able to choose which level of disclosure they wish for their real identity.
<input type="checkbox"/>	Other (please describe)	

c) Please describe what access research participants will have to study results, and any debriefing information that will be provided to participants post-participation.

Participating families will be sent a summary of the overall findings once the study is complete.

d) Would the revelation of participants' identity be particularly sensitive, for example, because they belong to a stigmatized group? If so, please describe any special measures that you will take to respect the wishes of your participants regarding the disclosure of their identity.

Participant identities will never be disclosed; only the researcher will have access.

e) In some research traditions, such as action research, and research of a socio-political nature, there can be concerns about giving participant groups a "voice". This is especially the case with groups that have been oppressed or whose views have been suppressed in their cultural location. If these concerns are relevant for your participant group, please describe how you will address them in your project.

Not applicable.

14. MULTI-JURISDICTIONAL RESEARCH

Does your research involve researchers affiliated with an institution other than Concordia? If so, please complete the following table, including the Concordia researcher's role and activities to be conducted at Concordia. If researchers have multiple institutional affiliations, please include a line for each institution.

Researcher's Name	Institutional Affiliation	Role in the research (e.g. principal investigator, co-investigator, collaborator)	What research activities will be conducted at each institution?
Not applicable	Not applicable	Not applicable	Not applicable

15. ADDITIONAL ISSUES

Bearing in mind the ethical guidelines of your academic or professional association, please comment on any other ethical concerns which may arise in the conduct of this research. For example, are there responsibilities to participants beyond the purposes of this study?

16. DECLARATION AND SIGNATURE

Study Title: The Psychosocial Effects of Having a Sibling with Autism Spectrum Disorder.

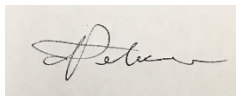
I hereby declare that this Summary Protocol Form accurately describes the research project or scholarly activity that I plan to conduct. I will submit a detailed modification request if I wish to make modifications to this research.

I agree to conduct all activities conducted in relation to the research described in this form in compliance with all applicable laws, regulations, and guidelines, including:

- The [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans](#)
- The policies and guidelines of the funding/award agency

- The [Official Policies of Concordia University](#), including the [Policy for the Ethical Review of Research Involving Human Participants](#), VPRGS-3.

Principal Investigator Signature: _____



Date: ___ November 20, 2018 _____

FACULTY SUPERVISOR STATEMENT (REQUIRED FOR STUDENT PRINCIPAL INVESTIGATORS):

I have read and approved this project. I affirm that it has received the appropriate academic approval, and that the student investigator is aware of the applicable policies and procedures governing the ethical conduct of human participant research at Concordia University. I agree to provide all necessary supervision to the student. I allow release of my nominative information as required by these policies and procedures in relation to this project.

Faculty Supervisor Signature: _____



Date: ___ November 19, 2018 _____

Appendix B
Recruitment Forms

Dear Participant,

My name is Jesseca Perlman and I am a Masters student in the Child Studies program in the Department of Education at Concordia University under the supervision of Dr. Nina Howe. I am in the process of collecting research for my thesis, which is looking at the experiences and stress management of children who have a sibling with an autism diagnosis. I would like to tell you a little about my research and goals with the hope that you and your family will consider participating in the study.

I am interested in the day-to-day experiences of typically developing children who have a sibling with autism. More specifically, I would like to investigate what they find difficult and what they find uplifting. In addition, I am interested in how children cope with stressors and how this may impact the sibling relationship. Ideally, the findings of this study will be able to provide centers and families with information to provide support for the nondisabled child.

If you agree to participate, you and your typically developing child will be asked to partake in a meeting with myself in a location of your choosing. The participating child needs to be between the ages of 5 and 14 and will be asked to complete a brief interview (approximately 15 minutes), a questionnaire concerning his/her coping strategies, and a questionnaire concerning his/her perceived sibling relationship quality. The interview questions will be adapted for the age and developmental level of the child, and the questionnaires can be read to child if preferred.

Parents will also be asked to complete a brief interview in order to gain insight into the interactions between the two children (the participating child and child with autism). In addition,

they will be asked to complete a demographic questionnaire to gather familial information, and a questionnaire assessing the sibling relationship quality. The meeting should take about one hour.

