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# The bigger picture: Piecing together the experiences of family members living with high-functioning children with Autism Spectrum Disorder

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Running head: ASD AND THE FAMILY

**The bigger picture: Piecing together the experiences of family members living with high-functioning children with Autism Spectrum Disorder**

MSc Thesis

Lauren Thomson

Supervisors: Dr. Paula Fletcher and Dr. Margaret Schneider

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### **Introduction**

Autism Spectrum Disorder (ASD) is a severe neurodevelopmental disorder that causes impairments in thinking, feeling, language and the ability to relate to others (American Psychiatric Association [APA], 2014). Approximately 1 in 68 children are currently diagnosed with ASD, with more males diagnosed than females. There is no cure for ASD, but early diagnosis and treatment is crucial in order to help these children reach their full potential, improve their quality of life and the quality of life for their families (Autism Society of Canada, 2014). The prevalence of ASD has increased significantly and caring for children with ASD can be stressful, time-consuming, and expensive for family members (Center of Disease Control [CDC], 2014). For these reasons, it is imperative that research explores the influences of living with children with ASD upon the family. This chapter will include a description of the characteristics, diagnosis, associated medical conditions, and treatments for ASD, as well as the evidence to date concerning the effects that living with children with ASD has upon the health and well-being of all family members.

## Chapter 1: Review of Literature

### 1.1 Autism Spectrum Disorder

*1.1.1 Characteristics and diagnosis.* The revised fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), which is used as a means of diagnosing children with ASD, merged four out of five of the autism disorders into one umbrella diagnosis in May 2013 (CDC, 2014). ASD is a spectrum disorder, meaning that there are individual differences in the number and severity of the signs and symptoms expressed, age of onset, level of functioning, and challenges with social interaction (Autism Society of Canada, 2014; CDC, 2014). The fifth disorder, Rett syndrome, was removed from the DSM-5 because of its genetic component (DeWeerdt, 2011). The changes made to the diagnostic criteria account for the variations in the signs, symptoms, and characteristics exhibited by individuals with ASD (APA, 2014). When reading this review of the literature it is critical to know that some of the studies were written before ASD became an umbrella term. As such these studies may refer to the specific disorders within the spectrum (i.e., autism, Asperger syndrome, pervasive developmental disorder not otherwise specified (PDD-NOS), Rett syndrome, and childhood disintegrative disorder).

There is no definitive means by which to detect ASD, but by the age of two or three, a multidisciplinary team of doctors and other trained professionals can diagnose children with ASD based on observations of specific characteristics and disabilities associated with the disorder (Autism Society of Canada, 2014), namely: (1) communication challenges, (2) difficulty relating to others, and (3) repetitive body movements and behaviours (APA, 2014). Under the first domain of communication challenges, children with ASD often have difficulty using and understanding language, possess limited topic areas when using language, use repetitive phrases,

and have limited speech (APA, 2014). Difficulty relating to others may include: trouble interacting with others, difficulty reading facial expressions, and a lack of eye contact (CDC, 2014). In addition, the domain of repetitive body movements and behaviours is comprised of hand flapping, as well as being overly dependent on routine (APA, 2014). An early diagnosis of ASD is essential, in order to allow treatments to have the greatest influence on the children's ability to function.

**1.1.2 Associated medical conditions.** There are a variety of comorbid medical and behavioural conditions that are often associated with ASD (CDC, 2014). Gastrointestinal (GI) disorders are among the most common medical conditions that affect 70% of all children with ASD, and are characterized by chronic constipation, diarrhea and/or inflamed bowel conditions (Autism Research Institution, 2014). Further, four out of five individuals with ASD exhibit chronic sleeping problems, which involve difficulty falling asleep and repeatedly waking up in the night (Richdale & Schreck, 2012). According to White, Oswald, Ollendick and Scahill, (2006), a high percentage of school-aged children with ASD also suffer from anxiety disorders such as simple phobias, generalized anxiety disorder, separation anxiety disorder, obsessive-compulsive disorder, and social phobia. Moreover, attention-deficit hyperactivity disorder (ADHD) is often found in conjunction with ASD, as one in every five children with ADHD displays autistic traits as well (Thompson, 2013). The signs and symptoms of ADHD include: inattention, hyperactivity and impulsivity (CDC, 2013), and have the potential to compromise daily functioning and quality of life for children with ASD.

**1.1.3 Treatment.** There is no cure for ASD, but there are a number of forms of early intervention treatments that can be put into place to address the signs and symptoms that are associated with this disorder (Autism Society of Canada, 2014). According to Autism Society of



Canada (2014), the term intervention treatment is used to define any program or service that helps children with ASD learn, develop, and improve their quality of life. Introducing these intervention treatments prior to the age of three has been demonstrated to enhance the development of skills and abilities among children with ASD. The success of these intervention treatments depends on a collaborative effort being put forth by both the families and a team of professionals, tailoring these intervention treatments to the specific needs of the children. The two behavioural interventions currently believed to be the most beneficial for ASD at present are Applied Behavior Analysis (ABA) and the Early Start Denver Model (Autism Speaks, 2014). These interventions help children with ASD to make meaningful changes in their behaviours by fostering skills such as looking, listening, and imitating, as well as developing the ability to understand the perspectives of others. Dietary treatments, such as removing certain types of foods from children's diets and the use of vitamins or mineral supplements, are also believed to improve some of the symptoms associated with ASD. These dietary guidelines are based on the idea that allergies, as well as an absence of certain vitamins and minerals, may be causing some of the symptoms experienced by children with ASD (CDC, 2014). In addition, medications are often prescribed to individuals with ASD in order to help with the medical conditions associated with this disorder, such as ADHD and chronic sleeping problems. These medical treatments are most effective when they are used in conjunction with other treatment strategies focused on the behaviour of the children with ASD (Autism Speaks Canada, 2014).

## **1.2 Effects of ASD on the Family**

The high demands of support and care associated with living with children with ASD has the potential to influence the health and well-being of all family members. ASD is rated as one of the most stressful childhood developmental disorders to manage, as the problems with

communication, emotional expression, and antisocial behaviours all combine to place tremendous strain on the families of these children (Gray, 2006). The stressors linked to ASD undoubtedly affect the health of family members, and additionally have the potential to influence the overall functioning of the family unit (Fletcher, Markoulakis & Bryden, 2012; Higgins, Bailey, & Pearce, 2005). This is supported by Bowen's family systems theory, which examined the family as an interconnected and interdependent emotional unit that is united in thinking, feeling and behaviour (Bowen, 1966; The Bowen Center for the Study of the Family, 2014). Bowen described the family as a system, whereby a change in one family member's functioning is predictive of changes in the functioning of other members of the family. For example, if one family member is feeling anxious, this can create heightened tension, which in turn may cause the anxiety to spread among the entire family unit. Further, this theory suggested that family members cannot be fully understood when isolated from each other, but rather that families must be observed as a unit (Bowen, 1966; The Bowen Center for the Study of the Family, 2014).

When examining the effects of living with children with disabilities, Turnbull et al. (2006) also stated that the family unit must be examined as a whole, because an understanding of both the nature of the children's disabilities and the interaction of all family members is necessary to fully assess this experience. Further, when exploring the lived experiences of the family members of children with ASD it is important to take into account that not all family members are similarly affected by the individuals with ASD (Hastings et al., 2005).

### **1.3 Psychological Effects of ASD on the Family**

The diverse sources of stress that coincide with living with children with ASD frequently lead to mental health issues for family members (Benson, 2006; Hastings et al., 2005), and compromise their overall well-being (Hastings et al. 2005). The strongest predictor of mental

health issues among family members of children with ASD is the severity of the behavioural symptoms exhibited by these children (Abbeduto, Seltzer & Shattuck, 2004; Plant & Sanders, 2007), resulting in depression (Abbeduto, Seltzer & Shattuck, 2004; Benson, 2006; Hartley, Seltzer, Head & Abbeduto, 2006; Walsh, Munder & Tudor, 2013) and anxiety (Angell, Meadan & Stoner, 2012; Benderix & Sivberg, 2007; Hodge, Hoffman & Sweeney, 2011). For example, Abbeduto et al. (2004) conducted a comparison study to assess the psychological well-being and ability to cope among mothers of youths with autism (n=174), Down syndrome (n=39), and Fragile X syndrome (n=22), using the Center of Epidemiological Studies-Depression Scale (CES-D). The results of this study indicated that mothers of children with autism reported higher levels of pessimism and feelings of depression, when compared to mothers of children with Down syndrome and Fragile X syndrome. Moreover, the authors reported that higher scores on the Autism Behavior Checklist (a measure of the adolescent behaviour symptoms) were predictive of these greater maternal depressive symptoms (Abbeduto, Seltzer, & Shattuck, 2004).

Similarly, Hartley, Seltzer, Head, and Abbeduto (2012) used the CES-D scale to compare the psychological well-being of fathers of individuals with Down syndrome (n=59), ASD (n=135), and Fragile X syndrome (n=46). The researchers found that 30% of fathers of children with ASD reported significantly higher levels of depressive symptoms than fathers of children with Down syndrome (7%) and Fragile X syndrome (16%). The term “ASD disadvantage” was used to describe the greater depressive symptoms in the fathers of children with ASD, when compared to the other two groups. This “ASD disadvantage” was related to advanced paternal age, heightened number of behavioural problems in the children, and increased maternal depressive symptoms (Hartley, Seltzer, Head, & Abbeduto, 2006).

Moreover, Gold (1993) compared 22 siblings of boys who were autistic (11 girls and 11 boys) with 34 siblings (17 girls and 17 boys) of typically developing boys on measures of depression. The participants ranged in age from 7 to 17 years, and they all lived with a brother who was autistic or with a typically developing brother. A self-report instrument called, The Children's Depression Inventory (CDI), was used to measure the siblings' symptoms of depression. As expected, both male and female siblings of boys who were autistic scored significantly higher on the CDI than their comparison group, suggesting that the siblings of boys who were autistic experienced a greater number of depressive symptoms than the siblings of the typically developing boys (Gold, 1993). This finding denoted the influence that living with children who are autistic may have on the psychological well-being of their typically developing siblings.

Hodge, Hoffman and Sweeney (2011) examined anxiety disorders in parents of children with ASD. The Symptom Assessment-45 Questionnaire (SA-45) was used to assess 269 mothers and fathers of children with autistic spectrum disorders (ASD) and 446 mothers and fathers of typically developing children. In this study, the researchers defined anxiety as the presence of any of the following conditions: obsessive-compulsive behaviours, general anxiety, paranoid ideation, and phobic anxiety. The results of the SA-45 indicated that both mothers and fathers scored higher on the obsessive-compulsive and paranoid ideation subscales of the questionnaire when compared to parents of typically developing children. It is important to note that only the mothers reported significantly higher scores on the general anxiety subscale. This study suggested that there were higher rates of anxiety disorders among parents of children with ASD when compared to parents of typically developing children, and that mothers in particular experienced higher levels of anxiety than fathers (Hodge, Hoffman, & Sweeney, 2011).

The anxiety experienced by siblings of children with ASD is under researched, but has been addressed in a few studies (Angell, Meadan, & Stoner, 2012; Benderix & Sivberg, 2007). For example, the lived experiences of siblings of children with ASD was explored by Angell et al. (2012), in order to identify their self-reported support needs. Results from semi-structured interviews administered to 12 siblings aged 7 to 15 demonstrated that they felt anxious about the futures of their siblings with ASD. Additionally, many participants felt unsafe and anxious when their siblings' displayed aggressive behaviours. Likewise, a case study of six female and eight male siblings of children with ASD further supported these findings that siblings of children with ASD experience anxiety as a result of physical violence committed by their siblings in the family home (Benderix & Sivberg, 2007).

#### **1.4 Social Effects of ASD on the Family**

Research has shown that family members of children who are autistic experience effects on their social lives as well, often as a result of the antisocial behaviours (e.g., problems with language, tantrums and inappropriate behaviours) displayed by the children with ASD (Gray, 1993). The most commonly cited social issues family members reported experiencing included: perceived stigma (Gray, 1993), marital tension/distress (Higgins, Bailey, & Pearce, 2005), and difficulty with maintaining interpersonal relationships (Petalas, Hastings, Nash, Reilly, & Dowey, 2012).

Gray (1993) concluded that the stigma these families experience when in public situations may be the most difficult social issue they encounter. The purpose of his study was to explore the extent of any perceived stigma, the nature of it, and the factors associated with parents' perceptions of this stigma. The participants consisted of 32 parents of children with autism (mothers, n=23; fathers, n=9). Data was collected through the use of one-on-one, semi-

structured interviews ranging from one hour to over four and a half hours in length, which were then transcribed and coded into themes. The results of this study indicated that the parents believed that they were stigmatized by their children's disorders. Further, some of the parents felt that their roles as parents of children who were autistic obscured their other sources of identity. One mother stated that, "I'm not a human being. I'm only the mother of a handicapped daughter and I don't have a mind of my own" (p. 109). The stigma associated with autism is unique because although this disorder can be extremely disruptive in nature, children with autism often appear typical in their physical appearance. Parents also discussed the awkwardness they felt around strangers as a result of their children's behaviours. Consequently, many parents isolated themselves and their families from the outside world in order to avoid this stigma. Parents in this study were also concerned with the effects of their children who were autistic on the social lives of their typically developing children. Many believed that their typically developing children paid a price for their siblings' disabilities, as they believed that they missed out on a "normal family" life. Participants gave examples such as a loss of family holidays and outings as being among their most significant losses as a family. Parents also commented on the stigmatization that these children experienced. For example, one parent talked about the fact that their typically developing child would never invite friends over or when he did, "The friend would come . . . and that friend would come once. Wouldn't come again" (Gray, 1993, p. 112).

Moreover, living with and caring for children with ASD has been shown to interfere with family members' ability to create and maintain healthy interpersonal relationships with each other and with their peers. For example, Higgins et al. (2005) distributed a survey to 53 parents (mothers, n=51; fathers, n=2) of children with ASD, to examine the relationship between ASD characteristics, family functioning and coping strategies. In addition to several other measures,

they used the Quality Marriage Index (QMI) to assess parents' overall marital quality and marital happiness. Results for the QMI suggested that the overall marital happiness ratings for the parents were low. The parents in this study acknowledged the high levels of stress associated with caring for children with ASD, which they perceived may have had a negative effect on their overall marital satisfaction.

The influence of ASD on interpersonal relationships was also supported by Petalas et al.'s (2012) study, which explored how typically developing adolescent siblings growing up with brothers with ASD made sense of their experiences. Twelve biological siblings of children with ASD, ranging in age from 14 to 17 years, were recruited for this study. Information was gathered using in-depth, semi-structured interviews and the results demonstrated the social effects these siblings experienced. For example, one participant stated that he spent little time interacting with others, and had received limited attention from his parents because of his brother's needs. Additionally, siblings reported prejudice, rejection, and misunderstanding from peers as a result of their siblings with ASD, which in turn caused them to feel anxious, embarrassed, and angry. In response, many siblings became silent and withdrew from interacting with others (Petalas et al., 2012).

### **1.5 Physical Effects of ASD on the Family**

The physical health effects of caring for children with ASD have been reported in the literature by family members, with particular emphasis on those experienced by the primary caregivers. Allik, Larsson, and Smedje (2005) examined the health-related quality of life (HRQL) of mothers and fathers of children with Asperger syndrome (AS) and high-functioning autism (HFA). The study sample consisted of 31 mothers and 30 fathers of children with AS/HFA, as well as 30 mothers and 29 fathers of typically developing children. A 12-item

Short-Form Health survey (SF-12) was used to measure parents' HRQL. The SF-12 creates two sets of scores, the Physical Component Summary (PCS-12) and the Mental Component Summary (MCS-12). Results showed that mothers of children with AS/HFA scored lower on the PCS-12 than the control group, which indicated that they had marginally poorer overall physical health. On the other hand, differences in PCS-12 scores between the fathers of children with AS/HFA and the control group were not significant, which suggested that they did not experience significantly poorer physical health. Researchers concluded that mothers, but not fathers, experienced poorer physical health as a result of the behavioural characteristics of their children (Allik et al., 2005).

Giallo, Wood, Jellett, and Porter (2011) assessed fatigue in 50 mothers of children with ASD (ages 2 to 5 years). The Fatigue Assessment Scale (FAS) was used to measure fatigue, with higher scores indicating higher levels of fatigue. Mothers reported moderate levels of fatigue; however, when compared to a community sample of 1122 mothers of typically developing children ages 0 to 5, the mothers of children with ASD reported significantly higher levels of fatigue. Multivariate regression analysis was then used to determine the potential factors associated with this fatigue. The results showed that low educational attainment, problematic child behaviours, poor diet, reduced exercise, and poor sleep were predictors of fatigue. Additionally, the findings in this study indicated that increased fatigue was related to increased levels of depression, stress, and anxiety. As such, this study demonstrated that mothers of children with ASD tended to report higher levels of fatigue, which had the potential to affect their overall well-being (Giallo et al., 2011).

Additionally, Smith, Seltzer, and Greenberg (2012) compared the daily health of mothers of adolescents with ASD (n=96), mothers of adolescents with Fragile X syndrome (FXS)



(n=112), and mothers from a nationally representative sample of mothers of children without disabilities (n=230). The Daily Diary Study protocol was developed for this study, which involved participants being interviewed by telephone each evening for 8 consecutive days (approximately 15 to 25 minutes in length, each time). During these interviews, participants discussed their daily experiences including: stressors, positive events, mood and any physical symptoms they experienced. The health symptoms reported by participants each night were then measured using an adapted version of the Larsen and Kasimatis' (1991) symptoms checklist. This checklist was used to analyze the specific health problems experienced by these participants, including: headache, backache, muscle soreness, fatigue, joint pain, muscle weakness, dizziness, nausea, diarrhea, constipation, menstrual-related symptoms, and hot flashes or flushes. The results of this study showed that mothers of children with ASD experienced significantly more daily health problems when compared to mothers of children with FXS and mothers of children without disabilities (Smith et al., 2012).