The study is not anticipated to be associated with any risk or cause stress to the participants. However, as the study involves children and the sensitivity of the subject matter many precautions will be taken to ensure the parents and child's comfort. The meeting will take place at a location and time of the participants choosing. An icebreaker will be engaged in between myself and the child in order to build rapport and make the child feel more at ease, and breaks will be given throughout the meeting. Parents can complete their questionnaires at their leisure, and all necessary materials will be provided if you choose to mail it a later date (i.e., stamp, addressed envelope).

Families will be advised that they have the right to withdraw their participation from the study for up to one month after the meeting. However, please be assured that all information will be kept confidential through the use of pseudonyms. No one, other than the primary researcher, will know the real names of the participants. This information is intended to be published in the future, and confidentially will be maintained. In addition, all the information will be stored on a password protected computer within a locked office. This study has received ethical approval from the University Human Research Ethics Committee.

If you are interested in participating, the next step involves two consent forms. One for the parent or guardian to complete, which ensures that they have read and understand the requirements of the study. The second is for the participating child, which will be read aloud to the child and requires verbal agreement.

I thank you for taking the time to consider participating in the study. Should you choose to participate, or if you have any questions or concerns, please contact me at the following

address: Jesseca.perlman@gmail.com. you may also contact my supervisor, Dr. Nina Howe (nina.howe@concordia.ca) or 514-848-2424 x2008. I would very much your participation in the study at your earliest convenience.

My best wishes to you and your family,

Jesseca Perlman



AUTISM RESEARCH STUDY



Do you:

- Have a child with autism who has a sibling without autism between ages 5 and 14?
- Want to better understand how your child without autism is coping?
- Want to further research on families with a child with autism?

Participation includes parent questionnaires, a brief parent interview, and a brief interview with a NON diagnosed sibling of a child with autism.

Children are compensated for their participation with a \$20 gift card.

If interested please email Jesseca at:
Jesseca.perlman@gmail.com



Appendix C

Consent Forms

**INFORMATION AND CONSENT FORM**

Study Title: Having a Sibling with Autism Spectrum Disorder.

Researcher: Jesseca Perlman

Researcher's Contact Information: Jesseca.perlman@gmail.com

Faculty Supervisor: Dr. Nina Howe

Faculty Supervisor's Contact Information: nina.howe@concordia.ca

Source of funding for the study: Not applicable.

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A. PURPOSE

The goal of this study is to gain insight into what it is like to have a sibling with ASD, from the typically developing sibling's perspective. I am interested in their views of their sibling relationship, and what they find enjoyable about being a sibling, and what they might find hard. I also want to understand what typically developing children do to manage any stress they might feel sometimes.

B. PROCEDURES

If you participate, the researcher would set up an appropriate time for the parent(s), typically developing child, and herself to meet.

Parents will be asked to complete two questionnaires and a short interview. The first is a demographic questionnaire, which gathers general familial information. Parents will also be asked to complete a measure concerning their perceptions of the sibling relationship (of the participating child and the child with autism). Lastly, parents will be asked to partake in a short interview to gain further insight into the perceived relationship of the two children.

The participating child will also be asked to answer questionnaires and engage in a short interview about their sibling with ASD. The questionnaires ask about the quality of their sibling

relationship, some enjoyments and struggles about being a sibling, and how they cope with such struggles. In total, the questionnaires should take approximately 10 minutes. If a child prefers, the researcher will read the questions aloud for the child. The interview will take an additional 10-15 minutes, and will also ask about their sibling relationship, the enjoyments and struggles, and coping styles.

C. RISKS AND BENEFITS

There are no foreseeable risks in this study. There are no direct benefits for the individuals participating in this study. However, the participants may gain knowledge about the sibling relationship, its strengths and weaknesses, and how this impacts the family unit.

D. CONFIDENTIALITY

The information we gather will be coded, which means that the participant will be identified by a code. Only the researcher will have a list that links the code to your name. All electronic data, such as the interviews, notes, and transcripts, will be saved on a password protected computer in Dr. Howe's research lab. All hard documents, such as the questionnaires, will be kept in a locked filing drawer also in Dr. Howe's research lab.

We intend to publish the results of the research. However, it will not be possible to identify you in the published results, because you and your children will only be identified by a number or pseudonym.

F. CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you and your children can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. If you decide that you don't want us to use your information, you must tell the researcher 1 month after the initial meeting. In the case of withdrawal, all information will be destroyed.

If participants are being offered compensation:

As a compensatory indemnity for participating in this research, all the children in the home will receive an age-appropriate gift. There are no negative consequences for not participating, stopping in the middle, or asking us not to use your information.

G. PARTICIPANT'S DECLARATION

I have read and understood this form. I have had the chance to ask questions and any questions have been answered. I agree to participate in this research under the conditions described.

NAME (please print)

SIGNATURE

DATE

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Child Assent Script

Hi (name)! My name is Jesseca, and I am doing a project for school and I would really like your help. I am very curious about how well siblings get along, how often they argue or fight, how much time they spend together...and those sorts of things.

If you say yes to helping me, I am going to ask you some questions about you and (sibling's name), and about your feelings, and how you cope with some of your feelings. The questions aren't hard! I will also interview you. The interview will be recorded on a tape recorder (show child recorder). Anything you tell me is our secret – no one will know what you told me. I won't tell your parents or your sibling, unless I think you are unsafe or need help.

If you get tired, we can take a break and try again. If you don't want to answer one of my questions you don't have to – you only have to tell me what you feel comfortable telling me. We can stop at any time if you want.

Do you think this is something you can help me with? If yes, that is great, and I am excited to get to know you! If not, that is completely okay.

Appendix D

Demographic Questionnaire for Parents

1. Please circle the appropriate marital status.

Single Married Divorced/Separated Other: _____

2. How many children are there in your home? _____

Please indicate the ages of your children. _____

3. Please indicate parental age

Mom: _____ Guardian: _____

Dad: _____

4. Please indicate your and your partner's education level and occupation.

Mom: _____

Dad: _____

Guardian: _____

5. Please circle the combined annual income level of your family.

- a. Under \$20,000 a year
- b. Between \$20,000 – \$35,000
- c. Between \$35,00 – \$50,000
- d. Between \$50,000 – \$75,000
- e. Over \$75,000 a year

6. Please describe your families' cultural and religious affiliations. _____

7. Please fill out the following information about your child with special needs.

- a. Age: _____
- b. Gender: _____
- c. Birth position within the family: 1 2 3 4
- d. The nature of your child's disability
 - i. Autistic Disorder
 - ii. Asperger's
 - iii. Other: _____
- e. Is your child's disability associated with any of the following?
 - i. Intellectual impairment
 - ii. Language impairment
 - iii. Neurodevelopmental disorder
 - iv. Other: _____
- f. Is there anything else you would like to share with us about your child with special needs? _____

8. Please fill out the following information about your child participating in the study.

- a. Age: _____
- b. Gender: _____
- c. Birth position within the family: 1 2 3 4
- d. Does s/he attend the same school as your child with special needs? _____

- e. Is there anything else you would like to share with us about your child?
-
-
-
9. Does your family receive help caring for your child with special needs WITHIN the home? If yes, please describe the assistance (i.e., number of hours, type of work).
-
-
10. Does your family receive help caring for your child with special needs OUTSIDE of the home? If yes, please describe the assistance (i.e., number of hours, type of resource).
-
-
11. Do your children WITHOUT special needs participate in any resources for themselves (i.e., support group, therapy)? _____
-
12. Aside from the diagnosis of your child with special needs, has your family experienced any of the following stressful life events in the past year? Please circle all that apply.
- a. Death of an immediate family member?
 - b. Death of an extended family member?
 - c. Divorce or separation of parents within the home?
 - d. Serious illness or injury of an immediate family member?
 - e. Moving?
 - f. Other: _____

Appendix E

Parental Expectations and Perceptions of Children's Sibling Relationships Questionnaire

For each question, please select the option that best describes your children's relationship.