### **1.6 Qualitative investigations of the lived experiences of families of children with ASD**

Past qualitative research exploring the lived experiences of family members of children with ASD have also illustrated the potential psychological, social, and physical effects that the entire family unit may report. Fletcher et al. (2012) examined the lived experiences of female, primary caregivers of children with ASD to gain an understanding of the costs and benefits of their experiences, and the perceived experiences of other family members. One-on-one, semi-structured interviews were used to capture the “voice” of eight mothers of children with ASD. The information gathered from these mothers provided insight into the means by which the health of all family members may be influenced when living with children with ASD. Mothers reported the psychological health issues of depression and anxiety that they associated with the

stressors of caring for their children with ASD. They often discussed placing the health of their children ahead of their own. Further, mothers spoke about their experiences of marital stress as a result of their children's diagnosis, and the subsequent influence this stress had on their overall family life. These women also mentioned the employment stress that their husbands' experienced as a result of the pressure to provide financial support for their families. Moreover, they perceived that the siblings of the children with ASD had increased stress and feelings of burden, due to a lack of attention from their parents, who were often tending to the needs of their siblings with ASD. Many of these mothers attributed the typically developing siblings' health issues to their increased responsibilities of helping to care for their siblings with ASD. The mothers in this study also discussed the physical health effects of caring for children with ASD. They spoke about their weight gain, lack of exercise and exhaustion. Moreover, many of the mothers believed their husbands' health was also affected, as a result of them putting their children's health needs ahead of their own. The costs of caring for children with ASD on the participants' social lives was also a recurring theme. The most commonly reported social costs included losing friends and experiencing difficult times with those friendships they managed to maintain. These mothers also commented that living with children with ASD affected their social outings and their family vacations. Moreover, these females talked about the social stigma they had experienced as a result of others' lack of understanding of the characteristics associated with ASD (Fletcher et al., 2012).

Nealy, O'Hare, Powers, and Swick (2012) similarly explored the lived experiences of family members of children with ASD, with the purpose of further identifying the influences of having children with ASD on family functioning. The sample consisted of eight women who identified themselves as mothers of children with ASD. One individual was the aunt of the child,

but self-identified as being the child's primary caregiver. Data was collected by first distributing family information forms to each participant, in order to obtain demographic information.

Additionally, each woman participated in a 20 to 45 minute semi-structured interview.

Following transcription and coding of the data, four major themes emerged. The first theme addressed the emotional influences of living with children with ASD, which consisted of the stress, worry, and guilt experienced by the mothers. The second theme of family effects looked at the overall influence of having children with ASD on their typically developing children and their spouses. Social effects were also discussed by all, but one participant. The mothers that experienced social effects stated that they had a reduction in quantity and quality of friendships as a result of their lack of time, inability to bring children to functions, and their fear of judgment and stigmatization. Finally, the theme of financial effects addressed the financial hardships their families faced due to poor insurance coverage, long travel distances to service providers, costs of knowledgeable babysitters, specialized foods, and safety devices (Nealy et al., 2012).

These results are further supported by Myers, Mackintosh, and Goin-Kochel's (2009) study of families of children with ASD, which used elements of qualitative research design. The purpose of their research was to listen to parents' own words on how raising children with ASD affected their lives and the lives of their families. Data was collected through an open-ended, web-based questionnaire from 493 parents (92% of whom were mothers) of children with ASD (n = 295), Asperger syndrome (n = 116), or PDD-NOS (n = 82), and qualitative content analysis was used to gain a deeper and more detailed understanding of their experiences. After coding the data, stress was the most frequently expressed theme by parents of children with ASD. Further, parents spoke about the difficult emotions of grief, sadness, despair, and guilt that they felt towards their children with ASD, as well as feelings of depression, that they brought up

either directly or indirectly. The third most frequent theme in the parents' responses was their concerns about the negative impacts that their other children experienced due to lack of attention, difficulty understanding the condition, and embarrassment. When discussing their families' physical health, parents of children with ASD mentioned the sleeping problems and exhaustion that they and their other children experienced as a result of getting little sleep (no more than an hour or two, some nights), which in turn influenced their overall health and well-being. Parents also discussed the social isolation that their families' experienced, stating that their "social lives had been restricted and their social contact reduced" (p. 680). The theme of social isolation was comprised of restrictions on where they could go and what they could do, lost friends, and mistreatment by strangers (Myers et al., 2009).

These studies provide evidence that the entire family unit is influenced by having children with ASD in the household, more specifically in the areas of psychological, social, and physical health. With this being said, all three of these studies are limited by the fact that they do not capture the unique perspective of each member within the family unit. The findings from the studies conducted by Fletcher et al. (2012) and Nealy et al. (2012) were solely from the perspectives of the primary caregivers of the family (i.e., mostly mothers). Additionally, although Myers et al. (2009) aimed to hear the "voices" of both parents of children with ASD, 92% of their participants were mothers. By obtaining the unique perspective from each member of the family unit (e.g., mothers, fathers and siblings), a more holistic understanding of the health effects of living with children with ASD upon the family unit may be generated.

DeGrace (2014) addressed the issue of underrepresentation of all members of the family in her phenomenological qualitative research. This study aimed to understand the experiences of families negotiating daily life and the meanings they ascribed to these experiences, when living

with children with severe autism. The sample consisted of five collective families who lived with children with autism. Each family consisted of two parents (mother and father), one child with autism, and one sibling of a child with autism. In-depth, semi-structured interviews were conducted with each family unit as a whole for approximately two hours, in order to provide a collective narrative of their experiences. The themes included: the whole family revolving around the autism; robbed as a family; occupy and pacify; and fleeting moments of feeling like a family. The results of this study suggested that families of children with autism have difficulty occupying their time in positive ways. Further, their lives tended to revolve around the needs of the children with ASD.

To my knowledge DeGrace's (2014) research is the only qualitative study that sheds light on the challenges experienced by all members of the family unit living with children with ASD, from the viewpoint of each individual family member. Each family member was provided with the opportunity to share his or her subjective experiences during the collective interview. However, conducting one collective interview per family unit poses some challenges. First, it may imply that all family members of children with ASD experience the same effects, which based on Hasting et al.'s (2005) research may not be reflective of others' experiences. Second, all of the family members may not have had the opportunity to provide equal contributions to the interviews. This may be a result of participants not feeling comfortable expressing their honest and personal experiences when in the presence of other family members, especially if their thoughts opposed the views of others.

### **1.7 Gaps in the Current Research**

The vast majority of research studies on ASD and the family to date are quantitative in nature, and typically focus on specific, individual members of the family, (i.e., mother, father, or

siblings of the children), rather than looking at the family unit as a whole. Additionally, this research examines specific areas of influence that ASD has upon family members, such as the psychological, social, or physical health effects. Further, the qualitative research that has looked at ASD and the family has typically reflected the subjective perspective of the mothers and therefore, fails to capture the “voice” of all members of the family. As a result, there is a lack of understanding of how each member of the family unit perceives him/herself to be uniquely affected by living with a child with ASD. Consequently, there is a lack of research investigating how the unique experience of each family member influences the overall functioning of the family unit. As such, the purpose of my research was to explore the experiences of family members living with a child with ASD.

## Chapter 2: Methodology

### 2.1 Purpose

The purpose of my research was to explore the experiences of family members living with a child with ASD. The specific research questions that were addressed included:

1. How is a family member affected by having a child with ASD in the family unit?
2. How does living with a child with ASD affect family functioning?

### 2.2 Research Design

Creswell (2013) stated that “Qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (p. 44). For this reason, a qualitative methodology was the most suitable approach to examine my research purpose, answer my research questions, and gain an in-depth understanding of how individuals living with children with ASD make sense of their experiences.

**2.2.1 Case study.** I used a case study methodological approach to guide the design of my qualitative study. More specifically, this methodology was used to determine what data was collected and how the data was collected. A case study design was the most suitable choice for my research that explored the lived experiences of multiple cases (i.e., family systems). Specifically, this was a collective case study design because I explored the lived experiences among multiple family systems to elucidate the phenomenon (Creswell, 2013). By recruiting multiple types of family systems, I gained different perspectives on the lived experiences of family members of children with ASD. Moreover, a case study design involves the use of multiple data sources (Creswell, 2013; Yin, 2003). For this reason, I collected multiple forms of data from each participant through face sheets, field notes, journaling, semi-structured

interviews, and member checks, which provided a holistic, in-depth understanding of the experiences of these cases.

**2.2.2 Ethics.** Prior to data collection, the Wilfrid Laurier University Ethics Board approved all procedures. Additionally, all participants who agreed to participate in the study were required to read an information letter and provide informed consent. Further, participants in this study under the age of 16 were required to have their primary caregiver provide consent, in addition to providing their own consent.

### **2.3 Sampling Strategy and Participants**

Purposeful sampling, more specifically criterion sampling and snowball sampling, were used to recruit participants that were “information rich” and therefore, could provide useful insight into the phenomenon being studied (Creswell, 2013). For the purpose of this study, the information rich population involved families of children with ASD. The inclusion criteria included the following: each family must have at least one typically developing sibling (above the age of 7) and one sibling with ASD (between the ages of 3-18), and the family members had to have regular interactions with the child with ASD. Additionally, I used snowball sampling, which is a participant recruitment strategy that involves asking existing participants if they can recommend any individuals that they believe may fit the criteria of the study (Creswell, 2013). I recruited four families of children with ASD, with four unique family experiences (i.e., a widowed parent family, a divorced parent family, a family where the dad had ASD as well, and a mother-father family), in order to explore how they were differentially and similarly affected by living with a child with ASD. My goal was to recruit as many families as possible, with the hopes of interviewing families with unique compositions. I chose to stop recruitment after four families as I did not come across any other families with a unique composition, as well the pool



of participants from which I had access to only had families of children with high-functioning ASD. Additionally, my supervisors and I felt that we had reached saturation among the data provided by the four families who had participated in my research study.

## **2.4 Tools and Procedures**

To collect the data for this study I used face sheets, semi-structured interviews, field notes, and member checks.

**2.4.1 Face sheets.** Prior to their one-on-one, semi-structured interviews, participants were given a face sheet via email or in person, according to their preference. The aim of this face sheet was to gain general information about the participants, which then helped me to contextualize their interviews. The face sheets collected basic socio-demographic and health information, as well as information pertaining to the family unit as a whole (Appendix A).

**2.4.2 Interviews.** One-on-one, semi-structured interviews were conducted with each member of the family unit in order to obtain their unique “voice” about their experiences. The participants were asked questions about their current health and well-being, their interpersonal relationships, as well as how they felt about themselves. Additionally, participants were asked to discuss the perceived dynamics of their family, as well as the roles and responsibilities of each family member, in order to gain an understanding of how family functioning was influenced by living with a child with ASD. Each interview ranged in length between 26 minutes and 97 minutes in length (siblings’ average: 34 minutes; parents’ average: 82 minutes), and was digitally recorded. I then transcribed each interview verbatim, and used pseudonyms to ensure each participant’s privacy and confidentiality (Appendix B).

**2.4.3 Field notes.** When in the field I took notes prior to, during, and after each interview. These field notes provided descriptive information about where and when the

interviews took place, as well as the atmosphere, setting, and any notable information about the participants (e.g., emotions, reactions, and demeanor throughout the interview) (Creswell, 2013). Additionally, the field notes included my personal thoughts and feelings as the project progressed. The field notes derived from my observations and insights provided context for understanding the data collected, which was then used during the transcription and analysis process (Creswell, 2013). For example, when one of the mothers stated that having a child with ASD caused her to become more emotional, I used the information from my field notes (i.e., notes about her body language and tone of voice) to illustrate that she felt this was a positive change. Using field notes during the analysis process is imperative because “recollections occasionally [make] it difficult to remember what precisely was being said or what exactly happened that made a situation stand out” (van Manen, 1990, p. 69).

**2.4.4 Member checks.** Upon transcription of the data collected from the interviews, I completed a member check for each of my participants. For the parents of the children with ASD this involved me sending them a member check by email to “correct, amend or extend” the data (Lincoln & Guba, 1985, p. 236). The siblings’ member checks were completed in the form of a second phone interview in order to insure that they understood the questions asked and to assist those who had difficulty reading and/or writing to answer the questions. The member checks provided me with the opportunity to ask the participants additional questions, and to clarify and/or elaborate on any unclear information that may have been provided during the interview. Furthermore, the member checks gave participants control over what data I was able to analyze, as they had the opportunity to look over their responses to the interview questions and omit or add any information they felt necessary. Although all of my participants were asked to partake in a member check, only five completed them (siblings: 3 completed; parents: 2

completed). All of the siblings answered the member check questions I had for them during their phone interviews. Additionally, one of the mothers answered all of the member check questions asked, and added in some additional information that she felt further exemplified her points throughout our interview. Furthermore, a different mother stated that she did not need to add, omit or clarify any of the information that she provided me with during our interview. The member checks were central to the trustworthiness of this qualitative research as “revealing research materials to the informants ensures that the researcher has accurately translated the informants' viewpoints into the data” (Krefting, 1991, p. 219).

## **2.5 Trustworthiness**

According to Lincoln and Guba (1985), the trustworthiness of a study is essential to assessing its ultimate worth. Credibility is a major criterion for establishing trustworthiness in the findings of a research study because it ensures confidence in the truth of the findings (Lincoln & Guba, 1985). The credibility of this study was strengthened by “the authority of the researcher”, which was the “I was there” element of credibility (Miles and Huberman, 1984). More specifically, my training in qualitative research, my past experiences with families of individuals with ASD and other disabilities, my use of rigorous methods, as well as my use of triangulation. I have completed a graduate level qualitative research course, where I gained an understanding of the process of conducting qualitative research (including but not limited to, research design, methodology, analysis, ethics and credibility) and completed the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans Course on Research Ethics (TCPS 2: CORE). Additionally, I am a member of a qualitative research group, whereby faculty members who conduct qualitative research, as well as undergraduate and graduate students who

are conducting qualitative research, regularly meet to discuss our ongoing qualitative research projects.

Further, I have extensive experience working directly with families, as well as with individuals with ASD and other disabilities (e.g., Down syndrome, acquired brain injury, cerebral palsy). Throughout my four years as an undergraduate student, I volunteered at an organization where I conducted art classes for children and adults with disabilities. I also worked at a group home caring for five elderly individuals with disabilities, and as a support worker for children with disabilities and/or mental health issues. Further, I have worked as a nanny for four different families, one of whom had a child with ASD. Currently, I am volunteering with an exercise program for children with disabilities as a one-on-one support worker for a boy with high-functioning ASD.

Additionally, as the researcher I was the key instrument in the data collection and analytic process (Creswell, 2013), because I was the one conducting the interviews and interpreting the data. To establish credibility prior to data collection, I completed an extensive literature review to ensure that I had an in-depth understanding of the phenomenon under study. Further, because I was the key instrument, it was important that I established a good rapport with all participants, such that they trusted me and felt comfortable disclosing their personal information with me. This rapport was established through the use of consent forms (Appendix C), member checks and regular communication with participants throughout their participation in my research study (Creswell, 2013).

**2.5.1 Triangulation.** The credibility and the confirmability of the data was enhanced by the use of data source triangulation, methodological triangulation, and investigator triangulation (Lincoln & Guba, 1985). Data source triangulation involves “the use of a variety of data

sources” (Patton, 2002, p. 247). For the purpose of this study, I gathered data from various family members of children with ASD (e.g., mothers, fathers, and siblings) to obtain different perspectives from individuals who have all experienced the same phenomenon. I also utilized methodological triangulation, which involved using more than one method of gathering data (i.e., face sheets, interviews, field notes, and member checks) (Patton, 2002). Additionally, investigator triangulation was achieved by having my supervisors, as well as members of the qualitative research group review and analyze the data collected from my participants (Patton, 2002).

## **2.6 Data Treatment**

**2.6.1 Qualitative analysis: Phenomenology.** I used the theoretical orientation of phenomenology to guide my research and to allow the “voice” of family members of children with ASD to be heard. The purpose of phenomenology is to distill individuals’ experiences with a phenomenon down to an “essence” of the experience by looking for common themes in the meanings participants give to their lived experiences with the phenomenon being studied (Creswell, 2013). This is accomplished by, “carefully and thoroughly capturing and describing how people experience some phenomenon - how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others” (Patton, 2002, p. 104).

Phenomenology was the most suitable theoretical orientation to use for my study because the aim of my study was to gain an in-depth understanding of the lived experiences of family members of children with ASD. Through the use of phenomenological research analysis, I was able to “transform lived experience into a textual expression of its essence – in such a way that the effects of the text is at once a reflective re-living and a reflective appropriation of something meaningful” (van Manen, 1990, p. 36). This was accomplished by using the participants’ direct

quotes, as well as my interpretations of their quotes to capture their experiences of living with children with ASD.

**2.6.2 Data analysis.** The first step of my analytical process was *époche*, which involved acknowledging my experiences, opinions, and biases, about the phenomenon being studied in order to have an open-mind when analyzing the experiences of my participants. This was accomplished by reviewing the notes I had made prior to each of my interviews, where I discussed my pre-existing opinions and thoughts about the phenomenon at that time. I reviewed these notes several times throughout the analytic process. Following data collection, the second step involved me coding the data for recurring themes using van Manen's (1990) selective approach. This approach involved reading the transcripts multiple times and highlighting statements or phrases that seemed to be revealing about the phenomenon being studied. As I read through and highlighted the transcripts, I began to write down my early thoughts regarding themes and subthemes on sticky notes and organizing them into categorical structures of the experience as suggested by van Manen (1990). The next step involved me sorting the highlighted statements and quotes into the subthemes, which I had already clustered into themes. I continued to code the data until my supervisors and I believed that saturation had been reached. Saturation is defined as "bringing new participants continually into the study until the data set is complete, as indicated by data replication or redundancy" (Bowen, 2008, p.142). The themes and subthemes were analyzed and discussed by a qualitative group. After approval from this group, I began to write the results of my research study.

### Chapter 3: Results

The participants in my study included four collective families of children with ASD; more specifically nine family members were recruited for this study (i.e., four mothers, two fathers, and three siblings). I originally recruited a fifth family, but after interviewing the single mother and her daughter I chose not to include their data, as they did not use the term ASD in their daily lives and therefore did not identify their family member as being a child with ASD. For this reason, the family members felt that my research questions, which aimed to explore how living with a child with ASD affected their lives, did not apply to their experiences. Those participants who were included in this study ranged in age from 9 to 47 years of age (mother's mean age = 43 years; father's mean age = 44 years; sibling's mean age = 12 years). Of the four families, two of them were mother-father families, and the remaining two families were single mother families (i.e., 1 widowed mother and 1 divorced mother). Four out of the six parents were employed at the time of the study, while two of the mothers had recently quit their jobs to stay at home with their children. One of the fathers and one of the siblings had also been formally diagnosed with a health condition (ASD and Attention Deficit Disorder [ADD], respectively).

All four of the families expressed that they currently lived with one child diagnosed with high-functioning ASD. The four children with ASD ranged from 9 to 16 years of age (mean age = 13 years) and all of the children were male. These children were formally diagnosed with ASD between the ages of 4 and 10 years, with a mean age of 6 years at the time of the diagnosis. Of the four children with ASD, three of them had also been diagnosed with ADHD, and one of them had been diagnosed with a mild Intellectual Disability (MID). Furthermore, two of these children were taking medication at the time of the study to reduce the symptoms of their ADHD;

and one was enrolled in Behavioural Therapy to reduce his behaviours associated with having ASD. All nine participants identified the mothers as being the primary caregivers of the children with ASD. Additionally, the majority of the participants rated their relationships with their family units as being excellent ( $n = 6$ ). Two of the remaining participants rated their relationships with their family units as being good, and one of them rated it as being fair. Furthermore, the majority of the family members also rated their relationships with the children with ASD as being excellent ( $n = 5$ ), whereas three of them rated it as being good, and the remaining family member believed their relationship to be fair.



### 3.1 Description of the family units

The following descriptions of the family units are intended to provide context for the results of this study and illustrate the uniqueness of each of the families that participated. The descriptions were generated from my field notes, my interactions with the families, as well as the participants' descriptions of themselves and their family members.

**3.1.1 *The Smith family.*** The “Smith family”, who described themselves as an extremely close family of three, experienced much hardship when the father of the family passed away in 2006 from an undisclosed cause. His death occurred just six months following their son's diagnosis of ASD. Although this family described experiencing some bumps along the way, it was evident through my interactions with them that they became closer as a result of their past experiences, and continued to have a positive outlook on life. The primary caregiver of the family, the mother, had recently quit her job as a chartered accountant to be with her family, and had gone back to school for a career change. She described herself as a “good person”, a “strong person”, a bit of an “introvert”, and “a little crazy at times” as a result of having a child with ASD. This family considered the mother to be the primary caregiver, as she was the one who was with the children all of the time and did all of the cooking, cleaning, and other chores around the house. The daughter was described in the interviews as being the extrovert of the family, the opposite of both her mother and brother. Additionally, she was described as being “mature for her age”, as a result of having to cope with the loss of her father and helping to care for her brother with ASD. Her brother was diagnosed with Asperger's and ADHD when he was four and a half years old. The mother stated that it was difficult to separate which of his behaviours resulted from him having ASD and which were characteristic of his ADHD. This changed when he started taking medication for his ADHD, which improved his ability to focus, and decreased

his hyperactivity and verbosity. As a result, she was then able to describe his ASD characteristics as: having obsessive behaviours, difficulty with transitions, “verbal nonsense”, and academic challenges such as a lack of motivation and organizational skills. For this study, I was able to speak with both the mother and daughter about their experiences.

**3.1.2 The Morris family.** The “Morris family”, a family of five (mother, father, two sons and a daughter) was unique in that both the father and the eldest son were diagnosed with ASD less than a year ago. At the time of the interview the family frequently mentioned that they were still coming to terms with the diagnosis and doing all that they could as a family to learn about ASD and how to manage its associated characteristics. As a result of the diagnosis being so new, this family had been struggling with caring for their son with ASD’s additional needs and juggling the rest of the responsibilities of being a family. For this reason the mother had recently quit her job as a nurse, in order to stay home, care for her children, and maintain the household. All family members described the mother as a bit of a “control freak”, who liked to do everything herself. This seemed to work well with the dynamics of her family, as her husband worked 10-hour days plus his commute time, and was usually gone in the morning before the kids were awake and was home around the time the kids were getting into bed. All of the members of this family considered the mother to be the primary caregiver, as she did absolutely everything to run the household. Since the husband/father of this family had also been diagnosed with ASD, the dynamics of this family were rare in that the father described being able to relate to his son with ASD’s thought processes, which allowed him to give advice and help teach him how to behave appropriately in social situations. This family member frequently mentioned the fact that the son with ASD was the main priority at the moment, and that much less attention was given to the other children. The son with ASD was often described as being highly aggressive

both verbally and physically, and this was said to be his most difficult behaviour for all family members to manage. He was also described as having sensory and transition issues, being extremely focused, and repetitive. I interviewed the mother, father, and eldest sibling (the daughter), for this research study. Additionally, I was able to get each family member's perceptions of the youngest sibling's experience.

**3.1.3 The Robinson family.** The "Robinson family" members often described themselves as appearing as a "typical" family, being a unit of four with two happily married parents and a son and a daughter, who all spent a lot of time together. With this being said, the family members stated that after taking a closer look, one would quickly come to realize that they were working hard to care for a child with additional needs. The parents described themselves as being "a bit reserved", as they would rather spend their free time as a family and did not get out much. Additionally, they both worked full-time, the husband as an office manager and the wife as an educational assistant. The mother described her life as being "special needs twenty-four/seven", as she worked with children with disabilities during the day and then returned home to care for her son with ASD and a Mild Intellectual Disability (MID). Although both parents identified the mother as being the primary caregiver of the family, they often mentioned that the husband had many responsibilities around the house too and that he did all that he could to care for their son with ASD. The only reason the wife was considered the primary caregiver was because the husband had to commute over an hour to work and for that reason, he had less time in the day to provide care in the home. Although I was not able to interview their teenage daughter, as she was dealing with some life changes and decided not to participate, she was described by her parents as not having any responsibilities in the home and not assisting in the care of her brother. The children were described by the parents as "golden children" who were a

bit spoiled. The parents described their son with ASD as being more independent now that he was older, but that he still required a significant amount of assistance as his characteristics of ASD included perseverative behaviours, self-stimming (arm flapping), and a lack of social skills. Although I was unable to interview the sibling of the child with ASD, I was able to get the parents' perceptions of her experience.

**3.1.4 The Lewis family.** The "Lewis family", was comprised of a mother and her two sons. The family was described as being close, but each having their own unique life struggles that required attention. The mother had an abusive childhood, but moved across the country to get married and start a new life. After having her two sons, her husband began spiraling out of control, abusing both drugs and alcohol. For this reason, she divorced him and battled for full custody of her children. She described the circumstances as getting full custody of her children one day, then the next day, getting the news that her youngest son had ASD and that she was going to be doing it all on her own. According to the mother, her son with ASD brought a lot of joy and happiness to her family. Although he struggled with sensory issues, being extremely routinized, having fixations, and difficulty with feelings, overall, he was a happy, upbeat child who often lightened the mood of the family. The eldest son dealt with anxiety, depression, and ADD, which put additional responsibilities on the mother. With this being said, although the mother was considered to be the primary caregiver of the family, as she was the only adult and the one with the tools to provide care for the child with ASD, the eldest son did all that he could to help relieve some of the responsibilities from his mother. Whether it was helping his brother in social situations or cooking dinner once a week, the eldest son stepped up as a caregiver in this family. The mother had recently started a new relationship, adding a unique set of struggles, but it was clear that her children were still her number one priority. Although this family had dealt

with many struggles, the love and support they had for each other was clearly evident through my interactions with them as a family. They all had an extremely positive outlook on life and discussed spending most of their free time together, doing fun things as a family. For this study, I interviewed both the mother and eldest son to discuss the experiences of having a family member with ASD. While the father of this child with ASD was not accessible to me, I did get the mother's perceptions of his experience.

### 3.2 Themes

Analysis of the data revealed six major themes regarding the lived experiences of family members of children with ASD. The themes that related to the family unit as a whole were: (1) “It is a big change”; (2) “It isn’t in the moment, it is *prepare* for the moment”; (3) “The whole education end of things...”; and (4) “I am just not feeling the best these days...”: ASD takes its toll. The themes associated with the unique experiences of family members were: (5) The sibling experience, and (6) The parent experience. The quotes used to support these themes included not only the family members’ perceptions of their own experiences, but also their perceptions of each other’s experiences. Additionally, verbatim quotes from each of the family members were used in order for their “voices” to be heard. Each theme will be discussed in turn (See Table 3 for a summary).

**Table 3: Themes and subthemes****The family experience**

<b>Themes</b>	<b>Subthemes</b>
“It is a big change”	<ul style="list-style-type: none"> <li>a) “Now we are at the stage where...”: The child with ASD changes over time</li> <li>b) You change as a person</li> <li>c) The plans change</li> <li>d) “It just makes it a lot more of a rollercoaster”: Ebbs and flows</li> </ul>
“It isn’t <i>in</i> the moment, it is <i>prepare</i> for the moment”: Being one step ahead	<ul style="list-style-type: none"> <li>a) “You’re on the lookout for things that are going to be troubling”</li> <li>b) Planning and scheduling ahead</li> </ul>
“The whole education end of things...”	<ul style="list-style-type: none"> <li>a) “Problems with school”</li> <li>b) “I have gotten advice and strategies from...”</li> <li>c) Leading other families in the right direction</li> </ul>
“I am just not feeling the best these days...”: ASD takes its toll	<ul style="list-style-type: none"> <li>a) “I don’t have a social life”</li> <li>b) “It’s draining”: Physically and emotionally</li> </ul>

**The unique experience**

<b>Themes</b>	<b>Subthemes</b>
The sibling experience	<ul style="list-style-type: none"> <li>a) “He like pushes you, and punches you and stuff”</li> <li>b) Growing up quickly</li> <li>c) “It takes up a lot of time when he is mad”</li> <li>d) “It doesn’t change things much”</li> </ul>
The parent experience	<ul style="list-style-type: none"> <li>a) “There is an element of defending your kid, and an element of defending yourself”</li> <li>b) “She does everything”</li> <li>c) Judgments from others</li> </ul>

The themes entitled: “It is a big change”; “It isn’t in the moment, it is prepare for the moment”; “The whole education end of things...”; and “I am just not feeling the best these days...”: ASD takes its toll, all reflect the experiences of the family units in relation to living with children with ASD.

### **3.3 “It is a big change”**

When reflecting on their past, all of the family members discussed the many changes that had ensued as a result of living with children with ASD. In doing so, they mentioned both the positive and negative changes that they had experienced. Four subthemes emerged from this theme: (a) “Now we are at the stage where...”: The child with ASD changes over time; (b) You change as a person (c) The plans change; and (d) “It just makes it a lot more of a rollercoaster”: Ebbs and flows. Each subtheme will be discussed in turn.

#### ***3.3.1 “Now we are at the stage where...”: The child with ASD changes over time***

When the participants spoke of their family members with ASD, they all mentioned that over the years there had been noticeable changes in the children’s behaviours. They often attributed this change to growing older. While most of my participants discussed the positive changes they noticed in the children with ASD, some of them felt their behaviours had become worse over time. To illustrate the positive changes, participants compared the behaviours exhibited by the children with ASD when they were younger to how they had been behaving more recently.

*The only time that we really had to acknowledge it [child’s negative behaviour] was when he was younger. He was in a far worse situation than he is now.... Ya he was um, like he would bang his head on walls, he wasn’t toilet trained until he was about five and a half years old. Um he could not handle crowds, he could not handle noises, he would go into like meltdowns. – Nancy (mother)*



One of the siblings believed that the improvement in behaviour was a result of the behavioural management classes the child with ASD had taken over the years. This was likely because the child with ASD was able to make meaningful changes in his behaviours by applying the new skills and strategies taught to him by the professionals.

*He used to hit his head against the wall. Now he has had some classes on how to control that and now he just tries to remove himself from the situation. He has done pretty well at changing. – **Scott** (sibling)*

Several of the parents stated that the children with ASD had grown up a lot, and as they matured, the types of stressors they dealt with had changed.

*And they grow up, and it does get better, seriously maturity, again it depends on how the kid is affected but, maturity does make a difference. The issues change. You know when they are young it is throwing sand in the sandbox. No matter how many times you tell them not to throw the sand, they throw the sand. Then, it becomes bigger issues, different issues, so the issues change. – **Samantha** (mother)*

*But I found we were lucky with [child's name] being so high-functioning that as he has gotten older, it has gotten a little bit easier. But then now we have got the high school stuff. You know, I think [wife's name] was talking about it that he was walking home for his very first time on his own this Friday. And I knew when I was his age, when I was growing up in [city name] I'd walk from [street name] to [street name] and no problem. But with [child's name] you don't want him to be taken advantage of. So there is always the stress of that. – **Bill** (father)*

The siblings did not discuss this idea, likely because they did not play much of a caregiving role in the lives of the children with ASD, therefore they may have been oblivious to these particular changes. On the contrary, some of the participants stated that they had seen their family members with ASD exhibit *more* negative behaviours as they grew older.

*Because he used to be – have a meltdown once a month, then it was every couple of weeks, then once a week. And then like the last little bit was several times a day, where he would have a meltdown several times a day. – **Harry** (father)*

One of the siblings stated that playing with her brother had become less fun as he had become more aggressive over time, indicating that his aggressive behaviours had affected their relationship with each other.

*Sometimes he like, he wants to play with me and my friends like he used to. But now whenever I am playing with my friends he always comes up and screams and then I have to play with him and all. But just sometimes I don't want to anymore because he is always screaming at me. Sometimes it is kind of not as much fun as it used to be because he is screaming now. But I, it is just different now. – **Stephanie** (sibling)*

All of the participants reflected on the changes in behaviour that they had observed in their family members with ASD as they aged. While most of the family members emphasized on the positive behaviour changes, a few of them believed that the children's behaviours had worsened. Of interest was the fact that the family members who stated that the children with ASD had become worse with age, came from families where the children had been diagnosed with ASD later in life, and therefore may not have received any early intervention treatments. Additionally, many of the participants believed these changes in behaviour had affected them personally in some way, whether it was the type of stressors they experienced as a result, or the relationship they shared with their family member with ASD.

### **3.3.2 You change as a person**

Not only did the participants discuss the ways in which the children with ASD had changed over time, but each participant also mentioned the ways in which they-themselves had been shaped as people. For instance, Miranda believed that having a child with ASD had made her more of an “emotional” person, as she cried more often than ever before.

*Um, I have never really cried before, and it just, talking about him makes me cry. [tearing up] So it is very interesting, like even going into school to talk about the fact that he got another pink slip, I would be bawling. And it is so not me. – **Miranda** (mother)*

Many of the parents had mentioned that after discovering that they had children with ASD, they changed their expectations for what life was going to be like from that moment onward.

*Um, you know you think, you're given this baby and you think there is this great life ahead of you, and then you find out that it is going to be a bit different. So it is not that life isn't still great, it just has a few more bumps in the road and certainly not what you thought being a parent was going to be like.... Everyone wants that perfect kid, that healthy kid. When you find out it's not, you just have to re-jig, change your expectations. I think that's what it is. I think expectations for you, and the kid, and you just have to change them a bit and make the best of it. – **Samantha** (mother)*

*I remember the day I got the diagnosis, and I wasn't surprised. I took him to get this testing. But um, you mourn, you feel that there is something lost, you know? Um, whether that be their childhood, um what your idea of being a parent to this child is going to be. You know, when you become a parent, you become a mom you think that, you have this idea of what being a mom is going to be like, and that isn't going to be your reality. Your reality is going to be a different reality and [pause] and I, I, I cried, I cried about it. I released it, but ya, there was definitely mourning, mourning like the death of what you thought it was going to be, and that, what is my kid going to go through? – **Andrea** (mother)*

While the parents spoke about changing their expectations, they often became extremely emotional (i.e., demonstrated through tears and body language), indicating that this was a painful topic for them to discuss. Some of the participants spoke about the ways in which living with children with ASD has caused them to be more open-minded and accepting of others.

*There are people I have met in my life that I could kind of understand a bit more because I have been around my brother. Um, kindergarten there was a boy named [boy's name], and he would stutter a lot too. So um, I was so used to it with my brother that I wouldn't question or make fun of it with him. – **Scott** (sibling)*

*So it has kind of opened my mind up to how difficult this world can be to people with challenges. Who just don't see it the way we do. And just can't take it as plain sight and take it for what it is. Um, so ya it has been, it makes you more open-minded. And a lot more patient. – **Nancy** (mother)*

The participants often spoke about the ways in which having a family member with ASD helped them to develop positive characteristics, such as patience or becoming more organized.

*So I have learned a lot more patience. And you know trying to do the dad-son things with him like playing baseball, or hockey, learning to skate I have just learned a lot more*

*patience with dealing with it. Instead of say, go out for an hour, maybe we will go out for 10 minutes, maybe that is what his attention span can handle. But maybe an hour later we are out there again and we are doing it again. So I think I have learned a lot more patience and understanding, towards everybody, because of the situation we have. – **Bill** (father)*

*Um, I have become this person who has to be extremely organized and detailed and um, able to adjust. Um and let me tell you I was a laid back, liked to play the drums in a rock band, um didn't finish college, so I could hitchhike around the US. To come from that, to go from that to go to this extremely organized, disciplined person, I mean um, ya, it is a big change. I have changed a lot, in ways that are good. – **Andrea** (mother)*

The majority of the time, the family members perceived the changes they had personally experienced as a result of living with children with ASD to be positive (i.e., more patient, organized, and open-minded). Additionally, some participants had expressed being more accepting and understanding of other individuals with disabilities. One of the mothers believed that her experiences had made her more emotional, which could be seen as either a positive or a negative characteristic change. Based on the mother's facial expressions and demeanor while she discussed becoming more emotional (i.e., smiling, tearing up), I believe she viewed it as a benefit of having a child with ASD.

### **3.3.3 The plans change**

As family members of children with ASD, the participants frequently reported having to sacrifice their plans at a second's notice because of the children with ASD. For instance, a few of the participants mentioned having to alter the timeframe of their plans because their family members with ASD did not want to leave the house.

*But the other day we were going to go for a walk with the puppies and when we told him we had to go he said, 'no no I don't want to go.' But he eventually came. We just waited and waited. He asked for a few more minutes so we gave him a few more minutes and then we left. – **Jade** (sibling)*

Nancy mentioned the worry she felt in social situations because she knew that at any moment her son could have a meltdown, which would cause her family to leave the social event. Based on

the information I obtained from my interviews, she likely removed her child from these situations in order to calm him down or avoid feelings of embarrassment for herself and her other family members.

*And there have been many times we have showed up, knowing that this could possibly last us 5 minutes and we will be back in the car going home. – Nancy (mother)*

Additionally, many of the participants spoke about times where they had gone out to social events, but had to leave because the children with ASD had meltdowns. The meltdowns were often discussed as being a result of the children's interactions with others, or being over-stimulated by the immediate environment.

*And we have been in situations with neighbours who are friends, and [child's name] will do something and it kind of put us in weird situations where it is like 'Ok, we have got to go.' – Harry (father)*

*And sometimes that means you change the plans drastically for everyone else. My [other child] and me .... we all have to rearrange everything according to the stimulus of the situation. Which I mean, the world isn't set up that way, it is not orderly. You see the other family enjoying their dinner and you know the happy birthday song is something that is awesome for them, but the happy birthday song at the table next to us means that we leave. – Andrea (mother)*

In some cases, the family members provided concrete examples of times in which they had to miss out on a social event altogether, because their children with ASD had meltdowns just prior to leaving the house.

*Silly things like trying to pack up the car because we are going to gran and granddads for dinner. If he had a meltdown in the driveway in the car seat, and he just lost it because we weren't doing what he wanted to do. He'd have a meltdown and go into crisis mode, trying to calm him down and we still have a 45 minute ride to grandparents house, 'sorry grandparents, we will catch you another time. We are going back home.' – Bill (father)*

Whether it involved altering the original plan, leaving the situation, worrying about having to leave, or not being able to go to an event altogether, all of the participants discussed having to change their social plans to accommodate for their children with ASD. Most of the

time, altering the plans resulted in family members sacrificing their own social lives in some way. Additionally, when family members managed to go out on social outings, they described spending most of their time worrying rather than enjoying the moment.