	How frequently would you say each of the following occurs in your children's relationship?	How much would you say this is a problem?	If this is a problem, how easy would it be for you to improve this if you wanted to?	How much would you like with this?
1. Physical aggression	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
2. Sharing	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
3. Jealousy	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
4. Playing together in a single activity	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

5. Competition	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
6. Respecting each other's property	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(5) It's not a problem (6) It's a small problem (7) It's a big problem (8) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
7. Rivalry	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
8. Sharing worries or concerns	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
9. Angry feelings	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
10. Loyalty or sticking up for one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

11. Arguing	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
12. Comforting one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
13. Fighting over territory or space	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
14. Protectiveness – looking out for each other's welfare	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
15. Feeling proud of one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
16. Fighting where the problem never gets worked out	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

17. Talking to each other, having conversations	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
18. Fighting over objects (games, toys, clothes, TV)	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
19. Helping one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
20. Threatening one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
21. Teaching (how to play a game, how to read, etc.)	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
22. Affections (hugging, kissing, saying "I love you", etc.)	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

23. Trying to control each other's behavior using phrases like, "Don't do that," "Stop it," or "Leave me alone"	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
24. Being kind or nice to one another	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
25. Going to each other for advice/support	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
26. Sharing inner secrets and feelings with each other	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help
27. Teasing or annoying each other	(1) Never (2) Rarely (3) Sometimes (4) Usually (5) Always	(1) It's not a problem (2) It's a small problem (3) It's a big problem (4) It's a very big problem	(1) Very difficult (2) Difficult (3) Neutral (4) Easy (5) Very easy	(1) No help (2) A little help (3) A lot of help

In general, how well would you say your children get along with one another?

1 2 3 4 5 6 7
 Very poorly Neutral Extremely well

Appendix F

Interview Questions for Parents

1. Can you tell me about your children's relationship?
 - Can you tell me about some specific examples of how they get along and interact with each other?
2. Can you describe the behavior of your child with ASD?
3. How do you think (child's name) behavior impacts the relationship of the two children?

Appendix G

Sibling Relationship Questionnaire

For each question, check the answer that is best for you.

1. How much do you help, show, or teach your brother/sister how to do something when he/she does not know how or cannot do it alone?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
2. How much do you and your brother/sister care about and love each other?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
3. How much do you tell your brother/sister what to do?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
4. How much do you and your brother/sister like the same things?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
5. How much do you and your brother/sister tell each other everything or share secrets?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
6. How much do you and your brother/sister pick on each other in mean ways (i.e., bug, insult, name calling)?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much

7. How much do you feel proud of your brother/sister?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
8. How much do you and your brother/sister cooperate and share objects with each other?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
9. How much do you and your sibling argue or get mad with each other?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
10. How much do you and your brother/sister spend free time together (go places together, play)?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
11. How much do you and your brother/sister have fun with each other?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much
12. How mean are you and your brother/sister to each other?
 Hardly at all
 Not too much
 Somewhat
 Very much
 Extremely much

Appendix H



Daily Events Scale for Siblings of Children with a Disability or Illness



Instructions: everyone has problems or hassles that bother them from time to time.

Below are some things that can make you feel upset, bothered, or stressed out.

For each problem below, we would like to know:

1. How often does this problem happen?
2. How stressed out does the problem make you feel?

Do you feel bothered about...?	How often does the problem happen? Never Sometimes Always 0 1 2 3 4 	How stressed out does the problem make you feel? Not at all A bit Very 0 1 2 3 4 
When my parents ask me to do jobs.		
Not being allowed to do the things I want to do.		
Arguing with my parents.		
Talking to friends about important personal things.		
When my sibling is upset, hurt, or crying.		
When my sibling hurts me verbally or physically.		
When my sibling goes into my room without asking, takes things, or makes it messy.		
Arguing with my sibling.		
Having to stop what I am doing or give in to my sibling so she/he does not get upset.		
When my sibling cries, screams, or yells because she/he does not want to do something.		



	Never 0	Sometimes 1 2	Always 3 4	Not at all 0	A bit 1 2	Very 3 4
						
When my sibling does not do what she/he was asked by myself or anyone else.						
When my sibling interrupts me.						
Reminding my sibling to do something.						
Having to do something for my sibling.						
When my sibling does not share things with me.						
When people ask questions about my siblings' disability.						
When people do not understand things about my sibling's disability.						
When my sibling embarrasses me at home or in public.						