### 3.3.4 “It just makes it a lot more of a rollercoaster”: Ebbs and flows

Participants from three out of the four family units discussed the ebbs and flows in their experiences of living with children with ASD. For example, various family members described the emotional rollercoaster the children with ASD themselves experienced on a day-to-day basis.

*And he is such a sweet kid. And when he is not postal he is such a sweet kid, just caring and like when he is in good [child’s name] mode he is like, he cares about everybody. He wants to make sure everybody is ok, that you know. But he is like Dr. Jekyll and Mr. Hyde, when he turns around, he is just horrible and just says horrible things. – Harry (father)*

*Or, it is all just very interesting to me. And [child’s name] does really have a soft heart and then he gets riled up and it is blown to crap. But in general, he is just a really kind and caring boy that just needs some help. – Miranda (mother)*

The siblings often mentioned that the children with ASD sometimes had good days and bad days. Depending on how their siblings were behaving each day, they spent more or less time with them.

*Sometimes, if he is having a bad day, then we don’t normally get along that well, but if he is having a good day, then we get along really good. – Jade (sibling)*

All of the mothers discussed the different phases they had gone through while living with their children with ASD, and how the different phases caused ebbs and flows in their emotions.

*Oh, um, again, different periods of our lives have been higher, or less, right. Having Asperger’s, and the same with autism, kids they go through a lot of, well [child’s name] has, a lot of phases I should say, where um there has been a certain behaviour, or concern. I mean he went through that period of high anxiety. So that was a very stressful time for me when he was threatening to hurt himself and all of that. So ya, then my stress level goes up because you’re dealing with a kid who has serious emotional issues. But then there will be a time when everything seems calm and we don’t have anything huge going on, so your stress level comes down. – Samantha (mother)*

*Um, I think it has its ups and downs. There are times when it is a blessing, because like I see all the social dilemmas that my [other child] comes home with and he doesn't, because he doesn't care. He doesn't get that emotionally involved so he doesn't care. He doesn't sweat the small stuff. It is just not his mechanics to do that. So sometimes I think, 'oh gosh, you are lucky for that'. And then on the flip side I think that because he doesn't know how to read people and situations, you're constantly worried about him being taken advantage of, or um, him being led astray somehow, not being safe. – Nancy (mother)*

Unlike many of the other participants, Andrea discussed her child's rollercoaster of emotions in more of a positive light.

*.... he has a reset button in a way. Once he has gotten upset and dealt with that, he doesn't hold a grudge. There is no such thing for [child's name]. And it can be surprising how much his mood can change like that. – Andrea (mother)*

While reflecting on what it was like living with children with ASD, most of the families felt that there were ebbs and flows to their experiences. They mentioned fluctuations in the children's behaviour, as well as the rollercoaster of emotions they experienced as a result of the different phases their children had gone through. While most of the time these changes had been seen as hindering their own experiences, Andrea saw her son's on/off switch as a positive characteristic, and wished she could acquire the ability to manage her own emotions in this way. The family that did not describe these ebbs and flows in their experiences did mention that their family member with ASD had been extremely mature and independent for the past little while, which could explain why they did not describe this particular family experience.

### **3.4 “It isn't *in* the moment, it is *prepare* for the moment”: Being one step ahead**

All of the family members revealed that they had spent a lot of the time actively looking into the future, and trying to be one step ahead of the children with ASD. The family members frequently mentioned having to think about what was happening next, rather than living in the moment, in order to preemptively avoid the children with ASD having meltdowns. The two subthemes, (a) “You're on the lookout for things that are going to be troubling”; and (b)

Planning and scheduling ahead, both described the concept of trying to anticipate triggers that would cause the children with ASD to have meltdowns, in order to prevent them from occurring in the first place.

### ***3.4.1 “You’re on the lookout for things that are going to be troubling”***

Many of the family members felt as though they were constantly on the lookout for situations or triggers in their environment that would initiate negative behaviours in the children with ASD. For example, Andrea discussed walking into situations before her child with ASD and surveying them for potential triggers.

*So, you’re on the lookout for things that are going to be troubling. And um, in a situation you walk in there first, and you survey the situation and you look for potential hazards. – Andrea (mother)*

Scott knew that his brother experienced sensory issues when his socks got wet, which would undoubtedly lead to a meltdown.

*Um, say um, he is having gym class outside and there is a bunch of snow. If he steps in it and gets snow into his boot he will get really mad about it. Sometimes he will refuse to participate in whatever they are asking him to do. He will blame the authority figure for that happening to him. – Scott (sibling)*

Similarly, Nancy knew from previous experiences that a reoccurring situation on the bus was likely to cause her son to be upset. In order to avoid her son getting angry, she explained that she was sure to talk to him about the situation each time they were waiting for the bus to arrive.

*Um, if we would go somewhere on the bus, he would sometimes yell at people because he liked that one single seat when you first get on the bus, and if someone was sitting there he would just go up to them and go ‘that’s my seat, get out of my...’ and I’d forget. So I would have to be like ‘Ok [child’s name], we are getting on the bus, and sometimes when we get on, there are other people, and we don’t get angry if someone else is sitting in the seat. We just take an empty seat and that is it’, right? So there used to be a lot of everything having to be walked through before we go. – Nancy (mother)*

In order to avoid triggering a situation Bill mentioned watching and interpreting the reactions of the individuals his son was talking with to see if the conversation was running smoothly. If he



could sense that the individual his son was speaking with was reacting negatively, Bill mentioned intervening or removing his son from the situation.

*Um, whenever [pause] we are in group settings I can kind of see, I can kind of see if something is going right or wrong.... I guess when I say I can kind of see it happening, other than watching him. I am watching the other kids and other adults. If it is an adult situation, I can kind of, I try to read them, how they are going to react to him, if that makes any sense. – **Bill** (father)*

Harry discussed his reality of having to look out for and manage any behaviours in his typically developed child that he believed would cause his son with ASD to get upset, even though most of the time it was not considered punishable behaviour.

*Um, in fact sometimes [sibling's name] will do something that we know will just cause [child's name] to freak out, and we will scream at [sibling's name], you know. Like, even though she is not doing anything bad, but we scream at her because we don't want to set off [child's name]. Which is a bit unfair to [sibling's name] I'd say, but um, I don't know. – **Harry** (father)*

When the family members were unable to halt a troubling situation from occurring before the children with ASD became upset, some of them mentioned knowing the warning signs that the children were on the verge of a meltdown. For example many of the family members described how the children looked and acted every time they were getting worked up.

*I know that it makes him very focused, and it can sometimes get him very anxious and worked up because he kind of moves his hands a lot, like really fast. And then he will - his face will get red and that's it. – **Jade** (sibling)*

*Um, he balls his fists – and he covers his ears. Um, and he seems to blink a lot. And he also goes 'ehkk, ehkk, ehkk' like he clears his throat a little bit. So I try and divert him from the situation. – **Miranda** (Mother)*

*He kinda just rolls his eyes and stuff. He kinda like scrunches his face and his nose and roles his eyes and stuff. When I see that I know to stay away from him. – **Stephanie** (sibling)*

In addition to watching for the triggers in the environment that may cause meltdowns, many of the family members stated that they felt they were constantly monitoring their *own* behaviours in

order to avoid getting the children with ASD upset. Instead of living in the moment, all of the family members' discussed having to "tread carefully" around the children with ASD. For example, the siblings spoke about being cautious about what they said around their brothers because they were worried about causing them to get upset.

*You should just tread carefully around them.... As much as I like poking fun at certain things, I am kind of worried that I will do that in a way that doesn't seem like a joke and like insult him. So I am kind of careful to insult something, so that he doesn't get offended. – **Scott** (sibling)*

*Cautious, like I don't want to say, he doesn't like when I bring up his ASD or his autism, like I can't talk about that in front of him or he will get upset. Like he will say like, he will get upset. I think it just makes him feel different, like awkward maybe because he thinks it is a flaw. – **Jade** (sibling)*

Harry voiced his dissatisfaction for having to tip toe around his son with ASD to avoid a meltdown. Additionally, he felt it was unfair that his typically developed children were expected to behave a certain way around their sibling.

*It's, you constantly feel like you're walking on eggshells because god forbid you set him off, you say the wrong thing, you do the wrong thing. Um and I think it is unfair for the other kids in the house because they have to be walking on eggshells as well, and [child's name] has to be treated differently. – **Harry** (father)*

Furthermore, many of the parents expressed their own cautious efforts to avoid putting their children with ASD in troubling situations. This was another way in which these family members were proactive, rather than reactive in mitigating the frequency and severity of meltdowns exhibited by these children with ASD.

*Um, just you know you never want anything badly to go with any of your kids. Um, and just with his diagnosis and you know some of the problems he was going through, the struggles he had, I wanted to try and bubble him as much as I could. – **Bill** (father)*

*I just I don't want – we say no to a lot of things and I just don't want to put him in those horrible situations where he is going to explode, or be upset because somebody did something wrong to another person. – **Miranda** (mother)*

The family members described the daily struggle of constantly being on the lookout for

meltdowns prior to their occurrence. Whether this was accomplished by watching for situations that may have caused the children to become upset, or being cautious about what they would say and how they would act, working to manipulate the environment around the needs of the children with ASD seemed to be a full time job for the family members. The family members contended that being proactive was better than being reactive to an event.

### ***3.4.2 Planning and scheduling ahead***

While the degree to which the children with ASD were routinized varied, most of the family members discussed having to constantly plan what was happening next in order to accommodate for the children's needs. The reasons why the participants planned ahead varied, but they all described doing so to some degree. For example, Samantha's son was extremely routinized and had to know their family's plans for each day of the week, so that he could personally prepare for what would be required of him.

*I have to tell [child's name] what is happening everyday, so every day he needs to know what we're doing today. So especially on the weekends, I mean during school he knows what he does. But he has to know what is happening, so we have a calendar, and I mark on the calendar what we're doing every day, [for] example what nights he is going to karate. So he knows he can go to that because he needs to know what's coming right. So when the weekend comes he will say to me, Friday night, 'Mom, what are we doing this weekend?' so I have to know what we have planned and then in his head he gets it figured out. 'Ok, Saturday she is going to make me go to the grocery store, or I have to go to the library.'* – **Samantha** (mother)

Additionally, Andrea's family followed nearly the exact same routine each day, which she believed benefited *all* of her family members.

*Oh ya. We have a routine. So it's um pretty much the same everyday.... To be honest, it – initially the goal was to have a schedule for [child's name], but we found that it kinda worked good for all of us.... We know what is expected, what is going to happen next. –* **Andrea** (mother)

For Miranda, she discussed the fact that her son was so focused on his routines that she had to do her best to follow the schedule she had in place, in order to avoid angering her son.

*Um, he is very regimented, um, if I say, 'Ok everyone get in the car. We need to go to the [store] and grandma's house – and we end up going to grandma's house first, everything is thrown off. Um he used to like throw a bit of a fit, um just 'you said bluhhhhh' and he would yell at me. – **Miranda** (mother)*

Bill discussed always having to let his son know twenty minutes before they had planned to leave for an outing, in order that he could prepare himself for the transition.

*Because we still have to give warnings to [child's name]. Like say I know right now he is down playing his PS4, if we were going out in 20 minutes, now would be the time I would go down and say 'Ok [child's name], you have 20 minutes then we have to pack up and then we are heading out.' Rather than going down right when we have to leave and go [child's name] shut it down, we are going!' it is just too fast for him. – **Bill** (father)*

Similarly for Nancy, the planning came into play when preparing for her child with ASD to leave for school each morning. Each day she had to get everything ready for her son and leave it all waiting for him at the front door.

*[Sibling's name] picks out her own clothes, [child's name] usually everything has to be picked out for him because if it is not in front of him, he will not remember to put it on. Um, [sibling's name] packs her own lunch, we are working on it with [child's name]. But I pretty much have to pack everything and leave it by the front door, otherwise it is forgotten. – **Nancy** (mother)*

Most of the family members spoke of the constant necessity to plan ahead and schedule their families' lives in order to accommodate for their children with ASD. Additionally, some of the parents spoke about having to strictly follow the plans they put in place, in order to avoid their sons having meltdowns. As a result, this likely affected the families' ability to be spontaneous, as they constantly had to be planning and thinking ahead. Overall, the family members each discussed how living with children with ASD involved having to constantly be one step ahead.

### **3.5 “The whole education end of things...”**

During their interviews all of the family members discussed the problems associated with education and learning to some degree. Although the context in which each family member

discussed these issues varied, all family members felt that education and learning was a major component of their experiences. Additionally, most family members felt that the education and learning process affected them personally and their families' lives in some way. This theme was subdivided into three subthemes: (a) "Problems with school"; (b) "I have gotten advice and strategies from..."; and (c) Leading other families in the right direction.

### ***3.5.1 "Problems with school"***

All of the family members mentioned the struggles the children with ASD had while at school. Whether it was mistreatment from the staff, bullying from other kids, or being misunderstood by others, family members often mentioned that they had to be more involved in the children's education as a result of the problems encountered while attending school. Two of the siblings spoke about situations where their siblings with ASD were being bullied at school, and they had to intervene in order to help diffuse the situation. For example, Stephanie mentioned being called upon by her sibling's teacher to help out.

*Um, sometimes at school, if he gets bullied, um like teachers they like, come get me and I get to help him out at recess and stuff if he is getting bullied, and at lunch I go and check on him, every, well a couple of days a week. – **Stephanie** (sibling)*

Harry also described a situation where his son had been punished by his teacher for hitting, even though he was just trying to defend himself while being bullied. The miscommunication between Harry's son and his teacher was likely a result of the communication challenges associated with having ASD.

*And he was getting into trouble on the bus and in school and stuff like that. And it is one of those things where, some kid would beat up on him and he would end up turning around and punching or kicking the kid. And the teachers would see him and he would get into trouble. And so they would ask him, 'Did you punch this kid?' and he would say 'Yes', so they would call us and say 'You know, [child's name] punched this kid'. And we would ask him 'Why did you punch this kid?' and he would say 'Well, three of them were punching and kicking me', 'Well did you tell them [the teachers] that?', 'Well no, they didn't ask me.' – **Harry** (father)*

From Nancy's perspective, her son's educational experiences resulted in negative behaviours at home, making it increasingly stressful for Nancy, as she had to work to manage these novel behaviours.

*The lessons that are going on aren't relevant and my fear was that it was just going to create behaviours that we don't need. And we were already seeing a lot of behaviour in grade three that we hadn't seen before, that I am convinced was brought on by anxiety because nothing that they were doing in class was relative to what he was working on with his EA. – Nancy (mother)*

Andrea discussed the reoccurring situation where her son's teachers did not know how to manage him, so they would call her to come and pick him up from school.

*One day there was a new student and they were moving these desks around and it was loud. And it was a change, and he had to change what peg his coat was on. And it just 'sheeeww' [made hand gestures of an explosion], ya it became a big, big problem and he became very loud and screamed and yelled. I got a call at work, 'Come pick him up.' .... Everyday I was getting a call 'You need to come pick up your son because you know, he's screaming and yelling', ya know, 'He's not fitting in, he's having a hard day', and I'm like 'Ok, I'm coming.' And I have to leave work. – Andrea (mother)*

All of the mothers spoke about having to interact frequently with their children's teachers as a result of outbursts or unequal treatment in the classroom.

*Academics, so motivating him to do homework, I have a lot more interaction with his teacher, right? I have to constantly be in contact with the teacher, either because there's issues at school, or because, you just have to be on top of them more, right? – Samantha (mother)*

All of my participants brought up situations where the children with ASD were having difficulties at school. Consequently, they all mentioned having to become more involved in the children's education. For siblings this involved dropping what they were doing to help deescalate the behaviours of their siblings with ASD, and for parents this involved becoming more involved in every aspect of the children's schooling.

### 3.5.2 “*I have gotten advice and strategies from...*”

Upon getting the children’s formal diagnosis of ASD, all of my participants mentioned having to learn techniques and strategies to effectively live with and care for their children. Although the pursuit of knowledge and coping strategies was common among all participants, the sources of this newfound knowledge varied. Many of the parents mentioned learning through experience. This often involved “trial and error” in order to identify what worked and what did not work for their children’s unique needs.

*Like you know, growing up he needed visual schedules, and reminders on the door. Stuff like that I put in place. I labeled his drawers so that he could find things. It wasn’t the most effective thing for him but we tried .... it is all trial and error. And a lot of, the typical stuff that is working – can work with one kid at school, you might think will work with him, but no, it’s almost like he needs a reminder to read the reminders. – Nancy (mother)*

Similarly, Andrea and Samantha spoke about their efforts to figure out what recreational activities worked best for their sons with ASD. It seemed as though individualized sports worked best for their children.

*But initially in the first couple of years of him going to school, it was very hard, very hard to figure out what worked and what didn’t work. It was a lot of trial and error to figure out what worked for us.... Like because my son doesn’t do team sports he does swimming. Oh, he’s an amazing swimmer. – Andrea (mother)*

*Like when he was in soccer, I knew it was just tough, like I knew and if he didn’t want to go I would be like “Ok, you don’t have to go to soccer”, because I started feeling bad for him, and for the other kids on the team. Like he would play soccer, and when he was done playing he would walk off the field, even if his shift wasn’t done, but in his mind, that all about me attitude, well he is done. And he would say that to me, I am done, ‘But your shift is still on’. To him that’s a foreign concept. Who cares about what your shift is, I’m done and I’m leaving. It is probably preventing him from being in team sports, I have him in karate and that is working amazing for him. – Samantha (mother)*

All of the sibling participants mentioned learning how to interact with the children with ASD through advice from their parents.

*Um, my mom said to just kind of stay out of it because he gets mad and then he hits. So, if he gets mad we have to stay away. – **Stephanie** (sibling)*

*If he is getting upset or anxious then I will leave the room because I know I will bug him if he gets really anxious.... My mom suggested it to me, that I should like leave the room. But I think it is a good idea too, she said it is um, better so that we don't get him annoyed any more. But I think it is a good idea because I don't want to like, get yelled at. – **Jade** (sibling)*

A few of the participants learned how to manage the behaviours of their children with ASD

through reading books and research articles.

*I have seen some paperwork laying around sometimes, talking about telling people around you you don't want to talk at the moment, writing down how irritating a situation is, certain ways of telling people how you feel. ...Um, [pause] she [mom] seems to know a lot about um, his methods of calming down, so she can remind him of it pretty easily. – **Scott** (sibling)*

*Absolutely, so I am just devouring books about him right now. – **Miranda** (mother)*

Bill found that the best way to gain the tools needed to care for his son with ASD was to speak with others in similar situations.

*I would just always get advice from people who went through what you're about to go through. And those people will be the tools, give you ideas, rather than you doing all the research online, they may have the phone number on their phone already. – **Bill** (father)*

Moreover, Andrea gained insight about how to provide optimal care by speaking with a trained professional.

*Um, because I have um, [pause] I have gotten advice and strategies from the counsellors and um, even my son's therapist about um, strategies that would help. – **Andrea** (mother)*

Although the source of the knowledge varied across each of the family members, they all mentioned developing strategies and tools for caring for their children with ASD. With this being said, it was often mentioned that the same tools might not work for all children with ASD because each child was unique and had different needs. For this reason, it appeared that learning through “trial and error” was integral when learning to care for children with ASD.



### 3.5.3 *Leading other families in the right direction*

The length of time in which each of the family members had been living with a child with ASD varied; however, all of the participants had advice that they wanted to share with other families of children with ASD, based on lessons they had learned. For the siblings, the advice was always concerning how to maintain a good relationship with the children with ASD.

*.... I know it can be kind of annoying because he can be mean sometimes, but you still have to stay with him, and know that even if the person sometimes criticizes you, or something, you can't take it personally. Because sometimes they are just saying it out of anger. So, you kind of just gotta, I don't know, let them be sometimes. Like let them have their time sometimes. Let them be alone. – **Jade** (sibling)*

*Um, it sounds cliché and annoying at times but, but it is something you just have to get used to. You can't change the things that you're most annoyed about. The occasional stuttering and stuff, you can't help that and you can't change that. It is just something you're going to have to live with. It shouldn't get in the way of a good friendship between you and your sibling. – **Scott** (sibling)*

Samantha's advice was to make sure to utilize the supports that were available to families in order to cope with the stressors associated with caring for children with ASD.

*Um, get your own support team, whether it is family or friends that you can turn too [crying]. Um, don't be afraid to walk away from your kid. Um, because they can drive you crazy. [cry laugh] So find something for you, whether it is going out with friends, or running, or being on a sport team. Find **something**. Otherwise that kid becomes all encompassing. Kind of your obsession [laughs]. So ya you have to look out for you for sure. – **Samantha** (mother)*

Miranda stated that families should listen to other people's advice, but to keep in mind that every child with ASD is different and requires a different set of tools.

*Take the good and listen to the bad, and then make up your own mind. I just, it is really hard. And everyone has an opinion, and everybody thinks they are an expert. But there are very few of those. So, and you know your kid, and you have to do what is right for them, so. And that is the hard part right, just having that filter, so I think I am quite good at having the filter. – **Miranda** (mother)*

Nancy's advice was to remember that having children with ASD is “not a life sentence.”

*It is not a life sentence meaning that it's not that they're not going to advance, that they are not going to um – that there are no opportunities for them. It is just a different way. And ya, be sad, nobody wants to hear that their child has anything, you know. Um, it is ok to be sad, but don't let that interfere with you helping them to move forward with it. And you will get the most unconditional love ever because they rely on you. They rely on you for their social cues and their thought processes. And until they can do that on their own they are very dependent on you, so you have to be strong. – Nancy (mother)*

For Bill, his advice was to never hold back your children with ASD from trying new things.

*And don't limit them, let them try whatever they want to try. Every kid is going to fail and they have to learn to fail as well. So you know, that failure may come more emotionally charged than a normal kid, but let them experience that as well. It is just going to help them more later on in life. – Bill (father)*

Although Harry was still trying to figure out what worked for his child with ASD, he had some insight for other families.

*I am not sure I am at a point where I can give any advice. I don't think I have a formula or any solution that works right now. Um, the only thing I can say is, you're not alone. – Harry (father)*

All of the family members felt it important to share what they had learned from their experiences of living with children with ASD with other families. With this being said, and as Miranda mentioned, it is important to keep in mind that each child with ASD is unique and each family is different, so what worked for one family, may not work for another.

### **3.6 “I am just not feeling the best these days...”: ASD takes its toll**

For the last theme relating to the family experience, all of the participants felt as though their quality of life had been compromised in some way as a result of living with children with ASD. For the parents, these compromises were often associated with the high demands of care and support their children required. For the siblings, they often mentioned the negative affects on their quality of life to be a result of the verbal and physical outbursts the children exhibited. The subthemes within this theme were: (a) “I don't have a social life”; and (b) “It's draining”: Physically and emotionally.

### 3.6.1 “*I don’t have a social life*”

Most of the participants reflected on specific instances that had been detrimental to their relationships with friends and family members. In particular, all of the female participants spoke about situations where their relationships with friends had ended as a result of the aggressive behaviours exhibited by their children with ASD.

*The girlfriend that told me my kid had issues, I stopped trying to explain it to her. You know, she can be closed minded and ignorant. Um, in a way do I put myself out there as much? No. For fear that people won’t understand, um, is that necessarily a good thing? I don’t know. – **Andrea** (mother)*

*Well actually, I have a friend, she is [friend’s name], and uh he hit her once and she is kind of mad at me still, and now we don’t talk that much anymore or whatever. It is because of him. He said sorry, but she is kind of still mad at him. Well, she is mad at me but um, I don’t know why. – **Stephanie** (sibling)*

Spending time with friends was perceived as nearly impossible for Samantha as she had difficulty getting childcare for her son with ASD and therefore spent her free time caring for her family.

*I mean, so I used to try and get a nanny from after school to 6 o’clock. And it was very hard to keep them because [child’s name] is so strong willed, and as you know, he’s quite a handful. So I found most of the people couldn’t handle him and the demands of looking after a boy with autism/Aspergers, or didn’t want to do it for babysitting wages. So yes. That would have changed things, because to go out with the girls on a Friday night, that just didn’t occur to me because I knew I had to get home for 6 o’clock because that babysitter had to leave. – **Samantha** (mother)*

For one of the siblings, most of their social relationships and supports were through online communities and chat rooms. Unfortunately, some of this individual’s online interactions became negative, as he felt people were using inappropriate and offensive language in reference to individuals with ASD.

*Um, sometimes when people on – one common insult online is people calling each other autistic. Someone, they will call someone who seems hyper or like a little side tracked autistic. I have a little less patience for that than most people seem to. – **Scott** (sibling)*

Two of the mothers isolated themselves from family and friends following the formal diagnosis of their sons with ASD. This was because they were trying to come to terms with the diagnosis and did not want to hear the opinions of others.

*Um, but I, kind of, avoided people for a while – maybe. And I didn't want to talk about it.... It was just kind of a three-month span....I was kind of not recluse, just not myself. Now, we did, like I said we did make a conscious effort to scale back, and not involve people. But I think that maybe – I took it a little too far. – **Miranda** (mother)*

Additionally, the family members repeatedly spoke about viewing themselves or their family negatively, when compared to others. For example, many of the family members compared their children with ASD to other typically developed children.

*I would say the worst part of my day would be going to the park. Because, everybody else would be running around doing their thing and he is like, underneath, playing on his own. Um, you see all these kids wanting to be interactive, whatever, and he is on his own.... I was at his school and I just looked out the window one day when they were on recess, and you just see your kid, sitting there by their self. It hurts. It makes you sad. – **Nancy** (mother)*

Other common comparisons the family members made were between their families and other families. Although many of the family members made this comparison, Andrea's explanation was most eloquent.

*And um, you don't want to be that person that goes 'Look at this family over here' you know they just go to hockey, they get in the car, they go home. Um, we take the bus to everything, it is really cold weather, we have to leave things. Our scenario is far more challenging it seems, at times than other people. You don't want to do that compare and contrast because that is not going to lead you anywhere good, but sometimes you do it. – **Andrea** (mother)*

Several of the participants made comparisons between themselves and their other family members. For Bill, this comparison was between how he had coped with having a child with ASD versus his wife.

*I know [wife's name] has had a harder time with it than I have, but I don't show the stress as much as what she does. I don't know, I wish I could explain it and tell you why*

*but I'm – I still think about it, I still stress about it, but I am not as open about talking about it as [wife's name] would be. – **Bill** (father)*

Whereas, in Jade's situation, she compared her abilities to that of her brother with ASD.

*He brags about things because sometimes he is better than me at things and that hurts my feelings. – **Jade** (sibling)*

The family members consistently spoke of spending less time with family and friends as a consequence of living with children with ASD. Additionally, by comparing themselves and their situations to others, it had the potential to be damaging to their relationships with others, as it could have negatively affected their interactions with those individuals.

### **3.6.2 “It's draining”:** *Physically and emotionally*

When asked about the effects living with children with ASD had upon their overall health, the participants spoke about how physically and emotionally draining the experience was for themselves and their family members. For instance, some of the participants felt that the experience affected the amount of sleep they obtained at night.

*So if I end up spending an extra three hours in bed because [child's name] won't fall asleep and I get up and leave bed when he is in bed, he is just going to get up and wake everybody. So I end up staying in bed with him for three hours when I should be working. So I end up spending an extra three hours up at night. So sometimes I'll go to work. Like I'll get up and go back to work at 10 or 11pm, right. Um so that is affecting me because I am not sleeping as much. – **Harry** (father)*

*When he kind of starts screaming and stuff. Like sometimes at night he gets, like he starts screaming, but only like, not that often. He screams in the night. And that kind of bothers me cuz I am sleeping... – **Stephanie** (sibling)*

Harry also believed that his wife experienced exhaustion as a result of caring for their child with ASD.

*But having a child with ASD just drains her [wife], drains her completely. And you know, she is exhausted so it affects us. I am convinced of that. – **Harry** (father)*

Some of the participants felt that living with children with ASD had caused them to feel exhausted and physically/emotionally drained. Through my interactions with these participants, it seemed that two of them felt that the exhaustion reduced their motivation to be active. On the contrary, Samantha and Andrea had a different experience as they both mentioned using physical activity as a way of coping with the stress associated with having sons with ASD.

*So running has been a way for me to get out, clear the head, have some time without him, and just be on my own. So if anything it has helped [both laugh]. It probably has helped that way. – **Samantha** (mother)*

*Then I uh, and I started going to the gym and I started taking these yoga classes. And the yoga class was when I felt most like myself. Maybe because of the deep breathing and being calm, but I started feeling like myself. – **Andrea** (mother)*

The negative emotions and feelings that the family members experienced throughout their journeys of living with children with ASD were also of significance. Embarrassment was a common feeling described by the siblings, often linked to the children with ASD's behaviours in public situations.

*Sometimes it feels like, I feel embarrassed so I teach him certain things. Um, sometimes I will say 'Don't say that word', and he will say 'Why?' So I have to explain what that means and I worry that he will still use it even if he knows what it is now, because it has more meaning to him. – **Scott** (sibling)*

*I don't know if [sibling's name] just has sometimes, maybe more recently, that, I hate saying this but, I don't know, [pause] maybe cuz she doesn't fully understand it she may be a little with some of her friends, hesitant to talk about it or even embarrassed a little bit by him and some of the mannerisms he has. Because he still does stim, there are some visual cues that you can see. – **Bill** (father)*

Guilt was another emotion many of the parents expressed harboring because in a way, they felt responsible for their children's diagnosis.

*Um, I harbor a lot of guilt, um, and I never feel like I have done enough for him. I never feel like I help him enough. And I just feel somehow that it is my job to fix him and I am not, not doing enough for him. – **Nancy** (mother)*

Additionally, many of the parents mentioned feeling a lot of worry about their children on a day-to-day basis, as well as worry about their children's future.

*I think anyways, 'oh my god what is he going to do when he goes to university and he is on his own'? And he can't figure out, to pick up his dirty laundry, or he obsesses and he runs out. Or like he has had issues with spending money online. And I think if I am not there who is going to control that? So I think there is a lot more worry. Parents think, my kids are going to grow up. And I know my kid will grow up, but will he ever be 100 percent independent? So I think there are more long-term concerns. – **Samantha** (mother)*

*And there is just that – you're always worrying. You always worry. Just simple things like when he wants to walk to Metro at lunch, um, will he be standing around to wait for his cash back? And if he doesn't will that cashier be the one to be like 'oh score', you know? If he gets excited about something and starts talking about something he can be very loud and it bother me to think people are looking at him. – **Nancy** (mother)*

One of the siblings spoke about how her brother's vocal outbursts affected the way she felt about herself. Of interest was that although Jade frequently mentioned that her brother hurt her feelings, she knows he did not mean to do it on purpose.

*Sometimes it affects my confidence because he will say I am not very smart, but I know he doesn't mean it, but it kind of, makes me think that I am not very smart. And like if he says something then I will kind of believe him even though he doesn't mean it. But I don't think he knows that I, that it hurts me. – **Jade** (sibling)*

As Harry struggled to figure out how to manage his son's behaviours, he expressed feeling powerless over both his emotions and the rest of his family's emotions.

*Then you can't help but feel powerless, you know. Like you don't want him to go through that, you don't want him to get angry or emotional, and you don't want to get angry and emotional, and you don't want the rest of your family to get emotional, but you're powerless. – **Harry** (father)*

The participants mentioned being drained by the physical and emotional effects they experienced as a result of living with children with ASD. One of the side effects of being drained that I noticed was the reduction in their motivation to be active, which could be detrimental to their overall health and well-being long-term. Andrea and Samantha had opposing

experiences as they both mentioned the increases in their physical activity levels, in order to cope with the stressors they experienced on a daily basis. Additionally, all of the family members discussed an array of negative feelings they experienced while living with children with ASD. For siblings, feelings of embarrassment and reduced confidence were discussed, whereas, parents mentioned feelings of worry, guilt and powerlessness. These negative feelings could have been detrimental, as they may have blurred the family members' perceptions of themselves, as well as the world around them.



The following two themes entitled, The sibling experience; and The parent experience, both reflect the unique experiences associated with being siblings or parents of children with ASD.

### 3.7 The sibling experience

While the majority of the experiences described by the participants were common across all of the family members, there were four themes specific to the siblings of the children with ASD. These themes were (a) “He like pushes you, and punches you and stuff”; (b) “It takes up a lot of time when he is mad”; (c) Growing up quickly; and (d) “It doesn’t change things much”.

#### 3.7.1 “He like pushes you, and punches you and stuff”

Although both the parents and siblings shared moments where the children with ASD displayed aggressive behaviours, most of the time the aggression was aimed towards the children’s siblings. All of the siblings shared examples of the physical or emotional aggression.

*Just, he yells a lot, and he like sometimes like hits you, he just like yells at you. I don’t know how to explain it. He just like gets upset, anxious and... – Jade (sibling)*

*Because he like, he doesn’t only do it once, he like pushes you, and punches you and stuff.... Usually it is, he gets into a situation with his friends or something and like, I, he just kind of gets mad at me for some reason. And then he hits and stuff. – Stephanie (sibling)*

One of the participants felt that his sibling with ASD instigated fights in order to display his aggression.

*He will disagree just for the sake of disagreeing at times just to kind of spread around his anger a little bit. – Scott (sibling)*

The parents also reflected on instances where the siblings of the children with ASD experienced both verbal and physical abuse from their siblings. Additionally, the parents often mentioned feeling sorry for their experiences of this abuse.

*Um, but I think often that he takes his frustration out on [sibling]. I mean [sibling] used to get beaten up all the time, I felt so sorry for [sibling]. I remember a doctor saying to me once 'You realize you can never leave your [other child] alone with your son, he might hurt [them]'. And I thought 'Oh my god, don't say things like that', but he was probably right. Not that [child's name] would ever hurt [other child] to be mean, he doesn't do it to be mean, but he just doesn't have that impulse control. – **Samantha** (mother)*

*Um, he doesn't hit me, and he doesn't hit [husband's name], but he certainly does hit his [sibling]. And this is why we kind of, we knew we needed more help. Because he was quite, I don't want to say violent, but there were times where he was violent, like aggressive. So, we needed that to stop. Like when you're hurting your siblings, something has to give. – **Miranda** (mother)*

When Harry spoke about the aggressive behaviour experienced by the siblings' of his child with ASD, he mentioned that it had affected their relationships with each other.

*It is just, because he will just get angry and just beat [siblings' names] up or scream at them. Like which is sad but, yesterday...[child's name] was saying to [sibling's name] 'Why won't you say you love me? You have never said you love me.' And [sibling's name] just wouldn't say he loves him he just – and you can see that [child's name] is devastated. – **Harry** (father)*

Based on these quotes it was evident that living with children with ASD involved the daily struggle of managing aggressive behaviours, and more specifically, managing the physical and emotional abuse typically experienced by the siblings of the children with ASD. Although the siblings were often the punching bag for the child with ASD, most of them mentioned that they knew that their siblings did not mean to hurt them, or that they knew they could not control their actions; however, acknowledgement of this did not erase the physical and/or emotional aggressions received at the hands of the siblings with ASD.

### **3.7.2 Growing up quickly**

When asked if living with their siblings with ASD had affected them in any way, all of the siblings mentioned having to grow up quickly, or that they had to become mature at a young age. Two of the siblings felt that they were mature because they had an increased number of

responsibilities in the home. In particular, Jade felt that she had to finish the chores her brother with ASD was unable to complete.

*Cuz I have to take on more responsibility because he is not taking on the responsibilities, but um it makes me have to take on that responsibility.... Like sometimes, if he doesn't want to do the dishes then I'll have to do them. Cuz he doesn't like to clean up, so I will have to clean up. – **Jade** (sibling)*

For Stephanie, she felt that having to care for herself a lot of the time when her parents were preoccupied had caused her to grow up quickly. When asked who takes care of her, Stephanie replied:

*Um [long pause; change in posture (head down, shoulders hunched)] me. Because my mom is usually – has to take care of [child's name] and my dad is never really home. – **Stephanie** (sibling)*

One participant felt that having to learn to be more tolerant of his sibling had prompted him to be mature at a young age.

*I've had to be a little more – tolerate a little more things than most people would have to put up with.... Um, him trying to say the same word over and over gain, just trying to ask him what he is trying to say. – **Scott** (sibling)*

When asked if they thought that living with siblings with ASD had affected their typically developed children in any ways, all of the mothers felt it had caused them to grow up quickly.

*So I always say [sibling's name] learned how to be tough at a really young age because she had to learn how to defend herself physically, and from his verbal attacks too. He can get mean to her. And it upsets her sometimes you know 'Why does [child's name] have to be so mean to me?', 'Why does he have to call me names?' It's hard to explain to a young girl why her brother does that, when sometimes I don't even understand why he does it. You can only say, 'Because he has Aspergers' so many times. So I think maybe that's probably what has forced her to grown up. – **Samantha** (mother)*

*And I um, sometimes I am really impressed with [sibling's] maturity to grasp things that a lot [of kids] wouldn't because [of] this experience with [a] brother [with ASD].... He has to behave himself. There is a certain behaviour that is expected from him. Where he sees his brother lose control. He says, 'I can't ever lose control, [child's name] can loose control.' He says 'I am expected to manage my moods, where you manage [child's name] moods.' Absolutely true. Not fair. – **Andrea** (mother)*

Miranda shared an example of how her typically developed child had taken on a caregiver role with her child with ASD's life to illustrate this increased maturity.