There are also good things that happen in our lives that make us feel happy.

Below are some things that can make you feel happy.

For each event, we would like to know:

1. How often does the good thing happen?
2. How happy does the good thing make you feel?

Do you feel happy about...	How often does this good thing happen? Never Sometimes Always 0 1 2 3 4 	How happy does the good thing make you feel? Not at all A bit Very 0 1 2 3 4 
When my parents help me with something.		
Spending time with my parents at home or going out.		
Spending time together as a family at home or going out.		
When my parents let me do something I want to do.		
Having a friend over at my house.		
Spending time or playing on my own.		
When my sibling learns something new.		
When my sibling tries hard at something.		
Helping my sibling to learn something new.		
When my sibling gives me a hug or a kiss.		
When my sibling does funny things.		
Spending time and playing with my sibling.		
When my sibling shares something with me.		

	Never 0	Sometimes 1 2	Always 3 4	Not at all 0	A bit 1 2	Very 3 4
						
Hearing good news about my sibling.						
When my day runs smoothly, without interruptions from my sibling.						

Appendix I

KIDCOPE

Please remember an unsettling event that happened recently (within the last month) concerning your sibling with autism. Once you have the memory, please read each of the coping strategies and circle *yes* if you used it, or *no* if you did not use it. If *yes*, you used it, please indicate how much that strategy helped by circling *not at all*, *a little*, or *a lot*.

Coping Strategy	Did You Do this?		How Much Did It Help?		
1. I just tried to forget it.	Yes	No	Not at all	A little	A lot
2. I did something like watch TV or played a game to forget it.	Yes	No	Not at all	A little	A lot
3. I stayed by myself.	Yes	No	Not at all	A little	A lot
4. I kept quiet about the problem.	Yes	No	Not at all	A little	A lot
5. I tried to see the good side of things.	Yes	No	Not at all	A little	A lot
6. I blamed myself for causing the problem.	Yes	No	Not at all	A little	A lot
7. I blamed someone else for causing the problem.	Yes	No	Not at all	A little	A lot
8. I tried to fix the problem by thinking of answers.	Yes	No	Not at all	A little	A lot
9. I tried to fix the problem by doing something or talking to someone.	Yes	No	Not at all	A little	A lot
10. I yelled, screamed, or got mad.	Yes	No	Not at all	A little	A lot
11. I tried to calm myself down.	Yes	No	Not at all	A little	A lot
12. I wished the problem had never happened.	Yes	No	Not at all	A little	A lot
13. I wished I could make things different.	Yes	No	Not at all	A little	A lot
14. I tried to feel better by spending time with others like family, grownups, or friends.	Yes	No	Not at all	A little	A lot
15. I didn't do anything because the problem couldn't be fixed.	Yes	No	Not at all	A little	A lot

Appendix J

Interview Questions for Focal Siblings

2. Can you tell me a little about (sibling's name)?
 - Can you tell me a few other things?
3. What does he/she like? Do for fun?
 - Is there anything else?
4. What does he/she not like?
 - Is there anything else?
5. What are some things you find hard about being a sibling to (name)?
 - Can you tell me a little more?
6. Do these things have an impact on you doing activities, such as things you like? Playing with friends?
 - What happens if you want to do something and your sibling doesn't?
7. How do you feel when these things happen? Do you feel it in your body? Your head?
Your feelings?
8. What do you do that helps you in these situations?
 - Can you tell me a little more?
9. Do you have to do things you might not want to do because of (name)?
 - What type of things?
 - Can you tell me a little more?
10. When you do these things that you might not want to do, how do you feel?
 - Can you tell me a little more?
11. What do you do to calm down and feel better?

- How do you calm down?
 - Can you tell me a little more?
12. What are some good things about being a brother/sister to (name)?
- Can you tell me a little more?
13. Can you tell me about a happy memory you have of the two of you?
- Can you tell me a little more?
14. Is there anything else you want to talk about?