*But I don't know .... it is interesting, [sibling's name] will say '[child's name] you have you brushed your teeth?' and little reminders here and there.... Looking back on [child's name], he was the baby that no one could console but me, and that probably forced [sibling's name] to grow up pretty quickly – **Miranda** (mother)*

Oftentimes the siblings felt that they had no choice but to grow up quickly in order to pick up the slack for the children with ASD, or to relieve some of the stress from their parents. Additionally, a few of the parents felt that the siblings had to grow up quickly because they had to fend for themselves more often as the children with ASD required more attention. Overall, regardless if they were the older siblings or the younger siblings of the children with ASD, it was shown that growing up quickly was an outcome of living with children with ASD.

### **3.7.3 “It takes up a lot of time when he is mad”: Less time with parents**

Unfortunately, it was commonly stated across all of the participants that the typically developed children in the families received less time and attention from their parents. All of the siblings felt that the children with ASD required more of their parents' energy, and that they received less time and attention as a result.

*My mom and my brother need a bit more time together because he sometimes needs help doing things, but I am more independent I don't need people watching over me to do something. She helps him out sometimes and gets him on the right track. – **Jade** (sibling)*

Specific to Stephanie's situation, she felt that her parents' efforts to manage her brother's aggressive behaviours were the main contributors to the lack of attention she received from them.

*No, because they kind of have to be occupied, they have to take care of [child's name] sometime....I kinda wish in the mornings [child's name] would take his pill right when he gets downstairs so there wouldn't be screaming and stuff. And then me and my mom can talk instead of having to be like, screaming at [child's name] to be nicer in the morning. – **Stephanie** (sibling)*

Additionally, when asked if they spent an equal amount of time with each of their children, the parents all stated that the children with ASD received more of their attention. For Andrea, this was because she was always on the lookout for things that were going to be upsetting for her son with ASD.

*His younger brother gets more attention. Um, just because of those differences. Like I said, you go into a house, you go to a party, you go into a movie, you're looking for things that might be upsetting for your younger son. – **Andrea** (mother)*

Many of the parents felt a sense of guilt about the fact that their children with ASD required more of their time and effort.

*I feel like because I am spending all my time with [child's name], I feel sometime they are going to say, 'What the hell. You don't care about us, like you only care about [child's name]', and 'is [child's name] your favourite?' Um, you know, so that upsets me to think about that, but you know I have tried to read a story to just [sibling's name], then [child's name] ends up doing something stupid, like where he just goes out of his room and wakes everybody up and stuff. – **Harry** (father)*

*Um, but I do find myself talking to [child's name] about [child's name] a lot. [child's name] is the focus right now and I am feeling really bad for the others. But [pause] everything changes, families are dynamic, everything is fluid, everything will all work out. – **Miranda** (mother)*

For Nancy, she spoke about “going easy” on her typically developed child when it came to responsibilities in the home because she felt guilty that her child with ASD required so much more of her attention.

*We probably haven't stuck hard enough on [sibling's name], I guess sometimes I feel sorry for her, thinking like 'Oh we expect you to do this, when he gets all of this help to do it, cuz he doesn't ever know where to start.' – **Nancy** (mother)*

Whether intentional or not, all of the participants conveyed that the typically developed children in the families received less attention from their parents in comparison to the children with ASD. Although the family members were aware that this unequal attention was present, it continued to be a reality for these siblings.

### 3.7.4 “It doesn’t change things much”

On the bright side, although the participants mentioned many of the hardships associated with being siblings of children with ASD, all of the siblings and some of the parents stated that the children’s diagnoses did not change their relationships with the siblings all that much.

*I don’t know, it wouldn’t really matter if [child’s name] had ASD or if he didn’t, cuz that’s just a symptom, it’s not like, it doesn’t change things majorly, would it? – **Jade** (sibling)*

*Um, I don’t really know like, cuz he still has time for us. So it doesn’t really mean anything and it doesn’t really make any changes. So, it doesn’t really mean anything to me. – **Stephanie** (sibling)*

One of the siblings felt that their relationship with their family member with ASD was similar to any sibling relationship. I believe that he came to this conclusion because he did not have a good reference point, as he did not spend much time with other kids his own age.

*Um, I don’t know how [pause] I don’t know how people who don’t have siblings with ASD are like, but I am – from what I heard I think we are pretty similar to anyone else. I don’t see much of a difference.... His having ASD hasn’t caused problems, but him being the brother that I have to take care of, has. – **Scott** (sibling)*

Nancy believed that when her daughter looked at her child with ASD, she did not see him as having a disability, rather she saw him as her brother.

*While they say he has autism then you look and say [child’s name] has autism, I think [his sibling] finds it very difficult to buy into it. Um, and because it is [sibling’s name] brother, he is just an annoyance to her, so there is no empathy, she doesn’t see the struggles. – **Nancy** (mother)*

Bill similarly stated that his daughter and son with ASD fought like typical siblings would.

*I think at the end of the day I think [sibling’s name] really feels bad that [pause] that he is not a normal kid, that he has issues, he has problems, he has stumbling blocks.... She loves him, um, they fight like brothers and sisters fight, it doesn’t matter if it is a normal kid or a kid on the spectrum, that is going to happen. – **Bill** (father)*

Andrea stated that the way her typically developed child cared for her son with ASD was the responsibility that any older sibling would have towards their sibling.

*Um, he is the older brother he has to do things right, um he is the leader. All those things about being the older brother. – **Andrea** (mother)*

Additionally, separating which sibling interactions were a result of the characteristics associated with ASD, and what was typical for siblings was a challenge for Samantha.

*But like I said at the beginning, it is hard to understand what is the Asperger's and what is just siblings being siblings. God knows I fought with my sisters, right? So sometimes it is hard to separate, what is Asperger's and what is just a brother and sister fighting. – **Samantha** (mother)*

While the results of this study demonstrated that there are many challenges associated with living with siblings with ASD, it was refreshing to hear that in many ways the relationships the typically developed siblings shared with the children with ASD were perceived as being similar to any other sibling relationship.

### **3.8 The parent experience**

When talking to the family members about their experiences, there were also a few themes that only applied to the parents of the children with ASD. Three themes reflected the parents' experiences: (a) "There is an element of defending your kid, and an element of defending yourself"; (b) "She does everything"; and (c) Judgments from others. Each will be discussed in turn.

#### **3.8.1 "There is an element of defending your kid, and an element of defending yourself"**

All of the parents spoke about defending and advocating as being part of the experience of having children with ASD. Many of the parents spoke about the importance of advocating in order for their children with ASD to get the services and support they needed in order to reach their full potential.

*You have to be so proactive, as their advocate, um, making sure your kid is getting what he needs as opposed to a non-affected child, who just goes through the system. – **Samantha** (Mother)*

*Like I said before we started the interview, um, see that, it is a dark tunnel that you're going through but there is a light at the end of the tunnel and that it can be a very positive experience but you have to advocate. This is not a job for lazy parents. There is no time for laziness, especially at the beginning stages. Um when they are young and have all these behaviours, there is no time to be lazy, there is no time to think 'Just let the doctors take care of it', because the doctors appointments are so few and far between that there is a lot of time being wasted. – Nancy (mother)*

Bill believed that his wife was the person in his family that spent the most time advocating for their son, especially when it came to his education.

*Um, she [wife] always, when we first found out, she was the one that spotted the odd thing here and there as [child's name] was growing up. Um and she has always taken the lead role, again because I work 10-11 hours a day, she's home she has time to advocate, to go to the school meeting, to fight for him. – Bill (father)*

In Andrea's case, she felt that her experience involved standing up for both her child with ASD, as well as herself. For example, she reflected on a situation she had at her son's school.

*And he would have like bumps and bruises, and how do you explain to people that he gets upset and hits his head. Until one of the teachers actually saw him go do it, you know. 'We need to know why he has a bruise on his head', and I'm like 'Because he ran over to the wall and he slammed his head into the wall', 'Why did he do that?', 'because uh, his brother had a toy that he wanted, and he wouldn't give it to him, and he is obsessed with Thomas the train right now and his brother took his Thomas the train and that's why.' They don't believe that story, so there is an element of defending your kid, and an element of defending yourself at times, you know? And I found that every time I walked into [school's name], I'm like what will I be explaining now? What will I be defending [child's name] for now? You know, he is not this terrible kid. It was very disheartening. – Andrea (mother)*

Additionally, some of the participants felt that as parents, they were constantly defending themselves. For example, Harry felt that his wife had to stand up for herself to their neighbor.

*And we have had other people like neighbours on the street making comments like oh you know, one of the neighbours has said something to the effect that '[child's name] is good with everybody except for [wife's name], like [wife's name] lets him get away with everything.' And uh, you know. So of course [wife's name] put them in their place, she stuck up for herself. – Harry (father)*



Similarly, Miranda described defending herself to her brother for choosing to give her son ASD medication.

*So, I did speak to my brother one day and I said 'Listen, this is what we're doing, I realize that you're upset that we are trying medication, but you have one child, and who is not violent with the other children. You don't live our life, you don't get an opinion. And it really upset me that you were so over the top.' He was actually, I don't know if it was more him or his wife, but they were really aggressive and 'How dare you give your child medication', and well, here is the thing, we have been working on this for so long. – **Miranda** (mother)*

As these quotes demonstrated, being parents of children with ASD involved having to constantly defend their children, as well as themselves and their choices on how to parent their children. This involved standing up to their children's school, their neighbours, and even their own family members, in order to be heard.

### 3.8.2 “*She does everything*”

When each of the participants were asked who the primary caregiver was for both the children with ASD and the rest of the family, every single participant reported that the mother was because “she did everything”. When the siblings were asked why they felt that their mom was the primary caregiver of the children with ASD, they each had unique responses. For Scott and Stephanie, their responses reflected both how their mothers cared for the children with ASD, as well as being responsible for the chores around their houses.

*Um, she gives him medicine to help him with his attention....I am sure there are more, I don't know them all. Um, she works, pays for the groceries, [pause] tried to remind us about the times we should be leaving for school and stuff. Packs our lunches and stuff. – **Scott** (sibling)*

*She cleans, um, she takes care of [child's name], and she does like all the chores in the house.... And um, like she is always home and sometimes like [child's name], he, he doesn't, like sometimes we would take the bus and he would get mad at our bus driver, so our bus driver was making him mad so because my mom was always like there, cause she use to always take us to the bus stop. Um, cause she was always there she would kind of like talk to [child's name] and make sure he was cooled down before he got on the bus and stuff. She helps him a lot. – **Stephanie** (sibling)*

Whereas Jade only discussed the ways in which her mother provided care for her brother with ASD.

*Because they are always together, and mommy and [child's name] are in a lot of ways a lot alike. Like they both like, they both are very independent and they both love reading. And ya.... She kind of like tells him to calm down, and tells him 'It's ok, it's ok' that kind of stuff. – **Jade** (sibling)*

Additionally, the two fathers that participated in this study identified their wives as the primary caregiver of their family because they “did everything” (i.e., chores, caring for the children, paying for bills).

*Oh, she is a saint. Well she does everything. She prepares breakfast for the kids, wakes up the kids, prepares breakfast for the kids, lunch for school, gets them ready for school, takes them to the school bus or [child's name] to the van. And then you know, cleaning during the day, walking the dogs, preparing dinner, getting the kids from school, taking them to every activity they have, like dance and stuff like that. Uh, feeding them, giving them snacks, feeding them, um [pause] and eventually if I am not home, putting them to bed, and going to bed herself. [both laugh] It is crazy. – **Harry** (father)*

*Um, she does the bills. Um, she – any education piece, because I will be honest a thousand years ago I did grade 7 and 8 math [laughs] She's an [wife's job] so she sees it a lot more often, she has a far better teaching strategy than what I do. Um, so [wife's name] takes more of the um, education, maybe a little more of the nurturing thing than what I would do. – **Bill** (father)*

The mothers often described that they were the primary caregivers of the children with ASD because of the many roles they played in the lives of their children.

*So you become part doctor, part teacher, part mom, you wear a lot more hats when you have a kid with Asperger's. – **Samantha** (mother)*

*Just because you have an understanding for it, you can't be his therapist, his mom, his doctor, his teacher, and that is what it basically was. They were leaving me to be every role of every caregiver. And I don't know, that just creates more dependence on me. – **Nancy** (mother)*

The mothers also stated that they did everything to take care of the house as well. When asked what their responsibilities were in the home, all of the mothers had similar responses.

*My roles and responsibilities? Like there's a lot of them! [both laugh] Like almost all of them..... And that's quite challenging, to be honest. Um I do all the cooking and the cleaning. – **Andrea** (mother)*

*How about everything, except a paycheck right now. – **Miranda** (mother)*

With this being said, of the families that did have a father, both mentioned that the fathers did try to help where they could.

*And trying to help out where I can because I am out of the house the most out of all of them for most of the day, so. I wish I was here to do more, but you know everyone has to work, and we have to pay for everything [laughs] so. – **Bill** (father)*

*And I like to be in control, and I mean it is probably just me, but if I said [husband's name] do this, I am sure he would be absolutely fine with it, but I like to control things so [laughs]. – **Miranda** (mother)*

*Um, I would say he follows my lead, but I would say right now there is not all that much that needs to be done. – **Nancy** (mother)*

Stephanie mentioned that when her sibling with ASD was having a good day, her father would intervene to care for them so that her mother could go out.

*Well if [child's name] is in a super bad mood she [mother] usually doesn't go to her meetings or out with friends or anything. But if [child's name] is having a good day she will go and my dad can watch us. – **Stephanie** (sibling)*

It was also believed that the fathers were the disciplinarians of the families.

*He gives him reminders. It will be him that is constantly fighting him to get into the shower and things like that. – **Nancy** (mother)*

*And you know that is – so often we have – as much as we have this special bond there are a lot of times where we are butting heads together because I will be making him – like I won't let him get away with stuff, and he gets angry with me. And invariably he will say, 'I hate you' and you know, 'don't talk to me', 'Don't look at me'. And you know when he eventually calms down, he is very good. – **Harry** (father)*

*Um but I still think there is few things that I think maybe being more the disciplinarian kind of, I'll stick to my guns more and say 'No you're not doing it.' – **Bill** (father)*

In all four of the family units, the mothers were considered by everyone to be the primary caregiver of the children with ASD, as well as the ones responsible for running the home. For the widowed family and the divorced family these results were inevitable, but for the two intact families these were noteworthy responses. With this being said, the families that did have fathers involved did state that they helped out at times, especially as the disciplinarians of the family.

### **3.8.3 Judgments from others**

The parents described the many judgments they had endured from others on a regular basis. All four of the families had children with high-functioning ASD, and many of the parents spoke of ASD as an invisible disability which caused outsiders to either not understand why their sons acted the way they did, or “not buy” that they were struggling with a disability.

*I find that people often look at him, and think what is wrong with that kid, or he is acting out. You know where if you have a child with Down syndrome, as soon as people look they go ‘Oh ok I get the kid’. So you’re right it’s kind of like they get a free pass. But ASD, doesn’t have that, they don’t walk around with a hat that says “I have autism”, right. And because [child’s name] is quite high-functioning people don’t see it because he is very verbal and always has been plus is very intelligent (an aspect of Aspergers), and he doesn’t flap his arms or that kind of stuff. So it is a hard thing for people to appreciate. I always wonder, people probably think I am a bad mom, or he is a bad kid. But I have learnt to say ‘who cares’. You don’t know my kid, you don’t know me, if you want to judge, judge. – **Samantha** (mother)*

*It is, and he doesn’t have a wheel chair, he doesn’t have like a stick that he needs. Like, he’s very typical looking and a lot of people don’t buy into it. And the thing is, the kids that are very typically affected by it, it is almost like they have it easier. Whereas someone like [child’s name], I mean the best compliment could be, ‘Well I would never have guessed he has autism’, ‘Thank you, we have worked very hard to keep it that way’ and not to hide it, but for him to advance. So you’re telling us that he is doing very well and that’s a great compliment. But when he is struggling, people forget that, because they see a typical kid. And they don’t, they don’t – it is almost like you’re saying it is a diagnosis but they are not seeing and they are not buying it, and they are not – they are just like ‘He is misbehaving. Your kid is spoiled, he’s a wacko!’ – **Nancy** (mother)*

The parents also spoke of situations in public where they felt people were watching and judging them because of their children's behaviour. Some of the parents had mentioned in their interviews that these experiences in public situations were what had caused them to be more open-minded and understanding of other families.

*Um, I have gone through you know, fourteen years of this, well he was diagnosed at three, ten years of you know, we try to get out to the mall and um he has a meltdown in the lineup of Zellers or The Super Store, people look at you and are like 'What the hell? You can't control your kid or whatever' well 'Shut the hell up. You have no idea what you're looking at.'* – **Bill** (father)

Two of the parents shared specific examples where they received verbal judgments from others that they considered to be their friends.

*And there were times a girlfriend and I, you know she had a son who was the same age and I wanted to be able to get a few more hours at work, and she said she would watch over my son for a couple hours between me getting off of work. And um, when he was over at her house, something about their place upset him, I think it was the loudness of the television, and he had a meltdown over there. And then when I went to pick him up she said 'There is something seriously wrong with your kid, like your kid has got serious issues and I think he really needs a therapist. And like he's, he's crazy and I don't ever want your kid coming over and playing with my son because I think he can be really bad to be around my son'. And I was like 'Wow, I mean I told you he has autism', I told her and stuff. I thought she understood. But she went automatically to a place where he was a bad person, not like he had this condition that he was working with and that he was terribly frustrated.* – **Andrea** (mother)

*And you know you – [child's name] was always painted as the bad guy.... Um, it is just, [child's name] doesn't like loud. And if he, everybody, a couple of neighbours say 'Oh well, he acts so badly my kids would never act like that' and it is not just [child's name] acting like that, it is just the amount of people in the backyard [that set him off].* – **Miranda** (mother)

Whereas, Harry described the judgment his family experienced from members of their extended family.

*Ya um, well with uh my in-laws I have always, I have always felt that before [child's name] got his diagnosis, I always felt that they were thinking that we were letting him get away with too much. And that he was being a jerk. So I have always kind of felt that they were judging us and judging [child's name] unfairly. I don't think that has really changed since the diagnosis. I don't think they really know what that means. Um and,*

*um, you know he is actually – they haven't really seen him have the meltdowns. No meltdowns directed to them as much. So they just see him reacting towards us, and us reacting to him. Um so that is kind of tough. – Harry (father)*

Learning to deal with the judgments outsiders passed on to their children with ASD was a common theme described by all of the parents. Whether this was from strangers, friends, or even family, judgments frequently happened as a result of the children with ASD's behaviour.

Although only the parents of the children with ASD expressed this theme, the siblings may have witnessed judgments as well but because of their age, may have been too naive to understand their meanings.

While some of the themes in this study were specific to the siblings' experiences as well as the parents' experiences, for the most part, the themes were consistently expressed by all of the members of the family units. Additionally, through my participants' perceptions of their own experiences, as well as their perceptions of their other family members' experiences, it is evident that living with children with ASD affected many aspects of their lives.

## Chapter 4: Discussion

The purpose of my research was to explore the experiences of family members living with children with ASD by specifically examining how family members were uniquely affected, as well as collectively affected as a family unit. Four families, for a total of nine family members, participated in this research study. By recruiting family units, I was able to obtain multiple perspectives on the experiences of living with children with ASD, which likely provided me with a more holistic understanding of this phenomenon. All of the family members had similar experiences across four of the themes, while the remaining two themes were specific to either being a parent or a sibling of children with ASD. Overall, the family members spoke of the various health compromising experiences they had living with children with ASD.

In this discussion I will begin by reviewing the subthemes that emerged from this study in comparison to current research, then from there I will review the seemingly novel findings. The first finding supported by the existing literature was that all of the family members spoke about the ways in which their social lives had been negatively affected by living with children with ASD. The most commonly reported effect on family members' social lives was the reduction of positive interactions with friends and family, often a result of their children with ASD's behaviours. For instance, Stephanie spoke of a friendship that ended after her brother hit her friend one day while they were playing together. The reduction in quality and quantity of friendships across the family members of children with ASD has been supported by previous research (Fletcher et al., 2012; Nealy et al., 2012; Myers et al., 2009). For example, Fletcher et al. (2012), discovered in their qualitative research that one of the most commonly reported costs associated with caring for children with ASD, was losing friends and having difficulty trying to preserve friendships.

In my findings, it was evident that family members frequently had to change their plans or not attend certain events as a result of the behaviours of the children with ASD. Examples of having to leave restaurants because of loud noises, or leaving parties because their children were over-stimulated, were commonly shared by participants during their interviews. These findings were also supported by Nealy et al.'s (2012) research, which found that mothers of children with ASD chose to miss out on social events as they worried about their children's behaviours and fear of judgment and stigma. In their research, missing out on social events was said to significantly affect the social lives of these mothers of the children with ASD.

Some of my participants spoke about the reduction in the quality and quantity of sleep they had per night. For example, Harry reported the exhaustion he experienced as he had to stay in bed with his son for three hours each night until he fell asleep, which caused him to have to stay up an extra three hours afterwards in order to finish working. This was supported by Myers, Mackintosh, and Goin-Kochel's (2009) findings that parents and siblings of children with ASD often experienced sleeping problems and exhaustion, as a result of getting little sleep at night, which in turn affected their overall health and well-being. The implications of continued lack of sleep is that if family members are not healthy, they may not have the energy to care for their children with ASD (or other children) to the best of their abilities.

The family members that participated in my research also discussed the many negative emotions that they had felt throughout their experiences (i.e., worry, guilt, embarrassment, reduced confidence). For example, Nancy mentioned the guilt she felt, as she believed it was her job to "fix" her son, and that she never felt that she had done enough to help him. Nealy et al. (2012) and Myers et al.'s (2009) participants also expressed feelings of guilt, as well as worry, sadness, and despair as a result of living with children with ASD. Additionally, all of the



siblings in my study described feeling embarrassed at times by their brothers with ASD. Scott mentioned the embarrassment he felt when his brother would say inappropriate things in public, a sentiment supported by Mascha and Boucher (2006), who similarly found that the siblings of children with ASD often felt embarrassed as a result of the children's behaviour in public situations. For this reason, programs should teach siblings of children with ASD coping mechanisms to manage the negative emotions they may experience.

Family members revealed that the children with ASD experienced difficulties while at school, which in turn affected their quality of life. The siblings of the children with ASD gave examples of times they were called upon by teachers to help diffuse troubling situations, whereas the parents spoke of having to interact with the schools more frequently as a result of the ways their children had been treated. While the existing research seems to neglect the effects these problems at school have upon the siblings of children with ASD, the experiences of parents have been noted. For instance, Stoner and Angell (2006) found that parents of children with ASD played many roles in the educational lives of their children, including: negotiator, monitor, supporter, and advocate. Their study also found that the level of involvement these parents had in their children's education was largely dependent on the amount of trust they had in the educational professionals in question. Perhaps, if ASD training for educators is improved, siblings of children with ASD would not be responsible for helping to diffuse situations at school.

All of the siblings and most of the parents reported that their other child(ren) had to grow up quickly due to having siblings with ASD. Additionally, as a result of the increased demands for support and care that the children with ASD required, they received less attention from their parents. For instance, Jade believed that she had to take on more responsibilities in her family

home in order to pick up the slack for her brother with ASD, who was often unable to finish his chores. Additionally, Stephanie stated that her brother received more attention from her parents because they had to manage his negative behaviours, which took up a lot of their time. These findings were consistent with Fletcher et al. (2012) and Petalas et al. (2012), who also found that the siblings of children with ASD often had increased responsibilities in the family and received less attention from their parents as a result of the needs of the children with ASD. This lack of attention, in addition to their increased responsibilities within the home, may have long-term consequences on the siblings' health and well-being, and therefore requires further investigation.

Throughout the interviews family members discussed the aggressive behaviours that the children with ASD often exhibited towards their siblings. Samantha had stated that her son with ASD often took out his anger on his sibling, and that their doctors had advised her to never leave her children home alone together, for fear that her child with ASD might hurt his siblings. Benderix and Sivberg (2007) similarly found that the siblings of children with ASD experienced physical violence from the children with ASD in their family homes, which often led them to feel unsafe and anxious. This speaks to the importance of teaching siblings of children with ASD coping mechanisms to deal with the aggressive behaviours they may endure.

Similar to Gray (1993) and Ryan (2010) the parents who participated in my study felt as though they experienced judgment from strangers, friends, and even members of their extended families. Andrea reflected on the time her friend offered to take care of her son with ASD after school one day, and when she went to pick him up, her friend stated that he was "crazy" and that she no longer wanted their kids to spend time together. Research by Fletcher et al. (2012) concurred with these findings, as mothers of children with ASD experienced social stigma as a result of others not understanding the characteristics associated with ASD.

Throughout my interviews, family members spoke of the ways having children with ASD changed them as people. When they spoke of these changes the focus seemed to be on the ways in which the experiences caused them to change positively, such as becoming more patient, organized, and understanding of others. In research conducted by Huinker (2012), which examined the experiences of individuals with a sibling diagnosed with ASD, siblings developed positive traits such as empathy and patience. Similarly, when exploring the experiences of parents of children with ASD, Angell, Meadan, and Stoner (2012) and Myers, Mackintosh, and Goin-Kochel (2009) found that parents reported becoming more patient, compassionate, and persistent. It is important to note that this is not meant to downplay the negatives associated with living with children with ASD.

Routines and scheduling were described as being essential in the lifestyles of family members of children with ASD. These routines and schedules seemed to create more stability in the emotional states of the children with ASD, which in turn affected their entire family units. For example, Samantha spoke about consistently having to let her son know the plans for the entire week, so that he could prepare for what was going to be asked of him. Similar to these findings, Larson (2005) found that mothers of children with autism used routines in order to provide predictable expectations for their children, in addition to allowing for transitions to run more smoothly. Further, she found that children with ASD often adhered to the routines as a result of the comforting predictability. This skillset should be shared with families of children who are “newly” diagnosed with ASD, as it may be a useful tool for managing their behaviours.

Many of the mothers who participated in my study talked about the mourning they experienced following the diagnosis of their sons with ASD. They discussed mourning the loss of what they thought family life was going to be like. For example, Samantha stated that when

she become a parent she had an idea of what life was going to be like, but when her child was diagnosed with ASD, she felt that she had to mourn the loss of the life she had anticipated. This is consistent with Monsson's (2010) findings in her study looking at chronic sorrow, which is described as a prolonged feeling of loss or sorrow, in parents of children with ASD. In this quantitative study it was found that 83% of her participants scored a high range on the Kendall Chronic Sorrow Instrument (KCSI) where chronic sorrow was expected to be present. This finding is important because it illustrated the pain parents may experience upon their children's diagnosis of ASD and the need for counseling services to be available for these parents as they learn to cope with caregiving for children with ASD.

My participants mentioned using many different resources in order to learn how to manage the behaviours of the children with ASD, such as talking with other individuals who had similar experiences, trial and error, and gaining information from books. In the literature, as well as in my research, trial and error seemed to be the most commonly discussed approach that was instrumental when living with children with ASD. For example, Larson (2005) discovered in her research that when it came to participation in activities for children with ASD, mothers often relied on the trial and error approach, which was draining and stressful for them as they tried to find a workable strategy to facilitate this participation. This finding was consistent with the trial and error technique that many family members spoke about using in my study, when learning how to manage the behaviours of the children with ASD. For instance, Andrea mentioned that she had tried enrolling her son in team sports but that she learned quickly that he worked better independently, and switched him into swimming. Using trial and error is good advice for other parents who may feel alone in their struggles to get their children with ASD involved in activities.

The majority of the research looking at ASD and the family identifies the mother as the primary caregiver of the children with ASD (Cabrera, Tamis-LeMonda, Bradley, Hofferth, & Lamb, 2000). These findings are consistent with the findings in my research whereby all of the family members stated that the mothers were the primary caregivers for the children with ASD, as well as the ones most responsible for managing the household. For example, Harry stated that his wife was “a saint” as she did absolutely everything to manage their family. Of interest in my study was that the two families with a father present, revealed that the role they played in the lives of their children with ASD was as disciplinarians. For example, Bill mentioned that he was more of the disciplinary figure because he tended to “stick to his guns” more often than his wife. These findings give insight into the caregiving experience of fathers of children with ASD and how their roles may differ from those of their wives, a finding that should be evaluated further. The most noticeable difference between the family units that participated in my study was that two of them had mother-father families, while the remaining two families were single mother families. It is important to consider the ways in which family life was different for these two types of families. For the two mother-father families, although the fathers worked, the mothers could go to them for help and support when needed. This helped to elevate some of the stressors and demands associated with them being parents of children with ASD. Whereas, the single mother families were often on their own when it came to parenting, and had to turn to friends and/or extended family for the additional supports they needed, supports that were not always available. In my opinion, this was problematic because these mothers’ friends and extended family likely did not live with children with ASD and therefore did not have a full understanding of what life was like living with children with ASD and the stressors associated with their roles as caregivers.

All of the parents talked about the importance of advocating for both themselves and their children with ASD. Nancy stated that as a parent of a child with ASD she could not be “lazy”, but rather, she had to continuously advocate in order to get her son the services he needed. These findings were consistent with Woodgate et al. (2008) who found in their qualitative research that parents often fought and advocated for their children in order to make “the system” work for them. Additionally, they found that families advocated to improve “the system” for other families who have children with ASD. While existing literature has discussed that parents have to advocate for their children with ASD, the finding that parents often felt as though they had to defend themselves is seemingly novel. For instance, Miranda felt that she had to defend the decision they had made to give her son medication in order to manage his behaviour, a decision her brother did not believe was a good idea. This finding is important because it shows the additional stress of having to defend one’s choices pertaining to children with ASD over and above the arduous task of caring for children with ASD. This identifies the need for services and supports for family members of children with ASD, and the potential for education regarding coping strategies.

There are other subthemes that emerged from this study that seemed to be unique contributions to existing research. For instance, all of the family members spoke about the ways in which the children with ASD changed over time. Scott mentioned that his brother had learned to control some of his negative behaviours such as hitting his head against the wall, as a result of the behavioural management classes he had been taking. On the contrary, Harry felt that over time his son with ASD had become worse, as the amount of negative behaviours exhibited by his child became more frequent. These findings denote the fact that the children with ASD may go through many different stages and that the behaviours they display may evolve as they age, both

positively and negatively, which contributes to the ebbs and flows of providing care. In most cases, the children with ASD seemed to become more mature and independent with age, but as these results demonstrate, this was not the case for *all* children.

Further, family members perceived that they constantly had to be on the lookout for triggers in the environment that were going to upset the children with ASD. They frequently mentioned being preoccupied while in public, as they focused on looking for any triggers in their environment that might cause their children with ASD to have a meltdown. Bill spoke about watching over his son while he was interacting with others in group settings and intervening if he saw that his son was getting upset, or that others were responding negatively to him. Although this finding was not directly supported by the literature, in a study by DeGrace (2004), families alluded to the fact that their lives often revolved around the children with ASD. The results of their study showed that as the demands of having children with ASD were nonstop, family members were constantly tending to the needs of their children with ASD (DeGrace, 2004).

Another seemingly novel finding that was present in this study was the ebbs and flows of caregiving the family members conveyed as being part of their experiences of living with children with ASD. This led the family members to reflect on the fluctuations in their emotions as they experienced these ups and downs associated with the different phases of the ASD journey. Many of the parents stated that they experienced increases and decreases in their anxiety and stress levels based on the current states of their children with ASD. Although this finding is understated in the recent research looking at ASD and the family, it is supported by Bowen's family systems theory (Bowen, 1966; The Bowen Center for the Study of the Family, 2014). This theory examined the family as an interconnected unit, whereby changes in one family member are predictive of changes in other family members. In line with this theory, the

fluctuations in the stress and anxiety levels of the family members of the children with ASD may be a result of the change in the level of functioning of the children with ASD. Additionally, while this finding may not be present in current ASD research, a qualitative study by Boyczuk and Fletcher (2016) similarly identified the ebbs and flows in the caregiver experience of sandwich generation caregivers who were simultaneously caring for their aging parents and their children. In their research, the ebbs and flows were often said to be dependent on the level of stress of the caregivers' current situation. The finding that there were ebbs and flows in my participants' experiences is significant because it addresses their ever-changing experience, highlighting the need for supports to be put in place for family members of children with ASD, to assist them in coping with the rollercoaster they may experience.

All of my participants spoke about having to be cautious about what they did or said around the children with ASD. Rather than living in the moment, they discussed constantly monitoring themselves in order to avoid meltdowns. Specifically, Jade knew not to mention her brother's ASD around him because she knew it made him feel different and would cause him to get upset. These findings may address the added stress that family members experienced as they felt that they were unable to speak openly and be their authentic selves when around the children with ASD.

While the family members discussed the challenges associated with being siblings of children with ASD, most of them recognized that in many ways the relationships they shared were "typical sibling relationships" in some respects. For instance, Bill mentioned that his children fought like any brother and sister would. Additionally, Scott stated that his brother with ASD did not cause many problems in their relationship, but that having to be an older brother that has to care for his sibling with ASD did cause problems. This insight is important because it



sheds light on the fact that families of children with ASD must work to decipher between “typical” sibling interactions and interactions that are the product of having typically developed and non-typically developed children.

Finally, the findings that my participants frequently made negative comparisons may be novel. My participants stated that they compared their families to families of typically developed children, they compared themselves to the children with ASD, and they compared their experiences to that of their other family members’ experiences. This finding is important because by viewing themselves negatively when compared to others, these family members may be affecting their social and emotional health and well-being. This is supported by White et al. (2006) who found that people who made frequent social comparisons were more likely to experience “envy, guilt, regret, and defensiveness, and to lie, blame others, and to have unmet cravings.” This finding is important as it further supports the importance of teaching family members of children with ASD coping mechanisms.

While many of the findings in this study were supported by the previous literature, much of the information gained contributes to the unique insight into the experiences of family members of children with ASD.

**4.1. Limitations.** Although there were many steps taken to ensure the trustworthiness of this study, there were limitations present. For instance, all of the family members lived with a boy with ASD. This may have influenced the results of this study, as living with a girl with ASD may have had its own unique set of challenges. As well, all four family units lived with children with high-functioning ASD, which likely reduced the transferability of these findings to individuals along the ASD spectrum. It was also difficult to distinguish whether the behaviours of the children with ASD were associated with ASD itself or secondary conditions. This is

because children with ASD frequently have comorbid conditions such as ADHD and/or MID. For this study, I was able to recruit four mothers, two fathers and three siblings. Additionally, the socioeconomic status (SES) of the families was not taken into consideration in this study. This may have influenced the results as SES could have affected the amount of supports and services the families were able to provide for the children with ASD (i.e., respite services, therapies and treatment interventions). Although the perceptions of the siblings and fathers were included in this study, the results may have been more reflective of the experiences of the mothers due to sheer numbers. Furthermore, within the four family units I recruited, I was unable to interview two of the siblings. One of the siblings was too young to participate in this study and the other was coping with some life changes during the time of the study and did not wish to participate. For this reason, I was unable to get their perceptions of their experiences, but rather their family members' perceptions of their experience. Finally, the demographics of the participants may have affected the results as all of the family members were Caucasian, so this study did not speak to the potential differences in experiences as a result of cultural upbringing.

**4.2 Future Research.** Most of the qualitative research looking at ASD and the family to date has focused on the perceptions of the mothers in these families. For this reason, future qualitative research looking at the experiences of family members living with children with ASD should put more emphasis on capturing the voices of the fathers and the siblings in these families. Additionally, future research should look at the unique experiences of stepsiblings, as well as stepparents, to determine whether they are affected differently by living with children with ASD when compared to biological family members. It may also be beneficial to recruit same sex couples, as their experiences may be unique and provide some useful insights as well. Furthermore, future researchers should aim to recruit more diverse family units including:

families with different SES, families who live with female children with ASD, as well as families who live with children who are lower functioning. From a methodological standpoint, future researchers exploring the experiences of family members living with children with ASD should conduct longitudinal studies in order to gain insight into how these experiences may be different at various points in time (e.g., at the beginning of the school year compared to summer vacation).

### Conclusion

It is undeniable that there are both positives and negatives associated with living with and caring for children with ASD, as demonstrated by my research. By having my participants reflect on their experiences of living with children with ASD as well as their perceptions of their family members' experiences, my study was able to provide an in-depth and holistic picture of the effects living with children with ASD have on the family as an interconnected unit.

Although all of the participants touched on ways in which their lives had been affected in negative ways, they all mentioned the silver linings of living with children with ASD. Samantha summed it up the best when she said:

*Like I said before, so much of [child's name] is ASD, and ASD is [child's name], you cannot separate the two.... Um, I wouldn't want it for anyone else, but you make the best of what you have. You just love them that much more. – **Samantha** (mother)*

The main implication of this research study is that it builds on the existing dearth of research looking at ASD and the family, as it captures the experiences of entire family units in order to give each family member a unique “voice”. It is anticipated that the results of this research study will contribute to the current knowledge base regarding the health of family members of children with ASD, and to provide insight into improving the current support services for both the children with ASD and their families. Moreover, these findings may highlight the need for further support and funding programs for these families, in an effort to maximize their quality of life and their ability to care for these children with ASD (i.e., supports for family members to attend together as family units, more training and supports for children with ASD in schools, in school buddy systems for both the children with ASD as well as their siblings). As well, family members may use the results of this study as a resource to better understand what to expect when living with children with ASD, because as Harry stated, it is

important to understand that as families living with children with ASD, they are “not alone” in their experience.

*I am hoping that in your results that you will find that it is not just my family. It is not just me. Everybody is going through the same thing to various degrees. And that everyone goes through the same emotions. And that by itself, would be great for someone to find that out, someone who is new, to say look, you're going to feel this way, you're going to – it is totally normal. – **Harry** (father)*

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**APPENDIX A: Face Sheets****Face Sheet: Parent**

The following face sheet is used to collect some basic demographic information. Personal information collected from this questionnaire will be kept confidential and you will not be identified personally in any reports resulting from this research. Participation in completing this face sheet is voluntary, and you may refrain from answering any questions. In advance, thank you for your time and help.

***Questions about you:***

**1. What is your date of birth? (mm/yyyy) \_\_\_\_\_**

**2. What is your gender?**

- Male  
 Female

**3. Are you:**

- Employed full-time: \_\_\_\_\_  
 Employed part-time: \_\_\_\_\_  
 Unemployed  
 On a leave of absence  
 Other, please specify: \_\_\_\_\_

**4. What is your relationship status?**

- Single  
 Married/ Common law  
 Separated  
 Divorced  
 Widowed  
 Other, please specify: \_\_\_\_\_

**5. Do you have any formally diagnosed health conditions/illnesses/impairments?**

- No  
 Yes

If yes, please specify:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**6. How many children do you have? \_\_\_\_\_**

***Questions about your family member with ASD:***

**7. What is your child's date of birth (mm/yyyy): \_\_\_\_\_**

**8. How old was your child when s(he) was first diagnosed with ASD?** \_\_\_\_\_

**9. What signs and symptoms of ASD does your child currently display?**

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**10. Does your child with ASD have any other conditions?**

- No
- Yes

If yes, please specify:

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**11. Does your child with ASD receive any treatments and/or therapies for any of his/her conditions?**

- No
- Yes

If yes, please specify:

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**12. What types of support(s) do you feel you provide for your child with ASD?**

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**13. Who is the primary caregiver of your child with ASD?**

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**14. How would you describe the relationship you currently share with your immediate family?**

- Excellent
- Good
- Fair
- Poor

**15. How would you describe the overall relationship between you and your child with ASD?**

- Excellent
- Good
- Fair
- Poor

**Thank you for taking the time to complete this face sheet!**

### Face Sheet: Sibling

The following face sheet is used to collect some basic demographic information. Personal information collected from this questionnaire will be kept confidential and you will not be identified personally in any reports resulting from this research. Participation in completing this face sheet is voluntary, and you may refrain from answering any questions. In advance, thank you for your time and help.

#### *Questions about you:*

**1. What is your date of birth? (mm/yyyy) \_\_\_\_\_**

**2. What is your gender?**

- Male
- Female

**3. Are you:**

- In school, if yes what grade? \_\_\_\_\_
- Employed full-time: \_\_\_\_\_
- Employed part-time: \_\_\_\_\_
- Unemployed
- Other, please: \_\_\_\_\_

**4. Do you have any formally diagnosed health conditions/illnesses/impairments?**

- No
- Yes

If yes, please specify:

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#### *Questions about your family:*

**5. Who is the person most responsible for taking care of your sibling with ASD?**

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**6. What types of support(s) do you feel you provide for your sibling with ASD?**

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**7. How would you describe the relationship you currently share with your immediate family?**

- Excellent
- Good
- Fair
- Poor

**8. How would you describe the overall relationship between you and your sibling with ASD?**

- Excellent
- Good
- Fair
- Poor

**Thank you for taking the time to complete this face sheet!**

## APPENDIX B: Interview Guides

### Interview Guide: Parent(s)

Before we begin I'd like to thank you for participating in my study and meeting with me to discuss your experiences of living with a child with ASD. Please do not hesitate to make comments and ask questions during this interview. Also, your participation is completely voluntary so if you do not feel comfortable answering any of the questions please let me know and I can turn the recorder off at any time. Before we start, do you have any questions for me? [pause] If not, let's begin. May I turn the tape recorder on? [Wait for the participant to respond affirmatively, and then turn on the tape recorder]. Okay, let's begin.

#### *Background information*

1. How would you describe yourself to a stranger?
  - Family
  - Job
  - Things you like to do
  - How do you think others' would describe you?

#### *Family system*

2. Please describe a typical day in the life of your family
  - Morning routine
  - Evening routine
  - Weekends
3. How do you think others would describe your family?
4. Tell me about the structure/dynamics of your family?
  - Your specific roles and responsibilities in the home
  - Your roles and responsibilities with respect to your child with ASD
  - Do you think your roles and responsibilities would be different if you didn't have a child with ASD?
  - Other family members' roles and responsibilities in the home
  - Other family members' roles and responsibilities with respect to your child with ASD?
5. Why do you consider yourself (or \_\_\_\_\_) to be the primary caregiver of your child with ASD?
6. Tell me about your relationships with each of your family members  
(Probe using face sheet)
  - Partner
  - Typically developing child(ren)
  - Child with ASD
  - What do you like to do with your family?
  - How much quality time do you feel you spend with your family?



*Effects of living with a child with ASD*

7. Can you tell me more about your child with ASD? (Probe using background questionnaire)
  - Diagnosis
  - Current signs and symptoms/typical behaviours
  - Treatments
  - Things you like best about your child with ASD
8. How would you describe the experience of having a child with ASD?
9. Has having a child with ASD affected your health?
  - Psychological
  - Social
  - Physical
  - Any other aspects?
10. What advice would you give an individual whose child was just diagnosed with ASD?

*End questions*

11. Given all that we've discussed, is there one word you can think of that would sum up your experience of living with a child with ASD?
12. Do you have anything else to add?
13. Do you have any questions for me?

### Interview Guide: Sibling

Before we begin I'd like to thank you for participating in my study and meeting with me to discuss your experiences of living with a child with ASD. Please do not hesitate to make comments and ask questions during this interview. Also, your participation is completely voluntary so if you do not feel comfortable answering any of the questions please let me know and I can turn the recorder off at any time.

#### *Background information*

1. How would you describe yourself to a stranger?
  - Things you like to do
  - Sports/activities
  - How do you think others would describe you?

#### *Family system*

2. Can you tell me what a typical day looks like for your family?
  - Morning routine
  - After school
  - Bedtime routine
  - Weekends
3. Do you do things to help your family?
  - Chores
  - Things to help your sibling with ASD or other siblings?
4. Why do you consider \_\_\_\_ to be most responsible for taking care of your sibling with ASD?
  - Is \_\_\_\_ most responsible for taking care of you as well?
5. Are there things your other family members (parent(s), sibling(s)) do to help out your family?
  - Do your other family members help take care of your sibling with ASD?
6. Tell me about your relationships with each of your family members
  - Parent(s)
  - Siblings
  - What do you like to do with your family?
  - How much quality time do you feel you spend with your family?

#### *Effects of living with a sibling with ASD*

7. Can you tell me more about your sibling with ASD?
  - What is your brother/sister like?
  - What is he/she good at?
  - What do you like best about your sibling?
  - Does he/she do things that you don't like?

- Relationship you have?
8. Can you describe what it is like having a sibling with ASD?
  9. Has having a sibling with ASD changed any aspect of your life?
    - How you feel about yourself
    - Health (time spent with friends, doing activities, playing outside)
    - Relationships (friends, family)
  10. What advice would you give to another child/adolescent whose sibling has ASD?

*End questions*

11. Is there one word you can think of that would sum up your experience of living with your sibling with ASD?
12. Do you have anything else you want to tell me about what life is like having a sibling with ASD?
13. Do you have any questions for me?

**APPENDIX C: Consent Forms****WILFRID LAURIER UNIVERSITY  
INFORMED CONSENT LETTER**

Principal Investigators: Lauren Thomson

Advisors: Dr. P. Fletcher & Dr. M. Schneider

You are invited to participate in a research study pertaining to the experiences of family members living with a child with ASD. The purpose of this research is to explore how family members perceive themselves to be affected by living with a child with ASD, as well as how they feel the experience influences their family functioning as a whole.

The principal researcher is a graduate student at Wilfrid Laurier University who is conducting this research for a master's thesis. The research advisors, Dr. P. Fletcher and Dr. M. Schneider are Professors in the Department of Kinesiology and Physical Education.

**INFORMATION**

Collective family units living with a child with ASD will be recruited to participate in this study. Potential participants will be given this consent form and the option to participate. The face sheet and consent form will take approximately 10 to 15 minutes to complete. The one-on-one interview will be scheduled at the participant's convenience and will be approximately 45-90 minutes in length. All interviews will be audiotaped and then transcribed verbatim. The participants will be sent a member check via mail (with a prepaid envelope) or e-mail and be asked to review the verbatim transcript of their interview. During the member check process, participants will have the opportunity to remove any specific information and quotations that they feel necessary. Additionally, member checks give the researcher the opportunity to ask the participants question to clarify and/or elaborate on any unclear information that may have been provided during the interview. Once this process has been completed, the member checks are to be returned to the researchers with any added or omitted information or clarification of questions from the researcher. The data collected from this research will be locked in the Kinesiology and Physical Education office at Wilfrid Laurier University on 232 King Street for five years.

**RISKS & BENEFITS**

The participants will be asked to divulge information about experiences that may result in loss of privacy and/or evoke an emotional response. However, this research will contribute to the overall knowledge of the effects of living with a child with ASD on family members. This will not only increase the awareness regarding these family members, but may also assist in the development of appropriate supports for these individuals. Participants will be told they can refrain from answering any questions with which they feel uncomfortable. As such, the benefits outweigh the risks.

Participants Initials: \_\_\_\_\_

**CONFIDENTIALITY**

All data will be stripped of identifiers. Each transcript and face sheet will be identified by a pseudonym and the names of participants will not appear on their corresponding information. A master sheet with the names will be kept separate from the data in order to match transcripts with the appropriate data collection tools. The raw data will only be made accessible to the researchers and her graduate advisors. All data will be locked securely in a filing cabinet in the Kinesiology and Physical Education Department research space located at 232 King Street. Anonymous quotations within the final report may be used. All documents and records from this study will remain within the possession of the researchers until the study is completed and the raw data will be store securely and kept for five years. Pseudonyms will be used in any/all the reports and publications.

**COMPENSATION**

There is no compensation for participating in this study.

**CONTACT**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher Lauren Thomson (thom5910@mylaurier.ca), Dr. P. Fletcher at pfletcher@wlu.ca or Dr. M. Schneider at mschneider@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

**PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, your data will be removed from the study and destroyed or returned to you. You have the right to refrain from answering any question(s) that cause you to feel uncomfortable and you may end the interview at any time.

**FEEDBACK AND PUBLICATION**

The results from this research may be presented in paper format, presentations, posters and/or lectures. As a token of appreciation for your participation, upon completion of this study in summer 2016, I will provide you with a brief summary of the key findings if requested.

Please note that I am obligated to report any instance of abuse in a family context to the appropriate authorities.

Participant Initials: \_\_\_\_\_

**CONSENT**

Check the box beside the statements in which you consent to participate.

- I have read and understand the information above. I have received a copy of the information form and I agree to participate in this study.

Participant's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I agree to be audiotaped during the interview.

Participant's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I consent to have my direct, de-identified quotations used in presentations/papers resulting from this study.

Participant's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

**Consent Form: Child****WILFRID LAURIER UNIVERSITY  
INFORMED CONSENT LETTER**

Principal Investigators: Lauren Thomson

Advisors: Dr. P. Fletcher & Dr. M. Schneider

You are invited to participate in a research study pertaining to the experiences of family members living with a child with ASD. The purpose of this research is to explore how family members perceive themselves to be affected by living with a child with ASD, as well as how they feel the experience influences their family functioning as a whole.

The principal researcher is a graduate student at Wilfrid Laurier University who is conducting this research for a master's thesis. The research advisors, Dr. P. Fletcher and Dr. M. Schneider are Professors in the Department of Kinesiology and Physical Education.

**INFORMATION**

Collective family units living with a child with ASD will be recruited to participate in this study. Potential participants will be given this consent form and the option to participate. The face sheet and consent form will take approximately 10 to 15 minutes to complete. The one-on-one interview will be scheduled at the participant's convenience and will be approximately 45-90 minutes in length. All interviews will be audiotaped and then transcribed verbatim. The participants will be sent a member check via mail (with a prepaid envelope) or e-mail and be asked to review the verbatim transcript of their interview. During the member check process, participants will have the opportunity to remove any specific information and quotations that they feel necessary. Additionally, member checks give the researcher the opportunity to ask the participants question to clarify and/or elaborate on any unclear information that may have been provided during the interview. Once this process has been completed, the member checks are to be returned to the researchers with any added or omitted information or clarification of questions from the researcher. The data collected from this research will be locked in the Kinesiology and Physical Education office at Wilfrid Laurier University on 232 King Street for five years.

**RISKS & BENEFITS**

The participants will be asked to divulge information about experiences that may result in loss of privacy and/or evoke an emotional response. However, this research will contribute to the overall knowledge of the effects of living with a child with ASD on family members. This will not only increase the awareness regarding these family members, but may also assist in the development of appropriate supports for these individuals. Participants will be told they can refrain from answering any questions with which they feel uncomfortable. As such, the benefits outweigh the risks.

Participants Initials: \_\_\_\_\_

**CONFIDENTIALITY**

All data will be stripped of identifiers. Each transcript and face sheet will be identified by a pseudonym and the names of participants will not appear on their corresponding information. A master sheet with the names will be kept separate from the data in order to match transcripts with the appropriate data collection tools. The raw data will only be made accessible to the researchers and her graduate advisors. All data will be locked securely in a filing cabinet in the Kinesiology and Physical Education Department research space located at 232 King Street. Anonymous quotations within the final report may be used. All documents and records from this study will remain within the possession of the researchers until the study is completed and the raw data will be store securely and kept for five years. Pseudonyms will be used in any/all the reports and publications.

**COMPENSATION**

There is no compensation for participating in this study.

**CONTACT**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher Lauren Thomson (thom5910@mylaurier.ca), Dr. P. Fletcher at pfletcher@wlu.ca or Dr. M. Schneider at mschneider@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

**PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, your data will be removed from the study and destroyed or returned to you. You have the right to refrain from answering any question(s) that cause you to feel uncomfortable and you may end the interview at any time.

**FEEDBACK AND PUBLICATION**

The results from this research may be presented in paper format, presentations, posters and/or lectures. As a token of appreciation for your participation, upon completion of this study in summer 2016, I will provide you with a brief summary of the key findings if requested.

Please note that I am obligated to report any instance of abuse in a family context to the appropriate authorities.

Participant Initials: \_\_\_\_\_



**CONSENT**

Check the box beside the statements in which you consent to participate.

- I have read and understand the information above. I have received a copy of the information form and I agree to participate in this study.

Child's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I agree to be audiotaped during the interview.

Child's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I consent to have my direct, de-identified quotations used in presentations/papers resulting from this study.

Child's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

**Consent Form: Parent/Proxy**  
**WILFRID LAURIER UNIVERSITY**  
**INFORMED CONSENT LETTER**

Principal Investigators: Lauren Thomson

Advisors: Dr. P. Fletcher & Dr. M. Schneider

You are invited to participate in a research study pertaining to the experiences of family members living with a child with ASD. The purpose of this research is to explore how family members perceive themselves to be affected by living with a child with ASD, as well as how they feel the experience influences their family functioning as a whole.

The principal researcher is a graduate student at Wilfrid Laurier University who is conducting this research for a master's thesis. The research advisors, Dr. P. Fletcher and Dr. M. Schneider are Professors in the Department of Kinesiology and Physical Education.

### **INFORMATION**

Collective family units living with a child with ASD will be recruited to participate in this study. Potential participants will be given this consent form and the option to participate. The face sheet and consent form will take approximately 10 to 15 minutes to complete. The one-on-one interview will be scheduled at the participant's convenience and will be approximately 45-90 minutes in length. All interviews will be audiotaped and then transcribed verbatim. The participants will be sent a member check via mail (with a prepaid envelope) or e-mail and be asked to review the verbatim transcript of their interview. During the member check process, participants will have the opportunity to remove any specific information and quotations that they feel necessary. Additionally, member checks give the researcher the opportunity to ask the participants question to clarify and/or elaborate on any unclear information that may have been provided during the interview. Once this process has been completed, the member checks are to be returned to the researchers with any added or omitted information or clarification of questions from the researcher. The data collected from this research will be locked in the Kinesiology and Physical Education office at Wilfrid Laurier University on 232 King Street for five years.

### **RISKS & BENEFITS**

The participants will be asked to divulge information about experiences that may result in loss of privacy and/or evoke an emotional response. However, this research will contribute to the overall knowledge of the effects of living with a child with ASD on family members. This will not only increase the awareness regarding these family members, but may also assist in the development of appropriate supports for these individuals. Participants will be told they can refrain from answering any questions with which they feel uncomfortable. As such, the benefits outweigh the risks.

Parent/Proxy Initials: \_\_\_\_\_

**CONFIDENTIALITY**

All data will be stripped of identifiers. Each transcript and face sheet will be identified by a pseudonym and the names of participants will not appear on their corresponding information. A master sheet with the names will be kept separate from the data in order to match transcripts with the appropriate data collection tools. The raw data will only be made accessible to the researchers and her graduate advisors. All data will be locked securely in a filing cabinet in the Kinesiology and Physical Education Department research space located at 232 King Street. Anonymous quotations within the final report may be used. All documents and records from this study will remain within the possession of the researchers until the study is completed and the raw data will be store securely and kept for five years. Pseudonyms will be used in any/all the reports and publications.

**COMPENSATION**

There is no compensation for participating in this study.

**CONTACT**

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher Lauren Thomson (thom5910@mylaurier.ca), Dr. P. Fletcher at pfletcher@wlu.ca or Dr. M. Schneider at mschneider@wlu.ca. This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 4994 or rbasso@wlu.ca.

**PARTICIPATION**

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, your data will be removed from the study and destroyed or returned to you. You have the right to refrain from answering any question(s) that cause you to feel uncomfortable and you may end the interview at any time.

**FEEDBACK AND PUBLICATION**

The results from this research may be presented in paper format, presentations, posters and/or lectures. As a token of appreciation for your participation, upon completion of this study in summer 2016, I will provide you with a brief summary of the key findings if requested.

Please note that I am obligated to report any instance of abuse in a family context to the appropriate authorities.

Parent/Proxy Initials: \_\_\_\_\_

**CONSENT**

Check the box beside the statements in which you consent to participate.

- I have read and understand the information above. I have received a copy of the information form and I agree that my child may participation in this study.

Parent/proxy's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I agree that my child may be audiotaped during the interview.

Parent/proxy's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_

- I consent to my child's direct, de-identified quotations being used in presentations/papers resulting from this study.

Parent/proxy's Signature \_\_\_\_\_

Date \_\_\_\_\_

Investigator's Signature \_\_\_\_\_

Date \_\_\_\_\_